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## **Grandparent Caregivers' Perceptions and Lived Experiences: Their Health and Wellbeing, Access to Health and State of Health Services in Zimbabwe**

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### **Cover Page Footnote**

I would like to thank International Postgraduate Research Scholarship and Australia Postgraduate Award for paying my tuition fees during my studies. I would also like to thank my supervisors Professors Robert Cumming and Elias Mpofu

*Research Article***Grandparent Caregivers' Perceptions and Lived Experiences: Their Health, Access to Health, and the State of Health Services in Zimbabwe**

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**Abstract**

The study explored the perceptions and lived experiences of self-rated health, access to health, and state of health services for grandparent caregivers in Zimbabwe. In-depth interviews using semi-structured interview guides were carried out to elicit perceptions of lived experiences from grandparent caregivers (N=31; Mean age= 65.7; SD= 10.7). The data was thematically analysed and the software Nvivo 10 was used to help categorize emergent themes. The study found that grandparent caregivers experienced multiple chronic and complex self-rated health conditions (e.g., High blood pressure (HBP), arthritis, diabetes, hypertension, back pain, and heart problems), which influenced their health and Quality of Life (QOL). They perceived health services as inaccessible without medical insurance and provision of health services in Zimbabwe as appalling and prohibitive, particularly in rural areas. The negative perceptions of health services impacted caregivers' willingness to seek the services when needed. Some of the caregivers resorted to traditional healers and religious leaders' services as alternatives to conventional health services for coping with poor physical and mental health. The high prevalence of self-reported chronic illnesses and the crisis in the health sector was lamented by most grandparent caregivers, indicating the need for access to quality health care and/or services, medical insurance, and social protection services.

*Keywords: self-rated health, wellbeing, health services, grandparents, caregivers*

**Introduction**

The majority of older caregivers in sub-Saharan Africa, particularly in Zimbabwe, are poverty-stricken, food insecure, and lack access to health and social services (Mhaka-Mutepfa, E. Mpofu, & R Cumming, 2015). Few African countries have provision of security grants or formal systems for caring for older persons and most of the elderly rely on traditional family structures. Migration, modernization, and urbanization have also diminished kin support for older persons (UN, 2016). Becoming a grandparent carer adds a layer of complexity and is typically not easy nor always voluntary as it affects health and well-being, particularly during the AIDS era that has hit sub-Saharan African countries harder than any other area (Mhaka-Mutepfa, E. Mpofu, & R. Cumming, 2015). The HIV and AIDS pandemic has shifted the role of grandparents from secondary caregivers of their grandchildren to primary caregivers for orphaned grandchildren.

In addition, in countries with a high prevalence of HIV/AIDS, many households are increasingly headed by the elderly leading to increased vulnerability to poverty (Aboderin & Beard, 2014). The elderly caregivers are likely to experience chronic health conditions, physical degeneration, and frailty as a result of the aging process, which is exacerbated by caregiving. Previous studies attest to the risks caregiving poses to health (e.g., stress and depression) (Hayslip & Smith, 2013), long term changes in stress responses (Kidman & Thurman, 2014; Oburu & Palméus, 2003), and an increased risk of infectious diseases (Aboderin & Beard, 2014). Women in many, if not all cultures, carry a disproportionate burden of household responsibilities and activities, a burden that may also pose a threat for progressive illness (Magen Mhaka-Mutepfa, Cumming, & Mporfu, 2014). Illness requires accessibility to health services which are well monitored and managed, not the case in low income countries.

Previous studies reported that lack of access to health services, poor state of primary health care facilities, and lack of human and material resources were associated with poor health and well-being, thus caregivers may fail to cope with caregiving roles (Cheng, Linda, & Kwok, 2013; Mugisha, 2013; Sayegh & Knight, 2011). The way people perceive their self-rated health and availability of health services has an impact on their subjective well-being. A carer who perceives his/her health as very bad and the state of health services as poor because of lack of resources (medication, personnel, water, etc) is not likely to seek medical treatment (McKoy-Davis et al., 2017). This decision further aggravates their health and well-being. For instance, *Newsday Zimbabwe* reported that the Zimbabwe government has relied on inadequate and irregular donor support (e.g., NGOs like UNICEF: United Nations Children's Fund) to run the public health systems (The-Editor, 2015). As a result, the government has failed to provide adequate health services to its people, especially the 90% of the population without medical insurance (*Newsday*, 2015), despite making empty promises.

Further, 90% of the population in Zimbabwe are not formally employed and are living below the poverty datum line; therefore, they cannot afford medical insurance (Mhaka-Mutepfa et al., 2015). However, beneficiaries of the public health system are not required to pay to access services, but drugs are hardly available in the public health facilities so patients have to buy from private pharmacies. The patients also have to commute, particularly those residing in rural areas, as pharmacies are located in urban areas. In addition, long queues and poor quality of service are common (Dhemba & Dhemba, 2015). The state of the health services and services rendered thus affect caregivers' perceptions, well-being, and their health-seeking behavior.

The paper (*Newsday*) also revealed a huge crisis in the health sector. For instance, in 2015, the government allocated 301 million USD to the health sector for a country of 13.5 million people, suggesting that on average each person was allocated 22 USD that year. Other sub-Saharan countries allocated much more, for example, South Africa allocated 650 USD per person, Botswana 390 USD per person, and Angola 200 USD per person. Furthermore, there are 1.6 doctors per 10,000 people and seven nurses per 10,000 people in Zimbabwe. The country also has shortage of specialists: four neurosurgeons, two heart surgeons, three dermatologists, and one venereologist, according to data in Zanu PF's 2013 election manifesto (*Newsday*, 2015). Zanu PF (Zimbabwe African National Union — Patriotic Front) has been the ruling party in Zimbabwe since independence from British colonial rule in 1980 and is still the ruling party. Health services have deteriorated during their empowerment because of corruption and mismanagement of resources.

### **Failure to Seek Health Services Because of Stigma**

Previous researchers in Zimbabwe reported positive perceptions of aged persons, with a few viewing the aged as “witches or wizards” (Kazeze, 2008; Ssengonzi, 2009). The strong sense of community, interdependence, and connectedness that existed in sub-Saharan Africa before the AIDS era has been eroded. Caregivers may feel ridiculed, unvalued, and disrespected because they are fostering HIV-infected orphans. The negative feelings and abuse may reduce caregivers health-seeking behaviors for fear of ridicule. The abuses (stigma and discrimination) of old persons were also found to be within the households and communities in Tanzania and South Africa and were hardly reported (Helpage-International, 2008; Kazeze, 2008; Ogunmefun, Gilbert, & Schatz, 2011). Stigma and discrimination may lead to social isolation and emotional distress among caregivers, thereby affecting their self-rated health status, self-reported symptoms, and well-being. Stigmatized caregivers may not seek health services lest they are stigmatized.

Studies in sub-Saharan Africa reported that stigma and discrimination were rampant and were perpetrated by professionals, particularly health personnel (AVERT, 2016). The People Living with HIV Stigma Index indicates that roughly one in every eight people living with HIV is being denied health services because of stigma and discrimination (UNAIDS, 2015). If caregivers are stigmatized by health personnel, seeking medical care for themselves and their grandchildren becomes a hurdle. Social exclusion and marginalization are major challenges facing older persons (Tran, Ohinmaa, & Nguyen, 2012), particularly caregivers of orphaned children. Information on stigma and prejudice is vital for the private and public sectors to formulate policies that enable caregivers and their grandchildren to access health services.

However, previous research has documented the benefits of caregiving to grandparent caregivers with personal and social resources (Fruhauf & Bundy-Faziolli, 2013; Hayslip & Smith, 2013; Mhaka-Mutepfa et al., 2015). The resources enable the caregivers to seek health services and therefore cope with caregiving. Further, perceptions of accessibility to health services and the state of health services are important to grandparent caregivers as they enhance their ability to manage their health by seeking services.

### **The Situation in Sub-Saharan Africa**

Approximately 50-60% of people living with HIV in sub-Saharan Africa are being cared for by an older person, with each older carer looking after an average of two people affected by HIV (United Nations, 2016). Studies in Lesotho and Namibia have revealed that the elderly spend up to 70% of their money on other people, mainly young children (Guyen & Leite, 2016). Some older people are sexually active and are also infected with HIV, and this state affects their health and carer roles (Kidman & Thurman, 2014), hence they need access to health services. In Botswana, 21% of people in their early 50s are HIV-positive, compared to 25% aged 15-49 years (Ama, Dwivedi, Shaibu, & Burnette, 2015). Poor health among the older people with carer responsibilities may impede their caregiving roles because they may worry about their own health. In many cases, the orphans are being looked after by their ailing grandparents, who also have needs of their own, exacerbating work overload and the poor health (Mhaka-Mutepfa et al., 2014).

In sub-Saharan African countries, financial strain and poor health were found to be a major problem among grandparent caregiver families, where grandparents are overwhelmed and children fare poorly (Matshalaga, 2004; Nyasani, Sterberg, & Smith, 2009). In addition, old age is often accompanied by a reduced capacity of income generation, senility, and a growing risk of chronic illness. Poverty in Zimbabwe is

estimated to be over 70% and the rate of unemployment is estimated to be over 85% (Newsday, 2015). These figures suggest that Zimbabwe has other urgent and pressing issues to resolve beyond the health of aging caregivers.

Caregivers' narratives of their perceptions and lived experiences of the health services should be captured to provide alternative and self-reported perspectives other than those of healthcare providers (Jones et al., 2016). The lived experiences of grandparent caregivers should be explored to enable stakeholders to formulate suggestions for resolving issues for the growing elderly population. Most of the elderly need access to health services since the disability adjusted life years (DALYS) are increasing (Aboderin & Beard, 2014). Life expectancy will have risen to 83 in developed countries and 74 in developing countries by 2050. The demographic transition is not supported by policies that address poverty, ill-health, and the state of health services in African countries, let alone Zimbabwe. The increase in numbers of older people is proportional to the burden of providing social services, particularly healthcare services which may affect the caregivers' health-seeking behaviors, therefore impacting their health and wellbeing (Tran et al., 2012).

Data on the impact of perceptions of livelihood strategies, self-rated health status, and state of health services for older people in Zimbabwe is unavailable, making tailored intervention difficult. The Zimbabwe government has enacted the Older Persons Act of 2012, which has not been implemented due to lack of funding (Dhemba & Dhemba, 2015). Without support services to grandparent caregivers, accumulated interpersonal losses (e.g. loss of a spouse, children, familiar environment, job income, physical health, and negative perceptions of health services) threaten the fulfilment of their daily living needs and life satisfaction (Tran et al., 2012). Other problems encountered by grandparent caregivers include age and gender discrimination, lack of access to health services, lower earning capacity, and limited access to land ownership.

This paper is part of a larger study that explored the perceptions and lived experiences of grandparent caregivers fostering grandchildren in Zimbabwe. The article explores caregivers' lived experiences and perceptions of their self-rated health, access to and state of health services in grandparent communities, and the stigma that affect their health-seeking behaviors. Self-rated health is an important aspect of self-perceived well-being (Taylor, 2013). A qualitative study of grandparent caregivers is therefore crucial for highlighting issues that need addressing to improve access to and quality of health care. Providing evidence that may help improve health care services for the elderly in Zimbabwe and other sub-Saharan African countries is of paramount importance as this impacts their well-being.

The health belief model appears to hold promise to advance understanding of perceived health and well-being in caregivers (Taylor, 2013). The health belief model explains and predicts health-related behaviors, particularly regarding the uptake of health services. Grandparent caregivers may perceive susceptibility to poor health and that certain diseases are severe with grave consequences. They may believe that accessing health services can overcome barriers and enable coping and managing of the diseases. If the caregivers do not see a health care behavior as risky or threatening, there is no stimulus to act. If perceived as risky, caregivers may have the expectation that seeking health services will be beneficial.

### **Goals of the Study**

This article focuses on the qualitative part of the study. The in-depth interviews corroborated and expanded on collected survey data, providing meaning to different

experiences. The purposes for mixing were expansion and complementarity. The interviews helped explain the survey findings, therefore enhancing the study's validity.

The objectives of this part of the study were:

1. To explore the perceptions and lived experiences of self-rated health, access to, and state of health services for grandparent caregivers in Zimbabwe.
2. To identify perceptions of instances of stigma and discrimination that affect health-seeking behavior by grandparent caregivers.

### **Method**

The qualitative approach used enabled caregivers' perceptions to be uncovered through direct questioning to complement the quantitative data. In-depth interviews using semi-structured interview guides were carried out to elicit lived experiences from the key informants. Narratives or stories of people's lived experiences, local histories, and shared knowledge to understand systematic behaviors were recorded. The qualitative data that were generated was analysed thematically. The descriptive data gathered from the semi-structured, open-ended interviews contributed to understanding grandparents' perceptions of self-rated health and health services.

### **Setting and Participants**

Zimbabwe is a landlocked country, bordered by South Africa, Zambia, Botswana, and Mozambique and made up of 10 provinces. Two of the 10 provinces of Zimbabwe (Harare and Mashonaland East) were selected as the sampling frame. Harare province is made up of seven districts, and Mashonaland East is made up of eight districts, mostly rural and farming area. The socioeconomic indicators and the prevalence of caregiving by grandparents in the chosen provinces are similar to the other eight. Most participants were primary caregivers.

Grandparents met the inclusion criteria if they were able to speak and understand Shona and/or English and were fostering grandchildren under 18 years of age. The 31 participants for this part of the study were selected from the total quant-qual sample (400) using purposive sampling so as to include different demographics (heterogeneous sampling). Nineteen participants resided in an urban setting (10 low-density and 9 high-density suburbs) and the other 12 resided in a rural setting. It had been anticipated that a maximum of 50 people would take part in the qualitative study but saturation (i.e., new ideas or opinions ceased to come up) was reached with 31.

### **Data Collection Procedures**

Approval to conduct research was given by the University of Sydney Ethics Committee and The Medical Research Council of Zimbabwe. Qualitative in-depth interviews with grandparent caregivers were used to collect data and the interview guide was piloted on two participants and adjusted for clarity. The in-depth interview question guidelines covered self-rated health of caregivers, perceptions of access to health services, perceptions towards state of health services and coping strategies, and prejudice, stigma, and discrimination. Questions probed lived experiences of caregivers in relation to their health, access and state of health services and discrimination. For instance, questions like "How has been your health?" and "How do you cope with being a caregiver for orphans?" and others were asked. Generally, questions asked were about health and services, fulfilment, or negative experiences the grandparents have encountered from carer responsibilities. The open-ended questions improved the research process and

enabled greater insight. All data were collected in the local language for the sampled districts.

Data on the caregivers' demographics and socioeconomic characteristics were also collected. Most of the respondents were interviewed at times convenient to them in their homes or outside the house. The latter was because there was no privacy in some of the homes because of overcrowding in certain communities (e.g., high-density suburb and farming areas). The investigator explained the purpose of the study and scheduled interviews with the participants. The caregivers signed consent forms or used a thumb print if illiterate. They also had to consent to the use of tape recorders to record interviews. Participants were assured of confidentiality and anonymity. The author conducted the interviews, and each lasted about 60 minutes.

### **Data Analysis**

After all data was collected, it was transcribed verbatim and the transcriptions were checked for accuracy against the audio tapes. The data was thematically analysed, and the software Nvivo 10 (Bazeley & Jackson, 2013) was used to help categorize emergent themes. The links between the themes to show prevalent thematic codes and mind maps were also drawn in Nvivo 10. Similarities, differences, and variations with other themes were determined using comparisons. The in-depth interviews provided meaning to different lived experiences. They added an explanatory detail on how the caregivers accessed health services despite limited resources and the state of health services in Zimbabwe. The recorded observations, feelings, and impressions that were written in a notebook during data collection so as to remember the reflections when transcribing was added in memos and annotations in Nvivo 10 during organization.

### **Results**

Data analysis revealed four overarching themes that described the lived experiences of grandparent caregivers for orphans. The themes that emerged included: 1. The self-rated health status of caregivers and that of household members; 2. perceived access to health services and strategies for coping; 3. perceptions of health services in grandparent caregivers' communities; and 4. prejudice, stigma, and discrimination experienced by grandparent caregivers. Verbatim quotes are used to explain the themes where possible.

### **Socio-demographic Characteristics of the Population**

A total of 31 grandparents (74% female) participated in this section of the study. Their ages ranged from 45-92 years ( $M=65.7$ ,  $SD=10.7$ ), with 26% in the 56-60 year age group. Of the caregivers, 13% were university graduates, 45% were primary school graduates, and 29% were high school graduates. Most of the caregivers were widowed (63%). The grandparents received income from work, self-employment, rentals, and support from their adult children. The average monthly income was 300USD. All the caregivers with the exception of one were religious and were actively involved in religious activities. Grandparents took up caregiving because the children's parents had died from AIDS (57%), were living in multigenerational households (33%), or the children's parents could not stay with their children (10%). Most of the caregivers got support (financial, social, physical, and emotional) from their surviving children (67%). Each carer fostered an average of three grandchildren (54% were orphans and the rest non-orphans). Thirty-five percent of caregivers were fostering orphans only, 19% non-orphans, and 45% were taking care of both orphans and non-orphans. Of the 96 grandchildren fostered, 20% were reported to have tested HIV-positive. Most of the



caregivers were fostering maternal grandchildren (55%), paternal (13%), and both maternal and paternal (32%). Nine percent of the children were not in school because their caregivers could not afford to pay school fees. The themes that were identified are elaborated in the next section. It should be noted that the themes overlap.

### **The Perceived Self-Rated Health of Caregivers and Household Members**

The results under this theme showed the oneness, unity, and solidarity among African communities. In African societies, oneness and sharing play a vital role. Caregivers reflected the aspect of collectivism in their health-related narratives. When asked how their health had been, grandparent caregivers included the health of all members living in their households.

Twenty-six participants (87%) reported their self-rated health as bad. The prevalence of physical limitations increased with age. High blood pressure (HBP) (8), arthritis (7), back pain (9), generalized pain (6), and HIV opportunistic infections (21) were recurrent words in participants' responses. The other ailments that were mentioned were heart problems, continuous cough, visual and hearing problems, headaches, and asthma. For instance, a carer reported the self-rated health status of people in her household:

*...I am depressed...My husband died in January this year from prostate cancer...We were eight in my family and six of my siblings died from HIV. Out of my seven grandchildren, four have tested positive. My other grandson who tested positive died last year from meningitis at 2 years...My son is mentally ill and I have to take him to Annex [mental health facility] for medication. He walks naked when sick...My four surviving daughters have all tested positive...My sisters left 10 children and my brother left four. AIDS is a disease that is prevalent in this house....*

(Participant 28; 57 years, female, rural)

This participant reported having several members of the household unwell particularly from HIV opportunistic infections. Four of the caregivers in the study divulged they were living with HIV and AIDs, and most caregivers had a spouse, children, relatives, and/or grandchildren who were living with HIV or had died from AIDs. Other caregivers cited their bad health and that of their husband, their adult children, and their grandchildren:

*...I am asthmatic and have high blood pressure (HBP) and I take hydrochlorothiazide (HCT). My husband was positive, but he did not tell me...I found his ARVs after he had died under the mattress...he was very promiscuous...One of my grandchildren is also sick and the parents are HIV-positive.*

(Participant 25; 65 years, female, rural)

*My health is not very good. I suffer from arthritis, hearing problems and visual. My wife has HBP. We cannot afford to go to the clinic for it is far off. At times we get headaches and do not sleep well because of problems....*

(Participant 7; 79 years, male, low urban)

*I have diabetes, gout, and ulcers...I am just a domestic worker and I earn very little. I am stressed because I live in a high socioeconomic status (SES) suburb and the fees are high...I cannot afford paying fees for two children (daughter and grandson) from my salary.*

(Participant 9; 54 years, female, low urban)

*My health is not good. I am HIV-positive and am on ARVs and cotrimoxale...plus arthritis...My husband is also positive. We do not have sex because we were separated long back. I also consult apostles/religious leaders when I have a problem because I don't pay. Sometimes I take herbs to control my illness.*

(Participant 14; 69 years, female, low urban)

Four caregivers (13%) reported health challenges resulting from caregiving roles. An excerpt to illustrate this point:

*I am always sick; my health is poor, particularly at night. Ohhh oh...I feel generalized pain, a headache...I feel I will die especially at night. I also feel shoulder pain. I work a lot during the day because I look after six orphans and cannot rest at night because of the pain. Caregiving is hard work and it makes me sick. There is no one to help me with chores.*

(Participant 24; 68 years, female, rural)

Four caregivers (13%) reported health challenges resulting from the aging process. For example, an excerpt from a caregiver:

*I have generalized pain...But manageable...I think pain is from old age, not caregiving. My wife was asthmatic, and she died in 2005.*

(Participant 15; 60 years, male, low urban)

Good physical health and positive perceptions are important for caregiver roles in general and for aging persons. For example, positive perceptions allow caregivers to recover more quickly, improve their ability to self-regulate, and buffer against energy depletion from care provisioning (M Mhaka-Mutepfa, 2018). This theme on the perceived self-rated health of caregivers leads to their perceived ability to access health services and strategies for coping.

### **Ability to Access Health Services and Strategies for Coping**

Three caregivers reported they did not seek medical care because they could not afford the costs. Clinics in rural areas were located at a long distance for some caregivers and the caregivers had to commute. For instance, a grandparent said:

*I do not go to the clinic, I cannot afford it...I get onto a bus...pay for the card and get a prescription. My grandchildren have no food and are not going to school. I only went back to the clinic once after I was bitten by a scorpion, but I was made to pay...I didn't have the money and they took my ID until I had paid despite being over 65.*

(Participant 24; 68 years, female, rural)

There is no monitoring of services and some corrupt health personnel may ask patients to pay for services even if they are over 65 years old.

Another grandparent caregiver reported two issues. One issue was on length of treatment and the other on failing to seek medical care. She attributed getting well to luck.

*When my four children were sick, they died. We were told to take them home. I guess the nurses knew they were dying and wanted to preserve beds for those who could recover. They were not given proper medication except Panadol and were kept in hospital for a short time. I hardly go to the clinic although I have back pain because of lack of money, I just ignore my pain...At times I get herbs from the traditional healer a few houses away. Two of my grandchildren who tested positive are always sick, but I cannot afford to go get free ARVs from the clinic. Moreover, the nurses are moody. I do not know how to help my grandchildren except give them herbs. Poverty is the same as dying.*

(Participant 3; 62 years, female, rural)

*I just went to hospital because friends said my ailment needed a doctor [coronary heart disease; CHD], otherwise I would have seen a sangoma [traditional healer]. They are cheaper. Going to hospital is the same as staying at home. They do not provide quality care for the sick...They make you wait even if you cannot breathe. ...Without money they do not treat you...I will not go back.*

(Participant 31; 79 years, female, rural)

*My eldest grandson is worse than me. He picks rubbish and is violent when not on medication. His medicine is finished... It costs 17 USD. My other grandchild has symptoms of HIV but has not been tested. He is always sick.*

(Participant 21; 75 years, female, high urban)

Chronic illnesses may cause depression and anxiety, which influence medication adherence (Taylor, 2013) and seeking services, particularly to caregivers on anti-retroviral drugs and those with diabetes or CHD. Management of chronic illnesses is

important for self-esteem and self-concept (Taylor, 2013), especially for elderly caregivers and their grandchildren. This influences their health-seeking behaviour. A caregiver had this to say:

*I have CHD and I am depressed. I was referred to a specialist but I have no money. One of the nurses told me to try a traditional healer but I am prayerful. Poverty is the problem and I worry a lot. I lost my children to HIV and I have to take care of my five grandchildren... We went to see religious advisers but there is no change. However, I feel better because I have taken action.*

(Participant 30; female, 62 years, rural)

### **Perceptions Toward State of Health Services in Grandparent Caregivers' Communities**

Twenty-two grandparent caregivers (73%) expressed lack of satisfaction with health services in the country. Eight caregivers (three low urban, four high urban, one rural) were somewhat satisfied. Those who were satisfied mentioned access to medical insurance, free medication at times, free consultations, and good service at some clinics. For instance, a grandmother who resided in a low-density urban area (high SES) illustrates her satisfaction:

*I am satisfied because each time I go to the clinic they ask me how I am feeling, and they give me free medication.*

(Participant 14; 68 years)

Dissatisfaction with health services in general was a recurrent theme by caregivers (seven urban low, five urban high, eleven rural). An excerpt from one of the grandparent caregivers who was not satisfied with health services:

*The health services leave a lot to be desired. My child had an accident and I feel more could have been done... My daughter gave birth and she died from HBP. They attend to patients late as if they do not get paid, and it is worse if you are known to be HIV-positive. They shun you.*

(Participant 16; 58 years, female, low urban)

Twenty six caregivers (87%) complained of long queues, inadequate personnel and medication shortages, expensive consultations, and poor service in general, particularly at large hospitals. Caregivers from the different residential areas expressed similar sentiments. For example:

*...Health services in our country need divine intervention, long winding queues at hospitals, no specialists, drugs and lack of courtesy. You arrive at 8 a.m and you may be attended to the following*

*morning. I would rather get treatment from a traditional healer.*

(Participant 12; 64 years, female, low urban)

One grandmother who resided in a rural area spoke of better treatment for HIV and AIDS and mental illnesses but not cancer as follows:

*...if people had not discovered ARVs, I would have lost all my children. I am satisfied with the way they treat AIDS. If they were not good at it...Cancer, aaa [shakes head], they still find it difficult 'cause they could not treat my husband...health services at Annex are better, my son (mentally ill) has improved...My daughters are also alive 'cause of ARVs ...same applies to my grandchildren.*

(Participant 28, 57 years, female, rural)

Five caregivers (17%) reported that they got ARVs, hydrochlorothiazide (HCT), salbutamol, and other common drugs for free if available at clinics. Other ailments and medications had to be paid for especially if patients were referred to specialists. A grandparent said:

*I have heart problems. I am on medication, but it is not working. I was referred to a private specialist doctor but I have no money. I cannot work because I feel tired. I have had this problem for almost two years and will eventually die because I cannot pay a specialist. My friends suggested traditional healers because they do not want money upfront, but I am a Christian.*

(Participant 29, 79 years, female, rural)

A grandparent made an observation that knowledge of ailment determined whether caregivers are satisfied with the state of health services. She stated:

*I am not satisfied because they don't give us information. People lack knowledge on ailments and treatment...Relatives should accompany their sick to assist in issues like taking medication correctly. I accompanied my sick daughter...I was given information on how to provide quality care to an HIV-positive patient...Now I care for my daughter and her children without any qualms.*

(Participant 20; 58 years, female, urban high)

Caregivers residing in urban areas reported the need for clean water and electricity as these were perennial problems and affected the state of health services. They also needed their own accommodation, and those with houses in high density urban suburbs (low SES) needed better accommodation as they were crowded. Other caregivers

shared a room with their children and grandchildren in one section of the urban high density area. An excerpt to illustrate these points:

*We need water, electricity, it is hardly available. And...Accommodation. Sewage is flowing everywhere, the toilets are blocked and 11 of us live in one-room...there is rubbish everywhere...The nurses tell you to go and fix sugar and salt solution for your diarrhoea at home. Most of the times we are treated badly...We have to carry our own water. The hospital toilets have poo... I have HBP and I get HCT for free at times, however, I am so depressed because of my living conditions and the sick people around me. I do not always take my medication because either way I will still die. If not from the HBP, maybe I will die from the dirty water we drink, sewage, or depression. I cannot even tell them I am depressed. People with poor mental health are ridiculed.*

(Participant 1; 65 years, male, urban high)

### **Prejudice, Stigma and Discrimination**

Four caregivers (13%) reported stigma and discrimination. Two caregivers (7%) said extended family members accused them of killing their children. Excerpts to illustrate this point:

*I was accused of killing them by my husband's relatives. When he died, they took everything...and they do not talk to us. They called me a witch.*

(Participant 25; 61 years, female, rural)

*This community does not really support each other. They say I murdered my husband. Family members are not supportive either except friends from church...My relatives are not supportive; they say I bring misfortune on myself because I killed my husband.*

(Participant 5; 59 years, female, rural)

*I had a difficult marriage and the community was not supportive. They talked about my husband's health and that he had died from AIDS. Some stopped talking about it when I joined a support group and announced my positive status. However, others shun the members of the support group.*

(Participant 10; 57 years, female, rural)

Another carer experienced stigma because she was staying with an orphan who was living with HIV and AIDS:

*My employers used to help me before...I was told my grandchildren were not my children, so I should not live with them. They do not want my granddaughter to play*

*with their children because she is positive. They also do not talk to her; I have to keep her in the servants' quarters.*

*(Participant 9; 54 years, female, low urban)*

The grandparent caregivers above experience stigma and discrimination. In addition, negative evaluation of the caregivers and their grandchildren based on group membership was present. When the need to interact and belong is denied through prejudice and stigmatization, it can have disastrous consequences to the health of the stigmatized person. Isolation of others may impair quality of life and well-being (Steptoe, Shankar, Demakakos, & Wardle, 2013) and may lead to depression.

### **Discussion**

The excerpts in this paper express difficulties in accessing health services and the poor state of health services in Zimbabwe. Caregivers' lived experiences and insights offer a unique perspective of the health system and how the elderly are handled. Many undocumented aspects, known only to the caregivers who visited health services, were revealed, highlighting issues which are relevant to improving the care quality in Zimbabwean health systems. Health outcomes are dependent on access and quality care at health facilities, and effective management across the health system. Caregivers avoided facilities perceived as unhelpful, thus failing to access health services. Resources determined how often caregivers sought medical services, hence the need for meaningful intervention.

Other caregivers resorted to traditional healers and religious leaders for health services because they could not afford conventional medicine or had no access to it. For some caregivers, traditional healers and religious advisors were a strategy for coping with chronic illnesses and depressive symptoms since most grandparent caregivers could not access health services in the current study.

### **Self-Rated Health, Access to Health Services and Strategies for Coping**

Grandparent caregivers with access to health services and other resources had better self-rated health than their counterparts regardless of whether they were fostering orphans or non-orphans. The finding contrasted the quantitative study in Zimbabwe that found that grandmothers fostering orphans lacked psychosocial support and had poorer mental health than those fostering non-orphans (Howard et al., 2006). However, Howard et al (2006) did not look at the utility of resources. Resources (e.g., support, income, social networks) were found to positively impact the health and well-being of caregivers (Mhaka-Mutepfa et al., 2015; Cheng et al. 2013; Mugisha et al., 2013; Sayegh & Knight, 2011). Likewise, perceptions of access to health services and state of health services were found to impact caregivers' health and wellbeing. However, access was impeded by lack of social protection and the state of health services. This finding was similar to reports from previous researchers in Uganda and Zimbabwe that not many caregivers benefit from social protection and health services in low income countries (Kamya & Poindexter, 2009; Pufall et al, 2014). This is because the countries are poor and cannot provide social protection and health services to all the needy people.

The current study found that grandparents experienced multiple chronic and complex self-rated health conditions (e.g., arthritis, diabetes, hypertension, back pain, and heart problems) which influenced their health and well-being. Poor health has a negative effect on caregivers' well-being if they do not seek health services. For example, back pain is one of the most common cause of disability in most countries and large numbers

of elderly people deal with it on a daily or intermittent basis (Taylor, 2013). Chronic illnesses have a negative effect on caregivers' well-being, suggesting the importance of providing caregivers access to health services. Their grandchildren also fail to access health services because their guardians are poor and some of them fear ridicule.

Nevertheless, caregivers in Zimbabwe were expected to get free treatment in public health centres after they attain age 65. However, this benefit only applies to public health services as mentioned by participants 24 and 30. Similarly, long queues, lack of immediate attention for seriously ill patients (shortage of human resources and drugs), delays after arriving at the healthcare facility, and being made to pay for health services in most healthcare centers, including some public health centers, have been reported before (Jones et al., 2016, Dhemba & Dhemba, 2015; Newsday, 2015). Grandparent caregivers thus perceive going to public health facilities as a waste of time, thereby impacting their health and well-being. In addition, younger grandparent caregivers (below 65 years) were not benefiting as they always had to pay for health services. Overall, costs of drugs and transport remained prohibitive, particularly in rural areas. Grandparents had to travel long distances to the city to buy drugs from pharmacies, despite lack of resources. These findings are consistent with previous studies (US Census Bureau 2012; Dhemba & Dhemba, 2015). Urban residents (60%) in Zimbabwe had better self-rated health than rural residents (8%) just like participants in previous studies in Ghana and South Africa (U.S Census Bureau, 2012). Health services (e.g., public hospitals and clinics) were more available in high density suburbs as these suburbs are densely populated. Despite the differences in numbers of health services, all groups had similar perceptions to self-rated health problems (arthritis, diabetes, HBP, back pain, etc).

A few caregivers (13%) mentioned seeking health services of traditional healers and/or religious advisors. Most of the grandparent caregivers (93%) were Christians and some of them would find it difficult to reveal seeking services of traditional healers as an alternative. This is because seeking health services of a traditional healer is often perceived as lack of faith in God. Christians in Zimbabwe believe God is insulted when we seek services from other beings, hence they may not mention using traditional healers as a strategy. However, the services by healers were perceived to play an important role in the delivery of mental health care in parts of sub-Saharan Africa including Zimbabwe (Madamombe, 2006). Western medicine is generally accepted throughout sub-Saharan Africa, although it has not replaced, but rather augmented indigenous health approaches.

Prohibitive medical costs also make it difficult to get medical attention so the poor resort to traditional healers who do not always demand cash up front and have no herb shortages. The Zimbabwe government, in 2002, regularized traditional medicine and this affects adherence (participant 14). This participant 14 was mixing pharmaceuticals and herbal medicine. Similar to findings by Madamombe (2006), some patients may disregard their doctor's advice or take herbal medicines that could have dangerous interactions with pharmaceuticals. Many patients fall victim to remedies that have not been tested and are offered outside the formal healthcare system. Despite the anomalies above, grandparent caregivers also had negative perceptions on the state of health services.

### **Perceptions of State of Health Services in Grandparent Caregivers' Communities**

Most of the caregivers (73%) expressed negative sentiments on the state of health services. Perceptions of the state of health services may impact caregivers' willingness to seek health services when needed. A few who resided in the upmarket suburb (low-density suburb) and had medical insurance had positive feelings towards the state of health services. They sought services of private doctors and hardly visited public clinics.



Generally, health personnel in private health care facilities are not overwhelmed, are paid handsomely, have drugs, and are bound to provide quality care to patients.

However, other caregivers who lived in the same area had different lived experiences from public hospitals consulted (participants 1 and 16). They reiterated the negative attitudes of health personnel and these seem to be reciprocated in the elderly caregivers. The caregivers' high rates of disease morbidity coincide with a lack of requisite primary health care. For instance, about 96% of the elderly with hypertension in Ghana have inadequate treatment (Lloyd- Sherlock , Beard , Minicuci , Ebrahim , & Chatterji 2014), just like caregivers in the current study. Most caregivers in both studies had no confidence in the state of health services. This finding is in stark contrast with Taylor's (2013) report in the USA that 54% of caregivers expressed high confidence in physicians. However, patients seeking psychological intervention (e.g., for depression or anxiety) in both high and low-income countries were said to evoke negative reactions from physicians (Taylor 2013), which was the case in this study. Attention by health personnel can be cursory regardless of type of economy as expressed by participant 1 and 16 above.

However, that may not be the only problem. Consistent with current findings, as people age, the number of medical problems increases, and people's ability to report their symptoms correctly and follow treatment guidelines decreases (Taylor, 2013). Taylor posited that 40% of people over 50 years have difficulties understanding instruction for their medication. They also may not comprehend why they have to adhere as stated above (participant 1), therefore they may not seek health services. Failure to adhere does not help chronic conditions which lead to reduced health related well-being (Taylor, 2013). Seeking health services and well-being are also affected by prejudice, stigma, and discrimination.

### **The Impact of Prejudice, Stigma, and Discrimination**

Stigmatizing grandparent caregivers is likely to affect whether they seek medical services or not, thereby impacting their self-rated health and well-being. Because of prejudice, stigma, and discrimination attached to AIDS, the role of full-time caregiving has tended to diminish the elderly's status, and their roles are often undervalued and viewed negatively (Kidman & Thurman, 2014; Yancura & Greenwood, 2013). However, current findings are inconsistent with previous findings in other sub-Saharan African countries that revealed that stigma and discrimination was rampant and was perpetrated by professionals, particularly health personnel. Stigma was present in Zimbabwe but not as rampant as it was a decade ago (Mhaka-Mutepfa et al., 2015). Sixteen percent of caregivers were affected by stigma in the current study, possibly because more people now understand the negative impact of stigma and almost everyone in the communities have someone close to them that has tested HIV-positive (requiring health services) or succumbed to the disease.

Nonetheless, prejudice, stigma, and discrimination were found to affect social relationships among caregivers, their extended families and communities, and whether caregivers would access health services. Social relationships are central to human well-being and are critically involved in the maintenance of health (Taylor, 2013). Isolation and emotional distress, proxies for stigma, become prominent problems at older ages due to stigma attached to HIV/AIDS (participant 9, 10, and 16), thereby limiting social networks (Marlatt-Carlini, 2005; Willie-Tyndale et al., 2016). In addition, grandparent caregivers taking care of their grandchildren may also get isolated because they are doing chores that are different from activities done by their cohort. However, anti-stigma advocates in Zimbabwe run campaigns to raise awareness of the struggles of the

stigmatized in hopes of breaking down stereotypes and building empathy and support. Methods of advocacy focus on getting to know the stigmatized, share life stories, answer questions, and encourage them to seek health services. The repercussions for stigma and discrimination may be irreversible (e.g., imminent death or suicide), hence there should be zero tolerance to stigma.

### **Policy Implications and Limitations**

The implications originating from this study would benefit most sub-Saharan African countries as they all have grandparents as caregivers to children and experience similar chronic conditions. They may have similar perceptions and lived experiences to access and state of health services. A system-wide approach is necessary to highlight where improvements could be made, which could benefit ill caregivers and ill children particularly in more resource-limited settings (Jones et al., 2016).

The findings suggest several interventions, which might improve and optimize the health system. Health personnel have to be professional to enable caregivers to seek services. Resources and health insurance should also be made available to the caregivers to enable accessing of health services. There should be an emergency route for serious health problems (e.g., CHD) and health promotion for adherence.

Previous studies reported that the number of non-orphaned fostered children were almost the same as fostered orphans in southern Africa (Grant & Yeatman, 2012; Hampshire et al., 2015) and so does the current study. These findings imply that all grandparent caregivers should have health insurance and should all benefit from social protection. National interventions are critical to boosting the pension coverage among the Zimbabwean populace to ensure financial independence in old age, and this action could change their perceptions of health services. With finances, grandparent caregivers can access health services of their choice (McKoy et al., 2017) and reduce the long queues in public health facilities.

The presence of non-communicable diseases (NCDs) among grandparents indicates the need for regular access to quality health care and/or services. The state of health services was lamented by most caregivers particularly in rural areas. Authorities must identify preventable failures in the care provided, through provision of health insurance, training health personnel to be empathetic, increase human resources, and avail drugs. A government drug subsidy programme can be introduced for the elderly. It is also difficult to provide quality health services without working on the determinants of health, especially eradicating poverty.

Future studies on grandparent caregivers should look into problems of accessing health services using large quantitative studies to generalize findings. Future research should also explore the perceptions of clinicians or health personnel as well as grandparent caregivers. Participants may have provided inaccurate accounts which may not be factual or representative of general experience (Jones et al., 2016). Responses of grandparent caregivers with chronic health conditions may have been influenced by their frail health.

Policies on health need monitoring and evaluating to ensure effective implementation. Under-developed and poorly implemented social welfare policies should be revisited. The Older Persons Act of 2012 could be updated and implemented as grandparents were not benefiting from public health services. African countries have a propensity of failing to implement policies, and this failure draws back development (Kaplan & Perez-Porter, 2014).

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