# THE CHANGING LANDSCAPE OF COMMUNITY-HOME-BASED CARE IN BOTSWANA: THE SITUATION OF ELECTED FAMILIES IN THE CAPITAL CITY

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## Abstract

Community home based care in Botswana was established at the height of the HIV and AIDS crisis when the hospitals were not able to absorb all patients. However, with the passage of time, community home based care needs to re-focus so it addresses emerging needs. The case studies presented in this paper were compiled from undergraduate nursing students' placement in and around the main city in Botswana. The attachment helped the students to learn the role of a nurse in the promotion of health, prevention of illnesses, and in the continuity of care for discharged patients. The case studies provide exemplars for the epidemiologic and demographic transitions in community-home-based care and sensitize health care providers, policy makers and researchers on how the needs of clients have evolved overtime and the implications of such evolution for policy, program, research, and curriculum.

**Keywords**: *Community home based care Botswana; Older adults; HIV and IAIDS; Non-communicable diseases; Botswana*

## Background and Introduction

As a result of emerging health problems, urbanization and movement of the people within and across borders along with decreasing reliance on farming as a means of livelihood (Bigombe, Betty, Khadiagala, & Gilbert, 2014; Duone, 2013), new health care needs of communities emerge. Health care delivery must therefore change so it is aligned to the defined care beneficiaries and their needs. Community home based care (CHBC) in Botswana started in 1995 as one of the country's responses to the AIDS epidemic (Ministry of Local Government, Botswana, 2005). Because of the high loads of patients who were straining available in-patient care resources, patients were discharged home when they were still sick and therefore needing care and support. Although the way CHBC was defined from the start suggests a comprehensive or broader view extending beyond HIV and AIDS, it was really a response, to AIDS and this was evidenced by the AIDS emphasis in both the definition and the goal of CHBC (Browning, 2009). As the country was facing the HIV and AIDS crisis that was affecting mainly the young adult population, this required that the program be tailored to young adults with AIDS; and risk factors and behaviour change education and counselling were mainly tailored to that population. CHBC clients were therefore usually young adults with AIDS being cared for by older family members such as parents and siblings. Family caregiving that was identified as pivotal to CHBC was mainly provided by females as traditional carers of the sick. Following the establishment of the national Anti-retroviral Therapy (ART) programme in 2002, the demographic profile of patients that one would find in a CHBC visit has since changed or is gradually changing; and this has implications for how the CBH programme moves forward. For instance, the increase in communicable diseases such as cancers, chronic respiratory disease, cardiovascular diseases and diabetes (World Health Organization, 2014) may result in community home-based care programme having older adults with non-communicable diseases than when the programme was established.

As nurses are the major providers of home care in the public health care delivery service in many countries including Botswana, nursing education must therefore expose students to community home based care in order that they can appreciate the role that nurses' play and the dynamics of community home based care. Exposure to home nursing can enhance the development of the right attitude and skill for home nursing. In this paper, the authors use selected families that undergraduate nursing students worked with in their field placement for a basic community based nursing course to provide evidence for the argument that a CHBC client is no longer defined by the AIDS diagnosis, that the young adult with HIV infection has now matured beyond young adulthood to ripe adulthood and parenthood, and that the caregiver may not necessarily be a parent, typically a mother, as it used to be the case. The data also show that the older CHBC patient frequently had non-communicable diseases that could occur along with or without HIV diagnosis. The typical earlier AIDS patient of CHBC would be a young adult with very young children or no children while the current CHBC patient is usually an older adult with more mature children. The paper also addresses the challenges that families are faced with in community home-based care as well as opportunities presented by their situations. The authors use selected family case studies across a 2004-2018 time gradient as exemplars for a changing landscape of CHBC and the dynamics of HIV and AIDS. First we look at the epidemiological transition taking into consideration the demography of HIV and NCDs, the living conditions of the surveyed families, and the challenges that CHBC families faced. The analysis is retrospective, comparing the demographic and disease characteristics of patients during the period 2004-2013 with those for the period 2014 to 2018. Rather than being based on any pre-determined criterion, the two periods are based on the shifts that were observed in the characteristics of the

patients and their caregivers in the community home based care programme that was coordinated by nurses in the city clinics.

**Briefing about the Students' Fieldwork Placement**

The nursing school's integrated basic community health nursing course is offered at the third level of a four-your baccalaureate degree programme with the aim of exposing students to the role of a nurse in community based primary health care. The course is team-taught by a group of instructors with each one of them being assigned a group of students and a community in the catchment area of a health clinic. One of the learning activities required of the students was to select a family that they visit, asses on selected areas of health, and if necessary, advise or refer for further assistance.

The family health assessment exercise helps the students to have a feel of the role of a nurse in the promotion of health, prevention of illnesses, and in the continuity of care for clients treated in out-patient clinics or those newly discharged from the hospital. The students are able to assess clients in their normal habitat for a more realistic education and support. The exercise also affords families an opportunity to interact on a one-to-one basis with a health care worker in their own homes where they can be free to voice their opinions or ask questions related to their health; and this is a rare opportunity for families given the shortage of qualified nurses in the health care delivery system. Each student or pair of students draws a schedule of visits with the family and lists activities for each visit including the tasks that families are expected to fulfil. The student-family interaction spans 13 weeks or the duration of university's semester.

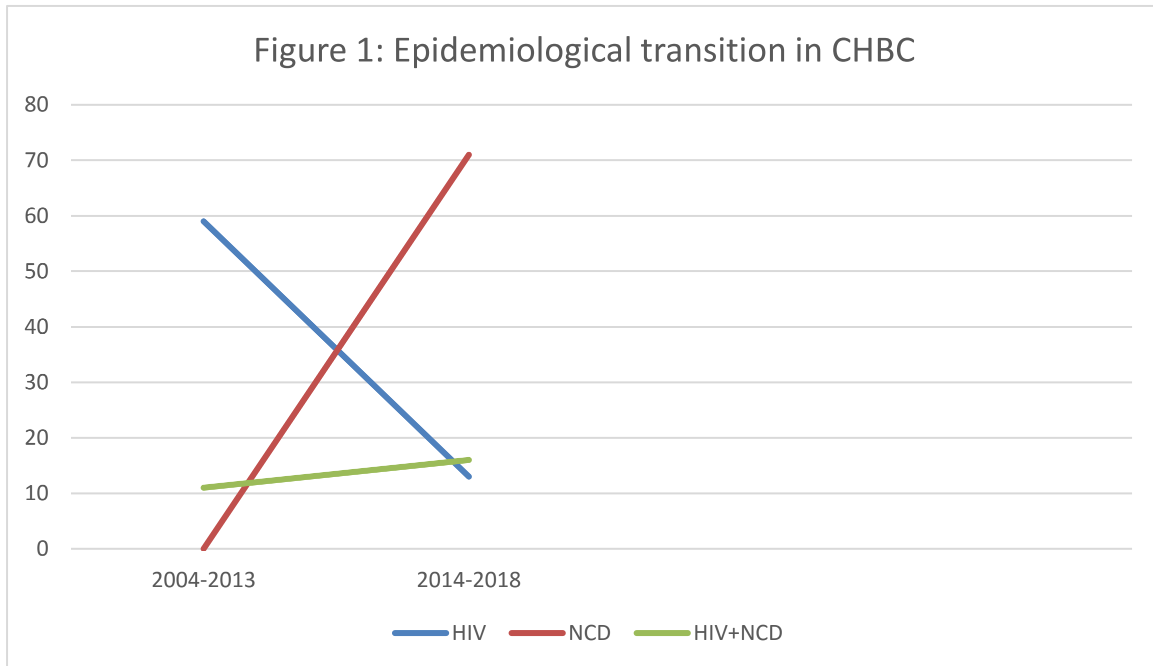
The case studies selected for this paper provide a trend in the changing profile of patients and caregivers that the students interacted with during the period 2004 to 2018, a period of about 14 years. Dissemination of this report on the case studies was given ethical exemption under Exempt Category 1 (research in educational settings) by the university's ethical review committee. The case studies illustrate the changing age and gender profile of patients and caregivers as well as the changing disease profile from HIV to non-communicable disease and comorbid HIV and non-communicable diseases. The demographic and epidemiological transitions have implications for policy and programme because they bring about a change in families' community home based care needs.

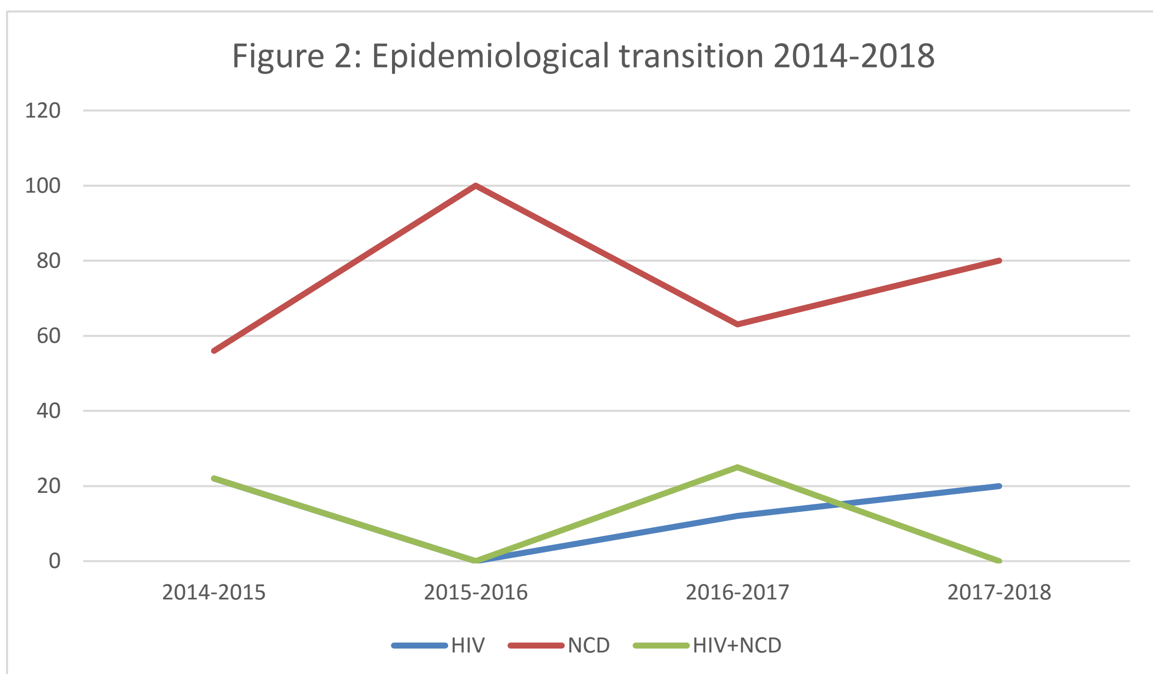
**Epidemiological Transition**

Epidemiological transition (ET) has been defined as the general shift from acute infectious diseases to chronic non-communicable diseases as a result of modernization and other developmental trends (Wahdan, 1996). Indicators of ET are patterns of mortality and morbidity; and such shifting patterns challenge governments and other stakeholders to tailor their health programmes to emerging problems. The cases studied revealed that during the period 2004 to 2013, AIDS dominated the diagnosis of patients on community home based care. Of the 20 families that students visited, 11(55%) had AIDS, 4(20% had non-communicable diseases, 3(15%) had both AIDS and non-communicable disease while the remaining 2(10%) had no member who was sick but had to be motivated on such areas as general cleanliness of the home environment and family planning. One of those diagnosed with AIDS died during the study period. Some of the patients were yet to be started on treatment which was at the time, dependent of the CD4 count. One case of non-communicable disease was that of a fractured femur.

During the period 2014-2018, 24 families were studied. About 3(13%) of the families had a patient with AIDS and one of those patients died during the study period; 17(71%) of the families had

a person with non-communicable diseases; 4(16%) of families had a patient with both HIV and a non-communicable disease. Common non-communicable diseases were hypertension, diabetes, cerebrovascular accident, and arthritis. Hypertension and diabetes frequently occurred together even though hypertension could occur alone. Arthritis frequently occurred with both diabetes and hypertension or any one of those. Brief descriptions of families during the earlier and later years of the community home based care are presented as exemplars for epidemiological transition. The cases illustrate not only the transition but a comprehensive picture of the family situation.



*Family A (2004-2013):*

*Mr. A is a 41 year-old male, unmarried and working as a technician. He is the head of the household. His family consists of 6 people: Himself, his 60 year-old mother; his 24 year-old brother who is unemployed and who helps with household chores; his 30-year-old male cousin who is working and helping Mr. A in breadwinning; another cousin, female aged 14 years who also helps with errands; and a $3^1/_4$ year old nephew. Mr A's family lives in a $2^1/_2$ type of house. However, he has built an extra one room in the yard that the family is also using. The refuse disposal sewage system and water supply are good. The living room is a little overcrowded with furniture but the general hygiene of the household is good. Mr. A has recently been a victim of neighbourhood crime whereby he was sprayed with a sedative chemical but has since recovered from the ordeal. Mr. B. is being treated for tuberculosis and he has declined HIV test. His mother has had to come in from the rural area to take care of him when his illness worsened because the 24-year old brother who had been providing care needed assistance; the mother brought with her a $3^1/_2$ year-old grandson who would have no one to take care of back in the rural area. Two cousins also moved in to help with caregiving. Mr. A started off with a private doctor. After some time with the private medical practitioner, it was becoming costly but the illness was not ameliorating and because he was diagnosed with tuberculosis, which would take a little long to treat. He then transferred to the public service. He has been frustrated in his effort to seek care from the public health services. At one point he went from clinic to clinic in search of a container for sputum specimen. He has also been discouraged by the long waiting time at the clinic because this has disturbed his work schedule. He can hardly appreciate the health talks delivered by nurses at the clinic before clients are attended to because he believes they delay service delivery. Mr. A's mother has privately expressed concern to the nursing student about his reluctance to test for HIV. The students referred the mother's concern to the clinic staff and action was still awaited when students completed their term of attachment.*

Family B (2014-2018)

*Ms B is a 70 year old female with diabetes and leg amputation. The family is a three generational one. She has four (4) grown-up children consisting of three daughters and one son aged 45, 35, 31, and 30 years. Most of the time the daughters are out looking for employment. Ms B. is widowed and she owns the house the family is living in. Ms B was diagnosed diabetes mellitus six years ago and that has led to amputation of her right leg. She is still learning how to use crutches. Her caregiver is her 45 year old daughter who is also working part time in a poverty reduction programme (Ipelegeng). Her son, who is the only family member with a stable job, lives with his wife in a rented room in the compound. Ms B. has 17 grandchildren and she lives with and takes care of 12 of them, four of whom are under the age of five years. Immunization records for three of the 4 children are up-to-date. However, the record for the $4^{th}$ child could not be found. Two of the grand children have some disability (cannot talk). The family's source of income is rental from one room in the compound. The grandchildren are the ones who prepare meals and often their grandmother has to wait a long time before being given food. Ms B reports that she does not eat well and that she has lost weight. She reports that her daughters do not help her with the bills and buying food. The yard and house are dirty. At 2PM, the beds are still unmade. The family has a water stand pipe in the yard, and water is kept in uncovered containers in the house. The family uses a pit latrine outside the main house. However, the $2^1/_2$ house that the son lives in has a toilet that uses water carriage system.*

**Changes in Demographic Profile of Patients and Caregivers**

Shifts in the distribution of population by age are said to be common in many countries. The shifts, which are related to decreasing fertility and mortality rates, bring about changes in the size, composition and living arrangements of families (United Nations, 2017). Similarly, the demographic profile of patients and caregivers studied for this paper demonstrated a shift in age and gender structures. Those studied in 2004 to 2013 had the majority of patients younger than 45 years. Seventy six percent (76%) of the patients were aged less than 45 to 49 years, whereas those aged 50 years or older constituted only 21%. From the period 2014 to 2018, the age profiles of patients changed upward. Only 21 % of the 24 patients were aged less than 45 years. The majority (19 = 79%) were aged 45 years and above. The mean age for patients during the period 2004-2013 was 40 years whereas that for the period 2014-2018 was 54 years. The gender profile of patients for the 2004-2013 period was 69% female and 31% males while that for the 2014-2018 period was 75% female and 25% male. Younger people increasingly played the role of caregiver, with the mean caregiver age being 42 years during the 2004-2013 period and 36 years during the 2014-2018 period. Caregivers' gender slightly changed as men increasingly played the caregiving role. Caregivers were 83% female and 17% males for 2004-2013 and were 56% female and 44% males for 2014-2018. Brief descriptions of families during the earlier and later years of the community home based care are presented as exemplars for the changing demographic profile. The cases illustrate not only the changing demographic profile but a comprehensive picture of the family situation.

Caregivers were found to be becoming diverse as grandchildren, neighbours, and close relatives gained prominence. Although females continued to be the dominant gender in caregiving (UNAIDS, 2008), the number of caregiving males increased. Only a few families could afford hired caregiving; and often where such resource was used, the standard of care was poorer that that

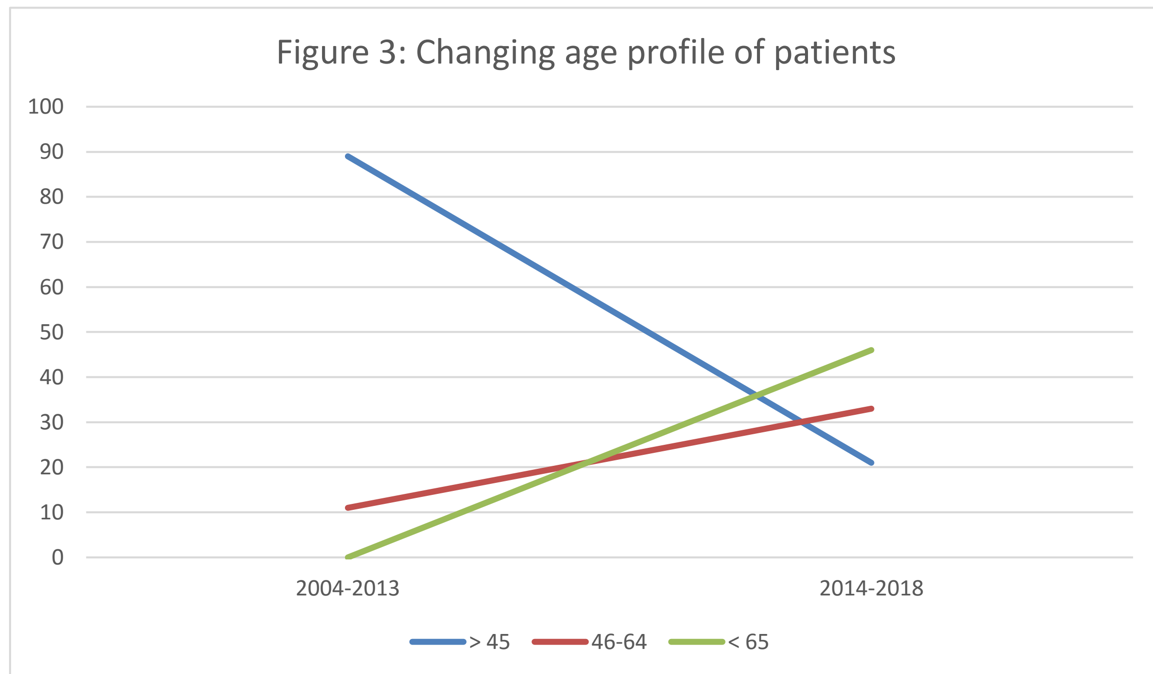


Figure 3: Changing age profile of patients

provided by family members and relatives.

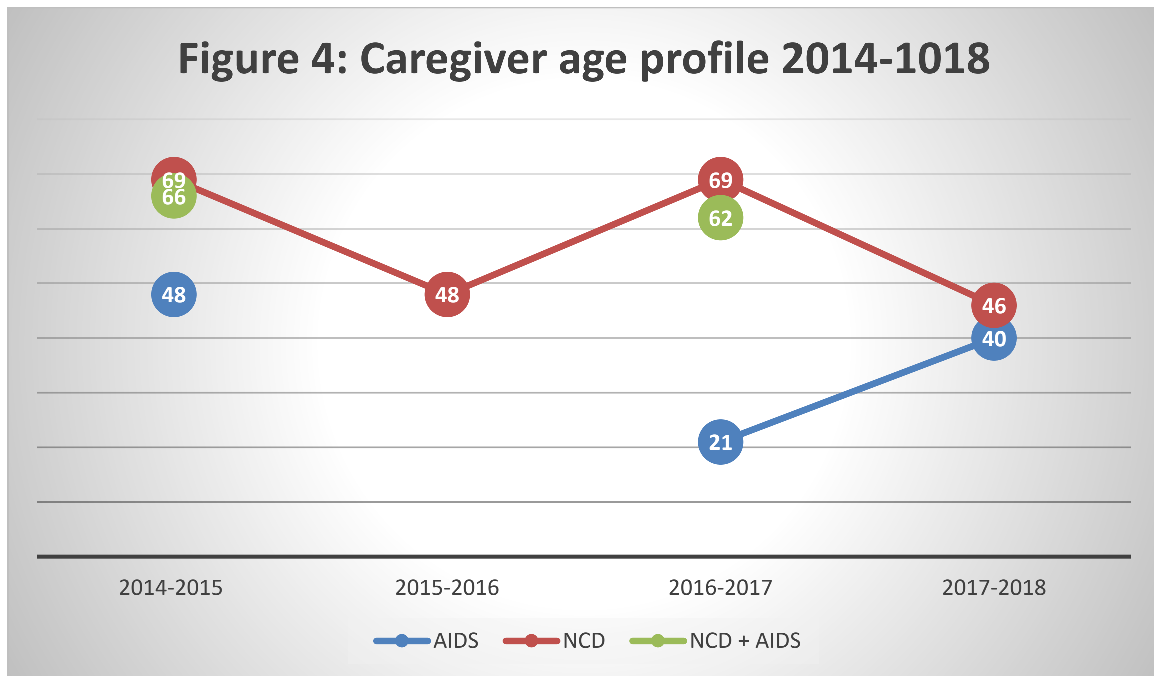


Figure 4: Caregiver age profile 2014-1018
69
66
48
48
69
62
46
40
21
2014-2015
2015-2016
2016-2017
2017-2018
AIDS
NCD
NCD + AIDS

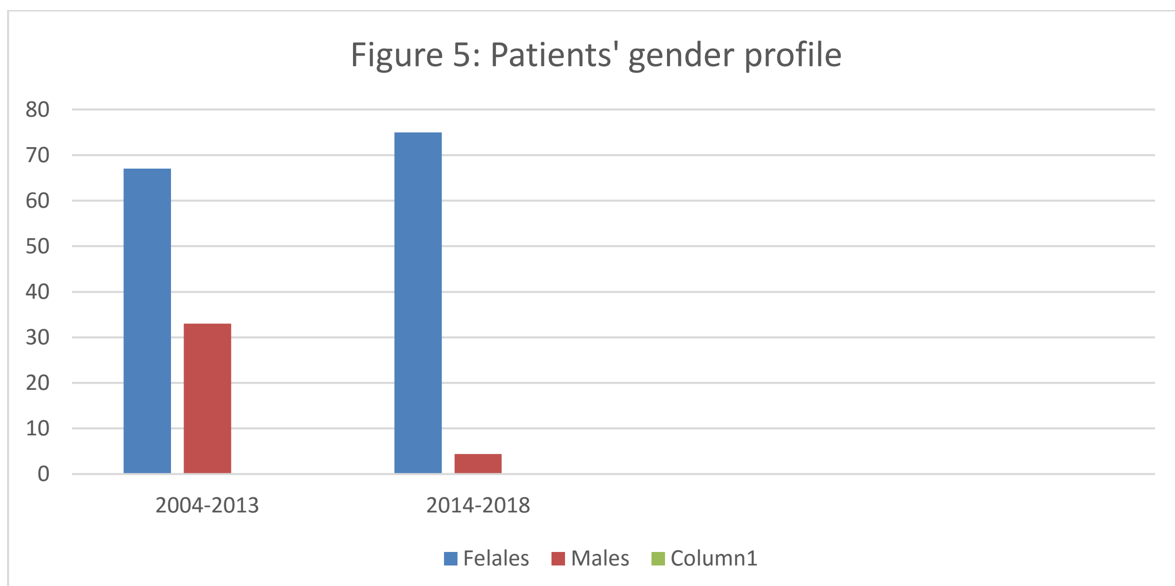
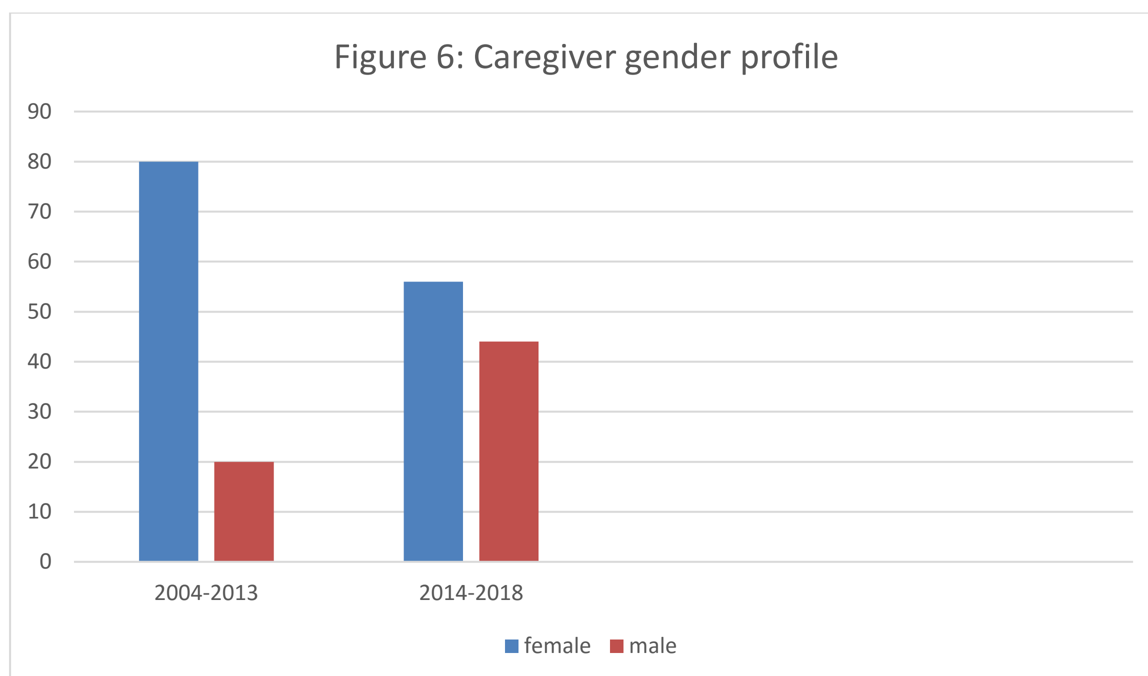


Figure 5: Patients' gender profile
80
70
60
50
40
30
20
10
0
2004-2013
2014-2018
Felales
Males
Column1




Family C, 2004-2013

*Mr. C is a 29 year-old father of 2 children under the age of 5 years. He is cohabiting with his 24-year old girlfriend. He is the head of a family of four people, and he is currently unemployed. Mr. has AIDS and is on antiretroviral and anti-tuberculosis treatment. Mr. C's girlfriend has neither felt no shown any sign of illness. She has not tested for HIV and does not see the need for it. She tested for HIV with negative results when she was expecting her one-year old son. The children's immunization record is good. Mr. C's family lives in a one-roomed house that serves as a kitchen a bedroom, a living room and a bathroom. The house presents a health risk with paraffin stored in bottles of drinks, objects lying all over the floor, cockroaches and bed-bugs infestation, occasional invasion by rodents, and dusty floor. The toilet is a temporary structure that does not meet the city council's standard of a pit latrine. The family has just been offered a residential plot and is yet to build a decent house and a toilet. The house is over-crowed making it difficult to keep it clean. The family has a waste bin that is kept uncovered. Fortunately, refuse does not stay long because the city council collects it twice a week. Mr. C's family has access to clean water and keeps water in the house in covered containers.*

Family D, 2014-2018

*The patient is a female and 83 years old with breast cancer and has had surgery to remove the affected breast. She also has hypertension and diabetes. 24 year old grandson is a caregiver. The family is middle-high class. However, members are not supportive of one another because of conflict over the family's estate. A well-to-do son lives in the adjacent yard but does not offer any support to his ailing mother. A daughter who lives out visits once a month to help with cleaning. The patient hires a taxi to go to the hospital and the grandson accompanies her. Another son never visits his mother even though he stays within the same town.*

### Summary of the Living Conditions of Surveyed Families

Household size ranged from three to eight people, with an average of five persons per household. The majority of families had cohabiting couples. The educational level of family heads ranged from standard seven to junior degree, with the majority having a junior secondary school certificate. The common type of housing was the basic minimum structure required by the City Council commonly referred to as “$2^1/_2$” which is a house with one living room, one bedroom, a kitchenette and a shower-toilet combination. The adequacy of space, in terms of furniture and the number of people living in the house was good to fair in most cases. Overcrowding was not always a result of too many people in the house, even though the average family size was 5 people usually occupying a “$2^1/_2$” house; it was often a result of families moving from old residences to new ones bringing furniture that the new transitional house could not accommodate. Kitchens were generally very small; and the closeness of the kitchen and the shower-toilet combination its closeness to the kitchen as is usually the case in 21/2 houses, presents a health risk, especially if the cleanliness of either the toilet or the kitchen is not maintained. This is because flies and cockroaches can easily move between the two places and contaminate food. The general hygiene of the kitchen was fairly good even though in some instances, there were cockroaches and mice. The major health risk in the kitchen was a gas cylinder that was kept inside the kitchen. Families were however, fully aware of the risk of keeping gas cylinders in the kitchen but they reported that, considering the high rate of crime, they preferred to keep them inside. In many cases, medications were kept in places where children could not easily reach them.

All surveyed families had access to clean water. Water was supplied by a water reticulation company, and the majority of families had at least a tap in the yard if they did not have running water in the kitchen and bathroom facilities. If water was kept in inside the house, it was usually in covered containers. The majority of surveyed households had a carriage human waste disposal system. The system in all the households was good, with no leakages and blockages. The condition of the toilets was generally good as they were clean, well ventilated, and free from offensive odours. Refuse was deposited in waste bins, which were regularly emptied by the city/village council. With regard to the utilization of health facilities, surveyed families were actively using the public health care services, especially child welfare and antenatal care. The majority of the children under five years of age had a complete record of immunizations. However, shortage of supplies often discouraged people from seeking help from the public clinic. Some families used prayer and faith in God to deal with their health problems. Only a few reported to be using the services of the traditional health care providers. However, some people reported using both the traditional and the western health care because they believed that each of the two systems has its own merits and shortfalls. Such respondents recommended that the two systems collaborate so that the society could reap the benefits of each. Where the traditional system was preferred, it was because it dealt with the root causes of illnesses, which were usually evil spirits and witchcraft whereas the Western health care system treated the symptoms. Other than HIV/AIDS and its commonly comorbid pulmonary tuberculosis, common chronic illness reported were asthma, hypertension, diabetes, arthritis, stroke, and prostate cancer.

### Challenges that Families in Community Home Based Care were Faced with

#### *Poverty*

The major challenge observed was that many families enrolled in community home based care were living in poverty or having limited capacity to provide basic materials needed in caregiving. Often families had a hard time choosing between caregiving and working (whether it be formal or

informal employment) so that they could meet the needs of the family. Although a few families had hired help to assist in patient care, many could not afford that. The government's assistance with basic commodities, notably food, was not always adequate to carry the family to the next month's supply. Compared to chronic illnesses such as hypertension, AIDS put an undue strain on resources such as food and housing because it often demanded that family sizes expand as others moved in to help with caregiving. This is because the person sick with AIDS often required labour intensive caregiving such as feeding, bathing, and medication administration. In addition, intimate care such as bathing and changing used linen often required a caregiver of the same gender with the patient. When the source of economic survival and primary caregiver became the care beneficiary himself or herself and the family was without economic means, this put the strain on the social services; and with staff shortages and poor follow-up systems, even diagnosing such situations could be difficult. Where families could not afford hired help, life became difficult as the children could be on their own as the economically active members of the family would go out to find work so they would be able to feed the family. A family scenario that follows provides a typical day in some families:

*Family E:*

*Mrs. E is a 54 year-old divorced mother for two grown up daughters and a grandmother to four grandchildren. She heads an extended family of seven people. She has had to terminate employment because of the illness and is therefore currently unemployed. Mrs. E has recently tested and diagnosed with AIDS after a long encouragement by nurses and community health motivators. She tested positive and has enrolled in anti-tuberculosis treatment. She is scheduled to enrol in ARV therapy at a little later time (2004-2013 period when CD4 count determined treatment commencement). She has difficulty ambulating. An old fracture on the leg is compounding her mobility problem. Mrs. E is still finding it difficult to accept the fact that she has AIDS.*

*Life in Mrs. E's family is very busy because there are children and a sick mother but there is nobody to take care of them during working hours as the two daughters are fulltime employed, working even during weekends. Dinner/lunch is prepared in the morning before the daughters leave for work. The daughters have to give the mother a bath and passive exercises before they leave for work. When children come back from school they serve themselves food that was prepared in the morning but they are too young to wash the dishes. An eight-year old grandson is often sent to collect Mrs. E's medications from the clinic when she runs out of supply. However, nurses usually refuse to give him the medication because he is under-age. He takes care of the younger children; he is the one who serves them food after school when the able-bodied adults are not there. He also helps in taking care of his grandmother. In the evening, the daughters wash the dishes and prepare the meal for the next day. It is therefore uncommon to find dirty dishes in the house. The family has clean water supply, a bin for household waste and a toilet, used mainly by adults. Cockroaches infest the house. When the children are on their own, they do not see the need to use the toilet and squat in the yard to relieve themselves. Mrs. E's family utilizes the health clinic well and members are satisfied with the services provided. Only, they wish the clinic could have a maternity ward, provide ARVs, and do CD4 counts so that the services they get from the hospital could be nearer to them. The family also uses the services of traditional healers. Children's immunization record is up-to-date.*

*Family F (2004-2013)*

*Family F consists of husband and wife both aged 35 years and their 3 sons aged 12, 7 and 1year. However, after the husband and breadwinner became sick, the children re-located to stay with their maternal grandparent in rural area. Mr. F has AIDS and tuberculosis and has had meningitis that*

*left him with hemiplegia. He is also on anti-hypertensive treatment. Before becoming sick, Mr. F was self-employed working as a builder. The wife was taking care of the children and the home. With the bread winner no longer working, it was costly to stay with the children who had to go to live with Grandma in the rural area. The family stays in one rented room where they sleep, cook, bath, and keep their belongings. The family has not paid rent regularly since the husband lost his job; however, the Landlord has so far been understanding. The family is getting some assistance with food from the department of Social Services; however, the food usually gets depleted before another supply. Hygiene of the house is excellent; so are water supply, sanitation and refuse storage and disposal.*

***Stigma Related to HIV and AIDS***

Whether it may be decreasing, levelling up or increasing, stigma related to HIV and AIDS is an enduring phenomenon that both patients and families must live with and that affects caregiving in a number of ways. Because of stigma, often family members chose to struggle on their own rather than face the embarrassment of registering a member for government's assistance. Some families were reluctant to go for HIV testing even when the symptoms warned or when a partner was sick or had died. Some even avoided encounter with health care providers for fear of being asked to test. Even when one family member could see the need for HIV test to confirm diagnosis, open discussion of such a concern with other members was difficult. When a parent was sick with AIDS and children were the care providers, it was a dilemma for the parent to face children and disclose her HIV status to them. This often caused delay in diagnosis and treatment.

Family G (2004-2013)

*Family G consists of a 51 year old single mother and her 3 of the 7 children aged 28, 17, and 14; employed home helper and her 18 months old daughter. Ms G who is the head of the family has been bed ridden for 4 months following stroke that followed her defaulting from antiretroviral treatment, and which left her with right sided hemiplegia. Ms. G has been lonely in living with her HIV status because she had not disclosed her status to her family members including her employed caregiver. The students worked with Ms G toward being open with her HIV status such that at the end, she was relieved after breaking the news; and the rest of the family appreciated that.*

## Opportunities

The support that some families, neighbours and relatives provided to caregiving families was commendable. Such support was common in AIDS care than it was for chronic non-communicable diseases. Relatives moved in to assist with caregiving; tenants in rented rooms and neighbours stepped in when the caregiver had other errands outside the home. Economic support from close others, albeit perhaps only temporary, flowed in when the breadwinner passed on. Even where bounds of marriage were not there to provide reassurance, cohabiting partners were listed as reliable caregivers. Another notable strength that presents an opportunity for leveraging is the role of grandparents in raising children. Unless there is rural urban separation created by migrations to urban areas, there is no evidence that the transitions that are passing through the society change the value of grandparent parenting or the expectation that grandparents will share the burden of parenting, if not take over the entire responsibility, as it occurs when biological parents die and leave orphans.

## Discussion

It is evident from the case studies that community home based care is increasingly having adult approaching 65 years of age or older than 65 years as the beneficiary of caregiving. These adults

are in three categories; those with non-communicable diseases, those with AIDS, and those with co-morbid AIDS and non-communicable diseases. Haacker, Bärnighausen, and Atun (2019) described what they called "the greying of AIDS" or a situation whereby there is increase in the population of older adults who have AIDS. Greying of AIDS adds complexity to the already relatively high risk of non-communicable diseases among older adults. Haacker et al. projected that the average age of a person living with HIV will increase from 40 years to 50 years between 2017 and 2030, and that the prevalence of cancers, cardiovascular diseases, and diabetes mellitus will increase by 2.5, 2.8, and 2.3, respectively, between 2015 and 2040. The emerging pattern of the co-morbidity of AIDS and non-communicable diseases challenges the health care system to come up with programmes that meet the needs of the emerging patients Haacker, et al.). Caregiving needs of HIV negative patients with non-communicable diseases usually revolve around assistance with activities of daily living and mobility. This situation may mean that community home based care that was initially developed to cater for young adults with HIV and AIDS has become irrelevant. Older people are best served by a programme specifically designed for them because their life aspirations are different from those of younger men and women who are still looking forward to a long life of career, marriage, and family.

Kane and Kane (2006) argued that because older people see their life as reaching a conclusion, they tend to look back to find meaning in the life that they have lived. Therefore older adults need to be empowered so they remain active in activities that they can still perform. They need a supportive environment that capitalizes on their strengths rather than over-estimate their fragility. They need to be provided with information about what they can do to make their lives meaningful. United Nations (2017) advised that planning for old age must be started early in people's tender age through means such as encouraging saving for retirement.

It has been noted that many public health systems in developing countries lack a fully developed support system and that as such, the bulk of caregiving support rests on the family (McNay, 2003). A concern has also been raised regarding the absence of old age policy that could cushion older adults from the caregiving burden of HIV and AIDS in many sub-Saharan Africa countries (King, 2008). Aboderin (2008) argued that the needs of older adults in many sub-Saharan Africa countries are neither known nor met. The difficulty in meeting the needs of older adults has been attributed to, among other things, lack of relevant training for staff (Aboderin, 2008). It has been some time since the establishment of the community home based care in Botswana, the country has gone through a period of high AIDS related deaths to that of ARV therapy and increased longevity with AIDS.

There is need to establish the profiles of community home based care clients and caregivers so that the programme can be best tailored to the needs of clients, caregivers, and families. Assessment tools that capture the personal demographic data for caregivers and care beneficiaries as well as their living situation need to be developed. Botswana's current old age pension scheme, that some have argued is failing not only to meet the needs of older adults but also to recognize their diversity (Bigombe, Betty, & Khadiagala, 2014), can be used to capture all older people registered under the scheme (those aged 65 years and above). It is important that such clients be defined in a way that accommodates the diversity of home based care clients.

It may be unrealistic to propose assessment of the household situation focusing on areas such as food, housing and finances for caregiving before a patient can be taken in for caregiving, considering that in many situations, alternatives are limited. However, this is something that may be considered (Nosseir, 2003) in case there may be an alternative; because otherwise caregiving may be stressful for the patient, caregiver, and the entire family as for instance, in one family, there was no

time for the caregivers to assist the children with school work. Sometimes caregiver's work was also be affected as in the case of a caregiver who needed to give the patient a bath and cook before going to work. Johri, Beland and Bergman (2003) have noted that if community home based care is not well managed, its outcome may defeat the good intentions of reducing the rates of hospitalization and the use of the social services.

As the number of older adults with co-morbid AIDS and non-communicable diseases increase, particular attention need to be given to the risk factors for non-communicable disease as understanding those may help reduce the prevalence of non-communicable disease among older adults with AIDS. In their investigation of the risk factors for non-communicable diseases in Botswana, Keetile, Navaneetham, Letamo, and Rakgoasi (2019) found that smoking, low consumption of fruits and vegetables were more common among the poor while smoking was more common among the non-poor people. The researchers recommended that the national non-communicable diseases strategy pay a special attention to the role of socio-economic status in the development on non-communicable diseases (Keetile et al., 2019).

Older adults frequently have multiple chronic conditions requiring use of multiple medications as was shown in some families reported in this paper. In some situations, medications were sourced from different outlets (over-the-counter, prescription, and traditional preparations). The implications of combining such medications may therefore remain unexamined, posing a risk to older adults. As has been noted some of the medications used in the treatment of AIDS may have side effects that increase the risk of non-communicable diseases (Haacker, Bärnighausen, & Atun, 2019). This observation is particularly worrisome when one considers older adults whose risk for such diseases is already high. When the older adult has poor memory, he/she may even repeat or miss medication doses. A programme of care that covers monitoring and assistance with medications in necessary for older adults. A count of prescribed medications that is currently used with antiretroviral therapy in Botswana could be one way of monitoring adherence to prescribed medications among older adults in community home based care.

As has been observed, older adults need a proactive programme of health promotion that emphasizes prevention and modification of risk factors such as low physical activity, obesity, use of alcohol and tobacco and poor diets. The programme must emphasize as well, respect the clients' cultural background, and a seamless follow-up of clients at different levels or settings including the home (Salmond & Echavarria, 2017). The World Health Organization has proposed an integrated and coordinated programme for older adults that is multidisciplinary, multi-level, and that attends to medical and social needs of the population over the life course in a manner that respects their dignity, autonomy, and capacity for self-management (deCarvalho, Epping-Jordan, Pot, Kelly, Toro, Thiyagajan, & Beard, 2017). It has been argued that the availability of data on the prevalence of chronic non-communicable diseases and their risk factors among older adults, levels of basic service provision to the population, and the extent to which older adults' health status and disability negatively impacts on the countries' social and economic development could raise political will and speed up appropriate response from policy makers (Aboderin, 2010).

As the proportion of the population of older adults in community home based care increases, those disciplines involved in home based care need to re-look at their curricula so as to determine if there is enough basic content for working with older adults. It has been reported that older adults under the care of professionals trained in working with older persons have shown fewer hospital admissions and fewer incidents of behaviours requiring physical restraints (Kovner, Mezey, & Harrington, 2002). Trained professionals could be able to make accurate assessment of caregiving

situation, intervene, or make referrals for immediate medical and social services' needs. deCarvalho, Epping-Jordan, Pot, Kelly, Toro, Thiyagajan, and Beard (2017) noted that because many of the assessment tools for older persons were developed in high income countries, such tools need to be validated in low and middle income countries.

The epidemiologic and demographic changes reported in this paper generate important new insight into policy and practice. The diagnosis of AIDS for older people brings about challenges of disclosure to caregivers, who are usually children. Probably due to the stigma associated with HIV and AIDS, parents worry about what the children will think of them; could it mean that they have engaged in irresponsible sexual behaviour? Obviously, failure to disclose, particularly when the patient cannot independently seek medical care because of sickness, will delay treatment. Similar to what was found in a Malawian study (Negin & Cumming, 2010), parents, who were usually mothers, were not comfortable disclosing their HIV status and AIDS diagnosis to their children who were their caregivers. Some were uncomfortable having their own children invade their privacy such as when they could not bath themselves. An even difficult situation was that of a son caregiver who was providing intimate care to his bed-ridden mother. Such situations were emotionally challenging but not much support was available to help both the caregiver and the client cope with them. It has been noted that AIDS care has focused on young people and neglected the sexual behaviour of adults (Knodel, Watkins, & VanLangingham, 2003). One would argue that attention needs also to be given to young caregivers providing care to parents of the opposite gender.

One observation made in the studied families is the nature of families that is not defined by marriage. Cohabitation was a frequent family structure in most of the household. It was rare to find a family with husband, wife and children. Mother and father were frequently unmarried but staying together, raising children, and providing support to one another, including caregiving. Although non-married couples were supportive of one another, in the absence of a binding contract between partners to be there for one another and their children, the future of the family is uncertain. The situation is even disturbing when one considers the economic hardship that families were going through. Harris, Charles, and Davies (2006) noted that the value of marriage has diminished, with contemporary relationships having high chances of failure because such relationships are continuously negotiated. Often when courtships break and each partner goes her/his way, the grandparent bears the burden of childcare, which itself has become even more challenging because of factors such as rising rates of young people's substance use and engagement in unprotected sexual activity.

Another important observation is that even with the shift from AIDS to chronic non-communicable diseases, women still make up the majority of both care beneficiaries and caregivers. This finding has also been observed in a previous study conducted in Zambia (Mbale & Chileshe-Chibangula, 2017). As it has been demonstrated in the studies families, women carry high burden of caregiving. Therefore women as mothers, particularly as single parents, and as grandmothers, need to be supported as they negotiate child rearing and caregiving in an environment that is frequently challenging both emotionally and financially. Efforts need to be made to reduce the burden of care among women through such strategies as respite care provided by community support groups (United Nations, 2017). However, we also need to acknowledge the increasing visibility of men in caregiving. Whereas an earlier study in Botswana had less that 10% of the studies families (Browning, 2008), an analysis of caregiver gender in this study showed that male caregivers increased from 20% in 2004-2013 to 44% in 2014-2018. Certainly, male caregiver will need to be assisted to cope with the emerging role of caregiving.

Households in the studied families tended to be extended with three generations and close relatives. Although generations were a source of support for one another, large households were an economic strain especially when food and housing were considered. This is especially disturbing because of the poverty situation that many families were in; with many economically productive members either looking for a job, doing irregular low-paying jobs, or being unable to work because of ill health. In order to reduce the burden of childcare on single women and grandparents, policies must support single women raising children alone through such means as foster care and assisting them with income generating projects.

## Summary of Recommendations

*A Policy for Older Adults*

A policy on the care of older adults (65 years and older) in Botswana is needed to guide the care of older adults, not only those designated covered by the home based care programme, but all those reaching the targeted age. A policy for older adult could support a strategy that focuses on the needs of older adults, that supports their recognition and value in the society, and that provides them with opportunities that maximize their functional abilities both in and outside the family. The policy must support life-long learning for older adults as long as they see the relevance of what they learn to their life situation. It needs to ensure that they are networked with those people who have been important to their lives because that will enhance their enjoyment of life.

*A Data Base for Older Adults*

There is need to keep a data base of older adults that will inform government and other stakeholders about how many people aged 65 years and above are there, where they are, who they are with and how they are related to that person, how their living situation is with regard to issues such as housing, health status and functional ability, safety, and economic means. Assessment tools should be able to capture required data about older persons. Registration of old age pensioners that the government has instituted can be expanded so that the assessment is more comprehensive than it is currently.

*A Consideration of Older Adults in HIV and AIDS Care*

HIV and AIDS care needs to pay special attention to older adults so that like any age group, they are taken through assessment, education and counselling in a language and approach that recognise and respect their age. The possibility of fear of disclosure to children must always be ruled out; and where necessary, both the parent and children must be assisted to be open with and to support one another. In their retrospective investigation into the possibility of leveraging AIDS services to incorporate non-communicable diseases in Botswana, Reid et al. (2016) found that four-out-of-five patients referred for non-AIDS medical problems were on antiretroviral therapy. Although the patients were not necessarily older adults as their mean age was 46,5 years, the fact that the most frequent diagnostic category was cardiovascular diseases suggests that the sample was not young. Reid et al. concluded that HIV programmes could be expanded so they are inclusive of non-communicable diseases. This expanded programming will certainly benefit older adults who make a significant proportion of those affected by non-communicable diseases.

*Need for Professionals with Basic Training on Care of the Older Adults*

As the population of older adults in Botswana steadily increases, there is need to provide basic training for professionals involved in the care of older adults such as social workers, nurses, and physiotherapist and to ensure that such professionals reach out to older adults in homes, hospitals and similar settings. Trained professionals can be instrumental in assessing older adults and their home

situations, as well as in designing and implementing health promotion programmes that emphasize healthy lifestyles for the prevention of non-communicable diseases and reduction of premature loss of functional capacity. Of particular importance would be assisting older persons in managing the many medications that they are frequently taking so as to reduce incidents of over/under-dosing and medication interactions. .

*Attention to Poverty and the Changing Gender Dynamics in Caregiving*

Grandparents and single parents need both material and emotional support that could ease the burden of caregiving. Support resources could be support groups, foster care, volunteer respite care, and government-supported income generating projects. As the population of male caregivers increase, men need to be assisted to cope with the responsibility not traditionally expected of them, such as when a son provides intimate care to a sick mother. In such situations, both care beneficiary and caregiver need focused counselling and orientation to the role.

## Limitations

The selected families may not give an accurate representation of families in the home based care group. First of all, only limited geographical area, mainly low income urban residence, was studied. Families were selected conveniently, and the objectives of the exercise were educational and not necessarily to study community home-based care. A study set out to target community home based, epidemiological profile of home based care clients, demographic profile of both clients and caregivers, and the home based care living conditions in wider and more diverse settings could give more convincing findings.

## Conclusion

Community home based care in Botswana was established at the height of the HIV and AIDS crisis when the hospitals were not able to absorb all patients. However, with the introduction of antiretroviral therapy and reduced AIDS related deaths, increase in the incidence of non-communicable diseases, and increasing population of older people, community home based care needs to re-focus in order that it can be able to address emerging needs. Such needs are the changing epidemiological and demographic profile of both patients and caregivers. There is need for policy that will guide re-focusing of the home based care programme and attention to the needs of the growing older adult population.

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