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Perceived Health Needs and Services Gaps for Elders on ARV Treatment - South East District, Botswana (2014-2015).

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ABSTRACT

Background: Health care of older people living with HIV and on ARV treatment has received very little attention in Botswana over the years. The 17.6% national HIV prevalence for Botswana excludes the older people as the Botswana Index AIDS Survey (BIAS) is focused on ages 10-64. This survey is meant to look at current national and district HIV estimations, sexual and preventive trends for each target group, compare HIV rates, behavior, knowledge, attitude, poverty and other factors related to HIV in order to come up with strategies to mitigate and enhance uptake of programs for prevention and control of HIV in Botswana. With little or no information on this group effective and targeted services are not possible hence this study.

Objective: To explore perceived health services needs and services gaps for HIV positive older people over 65 years by the older people attending ARV dispensing clinics and HCW in Gaborone and Greater Gaborone, Botswana (2014-2015).

Methods: A cross-sectional survey was conducted among 20 older people on ARV treatment and 15 Health Care Workers (nurses and pharmacy technicians) caring for them in Gaborone and Greater Gaborone (2014-2015). An in-depth interview guide was used to explore perceived health needs and services gaps of older people. Respondents were older people of age ranges 65 to 87 years who have been on ARV treatment for an average of 7 years (4 months to 13 years).

Results: Older people in Botswana are happy with curative and non-curative services offered as part of their care in ARV clinics. Curative services being ARV treatment, blood tests and consultation are offered consistently to the appreciation of all older people. Counselling services are not consistently done and older people advocate for its strengthening; targeted health education in non-existent, there is limited interaction with medical doctors due to language barrier, poor queue management results in older people waiting for long which is

attributed to staff shortage, poor defaulter identification and follow up are also not coordinated. The need for social support increases with their age and medical situation while need for improved nutrition or food ration remains critical for their health and wellbeing restoration. Above all pill burden due to comorbidities is in the increase therefore requiring coordinated patient management to maximise positive outcomes and minimise impact on older people.

Conclusion and Recommendations: Need for evidence based care initiatives can never be over emphasised. Despite that older people report high cases of disclosure and adherence, major needs and services gaps that need immediate response are inevitable basing on this study. Their high illiteracy rates impact adherence to services, openness to discuss sensitive issues, limits interaction with English speaking medical doctors and ultimately impact health outcomes. More skilled HCWs should be placed in Botswana ARV clinics to offer comprehensive and high quality services that meet the needs of older people. More longitudinal researches are recommended to better understand the journey of older people living with HIV in the mist of comorbidities. Coordination of services delivery among various professionals remains instrumental if we hope to maximise adherence and benefits of the services offered to older people.

DECLARATION

I, the undersigned Oarabile Dintwa, student number 749323, declare under oath that this Masters thesis I am submitting for assessment is the product of my own hard work and independent work under the guidance of my supervisor Dr. Tintswalo Hlungwani and my research mentor Dr. Poloko Kebaabetswe. No section of the report has been copied in whole or in part from other sources unless explicitly identified in quotation marks and with detailed, complete and accurate referencing. I also confirm that this thesis has not been submitted to any other examining body and has not been published.

Signature:  Date: 25th September 2015

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LIST OF ACRONYMS

AIDS- Acquired Immune Deficiency Syndrome

ART/ARV- Anti-retroviral Therapy

BAIS-Botswana AIDS Impact Survey

DHMT- District Health Management Team

HAART- Highly Active Antiretroviral Treatment

HCW-Health Care Workers

HIV- Human Immune Deficiency Virus

HREC- Human Research Ethics Committee

IDI-In-depth Interview

IDU- Injection Drug Users

IRB-Institutional Review Board

MPH- Master of Public Health

MOH- Ministry of Health

MSM- Men who have sex with Men

NACA- National AIDS Coordinating Agency

PID- Participant Identity

SADC- Southern African Development Community

SBCC- Social and Behaviour Change Communication

UB-University of Botswana

USAID- Joint United Nations Programme on HIV and AIDS

WITS- University of Witwatersrand

DEFINITION OF KEY TERMS

Older people: All individuals with a Botswana identity card who are aged 65 years and above(1).

Gaborone and Greater Gaborone: It refers to the city of Gaborone and surrounding areas being Tlokweng, Nkoyaphiri and Mogoditshane. Gaborone and Greater Gaborone is a designated service area set out by the Ministry of Health within the South East District for easy administration and management.

Health Care Workers: For this study it refers to any professional with a minimum of Diploma in a health related field who are officially assigned to work in ARV dispensing health facilities within Gaborone and Greater Gaborone, Botswana this could be Nurses, Counsellors and Pharmacy technicians).

Health Service's needs: For this study it refers to must provide needs that have a direct or indirect bearing on the health and wellbeing of the older people attending ARV dispensing clinics in Gaborone and Greater Gaborone.

Health Services gaps: For this study it refers to missing services that should be provided but are not that have a direct or indirect bearing on the health and wellbeing of the older people attending ARV dispensing clinics in Gaborone and Greater Gaborone .

MASA: Is a Setswana word meaning "New Dawn" the name which was given to the ARV

programme and its ARV dispensing clinics to signify the hope they have brought to Batswana living with HIV and AIDS to live longer

CHAPTER 1: INTRODUCTION TO THE STUDY

1.1 Background

Botswana, a landlocked country in the Southern part of Africa has the second highest HIV prevalence in the world after Swaziland (1). With a population of only 2,038,228 (2) the country has 17.6% (320 000) of its citizens living with HIV (1) and 198 553 receiving Highly Active Antiretroviral Therapy (HAART) (3). The 17.6% HIV prevalence excludes the older people as the Botswana Index AIDS Survey (BIAS) is focused on ages 10-64 (1). The BIAS is meant to look at current national and district HIV estimations, sexual and preventive trends for each target group, compare HIV rates, behavior, knowledge, attitude, poverty and other factors related to HIV in order to come up with strategies to mitigate and enhance uptake of programmes for prevention and control of HIV in Botswana (1). While at that it was further clarified that the ARV programme which is called MASA; their data from the Ministry of Health (MOH) is segregated in to children (0-13 years) who make 6.6% of all on HAART and adults (14 and above) (3) while "age specific data is kept at facility level", according to the MOH ARV programme Chief Health Officer bringing to light how lumped our data is as a country.

The focus of this study will be older people (this refers to all individuals aged 65 and above) who make 4% (89 464) of the total population of Botswana (38 868 males and 50 596 females) (2) and the numbers are projected to swell to 98 557 by 2021 and 129 459 by 2031 (4). Botswana has limited accessible data on the issues relating to the older people and HIV and AIDS. The

only literature found was from a population based study done by National AIDS Coordinating Agency (NACA), (5) which revealed the HIV prevalence among 65-69 years at 12.5% and 70-74 years to be at 10.8%. Of the 65-69 year olds, 11.6% are females and 13.6% are males while the 70-74 has 7.6% females and 14.4% males (5).

Literature from other countries suggests that adults over 50 years have relatively high risk due to their sexual practices and risk taking behaviors like low condom use and involvement in intergenerational relations with younger women who have difficulties negotiating condom use with them (6-9). Due to lack of evidence on the older people and HIV, Botswana continue to have more of its programmes and initiatives like HIV education, prevention, curative, care and support services being focused in schools, workplaces and young people based institutions therefore continuing to leave out the older people (10). Other countries are way ahead; for example it is known that older Canadians living with HIV face multiple forms of overlapping stigma and discrimination which contribute to high cases of social isolation and depression among their older people (11) and Uganda has a list of needs and challenges that impacts the health of their older people living with HIV like stigma, difficulty disclosing, delayed diagnosis and care-seeking, poor quality of patient–provider relationship, lack of adherence support and end-of-life issues (12, 13).

In literature it comes out clearly that, since the implementation of the ARV programme, the world continues to experience life expectancy growth (10, 14). Botswana's life expectancy which was reduced from 64 years in 1990 to 49 years in 2002 due to HIV and AIDS, is now going up again, at 53 years in 2012 among the infected (10) while Botswana's census conducted in 2011 showed an increase in life expectancy from 55.6 years in 2001 to 68 years in 2011 among the general public (2).

As life expectancy increase we expect the older generation on ARV treatment to live longer hence a need for the country to have programmes targeting this group for increased longevity. Botswana is lagging behind countries like South Africa, Uganda, Zimbabwe and Kenya who have done some research on their older people living with HIV and AIDS with the hope to inform policy and programming (12, 13, and 15).

It is clear Botswana has not prioritized this population as the National HIV and AIDS Strategic Framework for Botswana has only highlighted the following groups as key populations at risk of or affected by HIV and AIDS: men who have sex with men (MSM), migrants and mobile populations, sex workers, orphans and other vulnerable children, people with disabilities, women and girls, young women and young men. The older people are not included anywhere at all yet globally the population ageing with HIV is mostly within the ages 50 and above (9, 10, 16, and 17). Gaborone and Greater Gaborone where this research was conducted has highlighted their priority groups as youth, women, men and farm workers with no further details (18). These groups are targeted because it is believed most of HIV cases in Botswana are contracted through sexual contact. There is therefore limited data to support the exclusion of the older people (65 years and above) from national priorities while their level of risk to HIV and AIDS is unknown.

This research therefore was conducted to explore the health needs and health services gaps among the older people living with HIV and AIDS and are on ARV treatment which is an under researched population in Botswana with hope to guide future policy and planning for this population.

1.2 Justification of the Study

The major challenge faced by the world today is delivering evidence based and targeted health services which are effective, impactful, more individualized, streamlined and dynamic to maximize effects of clinical and non-clinical judgement on client's felt needs and services gaps(16). To achieve this countries, institutions and research bodies should invest in targeted research to inform programming as targeted services have proven to be effective (16). The '*Know your epidemic, Know your response'* principle was meant for countries to adequately address the challenges HIV pose to specific groups with understanding of the specific nature of the epidemic in their different locations, age groups and gender (19). Demographic shifts among people living with HIV therefore require up to date and targeted research hence the need for researchers to focus on this under researched population-the older people.

There is interest globally to focus on the older people living with HIV due to overwhelming evidence that by 2015 almost 50% of the patients receiving ARVs will be over 50 years (6, 7, 13, 22-24). The current momentum and evidence from developed countries provides an important opportunity for developing countries with high HIV prevalence and providing free ARVs like Botswana to ready themselves for the coming changes- their older people aging with HIV. Botswana can only ready itself through locally relevant evidence which can form a basis for new policies and interventions for this group.

This research therefore is intended to explore various health needs and services gaps as experienced by the older people and those caring for them to provide objective view on the needs and services gaps of the older people on ARV treatment in Botswana. No such study has been done in Botswana. All studies that have been done in developed and developing countries like USA, Canada, Uganda, Kenya, South Africa look at older people from 50 years and above (11,

16, 25) and this study propose to align older people to the Botswana National policy and focus on the 65 years and above. This is so because there is evidence that older people use more and various health services, therefore requiring that they be classified accordingly in order to respond to their real needs as they age (27).

This exploratory research therefore has the potential to increase attention to the health services needs and services gaps of the HIV positive older people in Botswana who are on ARV treatment. The study also present an opportunity to add new knowledge to this topic and hopefully findings from this study will stimulate further representative research that can influence policy, programming and future practices to meet the needs of the older people living with HIV in Botswana.

1.3 Study Aim:

To explore perceived health services needs and services gaps for HIV positive older people over 65 years by the older people attending ARV dispensing clinics and HCW in Gaborone and Greater Gaborone, Botswana (2014-2015).

1.4 Study Objectives:

1. To establish the current health services offered to HIV positive older people over 65 years attending MASA clinics in Gaborone and Greater Gaborone, Botswana (2014-2015) from older people and HCW.

2. To explore perceived health services needs by older people HIV positive patients over 65 years attending ARV dispensing clinics in Gaborone and Greater Gaborone, Botswana (2014-2015).

3. To explore perceived health service gaps for older people HIV positive patients over 65 years attending MASA clinics in Gaborone and Greater Gaborone, Botswana (2014-2015), as perceived by the older people and HCW who care for them.

4. To compare and analyse perceived health services needs and gaps as experienced by older people HIV positive patients over 65 years and ARV dispensing clinics Health Care Workers in Gaborone and Greater Gaborone, Botswana (2014-2015).

1.5 Statement of the Problem

Several decades into the AIDS pandemic, HIV transmission in most of the world remains firmly concentrated among sex workers, men who have sex with men (MSM), and/or injecting drug users (IDUs), and their sexual partners (19). In some parts of Africa including Botswana, where over two-thirds of infections occur globally, HIV has expanded outside these high-risk groups, creating generalized, predominantly heterosexual epidemics (20). With the discovery of ARVs, most people are aging with the disease (4, 14) hence current estimations that globally by 2015, subjects aged over 50 years will represent 50% of all people living with HIV undergoing clinical treatment (14).

In Botswana a population based study revealed the HIV prevalence among 65-69 years at 12.5% and 70-74 years to be at 10.8 %(5); regardless of this evidence that HIV and AIDS is no longer only for the young, Botswana HIV and AIDS research is still focused on the 15-49 year olds as they are perceived to be high risk due to sexual activity (1, 4, 5, 10, and 21). To date the health services needs and gaps of the older people on ARV treatment are not known and not researched on suggesting that the health system might not be addressing such needs nor reading itself for the future shift- having more older people on the ARV programme than any other group. This is also

evidenced by lack of programmes and policies to address the older people inevitable health needs both medical and non-medical in Botswana. The researcher conducted this research to explore health needs and services gaps as perceived by the older people and those caring for them in order to inform and influence policy towards care of this population. It remains clear that assumptions that drive current HIV prevention, treatment and care strategies and services for the older people are unsupported by rigorous evidence here in Botswana hence the need for this study.

CHAPTER 2: LITERATURE REVIEW

2.1 Burden of HIV/AIDS related to Older People

Demographic changes and the increasing availability and coverage of ARV imply that the burden of HIV is shifting to older age groups in sub-Saharan Africa (22). However, very little is known about the burden of disease and the unique considerations required to adequately treat and retain older Africans living with HIV (13). Between 2008 and 2010 Swaziland, Botswana, Kenya, South Africa and Mozambique published prevalence of men and women aged 50 years and above in their respective national population based surveys to be higher than the national HIV prevalence in this countries (19). This data presented a picture of a new direction in relation to HIV which cannot be overlooked. Most literature in Africa still addresses the older people as carers for those living with HIV and AIDS and AIDS orphans (20, 21) overlooking the fact that older people are no longer only over burdened by caring for others; they are faced with their own demise-aging with the disease themselves (22).

Regardless of all this pointers there is still limited data and research relating to the older people living with HIV in Botswana, a country that had the highest HIV prevalence in the world for almost two decades (20). Poor or skewed data capturing that exclude older people could have been influenced by international bodies like USAID as their global monitoring and reporting tools target 15-49 years only (19). Centre for Disease Control on the other hand made recommendations that leave out the older people per Botswana policy as some of their services, for example routine HIV testing recommends screening only through to age sixty four (19). As per guidance from USAID, there is collective agreement that being over 65 years of age is generally considered to be “older”, but in the context of aging and HIV “older” commonly refers to being over 50 years of age due to several reasons which include the lower life expectancy of

people who are HIV-positive compared to the general population, as well as the accelerated aging effects that may be associated with HIV infection and treatment (23). This argument does not hold water anymore considering increases in life expectancy that is being experienced by various countries like Botswana(4) offering free ARVs to its citizens. Therefore lumping health needs of a 50 year old who is usually still working and fully functional with a 75 year old who would have retired and sickly might pose long term health systems and services delivery challenges.

Basing on international projections by United States Census Bureau, the United Nations, statistical office of the European, regional surveys and scientific journals; increase in older population in the near future pose challenges to policy makers especially relating to increased life expectancy, increase in the burden of non-communicable diseases including HIV and AIDS in both developed and developing countries, changes in family structures which will call for care centres for older people and increased services expectations(24). HIV and AIDS has had and is still having a direct impact on Botswana older population. In recent years the country has experienced an increased life expectancy due to accessible ARVs (25), increased co morbidities (26), increased impact on the health systems especially health care costs and manpower, as well as increased dependency and need for social support (27). The longer they live the higher chances that they will compete with the young for limited prevention, curative, psychosocial resources (24). Regardless of the limited research on older people living with HIV, the following needs are some of those expressed in literature:

2.2 Preventive Needs of Older people

Globally there is a common stereotype that older people don't have sex or use drugs therefore resulting in very few HIV prevention efforts aimed at them (27). A national survey among at-risk people over 50 in the United States of America revealed that one sixth of older people are likely to use condoms and one fifth are likely to have been tested for HIV than at-risk people in their 20s (8). The situation of poor access to preventive services and care is worsened by doctors and nurses as often they do not consider HIV to be a risk for their older patients (8). They rarely or never asked patients older than 50 years questions about HIV/AIDS or discussed risk factor reduction (8). Ensuring that all adults have access to and receive recommended preventive services such as correct and consistent condom use instruction, HIV testing information, screenings for chronic conditions should be a cornerstone of public health efforts to promote health and prevent disease (28). Access to such preventive services help increase knowledge among the older people, prevent chronic diseases (co-morbidities), reduce associated complications, lower functional limitations and save money (28).

2.3 Curative Needs of Older people

There are many unanswered questions about the long term impact of HIV medication and several studies are ongoing looking at HIV and ageing (7). What is becoming clear is that older people living with HIV are more likely to experience medical conditions related to ageing at a younger age for example heart disease, dementia, depression high blood pressure, kidney problems and various forms of cancers (7, 29). This then requires older people to take many different medications at any given time to deal with their many health problems most of which are chronic. This has made it difficult for medical personnel to avoid drug interactions (30, 31). It has also been found that once on treatment, CD4 cell levels of older people do not recover as

quickly as in younger patients(7). Experience of worse side effects has been identified among older people though it is still unclear whether their side effects are worsened by ARV treatment, comorbidities or aging (7). A study in Australia has identified the following as common problems associated with older people on ARV treatment; polypharmacy, non-adherence, poor medication management at home (for example, storing medicines in unsuitable places) and poor communication with health professionals (32). Their curative needs go beyond management of their disease but need for skilled personnel and a health-care system that is ready for them (32). Clinicians need in-depth understanding of antiretroviral management, management of other comorbidities and complications typically associated with ageing (32). Curative needs of the elderly seem to be growing as they age.

2.4 Psychosocial Needs of Older people

There is strong evidence that there is higher prevalence of mental health problems amongst people living with HIV compared with the general population (32). Older people with HIV are at greater risk of anxiety or depression, AIDS-related discrimination, bereavement due to loss of spouse or relatives, loneliness, financial distress and lack of support are the major stressors among this group (33). As they age, older people report lower levels of coping self-efficacy, low levels of support from family members, high levels of loneliness and inactive life styles (33). According to Heckman et.al, older people need to be engaged in adaptive coping strategies, such as greater positive reappraisal and active lifestyle for better appreciation and coping (32).

2.5 Social needs of older people

Social needs of older people takes a variety of forms and they have a direct bearing on both their health and emotional needs (34). The need for tangible support, emotional support and feeling accepted is even greater among older adults with HIV/AIDS (27, 34). Family always tend to provide more instrumental (material/financial) support on a day to day basis while friends tend to provide more emotional support (35). Lack of such support has been shown to impact psychosocial functioning and increase internal stigma among older people (35, 36). According to Earnshaw and Chaudior, stigma, is prejudice, discounting, discrediting and discrimination directed towards persons perceived to have HIV or AIDS (34).

HIV related stigma has been identified as a major factor related to high cases of negative psychological states and poor health outcomes which include poor medication adherence, loneliness, depression and poor disclosure (36). This stigma also has an impact on lower levels of social support experienced by older people living with HIV and AIDS (35, 37, and 38).

2.6 Policies and strategies geared at addressing HIV/AIDS issues among older people

Exclusion of the older people has influenced HIV and AIDS policies, strategies and programming initiatives in Botswana in a great way as most are skewed to ages 15-49 who are termed high risk due to being sexually active(28). This can no longer be justified as statistics reveal otherwise; it is time to appreciate and embrace the new paradigm of increasing numbers of the older people living with HIV in order to initiate accessible and age friendly services (21). Some of the factors that influence the health services needs of the older people include age, sex, location, marital status, education, personal factors like knowledge about HIV, behaviour, attitude and cultural factors (12, 15) justifying why health services should be age specific, per the

relevant gender, location and needs based. This proves that there is much yet to be learnt about the older people and HIV in Botswana as the country does not have any programmes for their older citizens on ARV programme. It has also come out from other researchers that stigma directed to the older people affect their chances of seeking health services, leaving them less likely to disclose their status to others due to feelings of shame, guilt, anger, fear of being judged (11, 14, 15). This has been found to contribute to self-isolation which is common as age increases (15).

Addressing the many health needs and challenges faced by older people living with HIV requires a comprehensive response to prevention, treatment, care and support and such is only possible through evidence based research (19). HIV preventive services like information, education, behaviour change communication, condom supply, positive living education have been identified to have excluded the older people in Botswana (29). This is so because HIV and AIDS is still believed to be a 'younger person's disease' yet literature continues to reveal that older people engage in risky sexual related behaviours like multiple concurrent sexual relationships, inter-generational relationships and marriage with young women and young girls who have difficulties to negotiate condom use or refuse sex therefore increasing their risk of contracting HIV (22, 29, and 30). As is, most Physicians are less likely to discuss issues relating to HIV with older people due to low risk perceptions. A study of doctors in Texas found that most doctors rarely or never ask patients over 50 about HIV risk factors (40%) than they were to never or rarely ask patients under 30 (6.8%) (8).

Very few if any prevention efforts are aimed at the older people in Botswana leaving them less knowledgeable yet factors that influence their risks to HIV remain. If we acknowledge the older people are at risk we need to mainstream preventive, curative services and advertising campaigns

to incorporate images and issues concerning the older people persons in our educational tools. As it is, Botswana is in no position to initiate prevention programme for them as they do not know their issues hence justification for this study. Literature reveal that health care infrastructure is ill-equipped to handle the unique treatment and care needs of HIV positive older adults as health workers have limited capacity, skills and sound evidence in most cases to deal with complex health issues presented by the older people(32).

This study therefore set to explore preventive, curative, psycho social needs, personal needs, social needs and other needs of the older people, which the researcher hopes will provide an opportunity for policy makers to develop targeted and impactful services for this target group here in Botswana.

CHAPTER 3: METHODOLOGY

3.1 Study Design

The study is a qualitative approach meant to explore health needs and services gaps for the older people living with HIV and on ARV treatment in Gaborone and Greater Gaborone, Botswana. Source of data was interviews with older people on ARV treatment and interviews with health care workers who care for them in ARV dispensing clinics (MASA). Qualitative methods were used to accord the researcher an opportunity to explore subjective feelings of the older people, probe more in order to get in-depth understanding, meaning and experiences of the older people in an unstructured and flexible setting through the use of in depth interviews guide. The design was chosen basing on the researcher's grounding and experience with qualitative research and its ability to help the researcher answer the research question for this study.

3.2 Study Site

This study was carried out between the 19th February 2015 and 25th June 2015 in Gaborone and Greater Gaborone, Botswana. Gaborone and Greater Gaborone is not a formal or national designated area but a Ministry of Health initiated demarcation for administrative and easy access of services. It has left out Ramotswa village and included Nkoyaphiri and Mogoditshane due to their closer proximity to the city. The study area is therefore made of the capital city Gaborone and Greater Gaborone which comprise of an urban village within the proximity of the city called Tlokweng (10 km from the city) and surrounding areas being Mogoditshane and Nkoyaphiri. With a population of 227333, Gaborone has the largest population in Botswana (2) and an HIV prevalence of 17.1% (1). Tlokweng population is 35 982 while Mogoditshane and Nkoyaphiri has a population of 58 079 (2). The overall HIV prevalence for Gaborone and Greater Gaborone is 12.6% (1). Currently there are 27 health facilities in Gaborone and Greater Gaborone

dispensing ARVs including mobile health posts according to the Data Manager within the ARV Program in the Ministry of Health. This could be attributed to high rates of urbanization in Botswana as 61% of Botswana population is in towns and cities (3). Gaborone has the only centers of excellence for ARV programme therefore resulting in some residents of Tlokweng and Greater Gaborone taking their ARVs in Gaborone facilities. All in-depth interviews will be conducted at these areas only.

3.3 Study Population

The study population was on 20 older people over 65 years old, living with HIV and attending ARV dispensing clinic in Gaborone and Greater Gaborone; as well as 15 Health Care Workers working within ARV dispensing clinics in Gaborone and Greater Gaborone between February 2015 and June 2015. The older people and health workers were recruited based on having attended or worked at the participating clinic for at least 3 months prior to the interviews. Participants had to speak either Setswana or English to be eligible to participate in the study. For this study I targeted health care professionals with a minimum of Diploma in a health related field who are officially assigned to work in ARV dispensing facilities within Gaborone and Greater Gaborone, and this included Nurses, Counsellors and Pharmacy technicians.

3.4 Study Sample

Sampling for this study was done purposively from health facilities within Gaborone and Greater Gaborone among older people and health care workers. The researcher had a letter of permission from Ministry of Health and another from the District Health Management Team (DHMT) who are in charge of ARV dispensing clinics in Gaborone and Greater Gaborone. The letters were used to seek permission and explain the purpose of the study to clinic management. The researcher then worked with facility HCW to identify potential clients from those booked by

identifying patients who met the study criteria a day before the ARV clinic was scheduled. The researcher then approached individual patients in person during medical card collection in a secluded room every morning to introduce themselves and the study. On consenting to hear more about the study, they were taken to a private room for the interview processes. For those older people who were not able to avail themselves immediately for an interview the researcher scheduled appointments at a time and place convenient for them.

It was difficult to adhere to the desired levels of variation among the sites in terms of age and gender as the coming of the older people was dependent on their bookings which are 3 months apart mostly. Posed with this challenge the researcher resorted to recruiting the older people as and when they presented themselves to the facility regardless of their age and gender across facilities.

Health workers were recruited at the discretion of the researcher to meet the study aim and objectives and they all had worked at least 3 months or more within the ARV dispensing clinics during the time of the study. Recruitment was mainly on nurse prescribers, nurse dispensers, medical doctors and pharmacy technicians as they work closely with the population.

3.5 Data Collection

Data was collected using in-depth interviews by the researcher who is a Masters in Public Health student at University of the Witwatersrand. The study was conducted between February 2015 and June 2015 in Gaborone and Greater Gaborone, Botswana. Participants were recruited from the 12 main ARV dispensing clinics within Gaborone and Greater Gaborone. Health Care Workers in the various facilities helped the researcher access clients by allowing her to meet, greet and introduce her study to potential clients with letters of permission from Ministry of

Health and District Management Team during medical records collection every morning. After formal introductions and verbal consent to tell participants more about the study, the researcher took them to a secluded area where participants were taken through an informed consent process which gave the researcher an opportunity to explain all the details, benefits and risks of the study. Written informed consent was also sought for voice recording from each participant who consented before proceeding with interviews. The same process was followed for HCW after being purposively identified to participate in the study.

The researcher used an in-depth interview guide (IDI) during the interviews of both older people and HCW to guide the discussions. Participants were given a choice between use of either Setswana or English interview guide which are both available in the appendix. All interviews were audio taped with the interviewer noting any other non-verbal cues that were presented during the discussion. On average each interview took 30 minutes for both older people and health care workers.

An experienced data transcriber was identified and signed a confidentiality agreement before the transcription process started (see attached confidentiality agreement form in the appendix). All the verbatim transcripts of the audio recordings were handed to the transcriber after every interview for transcription in English and in Microsoft Word and researcher (Ms Oarabile Makgabana-Dintwa) reviewed and corrected each transcription before inputting a summary of her observations at the end of the transcriptions. All the transcripts were then de-identified before being imported into the Atlas.ti 7 software version 7 for qualitative analysis.

3.5.1 Semi- structured In-depth Interviews for Older People

The researcher conducted all 20 IDIs with older people from Gaborone and Greater Gaborone facilities. The focuses of the interviews were to explore perceived health services needs and services gaps as perceived by the older people themselves with emphasis on preventive, curative, psycho-social services and any other non-curative services and gaps. Older people were also given an opportunity to make recommendations towards their services needs and services gaps relating to their care within ARV dispensing clinics.

3.5.2 Semi structured In-depth Interviews for key informant -HCW:

A total of 15 health care workers were interviewed within Gaborone and Greater Gaborone using an IDI guide. The interviews explored services they offer to the older people, services they perceive necessary for the elderly which are currently not provided and services gaps which could be prevention, curative or psycho social related. HCW also discussed non curative gaps that are facility based, service providers related and those that could be as a result of other fellow patients. At the end they were given an opportunity to make recommendations towards the services needs and services gaps as they relate to the care of older people within ARV dispensing clinics.

3.6 Data Management and Storage

The translated transcripts were uploaded on Atlas.ti 7 software basing on whether it was an interview from an older person or HCW reflecting location of interview gender, age and participant identity numbers; for example (Older Person, G-West, Male, 73, PID 001) or reflecting the profession, gender, and years working in ARV dispensing clinic this way *(Nurse Dispenser, Female, 2 years in ARV clinic)*. All digital audio recordings have been saved on a computer with a secure password only known by the researcher while consents and transcripts

are stored in a lockable drawer only accessed by the researcher. All the consent forms and transcriptions will be destroyed two years after the completion of the study.

3.7 Piloting interview guides

Before the actual data collection, the researcher pre-tested the interview guides. The pre-test was conducted with two older people and one health care worker in Mochudi as was planned. Mochudi ARV clinic was selected due to its close proximity to the study site for convenience while the participants were randomly selected basing on availability during the pilot. Mochudi was also selected because of the same context as the study sites and to avoid using study participants for piloting. No changes were made to the tools as they proved easy to understand and acceptable among the participants.

3.8 Data analysis

Transcribed data from audio tapes after the interviews was translated to English on Microsoft Word and imported in to Atlas.ti 7 software which was used to analyse the qualitative data using deductive methods. The transcriptions and translations were done by an independent and experienced transcriber who is currently doing the same work for others within the University of Botswana. The researcher reviewed and corrected all transcriptions to ensure data was a true reflection of the interviews. The researcher read and re-read the transcripts from the software and then started coding to identify important and common themes related to the main aim of the study. A colleague who has experience in research, reviewed the codes after the researcher had coded to assess consistency in coding but ultimately the researcher decided on the final set of codes. Thereafter the researcher established patterns and relationships across themes.

Deductive codes were developed which are guided by the study objectives while still leaving opportunities to code inductively any new data that might come out of the study. Data collected from the older people was input on pre-set guiding themes which include: preventive services, curative services and psycho social services and personal needs, social needs, facility related needs and services gaps. The data was then linked to the demographic information of the older people like age, gender, and length of time on ARVs, location, marital status and educational level during analysis. This demographic data were collected during interviews. Once this was done the researcher established patterns and relationships across themes and demographic variables as presented in the findings.

Health Care Workers also identified and discussed health services they offer to older people, their perceived services needs and services gaps or unmet needs some of which have been raised by the older people during their in-depth interviews. Data from the older people and HCW was reviewed and compared to establish relationships across findings. Ultimately the findings on the health service's needs, services gaps and recommendations were presented and discussed as they came out of the study in relation to the study aim and objectives.

3.9 Ethical Considerations

Ethical approval for this study was obtained from the Human Research Ethics Committee (HREC) of the University of the Witwatersrand, South Africa (Date of approval: 19/11/2014; Clearance certificate number M140923) where the researcher is an MPH student. University of Botswana Institutional Review Board (IRB) where the researcher is an employee also approved the proposals on the 05/02/15: Ref. UBR/IRB/1546 and the researcher was also ethically cleared by the Ministry of Health Research Ethics Review Board on the 13/02/15: Ref. No HPDME 13/18/1 IX (207) to gain access to the health district. Lastly permission was granted by the

Gaborone District Health Management on the 18/02/15: Ref. GG DHMT/15/2/i for the researcher to have access to local facilities and patients.

3.9.1 Informed consent

All participants invited to take part in the study were given full details of the study after which they were required to voluntarily sign two informed written consent forms which gave the researcher permission to interview them as well as audio record the proceedings. All those who agreed to take part were given Participant Identity (PID) which the researcher had created to protect the identity of the participants. The researcher continually emphasized that participation in the study was strictly voluntary and participants were free to withdraw anytime they feel like. All interviews were conducted in a secluded place to adhere to high levels of privacy for each participant. The researcher did not pay any money to the study participants for their participation as they were interviewed during monthly visits at health facilities and health workers were followed to work places. Audio materials and study consent forms from the research are kept in a secure and lockable cabinet accessed only by the researcher. All the data stored by the researcher will be destroyed two years after completion of the study.

3.9.2 Confidentiality

Confidentiality was maintained at all levels with consent forms being kept by the researcher in a lockable drawer away from the other data that can be used to make a link between the consent and interview data. Audio records have been saved in a password protected laptop and shall be destroyed two years after publication of the study. Participant's anonymity was maintained and protected at all levels of the study as they were referred to using PID numbers only. The data

transcriber signed a confidentiality agreement form through which he committed not to disclose any data from the study.

3.10 Limitations of the study

Participants attending ARV clinics are mostly scheduled to come every three months and considering the number of older people on treatment it proved to be a slower process to identify them on a daily basis across Gaborone and Greater Gaborone facilities. The other challenge was the age difference between the researcher and the participants which might have contributed to some participants being uncomfortable to open up about personal or sensitive data which might have affected the outcome of the study. Although the study was not initially designed to be generalised to the whole nation because it is a qualitative study, it would have been a welcome development if it was a quantitative study considering the level of saturation which was reached during interviews. It was difficult to adhere to the desired levels of variation within the data collection sites in terms of age and gender as the coming of the older people to facilities was dependent on their bookings which are 3 months apart. The researcher ended up recruiting everybody who came in, therefore this data represent those older people who had booking within the study time only (February 2015-June 2015). This study covered only a Gaborone and Greater Gaborone in the southern part of Botswana therefore the results do not reflect the situation of older people affected by HIV/AIDS in other parts of the country. This needs to be taken into consideration when using the results of this research.

CHAPTER 4: FINDINGS FOR INTERVIEWS WITH OLDER PEOPLE

4.1 Introduction

This chapter summarises the findings from twenty (20) interviews with older people. Older people included: eleven (11) males and nine (9) females, age ranged from 65 to 87 years, with ten (10) married, five (5) widowed and five (5) divorced. Years on ARV treatment ranged from four months to thirteen (13) years. Of the 20 older people twelve (12) did not have any education, six (6) had only primary education and the last two had junior secondary education.

4.2 Emerging themes related to interviews with older people

The findings from older people will be organised and be presented in this four major themes:

- Experiences of older people living with HIV since diagnosis
- Services they are offered within ARV dispensing clinics in Gaborone and Greater Gaborone
- Description of health services needs and gaps as perceived by the older people
- Recommendations with regard to perceived services needs and gaps for the older people.

4.3 Thematic Framework for major themes related to interviews with older people

For each dominant theme, outlined in table 4.3, there were some associated key issues and concepts that served as the subsequent themes and resulted in the formation of thematic framework shown in the table 4.3

Experiences of older people living with HIV since diagnosis ▪ Testing for HIV ▪ How older people think they contracted HIV ▪ Disclosure ▪ Experience with ARV treatment
Services offered within ARV dispensing clinics in Gaborone and Greater Gaborone ▪ Curative services -ARV treatment -Blood tests -Consultation with the doctor ▪ Non curative services -Health education, morning prayers and motivation -Counselling -Condom distribution -Queue management
Description of health services needs and gaps as perceived by the older people ▪ Prevention needs ▪ Curative needs ▪ Psychosocial needs ▪ Other needs -Nutritional needs -Queue management -Respect
Recommendations with regard to perceived services needs and gaps for the older people. ▪ Prevention related recommendations ▪ Curative services related recommendations ▪ Psychosocial related recommendations -Stigma and disclosure -Promoting disclosure ▪ Other recommendations -Food rotation Queue management -Increase ARV supply -Avoid name calling

Table 4.3: Thematic framework from interviews with Health Care Workers

4.4 Experiences of Older People Living With HIV

This section of the report outlines older people experiences living with HIV. It focuses on their journey since diagnosis to date. The discussion will focus on the major themes that came from their experiences being: what motivated them to test, how they think they got HIV, disclosure and experiences with treatment.

4.4.1 HIV Testing

Fifteen of the twenty older people interviewed said they tested when very sick while the other five just tested as part of '*Know your status'* campaigns that were taking place in Botswana and there were never sick.

"I was bound to a wheelchair for years; I was almost dead. Nobody thought it could be HIV therefore we kept testing for everything else but HIV. I eventually begged doctors to test me. I am sure I got it caring for my son who passed on. Thanks to ARV treatment, I am well today."(Older person, female, 70 years)

"I tested because I was very sick. I started treatment with very low CD 4 count of 85, very sickly and I suspect I got HIV caring for others." (Older person, Male, 70 years)

Of all the twenty older people, only two males boldly shared that they tested because they suspected they could be infected with HIV from their risky behaviours.

"I started treatment 12 years ago with a CD4 of 74. I had pneumonia and herpes zoster and was very sick. I know I liked women and alcohol a lot. My doctor advised me to test and warned me to stop my risky behaviours as I was going to die. I was not surprised by the results." (Older person, male, 73 years).

"I am 67 years old now; I have been on treatment for the past 7 years. I will always be thankful to his wife who 'pushed me' tirelessly for many years to go and test in vain. I knew I liked women and alcohol but could not just do it until I was pushed." *(Older person, male, 67 years)*

The rest of the older people indicated that they experienced either recurring TB, unexplained loss of weight or many unexplained sicknesses which prompted their spouses or children to encourage them to go for HIV testing.

4.4.2 How older people think they contracted HIV

Participants were asked to identify their probable risk factors for HIV infection: Two females and one male thought they got HIV from caring for loved ones. Two males aged 67 and 73 were sure it was due to their risky behaviours while the rest of the older people had no idea how they might have got the virus. Three of the older people interviewed were infected yet their spouses were and are still HIV negative. The other five voluntarily shared that they were taking treatment with their spouses. Only one older person who has been on treatment for seven years, indicated that they struggled to accept their positive status for years trying to figure out how they got it.

"*My wife and I blamed each other and fought for years. Thanks to continuous counselling we finally accepted and started treatment 7 years ago." (Older person, male, 73 years).*

4.4.3 Disclosure

Of the interviewed older people majority (16) had disclosed either to their spouse, children, friend or colleague at work. Three of those who had not disclosed indicated that it is because they widows aged 68, 69 and 70 while the other male aged 66 was not comfortable discussing his status to anybody as he feels he is still well and can handle his health issues with ease.

4.4.4 Experience with ARV treatment

All older people praised ARV treatment as having given them an opportunity to live a healthy life again. Seventeen of them have never experienced side effects but good health. Only three experienced minor side effects; two experienced severe rash which lasted two months after treatment initiation, while the other is still experiencing continuous nausea but hope it will be resolved soon.

"Can you believe I started this treatment at age 54 and 13 years later I am still this strong? My life has changed for the good since starting ARV treatment, they saved my life and I thank the government of Botswana for that. I lost my spouse, friends and relatives who were big headed." (Older person, female, 67 years)

"I was a walking skeleton before starting treatment. I suffered from pneumonia, herpes zoster which left me bedridden; I could not eat and was told my CD4 was only 74. Today I am a gentleman, health and independent." (Older person, male, 73 years).

4.5 Services offered to Older People as part of HIV Care

Older people were asked to identify all curative and none curative services they are offered as part of their HIV care within Gaborone and Greater Gaborone health facilities. Services will be classified in this section of the report as curative and none curative.

4.5.1 Curative services

All Older people receive this three basic services being ARV treatment, bloods tests and review by a medical doctor consistently while some services vary per facility. This is what older people said about the services they receive:

4.5.1.1 ARV Treatment

All interviewees receive ARV treatment which is either prescribed by a nurse prescriber or a medical doctor and it is dispensed by either a nurse dispenser or a pharmacy technician. Every individual is given varying supplies depending on their doctor's assessment which vary from a month to three months' supply. Defaulters and those who had forgetfulness challenges were kept mostly on a month supply for close monitoring. Almost all older people are happy with the ARV treatment they receive except for two who said:

"I take this treatment but nobody tells me what it does exactly to my body and the virus. I agree ARVs are working because they saved my life but i wish somebody could tell me exactly how they work." (Older person, female, 69 years). This widow has been on treatment for five years now.

The other female, a 66 years old widow who has been on treatment for 10 years now says she wishes the government could come up with an HIV vaccine to inject them as taking treatment all her life is not easy especially after she lost her husband who was her source of support.

4.5.1.2 Blood Tests

All older people interviewed indicated that one of the major services they receive in their facilities was blood draws for various tests. All they know is that blood tests are done at various intervals mainly to assess the viral level in the body. Only a few older people had a clear understanding of their blood results.

"My doctor always collects blood, test then tell me my CD4. Right now I know it is around four hundred and something. I still need more explanation but I appreciate as all our doctors are foreigners."(Older person, male, 87)

"I always ask young Batswana nurses to come and interpret for me the blood results. They always use simple language and examples to help me understand my blood results better. I once

defaulted and treatment was stopped for a few months I thought I was going to die, since then I want to know everything and how I am doing". (Older person, female, 66 years)

To indicate the varying levels of satisfaction with this service some older people indicated that results are either never given to them or when they are given; they never understand what the results mean.

"*For the past five years my blood is collected all the time in this clinic but when I see the doctor to hear the results all he does is write them on my card and encourage me to continue taking my medication well. I always assume I am doing everything well though I wish somebody could explain my blood results to me. They collect lots of blood that is why this worries me."(Older person, female, 69 years)*

"If I had a choice and could afford I would have stayed with the private practitioner; when it comes to taking their time and explaining blood results, reminding you of your appointments surely they are far advanced. Here may be is because we are too many for one doctor. Apparently the doctors here see us (ARV patients) and everybody else. No wonder they forget or do not have time to give and explain results. I don't blame the doctors they are doing their best for us."(Older person, Female, 70 years)

Overall most of the older people were not satisfied with this service and wished it could be improved.

4.5.1.3 Consultation with the Doctor

All patients indicated that they are always seen by doctors on set dates. According to older people, doctors review and assess their disease progress, they consult them for many other medical conditions they have. Some indicated that doctors encourage them and provide counselling on matters relating to eating well, condom use and adherence to treatment. A few

challenges were raised in relation with rotation of doctors which make it difficult to establish a relationship with the doctors. Language barriers are a big issue as most (12) of the older people interviewed have never been to school at all yet almost all their doctors are foreigners who only use English as the medium of communication. Several of the older people who indicated that they have forgetfulness challenges or do not always understand the doctor said they bring somebody with them (spouses and or children) when they are to see a doctor because that is the most important visit.

4.6 Non Curative Services

Besides the curative services discussed earlier, older people identified some non-curative services they are offered in varying levels in different facilities. The following were identified as some of the non-curative services offered to older people: morning health education, prayers and motivation, counselling by various individuals, condom distribution, and queue management to assist older people not to queue. This section of the report will discuss each of the non- curative services as expressed by older people.

4.6.1 Health Education, Morning Prayers and Motivation

Less than half of the interviewees indicated that they constantly receive health education as part of their care. Education was said to focus on avoiding alcohol while on treatment, consistent and correct condom use, nutrition education, general positive living which includes disclosure, self-acceptance and adherence to treatment.

"Our nurses educate us on adherence to treatment, eating healthy and balance food as well as using condoms correctly every time. They give us chance to contribute to the discussions and motivate others too."(Older person, Male, 69 years).

A few older people indicated that they are not shy to openly educate and encourage others as they are not afraid of stigma. Their motivation is from experiences of what HIV did to them and their loved ones.

Health education is combined with prayers and words of motivation by both HCWs and patients. These services are offered every morning regardless and it is enjoyed by those who are in the facility before daily services resume. The service is led by health care workers and patients can volunteer to educate, pray or motivate others. Some older people do not view this service just as routine prayers and words of encouragement but more an opportunity for people to share experiences, share words of wisdom from the bible which relate to people living with incurable diseases like HIV.

"*It is this morning prayers that encouraged me to go to church and repent. I pray, share a scripture from the bible and educate others every morning when I am in the facility. I use myself as an example as I started treatment with a CD4 of 74. I repented and have been going to church for almost 11 years now, I stopped drinking and are faithful to my wife because of motivation I got from others when I started treatment. I have nothing to lose by sharing my wisdom and experiences with young people. We need to pray more for God's forgiveness," (Older person, Male, 73)*

It was evident from the interviews that older people who are never in the health facility early in the morning never enjoy this service.

4.6.2 Counselling

Older people have been offered various types of counselling depending on their needs, some have gone through adherence counselling every time they default from treatment or miss appointments and family counselling when they have challenges that are perpetuated or that affect family. Some indicated that they are offered counselling for general social problems like drinking. One of the older people who has been on treatment for three years defaulted to an extent that treatment had to be stopped.

"I used to forget to take treatment and finally they stopped giving it. All they did was offer me unending counselling by different people; doctors, nurses and pharmacy personnel for many months. I was worried that I would lose my life but they told me counselling was important before I start treatment again. It helped because I am now more motivated and do not forget my treatment."(Older person, female, 66 years)

4.6.3 Condom Distribution

A few of the older people indicated that they are given free condoms after being encouraged to use them correctly and consistently. Some indicated that they never ask for condoms as they are no longer sexually active. Only one older person complained that they are given very few condoms when they want more which affect their availability at home when they want to use them.

"I hate using condoms as they make sex unpleasant but because I am forced to use them I wish they could give me more so that I do not have to come back too often. I do not want to be labelled 'Mr Condoms' because I come back to ask for them many times as an older man."(Older person, Male, 73 years)

4.6.4 Queue management

Older people are aware and they indicated that there is government policy that allows older people 65 and above not to queue for health services. It is clear that older people who are visibly old and those who speak out if not identified by health workers benefit from this directive. There are challenges though as some patient's question the implementation of this policy in an HIV clinic as this is a behavioural related disease. Overall older people appreciate and feel this policy is a sign of respect from the government and it gives them honour.

"My clinic changed to the appointment system but those do not always work. For example I was here from 7:00 for a 7:30am appointment but now it is after 10 am and I am still here because of the several services I have to receive. I have seen the doctor, have to take bloods then I am going for ARV treatment collection. We thank the Government for this policy; otherwise I would leave this place at 4pm tired and hungry."(Older person, Male, 73 years)

Though some gaps were identified in delivery of non- curative services across facilities according to older people, those who received them appreciated and those who did not felt more needed to be done to fill that gap as the services were not consistently given like curative services yet they are very useful.

4.7 Health Services Needs and Services Gaps for Older People

This section of the report discusses health services needs identified by older people attending ARV clinics in Gaborone and Greater Gaborone. The results will be presented to highlight prevention, curative, psych-social needs and any other as identified by the older people. It is clear that as older people discuss their needs, they also highlighted the gaps which result in such needs.

4.7.1 Prevention Needs

From the interviews, older people identified health education needs which focus on adherence, avoiding use of traditional medicine, correct condom usage and nutrition as their biggest needs. They feel education used to be consistently offered when they started treatment and it is no longer happening. Some older people indicated that they depend on their children for health education because they get none in health facilities.

"*We need campaigns and education initiatives targeting older people as most of us are not educated. Most older people use traditional medicine- I am sure of that but nobody talk to them about it; some of us do not use condoms consistently but nobody educate us on the effects of such. I am married to a women 30 years my junior and need to hear how other older people in my situation deal with such situations- we used to share experiences and this is missing now in ARV clinics." (Older person, male, 73 years)*

4.7.2 Curative Needs

Older people seem happy overall with curative health services they are offered in Gaborone and Greater Gaborone health facilities. Regardless of this a few identified the following as some of their curative related needs; some request for simpler treatment regime as they forget easily if they take treatment more than once a day and some need health workers to explain their results better to improve their understanding of their health performance. Most older people on hypertension treatment expressed unhappiness with issues relating to drug in availability which they have to collect from other facilities and lastly they would like to be given longer term supplies so that they do not have to come back to the clinic too often.

One older person indicated that as they age it is difficult to cope with three tablets and want only one like other people on treatment. A few interviewees indicated that rotation of doctors make it difficult for them to share personal problems openly and therefore suggest that doctors be facility based for them to build relationships. Lastly a few older people would like to be given treatment for 3 to 6 months as monthly visits to facilities are proving to be expensive to them.

4.7.3 Psycho-social needs

Counselling was identified as one of the non-curative services offered in ARV clinics within Gaborone and Greater Gaborone facilities that most older people feel it is not enough, they need more of this service. Some seem to have social or personal issues that they want to discuss but with nobody to reach out to. One indicated during the interview that they wish people could ask them more about their problems so that they share knowing such people want to listen and help-right now they do not want to bother people hence their keeping quite.

Right now I have erectile dysfunction but have nobody to talk to. Everybody is always busy in this clinic and I have no idea who is the best person to offer me counselling. (Older person, Male, 75 years)

4.7.4 Other needs Expressed by Older People

4.7.4.1 Nutritional needs

Older people expressed having nutritional needs (food); they would like to be assisted with food ration or be given fruit basket as their current older age pension is not enough to buy food and other needs for the month. The also expressed a need for education on government social services so that they access such services especially food rations for destitute as most older people who are not working consider themselves to be destitute.

4.7.4.2 Queue Management

Older people indicated that they need to be supported not to queue as they cannot stand long queues in some health facilities. Those who are not visibly old indicated that people always complain whenever they initiate the issue of not queuing. They therefore encourage nurses to be proactive on this issue as some comments made by fellow patients are derogative.

"I overhead other patients complain that this respect should only be extended at post offices and banks not in an AIDS clinic as we are all here because of our deed. What an insult by our own children." (Older person, Male, 66 years)

4.7.4.3 Respect

They also indicated that they need to be respected and for their privacy to be respected and protected.

"*I am not happy that when older people ask for help HCW respond by shouting therefore attracting attention and in the process disclosing our conditions. Not all older people have hearing challenges. They need to respect older people and their privacy. (Older person, Male, 70 years)*

"I once forgot my appointment and came at the wrong time, instead of the HCW who was seeing me to just advise me appropriately; she called several nurses and told them how much I am not adhering to treatment and that they should consider stopping it until I bring somebody to support me. I felt disrespected but could not say much about it."(Older person, Female, 70 years).

Besides the above indicated needs and gaps, older people expressed gratitude to the HCWs who care for them with respect all the time. Most of them are thankful for the care, guidance and support they get from those mandated to care for them.

4.8 Recommendations with Regard to Perceived Services Needs and Gaps for the Older People

Owing to the services needs and gaps older people identified, the following recommendations were made and they will grouped as prevention, curative, psycho- social.

4.8.1 Prevention related recommendations

Older people recommend that health education should be revived, strengthened and targeted to older people. They acknowledge their understanding limitations due to lack of education and urge people to be patient with them. They propose that education be focused on some older people hiding behind culture and not acknowledging new ways of doing things- HIV is a new disease that require change of mind set. The other issue to be targeted with education is use of traditional medicine which according to some is still prevalent among the older people.

"Older people should stop being big headed and embrace ARV treatment. Those who have lost partners should avoid new relationships as it is a form of stress and risk since most of them cannot use condoms well. It is only through self-respect that most older people can live longer." (Older person, Female, 70 years).

Some emphasised the importance of sex education for older people as some of them are newly married, some are married to younger partners and some are widows looking for new partners. Still on education related recommendation, older people are of the suggestion that adherence education be strengthened as now it is rushed.

4.8.2 Curative related recommendations

Older people are happy with curative services and had this few recommendations which are related to their care:

Older people are concerned with the constant changing of doctors which make it difficult to establish relationships with them. This is a challenge as some issues are sensitive and cannot be shared with every doctor they meet. They recommend that doctors be assigned per clinic for continuity of care.

Older people indicated that they prefer getting to the health facility very early so that they finish early and go back home. Some are not happy with the booking system as they are not adhered to. They suggest that they be allowed to come as early as they can.

Older people who have forgetfulness challenges suggest that they all be given a single tablet that is taken once a day. Though most of them do not acknowledge that they forget taking treatment, a few who do wish there was a permanent solution to this as their forgetting will be increasing with their age. One older person who once defaulted and was stopped from taking the treatment for a while is quite fearful of forgetting treatment and is advocating for a vaccine.

Another major recommendation that cuts across was the appreciation that older people had for the health care workers caring for them. They recommend that such health care workers continue with their respect, support and availing of ARV stocks.

4.8.3 Psycho-social related recommendations

4.8.3.1 Stigma and Disclosure

Some older people who are worried about stigma and their HIV status disclosure are not happy that the clinic is separate from other clinics and therefore fuel stigma. One said this clinic discloses their status indirectly. They recommend that the clinic be integrated in to the rest of the clinic services. Still on the issue of stigma and disclosure some older people were not pleased with some nurses who shout when communicating with older people as they end up disclosing their status indirectly. They recommend that health workers respect them and their privacy.

4.8.3.2 Promoting disclosure by all older people

Older people advocate for disclosure which is visible from the twenty we interviewed. Most of them have disclosed either to their partners, family or colleagues. Most of them advocate and encourage fellow older people to disclose to significant others for support.

"I have disclosed my status to my children except one whom I do not trust, they drop me for my clinic visits, they sit in during consultation so that they listen and guide me, the remind me to take treatment, they make sure I eat well especially fruits hence my good health."(Older person, Female, 70 years)

4.8.4 Other Recommendations

4.8.4.1 Food Ration

Older people appreciate the care and respect they receive in facilities but recommend that the government assist them food rations or fruits as the P300 pension they receive is not enough. Some recommend that they be given P200 worth of fruits and vegetables every month to supplement and sustain their good health. Not only that, some recommend that government should consider giving older people on ARVs snacks while they are waiting in health facilities as they wait a bit longer especially those scheduled to see a medical doctor. Most of them attributed this requests to their level of poverty, loss of bread winners and the fact that they share their pension with grand children who are orphaned.

4.8.4.2 Queue Management

Older people are recommending that the government directive that older people should not queue for services should be implemented universally as in some facilities it seem not to be enforced fully. For this directive to be effective ARV clinic patients should be educated about it so that it does not come out as if it older people making such requests.

4.8.4.3 Increase of ARV Supply

Some older people are of the recommendation that they should be given at least 3 to 6 months' supply so that they do not come back very often as it is expensive.

4.8.4.4 Avoid name calling

Some male older people expressed displeasure at the use of the word 'Mdala' or 'Madala' which they feel is derogative and disrespectful. They recommend that they be called 'Monnamogolo' or 'Mogolo' which is respectful and culturally accepted.

CHAPTER 5: FINDINGS FOR INTERVIEWS WITH HEALTH CARE WORKERS

5.1 Introduction

This chapter summarises the findings from fifteen (15) interviews with Health Care Workers (HCW) from Gaborone and Greater Gaborone. HCW included eleven (11) nurses and four (4) pharmacists; twelve (12) of whom were females. The length of working on the ARV programme ranged from 6 months to 6 years.

The findings from HCW will be presented in four major themes:

- Experiences related to caring for older people living with HIV and on ARV treatment
- Services offered older people within ARV dispensing clinics in Gaborone and Greater Gaborone

- Perceived health services needs and gaps relating to the care for older people attending ARV clinics and
- Recommendations with regard to identified perceived services needs and gaps for the older people on ARV treatment.

5.1 Thematic framework of major themes from interviews with health care workers

For each dominant theme, outlined in table 5.1, there were some associated key issues and concepts that served as the subsequent themes and resulted in the formation of thematic framework shown in the table 5.1

Experiences of HCW Caring for Older People living with HIV Positive experiences ▪ Self-acceptance and disclosure ▪ Low defaulter rate ▪ Good adherence levels Negative experiences ▪ Poor adherence due to forgetfulness ▪ Low literacy rates ▪ Older people not keen on discussing sensitive issues
Services offered to older people according to HCWs ▪ **Curative services** -Vital signs assessment and consultation -Bleeding -Prescribing and dispensing of treatment - Referral for cancer screening - HIV Counselling and testing ▪ **Non curative services** -Morning health education -Counselling -Defaulters follow up ▪ **Administrative services** - Filling of patients documents and test results - Stock taking

Perceived health services needs and gaps for older people from HCWs ▪ Lack of targeted health education ▪ Need for targeted and consistent counselling ▪ English language interpretation ▪ Poor patient follow up ▪ Poor queue management ▪ Poor social support for older people ▪ Food ration support ▪ Pill burden due to comorbidity ▪ Lack of skilled personnel ▪ Loss of sight and hearing
Recommendations with regard to perceived services needs and gaps for the older people. ▪ Queue management for older patients ▪ Improve counselling services ▪ Manpower planning ▪ Establishment of shelter for older people ▪ Targeted health education and adherence counselling ▪ Social support for older people

Table 5.1: Thematic framework from interviews with health care workers

5.2 Experiences of HCW Caring for Older People living with HIV

This section of the report explores experiences of HCW caring for older people living with HIV in Gaborone and Greater Gaborone. The discussion will focus on the major themes that came from their experiences being: what is working well (positive experiences) and challenges while caring for older people.

5.2.1 Positive Experiences

Health care workers working in facilities based in Gaborone which are in the city centre indicated they have very few older people while those in Greater Gaborone (outskirts) have more. Most health care workers indicated they experience more challenges than positives while caring for older people. The following are some of the common positive experiences of HCW who care for older people:

5.2.2 Self-acceptance and disclosure

Older people do not seem worried about stigma like younger people. Most older people have self-accepted and therefore stigma does not seem to be a big issue for them hence high cases of disclosure among older people. These disclosure is also said to be helpful in getting older people the support from significant others and it makes patient follow up easier as health workers can contact those openly known to be the support system of older people in case of challenges like defaulting.

5.2.3 Low defaulter rate

According to some HCWs, older people who are well rarely default unless if they have forgetfulness problems. As proof of their commitment to their health care, if they are not sure about something they come back between appointments to enquire so that they do things right. HCW also indicated that they find older people to be easy and cooperative to work with as they are committed to their health.

"Older people become anxious if given monthly appointment as they sometimes come back before the actual date to verify their dates; same if they are given widely spaced appointments like three months they come back to verify. This shows their ultimate commitment to their health." (Nurse Dispenser, Female, 8 months in the ARV programme).

5.2.4 Good adherence levels

Adherence among older people is usually good/high except for those with forgetfulness challenges or without family support. All they need is to be given clear and repeated instructions. In cases of missed doses they are very honest than younger ones.

"Older people know their medication very well, when to take it and how to take it. About 75%-80% adhere well to their treatment and they follow instruction to the dot. I enjoy working with them as they are not influenced by many things, they self-control e.g. they avoid alcohol when on treatment; they disclose to significant others freely and they ask for help if they do not understand."(Pharmacist, Female, 1 year in ARV programme)

5.2.5 Challenges/Negative Experiences

Regardless of the positives raised above by a few HCW, most seem to experience more challenges while caring for older people on ARV treatment. The following were the major experiences raised by HCW:

5.2.5.1 Poor adherence due to forgetfulness

From HCW experiences, older people forget what they are told during health education, consultation and dispensary therefore requiring that the message be repeated several times. The older they are the higher the chances of forgetfulness and reduced adherence.

"We always have to look out for them and guide them otherwise they queue in wrong places only to be sent back, come on unscheduled dates, miss other scheduled services even while in the facility" (Nurse Prescriber and Dispenser, Female, 6 years in ARV clinic)

"Older people need holistic care and patience, they need nurses who can focus on other age related conditions and issues they deal with not just HIV as some take lots of medications and come for various appointments hence their forgetfulness. They have issues like stress and anger due to ill health, social problems like loss of children, spouse, being bread winners etc."(Nurse Dispenser, Male, 2 years in ARV clinic)

Older people are advised to set alarms to remind them of their appointments and pill time but for some it still does not work. Even when they are encouraged to bring care givers to support them, some don't as they want to be independent and do things on their own.

5.2.5.2 Low literacy rates

HCW seem to have deduced that the more educated older people are the better they are to manage. Those with more challenges are those without education. One nurse dispenser who have been with the programme now for a year from the outskirts of Gaborone said their situation is worse as several of their older people miss doses, dates for bloods collection and refills to an extent that they would queue the whole day for a doctor when they are supposed to have gone for refill only.

5.2.5.3 Older people not keen on discussing sensitive issues

HCW indicated that they find it a bit of a challenge to discuss sensitive issues with older people especially when they present with sexually transmitted infections as they respond by dismissing or cutting the conversation. Once they do not want to discuss an issue they ignore or dismiss it. In some instances when you talk about sexuality and condom use issues, they just laugh the issue off.

"This is a big challenge that we struggle with as HCWs. Already most older people want everybody to believe they got HIV through caring for others and not other means. Only a few admit to having contracted HIV through sexual contact. Sexuality issues are a no go area for them." (Nurse Prescriber, Female, 2 years with ARV programme).

5.2.5.4 Increased Workload

To effectively meet the health needs of older people and their challenges, there is need for more employees so that they can reserve time while others are not suffering or waiting for too long.

They need more education, continuous counselling and referral support where necessary as part of their care.

"Older people need more attention to understand basic things and it takes times which HCWs do not have. They need things repeated several times before they comprehend. They sometimes misinterpret what is said which is why HCWs advocate for family support at every visit." (Nurse Dispenser/Prescriber, Female, 6 on the ARV programme)

5.3 Services Offered to Older People according to Health Care Workers

This section presents themes related to services offered to older people by HCWs in ARV clinics. Major themes that emerged from discussions are:

- Curative services
- Non-curative services
- Administrative services

5.3.1 Curative services.

HCW across Gaborone and Greater Gaborone facilities provide consistent curative services to older people on ARV treatment. The most common services include the following:

5.3.1.1 Vital signs assessment and consultation

HCW especially nurses are involved in assessing vital signs of older people before consultation by the doctor or the nurse prescribers. Consultation is extended to many other different diseases like hypertension, diabetes, arthritis, gout, sexually transmitted infections, tuberculosis screening during their scheduled ARV visit.

"Vital signs assessment are critical in older people as we are able to identify other underlying issues besides HIV- for example for those with hypertension we assess for social problems and

intervene appropriately then encourage them to reduce salt, exercise, eat well and avoid stressors."(Nurse Dispenser, Female, 2 years on ARV programme)

5.3.1.2 Bleeding

All patients go through bleeding for various HIV related tests as prescribed by the consulting doctor e.g. liver function test, viral load, CD 4 at various times of their care. Bleeding is offered by nurses, phlebotomist or laboratory technologist.

5.3.1.3 Prescribing and dispending of treatment

Treatment is prescribed by medical doctors or nurse prescribers and then dispensed by pharmacy technicians or nurse dispensers. Before prescribing and dispensing, HCWs do pill count as a strategy to assess for adherence before the next refill and the process is participatory as older people are given an opportunity to lead the pill count.

5.3.1.4 Referral for Cancer screening

All our female patients are prone to cervical cancer by virtue of being older and HIV positive. They are referred to Bontleng clinic for Pap smear at set times. Most older people do not like the fact that they have to leave their facility to access it somewhere else.

5.3.1.5 HIV Counselling and Testing

All ARV facilities offer HIV counselling and testing services as they promote couple counselling and testing for HIV among other things. All patients seen within ARV facilities are encouraged to bring their partners for counselling and testing. Nurses assist with interpretation of results in a language understandable to older people if testing was done by the doctor.

5.4 Non curative services

According to HCWs non-curative services are offered in a consistent way though they are not targeted to older people.

5.4.1 Morning health education

It is done to educate all patients with emphasis on prevention, treatment, care and support. The focus is on issues like nutrition, adherence, disclosure, promotion of condom usage, awareness on available social services, positive living promotion, alcohol use reduction, encouraging all patients to avoid traditional medicine use while on treatment. It is initiated by HCWs but can then be led by patients who volunteer to share their life experiences related to prevention, treatment and care while taking ARVs. Some older patients miss this service though a good number does attend as most able bodied older people like coming very early to the facility.

5.4.2 Counselling

Counselling which can be individual, partner, family and group counselling before, during or after treatment initiation is offered basing on needs. Counselling is only mandatory at the beginning of treatment to assess for readiness, before the next supply to assess for adherence and motivate for continued adherence. During adherence counselling some activities like pill count are done to identify defaulters and inform decision making on future patient care.

5.4.3 Defaulters follow up

Defaulters follow up is sometimes done through telephonic contact or home visiting though transport continue to be a challenge for most facilities. If older people cannot be reached their buddies may be contacted only if they have disclosed.

"We followed up one of our older patient's months after they defaulted only to find they have long passed on. It was so embarrassing but the workload, lack of staff dedicated to identifying defaulters and none disclosure by some older people can sometimes make us look incompetent. How I wish we could identify and follow up defaulters immediately" (Nurse Dispenser, Female, 2.5 years in ARV programme)

5.5 Administrative services

The other major role of HCW working in ARV clinics is filling of patient's documents and blood test results as well as stock management to ensure medication is continually available. Stock availability of both ARV treatment and related medications is the responsibility of nurse dispensers and pharmacy technicians.

5.6 Perceived Health Services Needs and Gaps for Older People from HCWs

Health services needs and gaps for older people shall be presented according to thematic area which were identifies as; lack of targeted health education, need for targeted and consistent counselling, poor patient follow up, lack of English interpretation facilities which impacts communication between older people and medical doctor, need for social support, food rations and queue management to reduce waiting time by older people.

5.6.1 Lack of targeted health education

According to HCWs health education targeted for the elderly is not there at all- it needs to be improved. Health education that is done is general not targeted at all. This is worsened by the fact that some older people come late morning to the facility while education is done very early in the morning before services start. Due to older people's lower levels of literacy and comprehension, there is need for targeted health education and awareness initiatives. According to most HCWs, group health education is not effective for older people. They are best suited for one on one or small group education as they are slow and therefore need things to be repeated.

5.6.2 Need for targeted and consistent counselling

There is need for on-going counselling targeted at older people but it is not possible due to staff shortage in most facilities. Most older people are encouraged to always bring a relative for support to help reinforce messages from counselling sessions.

"Some older people who have been on ARV treatment for years still seem confused by basic things like how the virus is spread; some cannot recall the basic precautions for somebody living with HIV. Education and counselling should be strengthened for this group otherwise we are all at loss here." (Pharmacy Technician, Female, 4 years in ARV programme).

Adherence counselling needs to be strengthened as most do not adhere well as revealed through pill count. In the ideal situation, adherence counselling should be at every encounter or meeting as this is a special group with special needs but unfortunately this is not possible. Social counselling should also be consistently offered as older people have shown to struggle with social problems they do not readily disclose unless if asked. With current staffing challenges in facilities and ARV clinics this remains a big services need and gap for older people.

"Older people need to be attended to by vigilant officers who can look closely at their records so that they are not missed, so that they do not miss appointments and their challenges are addressed timely." (Nurse Prescriber and Dispenser, Female, 6 years in ARV clinic)

The other major gap is lack of a full time and qualified counsellors in ARV facilities as in most cases some patients who have challenges and seek counselling end up just being seen by the nearest staff member who can create the time though they might have minimal experience in counselling. Having said that some HCWs are not happy with older people who have been on treatment for a long time as they are said to take counselling services for granted.

5.6.3 English Language Interpretation

With over 90% of medical doctors who consult our older patients in ARV clinics being foreigners and with high illiteracy rates among older people, language is a big factor and most local health workers cannot assist as they are also too stretched by the workload. Older patients complain that they do not hear what doctors are saying but there is little that can be done. Doctors also have a challenge as they do not fully comprehend needs expressed by older people during consultation.

"If we are not there to interpreter sometimes the situation can be so bad that an older person would continually say their disease in Setswana and point where the problem is to no avail. This is frustrating to all parties and it is time we find a permanent solution to this problem of communication barrier due to foreign doctors." (Nurse Dispenser, Male, 1 year with ARV programme).

5.6.4 Poor patient follow up

Due to staff shortage and non-availability of transport it takes time for clinic staff to identify those lost to follow up and actually follow them. Sometimes they are followed after some months only to find they have long passed on. Overall according to HCWs the quality of care offered to older patients is not pleasing and they wish things could be improved. It was indicated that the data management system used in ARV clinics does not have the capacity to automatically identify those who missed their visits- it is done manually.

5.6.5 Poor queue management

Health workers acknowledge they have not been on point in enforcing this directive from the Office of the President that '*older person 65 years and above shall not queue for any services in both government and private services*'. What is evident is that most Batswana know about the directive but wait for health workers to enforce it.

"Queue management directive if not enforced fully it can have long term effects on older patient's adherence as their impatience is felt by the time they reach pharmacy. They even refuse education and counselling if they have waited long indicating lack of time, hunger and tiredness." (Pharmacy Technician, Female, 1 year with ARV programme).

5.6.6 Poor social support for older patients

Older people do not seem to have strong support systems though some are resistant to being supported as they want to proof their independence. Those with support eat well, adhere better to treatment and attend as scheduled. *"I always refer older people presenting with social problems to Social Workers but to tell the truth most of those with good support end up reaching her office while the rest don't. How I wish all older patients brought somebody to support them." (Nurse Dispenser, Male, 1 year with the ARV programme)*

One Pharmacy Technician indicated that in her facility she has observed a disturbing trend which needs to be looked at closely;

"*Older people without support are the ones on second line treatment due to poor adherence especially those who are really older- those over 70 years." (Pharmacy Technician, Female, 1 year on ARV programme).*

HCWs indicated that some older persons who are unwell can go for days without treatment because their children and grandchildren refuse to refill ARV treatment for them as they do not want to be associated with the HIV clinic and stigma there off. Lastly it was also indicated that some older patients on ARV treatment have challenges of alcohol use as this is revealed during liver function tests. This ultimately impacts their performance on treatment. Alcohol use was found to be worse among those without social support.

5.6.7 Food ration support

Most HCWs advocate for older people to be given rations as they are unemployed and their pension does not seem to meet their nutritional needs. They do not seem to eat well except those with well-off children and relatives. There is an observation that older people who do not eat well, do not seem to do well on ARV treatment.

"Some older patients who have had tuberculosis in the past and were put on ration for six months when it is stopped they literally cry to be kept on ration advancing reasons like poverty and not eating well at home. The government should supplement their pension- P300 cannot be enough." *(Nurse Prescriber, Female, 2 years on ARV programme)*

5.6.8 Pill burden due to co-morbidity:

Older people are taking treatment for more than one medical condition e.g. they are on long life treatment for HIV, diabetes, hypertension and sometimes tuberculosis. In recent years HCWs are seeing a trend of older people who sometimes refuse to take some treatments due to pill burden/fatigue.

"They have the right to say no to multiple treatments but we have realised this 'No' is not based on an informed decision. Their reasons are that they are tired of medications that we pile on

them. This is worse for those without social support like children or spouses."(Pharmacy Technician, Female, 4 years with ARV programme).

Education on co morbidities needs to be strengthened for older people to make informed decisions. The confusion and burden is not only on medications but also multiple visits and blood draws for other conditions.

5.6.9 Lack of skilled personnel

"Providing care for older persons is challenging, as they need specialized care, but of them majority live in rural areas, while most skilled personnel are in urban areas. Most of them need more social related counselling which we do not have the capacity to offer all the time as we are more focused on medical counselling. They present with multiple conditions which make management a challenge for inexperienced HCWs." (General Nurse, Female, 6 months in the ARV programme)

HCWs are of the opinion that, older people need staff who are equipped to deal with them as they have special needs. They need HCWs who are patient as they take so much time of the already stretched HCWs.

"Older people complain if the doctor is too slow saying he does not seem to know what he is doing but again complain if the doctor tries to be faster by saying he does not give them the attention they deserve. Older people can be difficult to please (Nurse Prescriber/Dispenser, Female, 6 years)"

5.6.9.1 Loss of sight and hearing

This is one gap that is not assessed continually but has a great impact on the day to day care of older adults.

"Partial vision and hearing are a challenge among the older people which in most cases we miss. Sight and hearing assessment should be included in their care consistently." (Nurse Dispenser, Female, 6 months with ARV programme).

5.7 Recommendations from Health Care Workers

Basing on their experiences, aspirations, services needs and gaps for older people interviewed HCWs identified the following recommendations which were presented as outlined below.

5.7.1 Queue management for older patients

HCWs suggest that older people should have their own queue so that the issue of delays in identifying them is reduced. On the same note doctors should designate time for the older patients to give them the attention they deserve while nurses should be encouraged to deal with them in a holistic way (look beyond HIV).

5.7.2 Improve counselling services

Older people present with social issues that require skilled counsellors. There is need to have Social Workers who are based in and around ARV clinics because when referred to far places they never reach where they should. Older people do not openly share if they have problems rather they wait to be asked. Having personnel dedicated to consulting them on issues beyond medical needs can go a long way in improving the quality of their lives.

5.7.3 Manpower planning

The government should plan for the 65 year olds and above as in the next few years they will be many in the ARV programme. Each ARV clinic should have a Data Clerk, Pharmacy

Technician, Auxiliary worker; Interpreters and Social Worker in addition to the current staffing in improve quality of care for older people. Almost all doctors in our facilities only speak English creating a huge communication gap between them and older patients therefore having interpreters can help speed up the process and improve quality of care. There are suggestions that ARV doctors would be best if they have Family Medicine background as they have the ability to deal with issues holistically.

5.7.4 Establishment of shelter for older people

Botswana should establish shelters for older people so that those without social support can be supported better, some have nobody to care for them and this impact their health negatively. The government should then consider establishing ARV clinics for older people within those homes.

5.7.5 Targeted Health Education and adherence counselling

Health education for older people on treatment should be frequent and in Setswana as most of them are not educated- right now they are lumped with everybody. Adherence should be emphasised at every opportunity

5.7.6 Social Support for older people

We should have and enforce policy that older people should come with care takers to every ARV visit- to ensure treatment adherence, timely attendance to scheduled visits and that their wellbeing is looked after.

CHAPTER 6: DISCUSSION

This chapter discusses some of the important issues that have emerged from the findings of the study. These include services needs and gaps as perceived by older people themselves and HCWs caring for them; disclosure of HIV status; Illiteracy among older people; Increased life expectancy; language barriers; lack of targeted health education and counselling services; lack of skilled and empowered health workforce; queue management policy for older people; pill burden and co-morbidities and social support were identified as some of the key needs and services gaps for this group.

6.1 Disclosure of HIV status

Results from this study have indicated that older people disclosed their status to significant others. Sixteen of the twenty interviewed had disclosed their status mainly for support. This was confirmed by HCWs as a positive thing when caring for older people. This is line with a 2010 national study in United Kingdom on older people- fifty years and above, where high levels of disclosure of HIV status within a wide range of settings and the overwhelmingly positive or neutral outcomes were reported (32). Another two studies in South Africa revealed high levels of

support and greater levels of acceptance for those who disclosed their HIV positive status (34, 35). It is clear that stigma and negativity that has always been associated with HIV disclosure has reduced significantly and this could be indicative of changing social values reported in other studies (34, 35).

Having said that, during interviews it was also clear that even though older people interviewed have disclosed they want their privacy and status to be protected from everybody else. Some indicated that they have problems with separation of the ARV clinic from other clinics and nurses who speak to them with raised voices as they are concerned about imposed structural disclosure of their HIV status. According to Vanable et al, structural factors result in disclosure of one's status without consent and these have negative psychological outcomes (38).

Regardless of disclosure being a good opportunity for support, some research has found that some older people use non-disclosure of one's HIV-positive sero-status as a strategy to manage stigma (36). A study in Canada revealed that older adults hid their HIV-seropositive status from their family members, including adult children, to reduce anticipated stigma (37). Even though non-disclosure can limit opportunity for social support, which can serve as a protective factor against stigma and other negative consequences of HIV, to date the relationship between stigma, disclosure and social support is still complex and requires further research (38).

6.2 Literacy among older people

The first ever national survey to establish the literacy rate in Botswana was carried out in 1993 (39, 40). The target population eligible for the literacy tests was "citizens aged 12-65 years old (39, 40). The data showed a clear upward trend in literacy rates for adults (15 to 65+) increased from 68.9% in 1993 to 81% in 2003 (39, 40). The 2003 survey expanded the target group to cover Botswana citizens from the ages of 10-70. On the other hand, the literacy rate for the

population aged (15 -65) years increased from 81% percent in 2003 to 88.6 percent in 2014(38). This data has excluded older people who are the target for this study. To date there is no clear representation on levels of literacy among older people in Botswana. In this study twelve out of the twenty older people were interviewed had never been to school, six had only primary education.

Illiteracy remains high among older people in the less developed regions (39). Available evidence suggests that, as of the year 2000, only about half of all persons 33 and older in the SADC region were literate (39) though there is a trend towards increasing literacy among older people in the region. This is a favourable development for the wellbeing of future older generations, since higher levels of education are associated with better health and economic status within the older population (39, 40).

6.3 Life expectancy

There is clear data that indicates that life expectancy has increased at a steady pace since inception of ARV treatment (10). Countries like Botswana experienced significant increase in life expectancy since introduction of free ARVs to most eligible citizens (10). Basing on current prevention, diagnosis, and treatment initiatives there is hope that life expectancy will continue to rise in the coming decades. Botswana's life expectancy which was reduced from 64 years in 1990 to 49 years in 2002 due to HIV and AIDS is now going up again, at 53 years in 2012 among the HIV infected (10) while the general public is at 68 years in 2011(2).

Basing on the research conducted the average years of older patients on ARV treatment was seven years with the lowest being four months and the longest thirteen years. Eight of this older people have been on ARV treatment over ten years and they proclaim high levels of health. There is hope that most of this older people still have more years of life left in them if current

medical monitoring and treatment remains unchanged and if nothing unexpected happens. But it should be noted that increase in life expectancy is crucially dependent on good adherence and other related factors like good diagnosis and monitoring (41). Increase in life expectancy has its own negative implications on health care and social welfare services mainly because the longer they live the more health services and social welfare services they need (41).

6.4 Language barriers

English language was identified as a communication and relationship building barrier between doctors and older patients on ARV treatment in Gaborone and Greater Gaborone. The biggest challenge is because older patients are not educated and therefore have very minimal English comprehension. According to some of the nurses this language barrier goes beyond just communication; it is reflected on lack of understanding of cultural beliefs which destroy relationships between foreign doctors and older patients. Language barrier impacts patients' ability to communicate their needs and issues to the best of their ability and for doctors to provide education and care confidently basing on patients expressed needs (32).

Studies have shown that patients who do not speak English generally fare worse in healthcare system (42). During medical training physicians are advised not to allow patients' friends or family members to act as translators as lack of linguistic capability to translate complex medical terms, can result in them using their emotions, personal beliefs or biases to please their relatives (42). The question is whether this advice can still be relevant when dealing with older people living with HIV who need social support upon which success of their medical care is based as they age. Use of full time interpreters is an option though it has been found not to help in bridging the relationship gap between doctors and patients (42).

6.5 Targeted health education and counselling services

Older people interviewed would like health education and counselling services to be strengthened as they do not benefit as per their expectations. They want education that is targeted to them as they believe they have special needs. Currently they are educated with everybody else within ARV clinics. One major issue raised by HCWs is that older people do not want to discuss sensitive issues relating to sex, sexually transmitted diseases and condom use yet some of them are still sexually active.

To develop relevant and responsive health education and counselling services, it would be critical that older people are involved in planning and deciding priority issues as they understand the issues that affect them better (43). The choice of appropriate and easily accessible communication methods that are suited for older people will also be key. A study in Kenya and Sudan revealed traditional methods such as songs and drama which were developed by older people, followed by discussions to be very effective (44). It should be acknowledged that as they age they go through ccognitive changes and learning ability slows down hence the need for strategies that will increase retention (46). Short-term memory is more dramatically affected by age than long-term memory hence the need to use multiple and strategies to enhance retention in older people (46).

In health education, the choice of language and examples used should be influenced by the level of education of the subjects (42). In this study almost all older people have never been to school therefore use of local language, simplified examples and explanations will be ideal.

Lack of data on the needs, services gaps, health, social and welfare challenges of older people limits experts' ability to develop targeted health education and counselling services (30). Most HIV/AIDS intervention programmes and policies base their strategic work plans on data on older

people from regional and international statistics especially South Africa and Uganda as well as the United States of America. All studies that have been done in developed and developing countries like USA, Canada, Uganda, Kenya, South Africa look at older people from 50 years and above (11, 16, 25) years while Botswana only consider their people as older from 65 years. To date Botswana as a country that was at the helm of the whole world for two decades as having the highest numbers of HIV and worst impact we do not have data on the very people who are pioneers and reference points for the effectiveness of our initiatives. Our programmes for older people if any are still externally guided, so programmes and policies are formulated without local contextual understanding (47).

6.6 Lack of skilled and empowered health workforce

The '*Know your epidemic, Know your response'* as a guiding principle used by Botswana National HIV Coordinating Agency recognizes that we can only adequately address the challenges HIV pose to specific groups only if we understand the specific nature of the epidemic in different locations and age groups (19). HIV and old age is a new experience to the medical field, therefore making older people who are growing older with HIV to be the pioneers from whom new things will be learnt as we go. The ageing process in patients with HIV infection whether on long-term antiretroviral therapy (ART) or not is still not well understood (23, 31, 32). Long-term side effects of ARVs are also still being discovered and with development or existence of comorbidities related to HIV and old age, the challenges are pilling therefore requiring relevant knowledge and skills (31, 32). Botswana health care infrastructure has proven to be ill-equipped to handle the unique prevention, treatment and care needs of HIV positive older adults. The biggest challenge is that currently HIV data in Botswana excludes older women and men aged 65 and above, and with lack of data, how can our health workers ever get to

understand the epidemics and be equipped to respond. Effective nursing training should include issues relating to older people and HIV considering its magnitude and impact (48).

6.7 Queue management policy for older people

The directive from the office of the president says;

'*Older people 65 years and above, pregnant women, men and women of uniform and the disabled shall not queue for services both in government and private services as a way to show our respect as a nation*'.

It is on this basis that every ARV clinic is expected to fully implement and adhere to this directive at all times. Implementation of these directives has come with challenges as some patients feel it is unfair to help older people who got HIV through their doing to skip the queue. Enforcement of the directive is also affected by on-going staff shortages in facilities which leave older people with no option but to initiate the request. It also came out during interviews that older adults who are not visibly old are usually denied an opportunity to take advantage of the directive unless if they are assisted by a health care professional.

Besides all this, older people appreciate this directive as a sign of appreciation and respect from the government and they recommend that HCWs be proactive in enforcing it.

6.8 Pill burden and co-morbidities

The life-saving medications that transformed the HIV epidemic nearly two decades ago have dramatically increased life expectancy for people living with HIV (29). This welcome advance has also created new challenges of pill burden and comorbidities. According to Center for Disease Control (CDC) between 20% and 75% of deaths among HIV positive individuals on antiretroviral treatment are now due to causes other than the AIDS-defining conditions (29).

Some of the major causes of death are attributable to alcohol use, liver disease, cardiovascular diseases, cancers, and renal diseases (29). The higher prevalence of comorbidities, polypharmacy, drug interactions and end-organ diseases among the older people requires a multidisciplinary approach (30, 31).

From this research it is clear that increasing number of chronic conditions and co-morbidities experienced by older patient's call that they be seen by different providers for social and health care services at different times. Ultimately this impacts coordination of care across health, social and welfare services. Some default not because they do not appreciate modern medicine but because the pill burden is more than they can bear. The fact that long-term effects of antiretroviral use are still being discovered, the development of comorbidities make this even more complicated. This rising comorbidities prevalence of chronic diseases among the near-elderly (50 to 64 years) will continue to drive gradual increases in comorbidity among the elderly with a huge increase in future health spending (50). This is clear even among those interviewed that some young older adults in their 65,66 67 year olds who just joined the older people group come in to the group with comorbidities like hypertension and diabetes which are very common in Botswana.

6.9 Social support

Social support is measured on the basis of the composition of the social network, frequency of contacts, exchange of support, and various forms of social participation (45). Social support is measured using basic relational factors like marital status (45). Considering the life expectancy of Batswana today (58 years) it is highly likely that at 65 years older people with or without HIV might have lost a spouse. In this particular study, only ten were still married and seven were widowed and the remaining three divorced. This has a great impact on social support of these

individuals as they age though the proportion of older persons living alone is lower in developing countries (8 per cent) than in developed countries (24 per cent) (51), this could be attributed to our African family structures- extended families. Research indicates that lack of social support and increase in stressors like loss of peers, isolation, chronic illness, impairments and financial problems increase depression among older people (45, 51). According to Mark Leys et al, people living alone are probably worse off than those who live with others (51).

Though older people were not directly asked about their dependents but it came out clearly that sixteen of the twenty had disclosed to their social network most of whom are family and friends. The level of the old-age support ratio has important implications on achievement of social and welfare services (pensions and public health). It is expected that dependency ratio by the 65 years old and above on the 14-64 years olds will reduce globally by 5050 as highlighted below (39, 49):

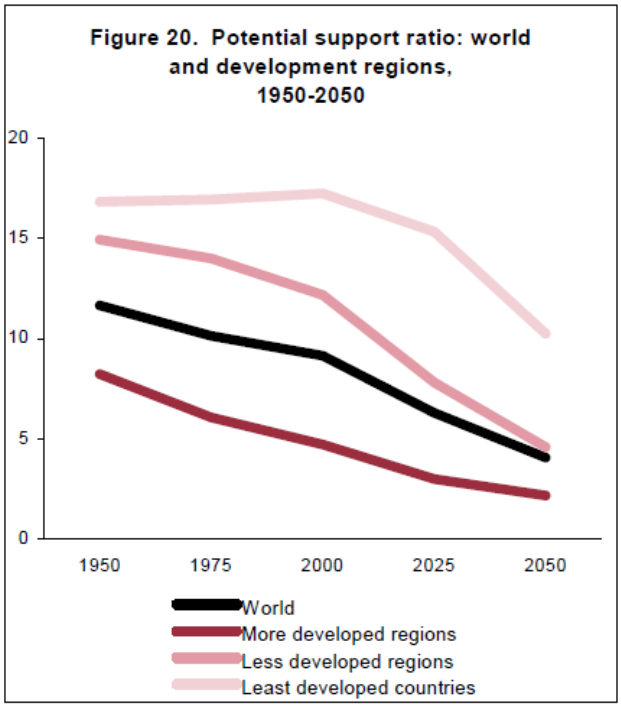

Figure 6.1: Potential support ratio: world and development regions, 1950-2050
Source: World Population Ageing 1950-2050. Population Division, DESA, United Nations

According to George, it is critical that older people are connected with various structures and networks within their cycle of support to maintain high levels of support as highlighted below (28). Both formal and informal networks are critical in ensuring older people get the support they need. This has a direct impact on their health and wellbeing factors (28, 45).

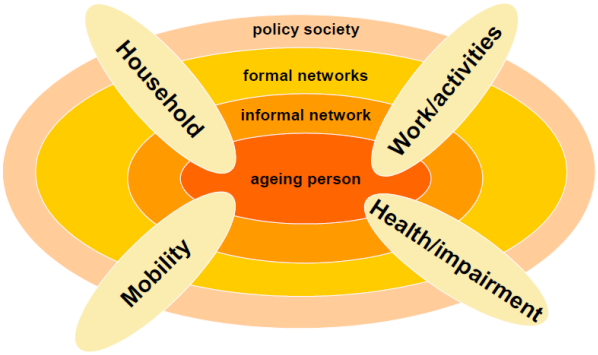

Figure 6.2: Model of conceptual frameworks- highlighting major factors at play in making older people feel appreciated and supported.
(*Source: Department of Sociology and Center for the Study of Aging. Duke University, Durham, North Carolina).*

6.10 Theories related to Old Age:

6.10.1 Disengagement Theory

It has to be appreciated according to the disengagement theory that in life there comes a time when old age arrives and older people and society engage in mutual separation (52). This could be through retirement from work; children growing up, getting married and moving out of the house. The trend is changing in Botswana as after disengagement we see parents moving in to children's homes especially in towns as they have no social support in rural areas for care and support when they have chronic conditions and HIV and AIDS.

6.10.2 Strategic investment of resources theory.

This theory focuses on the older adults' strategies to invest their declining social and psychological resources and their social welfare (52). Most older people at this age focus their

minimal resources in things that will give them more returns and reduce the impacts of their declining health, disability and welfare needs. This include relationships that older people establish as a way to maximize their health and wellbeing benefits. From this study it was clear that most older people had moved from their rural dwellings to stay with specific children they had chosen basing on their anticipated benefits. Most older people who are HIV positive are very strategic on what they use their pension funds on- basic needs fruits and vegetables as they want to restore their health.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

7.1 Conclusions

Overall older people in Gaborone and Greater Gaborone are happy with the care and support they get in ARV dispensing health facilities especially curative services while they had challenges with non-curative services.

Lack of information on the needs and services gaps of older people in Botswana have resulted in development of generic and haphazard services in care for the older people. Better understanding of this group could lead to better targeted curative, non-curative and psycho social services. The impact of HIV and AIDS on older people has become an area of increasing concern which demands a concerted response from everybody involved and most importantly older people themselves.

Overall analysis of the views of older people shows that most have accepted their HIV positive status and are thankful for the care and support they get from the government of Botswana and Health care workers caring for them. Preventive, curative and psycho social needs and services gaps were identified and found to exist but in varying levels. The able bodied those with social support and those whose basic needs are met seem to enjoy improved health and wellbeing than those without.

The level of disclosure, their openness to share their experiences and educate others is overwhelming and encouraging. It has potential to demystify disclosure as a bad thing among the HIV positive and appreciate disclosure as there is indication of changing social values and experiences by those who have disclosed. The majority of the respondents have services needs and gaps but they believe the positives outweigh the challenges they might be having some of which can be resolved with time. Generally curative services are better coordinated compared to

non-curative services as outlined by both older people and HCWs with minor challenges that can be resolved if targeted services for older people can be put in place appreciating older people have special needs.

Low illiteracy levels among older people have a major impact on their ability to benefit fully from the services offered. Older people have lower understanding of their medical conditions which impacts adherence and understanding of health education services. Staff shortage per facility has affected the delivery of critical services like targeted counselling, patient follow up, staff ability to interpret for foreign doctors working in ARV clinics and queue management and policy enforcement. Social support remains a major need for older adults especially those with medical challenges and it is an area that needs to be strengthened to ensure continued support for older people through their medical journey. Family is still the most important social structure to provide the first and most intensive level of support for older people affected by HIV and AIDS.

7.2 Recommendations

- Botswana needs to have HIV health care and prevention guidelines tailored to older people living with HIV and they should be evidence based. There is need for the health system to establish health promotion and disease prevention initiatives targeted to older people at every level of their care.
- Social support is a critical component of improved health and welfare for older people therefore there is need for the country to develop policies that guide establishment and sustained response to social support structures and needs of this population. This population require policies that look beyond health care and social services.

- There is need for better coordinated care for older people among curative, non- curative and psychosocial service providers owing to comorbidities that older people are struggling with.
- Public education and media campaigns must include and target messages at older people so that they are fully informed about the disease and can play a role as educators in their communities.
- HIV prevalence surveys -Botswana Index AIDS Survey should include older people 65 years and above rather than only focus on the ages 10-64. There should be no age limits to surveillance as HIV has no age boundaries.
- Training on care for older people is limited in training curriculum for health care professionals. Training of public health care workers should continually include care for older people living with HIV as little is known in this area.
- Involvement of beneficiaries in programme planning and execution is known to yield positive results as they have a better understanding of their needs. Just like youth, men and women of Botswana are engaged in health planning, the voice of the older people will go a long way in improving the current status quo.
- Older people continue to struggle to open up to discussion of sensitive and sexually explicit issues. There is need to identify barriers to their opening up. Confronting cultural norms, beliefs and recognising their role in the dynamics of old age and HIV and AIDS would help improve service provision to this group.

7.3 Recommendations for future research

- There is need for targeted research into many aspects of older people with HIV infection: how the government can adopt a strong client-centered approach to care for older people, to

better understand the complexity of older people's health care needs in order to improve integration between health services and community care.

- This data will be useful in development of targeted health education for older people. Considering older peoples specific needs there is need to move from generalised services to targeted care and services.
- Longitudinal studies are needed to assess the actual impact of HIV on aging and vice versa.

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APPENDICES

Appendix A- **Information sheet-*Key Informants (Health Care Workers)***

These information sheet and consent forms will be translated into Setswana. During the recruitment phase (December, 1- 2014 - January 31, 2015), the researcher will identify +

potential participants and will spend some time with each one individually to read and explain this information sheet and consent form to them and to answer any questions they may want to raise. Those agreeing to participate will be given a copy of the information sheet in their preferred language and allowed adequate time to reflect on its contents and their implications before being asked to sign the informed consent form.

Title: Perceived Health Needs and Services Gaps for Older people on ARV Treatment - Gaborone and Greater Gaborone, Botswana (2014-2015).

Consent form introduction:

Hello and welcome. Thank you for giving me your time. My name is Oarabile Makgabana-Dintwa. I work for the University of Botswana. I am a student at the University of Witwatersrand in South Africa. I am conducting this study as part of my degree requirements. The purpose of this study is to explore perceived health services needs and gaps of HIV positive older people over 65 years attending ARV dispensing clinics (MASA) as perceived by the older people themselves and Health Care Workers caring for them.

You are therefore invited to volunteer to participate in this research that is being conducted in Gaborone and Greater Gaborone. I urge you not to agree to participate in this study unless you fully understand what is asked of you and are completely happy with all the procedures involved. If you do not understand the information or have any other questions, feel free to ask me before we continue.

Purpose of this interview

The purpose of this study is to explore perceived health services needs and gaps of HIV positive older people over 65 years attending ARV dispensing clinics (MASA) as perceived by the older people themselves and Health Care Workers caring for them.

If you agree to take part in an individual interview, I will ask you some questions about your background and your experiences while attending to patients in this clinic. The interview will take a maximum of 60 minutes

You have been invited to take part in the study because you are one of the Health Managers or Health Care Workers working in ARV dispensing clinics in Gaborone and Greater Gaborone.

Your views will help me to understand your experience, needs and services gaps of patients attending this clinic from your view.

Who can participate?

Health Care workers who participate will either be a Manager within an ARV dispensing clinic or a Service Provider who has worked in the facility for at least 3 months.

What procedures are involved?

You are being asked to participate in an interview. With your consent, I will be asking you some personal information and questions related to your lived experiences, services needs and gaps. As I ask you questions, I will also be capturing the discussion in an audio tape only if you agree to it later. There are no right and wrong answers to the questions; I want to know about you, your experiences, needs and services gaps of the older people attending this clinic.

I would like to use a voice recorder to record what you say so that I do not miss anything. The audio tape will be destroyed after two years of the end of the project. After the interview the recordings will be written down word for word and then translated into English. I will be using this written document to write my research report. Your name will not be written in the documents but a unique identifier which will be a number ranging from 1 to 20 depending on when you were interviewed. No one outside of the interview will be able to tell, from the written document, what you have said or who have said it.

Are there any risks or discomforts from participating in this study?

We will conduct the interview in a private and safe place where we both will feel comfortable. I assure you that any information from you shall be kept in a safe and confidential way to protect what you have said even further.

Possible benefits of this study

There will be direct benefits from participating in this study for health workers and their facilities as the findings and recommendations can bring issues you were not aware of to your attention and prompt the Ministry of Health to act or improve their ways of doing things. This is the first study conducted on this population and therefore sharing your experiences, services needs and

gaps of the older people will add a new set of knowledge in this subject. Information collected from this study will be helpful in addressing challenges of older people attending at this facility and enhancing overall service delivery to this population in Botswana.

What are your rights as participant?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time without giving any reason. Please remember that you are free not to answer a question if it makes you feel uncomfortable. Also you are free to leave the interview at any stage and for any reason. Whether you chose to take part in the interview or not, it will not affect you in any way either as a Manager or Health Worker.

Confidentiality

All the information that you give in this study will be kept strictly confidential. The consent forms that you will be asked to sign will be securely stored and access will be limited to the researcher and supervisors at the University of the Witwatersrand. The consent forms cannot be linked to the answers you give to the questions since the answer form will, only have a unique identifier. The results of the study will be presented in a respectful manner and no information, which could enable anyone to identify you personally, will be reported. The researcher will work with colleagues and supervisors to make sure you are kept informed about the progress of the project and to share with you any reports or publications we produce.

Storage of study material

Study material like; audio tapes and interview tools will be kept for about two years after publication to allow for post publication analysis and thereafter be destroyed.

Costs

There is no cost to you participating in this study.

Compensation

You will not be paid for participating in this interview. You will be given P30.00 not as payment but to cover transport costs.

Who to Contact

If you have concerns about the study or your rights as a participant you can contact a representative of the Human Research Ethics Committee of the University of Witwatersrand which is an independent committee, established to help protect the rights of research participants at (011) 717 2230/1. In Botswana you can also contact a representative of the Ministry of Health at 363 3200.

For any questions or clarification about the study please contact Ms. Oarabile Makgabana-Dintwa. Email: Oarabile.dintwa@mopipi.ub.bw +267 355 4605 who is the Principal Investigator

Appendix B: Informed Consent Form- *Health Care Workers*

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. She explained to me the purpose, procedures involved, risks and benefits and my rights as a participant in the study.
I have received the information leaflet for the study and have had enough time to read it on my own and ask questions. I feel that my questions regarding participation in the study have been answered to my satisfaction.

I have been told that the information I give to the study will together with other information gathered from other people, be anonymously processed into a research report and scientific publications. I am aware that this report and any publications from it will be shared with the Ministry of Health to make improvements to the services offered to the older people.
I am aware that it is my right to withdraw my consent in this study without any reason. I hereby, freely and voluntarily give my consent to participate in the study.

Participant's Name.....

Participant's Signature.....Date.....

Researcher's Name.....

Researcher's Signature.....Date.....

Appendix C: Informed Consent Form—*Audio-tape (Health Care Workers)*

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. He explained to me the purpose, procedures involved, risks and benefits and my rights as a participant in the study.
I am aware that my voice will be recorded. I have been told that only the research team will hear the audio recordings. I have been told that the audio recordings will be destroyed two years after the study.

I am aware that it is my right to withdraw my consent in this study without any reason. I hereby, freely and voluntarily give my consent to be audio taped in the study.

Participant's Name.....

Participant's Signature.....Date.....

Researcher's Name.....

Researcher's Signature.....Date.....

Appendix D: Interview Guide - *Health Care Workers*

Part I: General Information **Date: ……**

No	Background Information	
1	Unique Identifier	__ __ __
2	Name of Facility	
3	Position of Health Professional	
4	Name of Facility	
5	Gender	
6	Area of Speciality	
7	Duration working in ARV dispensing facilities	

Part II: Interview guide for Health Managers and Health Workers

Question 1: Can you describe your experience working in this facility in regard to caring for the older people patients living with HIV and on ARV treatment.

Question 2: Can you describe the services you offer in this facility as part of your care for these older people patients. (Both curative and none curative)

Question 3: Can you describe your perceived health services gaps in the care for the older people attending this clinic? Probes

a. Prevention gaps

b. Curative gaps

c. Psycho-social gaps

d. Non-curative gaps; Probe (facility based, service provider related and fellow patient's related gaps)

Question 4: What recommendations would you give about?

a) The health services needs of older people on ARV treatment?

b) Health services gaps relating to care for the older people on ARV treatment?

Appendix E: Information Sheet –*The Older people*

This information sheet and consent form will be translated into Setswana. During the recruitment phase (December 1, 2014 - January 31, 2015), the researcher will identify potential participants and will spend some time with each one individually to read and explain this information sheet and consent form to them and to answer any questions that may arise. Those to participate will be given a copy of the information sheet in their preferred language and allowed adequate time to reflect on its contents and their implications before being asked to sign the informed consent form which is either written or through a finger print.

Title: Perceived Health Needs and Services Gaps for Older people on ARV Treatment - Gaborone and Greater Gaborone, Botswana (2014-2015).

Consent Form Introduction

Hello and welcome. Thank you for giving me your time. My name is Oarabile Makgabana-Dintwa. I work for the University of Botswana. I am a student at the University of Witwatersrand in South Africa. I am conducting this study as part of my degree requirements. The purpose of this study is to explore perceived health services needs and gaps of HIV positive older people over 65 years attending ARV dispensing clinics (MASA) as perceived by the older people themselves and Health Care Workers caring for them.

You are therefore invited to volunteer to participate in this research that is being conducted in Gaborone and Greater Gaborone. I urge you not to agree to participate in this study unless you fully understand what is asked of you and are completely happy with all the procedures involved. If you do not understand the information or have any other questions, feel free to ask me before we continue.

Purpose of this interview

The purpose of this study is to explore perceived health services needs and gaps of HIV positive older people over 65 years attending ARV dispensing clinics (MASA) as perceived by the older people themselves and Health Care Workers caring for them.

If you agree to take part in an individual interview, I will ask you some questions about your background and your experiences while attending this clinic. The interview will take a maximum of 60 minutes

You have been invited to take part in the study because you are one of the attendees of ARV dispensing clinics in Gaborone and Greater Gaborone. Your views will help me to understand your experience, needs and services gaps while attending this clinic.

Who can participate?

HIV positive older people attending any ARV dispensing clinic in Gaborone and Greater Gaborone (Gaborone and Greater Gaborone). Participants should have been on ARVs at that facility for at least 3 months consecutively. Both males and females are encouraged to participate and older people from all categories of the older people.

What procedures are involved?

You are being asked to participate in an interview. With your consent, I will be asking you some personal information and questions related to your experiences in relation to services needs and gaps of the older people attending this clinic. As I ask you questions, I will also be capturing the discussion in an audio tape only if you agree to it later. There are no right and wrong answers to the questions; I want to know about you, your experiences, needs and services gaps for the older people.

I would like to use a voice recorder to record what you say so that I do not miss anything. The audio tape will be destroyed after two years of the end of the project. After the interview the recordings will be written down word for word and then translated into English. I will be using this written document to write my research report. Your name will not be written in the documents but a unique identifier which will be a number ranging from 1 to 20 depending on when you were interviewed. No one outside of the interview will be able to tell, from the written document, what you have said.

Are there any risks or discomforts from participating in this study?

We will conduct the interview in a private and safe place where we both will feel comfortable. You may feel uncomfortable in answering some of the questions because some of them are personal. I assure you that any information from you shall be kept in a safe and confidential way to protect what you have said even further.

Possible benefits of this study

There will be direct benefits from participating in this study if the findings and recommendations are implemented by the Ministry of Health. This is the first study conducted on this population and therefore sharing your experiences, services needs and gaps of the older people will add a new set of knowledge in this subject. However, the information collected from this study will be helpful and taken in to account in addressing challenges of older people and enhancing their services delivery in Botswana.

What are your rights as participant?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time without giving any reason. Some of the questions might be very personal. Please remember that you are free not to answer a question if it makes you feel uncomfortable. Also you are free to leave the interview at any stage and for any reason. Whether you chose to take part in the interview or not, it will not affect your services in this facility.

Confidentiality

All the information that you give in this study will be kept strictly confidential. The consent forms that you will be asked to sign will be securely stored and access will be limited to the researcher and supervisors at the University of the Witwatersrand. The consent forms cannot be linked to the answers you give to the questions since the answer form will, only have a unique identifier. The results of the study will be presented in a respectful manner and no information, which could enable anyone to identify you personally, will be reported. The researcher will work with colleagues and supervisors to make sure you are kept informed about the progress of the project and to share with you any reports or publications we produce.

Storage of study material

Study material like; audio tapes and interview tools will be kept for about two years after publication to allow for post publication analysis and thereafter be destroyed.

Costs

There is no cost to you participating in this study.

Compensation

You will not be paid for participating in this interview. You will be given P30.00 not as payment but to cover transport costs.

Who to Contact

If you have concerns about the study or your rights as a participant you can contact a representative of the Human Research Ethics Committee of the University of Witwatersrand which is an independent committee, established to help protect the rights of research participants at (011) 717 2230/1. In Botswana you can also contact a representative of the Ministry of Health at 363 3200.

For any questions or clarification about the study please contact myself Ms. Oarabile Makgabana-Dintwa. Email: Oarabile.dintwa@mopipi.ub.bw _+267 355 4605 who is the principal investigator

Appendix F: Informed Consent Form-*Older People*

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. She explained to me the purpose, procedures involved, risks and benefits and my rights as a participant in the study.
I have received the information leaflet for the study and have had enough time to read it on my own and ask questions. I feel that my questions regarding participation in the study have been answered to my satisfaction.

I have been told that the information I give to the study will together with other information gathered from other people, be anonymously processed into a research report and scientific publications. I am aware that this report and any publications from it will be shared with the Ministry of Health to make improvements to the services they offer the older people.
I am aware that it is my right to withdraw my consent in this study without any reason. I hereby, freely and voluntarily give my consent to participate in the study.

Participant's Name.....

Participant's Signature.....Date.....

Participant finger print……

Researcher's Name.....

Researcher's Signature.....Date.....

Appendix G: Informed Consent Form—*Audio-Tape (Older People)*

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. He explained to me the purpose, procedures involved, risks and benefits and my rights as a participant in the study.

I am aware that my voice will be recorded. I have been told that only the research team will hear the audio recordings. I have been told that the audio recordings will be destroyed two years after the study.

I am aware that it is my right to withdraw my consent in this study without any reason. I hereby, freely and voluntarily give my consent to be audio taped in the study.

Participant's Name.....

Participant's Signature.....Date.....

Participant finger print……

Researcher's Name.....

Researcher's Signature.....Date.....

Appendix H: Interview Guide-*Older people*

Part I: General Information **Date: ……**

No	Background Information	
1	Unique Identifier	__ __ __
2	Name of Facility	
3	Sex	Male Female
4	Age of participant	
5	Marital Status	
6	Educational level	
7	Years/Months on ARV treatment	

Part II. Key Informant Interview Guide

Questions for key informants

Question 1: Can you describe your experience since diagnosis with HIV AND AIDS.

Question 2: Can you describe the services you are offered in this facility as part of HIV care for the older people patients. (Both curative and none curative)

Question 3: Please describe health services needs for the older people attending this clinic? Probes

a. Prevention gaps

b. Curative gaps

c. Psycho-social gaps

d. Non-curative gaps. Probe (facility based gaps, service provider related gaps and issues, fellow patients related gaps)

Question 4: What recommendations would you give about?

a) The health services needs of older people on ARV treatment?

b) Health services gaps discussed relating to care for the older people on ARV treatment?

Appendices I: Confidentiality Agreement - *Data Transcriber*

The undersigned acknowledges that the information handed to me in tapes for transcription shall be maintained in a confidential manner at all times; therefore it shall not be disclosed to any third party without written consent from the Principal Investigator (Ms Oarabile Makgabana-Dintwa).

I acknowledge that information furnished in this transcripts is in all respects confidential in nature and my organisation commits to maintaining such high levels of confidentiality at all levels in their mandate as failure to adhere might cause serious harm or damage to participants, the Institution where the principal investigator studies and the Principal investigator.

_____

Name of Transcribing Organization/Institution

_____ _____

Name of the representative(printed) Signature

_____

Witness

_____

Date

Appendix J: Ethical Clearance Certificate—*WITS University*

R14/49 Ms Oarabile Dintwa

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140923

NAME: (Principal Investigator)	Ms Oarabile Dintwa
DEPARTMENT:	School of Public Health South East District, Botswana
PROJECT TITLE:	Perceived Health Needs and Services Gaps for Elders on ARV Treatment - South East District, Botswana (2014-2015)
DATE CONSIDERED:	03/10/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Tintswalo Mercy Hlungwani

APPROVED BY: Professor Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 19/11/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

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

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix K: Letter of Permission to Access Clinics and Patients- *DHMT*

TELEPHONE: (267) 3133658
FAX : (267) 3907950
REFERENCE : DHMT

REPUBLIC OF BOTSWANA

Gaborone District Health Management
PRIVATE BAG 00258
GABORONE
BOTSWANA

Ref: GGDHMT/15/2/i

Oarabile M. Dintwa
University of Botswana
Private Bag 00705
Gaborone

18th February, 2015

Dear Madam,

RE: PERMISSION TO CONDUCT STUDY

Reference is made to your letter of request dated 17th February, 2015.

This serves to let you know that permission is granted to conduct a study entitled **'Perceived Health Needs and Services gaps for older people on ARV Treatment- South East District and Gaborone, Botswana'.**

This permits you to go into the health facility but you need to ask respondents for their participation. It should also not disturb patient care in any manner during the course of the visit.

The facilities allocated are all IDDC clinics in Greater Gaborone DHMT.

By copy of this letter the area Matrons and Nurse In-charges of all Health facilities in Greater Gaborone DHMT are informed of your intentions.

Yours faithfully,

Dr. G. M. Simoonga
Coordinator DHMT

GABORONE DHMT
PRIVATE BAG 0089, GABORONE
18 FEB 2015
PUBLIC HEALTH SPECIALIST

Appendix L: Permit to Conduct Research- *Ministry of Health*

Telephone: (267) 363200
FAX (267) 353100
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REPUBLIC OF BOTSWANA

REFERENCE NO: HPDME 13/18/1 IX (207) 13 February 2015

Health Research and Development Division
Notification of IRB Review: New Application

Oarabile Makgabana-Dintwa
P.O. Box 504769
Gaborone

Dear Ms Dintwa

PERMIT: PERCEIVED HEALTH NEEDS AND SERVICES GAPS FOR OLDER PEOPLE ON ARV TREATMENT – SOUTH EAST DISTRICT, BOTSWANA (2014 – 2015)

Your application for a research permit for the above stated research protocol refers. We note that your proposal has been reviewed and approved by the University of Botswana Research Ethics Committee.

Permission is therefore granted to conduct the above mentioned study. This approval is valid for a period of 1 year effective 13 February 2015.

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study.

Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



PP

P. Khulumani
For Permanent Secretary