

Older adults' experiences of formal community-based care services in Sebokeng – implications for long-term care management

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Hereby I would like to thank the following:

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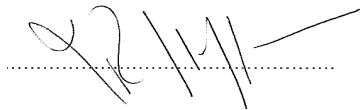
Ina-Lize Venter for professional language editing with heart. I am grateful.

My beautiful family. Wim, I cannot begin to tell you how much I appreciate your support during this course. You are the most patient and caring man I know. Miané, your sweet smile and cuddles are the best morale boosters in the world.

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PERMISSION TO SUBMIT ARTICLE FOR EXAMINATION PURPOSES

Ms S.M. Rankin (24845655) elected to write an article in partial fulfilment of the degree of Magister Scientiae in Gerontology. As her supervisor, I hereby grant permission for her to submit this article for examination purposes.

A handwritten signature in black ink, appearing to read 'J.R. Hoffman', is written over a horizontal dotted line.

J.R Hoffman (D.Phil, Oxon)

DECLARATION BY RESEARCHER

I, S.M. Rankin, hereby declare that this mini-dissertation; Older adults' experiences of formal community-based care services in Sebokeng – implications for long-term care management, is my own effort in cooperation with my supervisor, prof. J.R. Hoffman.

I also declare that all the literary sources used to inform this study have been referenced and acknowledged.

This mini-dissertation was proofread and edited by a professional language editor and submitted to Turn-it-in to confirm that no plagiarism had been committed

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DECLARATION BY LANGUAGE EDITOR

10 November 2018

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To whom it may concern:

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ABSTRACT

Title: Older adults' experiences of formal community-based care services in Sebokeng-implications for long-term care management

Key terms: formal long-term care; community-based care; good care; ethics of care; day care; home-based care

South Africa's older population is faced by far-reaching implications for long-term care. Informal long-term care is increasingly becoming less efficient in providing in their care needs. Families are rendered unable to care for their older family members by issues such as poverty, migration of younger adults, and HIV/AIDS. Non-communicable conditions such as diabetes and hypertension require life-long management and add to the financial strain families experience in providing long-term care for their older relatives. Residential care as formal long-term care option is not a viable solution either, as it is inaccessible to the majority of the older population. Formal long-term community care as a third option is advocated by South African policies and scholars alike. Even though formal long-term community care is perceived as a solution, studies show that community-based care poses some major challenges. There is, however, a gap in research, especially in South African literature, as to older adults' grounded experiences of the current formal day care and home-based care services.

The study undertook a grounded exploration of older adults' experiences of current formal community-based care services in Sebokeng. This exploration aimed at addressing the gap between the ideal of formal community-care systems and delivery, and its effective implementation in practice. The secondary aim was to ascertain what the older adults from this group perceived as good care.

The study was conducted using the interpretive descriptive design with an ethics of care approach as heuristic framework. In-depth interviews provided rich, descriptive data, which was then analysed using thematic analysis. The research sample consisted of 10 older adults making

use of community day care services and 10 using community home-based care. Participants were between the ages of 63 and 85 and the group consisted of 15 women and 5 men.

Findings showed that this group of older adults experience existing formal community-based care as fragmented and inadequate in meeting their care needs. Older adults address this care deficiency by making use of other forms of care such as informal care provided by family, friends or neighbours, and care from other community institutions (such as churches). Findings on what older adults regard as good care showed that there are four care principles to good care: access to resources, infrastructure and good care; attentiveness and responsiveness; companionship, and dignity. These four principles broadly correspond with the conceptualisation of good care in the ethics of care approaches.

The study concluded that long-term care for older adults should be provided and managed by government in partnership with communities (in support of family/informal care). For long-term programmes to provide good care, an ethics of care approach could be used to ensure that the needs of older adults are adequately and wholly met in a relational and situational manner.

OPSOMMING

Sleuteltermes: formele langtermynsorg; langtermynsorg; gemeenskapgebaseerde sorg; goeie sorg; sorgsaamheidsetiek; dagsorg; tuissorg

Suid-Afrika se ouer bevolking word met verreikende implikasies vir langtermynsorg gekonfronteer. Informele langtermynsorg skiet toenemend te kort in die voorsiening van ouer persone se versorgingsbehoefte. Faktore soos armoede, migrasie van jonger volwassenes en MIV/VIGS dra by tot gesinne en families se onvermoë om na ouer gesinslede om te sien. Nie-aanmeldbare toestande soos suikersiekte en hipertensie moet lewenslank bestuur word, en dra by tot die finansiële druk wat gesinne in die voorsiening van langtermynsorg aan ouer gesinslede ervaar. Residensiële sorg is ook nie 'n lewensvatbare opsie vir formele langtermynsorg nie, omdat meeste ouer volwassenes nie toegang daartoe het nie. Formele langtermynsorg is die derde opsie wat deur Suid-Afrikaanse beleid en vakkundiges aanbeveel word. Hoewel laasgenoemde as oplossing beskou word, is daar studies wat wys dat gemeenskapgebaseerde sorg beduidende probleme oplewer. Daar is egter, veral in Suid-Afrikaanse literatuur, 'n navorsingsgaping wat betref ouer volwassenes se begrepe ervarings van bestaande formele dagsorg- en tuisgebaseerde dienste.

Die studie het 'n begrepe ondersoek na ouer volwassenes se ervarings van bestaande formele gemeenskapgebaseerde versorgingsdienste in Sebokeng onderneem. Die doelwit van hierdie ondersoek was om die gaping aan te vul tussen die ideaal vir formele gemeenskapsorgstelsels en -lewering, en die daadwerklike implementering daarvan in die praktyk. Die sekondêre doel van die studie was om vas te stel wat ouer persone as goeie sorg ervaar.

Die studie is met behulp van 'n verklarend-beskrywende ontwerp gedoen met sorgsaamheidsetiek as heuristiese raamwerk. In-diepte onderhoude is aangewend om ryk, beskrywende data in te samel, wat by wyse van tematiese ontleding geanaliseer is. Die

navorsingsteekproef het bestaan uit 10 ouer volwassenes wat van gemeenskapgebaseerde dagsorgdienste, en 10 wat van gemeenskapgebaseerde tuissorgdienste gebruik maak. Deelnemers was tussen 63 en 85 jaar oud en die groep het bestaan uit 15 vroue en 5 mans.

Bevindinge het getoon dat die groep ouer deelnemers aan die studie bestaande formele gemeenskapgebaseerde sorg as ontoereikend en onderbroke ervaar, en dus nie na behore in hulle sorgbehoefte kan voorsien nie. Ouer volwassenes bied hierdie tekortkominge die hoof deur van ander bronne soos informele sorg en versorging van ander gemeenskapsinstellings (soos kerke) gebruik te maak. Ouer persone in die studie het vier versorgingsbeginsels van goeie versorging geïdentifiseer, naamlik: toegang tot hulpbronne, infrastruktuur en goeie versorging; oplettendheid en responsiwiteit; kameraadskap, en waardigheid. Hierdie vier beginsels kom in die breë ooreen met die konseptualisering van goeiesorg in die sorgsaamheidsetiek.

Die slotsom van die studie is dat die staat in samewerking met gemeenskappe (ter ondersteuning van informele/familiesorg) langtermynsorg aan ouer persone moet voorsien en dit moet bestuur. Sorgsaamheidsetiek kan help verseker dat ouer persone se behoeftes op toereikende en volledige wyse vervul word, en dat langtermynprogramme goeie versorging bied.

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CHAPTER 1: INTRODUCTION

Community-based caregiving as an answer to the increasing need for long-term care for older adults is internationally recognised (Chen *et al.*, 2017; Iparraguirre, 2017; Sharma & Marwah, 2017). The interface between ageing and community long-term care management has become an important area of research in developed countries for especially three reasons: rapid population ageing, changing family structures and concerns about care for older adults (Provencher *et al.*, 2014). The situation is no different for developing countries. This gap is especially visible in studies done on the older populations of sub-Saharan Africa and, more specifically, South Africa. Studies on the older population include research on older adults and the family, care institutions, and the caregivers of older adults. There is, however, a dearth of systematic documentation of older adults' unmet need for long-term care or how that care is, or should be, provided (Freeman & Hoffman, 2016).

This research is therefore a grounded exploration of the current long-term care situation in sub-Saharan Africa (SSA) and more specifically, South Africa: how older persons experience the long-term formal community-based care they receive and what they perceive as good care.

The report consists of three parts including an introduction and conceptualisation of the long-term care issue (Chapter 1), an article about the findings (Chapter 2), and the conclusions and recommendations (Chapter 3). Each chapter is followed by a reference list. The addenda of each chapter are collated after Chapter 3. This introductory chapter will explore the current state of care as well as the current policy and legislation pertaining to long-term community-based care in SSA more generally, and South Africa more specifically.

1.1 Literature review and background

Population ageing is a global phenomenon that has far-reaching implications for the availability and quality of long-term care for older adults worldwide. Between 2015 and 2030, the number of people in the world aged 60 years and older is projected to grow from 901 million to 1.4 billion (UN, 2015). The projected number of older adults by 2050 is nearly 2.1 billion (UN, 2015). According to the United Nation's report on world population ageing (WPA, 2015), the number of the "oldest-old" (75 years and older) is growing at a faster rate than the number of older adults overall. This increase in the number of older adults enlarges the pool of individuals prone to suffering from chronic, non-communicable diseases, thus also increasing the demands for long-term care (Nuscheler & Roeder, 2013; Murphy *et al.*, 2017). The support, management and financing of long-term care are major drivers of costs for older adults and governments alike. This is problematic as later life, especially in emerging economies, is associated with increased poverty (Barrientos *et al.*, 2003; Muruthi & Lewis, 2016; Murphy *et al.*, 2017).

The lack of financial resources has a direct impact on older adults' access to long-term care. In this context, long-term care implies support and services required by individuals with reduced cognitive or physical capacity for self-care for extended periods of time (Freeman & Hoffman, 2016). The main goal of long-term care is to facilitate individuals' achieving and maintaining optimal levels of personal functioning. Long-term care includes health, social, personal and supportive services to assist individuals with basic activities of daily living such as toileting, dressing, feeding, and/or instrumental activities of daily living that allow them to live with a greater degree of independence such as housework as well as intangible emotional care (Freeman & Hoffman, 2016).

1.2 Long-Term Care

To understand the current long-term care situation in SSA and, more specifically, South Africa, the following factors will be explored in this chapter:

- Demographics
- Epidemiology of ageing
- Long-term care policies pertaining to older adults
- Current experience of long-term care

1.2.1 Long-term care in SSA

Although ageing in SSA is a diverse experience, common trends that emphasise the growing need for long-term care include poverty, migration, and the rise of non-communicable diseases, HIV/AIDS and changing family structures (Darkwa & Mazibuko, 2002; Jesmin *et al.*, 2011; Schatz & Seeley, 2015; Zimmer & Das, 2014).

1.2.1.1 Demographics in SSA

SSA is the world's youngest region, but by 2015 its older population already numbered 46 million people (UN, 2015). It is projected that 2050 will see 161 million older adults living in SSA (UN, 2015). With this dramatic growth of the older population, the demand for long-term care will increase at an equal rate (Jesmin *et al.*, 2011). The rapid increase in the absolute numbers of older persons in SSA is a challenging phenomenon, especially in the context of scant long-term care systems and an overemphasis on the family as the main (and often only) source of care (Freeman & Hoffman, 2016; Keating, 2011).

1.2.1.2 Epidemiology of ageing in SSA

Older adults in this region face a large morbidity and disability burden, particularly from chronic diseases. Cardiovascular and circulatory disease, nutritional deficiencies, cirrhosis of the liver, and diabetes are major causes of disability-adjusted life years. They also suffer from high prevalence of hypertension, musculoskeletal disease, visual impairment, functional limitations, and depression (Aboderin & Beard, 2014; Lloyd-Sherlock *et al.*, 2014).

For policies to successfully address the long-term care deficiencies experienced by older adults, policy makers must keep in mind that poor health amongst the older population of SSA is often accompanied by little access to financial resources (Aboderin & Beard, 2014).

1.2.1.3 Long-term care policies pertaining to older adults in SSA

In view of both the demographic and epidemiological imperatives for a focus on long-term care for older persons, various policies or instruments relevant to long-term care exist for the SSA region. These policies have been drafted by the African Union and include the AU Policy Framework and Plan of Action on Ageing; Protocol to the African Charter on Human and People's Rights on the Rights of Older Persons in Africa; and the Common African Position on Long-term Care systems for Africa (WHO, 2017). A number of SSA countries, including Ethiopia, Ghana, Kenya, Mauritius, Uganda, South Africa, Tanzania and Zimbabwe, have ageing policies or national legislation pertaining to older adults.

However, with few exceptions, these policies and legislation have major shortcomings in addressing long-term care for older adults. These:

- don't provide a framework for integrating long-term care across various settings;
- often don't consider the cultural norms and expectations that form part of fundamental family involvement in long-term care provision;
- don't specify support mechanisms for caregivers;

- lack specifications on how to sustain financial support and workforce supply for the growing older population;
- don't address the lack in strategies for the improvement of access and affordability for poor and marginalised groups (WHO, 2017)

These policy shortcomings pose major challenges for the implementation of policy aims in the current situation of long-term care in SSA with a direct impact on how older persons experience care.

1.2.1.4 Current experiences of long-term care in SSA

Current experiences of formal long-term care are underscored by poverty in all its dimensions. Poverty is rampant in SSA and for most families, formal caregiving services for older adults are inaccessible; the responsibility falls on family members to provide informal long-term care to their older adults (Jesmin *et al.*, 2011). Apart from poverty as a driving force behind informal long-term care, it is still widely assumed that the African family cares for its elders and that this will be the case in future (Shaibu & Wallhagen, 2002; Dokpesi, 2014). Three examples of this attitude are Lesotho, Zimbabwe and Ghana. Lesotho has only two centres that provide residential care to destitute older adults. Both centres rely on donations as they are church-initiated and managed. Neither of these centres have facilities to provide geriatric care (Dhemba *et al.*, 2015). Although Zimbabwe is one of the few African countries that provide its older population with residential care (to the extent that the current socio-political situation allows it), it is seen as a last resort for especially the sick and the homeless (Dhemba *et al.*, 2015). Van Der Geest (2016) goes as far as to state that the welfare of older adults is not a priority for Ghana's politicians and policy-makers. The emphasis is on family care, and handing over the care of older adults to strangers is widely rejected (Van Der Geest, 2016). Although institutional care (to a very limited extent) fulfils a need for the poorest older adults who lack family support (Teka and Adamek, 2014), it is perceived as "un-African" and contrary to African culture (Aboderin *et al.*, 2015). From these examples it is clear that formal long-term care is equated to institutionalisation

and therefore not acknowledged as an option for long-term care in most SSA countries. This leaves older adults with little to no long-term care options outside the African family. In view of the changes experienced by the so-called traditional family and its growing inadequacy to meet the care needs of older adults, this belief that informal long-term care is sufficient in caring for older adults is problematic.

Although informal long-term care is the preferred pathway to care for SSA's older population, the care provided by families is becoming increasingly inadequate for meeting the needs of older adults (Hoffman *et al.*, 2016). Among others, three main factors contribute to this inability to provide care: 1) In SSA, the migration of young adults to cities results in an increase in the caregiving burden and poorer quality of life for older adults (Thrush & Hyder, 2014). 2) In urban areas, the quality of care and services for older adults is affected by crowded housing, limited financial resources, poor infrastructure, and arguably the growth in education and employment of women (Jesmin *et al.*, 2011, Dokpesi, 2015). 3) Traditionally, women have always been regarded as caregivers. In modern times, however, traditional gender roles are changing and we might well see female caregivers challenging gendered roles in the decades to come (Camlin *et al.*, 2014, Jesmin *et al.*, 2011).

Fewer caregivers available for long-term care will be especially detrimental to the care situation in the face of SSA's HIV/AIDS epidemic. Across this region, HIV/AIDS affects older adults in two profound ways. Older adults are losing their children, who would have been their caregivers in the future, and they have to provide care for their grandchildren after the loss of their parents to AIDS (Zimmer & Dayton, 2005; McKinnon *et al.*, 2013). In the life stage where they are the ones supposed to receive care, they have the added burden of being caregivers themselves (McKinnon *et al.*, 2013).

Another factor that plays a key role in the provision of informal long-term care in SSA is reciprocity. In Ghana, for example, an adult child will give the older parent the care he/she "deserves", based on how they perceived the type of care they received from that older parent

during his/her childhood (Van Der Geest, 2016). Should an adult child feel that a parent's care was inadequate during his/her childhood, he/she might feel disinclined to provide long-term care to the parent in old age.

1.2.2 Long-term care situation in South Africa

1.2.2.1 Demographics in South Africa

Identified as one of the most rapidly ageing populations in SSA, the phenomenon of population ageing is especially prevalent in South Africa. By 2017, the country's older population consisted of 4.8 million people, and this figure will steadily increase with South Africa seeing its older population reaching 11.6 million people by 2050 (UN, 2017). This population growth has a significant impact on older adults' need for care, as by 2015, only 24% of older adults had access to medical aid schemes, which left the majority without the means to access good medical care (Statistics South Africa, 2015).

In South Africa, ageing and long-term care management is unique compared to the rest of SSA. These differences, which will be explored in more detail, pertain to the historical legacies of poverty, inequalities, violence, and deprivation under the apartheid regime as well as the current HIV/AIDS epidemic (Tomita & Burns, 2013).

Apartheid policies saw the majority of people of colour excluded from education and career opportunities. As a consequence, they weren't able to use the income they did receive to make provision for their old age (Aboderin *et al.*, 2015). International studies found that forced relocation has far-reaching implications in that people that were relocated in the past, today find themselves in areas that are resource poor and unsuitable to the needs of older adults (Keating *et al.*, 2013).

Under apartheid rule, the majority of white South Africans enjoyed a standard of living comparable to that of the developed nations, while the lives of black citizens were characterised

by poverty, lack of education, and no or limited access to health and welfare services (Makiwane and Kwizera in Lombard & Kruger, 2009). Residential institutions for white older adults received substantial funding, while there was a lack of state funding to support similar residential institutions for older adults from other racial groups (Oakley, 1998) with the subsequent result that they essentially had to rely on family support and care.

South Africa has the world's highest number of people living with HIV/AIDS (Nyirenda *et al.*, 2013), which has a substantial effect on families. This epidemic has created a generation of orphans and sick children being cared for by older adults (Mutemwa & Adejumo, 2014; Lombard & Kruger, 2009; Phetlhu & Watson, 2014). Despite being in a situation where they are in need of care, older adults have to provide emotional and physical care, and caregiving is experienced as an economic burden (Phetlhu & Watson, 2014; Ice *et al.*, 2010 in Mutemwa & Adejumo, 2014). According to a study by Ice *et al.* in 2010 (in Mutemwa & Adejumo, 2014), caregiving is in fact primarily experienced as an economic burden.

1.2.2.2 Epidemiology of ageing in South Africa

Apart from the HIV/AIDS epidemic, older adults also suffer the burden of non-communicable diseases. The three most common medical conditions reported by older adults are high blood pressure, diabetes, and arthritis. These non-communicable conditions require life-long management, and with the improved longevity seen in recent history, this prolonged need for care places a strain on ageing-related resources and, consequently, on the availability of good formal long-term care (Hajat *et al.*, 2018)

1.2.2.3 Long-term care policies pertaining to older adults in South Africa

In South Africa there are two main pathways to long-term care for older adults: informal and formal care. Informal long-term care (unpaid care) is provided by family members, relatives, friends, or neighbours (Jesmin *et al.*, 2011). The majority of the South African older population relies on informal long-term care as they have limited access to residential homes (Bohman *et*

al., 2010). Informal long-term care in South Africa, just like the rest of SSA, is becoming increasingly unsustainable to address the long-term care challenge. In SSA there is a crisis in caregiving due to the fact that families are less and less able to provide sufficient support and care in meeting the needs of older adults (Aboderin, 2004; Dakwa and Mazibuko, 2002). Limited resources and the HIV pandemic are forcing older South Africans to be the main providers of economic support, as well as taking on the role of caregiver instead of being care-receivers (Bohman *et al.*, 2009, Hoffman, 2016)

Formal long-term care is care that is provided by paid professionals or carers (Cohen *et al.*, 2001). One form of formal long-term care is residential facilities. Residential facilities are institutions used for the purposes of providing accommodation and for providing a 24-hour service to older adults (SA Policy for Older Persons, 2005). Residential facilities, being mainly located in urban areas, however, do not always meet the needs of long-term care as the majority of South Africa's poor consists of older black people and is concentrated mostly in rural areas (Lombard & Kruger, 2009; Statistics SA, 2014), making these facilities inaccessible to the majority of South Africa's older population.

In an effort to address this issue, the Audit of Residential facilities (2010) recommended that residential homes should extend their community outreach programmes. The audit found that the key service providers that run the majority of residential care facilities are the bigger NGOs. In addition to providing frail care accommodation and assisted living facilities, such organisations already have outreach programmes in place, providing home help and meals on wheels, and the facilitation of support groups and luncheon clubs (Audit of Residential facilities, 2010). These community outreach programmes include home-based care, as the requirements are essentially similar to frail care. These programmes will put less of a burden on residential facilities while still allowing them to provide care services in the community.

Community-based care is a form of formal long-term care and aims to promote and maintain the independent functioning of older persons in a community (South African Policy for Older Persons, 2005). There are two types of formal community-based care:

- Day care

Day care is a service within a formal community-based facility, which provides social, recreational and health-related activities in a safe environment to individuals who cannot be left alone during the day due to healthcare or other needs (SA Policy for Older Persons, 2005).

- Home-based care

Home-based care is aimed at caring for housebound older persons as a result of frailty. This includes basic nursing, tidying the room, shopping, counselling, laundry, advice and support to clients and families in their homes (SA Policy for Older Persons, 2005). A person's home is perceived as an intimate space where one has the right to autonomy and safety (Silferberg *et al.*, 2007 in Holmberg *et al.*, 2012). The meaning and function of the home can be described as a familiar place of comfort, a centre for everyday experiences in space, time and social life, and as a protective space for privacy, identity and safety (Roush and Cox in Holmberg *et al.*, 2012). As the home is related to the concept of community, intimacy and loving relationships (Holmberg *et al.*, 2012), it creates a good space for quality long-term care.

Although the South African government supports and subsidises the entire continuum of formal care provision – from institutional to community care – the emphasis as set out in the Older Persons Act 13 of 2006 is on the three focus areas that were adopted during the Second World Assembly on Ageing (Plan of Action) held in Madrid in 2002:

- 1) *“Older persons and development, to be addressed by active participation in society; work and the ageing labour force; rural and urban development; access to knowledge, education and training; intergenerational solidarity; income security, social protection and poverty prevention; and provision in emergency situations.*

- 2) *Advancing health and wellbeing into old age, to be addressed by lifelong health promotion; universal and equal access to health services; HIV/AIDS; training of care providers and health professionals; mental health services, and disabilities.*
- 3) *Ensuring enabling and supportive environments to be addressed by housing and the living environment; care and support for caregivers; addressing neglect, abuse and violence; and communicating positive images of ageing” (SA Policy for Older Persons, 2005).*

The policy has two main aims. First, it aims at enabling older persons to live active, healthy and independently. The second goal is to create a supportive environment where older persons have access to services that will adequately meet their needs. To ensure that these aims are met, formal community-based services should include the following:

1. Providing nutritious meals such as Meals on Wheels or luncheon clubs;
2. Assistance with housework
3. Health and nursing care
4. Laundry services
5. Day care for older persons
6. Transportation services
7. Social and legal services, and
8. Access to care for protection, rehabilitation, social and mental stimulation in a secure environment and educational, cultural, spiritual and recreational services (SA Policy for Older Persons, 2005).

By rendering the abovementioned services, formal community-based care services are protecting the following rights of older persons, as stated in the Constitution Section 9 (South Africa, 1996):

- 1) Right to participate in community life
- 2) Right to participate in intergenerational programmes
- 3) Establish and participate in structures and associations for older persons
- 4) Access opportunities that promote his/her optimal level of social, physical, mental and emotional wellbeing.

Older adults and the management of organisations for older adults believe that community-based care are important services for meeting the needs of older adults *if* implemented according to policy (Tshesebe & Strydom, 2016). The current implementation, however, raises concerns and questions about the quality of the services provided by these programmes.

1.2.2.4 Current experiences of long-term care in South Africa

In South Africa, the goals of the policy – especially with the emphasis on formal community-care systems – have not yet been fully realised in practice. The national audit of home and formal community-based care (Friedman, 2010) found that about 50% of organisations did not receive any funding and that there was an overall lack of training for community caregivers as well as their managers. Organisations lack buildings from which to provide community services, they also do not have access to water, electricity or computer equipment (Strydom, 2008; Friedman *et al.*, 2010; Tshesebe & Strydom, 2016). According to Bohman *et al.* (2011), a high number of black African older adults live in extreme poverty, resulting in inadequate and undignified living conditions. In rural areas, these services are almost non-existent. Lack of adequate diet and proper sanitation, high poverty rates, and a lack of information on availability

and accessibility of services are all factors that contribute to the poor development of formal community-based services to older persons (Strydom, 2008; Rosenberg *et al*, 2005).

There is very little discussion of the relative roles of informal, state, and private sectors in meeting the care needs of older adults. Although there is an awareness of the fact that informal care is increasingly inadequate for meeting care needs, it is still being promoted as the key strategy for providing in the increased need for long-term care. Formal care, being unaffordable to the majority of the older adult population, is regarded as the alternative for older adults who do not have access to informal care (Freeman & Hoffman, 2016). On the other hand, the Older Persons' Policy (South African Policy for Older Persons, 2005) promotes formal community-based care as the best pathway to care for older adults.

1.3 Rationale for and aim of the study

It is against this background of the literature and policies studied that it becomes clear that an increase in the older population has far-reaching implications for long-term care. Poverty, migration of younger adults and HIV/AIDS render families unable to provide informal long-term care to older adults. Residential care as a formal long-term care option is not the only answer, as these are inaccessible to the majority of the older population. To address the increased need for long-term care to older adults and to support families, South African policies advocate formal long-term community-based care. Research shows that community-based care poses some significant challenges. There is, however, a gap in research, especially South African literature, as to older adults' experiences of formal day care and home-based care services. Therefore, this study aims to:

1. Address the undocumented experiences of existing formal community-care provision for older South Africans, and;
2. Explore what South African older adults regard as 'good' formal community-based care.

More specifically, the aim of this study is to explore older adults' experiences of current formal community-based care services in Sebokeng and thereby addressing the gap between the ideal of formal community-care systems and delivery, and its effective implementation in practice. Exploring what they regard as "good care" will provide the "ideal" of formal community-care systems and might provide guidance for effective implementation.

To this end, heuristic concepts are drawn from an ethics of care approach. Ethics of care speaks to the reflective experiences of participants as it is situational and relational (Leget, 2013). More specifically, Tronto's four cyclical phases of good care are related to in exploring what the Sebokeng older adults regard as good formal community-based care (Fisher & Tronto, 1990).

1.4 The Ethics of Care approach

Different practices of care value caring relations. Many individuals receiving care do not receive good care, but standards of care are built into practices, suggesting how care can be improved. Good care must meet actual needs and must be evaluated by both the caregiver and the care recipient. The ethics of care is based on reflective experience, experience open to all and across different cultures. It requires empirical findings, evaluations and judgements (Held, 2014).

From an ethics of care view, Tronto (1993) postulates that care can be defined as any specific activity that includes all actions undertaken to maintain, continue and repair our world so that we can live in it as well as possible. Our world includes our bodies, ourselves and our environment, which we try and weave into a life-sustaining web (Tronto, 1993). Optimal functioning of older adults in need of care in a community setting fits this conceptualisation of care as it attempts to promote and maintain the independent functioning of older persons in a community within that context.

An ethics of care approach furthermore posits sensitivity to the particularity of situations, rather than the features that can be generalised (Leget, 2013). It is sensitive to the way older adults' lives are informed by the specific context in which they live and receive care, their emotional attachment, and the vulnerability they experience because of the fact that they have mortal bodies (van Heijst, 2011).

The approach further argues that for community care to be good care, it has to occur in four cyclical phases (Fisher & Tronto, 1990). The first phase is caring *about*, which involves the caregiver being aware of and paying attention to existing care needs of the older adult. The caregiver listens to the spoken needs, recognises unspoken needs, and is therefore attentive to the needs of the older adult. In a care setting where the caregivers focus only on basic needs as perceived by them, older adults feel that interaction with caregivers is meaningless as they feel that the caregivers are not truly paying attention to them and their needs (Teka & Adamek, 2014).

Caring *for* is the phase where the caregiver assumes responsibility for organising resources or paying for the services that will meet the identified needs. It is during the second phase that informal care provision becomes problematic for South African families as poverty dramatically reduces resources required to care for older relatives. Community care aims at providing good care by caring during each phase, thus taking pressure off and supporting the families of older adults in need of long-term formal care.

The third phase consists of the instrumental aspects of caregiving: how care tasks are performed. This phase requires knowledge about how to care for older adults and implies competence. The caregiver knows how to bathe and dress the older adult so that dignity is still intact. The caregiver is also competent in looking after the older adults' psychosocial needs as identified during the first phase of caring. In some care settings, however, psychosocial needs are deemed unimportant and professional caregivers are not trained in meeting these needs of the older adults (Teka & Adamek, 2014).

Care receiving is the last phase and involves the responses of the person *receiving* the care. This phase requires responsiveness from the older adult. The older adult expresses satisfaction with the care received or communicates dissatisfaction with the care services. This also requires attentiveness by the caregiver, as they have to respond should the older adult feel that their needs weren't met by the care received.

As an ethics of care approach argues that care can only be good care if it takes place in all four phases, this research focuses on all four phases of good care as it relates to what older adults in South Africa may regard as good formal community-based care.

1.5 Empirical design

1.5.1 Research paradigm

Drawing on an ethics of care approach, this research is designed within the social constructivist paradigm. An ethics of care approach posits a situational and relational dimension (Leget, 2013). Social constructivism supports this notion, as it holds that in order to understand a person and his/her world, one has to learn their terms and practices. In studying the older adults' experiences of care, universal standards and principles are discarded and the grounded terms and practices relevant to their worlds of receiving care, are taken into account (Lock *et al.*, 2010: 19)

At the centre of 'meaning-making', is the social context. "Knowing" is created through shared social production (Thomas *et al.*, 2014). Social constructivism focuses on the construction of meaning in terms of the social, cultural, and historical dimensions of understanding. Qualitative research is used to discover meaning and understanding through the researcher's active involvement of the construction of meaning (Kim, 2014).

According to social constructivism, we construct our own social realities and experiences which can be analysed, deconstructed and reconstructed (Burr, 2003). Reality is reproduced by people acting on their interpretation and knowledge and this is an ongoing, dynamic process (Thomas *et al.*, 2014). The world of the older adult can only be explained and understood through interpretation, which considers the older adult as an individual constructing his own reality of the social environment he/she is functioning in (Patel *et al.*, 2011; Şimandan, 2014). It is through the narratives of participants that the researcher can interpret the older adults' experiences of care as it takes place in his/her world. This interpretation makes the interpretive descriptive methodology a good fit in the social constructivist paradigm (Şimandan, 2014).

1.5.2 Research design

The social constructivist paradigm essentially draws on a qualitative approach. Qualitative research is a naturalistic approach that offers the researcher an in-depth view into a complex phenomenon of ageing. The researcher is required to be engaged in the lives of the participants being studied; to hear their stories, grasp their points of view, and understand their meanings (Schoenberg, 2011; Kuckelman, Cobb & Forbes, 2002). This qualitative study was conducted using the interpretive description (ID) strategy (Thorne *et al.*, 2004). ID is a way to address complex, experiential questions that are relevant to applied health disciplines and is aligned to a constructivist orientation to inquiry (Hunt, 2009). ID allows the researcher to develop conceptual descriptions that present thematic patterns characterising the studied phenomenon. This strategy allows in-depth interviews to gather data as ID accounts for the individual variations within emerging thematic patterns (Thorne *et al.*, 2004)

In-depth interviews were used to gather in-depth, rich data. Two main questions were asked:

1. How do you experience the current care that you are receiving?

2. What, in your opinion, is good care?

1.5.3 Participants and sampling

The research was conducted in the Sebokeng area, Gauteng. Sebokeng is Sesotho for “gathering place”. By 2011, the national census indicated that the total population was 218,515 with 4.9% consisting of older adults. Of the population, 99.1 % is black African and 18.8% has no income (Statistics South Africa, 2015).

Although this community has a wide range of formal community-based care service providers (for example: Sebokeng Old Age Home Multi-purpose Centre, Empilisweni Elderly Support Club, Entokwezi Day Care Centre for the Aged, Tenyiko Home-Based Care, Lukanyo Day Care and Adult Centre) limited research is available on how these services are experienced by older adults. Sebokeng Age in Action is the gatekeeper of the community and has an established relationship with the NWU.

The manager of the Tshepong Day Care centre for the elderly is actively involved with all older persons who need care in the area, whether day care or home-based care. She provided lists of possible participants and recruitment was done by a field worker. Once recruited, participants were sampled using purposive homogeneous sampling. This method was used because older adults receiving care as part of their everyday experience, form a sociodemographical homogenous population (Bornstein *et al.*, 2013).

In SSA, gender determines access to care resources due to reciprocity (Van Der Geest, 2016). In this region (and especially South Africa) older women are increasingly accepting the role of parent, carer and breadwinner (Sidloyi & Bombela, 2016). With older women taking on multiple roles in the family, they are perceived as investing more into the care of family than men, thus leaving men without the option of reciprocal care. This causes them to be more dependent on formal systems of long-term care (Van Der Geest, 2016).

Ageing could potentially result in deteriorating health and physical strength, thus inducing a greater demand for long-term care (Phaswana-Mafuya *et al.*, 2013). This is especially true for the oldest old (aged 75 years and older) (Nuscheler & Roeder, 2013). It was with this in mind that participant were recruited to cover the age spectrum of old to oldest old.

The age within the sample group ranged from 63 to 85 years. The group consisted of 10 day care service users and 10 older adults in need of home-based care. It was aimed to have an equal gender distribution in the participant group. This was however not achieved, with the participant group consisting of 15 women and 5 men. The participants met the inclusion criteria of speaking Sesotho/Afrikaans/English and there were no older adults suffering from extreme forgetfulness or a diminished grasp on reality.

The participants were all poor and mostly relied on their state pension for survival. There were some financial support from family members, but the majority of older participants co-habited with their unemployed children and/or grandchildren. Houses are small and mostly built from corrugated steel and situated in dusty, uneven yards. Living conditions are hard, and especially participants without familial support suffer under these conditions.

1.5.4 Data analysis

Thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013) was used to analyse data gathered during in-depth interviews. The researcher familiarised herself with the data by transcribing the interviews, reading them, and noting any ideas that materialised from the transcriptions. Data was coded by the researcher and a co-coder. These codes were ordered into themes and data was grouped according to each theme. After ensuring that the themes worked in relation to the coded extracts, a thematic map of the analysis was generated. Theme names were refined through ongoing analysis. During the final phase of analysis, extracted examples were selected, analysed and related to the research questions and literature (Clarke & Braun, 2013).

1.6 Ethical considerations

This study was approved by the Health Research Ethics Committee (NWU-00055-17S1, see Annexure D: ethics approval certificate).

A field worker explained the research purpose and process to participants to ensure that they understood the study and the process. This explanation was done in the home language of the participants. It was made clear that the study was for academic research and that they wouldn't receive remuneration for participating. Potential participants were given time to decide whether they wanted to participate or not. Voluntary informed consent was obtained from each participant (verbally or in writing) after it was ascertained that they understood the study and felt comfortable participating. In the cases of illiterate participants, verbal consent was obtained in the presence of a witness and the consent form was countersigned by a literate witness. Participants were aware of and gave consent to interviews being recorded (See Annexure C: informed consent form.)

The participants' personal information was kept confidential and anonymity was ensured by assigning participants numbers and not using any names. Complete privacy was possible when interviewing home-bound participants. Interviews with day care users were conducted in the building while the other older adults were playing games outside. There wasn't complete anonymity however, as everyone knew when a person was being interviewed. The participants didn't mind this fact, and agreed to participate knowing that their responses were kept private and confidential.

According to the ethics of care approach, specific ethical dilemmas that arise are unique to the context in which each individual research project is conducted (Hoffman, 2016). The argument is that researchers have to approach each ethical challenge from the context in which the research is conducted (Renold *et al.*, 2008 in Hoffman, 2016).

Adhering to a monitoring plan ensured that the research was conducted in a professional and ethical manner. Regular updates on progress were provided to the supervisor.

1.7 Trustworthiness

Trustworthiness enhances the quality of qualitative research and is determined by five epistemological standards (Botma *et al.*, 2010: 233-234):

- Exploring the older adults' experiences as perceived by them added **truth value** to the study;
- Reaching data saturation as well as obtaining thick descriptions of experiences by using in-depth interviews ensured that the findings can be transferred to other contexts of older adults using community-based care. This research thus meets the standard of **applicability**;
- **Consistency** was guaranteed by describing how and what kind of data was collected and by making use of a co-coder;
- The research met the standard of **neutrality** by basing findings on the experiences and perceptions of the older adults and not allowing data to be influenced by the researcher's bias or perceptions, and;
- Quoting older adults' responses verbatim conveyed their feelings and enhanced the **authenticity** of the data.

1.8 Dissemination of findings

The results of this study are presented in article format and outlined in the following chapters:

1. Introduction that consists of a literature review and background and the research puzzle

2. Research article: "Formal community-based care: Older adults' experiences of home-based and day care services in Sebokeng."
3. Conclusions, limitations and recommendations

1.9 Bibliography

Aboderin, I. (2004). Decline in material family support for older people in urban Ghana, Africa: understanding processes of causes and change. *Journal of Gerontology: SOCIAL SCIENCES*, 59b(3), 128-137.

Aboderin, I. and Beard, J.R. (2014). Older people's health in sub-Saharan Africa. *The Lancet*, 385, 9-11. Retrieved from [.Doi: 10.1016/S0140-6736](https://doi.org/10.1016/S0140-6736)

Aboderin, I., Mbaka, C., Egesa, C., Owii, H.A. (2015). Human rights and residential care for older adults in sub-Saharan Africa: Case study of Kenya. In Meenan, H., Rees, N. and Doron, I. (Eds.), *Towards Human Rights in Residential Care for Older persons. International perspectives* (pp. 13-22). New York: Routledge.

Barrientos, A., Gorman, M. & Heslop, A. (2003). Old Age Poverty in Developing Countries: Contributions and Dependence in Later Life. *World Development*, 31(3), 555-570. Doi: 10.1016/S0305-750X(02)00211-5

Bohman, D.M., van Wyk, N.C., Ekman, S.L. (2009). Tradition in transition-intergenerational relations with focus on the aged and their family members in a South African context. *Scandinavian Journal of Caring Sciences*, 23, 446-455. Doi: 10.1111/j.1471-6712.2008.00640.x

Bohman, D.M., van Wyk, N.C., Ekman, S.-L. (2011). South Africans' experiences of being old and of care and caring in a transitional period. *International Journal of Older People Nursing*, 6, 187-195. Doi: 10.1111/j.1748-3743.2010.00225.x

Bornstein, M.H., Jager, J. & Putnick, D.L. (2013). Sampling in developmental science: Situations, shortcomings, solutions and standards. *Developmental Review*, 33, 357-370. Doi: 10/1016/j.dr.2013.08.003

Botma, Y., Greef, M., Mulaudzi, F.M. and Wright, S.C.D. (2010). *Research in Health Sciences*. Pearson Holdings: Cape Town.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101

Burr, V. (2015). *Social Constructionism*. New York: Routledge

Camlin, C.S., Snow, R.C. & Hosegood, V. (2014). Gendered Patterns of Migration in Rural South Africa. *Population, Space and Place*, 20, 528-551. Doi: 10.1002/psp.1794

Chen, H., Yang, H., Song, P., Wang, L. (2017). An Ambiguous Sense of Professional Identity: Community-Based Caregivers for Older Adults in China. *Ageing International*, 42, 236-250. Doi: 10.1007/s12126-016-9266-2

Clarke, V. & Braun, V. (2013). Teaching thematic analysis: Over-coming challenges and developing strategies for effective learning. *The Psychologist*, 26(2), 120-123. Retrieved from: <http://eprints.uwe.ac.uk/21155>

Cohen, M.C., Miller, J. & Weinrobe, M. (2001). Patterns of Informal and Formal Caregiving Among Elders With Private Long-Term Care Insurance. *The Gerontologist*, 41(2), 180-187. Doi: <https://doi.org/10.1093/geront/41.2.180>

Darkwa, O.K. & Mazibuko, F.N.M. (2002). Population aging and its impact on elderly welfare in Africa. *International Journal of Aging and human development*, 54(2), 107-123. Retrieved from: <http://journals.sagepub.com/doi/abs/10.2190/XTQG-6DXD-9XWE-9X85>

Dhemba, J. & Dhemba, B. (2015). Ageing and care of older persons in Southern Africa: Lesotho and Zimbabwe compared. *Social work and Society International online Journal*, 13(2). Retrieved from: <http://socwork.net/sws/article/view/435>

Dokpesi, A.O. (2015). The future of elderly care in Nigeria: borrowing a leaf from a foreign land. *Ageing International*, 40, 81-97. Doi 10.1007/s12126-014-9205-z

Fisher, B. & Tronto, J. (1990). Toward a feminist theory of caring. (In Tronto, J. 2010. Creating caring institutions: politics, plurality and purpose. *Ethics and Social Welfare*, 4(2), 158-171. Doi: 10.1080/17496535.2010.484259)

Freeman, E. & Hoffman, J.R. (2016). The future of long term care for vulnerable older adults in sub-Saharan Africa: a South African case study (In press).

Friedman, I., Mothibe, N., Ogunmetun, C. and Mbatha, T. (2010). A national audit of registered and unregistered home and community-based care (HCBC) organisations in South Africa. *Vulnerable Children and Youth Studies*, 7(4), 328-337. Doi: 10.1080/17450128.2012.673754

Hajat, C., Selwyn, A., Harris, M. & Yach, D. 2018. Preventive Interventions for the Second Half of Life: A Systematic Review. *American Journal of Health Promotion*, 32 (4), 1122-1139. Doi: 10.1177/0890117117712355

Hoffman, J.R (2016). Negotiating care for older people in South Africa: between the ideal and the pragmatics. In Hoffman, J. (Ed.) *Ageing in Sub-Saharan Africa. Spaces and practices of care*, (pp. 170-224). Bristol: Policy Press.

Hoffman, J.R. (2016). Research Integrity and the Mmogo-method®: Some Reflections. In Roos, V. (Ed.), *Understanding Relational and Group Experiences through the Mmogo-method®* (pp. 41-51). Cham: Springer.

Holmberg, M., Valmari, G. & Lundgren, S.M. (2012). Patients' experiences of homecare nursing: balancing the duality between obtaining care and to maintain dignity and self-determination. *Scandinavian Journal of Caring Sciences*, 26, 705-712. Doi: 10.1111/j.1471-6712.2012.00983.x

Hunt, M.R. (2009). Strengths and Challenges in the Use of Interpretive Description: Reflections Arising From a Study of the Moral Experience of Health Professionals in Humanitarian Work. *Qualitative Health Research*, 19(9), 1284-1292. Doi: 10.1177/1049732309344612

- Iparraguirre, J.L. (2017). Reductions in local government spending on community-based social care and unmet social care needs of older people in England. *The Journal of the Economics of Ageing (In press)*. Doi: [org/10.1016/j.jeoa.2017.07.001](https://doi.org/10.1016/j.jeoa.2017.07.001)
- Jesmin, S.S., Amin, I. & Ingman, S.R. (2011). Aging and caregiving crisis in the low and middle income societies. *Indian Journal of Gerontology*, 25(3), 309-328.
- Keating, N. (2011). Critical reflections on families of older adults. *Advances in Gerontology*, 24(2), 343-349.
- Keating, N., Eales, J. and Phillips, J.E. (2013). Age-Friendly Rural Communities: Conceptualizing "Best-Fit". *Canadian Journal on Ageing*, 32(4), 319-322. Doi: [10.1017/S0174980813000408](https://doi.org/10.1017/S0174980813000408)
- Kim, MS. (2014). Doing social constructivist research means making empathic and aesthetic connections with participants. *European Early Childhood Education Research Journal*, 22(4), 538-553. Doi: [10.1080/1350293X.2014.947835](https://doi.org/10.1080/1350293X.2014.947835)
- Kuckelman Cobb, A. & Forbes, S. (2002). Qualitative Research: what does it have to offer to the gerontologist? *Journal of Gerontology: MEDICAL SCIENCES*, 57A(4), 197-202.
- Lloyd-Sherlock, P., Beard, J., Minicuci, N., Ebrahim, S. & Chatterji, S. (2014). Hypertension among older adults in low-and middle-income countries: prevalence, awareness and control. *International Journal of Epidemiology*, 43(1), 116-128. Doi: [10.1093/ije/dyt215](https://doi.org/10.1093/ije/dyt215)
- Leget, C. (2013). Analyzing dignity: a perspective from the ethics of care. *Med Health Care and Philos*, 16, 945-952. Doi: [10.1007/s11019-012-9427-3](https://doi.org/10.1007/s11019-012-9427-3)
- Lock, A., Strong, T. (2010). *Social Constructionism. Sources and Stirrings in Theory and Practice*. Cambridge University Press. United Kingdom, Cambridge.
- Lombard, A. & Kruger, E. (2009). Older Persons: the Case of South Africa. *Ageing International*, 34, 119-135. Doi: [10.1007/s12126-009-9044-5](https://doi.org/10.1007/s12126-009-9044-5)

- McKinnon, B., Harper, S. & Moore, S. (2013). The relationship of living arrangements and depressive symptoms among older adults in sub-Saharan Africa. *BMC Public Health*, 13(682). Retrieved from: <http://www.biomedcentral.com.nwulib.nwu.ac.za/content/pdf/1471-2458-13-682.pdf>
- Moodley, K. (2011). Respect for patient autonomy. In Moodley, K., (Ed.) *MEDICAL ETHICS, LAW AND HUMAN RIGHTS. A South African perspective* (pp 41-56). Pretoria: Van Schaik.
- Murphy, A., Kowal, P., Albertini, M., Rechel, B., Chatterji, S. & Hanson, K. (2017). Family transfers and long-term care: An analysis of the WHO Study on global AGEing and adult health (SAGE). *The Journal of the Economics of Ageing* (In press).
- Muruthi, J.R. & Lewis, D.C. (2016). Factors Impacting Old-Age Economic Security: Views of Kenyan Rural-Dwelling Older Adults. *Journal of Ethnographic & Qualitative Research*, 2, 72-86.
- Mutemwa, M. & Adejumo, O. (2014). Health challenges of elderly people caring for children orphaned by AIDS in a community setting in South Africa. *African Journal for Physical, Health Education, Recreation and Dance*, October (Supplement 1:2): 336-347. Retrieved from: <https://repository.uwc.ac.za/handle/10566/1430>
- Nyirenda, M., Chatterji, S., RoCHAT, T., Mutevedzi, P. & Newell, M-L. (2013). Prevalence and correlates of depression among HIV-infected and –affected older people in rural South Africa. *Journal of affective disorders*, 151(1), 31-38. Doi: 10.1016/j.jad.2013.05.005
- Nuscheler, R. & Roeder, K. (2013). The political economy of long-term care. *European Economic Review*, 62, 154-173. Doi: 10.1016/j.euroecorev.2013.05.005
- Oakley, R.L. (1998). Local effects of new social welfare policy on ageing in South Africa. *Southern African Journal of Gerontology*, 7(1), 15-20.

Patel, C.J., Gali, V.S., Patel, D.V., & Parmar, R.D. (2011). The effects of information and communication technologies (ICTs) on higher education: From objectivism to social constructivism. *International Journal of Vocational and Technical Education*, 3(5), 113-120.

Phaswana-Mafuya, Nancy, Peltzer, Karl, Ramlagan, Shandir, Chirinda, Witness, & Kose, Zamakayise. (2013). Social and health determinants of gender differences in disability amongst older adults in South Africa. *Health SA Gesondheid (Online)*, 18(1), 1-9. Doi: 10.4102/hsag.v18i1.728

Phetlhu, D.R. & Watson, M. (2014). Challenges faced by grandparents caring for AIDS orphans in Koster, North West Province of South Africa: HIV/AIDs management and care. *African Journal for Physical Health Education, Recreation and Dance, Supplement 1*, 348-359.

Provencher, C., Keating, N., Warburton, J., Roos, V. (2014). Ageing and Community: Introduction to the Special Issue. *Journal of Community & Applied Social Psychology*, 24, 1-11. Doi: 10.1002/casp.2171

Rosenberg, A., Mabude, Z., Hartwig, K., Rooholamini, S., Tetteth, D.O. & Merson, M. (2005). Improving home-based care in Southern Africa: an analysis of project evaluation. *South African Journal of HIV Medicine*, 19, 30-36.

Schatz, E. & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health*, 10(10), 1185-1200. Doi: 10.1080/17441692.2015.1035664

Schoenberg, N.E. (2011). The qualitative portfolio of The Gerontologist: strong and getting stronger. *The Gerontologist*, 51(3), 281-284. Doi.org.nwulib.nwu.ac.za/geront/gnr032

Shaibu, S. & Wallhagen, M.I. (2002). Family caregiving of the elderly in Botswana: Boundaries of culturally acceptable options and resources. *Journal of Cross-Cultural Gerontology*, 17, 139. Doi:10.1023/A:1015886307661

Sharma, R. & Marwah, E.B. (2017). Rising Demand for Community Based Long-term Care Services for Senior Citizens in India. *Indian Journal of Gerontology*, 31(4), 519-528.

Sidloyi, S.S. & Bombela, N.J. (2016). Survival strategies of elderly women in Ngangelizwe Township, Mthatha, South Africa: Livelihoods, social networks and income. *Archives of Gerontology and Geriatrics*, 62, 43-52. Doi: 10.1016/j.archger.2015.09.006

Şimandan, M. (2014). Interpretative methodology and social constructivism. *Journal of Humanistic and Social Studies*, 1(9), 145-158.

South Africa. (2005). *South African Policy for Older Persons*. Department of Social Development: Pretoria.

South Africa. (2006). *Older Persons Act No. 13 of 2006*. Government Gazette, 479 (29346). Cape Town. 2 November 2006.

South Africa. (2008). *Social Assistance Amendment Act, no. 6 of 2008*. Government Gazette, 516 (31248). Cape Town. 14 July 2008.

Statistics South Africa. (2015). *Statistical release P0302*. Mid-year population 2015.

Statistics South Africa. (2015). *Census 2011*.

Statistics South Africa. (2015). *Vulnerable Groups Series ii: The Social Profile of Older Persons, 2011-2015*.

Strydom, H. (2008). The Future of Community-Based Services for Older Persons in South Africa. *Practice*, 20(2), 103-111. Doi: 10.1080/09503150802059002

Teka, A. & Adamek, M.A. (2014). "We prefer eating rather than greeting". Life in an elder care centre in Ethiopia. *Journal of Cross-Cultural Gerontology*, 29, 389-404. Doi: 10.1007/s10823-014-9244-7

Thomas, A., Menon, A., Boruff, J., Rodriguez, AM., Ahmed, S. (2014). Applications of social constructivist learning theories in knowledge translation for healthcare professionals: a scoping review. *Implementation Science*, 9, 1-20.

Thorne, S., Kirkham, R. & O'Flynn-Magee, K. (2004) The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1). Retrieved [14/11/2018] from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf

Thrush, A & Hyder, A. (2014.) The neglected burden of caregiving in low-and middle-income countries. *Disability and Health Journal*, 7(3), 262-272. Doi: 10/1016/j.dhjo.2014.01.003.

Tomita, A. & Burns, J.K. (2013). Depression, disability and functional status among community-dwelling older adults in South Africa: evidence from the first South African National Income Dynamics Study. *International Journal of Geriatric Psychiatry*, 28, 1270-1279. Doi: 10.1002/gpp.3945

Tronto, J. (1993). Moral boundaries: a political argument for an ethic of care. (In Lachman, V.D. 2012. *Applying the ethics of care to your nursing practice*. MEDSURE Nursing, 21(2), 112-116

Tshesebe, M. & Strydom, H. (2016). AN EVALUATION OF THE COMMUNITY-BASED CARE AND SUPPORT SERVICES FOR OLDER PERSONS IN A SPECIFIC COMMUNITY. *Social Work/Maatskaplike Werk*, 52(1), 1-18. Doi:<http://dx.doi.org/10.15270/52-1-476>

United Nations, Department of Economic and Social Affairs, Population Division (2015). *World Population Ageing 2015 (ST/ESA/SER.A/390)*.

United Nations, Department of Economic and Social Affairs, Population Division (2017). *World Population Ageing 2017 (ST/ESA/SER.A/408)*.

Van Der Geest, S. (2016). Will families in Ghana continue to care for older people? Logic and contradiction in policy. In Hoffman, J. & Pype, K. (Eds.), *Ageing in sub-Saharan Africa. Spaces and practices of care* (pp. 21-41). London: Policy Press.

Van Heijst, A. (2011). Professional loving care. 2011. (In Leget, C. 2013. Analyzing dignity: a perspective from the ethics of care. *Med. Health Care and Philos*, 16, 945-952. Doi: 10.1007/s1109-012-9427-3)

World Health Organization (2017). *Toward long-term care systems in sub-Saharan Africa: WGO series on long-term care*. Geneva: World Health Organization. Licence: CCBY-NC-SA 3.0 IGO.

Zimmer, Z. & Das, S. (2014). The Poorest of the Poor: Composition and Wealth of Older Person Households in Sub-Saharan Africa. *Research on Aging*, 36(3), 271-296. Doi: 10.1177/0164027513484589

Zimmer, Z & Dayton, J. (2005). Older Adults in sub-Saharan Africa living with children and grandchildren. *Population Studies*, 59(3), 295-312.

CHAPTER 2: FORMAL COMMUNITY-BASED CARE: OLDER ADULTS' EXPERIENCES OF HOME-BASED AND DAY CARE SERVICES IN SEBOKENG

ARTICLE: Formal community-based care: Older adults' experiences of home-based and day care services in Sebokeng

Abstract

This study aimed to explore older adults' experiences of formal community-based care in Sebokeng and to address the gap between the ideal of these care systems and delivery, and the effective practical implementation. The secondary aim was to ascertain what the older adults from this group perceived as good care. Results found formal community-based care to be inadequate in meeting older adults' long-term care needs, and identified access, attentiveness and responsiveness, companionship, and dignity as four main principles of care. The study concludes that an ethics of care approach could provide a good heuristic framework to explain good care, and that policy has to accommodate partnerships between government and communities in providing good long-term community-based care.

Key words: home-based care, day care services, ethics of care, good care

Introduction

Population ageing is a global process and although sub-Saharan Africa (SSA) is the world's youngest region, its older population increases at an annual rate of 3.2% (Zimmer & Das, 2014). This number is significant when compared to the global growth rate, which is 1% (Zimmer & Das, 2014). Of the sub-Saharan countries, South Africa is the second most rapidly ageing population with the absolute number of older people currently (2017) at 4.8 million (UN, 2017). By the year 2050, the number of older South Africans will have almost tripled to around 11.6 million people (UN, 2017). With this dramatic growth of the older population, the demand for long-term

care will increase at an equally dramatic pace (Jesmin *et al.*, 2011). With a growing demand on the formal long-term care system in South Africa, policy advocates formal community-based care as a solution to the long-term care challenge. Research on this form of care in South Africa is limited and no clear picture of the formal community long-term care situation exists. This study aims to explore older adults' experiences of formal community-based care in Sebokeng and to address the gap between the ideal of these care systems and delivery, and the effective practical implementation. Secondly, it aims to ascertain what the older adults from this group perceived as good care.

Background review

Common trends that impact the growing need for long-term care in SSA include poverty, migration, and the rise of non-communicable diseases, HIV/AIDS and changing family structures (Darkwa & Mazibuko, 2002; Jesmin *et al.*, 2011; Schatz & Seeley, 2015; Zimmer & Das, 2014). Although South Africa's older population is experiencing the same trends, its long-term care management is unique to the rest of SSA. This is mainly determined by two drivers: its historical legacies of poverty, inequality and deprivation under apartheid, and the current HIV/AIDS epidemic (Tomita and Burns, 2013).

South Africa's older population is uniquely characterised by their experience of apartheid (1948–1994). Apartheid saw the forcible removal of much of the black population to areas with inadequate educational resources, health services, and a lack of career opportunities that would enable them to make provision for their old age (United Nations, 1963 in Kobayashi *et al.*, 2017; Aboderin *et al.*, 2015). The results of forced relocations are still experienced today as many older adults live in areas unsuitable for older adults and affording them very limited access to resources (Keating *et al.*, 2013).

Adding pressure to the formal long-term care systems in South Africa is the country's quadruple burden of disease consisting of HIV/AIDS and TB, maternal and childhood diseases, non-communicable diseases, and violence and injuries (Naidoo, 2012). South Africa has the world's highest number of people living with HIV/AIDS (Nyirenda *et al.*, 2013). Few studies on HIV/AIDS have collected data on adults over the age of 54, but the literature available suggests substantial ageing with HIV and acquisition of HIV at older ages (Mojola *et al.*, 2015). It is estimated that South Africa will see a 50% increase in HIV infections among older adults over the next 15 years (Hontelez *et al.*, 2011 in Mojola *et al.*, 2015). This is a perturbing statistic considering that the country's already overburdened long-term care system will have to keep up with this increase.

Older women, even those not at risk of infection, are amongst those mainly affected by the pandemic. They bear the brunt of caring for the sick and dying as they have to care for their sick children and, often, for orphaned grandchildren (Ogunmefun *et al.* 2011; Mutemwa & Adejumo, 2014; Lombard & Kruger, 2009; Phetlhu and Watson, 2014). Caregiving is an economic burden on the older adults, especially those already in the throes of poverty. They are at an age where their care needs should be met, but instead they must provide emotional and physical care to their family members (Phetlhu & Watson, 2014; Ice *et al.*, 2010 in Mutemwa & Adejumo, 2014).

Apart from the HIV/AIDS epidemic, older adults also suffer the burden of non-communicable diseases. High blood pressure, diabetes and arthritis are the most common medical conditions affecting older adults (Lloyd-Sherlock *et al.*, 2014; Statistics SA, 2015).

In addition, older adults make up one of South Africa's most vulnerable groups and are especially exposed to violence (Buthelezi *et al.*, 2017). Eldercide is a leading cause of non-natural death amongst older South Africans, with a rate of 25.2 per 100 000 of the older population (Matzopoulos *et al.*, 2015). Eldercide increases as the population ages, and is therefore becoming more of a public health and social problem (Buthelezi *et al.*, 2017). As one of the factors of South

Africa's quadruple burden of disease, increased violence towards its older population will have a negative impact on social and health-related long-term care in South Africa.

There are two main options available to older adults in need of long-term care. Informal care is unpaid care provided to older adults by someone with whom they have a social relationship, such as a family member, relative, neighbour or friend (Jesmin *et al.*, 2011). Traditionally, women are perceived as caregivers to those in need of care. Research has shown that this trend in informal caregiving is still the norm as the majority of informal care activities are performed by female family members (Jesmin *et al.*, 2011; Yakubu & Schutte, 2018). Providing informal care involves helping with household chores, transport, social companionship, emotional support or arranging professional care (Jacobs *et al.*, 2016).

The majority of the South African older population relies on informal long-term care due to a lack of resources and limited access to formal care (Bohman *et al.*, 2011). However, according to Aboderin (2018), informal long-term care is increasingly unsustainable to address the long-term care challenge. There is an inadequate availability of family care, ranging from the complete absence of a family carer to the temporary absence of a family carer. Care provision is costly to families, as one family member has additional needs that have to be met, and whoever cares for the patient is unable to engage in gainful employment. The financial burden of care is greater amongst the poor and those who have to care for sufferers of dementia or related conditions (Aboderin, 2018.) Older adults are also increasingly being forced into the role of informal caregivers instead of receiving care due to limited resources, financial constraints and the HIV epidemic (Bohman *et al.*, 2009, Hoffman, 2016).

Formal long-term care is care that is provided by paid professionals or carers (Cohen *et al.*, 2001). One form of formal long-term care is residential facilities. Residential facilities are institutions that provide accommodation and a 24-hour service to older adults (South African Policy for Older Persons, 2005). Residential facilities, however, is inadequate in meeting the needs of South Africa's older population as they are mainly located in the former white areas and

the majority of older adults are poor and live in rural areas (Lombard & Kruger, 2009; Statistics SA, 2015).

As an option for addressing the shortcomings of these two options of long-term care, the South African Policy for Older Persons of 2005 advocates formal community-based care as the best pathway to long-term care for older adults. Community-based care is a form of formal long-term care that aims to promote and maintain the independent functioning of older persons in a community (SA Policy for Older Persons, 2005). The aim of community-based care is to be achieved by enabling active and independent living and creating a supportive environment where older adults' care needs are met.

Formal community-based care consists of two types of services. Day care provides older adults with social, recreational and health-related activities in a formal community-based facility. Home-based care, on the other hand, aims at caring for frail, housebound adults. This includes basic nursing, housework, shopping, counselling and support to clients and their families (South African Policy for Older Persons, 2005).

Theoretically, formal community-based care as set out by the policy seems promising. There are, however, concerns about the implementation and quality of community-based service programmes. The national audit of home and formal community-based care (Friedman, 2010) reported that community caregivers and managers lack adequate training and are mostly unprepared to meet the care demands of older adults. The quality of formal community-based care is also affected by limited human, material and infrastructure resources, and the absence of regulatory structures and oversight. Broadly, older adults are also underserved and experience a lack of access to good community care as a consequence of poor government coordination (WHO, 2017).

There is little discussion of the relative roles of informal, state, and private sectors in meeting the care needs of older adults (Freeman & Hoffman, 2016). Although there is an awareness of the fact that informal care is increasingly inadequate in meeting care needs, it is

still being promoted as the key strategy for providing for the increased need for long-term care (Freeman & Hoffman, 2016). Institutionalised formal long-term care is not the answer to the long-term care challenge, as institutionalised care is inaccessible to the majority of the older population – mostly due to poverty (Freeman & Hoffman, 2016). Formal community-based care is promoted by policy, but there is a lack of evidence of its implementation/outcomes in the practical setting of long-term care for older adults.

Aim of article

As a result of population ageing, South Africa's older population is faced by far-reaching implications in terms of long-term care. Although formal long-term community care is perceived as an answer, studies show that community-based care poses some major challenges such as a lack of infrastructure as well as inadequate resources such as food and inaccessible services (Strydom, 2008; Rosenberg *et al.*, 2005). There actually is a gap in research, especially South African literature, as to older adults' experiences of the current formal day care and home-based care services.

To address this gap in the research literature, this article aims to explore older adults' experiences of current formal community-based care services in Sebokeng as well as what older adults from this research group regard as good care. The purpose of these aims is to address the gap between the ideal of formal community-care systems and delivery, and its effective implementation in practice as experienced by the older adults in need of such services.

In addressing these gaps, an ethics of care approach will be drawn upon as a heuristic frame for understanding care. This approach is a fit tool for addressing long-term care challenges as its arguments focus on the complexity of care and care as an ongoing process.

Ethics of care as a heuristic frame

An ethics of care approach contextualises care as any specific activity that includes all actions undertaken to maintain, continue, and repair our world so that we can live in it as well as

possible (Tronto, 1993). This conceptualisation supports the proposed form of formal community-based care as good care, as these services aim to promote the independent functioning of adults in a situation where they are supported in having access to services that will meet their care needs (South African Policy for Older Adults, 2005).

However, meeting the care needs of older adults does not necessarily imply providing them with good care. The older adult can receive care that is inadequate for meeting his/her needs or is experienced as bad care. Within ethics of care, Tronto's four cyclical phases of good care provide a framework of how to provide care that relates to the needs of the older adult and is therefore experienced as good care (Fisher & Tronto, 1990).

For good care to take place, the caregiver must firstly care *about* the older adult receiving care. Caring can only take place if the caregiver is aware of the care receiver in an attentive manner (Tronto, 1998). This attentiveness implies being aware of both spoken and unspoken needs. During the second phase, the caregiver cares *for* the older adult by assuming responsibility for organising resources or paying for the services that will meet the identified needs. The third phase of good care entails *caregiving*. For care to be good, it has to be provided in a skilled and competent manner (Tronto, 1998). The last phase of the cycle of good care is *care receiving*. This phase involves the responses of the care receiver. The older adult has to respond to the care received. This response, in turn, will enable the caregiver to be more attentive to unmet needs, improving the care receivers' experience of the care situation.

An underlying principle of good care is respect for people. For ethics of care, this means recognising the older adult's need for autonomy and enabling him/her to make choices or at least be part of the decision-making about their care. Ethics of care postulates that, with good care, power inequality doesn't exist in the care situation, as the caregiver and care receiver are partners in ensuring that all care needs are adequately met (Black, 2005).

In exploring older adults' experience of formal community-based care, the ethic of care offers valuable heuristic concepts for a deeper understanding of the grounded experiences of the

participants in this research. As the approach argues that care can only be good care when it takes place in four phases, attention will be given to all four cyclical phases when relating what the Sebokeng older adults regard as good care.

Method

Research design

This qualitative study was conducted within a social constructive paradigm using the interpretive description (ID) strategy. ID is a way to address complex, experiential questions that are relevant to applied health disciplines and is aligned with a constructivist orientation to inquiry (Hunt, 2009). The product of ID research is a coherent conceptual description that taps thematic patterns and commonalities believed to characterise the studied phenomenon, and also accounts for individual variations that occur (Thorne *et al.*, 2004).

Twenty in-depth interviews were conducted to gather in-depth, rich data. The study centred on the main question:

How do you experience the current care that you are receiving?

Participants

The research was conducted in the Sebokeng area, Gauteng. Although there are listed day care and home-based care service providers in this area, limited research is available on how these services are experienced by older adults. The NWU also has an established relationship with Sebokeng Age in Action (see Annexure F: gatekeeper permission letter), which serves as the gatekeeper of the community.

The manager of the Tshepong Day Care centre for the elderly is actively involved with all older persons who need care in the area, whether day care or home-based care. She provided lists of possible participants and recruitment was done by a field worker. Once recruited, participants were sampled using purposive homogeneous sampling. This method was used

because older adults receiving community-based care form a sociodemographical homogenous population (Bornstein *et al.*, 2013).

As these older adults receive this care on a daily basis, they are knowledgeable on this topic and able to give insightful information on their everyday reflective experiences of formal community-based care (Botma *et al.*, 2014: 201). The participants met the inclusion criteria of being 60 years or older, speaking Sesotho/Afrikaans/English, and making use of day care and/or home-based care (see Annexure A: narrative summary of participant information). Participants that suffered from dementia, Alzheimer's, or any condition related to extreme forgetfulness or a diminished grasp on reality, were excluded from the study. The centre manager was informed of the inclusion and exclusion criteria, and identified potential participants based on this criteria.

The participants were all poor and mostly relied on their state pension for survival. A small number received financial support from family members, but the majority of older participants co-habited with their unemployed children and/or grandchildren. Houses are small and mostly built from corrugated steel and situated in dusty, uneven yards. Living conditions are hard, and especially participants without familial support suffer under these conditions.

Research procedure

The study was approved by AUTHeR (North-West University's Africa Unit for Transdisciplinary Health Research) and HREC (Health Research Ethics Committee, see Annexure D: Approved ethics certificate).

Sebokeng Age in Action is the gatekeeper of the older adult community of Sebokeng and a letter from its director granted permission for research to be done in the area (see Annexure F). After permission was granted, the manager at Tshepong Day Care Centre for the Elderly identified participants making use of day care as well as home-based care. The field worker visited the

sampled participants to explain the study and to obtain their consent to partake in the study. Illiterate participants gave verbal consent and had their forms co-signed by a witness.

In-depth interviews were conducted by the researcher, accompanied by an interpreter. This ensured that interviews were conducted in the interviewee's language of choice. Interviewing through trained interpreters allows for the interview to assume a more conversational nature because the subjectivity of the interpreter is used reflectively as part of the research process (Mommersteeg, 1999).

Interviews were conducted at either the day care centre or the participants' homes. At the day care centre, participants were interviewed while the other older adults were outside playing games. Home-bound participants were interviewed in separate rooms than family members that were home. Participants did not receive any compensation but received refreshments at the end of each interview. Each interview was transcribed as soon as possible after the interview and immediately stored on a password-protected computer.

The participants' anonymity was ensured by keeping personal information confidential and research data contained no references to names or addresses. Although complete privacy was possible when interviewing home-bound participants, day care centre users only had partial anonymity. Day care users knew when someone was being interviewed, but this didn't dissuade the older adults from participating.

Data analysis

Thematic analysis was used to analyse data gathered during the interpretive descriptive interviews (Braun & Clarke, 2006; Clarke & Braun, 2013). Interviews were transcribed by the researcher, read, and notes were made of ideas that became apparent from the transcriptions. Coding of the data was done by the researcher and a co-coder. Codes were ordered according to themes, and data was grouped according to each theme. A thematic map of the analysis was

generated once it was ensured that themes worked in relation to the coded extracts. Ongoing analysis was conducted to refine theme names. The final phase consisted of selecting extract samples, analysing them, and relating the data to the research questions and relevant literature (Clarke & Braun, 2013).

Ethical considerations

This study was approved by the HREC (Annexure D: Approved ethics certificate)

A final important consideration regarding this study concerned the ethical issues:

- receiving informed consent from the research participant to provide or undergo a specific role in the research project after having been truthfully and comprehensively informed about the research;
- protecting the identity of the research participant; and
- identifying any risk factors related to physical, emotional or any other kind of harm (Moodley, 2011).

Participants aren't research objects, but people with rights and choices. Consequently, research demands transparent communication with participants regarding the aims and procedures of the research project. A fieldworker visited potential participants at their homes (those who receive home-based care) and the day care centre. They were then informed of their role in the research process in their home language. They were assured that they were under no obligation to participate and that they wouldn't receive remuneration for their participation. Participants were given a few days to decide on their participation and then the field worker visited them again and obtained informed consent.

Confidentiality and anonymity were ensured by non-disclosure of any names or addresses, secure storage of informed consent forms, interviews and transcriptions, and restricted access to data. Physical risks were kept to a minimum by conducting interviews at

participants' homes or at their day care centres and giving healthy refreshments like fruit and safe water. The potential of emotional harm was considered where participants did not want to elaborate on a painful topic. A psychologist was available for support, should a participant experience emotional trauma.

Trustworthiness

Trustworthiness enhances the quality of qualitative research and is determined by five epistemological standards (Botma *et al.*, 2010: 233-234): truth value; applicability; consistency and neutrality. These 5 standards were met by exploring older adults' experiences based on their perceptions and reflective realities; reaching data saturation and obtaining rich descriptions of experiences by conducting in-depth interviews; describing the data gathering process and making use of a co-coder; not allowing findings to be influenced by the researcher's bias or perceptions; and by transcribing interviews verbatim and quoting participants' responses to convey their feelings.

Findings

Participants experienced care on a continuum with organised informal social care on the one end and organised home-based healthcare on the other. Across this continuum, their experiences of the care they currently receive could be categorised according to the following themes:

1. Older adults experience a lack of access to resources in the care situation

Lack of access and resources is experienced on three levels: organised 'informal'-familial social care, organised formal care, and day care. Where older adults are home-bound due to immobility, they need assistance with housework, bathing and other activities of daily living. These needs are mostly met by informal care and no professional help is needed. There were, however,

participants who did not have any family members willing to provide them with this much needed care and would benefit greatly from home-based community care. This is problematic as there are no formal home-based care services (as described and advocated by policy) in their immediate community. Community members provide home-based care for a fee, which makes it impossible for the older adults to obtain, as they do not have the means to pay for these services:

I: So you don't feel you can go to your children for help?

P: No, this is my house and I live here and they won't help me.

I: How do you feel about not having anyone to help you?

P: I can't do anything about it. My family lives very far away and I don't like confiding in people that I don't know.

I: How would you describe good care? What would good care be for you?

P: Being bathed, making sure that the house is clean but the problem with such care is that I will have to pay and the pension money I get it's so little so I won't be able to afford such."

Even in contexts of constraint, several participants make use of formal health care services for their short and long-term health needs. Clinics do provide home-based care to the extent of delivering chronic medication and, in some cases, monitoring blood pressure and sugar levels. This care is, however, mostly experienced as bad care in terms of access. Access to life-sustaining medication is mostly unreliable as the clinics often provide them with medication that makes them ill or only give them half the required dosages. In some cases, healthcare workers are regarded as incompetent and unable to provide skilled medical care.

"P: Not good at all the treatment they give me makes me sick and I swallow up (vomit). They said they are going to bring the pills to me but they never did.....The pills are not good for me at all, the pills make me swallowed up when I complain I get shouted at and get given the same pills."

Participants regard competent home-based care services as essential good care. Participants want healthcare workers to be reliable when delivering medication and knowledgeable in terms of the best treatment of their clients' illnesses:

"P: One can easily see how a person is, if the person is caring or not when you first speak to them. Some caregivers from the clinic promised to bring me pills but the month is almost over now and they haven't brought the pills still. I ended up fetching the pills myself, their unreliability is very bad."

Participants using the services of the day care centre all reported experiencing the care they received from the centre as good care. They did, however, feel that this care would improve greatly if they had access to financial resources and infrastructure. All the participants are poor and only receive a state pension. Often they don't have money for transport and then they cannot go to the centre. The centre requires a monthly contribution of R20 in order to provide them with food and sporting equipment, but this is insufficient and oftentimes the centre manager personally provides them with meals. This is highly appreciated by the participants, as it shows her dedication to their care and well-being.

The main factor influencing the experience of day care is the lack of funding and infrastructure. The centre consists of a single-roomed, corrugated iron structure and doesn't provide adequate shelter. The centre's manager experiences a dilemma in this regard as they do not have the financial means to obtain a proper building, and law states that they cannot receive funding if they do not have a proper building that meets all the requirements as stated by law.

"I: How would you describe the care that you receive here (at the day care centre)?"

P: It's very well but the only problem we have is that we don't have funding and the government says we must first have a proper shelter before we can get any type of funding from them. We contribute R20 per month.

I: So you would say the care workers here...?

P: Yes, they help us a lot and we also donate and sometimes we bring our own lunch boxes and sometimes the centre manager cooks for us from her own pocket.”

Having access to a safe and comfortable building, funding and transport would greatly improve access to the care they receive at the community day care centre. The centre’s lack of financial resources directly impacts access to the care potential the older adults receive as they do not receive meals, and cannot replace or improve equipment for the daily activities at the centre:

“P It’s hard, the care is not yet fully stable. It’s not the care that we deserve due to the struggles that we have here at the centre...food as it is essential, sports equipment such as balls, having our own shelter and sewing material.”

Good care is having access to resources and infrastructure as well as for it to be provided in a competent manner.

2. Care is characterised by attentiveness and responsiveness

Care that pays attention to the participants’ needs and responds to them in a way that is satisfactory to the participants, is seen as good care. With attentive care, they do not have to point out their needs; the caregiver is interested in them and cares about them and therefor pays attention to their wants and needs as an individual. One participant would have appreciated health care workers noticing she has trouble to complete instrumental tasks and to help her with it:

P: “They are there (points in a direction). They only come to ask, spit (saliva for testing) and then they look at that thing and then they go. There’s nobody that says “ouma, let me sweep for you”. And that time when I am shaking a lot, they came, but no one said “ouma, let me sweep for you”

Participants appreciate caregivers’ response to unspoken needs, because this responsiveness implies the caregiver provides care not because he/she has to, but because he/she cares enough about the participants’ well-being to *want* to provide care.

The majority of the participants furthermore feels that providing good care means treating the care receiver with respect. Older adults want their caregivers to recognise them as being in control of their own care and treating them with patience and understanding. On being asked how she would want to be cared for, one participant responded:

P: "With respect and should do things without me telling the person what to do."

Participants want to feel dignified when receiving care. They have self-worth and expect to be treated in a patient way and not to be "shouted at".

3. Configuration of informal and formal community-based care

Social care usually takes place in an individual's own home or care home, and aims to maintain quality of life of individuals suffering from long-term health conditions or support the age-related needs of older adults (Willis et al., 2016; Rand et al., 2017). Where participants from this study receive informal care, they negotiate their social care in a configuration of informal and formal, long-term community-based care settings.

- **Informal social care**

Informal social care spans across a wide care spectrum. Participants' experiences of informal social care form a rather homogenous group with companionship, financial support, instrumental help and physical care identified as the social care received to meet their everyday care needs. The majority of participants reported that the informal care they receive is more than adequate in meeting their needs and that they do not feel a need of "outsiders" to supplement the care received from their families.

"I: Is there anything you would like to change about the care they give you?"

P: Nothing at all the care is good, I get my pension money and buy nice things like meat and sweets and when my money is not in yet, my daughter and son get me the nice things."

This care in the private space is however, complemented by external community-based care

- Community-based social care

Social care in the community is mainly provided by the church and the day care centre. All the participants receiving care from the church and the day care centre expressed their satisfaction and gratitude toward these two care providers. In some cases, the church provides food parcels or meals, and on special occasions (Mother's Day) older adults receive treats. The older adults from this study place a high value on the spiritual care the church provides, and find great joy and peace in worshipping

Participants experience the care they receive from the day care centre as good care. The three main themes that emerged from these experiences are companionship, sporting activities, and the centre manager's regard for each older adult as an important individual. Participants indicated that meeting other older people and talking and playing games greatly relieve stress and feelings of depression. They also feel less lonely than before they started attending the centre. The sporting activities and games also contribute to their health and therefore improve their quality of life. The regard participants have for the manager was apparent in every interview. She cooks for them from her own pocket, shares her chronic medicine when the care workers didn't provide the adequate amount, and treats them with dignity and respect.

I: Why do you come to this centre?

P: It's very fun here and the elderly here are my friends and we walk in groups at times. I used to get very lonely but now I don't, I am very happy here."

Participants reported feeling lonely before they had access to the day care centre. Without these carers and other older adults to have conversations and share feelings and emotions with, they feel lonely. Participants regard loneliness as a very negative state as it causes them to feel depressed and physically ill. Especially day care users reported feeling happier and healthier since attending day care activities. Social care is most often associated with informal familial care.

Modern times have, however, seen a decline in the ability of the family to provide care spanning across a vast continuum. For the majority of South Africa's older population formal care is not a viable substitute as poverty makes it impossible to access these services. This situation has forced older adults to substitute their care by directing it using sources outside of the family and moving into the community.

The options for families to assist their older members with health care are limited and the only option for participants is the clinic in their area and the care workers bringing them medication. Participants indicated that, when they receive poor health care, they have nowhere to turn for additional help. They do, however, have options for additional care when it comes to social care provided by their families. Where families provide inadequate social care, the older adults use community-based care from the church and day care centre to complement the care they do receive.

Discussion

South African policy advocates community-based day care and home-based care services in meeting the long-term care needs of older adults (South African Policy for Older Persons, 2005). From the experiential narratives of the participants, it is clear that, currently, this aim is not being successfully met. Home-based care is fragmented and consists only of providing basic chronic medication. Services aimed at instrumental care or supporting dignified living is non-existent.

Older adults enjoy going to the day care centre as it addresses loneliness and inactive living. The long-term care received here, however, is inadequate in meeting all their care needs. Financial resources are required for transport, food, and shelter but they receive no government support. Being situated in a poverty-stricken area renders them unable to provide in their own financial needs. Older adults negotiate these shortcomings in the care they receive by organising social care from the church as well as informal care. Older adults' management of the division of tasks in their care networks is supported by the complementation model of care. According to this

model, formal and informal caregivers have capabilities best suited to different tasks (Litwak, 1985). Providing care is not always predictable and some tasks require the caregiver to be in close proximity at certain times. Other tasks require professional skills that the informal caregiver cannot perform (Litwak, 1985). According to this model, instrumental care is most often provided by informal carers, whereas formal caregivers provide support with personal or self-care (Dwyer & Coward 1991, Wolf *et al.*, 1997).

The following four interrelated care principles emerged from the experiential reflections of older adults in need of care, namely the importance of access to care, attentiveness and responsiveness of carers, companionship as care, dignity and choice through complementation of care systems:

Access to care

A large number of organisations lack buildings from which to provide community services, they also do not have access to water, electricity, or computer equipment (Strydom, 2008; Friedman *et al.*, 2010; Tshesebe & Strydom, 2016). Although infrastructure itself does not constitute good care, it has an impact on care and contributes to the care experience. Care does not meet needs if those in need cannot access it. Community-based care organisations are affected by high poverty rates and cannot provide good care for older adults in a situation where there are inadequate resources in terms of food, sanitation and accessibility of services (Strydom, 2008; Rosenberg *et al.*, 2005). Community caregivers – and in this case especially home-based healthcare workers – do not receive adequate skills training for providing long-term care to older adults. This means that community caregivers are largely unprepared for the demands of long-term care and, consequently, aren't in a position to provide good-quality care (Friedman, 2010)

Attentiveness and responsiveness of carers

A study conducted by Klaver and Baart (2016) identified nine types of attentiveness: relationship-based, meticulous, calculating, tolerating, settling, avoiding, process-oriented,

hurried and disciplining. The type of attentiveness that stands out from the data gathered from the participants from this study is relationship-based. Relationship-based attentiveness is relational and tunes to the person receiving care. This type of attentiveness is characterised by using knowledge about the care receiver, sensing, and keeping a broad view. This type of attentiveness in care is supported by an ethics of care approach, which is situational and relational (Leget, 2013)

Attentiveness is good care when the caregivers recognise unspoken needs and where the participants experience that the caregiver truly pays attention to them and their needs (Teka & Adamek, 2014). When considering Tronto's phases of care (1993), one can come to the conclusion that care starts with attentiveness and ends with attentiveness. The last phase of good care requires responsiveness from the older adult. The older adult expresses satisfaction with the care received or communicates dissatisfaction with the care services. This also requires attentiveness by the caregiver, as they have to respond should the older adults feel that their needs were not met by the care received.

Companionship as care

Participants described companionship as good care; not only because they feel supported by it, but also because it provides them with enjoyable recreational opportunities. Rook (1990) identifies companionship as social involvement in shared recreational or non-recreational activities with the aim of enjoyment. According to Bromell & Cagney (2013), companionship is an indicator of loneliness and does not offer social support but provides pleasure (Bromell & Cagney, 2013). Participants from this study did, however, indicate that they experience companionship as support given by informal care and the community-based day care. Participants enjoy taking part in conversation, sporting activities, and games at the daycare centre. It gives them pleasure to exercise, feel invigorated, and essentially to "feel young" again. These enjoyable activities create distance between them and the loneliness and stressors they

Dignity and choice through complementation of care systems

According to Nordenfelt (2009) dignity can be conceptualised in four forms: dignity of merit, dignity of moral stature, dignity of identity, and human dignity.

Dignity of merit is associated with prestige and can be bestowed upon people through some formal act or be achieved through deeds that deserve respect. *Dignity of moral stature* is associated with a special type of merit that is derived from behaviour that complies with moral standards. The third form, *dignity of identity*, is when we “attach to ourselves as integrated and autonomous persons, with a history and a future, with all our relationships to other human beings.” Autonomy, independence, respect and privacy are included in this form of dignity. Dignity of identity has the most relevance in the context of older adults as it can be changed by external factors such as illness, injury or old age. *Human dignity* is present in all human beings and to the same degree. It is based on basic human rights and as long as we exist, this form of dignity persists.

Dignity is a fundamental need for all people, but it is especially important for older adults who face multiple losses that come with ageing (Black & Dobbs, 2014). Research suggests that dignity in ageing is complex and that personal perspectives and interpretation within a broader social context are both important in understanding this multifaceted concept (Black & Dobbs, 2014).

Research shows that dignity pertains to three domains: identity (self-respect, pride, integrity, trust); human rights (equality, choice, human entitlement to dignity); and autonomy (independence, self-determination, freedom of choice, control) (Calnan, Badcott and Woolhead, 2006). Older adults configure their private (familial) and public (day care/church) care systems to negotiate their need for dignified care.

Ethics of care and the four principles of good care

The four principles of good care as deduced from the Sebokeng data are supported as well as strengthened by the ethics of care approach. Older adults regard care as good when they feel cared about, cared for, receive satisfactory care, and have the opportunity to respond to care received. Ethics of care supports paying close attention to the individual, recognising unspoken needs, and listening to spoken ones (Tonto, 1998). Attentiveness of the caregiver means the older adults do not have to ask for care; needs are recognised even before they are expressed. Older adults experience good care where they feel cared for. This phase of good care is, in this case, especially relevant to the informal care the older adults receive, i.e. family members provide them with personal care and financial support and this care is appreciated as good care. Care receiving implies skilled competence (Tronto, 1998). During this phase, older adults want to receive care that will improve their health situation. Older adults want to know that healthcare workers are competent and knowledgeable so that they can trust the care they receive. Good care during the last phase is regarded as having the opportunity to respond to the care they receive. They give direction to their care by making their own choices, which are respected by the caregiver.

Implications of the study

Research on formal long-term community-based care in South Africa is limited. This study will add to literature by sharing the experiences of those currently affected by the long-term care options available to older adults, and contribute to knowledge on how to provide them with care that they will experience as good care. The results showed that, although informal care might seem insufficient, it is still preferred by the majority of older adults from this study and families try to provide in their needs as best possible.

Older adults are not passive receivers of care. They negotiate gaps in their care by directing it toward complementing care options. This self-direction should be facilitated as much as possible by providing information about and access to available alternative care options. This

finding is supported by the identified care principles. In order to create good and effective guidelines, they should be based on lived experiences and be established by those receiving care. Older adults' care should be autonomous, starting with them stating how they want to be cared for.

Government should be made aware of the shortcomings of the implementation of legislation and policies. Government identified formal long-term community-based care as the answer to the current care shortcomings, but the lack of implementation means that there is no improvement in formal long-term care provision for older adults. Cooperation between government and communities is essential for making the vision of good long-term community-based care for older adults a reality.

Conclusion

This study had two aims: exploring and interpreting older adults' experiences of their current care situations and determining what they regard as good care. Results showed that home-based health care does not meet the needs of the older adults from this study and that care workers should receive better training in being professional and providing care that is of required standard.

Informal care is still the preferred way of care, with older adults expressing satisfaction with their informal care situation. When older adults feel that this care is inadequate, they try to obtain their care from other available options, which in this case is community-based care provided by a day care centre and, to a lesser extent, the church.

Policy implementation is unsuccessful in establishing formal long-term care services or creating a supportive environment for community organisations that provide long-term care to older adults. This is illustrated by the decrease in available services over a three year time span. In 2016 there was a number of home-based long-term care services. By 2018, the area in which this research was conducted had no social home-based care providers and no government day

care centres. Funding is a major problem for unregistered non-profit organisations that aim to address the lack of formal long-term care.

The findings of the research question, “What is good care?”, showed that older adults want care that gives them access to resources and professional, competent care; shows the caregiver is attentive to their needs and willing to respond accordingly; provides companionship; and affords them dignity with choice. With these principles of care that speak to the four cycles of good care postulated by the ethics of care, it is clear that using this approach as framework when creating community-based care programmes will fulfil older adults’ needs regarding good care.

Care is a complex concept that needs to be studied in its various forms and settings. With the lack of literature on formal long-term care provision to older South Africans, it is crucial that more comprehensive studies be conducted to get a better understanding of the true situation regarding long-term care in South Africa.

Bibliography

Aboderin, I. (2018). Optentia education workshop – Care economy. [<http://www.optentia.co.za/education.php>]

Aboderin, I., Mbaka, C., Egesa, C., Owii, H.A. (2015). Human rights and residential care for older adults in sub-Saharan Africa: Case study of Kenya. In Meenan, H., Rees, N. and Doron, I. (Eds.), *Towards Human Rights in Residential Care for Older persons. International perspectives* (pp. 13-22). New York: Routledge.

Black, R.M. (2005). Intersections of care: An analysis of culturally competent care, client centered care, and the feminist ethic of care. *Women, Work and Culture*, 24(4), 409-422.

Black, K. & Dobbs, D. (2014). Community-dwelling older adults' perceptions of dignity: core meanings, challenges, supports and opportunities. *Ageing & Society*, 34, 1292-1313. Doi: 10.1017/S0144686X13000020

Bohman, D.M., van Wyk, N.C., Ekman, S.-L. (2009). Tradition in transition-intergenerational relations with focus on the aged and their family members in a South African context. *Scandinavian Journal of Caring Sciences*, 23, 446-455. Doi: 10.1111/j.1471-6712.2008.00640.x

Bohman, D.M., van Wyk, N.C., Ekman, S.L. (2011). South Africans' experiences of being old and of care and caring in a transitional period. *International Journal of Older People Nursing*, 6, 187-195. Doi: 10.1111/j.1748-3743.2010.00225.x

Bornstein, M.H., Jager, J. & Putnick, D.L. (2013). Sampling in developmental science: Situations, shortcomings, solutions and standards. *Developmental Review*, 33, 357-370. Doi: 10/1016/j.dr.2013.08.003

Botma, Y., Greef, M., Mulaudzi, F.M. and Wright, S.C.D. (2010). *Research in Health Sciences*. Pearson Holdings: Cape Town.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Bromell, L. & Cagney, K.A. (2014). Companionship in the Neighborhood Context: Older Adults' Living Arrangements and Perceptions of Social Cohesion. *Research on Ageing*, 36(2), 228-243. Doi: 10.1177/0164027512475096

Buthelezi, S., Swart, L. & Seedat, M. (2017). The incidence and epidemiology of eldercide in the city of Johannesburg, South Africa. *Journal of Forensic and Legal Medicine*, 52, 82-88.

Calnan, M., Badcott, D. & Woolhead, G. (2006). Dignity under threat? A study of the experiences of older people in the United Kingdom. *International Journal of Health Services*, 36(2), 355-75.

Clarke, V. & Braun, V. (2013). Teaching thematic analysis: Over-coming challenges and developing strategies for effective learning. *The Psychologist*, 26(2), 120-123.

Cohen, M.C., Miller, J. & Weinrobe, M. (2001). Patterns of Informal and Formal Caregiving Among Elders With Private Long-Term Care Insurance. *The Gerontologist*, 41(2), 180-187. Doi: <https://doi.org/10.1093/geront/41.2.180>

Darkwa, O.K. & Mazibuko, F.N.M. (2002). Population aging and its impact on elderly welfare in Africa. *International Journal of Aging and Human Development*, 54(2), 107-123.

Dwyer J.W. & Coward R.T. (1991) A multivariate comparison of the involvement of adult sons versus daughters in the care of impaired adults. *Journal of Gerontology: Social Sciences*, 46(5), 259-269.

Fisher, B. & Tronto, J. (1990). Toward a feminist theory of caring. (In Tronto, J. 2010. Creating caring institutions: politics, plurality and purpose. *Ethics and Social Welfare*, 4(2), 158-171. Doi: 10.1080/17496535.2010.484259)

Freeman, E. & Hoffman, J.R. (in press). The future of long term care for vulnerable older adults in sub-Saharan Africa: a South African case study.

Friedman, I., Mothibe, N., Ogunmetun, C. and Mbatha, T. (2010). A national audit of registered and unregistered home and community-based care (HCBC) organisations in South Africa. *Vulnerable Children and Youth Studies*, 7(4), 328-337. Doi: 10.1080/17450128.2012.673754

Hoffman, J.R (2016). Negotiating care for older people in South Africa: between the ideal and the pragmatics. In Hoffman, J. (Ed.), *Ageing in Sub-Saharan Africa. Spaces and practices of care*, (pp. 170-224). Bristol: Policy Press.

Hunt, M.R. (2009). Strengths and Challenges in the Use of Interpretive Description: Reflections Arising From a Study of the Moral Experience of Health Professionals in Humanitarian Work. *Qualitative Health Research*, 19(9), 1284-1292. Doi: 10.1177/1049732309344612

Jacobs, M.T., Broese van Groenou, M.I., de Boer, A.H. and Deeg, D.J.H. (2014). Individual determinants of task division in older adults' mixed care networks. *Health and Social Care in the Community*, 22(1), 57–66 doi: 10.1111/hsc.12061

Jesmin, S.S., Amin, I. & Ingman, S.R. (2011). Aging and caregiving crisis in the low and middle income societies. *Indian Journal of Gerontology*, 25(3), 309-328.

Keating, N., Eales, J. and Phillips, J.E. (2013). Age-Friendly Rural Communities: Conceptualizing "Best-Fit". *Canadian Journal on Ageing*, 32(4), 319-322. Doi: 10.1017/S0174980813000408

Klaver, K., Baart, A.(2016). Managing socio-institutional enclosure: A grounded theory of caregivers' attentiveness in hospital care. *European Journal of Oncology Nursing*, 22, 99-102. Doi: doi.org/10.1016/j.ejon.2016.04.002

Kobayashi, L.C., Glymour, M.M., Kahn, K., Payne, C.F., Wagner, R.G., Montana, L., Berkman, L. (2017). Childhood deprivation and later-life cognitive function in a population-based study of older

rural South Africans. *Social Science & Medicine*, 190, 20-28. Doi: 10.1016/j.socscimed.2017.08.009

Leget, C. (2013). Analyzing dignity: a perspective from the ethics of care. *Med Health Care and Philos*, 16, 945-952. Doi: 10.1007/s11019-012-9427-3

Lombard, A. & Kruger, E. (2009). Older Persons: the Case of South Africa. *Ageing International*, 34, 119-135. Doi: 10.1007/s12126-009-9044-5

Lloyd-Sherlock, P., Beard, J., Minicuci, N., Ebrahim, S. & Chatterji, S. (2014). Hypertension among older adults in low-and middle-income countries: prevalence, awareness and control. *International Journal of Epidemiology*, 43(1), 116-128. Doi: 10.1093/ije/dyt215

Matzopoulos, R., Prinsloo, M., Pillay, M., van Wyk, V. et al. Injury-related mortality in South Africa: a retrospective descriptive study of post-mortem investigations. *Bull World Health Organ*, 93, 303-313.

Mojola, S.A., Williams, J., Angotti, N. & Gomez-Olive, F.X. 2015. HIV after 40 in rural South Africa: A life course approach to HIV vulnerability among middle aged and older adults. *Social Science & Medicine*, 143, 204-212. Doi.org/10.1016/j.socscimed.2015.08.023

Mommersteeg, G. Ethnographic encounters with elderly people and an interpreter. A fieldwork experience from Djenn Mali. *Southern African Journal of Gerontology*, 8(2), Doi: 10.21504/sajg.v8i2.170

Moodley, K. (2011). Respect for patient autonomy. In Moodley, K., (Ed.), *MEDICAL ETHICS, LAW AND HUMAN RIGHTS. A South African perspective*, (pp. 41-56). Pretoria: Van Schaik.

Mutemwa, M. & Adejumo, O. (2014). Health challenges of elderly people caring for children orphaned by AIDS in a community setting in South Africa. *African Journal for Physical, Health Education, Recreation and Dance*, (Supplement 1:2), 336-347. Retrieved from: <https://repository.uwc.ac.za/handle/10566/1430>

Naidoo, S. (2012). The South African national health insurance: a revolution in health-care delivery. *Journal of Public Health*, 34(1), 1149–150. Doi.org/10.1093/pubmed/fds008

Nordenfelt, L. 2004. The varieties of dignity. *Health Care Analysis*, 12, (2), 69–81.

Nyirenda, M., Chatterji, S., RoCHAT, T., Mutevedzi, P. & Newell, M-L. (2013). Prevalence and correlates of depression among HIV-infected and – affected older people in rural South Africa. *Journal of affective disorders*, 151(1), 31-38. Doi: 10.1016/j.jad.2013.05.005

Ogunmefun C, Gilbert L, Schatz E. (2011). Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. *Journal of Cross-Cultural Gerontology*, 26, 85–102.

Rand, S., Caiels, J., Collins, G. and Forder, J. (2017). Developing a proxy version of the Adult social care outcome toolkit (ASCOT). *Health and Quality of Life Outcomes*, 15, 108. DOI 10.1186/s12955-017-0682-0

Rook, K. S. (1990). Social relationships as a source of companionship: Implications for older adults' psychological well-being. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Wiley series on personality processes. Social support: An interactional view* (pp. 219-250). Oxford, England: John Wiley & Sons.

Rosenberg, A., Mabude, Z., Hartwig, K., Rooholamini, S., Tetteth, D.O. & Merson, M. (2005). Improving home-based care in Southern Africa: an analysis of project evaluation. *South African Journal of HIV Medicine*, 19, 30-36.

Schatz, E. & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health*, 10(10), 1185-1200. Doi: 10.1080/17441692.2015.1035664

South Africa. (2005). South African Policy for Older Persons. Department of Social Development: Pretoria.

Statistics South Africa. (2015). *Statistical release P0302. Mid-year population 2015*.

Strydom, H. (2008). The Future of Community-Based Services for Older Persons in South Africa. *Practice*, 20(2), 103-111. Doi: 10.1080/09503150802059002

Teka, A. & Adamek, M.A. (2014). "We prefer eating rather than greeting". Life in an elder care centre in Ethiopia. *Journal of Cross-Cultural Gerontology*, 29, 389-404. Doi: 10.1007/s10823-014-9244-7

Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1). Retrieved [14/11/2018] from http://ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf

Tomita, A. & Burns, J.K. (2013). Depression, disability and functional status among community-dwelling older adults in South Africa: evidence from the first South African National Income Dynamics Study. *International Journal of Geriatric. Psychiatry*, 28, 1270-1279. Doi: 10.1002/gpp.3945

Tronto, J. (1993). Moral boundaries: a political argument for an ethic of care. (In Lachman, V.D. 2012. Applying the ethics of care to your nursing practice. *MEDSURE Nursing*, 21(2), 112-116

Tronto, J. (1998) An ethic of care. *Generations*, 22 (3).

Tshesebe, M. & Strydom, H. (2016). AN EVALUATION OF THE COMMUNITY-BASED CARE AND SUPPORT SERVICES FOR OLDER PERSONS IN A SPECIFIC COMMUNITY. *Social Work/Maatskaplike Werk*, 52(1), 1-18. Doi:<http://dx.doi.org/10.15270/52-1-476>

United Nations, Department of Economic and Social Affairs, Population Division (2015). *World Population Ageing 2015* (ST/ESA/SER.A/390).

United Nations, Department of Economic and Social Affairs, Population Division (2017). *World Population Ageing 2017* (ST/ESA/SER.A/408).

Willis, R., Evandrou, M., Pathak, P. and Priya Khambhaita, P. (2016). Problems with measuring satisfaction with social care. *Health and Social Care in the Community*, 24(5), 587–59

Wolf, D.A., Freedman, V. & Soldo, B.J. (1997). The division of family labor: care for elderly parents. *The Journals of Gerontology*, 52B, 102-109

World Health Organization (2017). *Toward long-term care systems in sub-Saharan Africa: WGO series on long-term care*. Geneva: World Health Organization.

Yakabu, Y.A. & Schutte De Wet. (2018). Caregiver attributes and socio-demographic determinants of caregiving burden in selected low-income communities in Cape Town, South Africa. *Journal of Compassionate Health Care*, 5(3). Doi 10.1186/s40639-018-0046-6

Zimmer, Z. & Das, S. (2014). The Poorest of the Poor: Composition and Wealth of Older Person Households in Sub-Saharan Africa. *Research on Aging*, 36(3), 271-296. Doi: 10.1177/0164027513484589

CHAPTER 3: CONCLUSION

This chapter provides the conclusion, limitations and recommendations of this study. The review of the main conclusions is followed by a summary of the study's limitations, and, lastly, recommendations are made for future research.

The main aim of the study was to explore older adults' experiences of current formal community-based care services in Sebokeng. This exploration undertook to address the gap between the ideal of formal community care systems and delivery, and its effective implementation in practice. Secondly, the study was aimed at ascertaining what the older adults from this research group perceived as good care.

This qualitative study was conducted using the interpretive description (ID) strategy. Twenty participants (10 using home-based care services and 10 attending a community day care centre) from Sebokeng were interviewed, and the data was collected using in-depth interviews. The data was analysed by means of thematic analysis.

3.1 Concluding inferences

The conclusions drawn from the findings can be summarised on three levels: theoretical, policy-related, and programmatic.

3.1.1 Theoretical level

From the findings, the ethics of care approach emerged as a good heuristic framework for a deeper understanding of what good formal long-term care is. The responses of participants supported the four cyclical phases of good care as put forward by Fisher and Tronto (1990). Older adults indicated that they experienced good care when the caregiver paid attention to their spoken and especially unspoken needs (caring about); when care is organised and/or paid for them (caring for); when care is provided in a competent and professional manner (caregiving); and when caregivers responded to communication expressing satisfaction/dissatisfaction with the

care provided (care receiving). Within these cyclical phases, the following principles of good care were identified: access to infrastructure and resources; access to professional and competent care; attentiveness and responsiveness; companionship and dignity of choice.

Older people might find themselves in the situation of needing the assistance of others in meeting their needs, and, as a result, may have to change their sense of power in relations of care as they age (Tronto, 1998). Dignity and autonomy as principles of care confirm the argument of ethics of care, which is that power is an important issue in receiving care. Older adults are not powerless care receivers. Receiving care shouldn't place them at the mercy of a caregiver just because of the caregiver's perceived invulnerability. Caregiving must recognise the care receiver as the manager of the care situation and follow the direction of the care receiver (Black, 2005).

The complexity of care, as recognised by the ethics of care approach, is apparent from the findings of this study. Older adults are in need of care, but they also care for themselves, family members, and in some cases, even their neighbours. It is clear that care is needed across the entire lifespan, not only in old age, and therefore care for older adults cannot be viewed in isolation of the broader context of care (Tronto, 1998). Society's unwillingness to confront its own vulnerability is easily denied by identifying particular groups as especially vulnerable in order to strengthen the myth of our own invulnerable autonomy (Tronto, 1998).

Ethics of care also raises the moral question about equity in the provision of care to older adults (Tronto, 1998). Care resources are not equally distributed amongst the older population of South Africa. Neoliberalism (marketisation of public utilities and services) has infiltrated non-government and not-for-profit organisations, which are now expected to operate like businesses (Fraser *et al.*, 2017). By shifting care responsibilities from formal care to community care, care is relegated to those who lack economic and political power (Glenn, 2000:84 in Fraser *et al.*, 2017). The day care centre in this study is situated in a very poor community. They have to generate their own funds in order to meet the needs of the older

adults. The findings of this study illustrate that communities need support in providing much needed services. Responsibility for care should be shared by communities and government.

3.1.2 Care on policy level

The South African government proposes community-based services to address existing gaps in the long-term care of older adults (South African Policy for Older Persons, 2005). In exploring the experiences of participants living in resource-poor Sebokeng, the study found that formal community-based services fall short of meeting the care needs of older adults. Home-based care services are limited to monthly visits by health workers to distribute chronic medication, and do not provide social or instrumental services as described by the policy. Community day care services are inadequate in that they have to fund their services by being entrepreneurs, which is impossible, as they are situated in a community where members are poor and cannot contribute financially. This shift in care might be cost effective for government (Outcalt 2013, p. 88 in Fraser *et al.*, 2017) but shifting the cost to the impoverished older population of South Africa takes its toll on access and quality of essential long-term care.

To address these problems the WHO (2017) proposed general principles that apply to long-term care for older adults, and which should be considered in the drafting of new policies: long-term care must be affordable and accessible to poor and marginalised older adults; care must respect the self-choice of older adults, and should enable them to maintain their dignity; long-term care should enhance the intrinsic capacity of older adults; care should focus on the needs of the older adult as an individual; government must be responsible for providing and managing long-term care systems.

By adopting these principles, government can create a partnership with community-based initiatives in successfully meeting and managing the long-term care needs of older adults.

3.1.3 Care on a programmatic-practical level

Policy supports formal community-based care, but there are questions about the implementation and quality of the services provided by these programmes. Friedman (2010) reports that the national audit of home and formal community-based care found that about half of organisations did not receive any funding and that there was an overall lack of training for community caregivers as well as their managers. Organisations cannot render community services as they lack buildings, access to water, electricity, and computer equipment (Strydom, 2008; Friedman *et al.*, 2010). According to Bohman *et al.* (2011), a high number of black African older adults live in extreme poverty, resulting in inadequate and undignified living conditions. Lack of adequate diet and proper sanitation are but a few factors that contribute to the poor development of formal community-based services to older persons (Strydom, 2008). The study's findings support the limited available literature on community-based care in South Africa. There exists a gap between formal community care as advocated by policy and the effective implementation thereof in communities. Home-based care services aren't available in poorer areas and community day care centres are ill-equipped in meeting all the needs of older community members. It is clear that government must re-evaluate policy to ensure the successful inclusion of all older adults who require formal long-term care, and to provide much needed support in facilitating community programmes by providing funds and training in the provision of good quality care

3.2 Limitations of the study

During the beginning stages of this study, telephone listings showed that there was a relatively wide choice of formal community-based care centres providing home-based and day care services to older adults. However, this information was found to be outdated as many centres had already closed down due to mismanagement of funds, had shifted their services from older adults to children, and had discontinued day care services to become purely residential facilities. Formal long-term community-based care service providers seem to fall victim to unstable

conditions, which makes it difficult to get a more comprehensive picture of older adults' experiences of formal community-based long-term care.

In the area of Sebokeng, home-based care as defined by policy does not exist. The only home-based services delivered to older adults in this area are clinics that send health workers to deliver chronic medication and, occasionally, test sugar levels and measure blood pressure. This lack of home-based care services provides an incomplete picture of home-based care, and a satisfactory conclusion regarding these services remains elusive.

3.3 Recommendations

Following the conclusion of the study the following recommendations can be made:

3.3.1 Recommendations for future research

Limited literature exists on long-term care for older adults in South Africa. More research is needed to explore accessibility of long-term care options for older adults. As community-based care is the proposed solution to South Africa's long-term care deficiencies, it is vital for studies to focus on community-based care services for older adults and scrutinise legislation and policies that apply to these services. These studies should take place in urban as well as rural areas in order to get the full picture of the experiences of older adults across all geographies. Studies focussing on either home-based care services or day care will provide researchers with a deeper understanding of these services and the experiences thereof.

3.3.2 Recommendations for practice

From the results of this study it is clear that government needs to take an active role in providing and managing community long-term care services to older adults. Due to a lack of economic and political power, communities cannot meet the needs of their older population and will only be able to provide good quality care if they have infrastructure and access to financial resources in particular. Partnering with government will enable access to more resources and will

greatly improve care. For this to happen, policy makers will have to review the existing policy and make amendments so that the main responsibility of providing long-term care does not solely rest on the community and on families.

These findings on community care provide caregivers with the core principles of how to provide care to older adults, so that they will experience the care they receive as good. These principles of good care could enable caregivers and all long-term care stakeholders to provide older adults with good, dignified care and thus fulfilling the goal of facilitating quality of life.

3.4 Bibliography

Black, R.M. (2005). Intersections of care: An analysis of culturally competent care, client centered care, and the feminist ethic of care. *Women, Work and Culture*, 24(4), 409-422

Bohman, D.M., van Wyk, N.C., Ekman, S.-L. (2011). South Africans' experiences of being old and of care and caring in a transitional period. *International Journal of Older People Nursing*, 6, 187-195. Doi: 10.1111/j.1748-3743.2010.00225.x

Fisher, B. & Tronto, J. (1990). Toward a feminist theory of caring. (In Tronto, J. 2010. Creating caring institutions: politics, plurality and purpose. *Ethics and Social Welfare*, 4(2), 158-171. Doi: 10.1080/17496535.2010.484259)

Fraser, H., Taylor, N. & Morley, C. (2017). Critical social work and cross- species care: An intersectional perspective on ethics, principles and practices. In Pease, B. Vreugdenhill, A. & Stanford, S. (Eds.), *Critical Ethics of Care in Social Work : Transforming the Politics and Practices of Caring*, (pp. 229-240). London: Routledge.

Friedman, I., Mothibe, N., Ogunmetun, C. and Mbatha, T. (2010). A national audit of registered and unregistered home and community-based care (HCBC) organisations in South Africa. *Department of Social Development*

South Africa. (2005). South African Policy for Older Persons. *Department of Social Development*. Pretoria.

Strydom, H. (2008). The Future of Community-Based Services for Older Persons in South Africa. *Practice*, 20(2), 103-111. Doi: 10.1080/09503150802059002

Tronto, J. (1998) An ethic of care. *Generations*, 22(3).

World Health Organization (2017). *World Report on Ageing and Health*. Geneva: World Health 2017

ANNEXURE A: NARRATIVE SUMMARY OF PARTICIPANT INFORMATION

The study group consisted of twenty older adults: ten were reliant on home-based care services and ten attended the community day care centre. The age of the group ranged from old (63) to the oldest old (85). Gender was not presented equally, with 15 women and only 5 men participating in the study. All participants experienced poverty and were reliant on state pension. The two main non-communicable diseases reported by the majority of the group were diabetes and hypertension. Three of the five men were still married, with all the women being either widowed or unmarried. Only four participants lived on their own; the rest of the participants were living with their children or grandchildren or in multigenerational homes. Seven of the ten home-based care users lived in corrugated steel houses with the community day care centre also being a corrugated steel room. All but three older adults reported receiving care from their children or grandchildren. These three participants had family, but weren't on good terms with them. In all but one case, familial care was given by a female family member (granddaughter, daughter or daughter-in-law).

ANNEXURE B: INTERVIEW SCHEDULE

Interview schedule

Firstly the interviewer will ascertain whether the participant is still willing to be interviewed. The voice recorder is explained and permission is asked to use it. The interviewer introduces herself and the interpreter. The participant is given the option for the interview to be conducted in English or Setswana. Should Setswana be the preferred language for the interview, the interviewer will first ask the question in English and the interpreter will translate to Setswana and answers will be translated to English.

Introduction: The participant is asked about current health and well-being. The participant is asked whether he/she has any questions. The participant is reminded that he/she has the right to stop the interview should they feel too tired to continue. A 15 minute break and juice will be provided during the interview. He/she is thanked for his/her willingness to be part of the study.

Biographical information: Questions regarding age, living arrangements, marital status and the participant's economic situation will be asked to gather the participant's biographical information

Two in-depth questions will be asked, and each question will be supplemented with possible probing questions

Question 1: How do you experience the current care that you are receiving?

Probing questions:

- Are you receiving care from any organisation? (The term "care" will be fully explained. Should there still be some uncertainty, the term "help" will be used to clarify the question)
- Why do you make use of this organisation's care services?
- With which activities do they help you?
- How did you reach them to organise the care that you receive?
- Do they help you with everything you need?
- If no, with what would you like more help?
- What do you like about the person(s)/caregivers caring for you?
- What changes in the care you receive would make you feel better about the services?

Question 2: What, in your opinion, is good care?


Probing questions:

- Do you pay for the care you receive?
- Would you say it is good value for money? Why do you say yes/no?

- Do you feel that you would be better looked after if a family member or friend cared for you instead of a professional caregiver? If yes, why?

The interview ends with the researcher asking the participant if he/she has any questions. The participant is thanked for taking part in the study.

ANNEXURE C: INFORMED CONSENT FORM



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS

Health Research Ethics Committee
Faculty of Health Sciences
NORTH-WEST University
(Potchefstroom Campus)

2017 -07- 17

HREC Stamp

INFORMED CONSENT DOCUMENTATION FOR: _____

TITLE OF THE RESEARCH STUDY: Older adults' experiences of formal community-based care services in Sebokeng- implications for long-term care management

ETHICS REFERENCE NUMBERS:

PRINCIPAL INVESTIGATOR: Prof. JR Hoffman

POST GRADUATE STUDENT: M Rankin

ADDRESS: 27 Walter Sisulu Street, Potchefstroom

CONTACT NUMBER: 0761573745

You are being invited to take part in my research project on older adults' experiences of formal community-based care services in Sebokeng. This study forms part of the researcher's Masters degree in Gerontology. Please take some time to read this document, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. Should you withdraw from the study, the data you provided will immediately be destroyed

This study has been approved by the **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU-00055-17-S1)** and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international

HREC General WICF Version July 2018 Page 1 of 5

ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

What is this research study all about?

- *This study will be conducted in Sebokeng and will involve in-depth interviews. The researchers have received in practice training from her supervisor to conduct in-depth interviews.*
- *Approximately 20 participants will be included in this study, but this could change depending on how long it takes to get a full answer to the research question.*
- *We plan to explore older adults' experiences of current formal community-based care services in Sebokeng and to see whether these services you receive are of good quality.*

Why have you been invited to participate?

- *You have been invited to participate because Age in Action identified you as a user of home-based care/day care services.*
- *You have also complied with the following inclusion criteria:*
 - *60 years or older*
 - *Residing in Sebokeng*
 - *Speak English/Setswana/Afrikaans*
- *You will be expected to participate in interviews sharing how you experience the care that you currently receive from your care provider. You will also be asked about what your idea of good care is. Interviews will be about 45 minutes, but should you feel tired or unable to continue, interviews will take place in the form of two or three shorter interviews and will continue at a time you find convenient*

Will you gain anything from taking part in this research?

- *The gains for you if you take part in this study will be that you will be able to share your experiences with someone without it negatively influencing your care.*
- *The other gains of the study is for care stakeholders who will be made aware of the situations and that they could bring about positive change, should it be necessary*

Are there risks involved in you taking part in this research and what will be done to prevent them?

- *The risks to you in this study are that you may become tired during interviews but will be limited by stopping the interview for a 15 minute break, and provide you with some juice. Should you feel unable to continue, a second session will be scheduled for a time that is convenient for you*
- *The researcher will ask you questions about services or caregivers that could have caused you pain or negative feelings, and this may make you feel sad or uncomfortable but The researcher has information of helpers from Age in Action who will provide you with help in dealing with any negative feelings. I will immediately call the social worker should you feel distressed and will facilitate a counselling session*

- *There are more gains for you in joining this study than there are risks.*

How will we protect your confidentiality and who will see your findings?

- *Anonymity (that is, in no way will your results be linked to your identity) will be ensured by not allowing access to your personal information and not mentioning your identity in the study. Confidentiality (that is, I/we assure you that we will protect the information we have about you) will be ensured by not sharing it with any parties not part of the research. Reporting of findings will be anonymous by not mentioning your name or any personal information.*
- *Data will only be kept in electronic format. Only the researchers, supervisors and the AUTHeR office will have access to data. Data will be kept safe and secure in the researcher's office and will be password protected.*
- *Audio-recorded data will be transcribed by the researcher. As soon as data has been transcribed it will be deleted from the recorders. The transcripts will be stored on a password-protected computer. All co-coders will sign a confidentiality agreement.*
- *Data will be stored for 5 years at an office at the NWU.*

What will happen with the findings or samples?

- *The findings of this study will only be used for this study.*

How will you know about the results of this research?

- *We will give you the results of this research when the study has been completed at a time and place convenient for you.*

Will you be paid to take part in this study and are there any costs for you?

This study is not funded, the researcher will use her bursary to conduct this study. No, you will not be paid to take part in the study because there are no costs involved for you, if you take part in this study. Refreshments will be served during breaks in the interviews.

Is there anything else that you should know or do?

- *You can contact Maryna at 0761573745 if you have any further questions or have any problems.*
- *You can also contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 or carolien.vanzyl@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.*
- *You will receive a copy of this information and consent form for your own purposes.*

Declaration by participant

By signing below, I agree to take part in the research study titled: Older adults' experiences of formal community-based care services in Sebokeng- implications for long-term care management

I declare that:

- I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.
- The research was clearly explained to me.
- I have had a chance to ask questions to both the person getting the consent from me, as well as the researcher and all my questions have been answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be handled in a negative way if I do so.
- I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.

Signed at (place) on (date) 20....

.....
Signature of participant

.....
Signature of witness

Declaration by person obtaining consent

I (name) declare that:

- I clearly and in detail explained the information in this document to
.....
- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (place) on (date) 20....

.....
Signature of person obtaining consent

.....
Signature of witness

Declaration by researcher

I (name) declare that:

- I explained the information in this document to
or I had it explained by who I trained for this purpose.
- I did/did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them
or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (place) on (date) 20....

.....
Signature of researcher

.....
Signature of witness

ANNEXURE D: APPROVED ETHICS CERTIFICATE



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Private Bag X6001, Potchefstroom,
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Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Institutional Research Ethics Regulatory Committee

Tel: +27 18 299 4849

Email: Ethics@nwu.ac.za

ETHICS APPROVAL CERTIFICATE OF STUDY

Based on approval by Health Research Ethics Committee (HREC) on 21/07/2017 after being reviewed at the meeting held on 17/05/2017, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your study as indicated below. This implies that the NWU-IRERC grants its permission that provided the special conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Older adults' experiences of formal community-based care services in Sebokeng – implications for long-term care management.																																											
Study Leader/Supervisor:	Prof JR Hoffman																																										
Student:	M Rankin-24845655																																										
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>0</td><td>5</td><td>5</td><td>-</td><td>1</td><td>7</td><td>-</td><td>A</td><td>1</td></tr><tr><td colspan="3">Institution</td><td colspan="3">Study Number</td><td colspan="3">Year</td><td colspan="3">Status</td></tr><tr><td colspan="15"><small>Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</small></td></tr></table>	N	W	U	-	0	0	0	5	5	-	1	7	-	A	1	Institution			Study Number			Year			Status			<small>Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation</small>														
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Application Type: Single Study																																											
Commencement date: 2017-07-21																																											
Risk: Medium																																											
Continuation of the study is dependent on receipt of the annual (or as otherwise stipulated) monitoring report and the concomitant issuing of a letter of continuation.																																											

Special conditions of the approval (if applicable):

- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The study leader (principle investigator) must report in the prescribed format to the NWU-IRERC via HREC:
 - annually (or as otherwise requested) on the monitoring of the study, and upon completion of the study
 - without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.
- Annually a number of studies may be randomly selected for an external audit.
- The approval applies strictly to the proposal as stipulated in the application form. Would any changes to the proposal be deemed necessary during the course of the study, the study leader must apply for approval of these amendments at the HREC, prior to implementation. Would there be deviation from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the study may be started.
- In the interest of ethical responsibility the NWU-IRERC and HREC retains the right to:
 - request access to any information or data at any time during the course or after completion of the study;
 - to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.
 - withdraw or postpone approval if:
 - any unethical principles or practices of the study are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the HREC or that information has been false or misrepresented,
 - the required amendments, annual (or otherwise stipulated) report and reporting of adverse events or incidents was not done in a timely manner and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.
- HREC can be contacted for further information or any report templates via Ethics-HRECApp@nwu.ac.za or 018 299 1206.

The IRERC would like to remain at your service as scientist and researcher, and wishes you well with your study. Please do not hesitate to contact the IRERC or HREC for any further enquiries or requests for assistance.

Yours sincerely

Prof LA
Du Plessis

Digitally signed by
Prof LA Du Plessis
Date: 2017.08.05
11:31:35 +02'00'

Prof Linda du Plessis

Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)

ANNEXURE E: INTENDED JOURNAL AND INSTRUCTIONS FOR AUTHORS

The article from this mini-dissertation will be submitted to the International Journal of Care and Caring for possible publication.

Instructions for authors

“Research articles should be between 4000 and 8000 words long with up to 4 key words and an abstract of up to 100 words. These submissions will be double-blind peer reviewed. Research articles should contribute to advances in knowledge, theory or methods. Articles based on comparative international analysis, critical analysis of policy or practice, or which explore care and caring in global or transnational perspective are encouraged. Authors should indicate if their article presents new empirical findings or is based on methodological innovation and should write in a style suitable for IJCC’s academic, NGO, policy and practitioner audiences.

Style

1. British English spelling and punctuation is preferred.
2. Non-discriminatory language is mandatory.
3. Explanatory notes should be kept to a minimum. If it is necessary to use them, they must be numbered consecutively in the text and listed at the end of the article. Please do not embed notes in the text.
4. Do not embed bibliographic references in the text, footnotes, live links or macros; the final submitted file should be clear of track changes and ready for print.
5. Tables and charts should be separated from the text and submitted in a Word or Excel file, with their placement in the text clearly indicated by inserting: ‘Table X here’. Please provide numbers, titles and sources (where appropriate).

6. Figures, diagrams and maps should be separated from the text and, ideally, submitted in an
7. Encapsulated PostScript (.eps) file. Figures created in Word or Excel are acceptable in those file formats. If the figures, diagrams and maps are in other formats (i.e. have been pasted into a Word file rather than created in it) please contact dave.j.worth@bristol.ac.uk for advice. Please indicate where figures should be placed in the text, by inserting: 'Figure X here' and provide numbers, titles and sources (where appropriate).

References

1. A custom version of the Harvard system of referencing is used:
2. In-text citations: give the author's surname followed by year of publication in brackets, and where there are three or more authors, use 'et al'.
3. List all references in full at the end of the article and remove any references not cited in the text
4. Book and journal titles should be in italics
5. Website details should be placed at the end of the reference. Do not include dates of access to websites
6. Spell out all acronyms in first instance."

ANNEXURE F: GATEKEEPER PERMISSION LETTER



NPO Number
170-335

24 April 2017

Subject: Endorsement of proposed research study by Ms Maryna Rankin: "Older adults' experiences of formal community-based care services in Sebokeng- Implications for long-term care management"

To whom this may concern at North West University's Research Ethics Committee

Age-in-Action is a NGO working with and for older people in South Africa. Ensuring older adults have access to long-term social and health care is one of our key priorities. We are therefore excited to be part of Ms Rankin's research on the long term care needs of older persons in Sebokeng.

The Gauteng office of Age-in-Action has discussed this research with Professor Jaco Hoffman over the course of several months and we are pleased to support the research by linking the researchers with our satellite office in Vanderbijlpark so that they can assist them.

Yours faithfully

Jubilee Matlou
Gauteng Provincial Director

Professional Council Registration number: 10-17483

AGE - IN - ACTION
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