DEVELOPING STRATEGIES TO IMPROVE SUPPORT FOR GRANDPARENTS CARING FOR AIDS ORPHANS IN THE WESTERN CAPE PROVINCE

University of the Western Cape

Furaha Akimanimpaye

Student Number: 2414761

A thesis submitted in fulfilment of the requirements for the degree Philosophiae Doctor in Nursing in the Faculty of Community and Health Sciences, University of the Western Cape

Supervisor: Prof. Deliwe René Phetlhu

Co-supervisor: Dr Million Bimerew

2021

Abstract

Literature evidence on challenges facing the grandparents caring for AIDS orphaned children has shown inaccessibility to health care services, inability to afford basic needs, absence of social security provisions (with the exception of the pension scheme) and lack of attention from the government and Non-Government Organizations (NGOs). In South Africa, there is insufficient documented evidence of available sustainable approaches to supporting grandparents caring for AIDS orphans in all health dimensions. This study aimed to develop strategies to improve support for grandparents caring for AIDS orphans in the Western Cape Province of South Africa.

A multi-method approach was employed in Phase One of the study using both quantitative and qualitative designs. Semi-structured interviews were used to collect the qualitative data. Thematic analysis was used to analyse the qualitative data using the application of the ATLAS.ti. 7 package.

A structured checklist and an audit were used to collect quantitative data. The quantitative data was analysed using the Statistical Package for Social Science (SPSS) Version 25. The findings for both qualitative and quantitative data were triangulated during the data interpretation stage, hence permitting the researcher to compare and contrast the findings and develop strategies in Phase Two of the study. Trustworthiness of the qualitative data was ensured as well as validity and reliability for the quantitative set of data.

Phase Two of the study involved the development of strategies to improve support given to grandparents caring for AIDS orphans using the Delphi method. To ensure that the study was undertaken ethically, permission was sought from all relevant authorities. The study was explained to the potential participants and consent forms signed by those who volunteered to participate. The principles of respect for person, beneficence and non-maleficence, justice, as well as confidentiality and data protection were adhered to.

KEYWORDS: Grandparents; Support; Strategies; Orphan; Government, HIV and AIDS

Declaration

I, Furaha Akimanimpaye declare that the research entitled "**Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape Province**" is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources used or quoted have been indicated and acknowledged as complete references.

Name: Furaha Akimanimpaye Date: 12 July 2021

DEDICATION

In loving memory of my late parents; You envisioned my potential early and demonstrated complete confidence in my ability to shine in my formative years. I will forever be grateful.

To Issa Boubou and all my siblings who left me early; You all have been a source of inspiration to study further, may your souls continue to rest in eternal peace.

To all grandparents doing a great job of raising AIDS orphans, and all people affected by HIV and AIDS pandemic.

ACKNOWLEDGEMENT

Firstly, I am grateful to the Almighty Allah, the Most Gracious, the Most Merciful, for His trustworthy guidance and strength bestowed upon me through this endeavour.

I am also indebted to my supervisor Prof Deliwe R Phetlhu, and the co-supervisor Dr Million for their persistent advice and guidance throughout the research.

My deepest gratitude goes to all grandparents caring for AIDS orphans who took part in the study despite their challenging situations.

I also extend my sincere gratitude to all multidisciplinary health workers and all social services personnel who participated in my study despite their tight schedules. And work pressure.

My gratitude goes to all NGO managers who made it easy for me to access grandparents in their perspective areas and use your offices. May God Bless the incredible work that you are doing for the community.

I want to thank all my research assistants, who have been there with me in different locations; you have been my source of strength.

My fond appreciation goes to my husband and my children for being patient and supportive and sustaining prayers for my success.

My sincere gratitude goes to my colleagues for their understanding and continuous support.

Finally, special thanks go to my friends for their understanding when I had to miss numerous important gatherings to focus on the dissertation.

I would also like to thank Whafieka Martin who has assisted me with the editing of the thesis.

CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

LIST OF ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome

ANSI: The American National Standards Institute

ART: Antiretroviral Therapy

ARVs: Antiretroviral drugs

ASQ: American Society of Quality

CS: Conclusions statements

CWD: Catholic Welfare and Development CWD

GAPA: Grandmothers Against Poverty and AIDS

GPCFAO: Grandparents caring for AIDS orphans

HIV: Human Immunodeficiency

MDT: Multidisciplinary Team

MUSA: The South African Red Cross Society and the Muthande Society for the Aged

NGO: Non-Government Organizations

NOAH: Neighbourhood Old Age Homes

NPO: Non-Profit Organization

PPE: Personal Protective Equipment

SAOPF: The South African Older Persons' Forum

TQM: Total Quality Management

UNICEF: The United Nations Children Fund

WHO: World Health Organization

1 CHAPTER ONE: ORIENTATION TO THE STUDY

1.1 Introduction

AIDS is amongst the leading causes of death globally (Mahy, Marsh, Sabin, Wanyeki, Daher, & Ghys, 2019). The prevalence of HIV is highest in sub-Saharan countries, with South Africa carrying a burden of 7.9 million people living with HIV (SA stats, 2019). One of the dire consequences of the HIV epidemic is that young people are dying and leaving behind older people to care for their children with limited resources, impacting their economic, social, physical, and psychological health (Osafo, Knizek, Mugisha, & Kinyanda, 2017; Mtshali, 2016). The burden is further exacerbated by the fact that older people themselves may have developed care needs from the ageing process, which could be associated with the lack of formal and informal support (Dolbin-MacNab & Yancura, 2018).

In response to the needs and rights of AIDS orphans in the world and South Africa, support systems have shifted from its initial focus of orphanages to foster families as primary caretakers of AIDS orphans (Kidman & Heyman, 2016). However, most research conducted on this topic argues that caring for AIDS-orphaned children adds severe strain on caregivers and households due to higher dependency burdens (Tanyi, Pelser, & Okeibunor, 2018; Kalomo, Lee, Lightfoot, & Freeman, 2018; Block, 2018). Caring for a dependent child encompasses various undertakings, including attending to their medical, financial, and emotional needs. AIDS orphans often have special needs that intensify the caregiving; they are more likely to be leaving with HIV, experience bereavement and AIDS-related stigma, and have emotional and behavioural problems (Block,

2018; Schatz, Seeley, & Zalwango, 2018; Kalomo, & Besthorn, 2018). The situation can worsen when caregivers are grandparents who, in most cases, are in their twilight years.

In South Africa, although the prevalence of HIV is low amongst older persons compared to the working-class population (SA statistic, 2019), their homes, physical, mental and social wellbeing are being affected by the increased AIDS-related morbidity and mortality in their family (Hlongwane & Madiba, 2020; UNAIDS, 2019). This is caused by the increased morbidity and mortality rates of AIDS-associated illnesses amongst the younger generation, leaving older people to provide care to the orphans left behind instead of being cared for themselves (Bartlett, 2019; Niehaus, 2017). The high HIV epidemic in South Africa contributes to the continued rise in the number of AIDS orphans in communities, prompting the country to be counted amongst the world's highest burdened countries (Bartlett, 2019).

Empirical evidence shows that grandparents are becoming the primary bearers of the burden of caring for those living with and affected by HIV, making them the most suitable primary caretakers of orphaned grandchildren (Osafo *et al*., 2017; Matovu, Rankin & Wallhagen, 2020). Besides, raising grandchildren on a full-time basis is expected from most grandparents after the death of their children. However, grandparents are not afforded the time to adjust to this transition and to deal with their own emotions due to their loss before assuming the role of caregiver leading to emotional strain (Matovu & Wallhagen, 2020).

The literature shows that caregiving duties add pressure to grandparents already overburdened with emotional, physical, nutritional stresses, limited resources, and limited support (Bartlett,

2019; Matovu & Wallhagen, 2020; Kalomo, & Taukeni, 2020). Furthermore, caregiving responsibilities increase tension to their general wellbeing, thus triggering a growing need to improve the support given to them in their caring responsibilities. To this end, governments and Non-Government Organizations (NGO's) seek to strengthen the existing commitments and create a supportive environment for the affected orphans. Hence, the government developed a social assistance system that includes several social grants aimed at supporting households in caring for AIDS orphans and foster families (Kidman & Heymann, 2016).

The current policy (The Children's Act 38 of 2005) has harsh eligibility requirements placed on foster grants that limit grandparents to benefit as foster parents. Instead, they are considered natural parents who possess the duty of supporting and caring for orphans following the death of their parents. The above problem is embedded in the legal obligation for a grandparent as a sole parent after the death of their child (Children's Act 38 of 2005; Chinyoka, 2018). According to the Children's right policy, a primary caregiver is a person who has formal or informal parental responsibility or rights to care for AIDS orphans and who exercises that responsibility and right (Basson, 2017).

The South African government places stricter judgment and more explicit boundaries regarding which relatives are eligible to receive state support to provide care to children through the foster care system. For a child to be eligible to receive a foster care grant, the child's caregivers do not have to be a legal "duty of support" to the child at the time of the application (Saldulker, 2012). According to the judgement, biological parents and siblings have a lawful/legal duty of support, whereas, adoptive parents only have to assist a child when the adoption process is concluded.

Both maternal and paternal grandparents have a standard law duty to supporting their grandchildren, but aunts and uncles bear no obligation of supporting their nieces and nephews (Chinyoka, 2018).

Therefore, when the AIDS orphan is living with the grandparent, then the grandparent is not eligible for the Foster care grant (FCG). However, the above judgement is softened upon submission of relevant documents (birth certificate and ID), and providing evidence of inability to support the grandchild, even with the child support grant (Hall; Skelton & Sibanda, 2016).

During the 2020 budget speech, the Finance Minister confirmed that foster families would be provided with the foster grant of R1040,00 per month, which will be paid out until the child turns 18 years old. If the child is living with a disability, the foster family can get an additional care dependency grant of R1860, 00. This is in spite of the fact that these foster parents are often at the age where they are economically active and gainfully employed. In contrast, grandparents caring for AIDS orphans only qualify to receive the child support grant of R445 and not a foster grant. Hence, the grandparents' old age pension money of R1860,00 per month (Budget speech, 2020) intended for their well-being is channelled to care for their grandchildren as the child support grant is little compared to the foster grant (Dunham & Flores-Yeffal, 2019; Block, 2018). The situation is made worse when the grandparent(s) caring for an AIDS orphan is under the age of 60 and unemployed, as they will only qualify for the child grant and not the pension grant (Mtshali, 2016).

Grandparents may be eligible for the child support grant; still, it may be difficult to qualify due to failure to supply the required documentation, which may not be readily available if they are not

registered with the Department of Home Affairs (Kadungure, 2017; Mashau & Tugli, 2019). Despite efforts from the government to reinforce and support the capacity of families caring for AIDS orphans, it is argued that grandparents caring for AIDS orphans experience complicated administrative procedures, which make it difficult for them to access social grants allocated to foster families (Breckenridge, Black-Hughes, Rautenbach & McKinley, 2019). According to Mzimela (2019), there is evidence that grandparents attempt to gain access to services provided by the government and NGO's. However, injudicious beliefs and attitudes stated above serve to exclude older people from developmental programmes that could help them and the children they support. Therefore, this implicates their health heavily, causing long term complications on their quality of health (Kalomo & Liao, 2018).

In South Africa, most grandparents caring for AIDS orphans live in township communities. They make use of primary health care professional nurses who are employed by the Department of Health, and social workers as well as psychologists who are employed by the department of social development. These professionals are referred to as a Multidisciplinary team in this study. They can identify the support needs of the grandparents and provide recommendations to improve the care and support of these grandparents, which will be presented in this study.

Since it is crucial for the grandparents to have a good quality of health, the researcher investigated their experiences while caring for AIDS orphans, their necessities, and how they handle the challenges of caring for these orphans. Consequently, the researcher explored the biophysical, psychological, physical, environmental, and sociocultural impacts on grandparents caring for AIDS orphans in the Western Cape Province.

1.2 Research problem

Grandparents are often the primary caregivers of AIDS orphans, and they face various challenges while providing care to these children. Such challenges usually include physical (such as body pains and backache), socio-cultural (such as stigma and discrimination), psychological (such as anxiety and depression, stress and feeling of inferiority), physical environment (lack of houses) and inadequate financial resources to meet the orphans' needs (Kalomo & Liao, 2018). It is common for grandparents to hide the presence of the disease in their household for fear of stigmatization, discrimination, and isolation in the community; in so doing, they give up the opportunities to receive support from the community. Grandparents caring for AIDS orphans are often unable to continue to engage in income generation activities to support themselves and their household, because of their advancing age, age discrimination in the workplace, and their care responsibilities (Oduaran & Oduaran, 2018; United Nations, 2016).

A general lack of resources, stress related to caregiving and support for orphaned grandchildren are major concerns to older caregivers (United Nations Programme on HIV and AIDS [UNAIDS], 2015). Government policies and programmes designed and implemented to mitigate the effects of HIV and AIDS have thus far focused on young people of reproductive age and have not addressed the needs of grandparents caring for AIDS orphans (Kalomo & Liao, 2018). Grandparents are neither targeted in awareness programmes nor supported in their caregiving responsibilities; in short, they are ill-equipped to cope with the burden of care in general (Fauk, Mwakinyali, Putra & Mwanri, 2017). In South Africa, there is insufficient empirical evidence to inform a sustainable approach that support grandparents caring for AIDS orphans holistically (biophysical, socio-

cultural, psychological, physical environment, and health system) despite the efforts made by some researchers worldwide and in South Africa (Mtshali, 2016).

Hence, there is a need to systematically explore the experiences of grandparents caring for AIDS orphans regarding their needs, challenges, and coping mechanisms. Although a support structure has been put in place to foster care, it is not accessible to all grandparents who often experience complicated administrative processes and are seen as natural parents who do not qualify for the child foster care grant. To this end, there are no strategies available to support grandparents in their role as primary caregivers.

1.3 Purpose of the study

The study aims to develop strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province of South Africa.

1.4 Objectives of the study

The objectives of this study were as follows:

i. Objective One: To explore the experiences of grandparents caring for AIDS orphans in Western Cape Province of South Africa;
ii. Objective Two: To determine the available support (in terms of biophysical, psychological, social-economic, environmental, and health services) for grandparents caring for AIDS orphans in Western Cape Province of South Africa;
iii. Objective Three: To determine the grandparents' perception of the availability of support given to them in Western Cape Province of South Africa;

iv. Objective Four: To compare the grandparents' perceptions of available support with the available support for grandparents caring for AIDS orphans in Western Cape Province of South Africa; and

v. Objective Five: To develop strategies to improve the support given to grandparents caring for AIDS orphans in Western Cape Province of South Africa.

1.5 Research questions

Based on the above, the following research questions were used in this study:

a) **RQ1:** What are the experiences of grandparents caring for AIDS orphans in Western Cape Province of South Africa?

b) **RQ2:** What are the available support (in terms of biophysical, psychological, social-economic, environmental, and health services) for grandparents caring for AIDS orphans in Western Cape Province of South Africa?

c) **RQ3**: What are the grandparents' perceptions of the availability of support given to them in the Western Cape Province of South Africa?

d) **RQ4:** What are the grandparents' perceptions of the availability of support with the available support for grandparents caring for AIDS orphans in Western Cape Province of South Africa?

e) **RQ5**: How can strategies improve the support given to grandparents caring for AIDS orphans in Western Cape Province of South Africa be developed?

1.6 Significance of the study

The significance of this study is outlined in four parts:

a) In terms of the evidence, it would highlight the central and crucial role played by grandparents caring for AIDS orphans in South Africa in the care management of the HIV and AIDS epidemic, and a need to support grandparents caring for AIDS orphans comprehensively.

b) The significance of the study to the Primary health care (PHC) system in terms of coordinating responses to grandparents 'situation and needs at a PHC level; the study would have significance for public health care delivery at a community and household levels.

c) The results of this study has potential to assist in appropriate policy development and implementation.

d) The significance of the study in terms of the research in the subject area, the parts are explained below:

1.7 Contribution of the study

The findings of the study would provide the following:

a) Provide relevant information to developed strategies that would promote and guide collaboration among stakeholders between non-profit organizations or non-Government Organizations (NGOs), Community-based Organizations (CBOs), and government structures to improve the support given to grandparents caring for AIDS orphans.

b) The study findings and the developed strategies may be further used by stakeholders to encourage lobbying of government ministries to mainstream the support needs of grandparents caring for AIDS orphans in their programs and policies and to close gaps in

existing policies, hence develop a robust policy that addresses the needs of grandparents caring for AIDS orphans.

c) The findings of this study can contribute to community nursing practice at PHC level by introducing support systems to grandparents caring for AIDS orphans such as providing proper health assessment, relevant information regarding the care of grandchildren living with HIV, the treatment and management of HIV and initiating proper referral systems to other members of the multidisciplinary team (MDT) when the need arises.

d) The study's findings can also contribute to the research by providing baseline data for other researchers to broaden the strategies further than the Western Cape Province. The researcher will make recommendations in the dissertation, based on the study outcomes and how the role and contribution of grandparents in the management of AIDS orphans may be acknowledged and strengthened.

1.8 Conceptual framework

A conceptual framework refers to the analytical structure that directs a research study. It gives a brief description of the theory, or aspect of a theory to be verified by a research project (Bryman, 2017). Further, a conceptual framework describes the basic structure of thoughts within which a research study is conducted, and the results understood (Creswell, 2014). This study adopted two frameworks, one in each phase of the study. The dimensions model of community health nursing which is a revision of the previously titled epidemiologic prevention process model (EPPM; Clark, 2003) in Phase One and the TQM philosophy by Tenner and De Toro (1992) in Phase Two.

1.8.1 The Dimensions Model of Community Health Nursing

Clark's (2008) dimensions model of community health nursing is designed for community health. This model is a revision of the previously titled Epidemiologic prevention (EPP) Model. The model was developed to guide community health nursing practice and research. The model incorporates the nursing process and the level of preventions as well as an epidemiologic perspective on the factors influencing health and illness. The model also includes public health perspectives and directs assessment of health needs, planning, implementation, and evaluation of health care services at primary, secondary, and tertiary levels of prevention.

The framework guided the process of examining the currently available support for grandparents in the Western Cape and identifying the challenges they experienced in their everyday life. All information obtained provided the baseline data for developing holistic packaged strategies applicable to grandparents caring for AIDS orphans. The application of the framework is used in Phase One of the study, attempting to ascertain the wellness of grandparents in order for the researcher to develop strategies that apply to them aimed at improving their holistic health and during the evaluation of the strategies. Figure 1 illustrates the different dimensions of the conceptual framework that guided Phase One of the study.

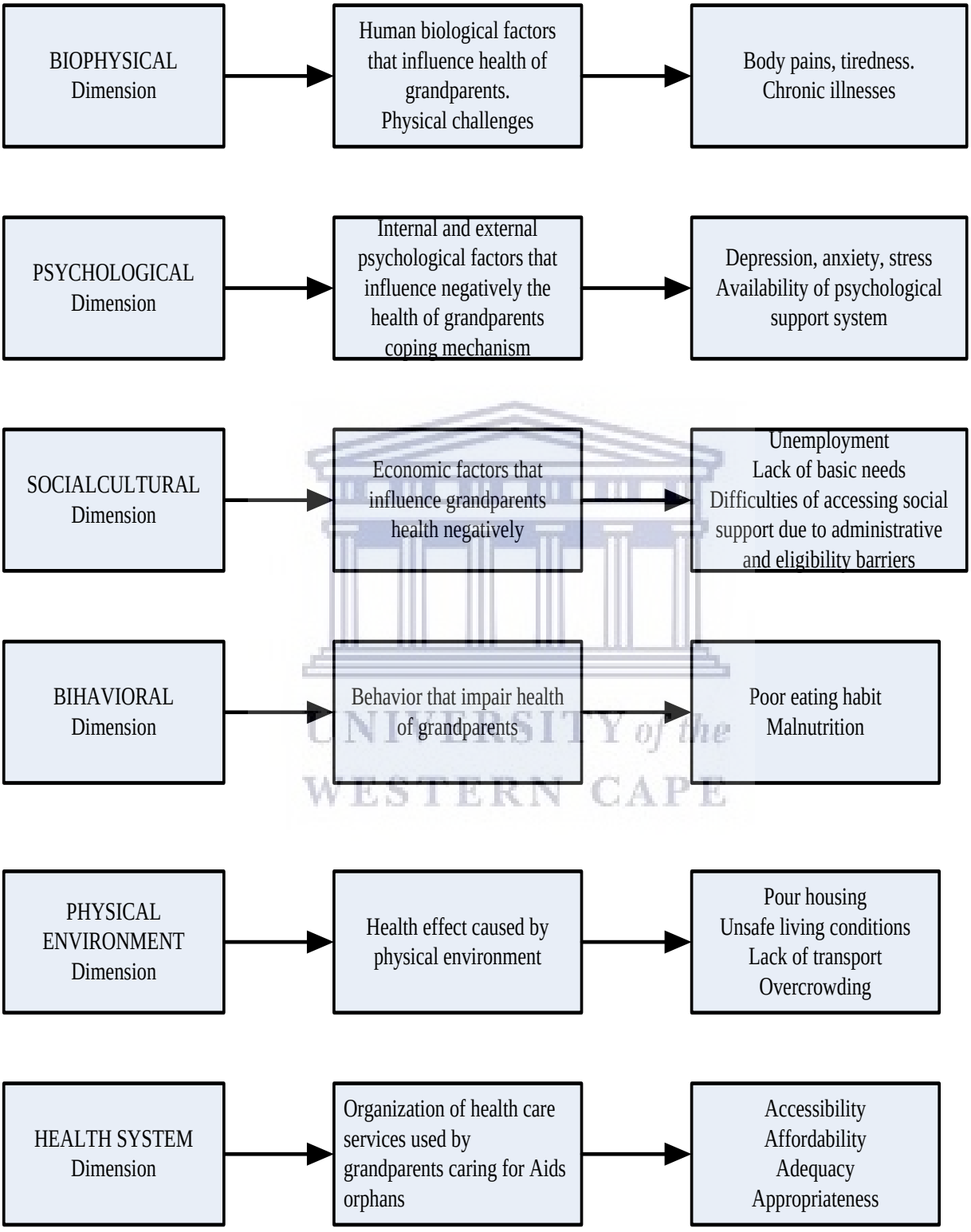


Figure 3 The dimensions model of community health nursing

1.8.2 Application of the Dimensions Model of Community Health Nursing

In this study, the model was used to assess the health status and support needs of grandparents caring for AIDS orphans, and also guided in planning the holistic interventions to meet those needs. The model indicates that underlying factors in each of the six dimensions of the model (biophysical, psychological, physical/environmental, behavioural, socio-cultural, and health services) contribute to the health support needs for grandparents caring for AIDS orphans. This model acknowledged the interaction of multiple factors in grandparent's health and illness and guided in planning that these support needs are considered when their optimum well-being is envisaged. Follows is a discussion of the application of the model.

1.8.2.1 Biophysical Dimension

This dimension includes aspects related to human biological factors that influence health. These factors may be related to age, developmental level and physiological functions. The physical status of grandparents affects the functioning of the family, and also the way members relate to one another (Clark, 2008); hence the Assessment begins with the gathering of data to identify the physical needs of the grandparents caring for AIDS orphans. Knowledge of the age, sex and race of family members as well as information related to genetic inheritance can help with the identification of health problems and the planning of grandparents caring for AIDS orphans.

1.8.2.2 Psychological Dimension

The psychological dimension encompasses the health effect of both internal and external psychological environment such as depression and the extent of coping behaviours.

The assessment includes communication patters, family emotional strengths and coping strategies.

a. **Communication Patterns** refers to communication being assessed in terms of both content and process to ascertain the grandparent's emotions and the way in which they communicate with the family and the rest of the community. A positive self-image of grandparents caring for AIDS orphans is the result of daily interactions that boost their feeling of self-worth. The self-esteem of grandparents can be assessed by observing non-verbal behaviour as well as communication patterns with others.

b) **Family emotional strengths** is assessed through the identification of the relationship of the direct family members and identification of the rest of the community as family and community supportive mechanism. Evidence of family cohesion and the degree of sensitivity to others should be observed, for example the degree to which family members support and praise each other.

c) **Coping strategies** are used by grandparents caring for AIDS orphans as behaviours that help them adapt to stress or change; they are characterised by positive problem-solving methods that prevent or resolve crises, they are described as external or internal coping strategies (Clark, 2008). Internal coping strategies rely on resources within the family such as role flexibility, joint problem solving and the interpretation of stressful conditions, whereas external strategies rely on outside help to meet its demands such as seeking information, maintaining community linkages, and seeking spiritual or social support. Defence mechanisms also can be used as a coping strategy and include tactics for avoiding

recognition of problems, denial, isolation, and projection. Defence mechanisms are not considered problematic unless they interfere with coping (Clark, 2008).

1.8.2.3 *Sociocultural Dimension*

The sociocultural dimension consists of those factors within the social environment that influence the health of the grandparents caring for AIDS orphans either positively or negatively and include elements of the social structures such as the roles of the family members, religion, economic status, employment, external resources, and relational support systems. A discussion of these are provided below.

a. **Roles of the family members**: Roles are the social expected behaviour patterns determined by a person's position or status in the family or society (Clark, 2008). In the society, people fulfil certain roles, such as professional roles (teachers, doctors, nurses, etc.) whereas in the family structure, the roles include those of breadwinner. The presence or absence of these roles, should be assessed and their influence on the health of the grandparents caring for AIDS orphans should also be determined. The roles overload should also be assessed and this occurs when grandparents caring for AIDS orphans assume multiple roles and are confronted with too many role expectations at the same time, which may influence their health negatively.

b) **Religion**: Religious beliefs and practices should be assessed as they can have an important influence on the health of the grandparents caring for AIDS orphans. Strong religious

practices may, for example, provide a source of emotional support in times of crisis (Clark, 2008).

c) **Culture**: Information regarding cultural practices is an invaluable aid in the building of relationships and planning of family interventions. Principles of cultural assessment would include viewing all cultures in the context in which they are developed; examining underlying premises for culturally determined beliefs and behaviours, interpretation of the meaning and purpose of behaviour in the context of a specific culture, and recognition of the potential intra-cultural variation.

d) **Social class and economic status**: Social class and economic status can profoundly affect the health of grandparents caring for AIDS orphan. According to Clark (2008), the family's social class influences lifestyle, interactions with the external environment, and the structural and functional characteristics of a family. Also, economic status is closely related to social class and educational level. Hence, assessment of the social class and economic status of grandparents caring for AIDS orphans would be important in planning for referral to community resources (example, social grants).

e) **Employment**: Employment factors may affect grandparent's health in the following ways: job-related stress resulting in illness; hazards in the workplace, and job-related problems and time constraints that might interfere with the commitments of caring for the AIDS orphans.

f) **External resources:** External resources include the resources in the community which are available to assist the grandparents with caring for the AIDS orphans. Examples of such resources are financial assistance (formal and informal), transportation, housing, healthcare, and education.

g) Lastly, **relational support** systems which include kin networks, friends and neighbours.

1.8.2.4 *Behavioural Dimension*

Behavioural dimension can influence the health of the grandparents caring for AIDS orphans negatively or positively and includes the following behaviours that might impair the health of the grandparents caring for AIDS orphans: Family consumption patterns, rest and sleeping patterns, exercise and leisure patterns, and the household safety practices.

a) **Family consumption patterns:** The nutritional status of grandparents caring for AIDS orphans can be assessed by the physical assessment and by observing how they select, purchase and prepare their food. If nutritional impairment is noticed, an assessment should be done to determine the underlying causes. Cultural patterns should be determined in the selection, preparation and consumption of food. Other consumption patterns which need to be determined include the use of alcohol, drugs, medications, tobacco and caffeine.

b) **Rest and sleep:** The rest and sleep patterns of grandparents caring for AIDS orphans is assessed as the lack of rest and sleep may cause problem to grandparents. For example

when there is a small baby in the house who sleeps during the day and cries at night, the grandparent would need help to deal with these problems.

c) **Exercise and leisure:** The lack of exercises and leisure can negatively affect the health of the grandparents caring for AIDS orphans, hence need to be assessed. High costs and low income may limit exercise and leisure activities, but should not eliminate them. Regular exercise and leisure activities are necessary for good health and, if they include the whole family, will promote family solidarity. The grandparents that cannot afford costly activities should be assisted to plan for low-cost activities to enhance family cohesion.

d) **Household and other safety practices:** In the assessment of the behavioural dimension of grandparent's health, the following family practices should be considered: The proper disposal of hazardous substances, safety education of children, and the safe use of appliances such as electrical appliances.

1.8.2.5 *Physical /Environmental Dimension*

The physical and environmental dimension includes the health effect of factors in the physical environment such as weather, geographic location and hazard posed by poor housing and unsafe living conditions.The physical dimension includes the home environment, and the functionality of the family (functional or dysfunctional family relationships). A crowded, unhygienic or unsafe home can cause physical and psychological health problems among grandparents caring for AIDS orphans. Therefore, it is crucial to establish the address, whether the family owns or rents the home, whether the house is big enough for the family, the presence of sanitation and water, safety

hazards, and emergency plans for fires or disasters when assessing the physical, and environment aspect.

1.8.2.6 *Health system Dimension*

The health system dimension describes the way the health care services are organised and include the grandparent's response to illness and the use of health care services (their availability, accessibility, affordability, appropriateness and adequacy).

a. **Family response to illness**: Assessment of the biophysical, psychological, physical, social and behavioural dimensions of the grandparents caring for AIDS orphans should give a general idea of the health status of the grandparents and the strategies used by them to stay healthy. An assessment should also be done of how both grandparents and orphans in their care copes with illness. Sometimes traditional remedies or cultural practices are used before a health care provider is consulted. These practices should also be assessed to determine whether they are harmful.

b. **The use of health care services:** Health care services should be assessed for availability, accessibility, affordability, equity and effectiveness. Older person's health needs differ with respect to various illnesses. In the case of an acute illness, the need includes providing or obtaining health care, re-assigning the caregiving roles and supporting the sick person. With chronic illness, additional needs would include avoiding or coping with medical crises, preserving the quality of life and arranging chronic medications. When the family is faced with a terminal illness, grandparents' needs would include dealing with shock and

fear, and minimising pain and discomfort. It is important to find out where the grandparents caring for AIDS orphans go for the healthcare services and whether the service provides any preventive and promotive health services.

1.9 Strategy Development

Strategy formulation guides the managers in defining their core business, the end it seeks, and the means it will use to accomplish that end (Fuertes, Alfaro, Vargas, Gutierrez, Ternero, & Sabattin, 2020). In this study, the strategy formulation guides the managers at the healthcare facilities (clinics /community health centres) to define their core business, which is the proper provision of support to grandparents caring for AIDS orphans, to maximise service delivery through policy implementation. The strategic formulation design used in this study is recommended by Pearce and Robinson (2000). The strategy components include organizations 'mission, internal analysis, external environment, strategic analysis, action plans, and short-term objectives, functional tactics, policies that empower action, restructuring, re-engineering, and refocusing the organization, strategic control and measures taken to promote continuous support.

These components coupled with the total quality management (TQM) framework, was adopted by the researcher to focus on the vision, mission, values and principles, goals and objectives, and action plans. The formulated actions were further subjected to quality assurance for its authenticity and applicability through the Delphi process in phase two of the study. The researcher adopted the Delphi Technique of obtaining consensus to develop strategies following the TQM process that identified problems in the provision of support given to grandparents caring for AIDS orphans from the conclusion statements obtained from the data analysis.

1.9.1 Total Quality Management (TQM)

TQM is a widely used philosophy that is continuously used by managers of public healthcare services to improve these public services (Shafiq, Lasrado, & Hafeez, 2019; Jarrett, 2015; Beer, 2020)). The scope of TQM approach is used for the continuous improvement of every process within healthcare to improve the operational performance of organizations, which ultimately affects the other dimensions of performance such as financial performance, customer satisfaction, and other stakeholders' performance.

The word "quality" has many different definitions, ranging from conventional to those that are strategic (O'Neill, Sohal, & Teng, 2016). The American National Standards Institute (ANSI) and American Society of Quality (ASQ) define quality as the totality of features and characteristics of care or service that bears on its ability to satisfy given needs (Shafiq *et al.*, 2019). The view of quality as the satisfaction of customer needs is often called fitness for use (Baidoun, Salem, & Omran, 2018). TQM is thus an accepted management process in industries to interact with the competitive marketplace and focus on the quality of products and ensure customer satisfaction at every stage, internally and externally (Chiarini & Vagnoni, 2017). A considerable amount of the TQM literature has found a positive association between TQM implementation and organizational performance (García-Bernal & Ramírez-Alesón, 2015; O'Neill *et al*., 2016).

Although TQM had its roots established predominantly in industry, many researchers believe that TQM's philosophy can be applied to health, the complex nature of its organizations, and deficiencies in service notwithstanding (Jarrett, 2015). Quality of service has dominated discussions and emerged as key issues in the health sector in the recent past (Balasubramanian,

2016) and TQM has been widely applied in the clinical field with successful outcomes (Baidoun, Salem, & Omran, 2018). Hence, TQM is viewed as a system that improve the quality of healthcare services throughout the healthcare organization, and has been accepted as a major long-term strategic initiative towards continuously improvement of the quality of healthcare (Chiarini & Vagnoni, 2017).

The key concepts of TQM in healthcare start with top management leadership with the emphasis on process and customer focus. Therefore, implementing TQM in developing effective strategies to improve the support given to grandparents caring for AIDS orphans would require quality management awareness, training, and framework development as well as the development of customer awareness (Albejaidi, 2018). TQM is not a short-term solution; it must be understood and practiced as a long-term strategic commitment. The theoretical foundations of TQM philosophy will be explored as a means of demonstrating how TQM can be applied to develop strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa.

1.9.2 TQM Application

In this study, TQM is defined as a comprehensive, people-focused healthcare management system that involves all healthcare employees at all levels, and continually aims to improve the quality of processes, products, and healthcare services to increase customer satisfaction (Tonjang & Natcha, 2020). TQM is based on three fundamental principles that encompass its overall concept and, if they are efficiently administered, will promote the continuous improvement of the healthcare organization. The three fundamental principles of TQM are: focus on the customers, internal and

external; process improvement and total involvement along with six supporting elements of leadership, teamwork, communications, continuous improvement, employee involvement, education, and training (Van Schoten, de Blok, Spreeuwenberg, Groenewegen, & Wagner, 2016).

Lack of management support, lack of employee involvement, poor leadership, lack of training, inappropriate organizational culture, lack of recognition and reward for success, and hierarchical and authoritative organizational structure is the most cited barriers to successful TQM implementation in developing countries (Van Schoten, de Blok, Spreeuwenberg, Groenewegen, & Wagner, 2016). Hence, in order to improve the health status of grandparents caring for AIDS orphans, the above need to be considered when developing strategies within the healthcare services.

1.9.3 The Principles of TQM

The principles and elements of TQM will now be discussed and applied to the application of strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa. Table 1.1 below presents a graphical presentation of the TQM approach.

Table 1.1 A graphical presentation of the principles of the TQM approach (Tenner & De Toro, 1992)

OBJECTIVE	**CONTINOUS IMPROVEMENT**		
PRINCIPLE	Customer Focus	Process Improvement	Total Involvement
ELEMENTS	Leadership		

	Team Work	Communications
	Continuous Improvement Employee Involvement Education and training	

The first principle of TQM is the customer focus, based on the objectives and principles of TQM, as adopted by Tenner and De Toro (1992), the system must understand its customers' requirements to ensure effective service delivery. This principle requires the total system to have organizational plans and priorities to ensure complete customer support, and that the total system should dedicate to achieving the highest standards of performance as required by their customers. From the TQM perspective, the customer is the judge of quality, and the organization achieves quality when the customer's needs are met (El-Tohamy & Al Raoush, 2015; lotaibi, Yusoff, Mokhtar, & Taib, 2020).

Hence, when applying this principle to this study, external customers are referred as the grandparents caring for AIDS orphans, and the strategies to improve the support given to grandparents caring for AIDS orphans should be external custom driven (grandparents caring for AIDS orphans and all the strategic decisions healthcare institutions should be customer focused, and adhere to ethics principles, quality patient health care and safety (Nasim, 2018).

The focus should also be on the demands and genuine needs of grandparents caring for AIDS orphans. On the other hand, the internal customers in this study are referred to the healthcare personnel (Multidisciplinary team), since they provide service to the grandparents caring for AIDS

orphans, and build on certain areas such as employee training, and effective communication systems.

The second principle is the process involvement, and its basis is the assumption that a good work results from a series of well-coordinated and interrelated steps and activities of the total system, every sub-system, every activity, and every person at every level in an output (lotaibi, Yusoff, Mokhtar, & Taib, 2020). In this study, process involvement would promote a holistic good health of the grandparents caring for AIDS orphans, and would be a results of a consistent team effort of the multidisciplinary team (Professional team, social workers, nutritionist, psychologist, medical doctors)

The third principle is described as the total involvement principle, and encompass a systematic, integrated, consistent, value-based, organization-wide perspective involving everyone's total system and everything. It begins with the senior management's active leadership and includes efforts that fully and creatively utilise the talents of all employees in the system. This is regardless of their position or status, to share responsibility and be involved in the enterprise of continuous improvement in all sub-systems and activities in the system to gain a competitive advantage in the marketplace. It includes the internal interrelationships among the various sub-systems of the system and the relationships with customers (Ginter, Duncan, & Swayne, 2018). In this study, this principle will be applied by involving everyone involved in promoting good health of grandparents from the top management in healthcare management, Multidisciplinary team to other various stakeholders in government and non-government organizations in the communities, and grandparents themselves.

The principles have supporting elements namely leadership, teamwork, communication, continuous improvement, employee involvement, education, and training, and are applied to guide the researcher in the development of the strategy's objectives, functional plans and tactics because it addresses the critical issues involved in the management of human resources. The supporting elements of TQM are described below:

1.10 Leadership

The supporting element of leadership refers to the fact that leaders should advocate, teach, and guide healthcare workers and other government and Non-government personnel in implementing strategies to improve the support given to grandparents caring for AIDS orphans based on TQM philosophy. Furthermore, the health facilities managers must be the central point of developing the knowledge and skills of the multidisciplinary team (MDT) through quality education in community nursing practices (Ingelsson, Bäckström, & Snyder, 2018).

1.10.1 Teamwork

The success of healthcare facilities depends increasingly on the knowledge, skills, and motivation of its workforce (Muruganantham, Vinodh, Arun, & Ramesh, 2018). In this study, healthcare workers work as a team that includes community health nurses, psychologists, and social workers. Thus, it is worth mentioning that strategies to improve support given to grandparents would benefit from the solid MDT teamwork, because the healthcare services cannot be limited to a certain areas as relationship cuts across different units ranging from the assessment section to the consultation section and the pharmacy department for collection of chronic medication.

1.10.1.1 *Communication*

The process of continuous improvement and improving the support given to grandparents caring for AIDS orphans based on the TQM philosophy should communicate to internal and external customers. In this study, the various means of communication and channels should be flexible and not too formal. These could be done through line officers to top management to facilitate proper information dissemination. Various healthcare staff should be continuously kept abreast of the new development regarding grandparents caring for AIDS orphans using notice boards and staff meetings to disseminate information for clarity and understanding.

1.10.1.2 *Continuous Improvement and Learning*

Continuous improvement of strategies is part of the healthcare management in achieving the highest performance, and requires a well-defined and a well-executed approach (Al-Hyari, Abu Hammour, Abu Zaid, & Haffar, 2016). Learning refers to the adaptation to changes that leads to new goals or approaches (Ajmal, Tuomi, Helo, & Sandhu, 2020). Hence, improvements and learning need to be embedded in the way healthcare organizations operate because they will help grandparents access the suitable and proper care (Ajmal, Tuomi, Helo, & Sandhu, 2020). The process of continuous improvement must then contain regular cycles of planning, execution, and evolution which can be achieved by planning workshops in the communities aiming at improving the support given to grandparents caring for AIDS orphans, sending staff members to various national and international conferences and learn from other successful countries and, also do regular monitoring and evaluation (Baidoun & Omran, 2018).

1.10.1.3 *Employee Involvement*

The employee involvement as a supporting element of TQM is the essence of the organization, and their full involvement enables their abilities to be used for the organization's benefit. Hence, improving the support given to grandparents caring for AIDS orphans would require knowledgeable and motivated Multidisciplinary health workers. Management in healthcare should, therefore, ensure that the MDT team are involved in all decision-making processes.

1.10.1.4 *Education and Training*

Education and training is the last element of the principles of TQM and affirm that training is part of the management of all systems and processes. The provision of healthcare services is largely dependent on the sufficiency of the health workforce in terms of the quality of skills they possess, how and where they are deployed and how they are managed (Ashmore & Gilson, 2015). Therefore, healthcare management should avail the workers the opportunity to improve themselves on the job by offering regular in-service training, seminars, workshops, and refresher courses to update their skills in the management of older persons, which in turn will benefit grandparents caring for AIDS orphans. Management can then provide the opportunity of training leave and sponsorship to the MDT team to improve their potential.

1.11 Central Theoretical Argument

Determining the available support for grandparents caring for AIDS orphans in the Western Cape Province and comparing it with their perception of the availability of resources to support them; in addition to exploring their experiences in which their needs, unpacked challenges and coping

strategies contributed to the development of strategies that will improve the support given to them in the Western Cape Province of South Africa.

1.12 Operational Definition of Key Concepts

Orphan: According to Thomas, Tan, Ahmed and Grigorenko, (2020) an orphan is a child who has lost a mother (maternal) or a father (paternal) or both parents (double). In this study, an orphan refers to a child under the age of eighteen who has lost one or both parents due to AIDS related complications and is currently under the care of a grandparent/s.

Grandparent: Grandparent means the father or mother of someone's father or mother (Reed, 2018). In this study, grandparent refers to an older person from the age of 55 years who has lost a son or daughter or son-in-law or daughter-in-law as a result of AIDS-related complications and must use his or her time, and resource to care for the orphan/s.

Caring: Rosa, Horton-Deutsch and Watson (2018) define caring as any form of physical, emotional, social or spiritual assistance provided to reduce suffering, facilitate healing, and promote dignity or to support people with chronic or terminal illnesses. For the purpose of this study, caring implies the tasks that grandparents are expected to undertake so as to meet the needs of AIDS orphans.

AIDS: The acronym AIDS refers to the Acquired Immune Deficiency Syndrome (Oberth & Whiteside, 2016). According to UNAIDS (2016), AIDS describes a syndrome of opportunistic infections and diseases that can develop as immunosuppression deepens along the continuum of HIV infection (from acute infection to death).In this

study, AIDS refers to a disease, which has deprived orphans an opportunity to live with their parents.

Strategies: Strategies are defined as the plans of action designed to achieve a long term or overall aim (Nickols, 2016). In this study it refers to a combination of programmed foundations or plans to improved policies designed to improve the support provided to grandparents caring for AIDS orphans. In this study, strategies are carefully designed plans of action created in conjunction with experts in the field of HIV and AIDS. The aim of the plan is to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa.

Support The meaning of support is to give help or assistance to someone (Karen; Melrose; Gordon; Brown; Alex &Wood, 2015). In this study, support was considered as any kind of action of providing for or maintaining the physical, psychological, socio- economic element of grandparents in order for them to be able to provide necessary care to AIDS orphans.

Multidisciplinary Team (MDT) Multidisciplinary team (MDT) refers to a group of professionals from one or more clinical disciplines who come together to make decisions regarding recommended treatment of individual patients (Sidpra, Chhabda, Gaier, Alwis, Kumar, & Mankad, 2020).

In this study, the multidisciplinary team (MDT) encompasses professional nurses, certified and licensed by the South African Nursing Council (SANC); social workers and psychologist providing care for grandparents caring for AIDS orphans and managers in social developments services (government and non-government) in the selected study setting.

Healthcare Facilities	Healthcare facilities in South Africa are approved basic primary health care, to highly specialised, hi-tech health services available in both the public and private sectors (Ashmore & Gilson, 2015; Centres for Disease Control and Prevention, 2020). In this study, healthcare facilities refer to any operating, approved, and licensed healthcare facility by the Department of Health (DoH) operating at the Primary healthcare level (PHC), secondary and tertiary healthcare to render services in the Western Cape Province, South Africa.

1.13 Outline of the Thesis

This thesis is presented in the following seven chapters.

Chapter One provides the orientation of the study which included the background information on the study, the problem statement, research objectives, purpose of the study, and the significance of the study. Additionally, this chapter presents the conceptual framework that guided the study and the operational definition of the key concepts.

Chapter Two elaborates on the Literature Review for the study and covers aspects relating to support provided to grandparents caring for AIDS orphans, their role, and the challenges they face while providing care of AIDS orphans.

Chapter Three provides a discussion of the research methodology employed in the study and details the research design, study population, sampling methods, data collection methods and techniques, the instruments used as well as data analysis employed in the study.

Chapter Four presents and describes in detail the results of the qualitative part of the study. The chapter is organised in three parts: a) An overview of participants' characteristics; b) Qualitative findings of the study in line with Objective One; c) Presents the discussion of the findings.

Chapter Five presents the quantitative results. The chapter ends with a discussion, integration of qualitative and quantitative data, and concluding statements.

Chapter Six discuss the development of strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province of South Africa. The chapter highlights the various steps and outcomes that will improve the support offered to grandparents caring for AIDS orphans.

Chapter Seven provides the conclusion, limitations and recommendations of the study.

1.14 Summary of Chapter One

This chapter provided an introduction to the study, the purpose, objectives, and significance. The chapter also provides a brief background about the current status and effect of grandparents caring for AIDS orphans. The problem statement was explained, with emphasis on the research questions and the significance of the study. The researcher mentioned the study's motivation, allowing the reader to understand the researcher's decisions to conduct this study. The chapter provided the conceptual frameworks that were used in both phases of the study. The next chapter presents the literature review related to support given to grandparents caring for AIDS orphans.

2 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The impact of the HIV and AIDS pandemic is being felt globally in all spheres of life. Studies have been conducted on various aspects of the epidemic in an attempt to eliminate it. However, HIV infection and AIDS are still damaging various communities and remains a global health crisis (Kidman & Heyman, 2016). AIDS related deaths are living countless number of orphans behind, most of whom have lost one or both parents, and the figure is growing annually (UN, 2016). It is argued that the high mortality rate of AIDS-related disease poses a severe economic burden to the extended family, mainly to grandparents, who are seen as the primary carers of the children orphaned by the AIDS epidemic (MacNab & Yancura, 2018). Consequently, in many instances, grandparents take over the responsibility to provide care and fulfil their orphans' grandchildren's needs despite facing dire financial, health, and economic problems of their own (UNICEF, 2011).

This literature review highlights the extent of the HIV and AIDS epidemic and the role of grandparents in providing care to orphaned grandchildren. The chapter further highlights the challenges faces by grandparents caring for AIDS orphans and their capacity and means of coping with the demands of being the primary caregivers for their AIDS orphaned grandchildren. Furthermore, the available support system that has been documented in the literature will be discussed in this chapter. For this literature review, several databases were consulted, including EBSCO Host, CINAHL, Medline, Psych Articles, Medline, Scopus, Nursing academic edition, and Cochrane library. In keeping with the theme of the review, the keywords included “grandparents”, “orphans”, and “support”.

2.2 The history and status of HIV and AIDS

Since the beginning of HIV and AIDS in the early 1980s, the world had to deal with its incessant rise at a frightening rate around the world with growing numbers of new infections each year. The HIV epidemic has spread, with about 78 million people reported having been infected since its start 75.7 million [55.9 million–100 million] people have become infected with HIV since the start of the epidemic. (UNAIDS, 2020). In 2019, around 690 000 [500 000–970 000] people died from AIDS-related illnesses worldwide, and about 21.8 million people had died of HIV and AIDS-related illnesses 20 years after the epidemic was first noticed.

By the end of 2019, the number of people living with HIV has risen to 38 million people, of the 38 million people living with HIV and AIDS, 25 million were from sub-Saharan countries, accounting for nearly 70% of the global prevalence (UNAIDS, 2020); 1.7 million [1.2 million–2.2 million] people became newly infected with HIV in 2019. Consequently, the HIV and AIDS pandemic continues to be one of the primary causes of morbidity and mortality, especially in sub-Saharan (Velloza, Kemp, Aunon, Ramaiya, Creegan, & Simoni, 2020).

Statistics South Africa (2019) estimates the prevalence of HIV and AIDS in South Africa at 7.9 million out of the 54 million population. The number of persons living with HIV in South Africa increased from an estimated 4.25 million in 2002 to 7.52 million by 2018. In 2018, an estimated 13.1% of the total population was living with HIV. Additionally, the UNAIDS report ranked South Africa as the third highest contributor of all new HIV infections in Southern Africa (UNAIDS, 2017). One can assume that the high morbidity and mortality rate of HIV and AIDS noted in South Africa for the previous years is connected to the South African government's response to the HIV

epidemic which was described as denialist and estimated to have resulted in the deaths of 330,000 people because lifesaving antiretroviral therapy (ART) was not provided (Simelela *et al*., 2015).

Recently, the South African Government made a tremendous effort toward the fight against HIV. One of its main priorities was to develop strategies and policies targeting the HIV and AIDS epidemic to reduce new infections and provide the best treatment as quickly as possible, all in line with global efforts to address the HIV epidemic (DoH, 2016; Johnson 2017; Dorrington, & Moolla, 2016; WHO, 2016; Motsoaledi, 2014). Some of the strategies include increasing the number of patients with HIV who are initiated on ART and followed up and managed by a nurse, as documented in the National Strategic Plan (NSP, 2017-2022) and this has increased the number of patients receiving treatment to 4.4 million people which equal to 61% of the people living with HIV in the country (UNAIDS, 2018).

Similarly, since 2016, South Africa's HIV programme implemented the universal "Test and Treat principle," whereby everyone with a definite test diagnosis is eligible to start treatment as opposed to the previous standard of starting on ART on CD4 count below 500, which was implemented in 2015 (SANAC, 2017). Respectively, in South Africa, a huge improvement has been made in getting people to test for HIV as now the country is almost meeting its 90-90-90 targets, with 86% of people aware of their status (SANAC, 2017). Hence, reducing the number of AIDS-related deaths has declined consistently since 2007, from 276 921 to 115 167 AIDS-related deaths in 2018 (UNAIDS, 2018).

According to UNAIDS (2018), access to ART has changed the patterns of HIV and AIDS mortality and has extended the lifespan of people living with HIV in South Africa. Although a decline in mortality rate can be observed, the HIV and AIDS epidemic in South Africa continues to distress families and communities because it has the world's largest number of people living with HIV (UNAIDS, 2018). There is an estimated 3.7 million orphans in South Africa, and close to half of them have lost their parents to AIDS-related diseases (Hall, Richter, Mokomane & Lake, 2018**).** Likewise, the UNICEF report (2018) confirmed that approximately 17.7 million children under the age of 18 had lost one or both parents to AIDS internationally (sub-Saharan countries alone counting an estimated 14.800.000 of AIDS orphans) and millions more have been affected by the epidemic, through an increased risk of poverty, homelessness, school dropout, discrimination and loss of opportunities (UNAIDS, 2017).

2.3 The history of caring for orphans in an African context

Historically, in the African perspective, there was a system whereby extended families provided care to the orphans, and that system catered to the needs of individuals within the family. The system ensured that nobody would starve when other family members had enough, and no child would live alone even if all the biological parents died (Palmer & Gasman, 2008). Thus, the concept, "It takes a village to bring up a child" is familiar within an African context (Palmer & Gasman, 2008). This understanding is shared by Tamasane and Head (2010), who suggested that a child in the African context, has many "fathers" and "mothers". For example, the system considers the brothers of the natural father as the fathers, while the mother's sisters are the child's mothers. To this end, the author proposed an opposing view that there are no orphans in "traditional" Africa.

If the natural parents of a child die, the other "fathers" and "mothers" in the extended family automatically take custody of the child (Tamasane & Head, 2010). Most studies conducted in the nineties illustrated that children, orphaned or not, have often been cared for by their immediate extended family. The studies also indicated that in the African culture, caring for AIDS orphans is mainly shifted to maternal relatives (Upton, 2003; Geiselhart, Gwebu, & Krüger, 2008; Block, 2016) and depends on the marital status of the mother (Block, 2014). Upon the death of the married mothers, the extended paternal family would generally take care of the children. For the children of single or separated mothers who had died, it was mainly the maternal grandparents who took over care responsibilities (Block, 2016).

As the HIV and AIDS epidemic progressed in the 2000s to present day, the extended family is no longer able to provide support to orphans as was historically the case in African culture as the increased number of AIDS orphans and AIDS-related deaths amongst young extended families impacted traditional care roles (Wild & Gaibie, 2014; Fauk, Mwakinyali, Putra & Mwanri 2017; Van Heerden & Wild, 2018).

It is for the above reasons that non-governmental organizations (NGOs) have set up institutional orphanages as supporting mechanisms to assist children orphaned by AIDS (Nnama-Okechukwu, & Okoye, 2019). However, orphanages can only assist a limited number of orphans (Brodie & Pearce, 2017). Furthermore, the literature argues that the use of orphanages do not provide children with a positive family environment which consequently causes solitude, vulnerability, anxiety and depression (Tadesse *et al.,* 2014). For this reason, and from an African perspective,

institutional orphanages and foster care placement adoption outside the extended family can only be chosen as an alternative when all other options are exhausted as it intrudes upon the values of African families (Tamasane & Head, 2010; Chaitkin *et al.*, 2017; Martins & Zulaika, 2016).

2.4 The role of grandparents as primary caregivers of AIDS orphans

Worldwide, it is common for grandparents to serve as replacement parents to their orphan grandchildren (Sadruddin, Ponguta, Zonderman, Wiley, Grimshaw, & Panter-Brick, 2019). Often this happens in response to family predicaments and other challenges such as poverty, disease epidemics, and migration (Hayslip, Fruhauf, & Dolbin-MacNab, 2019; MacNab & Yancura, 2019). Due to the fatal consequences of the HIV and AIDS pandemic such as the premature death of young people of childbearing age, grandparents became the most suitable replacement caregivers because they have experience in raising children and are believed to share in equal measure the parents' interest and affection for the orphaned children (Wild & Gaibie, 2014; Dolbin-MacNab & Few-Demo, 2020). Also, grandparents are always believed to be available to provide care to grandchildren because at their age they may have fewer responsibilities (Wang, Hayslip, Sun, & Zhu, 2019). It has been argued that grandparents' role as caregivers is not always liberally chosen by them, but that they are coerced into these roles by familial prospects and cultural norms (Kidman & Heymann, 2016).

In many African communities, orphans who are left behind after the death of their parents are confronted by a series of traumatic and psychological challenges such as poverty, malnutrition, stigma and exploitation, which occur when parents who are supposed to raise their children die prematurely due to AIDS and HIV-related illnesses. Hence, these parents leave children without

any form of support, parental love, guidance and resources (Phetlhu &Watson, 2014). The care of an orphan is then placed on the immediate families, with the main expectation being placed on grandparents (Phetlhu & Watson, 2014; Wild & Gaibie, 2014; Block, 2016). Hence, there is an assumption that many grandparents will undertake this parenting role often under coercion reinforced by a cultural and moral obligation to assume the role of the caregiver to the children in order to keep them in the family circle (Dolbin-MacNab & Yancura, 2018; Mtshali, 2016).

Under what is considered to be normal circumstances, the role of grandparents is to advice, direct, and lead their families. However, due to the HIV and AIDS crisis, grandparents are now crucial to the survival of an increasing number of HIV and AIDS orphans thus fulfilling a gap left by other population groups in providing care and support of their orphans left behind (Schatz, Seeley, & Zalwango, 2018; Rutakumwa, Zalwango, Richards & Seeley 2015; Harris,Wilfong, Thang, & Kim, 2017; & Nguyen, 2016). Unfortunately, these grandparents are assuming these caregiver roles when they should be the recipients of care and support (Di Gessa, Glaser & Tinker, 2016; Aldwin, Kowal & Chatterji, 2019). Caring for orphans entails many responsibilities ranging from financial support for tuition and other scholastic requirements, to medical attention when required day-to-day nurturing care, which consequently affects the physical health of these grandparents (Di Gessa *et al.*, 2016). Moreover, most grandparents play this challenging role with limited resources at their disposal and no recognition for their efforts (Lee & Blitz, 2016).

2.5 A public health response to support grandparents caring for AIDS orphans

By definition, public health is not about individual patients but focuses and attends to a wide range of disease and health threats such as disease, and health conditions and problems affecting people

collectively, or the public (Kalomo, Lightfoot, & Freeman, 2018). Thus, public health care aims to provide maximum health benefits to the most significant number of people. A public health approach to a health problem is interdisciplinary and draws upon knowledge from multiple disciplines (Harley & Teaster, 2015). Its interdisciplinarity has enabled the public health field to be innovative and responsive to a wide range of illnesses, injuries, and diseases conditions, such as HIV and AIDS epidemics.

Since 1994, the South African government adopted Primary Health Care (PHC) in an attempt to address the inequalities inherited from the past that used the District Health System as an implementation strategy to ensure that comprehensive health services are accessible and responsive to the needs of various communities (Fusheini & Eyles, 2016). The need to address HIV has been declared a public health priority (UNAIDS, 2019). Among the principles that PHC promotes is a multisectoral approach to address community and family healthcare needs (Salunke & Lal, 2017).

Given the multifaceted and complex issues presented by the HIV and AIDS epidemic, Primary Health Care, with its comprehensive and intersectoral approach addresses health problems and the wellbeing of communities, may be the most appropriate intervention to address challenges faced by households affected by HIV and AIDS (UNAIDS, 2019; Dwyer-Lindgren, Cork, Sligar, Steuben, Wilson, Provost & Biehl, 2019). Intersectoral collaboration (ISC) is a process of interaction in which two or more parties identify mutual interests and agree to work together towards a common goal (Corbin, 2017).

The term Intersectoral collaboration (ISC) refers to the collaboration between government departments. However, within a PHC context, it entails collaboration between government, business, communities, and other significant role players in society, to link health care providers to other aspects of socio-economic development that are strictly related to health (Corbin, 2017; Watkins *et al.*, 2017). A critical element of ISC is intersectoral action. Government, business, and strong community participation are essential to all aspects of a comprehensive approach to HIV and AIDS. Nonetheless, the PHC approach has not been applied in South Africa at the district level to address the multiple problems presented by AIDS-related deaths to grandparents caring for AIDS orphans.

2.6 Social security and caregiving

There are various social security grants available in South Africa (Moosa & Patel, 2020). However, all social grants payable in South Africa are means-tested, based on an applicant's income and assets. In the case of a social pension, the means test is applied to the couple's income and assets, if the applicant is married. In most other grants, the total income of a household is taken into account in determining an applicant's eligibility for a grant.

The child support grant (CSG) is designed to target the primary caregiver of vulnerable children up to 18 years of age, who are living in poverty. The CSG targets the “primary caregiver” instead of the child's mother, as many children are raised away from their biological parents, due to expansive kinship structures, the detrimental effects of the HIV and AIDS pandemic on households, and the legacy of economic migration (Granlund & Hochfeld, 2020). Research has shown the significant value that the CSG has for poor households, particularly with improved

nutrition and food security, and positive educational effects (Satumba, Bayat & Mohamed 2017; Khosa & Kaseke, 2017). The number of children benefitting from the grant increased from 5.5 million in 2005 to 12 million in 2017 (DSD, 2018).

The foster care grant (FGC) aims at addressing the needs of orphans or other vulnerable children and targets children up to the age of 18 years who have been placed in the care of a foster parent by a Court of Law. Only foster parents of children placed in their care through a Court of Law, and not family members of the child, are eligible for this grant (Hall, Skelton & Sibanda, 2016).

The state Disability Grant (DG), which covers disabled persons, including those persons suffering from chronic illness including HIV and AIDS-related illness, and has been in existence since the 2001/2002 financial year and targets working age (18 years and older). Its purpose is to provide financial assistance to persons with a severe disability. However, as for persons living with AIDS, the grant is withdrawn when their condition improves, and their CD4 count rises, as they are considered to be able to work and no longer qualify for the DG (Govender, Fried, Birch, Chimbindi, & Cleary, 2015; Kelly, 2019). Also, eligibility criteria excludes children who are HIV positive from obtaining a disability grant unless their illness requires permanent home-based care (Meintjes, Budlender, Giese & Johnson, 2005).

The Care Dependency Grant also known as CDG is the programme that the government adopted to realise the rights of children with disabilities. A parent, guardian, foster or custodian is able to apply for the CDG if the child is younger than 18 years and in need of full time care due to

mental and/or physical disability. In this case, the child must need and have permanent home-based care (SASSA, 2018).

Despite the existence of these social security safety nets, grandparents caring for AIDS orphans who are eligible for the grant often experience several barriers in accessing the above social grants (Delany, & Jehoma, 2016; Dolbin-MacNab, & Yancura, 2018). Barriers to accessing a grant include complicated application criteria; an incapability to present official documents such as a bar-coded ID and a birth certificate (Patel, & Plagerson, 2016; Dolbin-MacNab, & Yancura, 2018). The literature argues that the value of grants, such as the child support grant is set at too low a level to have a meaningful effect on poverty alleviation in beneficiaries' households (Delany, Jehoma, & Lake, 2016). Also, the narrow legislated purpose of the care dependency grant, unclear eligibility criteria, and cumbersome assessment procedures also add to the grant's inaccessibility (Dolbin-MacNab, & Yancura, 2018). Hence, several bureaucratic barriers and systemic challenges reduce the uptake of grants by people who need such assistance, especially members of households such as grandparents affected by AIDS (Delany & Jehoma, 2016).

2.7 Stigma and discrimination of HIV/ADS affected households

Friedland *et al.* (2018) defined stigma as the undesirable attribute of an individual that lessens the individual's status in society's eyes. Stigma holds the power that distinguishes, controls or excludes the actions of some groups along the lines of inequalities in society (Gilbert, 2016). Grandparents caring for AIDS orphans experience social exclusion generally. However, when AIDS orphans co-reside in a household, all members experience social exclusion as a result of stigmatization of

the disease (Friedland *et al*., 2020). Social ties and traditional support mechanisms may be weakened when ignorance and stigma marginalise a family affected by HIV and AIDS, leaving them excluded, isolated and alone, and without the benefit of community support (Mashegoane & Mohale, 2016).

AIDS is such an attachment to a household, family or individual and may result in discrimination experienced by grandparents and the family, which prompts silence over their HIV status and has a significantly negative and constant impact on their lives (Friedland *et al.;* 2020). Hence, detrimental thoughts and behaviours of others, including friends, healthcare providers, government officials, the community, and families, regarding AIDS result in the stigmatization of grandparents caring for AIDS orphans (Mohale, 2016; Phetlhu & Watson, 2014). Research shows that HIV and AIDS-related stigma manifests itself in multiple ways, including self-isolation, voluntary withdrawal from social interaction, and shame (Friedland *et al*., 2018). Some underlying perceptions of stigma are that HIV and AIDS is a threat to community values, safety, and solidarity (Visser, 2018). Stigma may, therefore, extend beyond the grandparents caring for AIDS orphans and other family members.

HIV-related stigma has been particularly difficult to combat because infected and affected persons sometimes stigmatise themselves through fear before others stigmatise them. As a consequence, stigma may indeed facilitate the spread of the disease by denying the possibility of infection, discouraging HIV testing, and undermining care efforts (Visser, 2018). Stigma has been cited as one of the greatest obstacles in combating the HIV and AIDS epidemics (Aggleton, Dos Santos, Kruger, Mellors, Wolvaardt & Van Der Ryst, 2014). Moreover, social ties and traditional support

mechanisms can be weakened when ignorance and stigma result in the marginalization of a family affected by HIV and AIDS, leaving the members feeling ashamed and isolated (Thepthien & Srivanichakorn, 2016). As a consequence, many grandparents caring for AIDS orphans are hampered in their efforts to care for the orphans: they are reluctant to seek help and access resources externally and feel they are failing in their role as caregivers because they are unable to protect their families from the effects of stigmatization (Melis, Fikadu, & Lemma, 2020)

2.8 Experiences and challenges faced by grandparents caring for AIDS orphans

Taking care of AIDS orphans ranging from infants to teenagers can be physically demanding for grandparents (Matovu *et al.,* 2019). Therefore, adding more pressure and strain to the grandparents' already age-compromised immune system (Shaibu, 2016). Their common challenges range from physical, psychological, and socio-economic challenges (Dolbin-MacNab & Yancura, 2018). Thus, grandparents are prone to more risk of developing chronic illnesses such as cardiovascular and respiratory conditions (Hayslip, Fruhauf & Dolbin-MacNab, 2019). A qualitative study conducted in Koster, South Africa, reported that grandparents were more concerned about the illnesses of the orphans than their illnesses, and most of the participants were diabetic and hypertensive already, which put their cardiovascular health at risk (Phetlhu & Watson, 2014). The same study highlighted how grandparents become physically exhausted and tired from frequent visits to health facilities to save their sick orphans.

The psychological challenge is an essential challenge faced by grandparents caring for AIDS orphans. It is mostly due to recurrent experiences of loss and grief for their children dying from AIDS-related illnesses and their relation to caregiver burden (Lee & Blitz, 2018; Phetlhu &

Watson, 2014). The psychological challenges of these grandparents are also related to assuming parenting again, which usually involves a great deal of stress (Dunham & Flores-Yeffal, 2019). The inability of grandparents to cope with these stressful situations may consequently predispose them to reflect symptoms of stress as they are older and more vulnerable to developing health-related problems (Matovu *et al.,* 2019). A qualitative study conducted in South Africa found that grandparents had difficulties coping with repeated experiences of the death of their children due to AIDS and the resultant care giving role towards their grandchildren (Mashegoane & Mohale, 2016; Cortopassi, Driver, Eaton, & Kalichman, 2019). Another study conducted in the USA confirmed that grandparents caring for orphans struggle with caregiving duties, hence causing them high-stress levels (Lee & Blitz, 2018).

The study conducted by Lee and Bliz (2016) also revealed that grandparents caring for AIDS orphans feel less happy and less satisfied than non-caregiving grandparents. They also reported more depression among AIDS orphans care givers than non-caregivers because of the multiple ongoing roles they have to play while they struggle to maintain their social life. Therefore, caregiving grandparents end up depressed, stressed, and burnout, with feelings of inadequacy in society, and helplessness (Lee & Blitz, 2016; Dunham & Flores-Yeffal, 2019). Another source of stress amongst grandparents caring for AIDS orphans is that they struggle to respond to the orphan's psychological, legal, economic and essential needs (Mtshali, 2016; Samuel, Marsack, Johnson, LeRoy, Lysack, & Lichtenberg, 2017).

Economic challenges also compound the challenge grandparents caring for AIDS orphans face as the primary caregivers. They are expected to meet the needs and demands of the orphans'

underprivileged conditions. Raising an orphan child, particularly for grandparents depending on social grants, places financial burdens on the caregiving grandparents. According to Kidman and Heymann (2009), young orphans taken care of by their grandparents were malnourished due to the inability to cope with the increasing number of orphans in one household. In many instances, grandparents do not have the resources to care for their AIDS orphans (Goldberg, & Short, 2016). In South Africa, grandparents caring for children affected by AIDS deaths cited scarcity of food and day-to-day struggle to get enough food to feed the family as a challenge (Hoffman, 2018). The costs of feeding, clothing, and paying school fees are significant concerns for caregiving grandparents.

Inadequate housing is another critical challenge faced by grandparents caring for AIDS orphaned grandchildren (Chazan, 2014). The grandparents who live in townships face the challenge of trying to accommodate their orphaned grandchildren in inadequate housing structures such as shacks and Reconstruction and Development Programme (RDP) houses. Thus, it becomes a problem as the grandchildren grow older and need their own space and privacy. Some grandparents who live in shacks or informal settlements on the outskirts of the cities live without electricity, running water and a sewerage system, which are the basic primary needs for survival in the city (Chazan, 2014). Lack of these amenities not only impact the grandparent but also the child who may suffer different conditions from physical health to self-esteem.

2.9 Caregiving in urban areas and rural areas

Challenges of caregiving faced by grandparents caring for AIDS orphans who reside in urban areas and rural areas may differ. Grandparents in rural areas are affected by the rural to urban

migration of young, men and women, who seek job and education opportunities in an urban centre, which apart from a loss of support, results in large numbers of grandparents becoming primary carers to young children who are left in their care (Dolbin-MacNab,& Yancura, 2018).

Some studies have highlighted the implications of migration of younger kin. The grandparents are left behind in a rural area with limited resources, yet have to take care of sick and dying adult kin when they return to their rural home from an urban area (Mtshali, 2016). Rural areas are generally under-resourced compare to urban areas and are typically characterised by poor infrastructure, roads, dams, electricity supply, and telecommunication (United Nations, 2016; Mtshali, 2016). The geographical distance between most urban areas and rural areas in sub-Saharan Africa also limits accessibility to support from well-resourced urban areas and makes it difficult for urban-based kin to send remittances to elderly parents, depriving them of income and complicating caregiving further (Shaibu, 2016).

Grandparents in urban areas are better informed about HIV and AIDS than their counterparts in rural areas (UNAIDS, 2015; Dolbin-MacNab & Yancura, 2018). Thus, wide disparities exist in the social and economic conditions of grandparents and their households in rural areas and urban areas of sub-Saharan Africa. These disparities are often due to greater investment in towns and cities, stimulating economic growth and employment opportunities. As a consequence, rural-based young men and women are attracted to urban areas, thereby denying rural areas support and development from young and dynamic inhabitants (Matovu *et al*., 2019).

Although an increasing number of grandparents in rural areas provide care with limited resources and under difficult conditions, there is no evidence of a corresponding rise in formal support for these caregivers. Support for older persons in non-urban and urban settings varies. In non-urban areas, older persons depend largely on a traditional kinship support system or network, and help is provided when needed by extended family and members of the surrounding community (UNAIDS, 2015; Dolbin-MacNab, & Yancura, 2018). In urban areas, older persons may depend on non-profit organizations and municipalities for services, as well as members of their immediate family for assistance with daily needs and activities (Block, 2018; Mhaka-Mutepfa, 2018). Given disparities between the resource bases of urban areas and non-urban areas, this study will attempt to highlight crucial resource needs and coping mechanisms of grandparents caring for AIDS orphans.

2.10 Grandparents' responses to caregiving and coping mechanism

The consequences of grandparents parenting the orphans include role transformation, and financial constraints leading to poor health (physical, emotional, and socio-economic). For most grandparents, caring for grandchildren forced them to abandon some of their traditional livelihood because of the overwhelming caregiving demands that necessitated a change in their activities of daily living (Shaibu, 2016; Mhaka-Mutepfa, Mpofu, Moore & Ingman, 2017). Literature argues that the elderly are the very segments of society that ought to be receiving protection and care, but instead, these grandmothers attempt to stretch their meager pension to provide food and schooling for their orphaned grandchildren (Mtshali, 2016; Mhaka-Mutepfa, Mpofu, Moore & Ingman, 2017; Matovu *et al*., 2019).

Despite all the challenges, grandparents are willing to assume the new roles and responsibilities of raising their AIDS orphaned grandkids (Dolbin-MacNab, & Yancura, 2018). However, their ageing health gets overwhelmed by this stressful new role, which makes grandparents vulnerable to certain types of illnesses as they try to cope with family responsibilities in their old age. The following paragraphs discuss the grandparent's response to caregiving.

2.10.1 Poor Health

Grandparents caring for AIDS orphans experience physical and emotional health-related illnesses that impact their psychological wellbeing. Grandparents often complain about problems such as depression, stress, and burnout, feelings of inadequacy, helplessness, guilt, loss of self-esteem and confidence (Lee & Blitz, 2020). Grandparents become anxious and worried that their grandchildren might die if the parent died of AIDS-related illnesses and they make an effort to look strong for the sake of their grandchildren (Mpofu & Cumming, 2015; Dolbin-MacNab & Yancura, 2018). Studies have shown that in trying to cope with the demand of caring with no adequate resource, grandparents risk suffering from numerous emotional, as well as social isolation (Dolbin-MacNab & Yancura, 2018).

Additionally, grandparents may be too old to take care of the grandchildren, and they may be sick and tired of caretaking roles which add extra strain to their physical and mental wellbeing, increasing their vulnerability to chronic stress and psychological problems such as depression and anxiety (Mugisha & Kinyanda, 2017). A study conducted in China revealed high levels of depression symptoms among adult caregivers who are caring for AIDS orphaned children and they are unable to adjust and respond to the new demands made upon them (Dolbin-MacNab &

Yancura, 2018). Furthermore, grandparents acquire general body aches and pains attributed to degenerative disorders like arthritis and hard labour, as they continue to engage in manual activities to earn income to take care of their orphans' grandchildren (Shaibu, 2016; Mathilda, Mukombwe, Doreen, & Clara, 2015).

2.10.2 Emotional grief and depression

Emotional distress seems to arise from anxiety over the inability to provide a desired standard of care, burn-out and physical pressures of daily and parenting activities, and from sadness and grief over losing adult children either to migration, illness, or incarceration (Matovu *et al.*, 2019). Literature shows that grandparents caring for AIDS orphans are suffering from emotional distress and depression due to limited social support (Phetlhu & Watson, 2014; Mtshali, 2015; Dunham & Flores-Yeffal, 2019). The symptoms of this depression include sadness, despair, hopelessness, low self-esteem, feelings of helplessness, and a loss of interest in life (Kalomo &Taukeni, 2020). The research unearthed that Grandparents are depressed because of burying their children consecutively due to AIDS (Matovu *et al.*, 2019), they felt helpless due to raising many grandchildren without a support system in place (Wild, Cluver, & Kuo, 2015).

2.10.3 Coping mechanisms

Despite these challenges, grandparents caring for AIDS orphans still find ways to cope. Grandparents occupy themselves in a variety of resilient processes such as relying on their spirituality and accessing support from friends, extended family, and the broader community (Dolbin-MacNab *et al.*, 2016).

On the other hand, some grandparents caring for AIDS orphans cope with financial burden by tiling the land and selling any surplus, while others grow vegetables, maize (Mathilda, Mukombwe, Doreen, & Clara, 2015).

2.11 Support needs of the grandparents caring for AIDS Orphans

Apart from the valuable role that grandparents play as caregivers, their resources are limited, prompting a range of areas of concern and need for them. Various research has established the support needs for grandparents caring for AIDS orphans in some sub-Saharan countries, including South Africa (WHO, 2016; Dunham & Flores-Yeffal, 2019). According to the World Health Organization (WHO, 2016), older people who are caregivers to AIDS orphans are identified as a group who are in serious financial need, and literature around the world concurs with the suggestion. Most researchers conclude that cash transfers in the form of a social grant to grandparent caregivers prevented their household from falling into deeper poverty (Dolbin-MacNab & Yancura, 2018). Some studies found that grandparents need support with legal matters, such as issues of conflict, property rights, and eligibility for social security benefits (Satumba, Bayat, & Mohamed, 2017). In South Africa, no policy provisions are available for older persons who care for AIDS orphans, which support is essential if the burden of care on affected older persons is to be addressed.

2.12 Summary

This chapter reviewed literature relating to grandparents caring for AIDS orphans as a measure of improving the support given to them. The challenges faced with the grandparents were explored

alongside the effects of physical, socio-economic, and emotional that impact on the grandparent's wellbeing. The next chapter addresses the design and methods applied to the study.

3 CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

Chapter Two presented a review of the literature on relevant concepts regarding grandparents caring for AIDS orphans. This chapter aims to outline and discuss the methodology used in this study. The chapter will start by outlining the researcher's philosophical assumption. The research design and research methods used are also described. Detailed information describing the first phase of the study where qualitative and quantitative techniques used to collect and analyse data are explained. The Delphi process used in phase two of the study is also presented. Furthermore, activities and steps to enhance the academic rigour and adherence to ethical requirements of research are presented.

3.2 Philosophical assumptions of the study

Assumptions are beliefs and ideas that human beings hold true (Kivunja, & Kuyini, 2017). Belief is defined as an act of faith, which does not have empirical evidence to support it (Creswell & Creswell, 2018). Therefore, in research, philosophical assumptions are used as a theoretical framework which guide the researcher to collect, analyse and interpret the data (Packer, 2017). It is imperative for the researcher to state their philosophical assumption in the study so that their viewpoint can be understood better. In light of the current study, the researcher's assumptions are based on the following scopes: ontology, epistemology and research methodology, which are discussed below.

3.2.1 Ontology

Ontology refers to the nature of reality and the nature of human beings in the world (Denzin & Lincoln, 2018; Creswell, 2014). The ontological dimension of the researcher is that of a pragmatist. In this school of thought, the concern is on what works and solutions to the problem instead of laying emphasis on methods (Kivunja, & Kuyini, 2017). Objectivity is based on the fact that reality is constantly changing and that we learn best through applying our experiences and thoughts to problems, as they arise (Gruber, 2018). Reality in the context of this study is concerned with what works and leads to solutions to the problems and that is why a multi-method approach was chosen to conduct the study (Creswell, & Creswell, 2018).

3.2.2 Epistemology

Epistemology speaks to the relationship between the participants and the researcher during knowledge generation (Creswell 2014). In this study, the researcher together with the participants, were actively involved in the investigation. Epistemologically, the researcher perceived grandparents caring for AIDS orphans as the main contributors to the study. Through interactions with them, the researcher sought to unearth their experiences and ideas in constructing knowledge as they assisted in developing the core specific to their needs. People involved in decision making (managers), multidisciplinary team (professional nurses, social workers, and psychologist) and experts were perceived as colleagues who can help to address the identified challenges. Therefore, the researcher related meaningfully with these participants not just as individuals but as a team that worked together to draw a specific plan for addressing the challenges experienced by grandparents caring for AIDS orphans.

3.2.3 Methodological assumptions

Methodological assumptions address the methods used by the researcher to investigate the reality of the study (Creswell 2014). Given the nature of the research questions of the empirical study, the employment of a single quantitative or qualitative data collection technique on its own would not have enabled the researcher to capture the complex and multiple dimness of the impact of lack of support on grandparents caring for AIDS orphans (Cram & Mertens, 2015). The study was conducted in two phases. In Phase One, a multi-method approach was used which included both quantitative and qualitative research techniques, and both data sets were separated until the point of triangulation which involved the integration, connection, and embedding of these two data sets during data interpretation (Creswell & Creswell, 2018; Hughes, 2016; Cram & Mertens, 2015). Both qualitative and quantitative approaches have particular strengths and weaknesses, but when used together, the weaknesses of one approach would be mitigated by the strengths of the other (Morse, 2016).

In Phase Two, the Delphi technique was used to develop strategies to improve the support given to grandparents caring for AIDS orphans. A summary of the methodology applied is illustrated in Table 3.1

Table 3.1 Summary of the study methodology

PHASE ONE: EMPERICAL PHASE					
Objectives	**Approach/ Design**	**Population/ Sample**	**Sampling Method**	**Data Collection**	**Data Analysis**
1. To explore the experiences of grandparents caring for AIDS orphans in the Western Cape Province of South Africa.	Qualitative approach/ exploratory and descriptive	Grandparents caring for AIDS orphans (N = 25)	Purposive sampling	Individual Semi - Structured open-ended interviews	Qualitative Computer data analysis package (ATLAS, ti.7).Inductive content analysis.
2. To determine the available support (psychological, social and physical) for grandparents caring for AIDS orphans in the Western Cape Province of South Africa.	Quantitative approach/ survey	Managers in selected government departments and non-government organizations (N=15) and multidisciplinary team in selected clinics that serve Khayelitsha, Mitchell's plain and Grabouw areas **(N= 50)**	Stratified random sampling and all-inclusive purposive sampling	Questionnaire	Descriptive and inferential Statistics

3. To determine the grandparents' perception on the availability of support given to them in the western cape province of south Africa.	Quantitative approach /survey	Grandparents caring for AIDS orphans. (N= 26)	Snowball sampling	Checklist	Quantitative Computer data analysis package
4. To compare the grandparent's definition of availability of support with the available support for grandparents caring for AIDS orphans in Western Cape Province of South Africa.	Quantitative /comparative analysis	Recorded data from objectives 2 & 3.	Documentation from 2 and 3	Checklist	Correlations
PHASE TWO: STRATEGY DEVELOPMENT PHASE					
5. To develop strategies that will improve the support given to grandparents caring for AIDS orphans in Western Cape Province of South Africa.	Quantitative	Experts from social and health services (N= 11)	Purposive sampling	Multiple Questionnaires by e mail.	Ranking analysis

3.3 PHASE ONE: EMPIRICAL PHASE

Phase One is the empirical phase of the study that deals with the four objectives as previously explained in Chapter One. It comprises of three populations which were chosen based on the objectives of the study. The four objectives were organised in two parts. Part One involved a qualitative study aimed to answer the first study objective. In Part two, a quantitative approach was conducted and aimed at answering the second, third and the fourth objectives of the study.

3.4 Research Approach

As described earlier in Chapter One of this study, this research was conducted using multi-method approach. The approach combines both qualitative and quantitative forms of data collection to investigate a phenomenon of interest (Buckley, 2018). The choice of a multi-method approach allows for exploration of different layers of the phenomenon with the aim to get a comprehensive view in a quest to solve complex problems (Brannen, 2017).

3.4.1 Qualitative and Quantitative research

3.4.1.1 *Qualitative research*

Qualitative research techniques are mainly used for exploratory purposes and usually to explore and describe the phenomena which may not be suited to quantitative measures (Brannen, 2017). Qualitative data typically have a richness and a complexity that are lacking in quantitative data (Creswell & Creswell, 2018). Thus, qualitative research techniques and the data they elicit are less bounded by a researcher's assumptions and are more likely to be sensitive to unexpected findings (Brannen, 2017; Buckley, 2018).

The reason for including qualitative research in the present study was to gain an understanding of caregiving and the support needs of grandparents caring for AIDS orphans specifically. The qualitative methods would allow the researcher to probe the respondents' responses and would facilitate the collection of narratives about the respondents' needs, experiences, of caregiving and knowledge and beliefs about HIV and AIDS.

However, qualitative research has limitations. One limitation is a dependence on a conceptual framework to guide the inquiry on the issues to be examined (Brannen, 2017). A qualitative study needs to indicate moreover how or where a researcher positions him/herself; biases in the investigation and the data collected may stem from the researcher's social class or cultural position (Creswell, 2014).

3.4.1.2 *Quantitative research*

Quantitative research involves a collective strength of multiple variables (Creswell, 2014). However, a single quantitative enquiry technique was employed in the present study, namely a survey. A survey is typically a cross-sectional (but may be a longitudinal) data collection technique in which a pre-constructed questionnaire is used to collect data (Rutberg & Bouikidis, 2018). The quantitative nature of a survey is generally reliant on the recruitment of a representative sample of the population of interest (Nieswiadomy & Bailey, 2018). The requirement of a randomly selected sample is to be able to generalise findings from the sample to the study population, so that inferences may be made about certain characteristics, attitudes, and/or behaviour of the population of interest (Buckley, 2018).

Quantitative data are measurable units of information and are amenable to statistical manipulation through the application of different scientific techniques (Polit & Beck, 2014).

The main purpose of quantitative data is to define and measure the magnitude of the problem under investigation.

However, the data are limited in that they do not describe or capture human aspects of the problem, such as actors' perceptions, feelings and views (Creswell & Creswell, 2018). Also, quantitative research approach and the use of a survey design in the present study is limited in that the data collected does not allow for sufficient understanding of complex issues nor have the flexibility to explore sensitive issues such as the challenges faced by grandparents caring for AIDS orphans effects of HIV and AIDS from their unique perspective and (Albers, 2017; Brannen, 2017). In order to compensate for this weakness, the present study employed qualitative research techniques in conjunction with and complementary to a quantitative research technique.

3.4.1.3 *Multi-methods approach*

Given the limitations of both quantitative and qualitative research methods, respectively, a multi-methods approach was selected in order to achieve an in-depth understanding of a complex phenomenon, this approach uses a combination of qualitative and quantitative methods to investigate a problem and provided validation of the data, and findings of the analyses of the data elicited through the employment of multiple techniques (Schoonenboom, Johnson, Froehlich, 2018).

Qualitative and quantitative research approaches are located at opposite ends of a continuum of methodological approaches, and each has its own principles and assumptions (Brannen, 2017). The advantages and disadvantages of the use of a particular technique and a particular approach in the study were weighed in terms of the study's objectives. The employment of a

Multi-methods approach would thus help to compensate for the weaknesses of a particular technique with the strengths of another), and so strengthen the study findings and provide an improved understanding of the problem overall (Brannen, 2017).

The data produced through the employment of the multiple techniques would be triangulated, which would further help to balance integral weaknesses of the methods and help to correlate the findings.

3.5 Research Design

The research design employed in the present study is described below. However, no single research design can be identified as the most appropriate design for investigations of the problem of HIV and AIDS and its effects on grandparents caring for AIDS orphans, nor is the employment of a particular research method, or the use of a particular research design of concern in this study, but rather how to collect data most effectively to serve and meet the study's objectives (Hughes, 2016).

3.5.1 Exploratory Design

According to Polit and Beck (2018), an exploratory research design is a method of exploring an area of human experience in order to understand a person's world perception. Furthermore, it is referred to as an approach that follows an interpretative form that enables the researcher and the participants to make the world visible, because it involves interactions using narratives and language that convey meaning to both of them (Palagi, Gandon, Giboin, & Troncy, 2017).

The design was selected for this study because of its ability to discover new knowledge from the perspective of the grandparents caring for AIDS and HIV orphans. The design provided

insight into the problem under investigation as the grandparents were free to express themselves, in an unhindered manner without bias or interference. The experiences and challenges of grandparents caring for AIDS and HIV orphans were explored in depth.

3.5.2 Descriptive design

In this study, the descriptive research design aimed at describing an accurate representation of the grandparents' situations (Polit & Beck, 2018). Also, the descriptive design aimed to drive observation, description and documentation of naturally occurring situations that help with vivid and detailed exploration (Creswell & Creswell, 2018). The idea is to portray the influence or impact of caregiving on grandparents as they experienced them (Creswell, 2014). The descriptive design also allowed the researcher to highlight the type and nature of the support given to grandparents and to describe their coping mechanism to alleviate the effect of caregiving on their health.

3.5.2.1 *Cross-Sectional Survey Design*

According to Bryman (2017), a cross-sectional survey design allows the collection of data from many different individuals at a single point in time intending to collect a body of quantifiable data systematically in respect of several variables which are then examined to discern patterns of association and only summarises said outcome using descriptive statistics. Bryman's emphasis is on survey research being conducted to provide a quantitative description of the individuals or other units concerned in a study. His emphasis on the quantification of variables and sampling from known populations shows how survey researchers may share a similar scientific view of the nature of the research task from that adopted by researchers using qualitative research. Bryman's description of Cross-sectional survey is employed for the

quantitative strand of this study, but the survey data complemented with qualitative research data.

In this study, the cross-sectional survey design was used to investigate and describe the practice of Multidisciplinary team (professional nurses, social workers, psychologists) and also included Government and Non-Government organizations (NGOs) officials in dealing with grandparents caring for AIDS orphans. Information was obtained from different participants at a single point in time.

3.6 Research setting

The study was conducted in the Western Cape Province, South Africa. The Western Cape Province is situated in the southwest of the Republic of South Africa and covers a land surface of 129,307km2 which is 10.6% of the country's total land surface. The province is divided into five rural district municipalities namely Cape Winelands, Garden Route, Overberg, West Coast and Central Karoo, and the metropolitan district of the City of Cape Town. The study was conducted in two districts which are the City of Cape Town Metropolitan municipality (Khayelitsha and Mitchell's Plain) located in the urban area of Cape Town and Overberg municipality (Grabouw) which is a rural, farming area.

The three areas were selected due to the high prevalence of HIV infection; the high poverty rate, poor education rate, and a high crime rate (SANAC, 2017; Simbayi *et al.*, 2019), thus producing inexplicable numbers of orphans in their communities (HSRC, 2018). Another motivation was to get a representation of both rural and urban views on the support given to grandparents caring for AIDS orphans.

Simbayi *et al.* (2019) argue that race groups influence the high HIV prevalence rate, and black Africans bore the most considerable burden of HIV infection, followed by "*Coloureds*", with the second-highest prevalence. The researchers further argued that the high HIV prevalence rate is also influenced by locality types, highlighting that HIV prevalence is highest in farming areas, followed by tribal areas, with urban areas displaying the lowest estimates. This prompted the researcher to conduct a study in these areas.

The specific informants for the study were accessed through non-Government organizations (NGOs) that supported HIV and AIDS households in those areas; and both departments of Health and/or Social Development in those areas. Figure 2 illustrates the Western Cape district municipalities, and the following paragraphs discuss the three research areas subdistricts (sites).

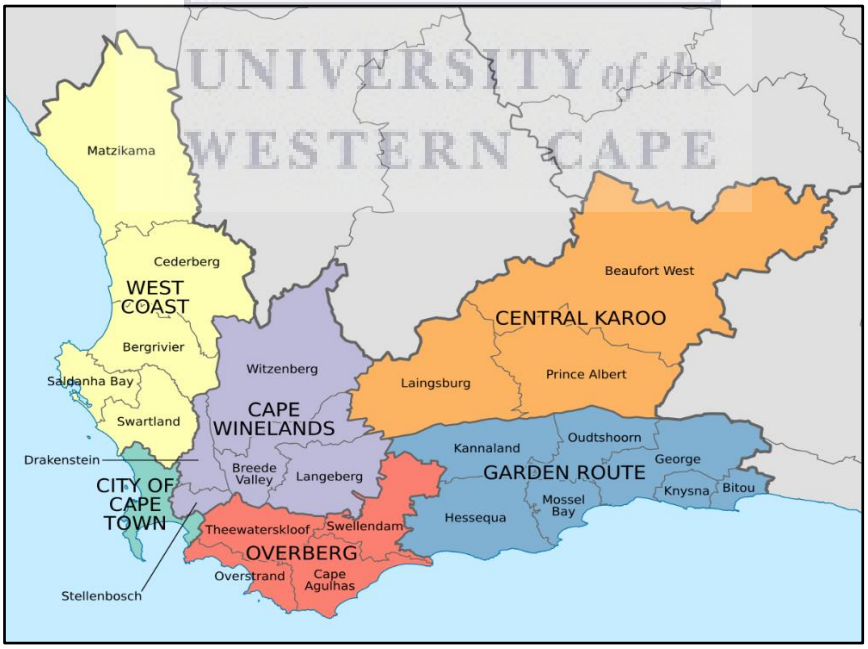


Figure 4 Western Cape District Municipalities

3.6.1 Khayelitsha Sub-district

Khayelitsha is a peri-urban township near Cape Town whose residents are mainly of black African origin. It has a population of approximately 500,000 people (Stat SA, 2011) with 60% of inhabitants living in informal housing. Extreme poverty, attached with poor community infrastructure, lead to immense crime rates, gangs, violence, drugs as well as other societal problems. Khayelitsha is amongst the South African townships with a high HIV prevalence rate and highest incidences of HIV infections in South Africa (Phelanyane, Boulle, & Kalk, 2020 July; Western Cape Provincial AIDS Council, 2018/19), prompting a high number of AIDS orphans. In 2018, it was estimated that there were as many as 14,000 orphans in Khayelitsha, and the majority of infections are as a result of the AIDS pandemic (Western Cape Government directories, 2018).

Khayelitsha healthcare facilities are composed of a District Hospital, which is a public health facility with the status of a District Hospital. This hospital operates in the Khayelitsha Health District of the Metro Region and is under the mandate of the Western Cape Department of Health. The 300-bed medical facility provides support to the surrounding primary healthcare facilities to ensure that patients receive care at the lowest level of entry into the healthcare system.

There are three Community Health Clinic (CHC) which are managed by provincial government clinics in Khayelitsha, and there are also numerous small municipal clinics throughout the township (10). These clinics play an essential role as centres of primary healthcare by providing a variety of healthcare services to children, women and, youth and men's health. Services

offered at these include child health, family planning, TB treatment, HIV testing, Pap smears and treatment and diagnosis of sexually transmitted infections (STIs). These health facilities are managed and operated by the local government authority of the City of Cape Town. There is more than eight NGO'S that are involved with HIV and AIDS in Khayelitsha.

3.6.2 Mitchells Plain Sub-district

Mitchells Plain is a largely "*Coloured*" (mixed race) township (91%) located on the Cape Flats on the False Bay coast between Muizenberg and Khayelitsha and as an estimated population of 290,000 --305,000 (Census 2011, Statistics South Africa). The community is struggling with major issues of crime, security and gangs, drugs and a high prevalence of HIV and AIDS. Only 35% of those aged 20 years and older have completed Grade 12. HIV and AIDS prevalence in this township is also high prompting increased numbers of grandparents who are caregivers to AIDS orphans.

Mitchells Plain has numerous medical centres and hospitals to cater for the healthcare and medical needs of the local community. They include Mitchell's Plain District Hospital, Mitchells Plain CHC, Mitchells Plain Day Hospital, and ten (10) small clinics that are managed by the City of Cape Town. Four (4) NGO's that are involved with HIV and AIDS were identified in Mitchell's Plain Sub-district.

3.6.3 Grabouw Sub-district

Grabouw is located some 65 km south-east of Cape Town. It is a farming township of about 65,000 people with a known HIV infection rate of 34% in addition to having one of the highest TB infection rates in the country (Census 2011, Statistics South Africa). In this community, 40% of households survive on less than R2 000 per month. This rural area was selected in order

to get a broader representation of views on the state of grandparents caring for AIDS orphans in rural/farming areas compared to grandparents in urban areas. The Grabouw community has three clinics but the town has no public hospital. If people needed medical care after hours, they are forced to travel to Somerset West or Caledon (about a half-hour drive). Only two (2) NGO's that are involved with HIV and AIDS were identified in the Grabouw Sub-district.

3.7 Research Method

In this section, a detailed description of the research method is highlighted and discussed in relation to population, sampling, data collection and data analysis. This section will be discussed in two parts, that is qualitative as part one and quantitative as part two.

3.8 Part One: Qualitative strand: Objective One

3.8.1 Population

A population is defined as the total number of units from which data can potentially be collected and these units may be individuals, organizations, events or artefacts and theoretically specified aggregation of study elements (Polit & Beck, 2018). The population for the study consisted of all grandparents (male and female) aged 50 years and over who take care of AIDS orphans (who might or might not have been infected with the virus) living in households in urban settings or non-urban settings in three different areas of the Western Cape (WC) and associated with NGOs within the described settings.

3.8.2 Sampling Technique

Sampling refers to the researcher's process of selecting the study participants from a population to obtain information regarding a phenomenon in a way that represents the population of

interest (Creswell & Creswell, 2018). It involves taking any portion of a population as representative of that population (Creswell & Creswell, 2018). In the current study, purposive sampling was used to select grandparents caring for AIDS orphans through non-Government organizations (NGO's). This method was selected because it allowed the researcher the opportunity to focus on participants who are experienced and have in-depth knowledge of the phenomenon under study (Creswell, 2014). Purposive sampling technique is used in research when the data needed for the study can only be provided by a particular population knowledgeable in the area of research or have experienced the phenomenon under investigation (Polit and Beck, 2018). The grandparents and the NGOs were then recruited in the following way:

The households of the grandparents appeared on the lists of clients of NGOs that supported HIV and AIDS households in those areas. A database of NGOs in the province was obtained from the Department of Social Development. Upon receiving permission to collect data from the Department of Social Development, the researcher accessed the record of all registered NGOs serving clients affected by HIV and AIDS within the described settings. These NGOs were then allocated numbers in chronological order, by the sub-district. The researcher placed pieces of papers with these numbers in a box which was shaken, and the researcher drew papers from the box, one-by-one, the researcher identified three numbers representing three NGOs. The researcher then approached the NGOs to access and select grandparents from the list of these three NGOs. The field workers from the selected NGOs assisted the researcher in getting hold of the grandparents caring for HIV and AIDS orphans. The field workers then contacted potential participants, and they invited them to participate in the study. They informed grandparents caring for the HIV and AIDS orphans about the research and the possibility of the researcher contacting them. The appointment time for the interview was given by the

fieldworkers and scheduled at a time and place convenient to the participants. All participants chose to meet at the NGO's instead of having interviews in their homes, which minimised the risk of raising community members' suspicions about HIV and AIDS affected households, thus minimising the stigma issue. Fieldworkers recruited a sufficient number of grandparents from the list until saturation was reached.

3.8.2.1 *Inclusion criteria*

Participants were eligible if they met the following conditions:

a) **Age**: Being a grandparent from the age of 50 years and above. The researcher set a cut-off age of 50 years based on three considerations: in an African context, grandparents falling in the age of category 50–59 years old are traditionally viewed as old and responded to accordingly (Alderslade, 2019). Also, a previous research conducted on grandparents caring for AIDS orphans in the Western Cape Province found a need to lower the cut-off age to 50 years in order to recruit a sufficiently large sample of carers (Ferreira *et al.*, 2001).

b) **Loss of a child to AIDS**: Grandparent/s who has lost a son/daughter or son/daughter-in-law resulting from AIDS-related illness and have AIDS orphans in their care.

c) **Employment Status**: Grandparent/s could be still working or unemployed or retired.

d) **Residency:** Grandparent/s should reside in the research focus area for this study.

e) **Affiliation to NGO:** Grandparents who are involved with NGOs and obtain some form of support from them.

The participants who met the above inclusion criteria were deemed knowledgeable and experienced enough to provide rich information on the phenomenon under study.

3.8.3 Sample size

According to Polit and Beck (2018), sample size refers to the number of participants in a sample. It is advised to use the largest sample possible and ensure that the population is representative. However, the proposition that a larger sample is better does not apply in qualitative studies; what is essential is reaching data saturation (Burns & Grove, 2014). Data saturation is the point at which new data no longer emerge during the collection process (Burns & Grove, 2014). In this research, a minimum sample size of thirty (30) grandparents caring for AIDS orphans was proposed, and the figure was decided upon due to the available resource and time constraints, however, data saturation was intended to be the final deciding factor. The sample size was intended to be divided equally between urban and rural areas, however, due to the data saturation principle only twenty-five (25) participants were interviewed: nine (9) in Khayelitsha, eight (8) in Michell's Plain and eight (8) in Grabouw.

3.8.4 Pre-test

The pre-test is a useful technique for improving validity in qualitative data collection procedures and interpretation (Hilton, 2017). It involves simulating the formal data collection process on a small scale to identify practical problems concerning data collection instruments, sessions, and methodology (Hansen, 2020). Furthermore, a pre-test aided in establishing the researcher's ability to conduct interviews, to deal with unexpected challenges and to ensure that the questions posed explore and describe what was intended (Buschle, Reiter, & Bethmann, 2020). For example, it helps researchers to determine the quality of the questions and the probing questions that could be envisaged. Therefore, the purpose of the pre-test in the current study was to help the researcher identify the type of environment in which data would

be collected and how it would proceed, to identify any initial problems with data collection and to make the necessary amendments.

The pre-test further helped the researcher to identify the misunderstandings of different questions and equally helped to determine if there were limitations or weaknesses in the interview design (Creswell, 2014b). The pre-test was conducted with three grandparents caring for AIDS orphans in each study setting, and the result was that participants understood the questions/issues discussed and responded appropriately. However, the three participants (in each study setting) were excluded in the subsequent interviews. There were no major changes done on the tool after the pilot study.

3.8.5 Data collection methods

Data collection is the precise, systematic gathering of information relevant to the research purpose or topic objectives (Polit & Beck, 2018). Researcher must carefully consider the type of information needed to answer the research question (Gray, Grove, & Sutherland, 2016). In a multi-method approach, data collection techniques are planned as part of the research design. The quality of data collection techniques defines the accuracy of research conclusions, and data collection procedures are equally critical (Creswell, 2014a).

In this step of the study, face-to-face semi-structured individual interviews with open-ended questions were conducted to collect data among grandparents caring for AIDS orphans. The aim was to explore and understand their experience, needs, challenges and their coping mechanisms while caring for AIDS orphans. The researcher asked predetermined questions using an Interview Guide (**Appendix 4)** and allowed for each participant to express themselves freely. The guide directed the researcher to control the interview sessions properly.

This method of data collection was chosen for grandparents because the researcher believed that participants could provide rich and in-depth data related to their experiences as the main caregivers of orphans. Furthermore, the method was selected because the researcher wanted to have personal and informal interaction with the grandparents caring of AIDS orphans, some of whom may not be literate and unable to complete a questionnaire. Moreover, it provided a basis for asking all the participants the same questions based on their experiences and about the support given to them, though with little variations. This made it possible to access a more detailed and wider perspective for understanding the subject under investigation.

By using predetermined open-ended interview questions, the researcher was able to probe for more elaboration of issues throughout the discussions. To facilitate the meetings, the researcher used communication techniques such as clarifying, probing, reflecting, paraphrasing and summarising. The interviews lasted between 30 to 60 minutes. With the consent of grandparents, the researcher recorded the interviews on a voice recorder. Pre-interview meetings were held with the grandparents where ethical issues regarding the study and an Information Sheet (**Appendix 6**) was explained.

3.8.5.1 *Semi-structured Interview Guide*

Interviewing is a process of verbal communication between the researcher and the participants for the purpose of collecting thick and rich data from participants in various settings (Creswell, 2014a). In-depth interviews are open-ended questions to obtain data of participants meaning that they ascribe to their world and how they make sense of important events (Gray, Grove, & Sutherland, 2016). Due to the sensitive nature of this study, a semi-structured interview guide (**Appendix 4**) with open-ended questions was designed as a tool for data collection. Thus, the

guide allowed for free expression from grandparents and assisted in exploring and describing how the challenges faced by grandparents in caring for AIDS orphans can be addressed.

Designing the interview guide followed the principles of a more general and structured nature to more specific questions. Questions were constructed for an effective semi-structured interview process to allow for adequate narration of participants 'experiences. They were brief, precise, neutral and open-ended, which allowed the researcher access to information that had not been anticipated, but it was flexible in that it allowed both the interviewer and the interviewee to diverge from the questions in order to pursue an idea/issue or to provide a detailed explanation. Questions were developed directly from the research questions that were the focus for the research.

3.8.6 Data Collection Process

On the day of interviews, managers of the NGOs welcomed the researcher and the research assistant and introduced them to the grandparents caring for AIDS orphans. The research team explained the aim of the study thoroughly and requested grandparents to sign a Consent Form (**Appendix 2**); if unable to read and write, the content of the document was explained to them and they were able to give verbal consent. Also, the consent form document was translated into the Xhosa language for the grandparents who are not English speaking **(Appendix 1**). The researcher made use of an experienced research assistant who was fluent in the English, Xhosa and Afrikaans languages to accommodate grandparents who did not speak English.

Data collection commenced with the Khayelitsha Community, then Mitchells Plain and ended in the rural area of Grabouw. The selected participants were informed about the interviews prior by the NGO'S field workers and they helped to prepare them as well as getting the room/s

ready for interviews. All English-speaking participants were interviewed by the researcher while the research assistant conducted all Xhosa interviews. Before the commencement of the interview, the researcher ensured that the setting was conducive and free from interruptions. Thus, the participants felt comfortable to share their experiences without fear of any overhearing.

The interview room had a table and two chairs which allowed for face-to-face interaction that facilitated observation and enhanced interaction. All participants were welcomed and were encouraged to relax and feel at ease. The researcher and the research assistant introduced themselves and explained the purpose of the interview; they also explained that the interview would be recorded for the purpose of capturing the information, and that anonymity of the participants' identities, as well as the confidentiality of the information were guaranteed. The Consent Forms and the Information Sheet were collected after it was duly signed and the permission to be recorded was sought.

The recorder was prepared before the recording and extra batteries were made available. The interviews were started as a social conversation in a relaxed and trusting atmosphere and gradually moved to become a highly interactive event. Thereafter, the researcher started to pose the questions for participants to respond. During the interviews, the participants were encouraged to express their feelings regarding caring for AIDS orphans, and to discuss their experiences and opinions regarding the support system available to them.

The interviewer's listening skills were essential in identifying emerging issues that had not been considered earlier yet were applicable to the research (Creswell & Creswell, 2018). Probing questions enabled a better understanding of the experiences, thereby providing a more

involved experience (Merriam, 2014). While the participants did most of the talking, the researcher listened to responses, and wrote down notes. The researcher was attentive to the responses in order to identify the new emerging lines of inquiry that were directly related to the phenomenon under study, and further explored these through probes. When the participants diverted from the main question asked to other aspects that were not related to the study, the researcher guided them back to the focus of the interview.

However, the researcher kept the neutral researcher role by allowing free expression of the participants 'experiences without being judgmental and by avoiding any leading questions. Non-verbal communication, such as the facial expression and tone of voice were also noted. As a measure of good interviewing procedure (four [4] months after interviews), the researcher went back to the participants to verify whether the researcher understood what they shared with her and what they meant (Polit & Beck, 2018). This is referred to as member checking (Candela, 2019). Furthermore, the researcher ensured she paraphrased and read the participants 'responses back to them to ensure that they have the same understanding of the issue under discussion.

Field notes were written during and after each interview and attached to the corresponding recordings. The researcher and the research assistant used facilitative communicative techniques such as probing questions, clarifying a point, observing and expressing non-verbal encouragement and minimal verbal response as well as concluding to facilitate interviews and discussions. All these techniques helped to acquire more useful and detailed information from the participants. Saturation was reached when participants were no longer giving "new" information. The interviews were audio recorded while the researcher and the research assistant

took notes of non-verbal communications. At the end of each interview, notes were compared. Each interview took approximately 30 to 60 minutes duration.

3.8.6.1 *Field notes*

Field notes are the detailed notes gathered in the process of data collection and observations that are made by the researcher (Creswell & Creswell, 2018). The field notes tend to capture points or issues which the researcher missed during the interviews (Denzin & Lincoln, 2018). In this study, the researcher took the field notes immediately after each interview, these were observatory in nature and included the aspect of facial expression of sadness, regrets, crying, and pain in grandparent's voice as indicated by Polit and Beck (2018), to prevent the researcher from forgetting some aspects that might affect the research findings. According to Creswell (2014a), field notes include descriptive notes, which are the descriptions of the participants, the physical setting, the interviewer's account of particular events that happened and activities that took place during the interview.

3.8.7 Analysis

According to Denzin and Lincoln (2018), data analysis starts with organization of data, which involves the transcription, organization and development of categories and coding of data. The objective of qualitative analysis is to produce a thorough, systematic recording of the themes and issues addressed in the interview and to link the themes and the interviews together under the reasonable comprehensive category system (Denzin & Lincoln, 2018; Creswell, 2014b). In this study, data analysis followed a thematic content approach which was achieved using the ATLAS.ti.packages. All the concepts were coded, transcribed and analysed using a thematic approach.

Complete readings were done to filter and clean the data, to familiarise and immerse self in the data and ensure that the participant became the focus of analysis. The considerable size of data was condensed and categorised to a manageable size. The researcher referred to a code book and ideas were written down as they occurred to the researcher. The codebook served as a reference throughout the study.

The codebook was developed iteratively by reaching a consensus on the analysis of shared transcripts to create an all-encompassing set of codes. The ATLAS TI software programme was used to maintain an electronic database of the consensus analysis of transcripts, information about each code, and a detailed log about the process of developing the codebook. Each transcript was read and re-read to gain insight into participants 'experiences and enabled the researcher to arrive at a description of the participants' feelings in order to make meaning of them.

The researcher with the research assistant immediately transcribed the interviews in order not to lose vital data, then organised and categorised them in different themes. The interview data were coded with letters and colours and grouped according to each participant's identification. A code was assigned to individual text and line numbering was allocated to text, which enabled the researcher to trace back from which text the data was extracted. Codes served as pointers to the data set and to ascertain the variety of ideas mentioned in the data as they assisted the researcher to identify areas with important issues and also facilitated quicker retrieval.

Development of the themes was done by immersion in the data and field notes served as points of reference coupled with an experienced independent coder who coded the data and after a consensus discussion took place. This added credibility to the study. The findings of Phase One

were used to develop the strategies in Phase Two. Because of the difference in the characteristics of the population per setting, analysis was done separately; comparison and integration followed in order to make meaningful interpretation.

3.8.8 Validation of Data

Data validation is the means by which participants confirm information already provided or change it to new information if they feel that what was initially provided was not accurate (Ravitch & Carl, 2019). In this line, after each interview, the audiotapes were played back to the participants to have them confirm or make any necessary changes so that any new idea that could have emerged could be clarified. In the case of any changes arising, a special note was made. This extra information was later incorporated into the transcripts. In cases where the researcher wanted further clarification on any new topic, a return to see participants was arranged. In addition, listening to the audio recording by the supervisor and the co-supervisor also served as member checking and this was done to ensure that the recorded information was clear and of high quality.

3.8.9 Transcription Procedure

According to Castleberry and Nolen (2018), data transcription is the process of transforming verbal and visual data into words, and the process can only be achievable after interviews have been recorded accurately. For the current study, the researcher immediately transcribed all the interviews to avoid missing relevant data. Moser and Korstjens (2018) advise that researchers should personally transcribe the interviews as in doing so they live with the data, familiarising themselves with and immersing themselves within it. Therefore, the researcher followed these steps as it allowed for easy detection and recognition of recurrent ideas and patterns. The

preliminary analytic procedure was used to make the quantity of data more manageable while at the same time maintaining the quality (Creswell, 2014; Castleberry & Nolen, 2018).

3.8.10 Data Cleaning

Cleaning of data is a means of denoting unsound information in the transcribed data. The denoted information is not related to the research topic under investigation (Chu & Ilyas, 2016). Therefore, the researcher read through the transcripts several times to get rid of information that was unrelated to the topic under investigation. The researcher also compared the data with the field notes collected. The unnecessary information in the transcribed data was then filtered out to make the content more inclusive and easier for coding of data.

3.8.11 Coding

Coding is an interpretive technique of qualitative data analysis, and the method assists the researcher to resolve the problem of repeating the same thing and arrange different information given in the interviews conducted (Wicks, 2017). In this study, the researcher completed analysis by the use of computer software called *Atlas. it* version 8.2. The researcher entered the transcribed word documents into the *Atlas ti* software, and saved the transcribed individual interviews accordingly (e.g., participant 1) in which order the researcher completed the interviews. The dynamic process associated with thematic content data analysis is what the researcher went through by following the steps below:

a) Reading through the document line by line.

b) Highlighting important phrases and sentences.

c) Coding them accordingly and then sorting information that relates to the objectives of the study.

d) Assigning codes to each sentence to represent a meaningful unit.

Assigned codes were reasonably short. Some were newly created while others were as per the original phrases from the data. Codes that had similar labels or colours were put together as families.

3.8.12 Creating of Families and Themes

As previously mentioned, the codes that looked similar were combined to create "families", and similar families were, in turn, put together to form themes. Thereafter, the researcher used the inductive approach to thoroughly read the transcripts in an attempt to generate recurring patterns. Thus, the researcher used an inductive reasoning process to identify themes and categories to develop a detailed description of the phenomenon (Polit & Beck, 2018). Alongside coding, the researcher created memos to assist with initial discussions. Memos are notes made by the researcher on the side of coding to help the researcher remember the reason or purpose of some coding. At this point in the research, the researcher organised themes and categories with respect to the research objectives.

3.8.13 Scientific Rigour

In qualitative research, trustworthiness of the quality of data collected is examined in terms of confirmability, dependability, credibility and transferability (Smith & McGannon, 2018). Polit and Beck (2018) confirm that trustworthiness is ensuring scientific rigour in qualitative research without sacrificing relevance, and that findings in qualitative research must reflect the truth on the ground as experienced by human beings. Follows is the discussion of how trustworthiness was applied in this study.

3.8.13.1 *Credibility*

The credibility of a study is the means of ensuring that the researcher institutes and displays the "true" picture of the phenomenon of the study (Tracy, 2019). Credibility may be ensured by member checking, peer debriefing, triangulating the different methods of data collected, and prolonged engagement with participants (Connelly, 2016). Member-checking credibility was adopted by asking the participants to check the transcribed data to ensure that their views were accurately represented. For the participants who could not read, the researcher and the research assistant read the transcripts to them. Multiple reviews of the field notes, audiotapes were used for data collection, data were transcribed verbatim, the neutrality of the researcher during the interviews, careful handling of the emotional expressions and the examination of the findings by an independent coder and supervisor (Daniel, 2019).

There was prolonged engagement with the participants and the data collected. The purpose for this engagement was to create rapport, verify information provided by the participants and to be familiarised with the grandparents caring for AIDS orphans in the various settings. Persistent observation was carried out in this study to identify some essential factors that could reveal additional experience of grandparents caring for AIDS orphans. Non-verbal communication played a vital role in bringing out the participants' behaviour during the interviews.

3.8.13.2 *Confirmability*

Confirmability is the ability of findings in the current research to be confirmed by other researchers (Cypress, 2017). It is also the situation where the researcher makes meaning of the phenomenon under investigation from the point of view of the participants and also to

understand the meaning of participants' experiences in the context of the study (Graneheim, Lindgren, & Lundman, 2017). In this study, confirmability was realised when the research results represented the precise description of grandparents' experiences as they lived and perceived them. Therefore, confirmability was achieved by documenting thick description of the process as an audit trail. A research audit aims at illustrating clear thought processes as well as evidence that establish conclusion in a research evaluation process. In the current study, the researcher recorded events associated with the study over time and documented all the processes of the study, which can easily be followed by anyone interested and still acquire similar results.

3.8.13.3 *Transferability*

Transferability relates to the degree to which research findings can be applied to other people or settings with similar context (Maxwell, 2020). Transferability has a goal of offering widespread information on the fieldwork which could help generalization of the collected data to other groups of people and/or settings (Hansen, 2020). In this study, transferability was achieved by providing detailed descriptions of the participants' characteristics, the phenomenon under study, and the researcher's reports on findings to encourage replicability.

3.8.13.4 *Dependability*

Dependability is the state of data consistency over time (Hansen, 2020). In qualitative research, dependability aims at ensuring consistent results of a study, which could easily be verified by another researcher in a different but similar context or setting (Polit & Beck, 2018). In this study, the researcher demonstrated the truthfulness of the data collected and analysed by presenting it as it is. Furthermore, dependability was also achieved through external audits. The external audit is the process of examining data processes of the research study and the main

purpose of external audit is to evaluate the accuracy of the research findings and how it is applied in the study (Creswell, 2014). In this study, the external audit was achieved through frequent checks of every stage of the research process and the transcribed data by the supervisor. Furthermore, an independent coder was employed to code the transcribed data, and thereafter, the findings were presented to the study supervisor.

3.9 Part Two: Quantitative Strand: Objectives Two, Three and Four

Quantitative research refers to an inquiry that uses a general set of formal, orderly, systematic, disciplined procedures to acquire numeric evidence i.e. evidence that is rooted in objective reality rather than in the personal beliefs or views of the researcher (Burns & Grove, 2014). In quantitative research, evidence is gathered logically through several steps, using a pre-specified plan that applies mechanisms to control the study and formal instruments to collect the necessary information (Polit & Beck, 2018). This ensures that bias is minimised and increases the validity and reliability of the study (Hancock, Stapleton, & Mueller, 2018). The purpose of using this method in this study was to gather data using different questionnaires to answer the research objectives two, three and four, as well as understand the nature of the phenomena and generate new knowledge and meaning for which no study had previously done (Burns, & Grove, 2014). Furthermore, MDT health workers and social development personnel are presumed to be too busy to yield to other forms of data collection techniques.

Two populations were explored with this method, which are termed Population 2 and Population 3. Population 2 was the multidisciplinary team (MDT) while Population 3 was the personnel from social development. For both populations, different job descriptions are involved. Thus, they were selected based on meeting the criteria set for the study. The following

sections discuss the population, research method, the sampling method, the pilot study, data collection and data analysis for the quantitative part of Phase One of the study.

3.9.1 Population

Population 2 comprised of fifty (50) Multidisciplinary team health workers who are referred to as MDT which are the professional nurses, psychologists and social workers in the selected study setting, while Population 3 comprised of fifteen (15) social development personnel (managers in government and non-government organizations) that served in the Khayelitsha, Mitchell's Plain and Grabouw areas.

3.9.2 Sampling method

The researcher employed a two-step sampling approach. Firstly, a stratified sampling strategy was used to select thirteen (13) community health centres [five (5) clinics in Khayelitsha, five (5) in Mitchell's plain and three (3) in Grabouw]. The same sampling strategy was used to select three (3) social developments services [one (1) in Khayelitsha, one (1) in Mitchell's Plain and one (1) in Grabouw]. Secondly, within each clinic and the social development service, the sample size was determined by employing an all-inclusive sampling method due to the small number of the population, but with some exclusion criteria. An all-inclusive sampling was considered fit for this study based on the assumption that the participants who possessed important information required for the study were few; therefore, excluding will further reduce the sample.

3.9.2.1 *Sample size*

The target sample size for the quantitative part was sixty-five (65) participants, which included Fifty (50) MDT participants (professional nurses, psychologists and social workers) from five

(5) clinics in Khayelitsha, five 95) clinics in Mitchell's plain and three (3) clinics in Grabouw as previously mentioned. Each clinic had at least three (3) professional nurses, one (1) psychologist and one91) social worker. In addition, fifteen (15) managers were selected (five (5) managers each from three (3) social developments services sites).

3.9.2.2 *Inclusion criteria*

i. The multidisciplinary team workers (MDT) included professional nurses, psychologist and social workers working in the clinics and community health centres for more than one year.
ii. MDT who are knowledgeable and working closely with grandparents caring for AIDS orphans and willing to participate in the study for the duration of data collection.
iii. Social development personnel who held a managerial position for more than six months.

3.9.2.3 *Exclusion criteria*

i. MDT who have not spent up to one year in the community health centres.
ii. Managers who have not held managerial positions for up to six months.

3.9.2.4 *Recruitment of participants*

Upon receiving the permission from the University of the Western Cape, both Western Cape Department of Health, City of Cape Town, and Western Cape Department of Social Development approved the study and provided the access to their health and social facilities and services (**Appendix 9**).

Population two (2) MDT were recruited through their facility managers after the researcher presented the study to them. The researcher was granted direct access to Population 3 after

presenting the ethics letter from the University and the permission from the social development head office.

The researcher made telephonically appointment to meet facility managers, and on the day of the meeting, the researcher was introduced to the various clinics and social development services. The researcher requested a comprehensive list of the names and contact details of all the potential participants. Thereafter, a request was made to meet the potential participants in the various clinics and social development offices. The researcher was allowed to provide a detailed explanation of the study, as well as to seek their commitment and cooperation for the overall success of the study. Those who were not present at these briefing meetings were contacted telephonically.

During the briefing meetings, the following issues were discussed: the importance of the study, the name of the researcher; the institution supporting the study; the participant's right to choose to participate in the study or not without any external influence, the responsibilities of the researcher towards the participants and the research study, the potential risks and benefits that could result from participation in the study, the approximate time it would take to complete the form, and the person's right to withhold information or withdraw from the study at any given time without any consequence (Polit, & Beck, 2014).

3.9.3 Data collection

The following section provides a discussion of the steps taken in the data collection process, commencing with the data collection tool and concluding with the data collection process.

3.9.3.1 *Data Collection Tools*

The study used self-administered questionnaires as the research instruments for the quantitative part. A questionnaire is a systematically prepared self-report form or document with a set of questions deliberately designed to elicit responses from respondents or research informants to collect data or information (Polit & Beck, 2014). All items in the tools were deemed relevant to an understanding of the nature, extent and problems of grandparents caring for AIDS orphans.

The researcher developed instruments in English. The rationale for the use of questionnaires is based on the fact that it is difficult to collect data from the MDT team and managers in social development services staff due to their busy and unpredictable schedules, thus making other methods of data collection unsuitable. Furthermore, it is cost-effective compared to face-to-face interviews, telephonic interviews or electronic questionnaires. It is easier to administer and uses less personnel. Moreso, the researcher, was able to monitor participants and decide on the appropriate time to distribute and collect questionnaires from them (Polit & Beck, 2014).

Development of the Questionnaires

The researcher developed the questionnaires from the evidence of best practice standards compared to the current practice in health care (Haber, 2019). The developed standard specified what should be provided to grandparents caring for AIDS orphans; hence, they were adapted to suit the particular objectives, design and context of the present study. The questionnaires also included the structure of care given (such as resources and services available for grandparents caring for AIDS orphans) and the process of care (such as investigating psychological, social and physical factors). Furthermore, the development of the questionnaires

was based on the extensive literature relating to the objectives of the study. The following paragraphs discuss the development of both questionnaires used for the MDT healthcare team and managers from the social development.

The MDT Questionnaire

The MDT questionnaire (**Appendix 7**) included both fixed-response and open-ended items and incorporated skip patterns. Thus, while the tool aimed primarily at capturing quantifiable data, to describe the situations, problems and support needs of grandparents caring for AIDS orphans, it also provided for the capture of narrative responses. The questionnaire was divided into three sections. Section A comprised of the demographics data of the respondents, whereas Section B and Section C determined the available support provided to grandparents in terms of psychological, social and physical support. Therefore, the tool evaluated the knowledge and attitudes of MDT on the challenges faced by grandparents caring for AIDS orphans in their services and the recommendations aimed at solving the identified challenges. The tool was tested, and table 3.2 below represents the reliability test on the perceived support given to grandparents caring for AIDS orphans.

Table 3.2 Reliability test: Multidisciplinary team questionnaire

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardised Items	N of Items
.719	.754	12

Social Development Questionnaire

The researcher constructed the social development questionnaire (**Appendix 8**) in two sections: Section 1 provided for the demographics of the participants and Section 2 comprised of fixed-response items, in which responses could be measured using ordinal agreement (Likert) scales with ordinal variables such as 1 = excellent; 2 = good; 3 = fair; 4 = poor. The researcher also tested the questionnaire, and table 3.3 below show the reliability test.

Table 3.3 Reliability test: Social development questionnaire.

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardised Items	N of Items
.811	.814	9

3.9.3.2 *Pre test*

A pre-test is a small-scale version of a full-scale study. It considers the entire study but uses a sample smaller than the target population in the same study setting (Polit & Beck, 2018). A pre-test aims to investigate the feasibility of the proposed study and detect possible flaws in the data collection instruments (Buschle, Reiter, & Bethmann, 2020). Furthermore, it enables the researcher to avoid any pitfalls in the study‘s data collection process by giving insights into the unexpected problems and allows the researcher to gain experience with the data before the actual implementation of the study (Polit & Beck, 2018).

Consequently, the researcher can deal with unforeseen problems such as rephrasing ambiguous instructions or wording, terminology, sequence and length of the questions. In this study, the researcher submitted the questionnaires for comments and suggestions to seven (7) respondents: four (4) for the MDT questionnaire and three (3) for the social development questionnaire. The pre-test population had similar characteristics to the study population. The researcher made the recommendations concerning the organization of the items (e.g. keeping similar concepts together, so that the questionnaire can follow a logical sequence). The researcher incorporated the changes into the surveys before data collection.

3.9.4 Data collection process

The researcher collected Data from MDT, and managers from the social development using two different questionnaires (**Appendix7 and Appendix 8)**. The researcher selected this data collection method for these two populations because it could evaluate fully the services given to grandparents caring for AIDS orphans. It also examined whether the services provided by the government was reaching grandparents caring for AIDS orphans.

The researcher held a Pre-data collection meeting separately, starting by the Multidisciplinary team (nurses, social workers and psychologists) followed by managers in the social development services. At these meetings, the researcher explained the content of the questionnaire, ethical issues regarding the study and the information sheet. The researcher assured participants of the anonymity and confidentiality.

On the day of data collection, the researcher provided the questionnaires (**Appendix 7 and Appendix 8**), Information sheets (**Appendix 6**) and requested them to sign the consent form

(**Appendix 2).** The researcher administered the documents manually in sealed envelopes and handed the envelope personally to the participants who volunteered to participate in the study. The participants received the questionnaire in their respective offices. The researcher indicated a due date for retrieval of the questionnaires, which was respected by them. The researcher allowed the participants to ask questions, and the response rate was 100%.

3.9.5 Data Analysis

Data were analysed using the Statistical Package for Social Science (SPSS) Version 25. The researcher analysed the data with the assistance of the statistician employing the application of SPSS Version 25 software programme. The researcher reported the results using descriptive and inferential statistics in frequencies (f), means (M), percentages (%) and standard deviation. Where the researcher noted the discrepancies, the researcher traced the original questionnaire through its unique identification number, and the researcher corrected data entry item accordingly. The researcher analysed open-ended questions on each questionnaire using content analysis which the researcher will discuss in the analysis and interpretation of data in chapter five.

3.9.6 Validation of findings with grandparents

After obtaining the results of the MDT team and social developments personnel, a follow up was done on the previous interviewed grandparents caring for AIDS orphans (N=25), and descriptive comparisons was made. This exercise aimed to compare the grandparents' definition of availability of support with the available support reported by the latter populations, hence answering Objective Four of the study: To compare the grandparents' perceptions of available support with the available support for grandparents caring for AIDS orphans in Western Cape Province of South Africa.

3.9.6.1 *Population and Sample*

The same grandparents who participated in a qualitative part of the study (population one; *N*=25) formed the sample for this objective. However, the NGO field workers added one extra participant who missed the previous interviews due to illness, hence the total number of the population for the validation came to twenty-six (*N*=26). This addition did add value to the study data because despite the participant having missed the first interview, she was still informed enough to give input for the comparison.

3.9.6.2 *Data collection*

The researcher approached the previous interviewed participants to participate in the quantitative comparative study. Ethical issues regarding the research and the Information Sheet were explained to all grandparents caring for AIDS orphans. The researcher explained the purpose of the study, assured grandparents of anonymity and confidentiality and requested them to sign the Consent Forms (**Appendix 2).** Data from grandparents were collected using a checklist questionnaire (**Appendix 11**); listing the primary services that supposed to be provided to them as identified in the Quantitative Survey of the MDT. The researcher chose this method because it can evaluate fully the services given to grandparents caring for AIDS orphans, and it also looked at whether the services provided from the government is reaching grandparents caring for AIDS orphans.

3.9.6.3 *Data analysis*

Descriptive statistics were computed using correlations. The data provided a comparative analysis which addressed Objective Four. Frequencies and percentages of perceived supports and the socio-demographic characteristics of the respondents were provided, the statistics

obtained on the perceived availability of support were compared with the available support reported by grandparents caring for AIDS orphans. Comparisons were also made between grandparents from urban areas and those from rural areas.

3.10 PHASE TWO: OBJECTIVE 5 - STRATEGY DEVELOPMENT

Objective Five was to develop strategies to improve the support given to grandparents caring for AIDS orphans in Western Cape Province of South Africa. Phase Two of the study addressed the main objective of the study which aimed at developing strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province of South Africa. The development of the strategies was based on the Phase One findings through conclusion statements and the TQM philosophy as adopted by Tenner and De Toro (1992).

3.10.1 The Delphi research method

The Delphi technique is a widely used and accepted method for gathering data from respondents within their domain of expertise. It is designed as a group of communication process that aims at conducting detailed examinations and discussions of a specific issue for goal setting, policy investigation or predicting occurrence for future events (Sekayi & Kennedy, 2017). It employs multiple iterations commonly called rounds which are designed to develop a consensus concerning a specific topic through a feedback process. In each round every participant works through a questionnaire which is returned to the researcher who edits, and return same to every participant with a statement of the position of the whole group and the participant's position. A summation of comments made enable each participant to be aware of the range and reasons underlying each opinion in each round (Brady, 2015).

In this study, the researcher used a Delphi technique to obtain consensus for strategies that will improve the support for grandparents caring for AIDS orphans in the Western Cape Province. The researcher chose the method based on the value that it is believed to be a more potent methodology for a rigorous query of experts and stakeholders (Brady, Jason, & Glenwick, 2015); hence, it served the purpose of obtaining the most reliable opinions and agreement from experts. The data which formed the basis of the Delphi was from the conclusion statements (see chapter five) developed from the results of Objectives One to Four.

3.10.1.1 *Types of Delphi*

The Delphi process can be either quantitative, qualitative, or both. The various types have further been clustered together into three and referred to as conventional or classical, real-time, or modified and policy Delphi (Brady, Jason, & Glenwick, 2015).

3.10.1.2 *The conventional/classical Delphi*

The conventional Delphi refers to the classical forum for the prioritization of facts. It consists of a questionnaire sent out to a group of experts, with a second questionnaire based on the results of the first. Responses to the questionnaires are anonymous with the participants known only to the researchers but not necessarily to the other participants (Avella, 2016).

3.10.1.3 *The modified Delphi*

The modified Delphi require panellists to meet face-to-face as a group with an experienced moderator to handle the session. It is a shorter variant, and the process takes place during a meeting, using mechanisms to immediately summarise responses from the respondents (Toronto, 2017). Developing and understanding a subject and the fact that participants should

possess knowledge is central to this Delphi method since it represents key features in qualitative research (Brady, Jason, & Glenwick, 2015).

3.10.1.4 *The policy Delphi*

The policy Delphi is used when the aim is to devise a strategy to address a specific problem. It entails the constitution of a forum for ideas where the decision-maker (or researcher) is interested in having an informed group present options and supporting evidence rather than having the group reach a consensus (Avella, 2016; Messner *et al*., 2016). In this study, the researcher used the conventional Delphi because it can collect information from a range of experts and panellists in different locations who can be included anonymously, thus avoiding dominance by one member. The researcher believes that ideas generated by these experts and stakeholders are rigorous and can contribute significantly to broadening knowledge within the community nursing profession towards a final decision that will lead to the creation of a sustainable and verifiable document.

3.10.2 Population and sampling technique

Prospective participants were identified before the commencement of the process (Avella, 2016). The population refers to persons whom the researcher assumes to possess the information required to which there is no specific number or size but must be broad enough to take care of all aspects of discipline to provide the needed information (Kemp & Avella, 2016). The population for this study was eleven (11) experts and they were persons in the field of community nursing, public health, HIV and AIDS, and social services. The purposive sampling technique was applied to select the experts for this part of the study.

3.10.3 Recruitment

The researcher identified the panellists and obtained their contact details. The researcher assembled information of all regional, national and international professionals who were knowledgeable, and who hold experience in the field of elderly, HIV and AIDS, community nursing and public health policy. The researcher solicited their availability and their willingness to serve on the panel. The researcher made contact personally, and via email, but in some cases, the panellists did not require the researcher's physical presence as they were satisfied with the information received through electronic media. The following were the selection criteria for the experts:

3.10.3.1 *Inclusion Criteria*

As the Delphi procedure rests on the adequate identification of experts and their participation, an initial task was to operationalise the concept of "expert"; hence, the researcher used the following indicators of expertise in health and social services:

i. Publications in the field of HIV and AIDS, especially grandparents caring for AIDS orphans, social development and public health policy and/or being involved in elderly and HIV and AIDS based research, ideally over an extended period of five (5) years and more.
ii. Professional nurses (head of units) with an extended work experience period of five (5) years and more of services in the field of community nursing.
iii. Involvement in the teaching for an extended period of more than five years (5) in the field of community nursing in the tertiary academic environment.

iv. Top management staff in social development with work experience of more than five (5) years.

v. An operational MDT (social workers, psychologist and professional nurses) in any managerial or decision-making position.

vi. Management of NGO's for more than five (5) years in the field of HIV and AIDS.

vii. A Multidisciplinary operational team in any managerial or decision-making position.

3.10.3.2 *Exclusion criteria*

The study excluded those who do not fit into any of the above criteria.

3.10.4 Data Collection Tool

A self-administered questionnaire was used for data collection (**Appendix 1**).

3.10.4.1 *Development of the questionnaire*

A summary of conclusion statements from the problems identified in phase one (1), lead to the development of five (5) objectives. These were translated into aims and performance objectives backed by the TQM principles that served as a framework to guide the development of the strategies. Performance objectives were stated in the form of tactical actions and expected outcomes for interventions to achieve adoption, implementation, and sustainability of the strategies that would improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa.

3.10.4.2 *Format of the questionnaire*

The first draft of the strategies was developed by the researcher based on the identified problems and conclusion statements drawn in Phase one. A sixty-five (65) item questionnaire

was developed from the performance objectives of the TQM philosophy. The vision and mission statements for the healthcare facilities were developed. This enabled aims and objectives to be created which laid the foundation for the questions posed in the questionnaire to the panellists. The initial questionnaire was divided into two documents. The first document contained the draft overview of the research problem and its findings, while the second document was the proper questionnaire.

The researcher divided the questionnaire into two sections: Section A determined demographics of the panellists, and Section B requested inputs from the panellists about the original strategy in a quantitative and open-ended-question format. This required panellists to comment and motivate regarding the scores they assigned to each domain if those scores fell below 75.0%. Comments were also solicited on the overall strategic document, which served as a baseline for the next phases that were formulated in an open-ended question using a Likert scale of five (5) with ratings of 5= strongly agree; 4 = Agree; 1= Neutral; 3= strongly disagree, and 2= Disagree.

3.10.5 Pre- test

After drafting the questionnaire, the researcher gave it to three (3) independent staff members: a lecturer at the tertiary level in community nursing, a manager of an NGO involved with grandparents caring for AIDS orphans and a public health consultant. They made suggestions about the voluminous nature of the draft document and its technical nature. These suggestions helped in reducing the size of the document and reframing the questions.

3.10.6 Data collection process

The researcher sent the information sheet (**Appendix 12**) and consent form (**Appendix 2**) to the selected experts before the commencement of the study, and the experts agreed to serve on the panel. Initially, they indicated their preferences on how they would like to receive their questionnaire. Some preferred to receive it electronically, while others requested both hard and soft copies. The researcher played a vital role in reminding the participants of the dearth of immediate response, and the researcher made follow-up phone calls to panellists as a reminder.

3.10.7 Data Collection Technique

The data collection method in a Delphi technique is called rounds (Brady, 2015). In this phase, data collection occurred in the following three rounds:

3.10.7.1 Round One

This process began with a quantitative and open-ended questionnaire (**Appendix 13**) which served as the cornerstone for soliciting specific information from the experts/panellists. The researcher sought their input and opinions regarding the authenticity, applicability, and measurability of the objectives and action plans for the draft strategies (**Appendix 15**) with a sixty-five (65) item close-ended and open-ended questionnaire. Data from the first round were analysed using SPSS Version 27 Software Programme, while the qualitative aspect was arranged according to the themes that arose from each panellist's recommendations and classified quantitatively for content analysis techniques (Avella, 2016).

Where several different terms were used for what appears to be the same issue, the researcher grouped them to provide a universal description. The researcher verified these descriptions and

grouping systems to ensure fair data representation. The researcher did not add items during analysis and maintained wording used by panellists with minor editing. The quantitative analysis allowed for median and modal answers to be discovered. The consensus was defined at 75.0% or more of the respondents 'agreement with a statement in all domains.

3.10.7.2 *Round Two*

Round two was the second phase of data collection in which some participants with below 75% consensus received a second questionnaire (**Appendix 14**) to review their responses. The researcher asked participants to recheck the summarised items based on the information provided in Round One. Ascertaining the level of collective opinion was determined employing descriptive and inferential statistics. The data from the ratings of the items to be analysed were conducted by producing statistical summaries for each item. Central tendencies (means, medians and mode) and levels of dispersion (standard deviation) were computed to provide participants with information about pooled opinions, enabled participants to gauge their response to that of the group.

3.10.7.3 *Round Three*

Round Three provided a final opportunity for participants to revise their judgments. A consensus agreement of 75.0% formed the basis for accepting the panellists' opinion as none of the panellists reviewed their responses further (Brady, Jason, & Glenwick, 2015).

3.10.8 Response Rate

In contrast to the common occurrence in Delphi studies that record a high attrition rate (Avella, 2016), only one panellist out of the initial twelve could not serve on the panel as planned. The

panellist was the lecturer in community nursing at a tertiary institution who was unable to attend due to work constraints. The response rate was thus 92.0 %.

3.10.9 Data Analysis

Data were analysed using both quantitative and qualitative methods. The researcher distributed Twelve (12) questionnaires with eleven (11) duly completed and returned, giving a response rate of 92%. The questionnaires from the panellists were assigned a code number for identification purposes before entry into the computer (Microsoft Excel) for analysis using SPSS Version 27 Software Programme. Where discrepancies were noted, the original questionnaire was traced through its unique identification number and corrected accordingly.

Data were interpreted through descriptive analysis by an initial conversion of the scores into percentages and reported in measures of central tendencies such as frequencies (f), median, and mode, whereas the qualitative aspect was grouped according to the categories and themes that arose from each statement and reported accordingly. The second questionnaire was analysed in the measures of central tendency alone because there was no qualitative aspect.

3.10.10 Validity of the Questionnaire

The researcher ensured Content validity by constructing the questionnaires based on the identified problems and the literature search based on the TQM philosophy. The researcher conducted consultations with experts in community nursing, HIV and AIDS, Social Services, and Public health fields. Furthermore, the researcher conducted a pilot study with a population with similar characteristics as the study population and incorporated their suggestions into the final questionnaire. The researcher consulted with the supervisor, statistician, as well as the

diligent and rigorous selection of panellists who are experts in their chosen field, which increased the credibility of the tool.

3.10.11 Reliability of the questionnaire

The researcher developed the questionnaire based on the objective of this phase in consultation with experts, including a statistician to enhance measurement using Cronbach‘s Alpha. This yielded values that were higher than 0.5. (Table 3.4)

Table 3.4 Cronbach Alpha Reliability of Delphi Questionnaire

	Cronbach's Alpha
Vision Statement	0.701
Mission Statement	0.919
Value Statement	0.669
Principles	0.863
Objective1	0.729
Objective2	0.630
Objective3	0.784
Objective4	0.929
Objective5	0.867

Table 3.4 shows that Cronbach’s alpha is more than 0.6, thus regarded as high and appropriate, as seen in the table, which has the domain of the entire question scoring above 0.5.

3.11 Measures in Quantitative Study

Measures of rigour in the quantitative strand will be discussed in terms of terms of validity and reliability.

3.11.1 Validity

The validity of an instrument is a determination of the extent to which the instrument adequately measures what it is intended to measure and the integrity of the result generated from it (Brannen, 2017). In this study, the researcher tested all the instruments for validity and reliability using the Cronbach alpha (α) coefficient before being used. Normally, the Cronbach coefficient of the items' scale should be above 0.6 (Souza, Alexandre, & Guirardello, 2017). The Cronbach coefficient of the instruments used in the study was above 0.7 (table 3.2; 3.3 & table 3.4), which indicated good internal consistency, meaning that items that make up the used scale hang together, and no single item in the scale suppressed the alpha level. Therefore, the used instruments measured what it was intended to measure.

3.11.2 Construct validity

Construct validity is the degree to which a group of variables represents the construct to be measured (Brown, 2000). To establish the construct validity, some predictions are made based on the construction of hypotheses, and these predictions are tested to support the instrument validity (Souza, Alexandre, & Guirardello, 2017). In this study, the researcher maintained construct validity by using experts to make judgments about the developed vision and mission statements to form strategies.

3.11.3 Content validity

Content validity is used to measure variables of interest and is obtained from three sources, namely: literature, representative of relevant populations, and experts (Burn & Grove, 2014). Addressing content validity also should begin with instrument development. In this study, content validity was ensured through an extensive literature review and consultation of experts.

Furthermore, the researcher conducted a pre-test with a population that had similar characteristics as the study population to ensure that participants would understand the constructs and terminology of the questionnaires. The findings from the literature review and suggestions from pre-test studies were incorporated into the final questionnaires in consultation with the supervisor and the experienced statistician who worked in the Statistic Department at the University of the Western Cape.

3.12 Ethical Consideration

All research that focuses primarily on human beings must be of a high standard that protects the rights of the participants (Polit & Beck, 2018). The principles of beneficence, respect for persons, and justice are the fundamental ethical principles in research, which function to protect the participants' human rights of self-determination, privacy, anonymity, confidentiality, fair treatment and protection from discomfort and harm must be adhered to (Burns & Grove, 2014, Brittain *et al*., 2020). Approval to conduct this study was duly obtained from the University of the Western Cape Ethics Committee (**Appendix 5**), and permission was obtained from the various health institutions (**Appendix 9**) and social services (**Appendix 10**) where the study was conducted. Thereafter, consent for the study was obtained by asking participants to fill and return the consent forms after due explanation of the study.

The researcher provided detailed information on the aims, objectives, potential benefits of the study, data collection process, and the voluntary nature of their participation. Voluntary consent was obtained when the participants demonstrated a clear understanding of the essential information provided. In respect of the adherence to the principle of the fundamental rights of the participants, the study paid serious attention to the following:

3.12.1.1 *Principle of Beneficence*

The principle of beneficence can be described as doing good and preventing harm, which may be physical, emotional, spiritual, social, economic, or legal (Creswell & Creswell, 2018). The researcher has a responsibility to conduct research that will protect participants from discomfort and harm while bringing about the greatest possible benefits and minimising all risks involved in the research (Brittain *et al.,* 2020). In this part of the study, the researcher did not envisage any harm in the process of research. Participants were protected from physical and psychological harm since careful thought was given to avoid intrusion into the participants' wellbeing. The contact details (mobile number and email address) of the researcher and the supervisor were made available to participants should they require further clarification.

3.12.1.2 *Freedom from exploitation*

The researcher has the responsibility to ensure that the participant is not placed in a disadvantaged position, is not exposed to an unprepared situation and is not exploited in any way (Polit & Beck, 2014; Brittain *et al.,* 2020). In this study, the researcher ensured freedom from exploitation by informing the participants of the nature and purpose of the research (**Appendix 3 and Appendix 6**) and assuring the participant of his/her voluntary participation in the study and that all information shared with the researcher during the study will not be used against him/her or his/her respective MDT department/unit in the clinic either as a staff member or grandparent seeking care in any way.

3.12.1.3 *Risk Benefit Ratio*

While agreeing to the fact that investigations that entail divulging personal information may result in some emotional discomfort, there was no foreseeable physical, emotional, spiritual,

social, economic or legal risks involved in this study except for the time that each individual invested in the completion of the questionnaire and granting interviews.

3.12.1.4 *Respect for persons*

This principle of respect refers to the researcher's acknowledgment that the participant is an autonomous individual who is capable of self-determination and individual choice (Babbie & Mouton, 2012). Respect for persons also includes the protection of those individuals with diminished autonomy such as the widows, orphans, and the handicaps (Polit & Beck, 2014). In this study, all subjects were treated as autonomous agents as they were informed that their participation in the study was voluntary and that they have the right to withdraw from the study at any time without penalty (**Appendix 2**).

3.12.1.5 *Right to full disclosure*

Full disclosure means that the researcher fully informs the participant of the following:

1. The purpose of the study.
2. The person's right to voluntarily choose to participate in the study or not.
3. The responsibilities of the researcher towards the participant and the research study.
4. The potential risks and benefits that could result from participation in the study and
5. The person's right to withhold information or withdraw from the study at any given time without any consequence (Burns & Grove, 2014).

Participants were informed that the information they provided would assist policy makers and the planners of support programmes for older caregivers such as themselves but that participation in the study would not offer them any direct material benefit (**Appendix 6**)

In this study, the right to full disclosure was further respected by ensuring that each questionnaire was accompanied by a cover letter so that each participant was fully informed about every aspect of the study.

3.12.1.6 *Right to privacy*

Privacy is the freely chosen ability of the participant to decide when, how, and under which circumstances personal information may be shared with others (Burns & Grove, 2014). Thus, when a participant agrees to partake in a research study it is the researcher's responsibility to ensure that all data collected throughout the study will be kept confidential through the processes of anonymity and confidentiality. Anonymity is ensured by keeping the identities of the participants secret while confidentiality is assured by keeping all data that was gathered during the study safe, and guarding against any information being divulged or shared with any other person (Burns & Grove, 2014; Polit & Beck, 2014).

The researcher ensured anonymity and confidentiality by keeping the names, contact details of participants, and the study setting to the researcher, the supervisor, and the statistician. The researcher assigned a unique code number to each participant's questionnaire, and the transcribed interviews. The researcher kept all the collected information in a locked filing cabinet at the office, and all computers and backup media on which data was stored, were password protected.

The researcher stored the master lists containing individual participant names, contact information, and numerical identifiers separately from the surveys. All raw data collected shall remain the property of the University of the Western Cape, and paper versions of the completed

survey will be destroyed by shredding five years after the conclusion of the project. In addition, electronic data will be deleted upon completion of the project.

3.12.1.7 *Informed consent*

Informed consent means the prospective participant agrees to participate in the research study after receiving the necessary information (**Appendix 2**), with the person having an adequate understanding of the research that is to be conducted, a free choice to take part in the study, and being capable to make such a decision (Creswell & Creswell, 2018). If the participant complies with all these elements, a written consent form is signed by the participant. Informed written consent must also be sought from the research site and the relevant authorities where the research will be conducted (Burns & Grove, 2014). In this study, ethics clearance was issued by the University of the Western Cape Higher Degrees Ethics Committee before the commencement of the study. The researcher provided Participants with a cover letter about the research study.

3.12.1.8 *Review by ethical committee*

The researcher submitted the research proposal to the ethical committee of the University of the Western Cape for review and for permission to conduct the research. A full proposal indicating the topic of the research, the purpose of the research, the research design and the ethical consideration that the researcher would adhere to was submitted. The researcher was granted permission to conduct the study for the University of the Western Cape **(Appendix 5**). Permission from Social Services to collect data from various NGO's and social development offices was given (**Appendix 10**); and the permission to collect data from MDT team from different healthcare facilities was given from the Department of Health (**Appendix 9**).

3.13 Limitations of the study

All research methodology and research designs have biases and limitations, and the present study had its constraints. Follows is a discussion of the study's limitations and how it was managed. All interviewed grandparents appeared on a list of clients of NGOs; thus, the sample was biased towards grandparents caring for AIDS orphans who had access to some form of intermediate support from NGOs. The results of the study cannot, therefore, represent the general population of grandparents caring for AIDS orphans, who do not have access to some form of assistance from NGOs or other support agencies or those who receive government subsidisation. Moreover, a large number of affected grandparents caring for AIDS orphans who do not have access to support from subsidised NGOs are not represented.

Due to time constraints and lack of sufficient funds, it was not possible to involve a wider research setting for the study and to include a larger study population to obtain more diverse responses. The sample was drawn from only three subdistricts of the Western Cape Province of South Africa. Thus, the situations, caregiving practices and challenges of affected grandparents in the other part of South Africa may differ. Therefore, findings from this study are not generalizable to the affected grandparents caring for AIDS orphans in the other provinces, or to South Africa as a whole.

3.14 Summary

This chapter outlined the methodology used for conducting the research and provided a detailed discussion of the qualitative and quantitative research designs. The research design was described following the aim and objectives of the study, and the research methods were described concerning the two major phases of the study, namely Phase One and Two. Both phases were discussed with the research instrument, population, the sampling method, data collection, and data analysis of the study. The chapter also discussed the Delphi technique adopted in developing strategies to improve support for grandparents caring for AIDS orphans. The scientific rigour of the study was explained and the chapter concluded with a portrayal of the ethical considerations of the study. The next chapter presents the qualitative findings of the study.

4 CHAPTER FOUR: RESULTS OF QUALITATIVE DATA AND DISCUSSION

4.1 Introduction

Chapter Three outlined the research methodology used in the study. This chapter presents and describes in detail the results of the qualitative strand that explored Objective One of the study. The chapter is organised in three parts which comprises an overview of participants' characteristics; presentation of the qualitative findings of the study in line with objective one; the chapter end with as a discussion of the findings.

4.2 Overview of the participants' characteristics

Twenty-five (25) grandparents caring for AIDS orphans were interviewed individually using a semi-structured interview guide. The number of participants was determined by data saturation. All the grandparents who participated in the study were females. It is worth mentioning that males were included in the study; however, the researcher did not come across male grandparents caring for AIDS orphans during recruitment.

Out of the twenty-five (25) grandparents interviewed, four (4) were married and living with their husbands, five (5) were divorced, seven (7) were single (never married); and nine (9) were widows. Furthermore, only two (2) grandparents were still working, one (1) grandparent was a domestic worker, and another one worked in a fast-food restaurant.

As shown in Table 4.1, all grandparents who participated in this study were between 56 to 75 years old, the majority of grandparents 71% (18) were between 60 to 70 years old, while 16.5% (4) ranged from 71 to 75 years and 12.5% (3) were between the ages of 56 to 59 years. The

participants were recruited from three different locations; namely, Khayelitsha at 36% (9), Mitchell's plain at 32%, and Grabouw at 32% (n=8). Most of the participants (88%: n=22) were retired, and out of the two (2) who were still gainfully employed, one had a professional position, and the second worked as unskilled labour. The number of years that the participants cared for orphans ranged from 2 to 20 years.

In this study, the total number of AIDS orphans cared by grandparents was 53, ranging from 6 months old to 20 years old, with the majority (30) 57% of them being between 3 to 13 years, followed by (21) 39% of them between 14 to 20 years, and a few of them (2) 4%) ranged from 6 months to 8 months old. Grandparents caring for AIDS orphans had between one (1) and four (4) orphaned grandchildren in their care. The majority of grandchildren in the study were considered healthy, with 37 (70%) of all orphans having tested HIV negative while 16 (30%) tested positive for HIV.

Table 4.1: Demographic information of participants

Variable		Number*(N=25)*	Percentage (%)
Age	56 - 59 years	3	12.5%
	60 – 70 years	18	71%)
	71 -75 years	4	16.5%
Marital status	Married	4	16%
	Widowed	9	36%
	Never married	7	28%
	Divorced	5	20%
Study location	Khayelitsha	9	36%
	Mitchell's plain	8	32%
	Grabouw	8	32%
Employment	Retired	22	88%
	Unemployed	1	1
	Employed	2	12%
Number of children under Grandparents 'care (n=53)	6 to 8 Months	2	4%
	3-13 years	30	57%
	14 -20 years	21	39%
HIV status of the children	HIV Negative	37	70%
	HIV Positive	16	30%

4.3 Qualitative findings of the study in line with objective one

This section presents the results pertaining to objective one of the study; which was to explore the challenges experienced by grandparents caring for AIDS orphans. Six main themes emerged from the collected data. Each theme was further divided into categories and sub-categories. Extracts from the participants responses were used to support the descriptions of the themes. The exact language and phrases that were used by the participants were maintained,

but for clarity, some grammatical amendments were made. Table 4.2 presents the summary of the themes, categories and sub-categories that emerged from the collected data.

Table 4.2 Categories, themes, and sub-themes emerged from qualitative results

Objective one: **To explore the experiences for grandparents caring for AIDS orphans in Western Cape Province of South Africa.**		
Themes	**Categories**	**Sub-themes**
1.Theme one: Challenges experienced by grandparents	1.1 Financial challenges	1.1.1 Poverty and lack of income 1.1.2 Difficulties accessing social grants
	1.2 Lack of support structures	1.2.1 Families support 1.2.2 NGO's support 1.2.3 Community and churches support
	1.3 Challenges with orphans behaviours	1.3.1 Disobedience, alcohol and drugs use amongst teenage orphans 1.3.2 Increasing demands 1.3.3 Poor academic results
	1.4 Perceived HIV and AIDS stigma in the community	1.4.1 Fear to disclose HIV status
2. **Theme two**: Grandparents response to the experienced challenges	2.1. General health response	2.1.1 Biophysical health 2.1.2 Emotional health 2.1.3 Social isolation
	2.2 Coping mechanism as a survival tactic	2.2.1 Happy with the kids 2.2.2 Talking to a friend 2.2.3 Sobbing as a method of reassurance
	2.3 Financial assistance appreciation	2.3.1 Income from children 2.3.2 Income from salary (own salary /husband) 2.3.3 Income from pension grant
3. Theme three: Grandparent's motivation to be the primary caregiver of orphans.	3.1 Personal motivation	3.1.1 Family bond and love of the children 3.1.2 Circumstances 3.1.3Absent biological parents
4.Theme four : Quality of health care services	4.1 Public health care services uses	4.1.1 Affordability 4.1.2 Accessibility 4.1.3 Level of satisfaction of care
5. **Theme Five:** Quality of social services.	5.1 Grandparents views on government system	5.1.1 Inadequate service delivery

4.4 Theme One: Challenges experienced by grandparents

Grandparents have taken on the primary responsibility to care for their AIDS orphaned grandchildren; however, this puts a strain on the grandparents taking the burden of raising these children. The emotional, physical, social, and financial challenges are vast. The participants in this study generally agreed that the challenges they experience while taking care of their orphaned grandchildren affect them in one way or the other often resulting in different manifestations, which are unique to each grandparent. These challenges were sub-divided into the following: Financial challenges, lack of Support Structures, challenges with Orphans Behaviours, and Perceived HIV and AIDS Stigma in the Community.

4.4.1 Financial challenges

The majority of grandparents caring for AIDS orphans complained that being a full-time caregiver to their orphaned grandchildren impacted on their financial status. The followings are findings regarding the financial challenges that they face.

4.4.1.1 *Poverty and lack of income*

Participants reported that they had challenges affording basic needs for their grandchildren since most of them were unemployed and the incomes they receive from the social services (child support grant and pension grant) are limited and insufficient to cover the monthly expenses, food, electricity, access to education, and health care while attending to their personal needs.

In this study, grandparents caring for AIDS orphans reported that they did not receive any additional financial support. Therefore, they lived in a situation of severe poverty leading to serious difficulties as they strive to meet children's basic needs such as clothing, shelter, food, and access to health care and education. They admitted that they are struggling to put food on the table, and they find it very difficult to meet their grandchildren's basic needs, including school needs. The following is an extract from the interviews;

> *"My main need is the food, school uniform for the kids, electricity, and money for them because the school all the time they ask for money for this and that and most of the time I don't have them. And that makes me sad because my kids will be looked down on at school. After all, other children brought, but my children don't have."*[P10; Age 73; Female]

On the other hand, for those grandparents who have been receiving some financial assistance, they reported that the money received was not enough to cover the nutritional and other basic needs of the children, such as school uniforms and other children's needs, as they are growing in age. This was confirmed by Participant 8 who mentioned,

> *"The remaining amount [of their social grant] I use for the clothes and electricity. And now that winter is coming; I must buy warm clothes for my grandchildren."*[P8; Age 62; Female]

Another participant mentioned that she could not afford clothes and shoes for them; she reported the following when asked if the money she received for the child support grant was sufficient:

> *"No, it is not enough because during the December holidays, I must buy the children clothes and they are very expensive, the shoes cost about R1000.00 per person. I bought clothes for the last in December last year. There must be food as well, and the girls*

would want their hair done, and they cost about R150.00. All of these things should be covered by this small amount that I am getting." [P5; Age 59; Female]

Additionally, another participant (P2) mentioned that she was using her pension money to fulfil the orphan's needs instead of taking care of herself,

"Another thing is the pension grant that I am using buying uniforms while I cannot even buy myself a pair of shoes because I cannot afford it." [P2; Age 64; Female]

Some grandparents indicated that they were still working as they needed the money. They also reported that being employed hinders their day-to-day activities of taking care of their grandchildren and the difficulties that come with taking them to the hospital for their monthly check-ups, which are obligatory as the requirements of their treatment differ from adult patients.

4.4.1.2 *Difficulties accessing social grants*

Grandparents caring for AIDS orphans reported the slow procedure to process the social grant applications as a challenge. Some of them further reported that they are not aware of what the process entails and do not understand what is required from; consequently, they were tossed from one office to another. One participant (P20) said,

"They only helped me at first when I arrived there; then they send me to see the magistrate at the court. Then when you come back, you won't be assisted by the same person, which makes it complicated because it is like starting from the beginning. This new person would ask you to bring other documents, and you find yourself going backwards. I started in 2008 to do all these processes. But I received the social grant in 2013. They explained that the money for the young child is there, but it is written in the name of the mother. I went to a certain place in town where they are helping with

similar issues. I explained my problem, they tried to help me then they promised me to get the money before the month of February 2018, and I got the money. If it was not for them, I was not going to receive the money." [P20; Age 71; Female]

During the interviews, some of the grandparents indicated that they found it difficult to access different types of grants for their orphaned grandchildren. Participants also mentioned that they were informed by the social development personnel to "bring documents". However, most of the grandparents often did not know where to source the required documents because most of the children were born to single mothers, who often did not disclose the identities of the biological fathers. Unfortunately, when these single mothers passed on, the grandparents were "stuck" with the duty of caring for the child/ren. In this regard, one grandmother (P21) said,

"*The only thing I always talk about is one thing; the application of foster care grant process is delayed because I can't get documents and is not fair that I have to go through all of this hardship without help at my age."* [P21; Age 67; Female]

Still, grandparents caring for AIDS orphans experience a problem of lack of birth certificates for the orphaned grandchildren. Grandparents often find it difficult to register the orphans for assistance without these vital documents, and, obtaining a birth certificate when no such documents were available, entailed finding some witnesses to prove a biological connection with the orphans. To make matters worse, in most cases, contact with the orphans' father after the death of his wife/partner has been lost. Often, as explained by the participant (P19) below, there was no contact between the in-laws after parental deaths,

"Yet, I cannot turn to their father for help because he also went to Cape Town and he never came back to look for his sons or speak to me." [P19; Age 62; Female]

Conversely, some grandparents (P4, P7) caring for AIDS orphans indicated that they were uninformed regarding any additional support that they were entitled to get, such as foster grant from the government.

> *"I didn't even know that the grandchildren were supposed to get a foster care grant. I was told that I could get child support for her [an orphaned grandchild], but at SASSA they told me that the child could not get the money because she is not disabled only if she was disabled she was going to get the money."* [P4; Age 67; Female]

P7 also confirmed that she was not aware of the foster care grant:

> *"No, I don't know of any support that I was supposed to get. I have never heard of anything like that [foster care grant]. What I know is that you get the money for the children that you not related with if you are related you won't get anything because the children are like yours."* [P7; Age 67; Female]

An additional problem faced by grandparents is related to delays in accessing governmental support for those who are registered. Some participants mentioned that they would spend days visiting the Social Development offices in vain with no clear explanation provided. Due to a lack of knowledge regarding legal procedures to challenge the situation, most grandmothers would not take any further action.

> *"I applied for a child support grant for my sick grandchild, and I gave the documents two years ago, but I am still waiting for the money. They would send me up and down telling me to wait. The doctor from side C clinic wrote a letter, even from that letter still I am not getting the money." [*P25; Age 60; Female]

4.4.1.3 *Identified problems*

Based on the responses of the participants, a range of problems have been identified.

1) Inadequate social grants to cover all the needs.
2) Difficulties accessing social grants.
3) Lack of birth certificates for grandchildren.
4) Slow process for social grant application.
5) Lack of clear communication between social service personnel and grandparents caring for AIDS orphans.
6) Lack of knowledge of different types of grants available to grandparents caring for AIDS orphans.
7) Grandparents caring for AIDS orphans are not aware of the rights of the children in their care, and they are being taken for granted by the system.

4.4.2 Lack of support structures

Lack of support structures emerged from interviewed grandparents, and the lack of support ranged from formal to informal. The following section provides a report on the lack of support received from the families, NGOs, and the community and churches.

4.4.2.1 *Families support*

Receiving support (emotional, physical and financial) is critical to grandparents caring for AIDS orphans. Some participants indicated that they did not receive any support apart from their pension grant nor any support from family member or neighbours. One participant recounted how a family member refused to help her, but did not feel discouraged from taking care of the orphaned grandchildren.

"I am not getting any support from anyone, even my own family. They do not want to help me, but I have no choice because I love my grandchildren." [P17; Age 62; Female]

"I am not getting any support from anyone else. Everyone is busy with their lives and their own problems, and even my own daughter doesn't care about these children she said that it is not her responsibility."[P20; Age 71; Female]

Her eyes filled with tears when she explained how she was shocked by the situation she found herself in and how she struggled to look after her deceased daughter without family help.

"To tell you the truth, this was a big shock of my life. I was not expecting to get old like this, but what shocked me most is the way my daughter is behaving. She doesn't want to help me to raise her own sister's kids, even when she was still in the hospital, I had to look after her myself. Nobody wanted to help her and touch her things because she had TB, but nothing happened to me, my child died a very painful death."[P20; Age 71; Female]

Some participants felt abandoned by their families and shared a sense of helplessness. Additionally, grandparents were forced to cope with stigma associated with caring for someone living with HIV. Family members disassociated from the children due to the stigma attached, causing grandparents to assume the full responsibility of providing care for the children in their old age.

"… Sometimes, I do feel abandoned… My own family don't help me to raise the kids, even ones who have kids their age don't want my kids to be around theirs because they think that they can infect them with AIDS. So I am always close to them."[P21; Age 67; Female]

Conversely, there were participants who reported receiving support from family members, although participants were forced to remind these family members before an offer to help was made. In this regard, P22 and P11 mentioned,

> *"My sisters do help me sometimes because they are working, they would give me some food and old clothes for the kids from their own children."* [P22; Age 72; Female]
>
> *"Sometimes, they help but not always. For them to help me, I have to remind them…"* [P11; Age 69; Female]

4.4.2.2 *NGO's Support*

Non-Governmental Organizations (NGOs) have played a crucial role in assisting disadvantaged communities to address various social issues. Notably, the Umthawelanga NGO in the Khayelitsha community helps grandparents caring for AIDS orphans by assisting them with their social grants application processes. NGOs also offer counselling to the carers of AIDS orphaned children, although the counselling service has stopped due to a lack of funding. These NGOs also offer assistance to children by helping them with their homework and created a support group for the grandparents. One participant (P4) confirmed that the support group was instrumental in getting the foster care grant, whereas P6 mentioned that they help the children with homework;

> *"I received it [Foster care grant] because of the support group at Umthawelanga. It wasn't easy to get it [foster care grant], but Umthawelanga tried to support me. I didn't even know that the grandchildren were supposed to get foster care because my own children never got the grant. So, I received this grant because of the sick child."* [P4; Age 67; Female]

"They provide counselling for the kids and help kids with homework. They try everything to help us."[P 6; Age 56; Female]

Most NGOs only provide counselling and other services but not financial aid; as illustrated in the following statement from P9;

"Here they only provide counselling, no other support" [P 9; Age 58; Female]

Also, not all the NGOs provide continuous support to grandparents caring for AIDS orphans. Some participants mentioned that the support they received was not consistent. They also experienced a sudden discontinuation of support from some of the NGOs. These grandparents were perplexed as to why they received assistance for a short and limited period, as it provided additional resources necessary for the care of AIDS orphaned children. One participant (P21) recounted;

"They used to call us at the end of the year to give us food and clothes, and now I don't know why they stopped…" [P 21; Age 67; Female]

4.4.2.3 *Support from the Community and Church*

Most grandparents mentioned that they received additional support from their neighbours to raise their orphaned grandchildren. They reported that the types of support range from behaviours assistance to food.

"My neighbours are nice to my kids, sometimes when I don't have food, I would send them to the neighbours to get some and they don't complain." [P10; Age 73; Female]

"Yes, I am getting some support, because I have a woman staying in front of me and she would tell me please don't smack her [referring to the

grandchild]. I will also help you to talk to her… Even now, I have the key in my bag if Charmaine will arrive from school, they will call her in their house and help her until I arrive. And you know I have this, if the child is wrong, they can punish them, I told them if they are parents they must do as parents not to wait for me to tell me, as long as they don't kill them. Because I told them if I am not there, you are there don't wait for me." [P 9; Age 58; Female].

However, not all participants seemed to have a good relationship with their neighbours. Some participants (P11, P18, and P20) mentioned that their neighbours did not "care" nor offer any support towards raising their grandchildren. Instead, they would gossip about their situation, increasing the stigma around care for AIDS orphans. One participant (P11) mentioned,

"I am not getting any support from anyone, my neighbours are just neighbours by name there's no relationship. They like to gossip about people …" [P11; Age 69; Female]

"My neighbours got issues. They don't like my children. They always report to me about their bad behaviour. Although children are just playing. You would hear them saying "they shouldn't play here because they could break our windows."[P18; Age 73; Female]

Other participants (P23, P20) referred not sharing their problems with their neighbours.

"I am not getting any support from anyone; I really like to keep my life private. I don't like the community to know about my problem. My neighbours are backstabbers so I don't like to show them that I am struggling with my children." [P23; Age 65; Female]

"No, I am not getting any support from anyone, my neighbours are mocking me [she has stigma associated problems because 2 of her children died from

AIDS]. There's no relationship. They gossip about my family, so I don't even tell them when my daughter is in the hospital. I like to keep it to myself." [P 20; Age 71; Female]

Some of the participants (P2, P13) revealed they get some support from their churches, in the form of food parcels, clothing and counselling from their pastor and fellow churches members.

"I think a lot, I went to my pastor, and he said I need to let it out to God. This battle is not mine…I get some support. They would come in the house to talk to them (my grandchildren)." [P2; Age 64; Female]

"Only the church sometimes gives me clothes for them [my grandchildren] and sometimes they provide food parcel." [P13; Age 64; Female]

4.4.2.4 *Identified problems*

1) There is lack of support from other family members to care for AIDS orphans.
2) The caregivers and carers of AIDS orphaned children are also stigmatised.
3) There is a lack of contact between the living biological parent and the grandparent carers.
4) While NGOs offer some level of support to grandparents who care for AIDS orphaned children, the support is inconsistent and unreliable.

4.4.3 Challenges with Orphans Behaviours

4.4.3.1 *Disobedience, alcohol and drug use amongst teenagers raised by grandparents*

Participants mentioned that they worried and stressed about their grandchildren, who were disobedient and not interested in schoolwork. They also mentioned that they found it very difficult to cope with teenagers' misbehaviours, and that it placed additional strain on their

overall health and wellbeing. Unfortunately, alcohol and drug abuse is rife among orphaned teenagers, making them less interested in getting an education. One grandmother (P20) said,

> *"I am having trouble with the teenager, he started smoking, and he is not listening to me, at school I was called because he was caught with dagga smoking at school, and he was given the last warning, but I am very worried about his future, he is not interested in school."* [P20; Age 71; Female]

Other participants (P5, P14) also complained about drinking behaviours of the grandchildren they are parenting. These are their recounted experiences:

> *"Yes, all four of them [AIDS orphaned children] are staying with me, but because the older child drinks too much, I told them they are old now they need to find their own place. Each and every person must be responsible for his or her life. I have played my part and you are old now. Now another son is staying alone in Site C next to police station. The other one is working at Stellenbosch University. I told him to look for a place to rent. He is problematic because he drinks a lot but when he is not drinking, he is a good boy."* [P5; Age 59; Female]

> *"The last two grandchildren are doing nothing. They don't want to go to school, they are just sitting at home. At times at school, they would call me complaining about the behaviour of these children because they are on drugs."* [P14; Age 69; Female]

4.4.3.2 *Increasing demands from teenagers*

Some participants raised concerns regarding raising teenagers at their advanced age and declining health. They highlighted the challenging nature of disciplining teenagers. Other participants suggested that increase demands from teenagers, asking expensive items from poor

grandparents constitute a huge challenge. Therefore, some teenagers end up displaying certain unacceptable behaviour in society and others become rebellious. Following is a quotation from one of the interviews;

> *"The girl is very troubling [referring to the grandchild]. She's fifteen but sleeps around. She went missing I was looking all over without a sign of her."* [P3; Age 75; Female]

Another participant (P6) expressed the frustration because she is not working, and she is below the age of 60 and not receiving pension grant. She also mention that the government doesn't make it easier for them, that they are expected to save the money to meet the orphans' needs. This is what she said;

> *"These children want everything, and the government says we must save money for them so we cannot use all of the money [money from child support grant], but the money is not even enough, I am not earning social grant. My son gets temporally jobs, so he supports only at that particular time when he's got lucky. The same child that wants to go to a farewell is asking for a cell phone .I asked if she wants them both "she said yes. Then, I told her she needs to choose one. She said, "That means am going to have a cell phone in a long time." I think she was asking me all these because she knows that they are getting money, yet they don't even know how small the money is…"*[P6; Age 56; Female]

4.4.3.3 *Poor academic results from orphans*

Due to continuous unacceptable behaviours, some orphans tend to underperform at school. A participant mentioned that her grandchildren used to stay away from school, and she was not

aware of it as they prepared for school in the morning but instead of going to school, they ended up in their own activities, which has nothing to do with school, at the end they failed:

> *"The two children did not do well [in school]. I have their reports with me. I went to school and talked with their teachers, so we are helping each other to their schoolwork, I was told from school that they tend to be absent a lot from school [both grandchildren]. I did not know that because I send them to school. When they are going to school, they were lying they would go to their friends and watch movies [instead of attending school]. The teacher also told me not to give them money and I told the kids that they are going to get nothing from me because when I give them money they don't come early from school."* [P24; Age 74; Female]

4.4.3.4 *Identified problems*

1. Grandparents caring for teenage AIDS orphans feel frustration and hopelessness due to their misbehaviours.
2. Grandparents lack the skill-set and energy to deal with the teenagers' deviant behaviours, which consequently affects their emotional state as they worry about their grandchildren's future.

4.4.4 Perceived HIV and AIDS Stigma in the Community

4.4.4.1 *Fear to disclose the HIV status of the orphans*

Some grandparents find it difficult to disclose the status of their grandchildren who are HIV positive, and or the cause of their children's death because they are scared to be mocked by their neighbours and other family members. This is what a participant had to say:

"No one knows [the HIV status of the orphaned child] only the family members. If they can know from the area, they would mock at her [the HIV positive grandchild]. Even when her eyes were red, they used to mock at her at school. Then, I told her that if they mock you again just tell them you are loved at your home." [P4; Age 67; Female]

Another participant was asked if she knew the status of her daughter before her death and she replied that her daughter never disclosed her status to her. Following is her account;

"I really don't know, maybe she was scared. Yes, even me, I was scared of HIV and AIDS first but now I am fine, it is a disease like other disease [HIV and AIDS]. I don't have a problem. I just wish my daughter didn't have to hide it from me because I was always wondering what happened to her, she was so sick and lost a lot of weight." [P18; Age 73; Female]

However, another participant was pleased to disclose the orphan grandchild's status to her neighbours as she was convinced that the community are aware of HIV and AIDS

"You know what? Stigma wise, I don't mind because in these days people know about it. No one is worried about HIV and AIDS anymore. Secondly, when they died [their mother and my other son] I did not hide it. I said it straight to everyone so that people don't have the chance to whisper and said something bad about it (HIV and AIDS infected orphan)." [P8; Age 62; Female]

4.4.4.2 *Identified problem*

HIV related stigma remains endemic in communities causing some grandparents caring for AIDS/HIV children not to disclose the status of their orphan grandchildren.

4.5 Theme Two: Grandparents response to the experienced challenges.

4.5.1 General health response

Participants reported that looking after the kids in their old age was tedious and have a negative impact on their overall health. Some grandparents has been diagnosed with high blood pressure, others with different heart diseases and they reported being very stressed which impact on their emotional well-being. The following paragraphs will discuss biophysical health impact, emotional health impacts, and social health impact

4.5.1.1 *Biophysical health*

Most grandparents caring for AIDS orphans mentioned facing compounded health risks, given the multiple roles they assume such as parenting chronically ill children living with HIV.

The study participants indicated a decreased physical strengths while caring for AIDS orphans in their old age, especially among the ones looking after smaller children. They reported experiencing exhaustion due to lack of break and constantly looking after small children. Other grandparents caring for AIDS orphans reported experiencing intense physical exertion while running the household and doing all the house duties without help and with no time to repose.

"Yes I do get tired and have pains only when I have to take them to the clinic;

they have dates for the clinic." [P10; Age 73; Female]

Taking care of an AIDS orphan can require grandparents to take on a variety of energy sapping tasks, which can be physically draining. The participants suggested activities such as bathing, feeding, toileting, transporting kids to school and to the clinics. For grandchildren living with HIV, additional activities such as coordination of medical appointments for the kids and ensuring that they eat properly is also required of these grandparents. One participant (P12) mentioned,

"I feel tired from looking after them [AIDS orphaned grandchildren]. I have to wash their clothes and cook for them, the young one need to be washed as well and my back get very painful. Also, my knees are starting to pain." [P12; Age 60; Female]

Another participant (P16) reported that she is worried about her declining health because she does not have money to buy healthy foods for the grandchildren living with HIV to improve their adherence to their medications.

"My child, I can feel that I am getting weaker every day, I already have diabetes and I don't have enough money to buy health food." [P16; Age 68; Female]

Participants (P3) also reported that they find themselves very exhausted trying to ensure that everyone is attended to. This was reported by Participant 3 in the following quote*:*

"My body gets tired. I went to the clinic and they explained to me that I am starting to suffer from heart disease, my legs started to be weak and now I am having the flu, honestly, I don't feel well." [P3; Age 75; Female]

4.5.1.2 *Emotional health*

Many' of the grandparents caring for AIDS orphans indicated that they experienced some level of strain while taking care of their AIDS orphans. They also reported emotional distress and emotional demands due to caregiving duties in their old age. Moreover, the death of their own children and grief were reported as the main roots of their decline in their psychological wellbeing. A participant (P15) mentioned that her health suffers due to the strain of providing care to the children,

"I am still healthy, and I have no serious illness yet, but looking after the children is a full-time job and tiring. I often feel very tired and need a rest,

my body is painful, and I get constant headaches, but to tell you the truth, I am not looking to the future [P15; Age 70; Female]

A number of other grandparents caring for AIDS orphans reported that they worry about the future of their orphaned grandchildren in case they [grandparents] die. In this regard, P16 said,

"I had high blood pressure since 2013 after my daughter passed away. I think it was due to stress. Now last year, at the clinic, they told me that I have diabetes as well and this is stressing me a lot because my own mother died with this disease without a leg. I just wonder what will happen to my poor kids [referring to orphaned grandchildren] because I am the only family they know." [P16; Age 68; Female]

Another participant (P6) also mentioned that she cannot sleep, thinking about the future of her orphaned grandchildren and said,

"It is breaking my heart, sometimes I can't sleep thinking about the children and their future, sometimes I cry, there are times when you are feeling" I can't ..."[P6; Age 56; Female]

Another participant reported that dealing with irresponsible adult grandchildren placed enormous stress on her. She reported that her 20-year-old grandson was inconsiderate and did not consider how his grandparents feel. She (P2) said,

"But we have a problem of my grandchild who is 20 years old boy. He is very troublesome. Firstly, he dropped out of school from grade 10 and didn't want to go there again. It is like he has anger issues because he didn't grow up with his father but with me. He told me that he wants to go to the circumcision. I told him that he should go to his father in the Eastern Cape. When he got there, he dated a 13-year-old girl. He slept with this 13 year old girl then her mother said he raped her. He went to prison but came back again. Now his

father asked me to stay with him again. But in the house, he doesn't like to do anything at all like cleaning or cooking and he likes to fights a lot. I told him that I have high blood pressure and diabetes all because of him, I don't know what is it that he wants me to do. When he was not staying with me last year, I did not get sick but now I am because he came back and stressing me a lot [with his unacceptable conducts]. These children are just doing whatever they want, they don't care how you are feeling." [P2; Age 64; Female]

Some grandparents reported feeling helpless because they could not handle multiple problems at the same time. A participant (P23) reported feeling powerless as she was challenged by a double loss whereby, she lost her daughter and another one was critically ill, and she had to look after her as well as at home together with two of her grandchildren. This participant was emotional tears rolled down while she was shared her situation, she is blaming herself and asking why all this is happening to her:

"I think too much and now I am getting sick when I see my child losing her young life in front of me and I cannot help her. She is suffering and her body is finished. I feel helpless and feel bad. I always ask myself why me? Why only my children would die with AIDS. I think I am cursed to get old without children." [P23; Age 65; Female]

4.5.1.3 *Social isolation*

Some grandparents reported that after disclosing the HIV status of their AIDS orphaned grandchildren, their social relationships with some family and friends changed. They reported experiencing social isolation from their social network. They also mentioned that taking care of their AIDS orphaned grandchildren takes away time they used to spend with their friends who are free from parental responsibilities.

"I am now used to this life, yes, it is not a good life because at my age, as at my age I am not expected to be looking after the children, I supposed to be relaxing and wait for my days but like I said I have accepted this situation that I found myself in."[P17; Age 62; Female]

4.5.2 Coping mechanism as a survival tactic

Despite the negative experiences that were reported by the participants, there were some experiences that represented a glimpse of hope. The grandparents had to find coping mechanisms that aided them to live their lives despite the adversities they faced daily in caring for the orphaned children. These coping mechanisms ranged from what the children represented to them in a personal way to how their outside relationships helped them cope.

4.5.2.1 *Happy with the kids*

The study participants cited that the love they have for their grandchildren is their main source of comfort and strength. Despite the challenges that accompanies raising the children, participants admitted that they brought them joy and solace; a piece of their own children to hang on to. One participant (P15) said,

"I am happy with my kids; I love them and although they make me tired, but I feel happy to be with them." [P15; Age 70; Female]

4.5.2.2 *Talking to a friend*

In most cases, grandparents reported their sense of isolation due to what they are going through. However, grandparents who are working reported that talking to a friend or to a colleague served as a coping mechanism because counselling services were not available to them in their area. In this regard, one participant (P6) said,

"Because I am a counsellor, I would go to school because I know the teachers and I would talk to them and open up to them." [P6; Age 56; Female]

4.5.2.3 *Sobbing as a method of reassurance*

Throughout the interviews, the provision of counselling appeared to be the one strategy that grandparents believed will help them cope better with their situation. However, it was evident that it was not accessible in their area and if so, was not consistent. In lieu of that, participants mentioned that they struggled to cope mostly due to poverty. Some participants resorted to crying as an emotional outlet to ease their pain. Sobbing and crying were reported to alleviate emotional distress and burden and assisted grandparents to feel better and move forward. Participant (P10) said,

"So far, I haven't had any counselling, you are the first person who is speaking to me regarding my child. When I am sad, I always hide myself from the children and cry. This helps to ease the sadness." [P10; Age 73; Female]

Although the majority of grandparents caring for AIDS orphans reported that they experience emotional distress while carrying out their caregiving duties, none of them received any counselling from their local clinic/s. However, there were a participants who indicated that they received counselling from an NGO operating in Khayelitsha.

4.5.2.4 *Identified problem*

1) Grandparents caring for AIDS orphans are struggling to cope with their emotional challenges due to lack of counselling.
2) Grandparents rely on the love they have for their grandchildren and talking to people as a coping mechanism in the absence of counselling services.

4.5.3 Financial assistance appreciation

The majority of grandparents indicated that they did not receive financial assistance formally; however, few grandparents appreciated the support they received from family members, getting monthly salary and receiving monthly pension grants.

4.5.3.1 *Income from children*

Some of the grandparents indicated that they receive some form of support from their adult children, especially their adult children. One participant (P14) said,

> *"My two children also buy food for us on top of the food we buy, so it makes a difference."* [P14; Age 69; Female]

Participants (P13) also mentioned that the nature of this support was unreliable in the long-term because most of their children did not have stable employment or are involved in illicit work and gangsterism.

> "*My son also buys food for us, but like I said you cannot rely on him because he is involved in gang and sometimes, he is in jail…"* [P13; Age 64; Female]

However, grandparents also acknowledge that their own children also struggle to put their lives in order; hence grandparents do not blame them for the lack of support.

> *"My children are occupied with their own life, sometimes they do give me some money to buy grocery, but they are also struggling. I don't blame them."*
>
> [P10; Age 73; Female]

4.5.3.2 *Income from salary and support from spouse*

Income from grandparents themselves and/or their partners (who are employed) was reported as another source of income that helped some grandparents to care for their AIDS orphaned

grandchildren. A participant (P15) mentioned that it would be very difficult to care for these grandchildren without this support and said,

> *"My husband still works because we cannot cope without working. Everything is very expensive. We want to give these children the love and the home although we cannot be like their parents or provide, but we are trying to help them as much as we can."* [P15; Age 70; Female]

4.5.3.3 *Income from pension grant*

Most participants identified pension grant as their main source of income. However, they further reported that they used their pension to meet the needs of the children such as clothing, food, school uniform and school fees and medical expense. Because the childcare grant is not sufficient. One participant (P13) said,

> *"I get pension grant for myself although I use it to take care of my grandchildren because the child support grant is not sufficient to take care of them."* [P13; Age 64; Female]

4.5.3.4 *Identified problem*

Grandparents do not have a stable income except for the pension grant which is not being used for the purpose it was intended to.

4.6 Theme Three: Grandparent's motivation to be the primary caregivers of AIDS Orphans

Society expects grandparents to carry the burden of caring for AIDS orphans after the death of their parents. The provision of primary care to AIDS orphans is a difficult and daunting task to

fulfil but can be a rewarding one for some grandparents. Follows are the different views of the grandparents regarding their motivation for providing care to their orphan grandchildren.

4.6.1 Personal Motivation

4.6.1.1 *Strengthening family bond and love of the children*

Grandparents indicated the need to unite the family after the death of their children was the main reason, they decide to take care of their grandchildren. They reiterated their undying love they had for their grandchildren and believed that being the primary caregivers to the orphans was the best decision they made since the children have no one else except their grandparents. Participants (P14, P18) confirmed this and said,

> *"I feel like it is my responsibility to help my grandchild. No one can love him more than I do after his mother's death. I feel that although he is infected [living with HIV] he still deserves to be loved and get affection because it was not his fault."* [P14; Age 69; Female]

Participant 18 said,

> *"I love the children and they had no one else except me. I was not going to reject my own children. The poor children went through a very difficult time. First, it was their father who died first then their mother who is my elder daughter followed after 8 months."* [P18; Age 73; Female]

4.6.1.2 *Circumstances*

Some children found themselves with no one except their grandparents to care for them after the death of their primary care taker (parents), and most of them already were leaving with their grandparents before death of the parents.

"I love the children and they had no one else except me. I was not going to reject my own children. The poor children went through a very difficult time. First, it was their father who died first then their mother who is my elder daughter followed after 8 months." [P18; Age 73; Female]

4.6.1.3 *Absent biological parents*

The absence of living parents was cited as another reason grandparents decided to take care of their orphaned grandchildren after the death of one of the parents. Some of the grandmothers (P22, P8) mentioned that most of the time, they were unaware of the identity of the biological fathers of their grandchildren. They did not attempt to locate them as their daughters did not divulge their identities in their lifetimes.

"*To be honest with you, I don't even know who the father of my grandchildren is, my daughter never told me who was the father [before the death of the daughter], she had different boyfriends and I don't know who to blame. As for the girlfriend of my son, she is not responsible she came and dropped the baby with my son and since then she never turned back. I heard that she is always drunk and use drug .My grandchildren are better off with me. They've suffered enough."* [P22; Age 72; Female]

Some parents were absent parents before the death of the other partner. A participant (P8) explained how her own daughter was an absent parent and said,

"My daughter was very irresponsible when she gave birth. After 3 months, she took the child to the clinic to check if he is positive or negative because she was positive already, so when she came, she was down when I asked her what is wrong, she told me that the baby was also HIV positive and it touched my heart. After a few months, she started her ways again, because

she wasn't staying with us, she was staying with this boyfriend this month, and changing the boyfriend next month…So, I decided to keep the baby and let her go where she wants to go because I couldn't stop her." [P8; Age 62; Female]

Other grandparents indicated that they knew the biological fathers, but the fathers could not afford to take care of their children as they were unemployed. This is illustrated in the following quote from a participant (P6) who said,

"*At least Charmaine is lucky because now there is someone from Zimbabwe who located the father, but he is not interested also because he told me this, 'I am not interested, I love the child, but I also have HIV. If you have this disease, it is very difficult. Please mama, you can have Charmaine.'and I said, 'No man, Charmaine needs your love.' but he is not really interested.* [P6; Age 56; Female]

Grandparents caring for AIDS orphans reported that some of the biological parents refused to take their ARV medications and continued to indulge in excessive alcohol consumption. In these situations, grandparents were left with no choice but to take care of their grandchildren.

"Since 2006, she was not working anymore and when she found out that she was infected with HIV/AIDS [her daughter], she became very sick and refused to take her tablets and also, she used to drink a lot, so I had to step in and take care of the grand children before even her death." [P17; Age 62; Female]

Drug and alcohol abuse was one of the major factors that motivated grandparents (P13) to become the primary caregiver of their grandchildren. Neglect of the children forced the grandparent/s (P5) to take the children in their care while their mothers were still alive. In this regard, the grandparents confirmed and said,

"I decided to take them because they needed me as their grandmother. First of all, I took my 3 grandchildren while their mother was still alive because she was neglecting them, and she was addicted with drugs [her daughter who is infected with HIV/AIDS]. I was afraid that even the elder granddaughter will end up like her. I decided also to take Alma [her son's daughter] because her mother passed away and they were staying with me, so she is like my daughter. I did not have a choice but to keep her with me…" [P13; Age 64; Female]

"*Yes she is the one that called me [her HIV/AIDS infected daughter who is on drugs] and told me that she has a daughter that is four (4) years old, of which she never told me before. My daughter was on Drug use and stayed behind the bridge until she was locked behind bars because of the drugs. She was pregnant when she was at the prison because she came back with other baby boy. She is now coming from the prison and she remembered that she left one month old child in ACVV [Welfare organization] and she went over that place to look for that child. The child stayed there for four month then I was called here at Mthawelanga. They asked me if I still want the child and I agreed to take the child. I stayed with the child since she was 5 months and she is now four years old. I looked after the child all these years."* [P5; Age 59; Female).

4.6.1.4 *Identified problem*

1. A lack of parental assistance amongst parents who are still alive exists as they ignore their children and burden the grandparents with the responsibilities of taking care of the children without the provision of resources.

4.7 Theme Four: Quality of health care services used by Grandparents caring for AIDS Orphans

Caring for children involves visits to healthcare facilities, especially when caring for HIV and AIDS infected children. Grandparents themselves also are prone to developing chronic diseases that require frequent monitoring. It is vital for them to have an appropriate healthcare system in place, which is both affordable and easily accessible. Below is the description of healthcare services used by both grandparents and the children in their care.

4.7.1 Public healthcare services used

4.7.1.1 *Affordability*

All participants reported that they made use of public services to address their health care needs and those of the orphans. Participants reported that they made use of the closest local clinics and community health centres, and that they were satisfied concerning affordability, as they received free health care services. However, one participant mentioned that although they did not pay for health care services, they felt that the health care providers at the clinic did not always go the extra mile to help the children. In such a situation, these grandparents were forced to use private doctors, which incurred additional costs on their already stretched budget. One participant (P8) confirmed this and said,

> *"You know what? Like today, this morning, I went to draw R500 [29 $] to take them to the doctor. They went to a [private] doctor because I think there is something wrong with their blood, and that is the money that I supposed to use to pay this and that"* [P8; Age 62; Female]

When asked why she used a private doctor, she (P8) then replied,

"I took them [grandchildren] to the clinic, it did not help [she was told that there is no skin medication] and then I took them to Mitchell's plain [to a private doctor], did not help also, but now I think that there is something that is around other children maybe from the crèche." [P8; Age 62; Female]

4.7.1.2 *Accessibility*

Some of the participants in this study reported that they had to travel long distances to reach the nearest clinic. Participants also mentioned that this was exacerbated in the winter months when they had to walk in the rain, sometimes with small children.

"I am happy I have no complain, the problem is that I walk a long distance to get there, and it is always worse in winter to walk to the clinic in the rain sometimes with small children." [P17; Age 62; Female]

4.7.1.3 *Level of satisfaction of care*

Most participants reported that they were satisfied by the services provided to them at their local clinic/s. However, a few participants (P2, P5) expressed their dissatisfaction because of the long waiting times before they could be seen by the doctor and the way they were treated. Participants revealed that during clinic consultations, health care providers did not enquire about their situation at home. They also mentioned that they were not given an opportunity to discuss their issues and disclose their problems.

"They are very slow. You would be there all day long waiting to be seen by the nurses. It is worse I am diabetic if I am hungry, I need to eat."[P2; Age 64; Female]

"I am only satisfied with the treatment they are giving me nothing else."

[P5; Age 59; Female]

On a positive note, participants who were adherence club members (group-based adherence-enhancing intervention designed to address the challenges of clinic congestion, poor retention in care and adherence to medication) were more satisfied than participants who were not club members as they did not need to wait for long periods of time in the queues. However, they mentioned that when they brought the children to the clinic, they still had to wait in long queues.

"…yes, I am a club member and there at the club they would just call us by our folders, and they give us our treatment, but otherwise, they don't care about you and your problems." [P19; Age 62; Female]

4.7.1.4 *Identified problems*

1. Transport appears to be a problem for grandparents who stay far from the clinics.
2. There appears to be issues pertaining to attitudes from multidisciplinary health workers toward grandparents caring for AIDS orphans.

4.8 Theme Five: Quality of social services

4.8.1 Grandparents views on government service delivery

Grandparents caring for AIDS orphans had different understanding on government services delivery, below is the description of their views. The majority of grandparents caring for AIDS orphans indicated various problems in their caring roles. Grandparents struggled to access governmental assistance for themselves and the orphans in their care. Some of the grandparents were below 60 years and did not qualify to register for an old-age grant. Other grandparents

reported that it took to receive the grant after the application was made. They accused the social services of being very slow and that they turned "a blind eye" on their problem. Some orphans did not have the necessary documents such as birth certificates, which made it difficult for the grandparents to apply for social grants. Furthermore, they indicated that the governmental procedures were complicated which prevented grandparents from accessing foster care grants.

4.8.1.1 *Inadequate service delivery*

The results from interviews revealed that most grandparents were condemning the government for failing them. Most of the interviewed grandparents felt that government should change some of the procedures or policies to make it more approachable. Grandparents caring for AIDS orphans shared feelings of being abandoned by the government and requested formal support from the government. Participants (P1, P2, P3, P22) confirmed this and said,

> *"Everything in this South Africa must eventually change. If we are growing these children the government must be near to us, so that whenever we have problems, we know who to contact. Otherwise, there's a lot that needs to be done by the government."* [P2; Age 64; Female]
>
> *"Yes, and it is worse if you want to see the social worker, you first have to make an appointment even if it is an emergency. You will see them next month. You need to wait and when it is time to see them about that particular problem you had by then you would be forgetting what the problem was about."* [P3; Age 75; Female]
>
> *"No, they are not helping [Government], because we can't get the services we were supposed to get. I wanted those food parcels they are supplying but they refused to give to me because I earn a social grant [pension grant]. I always tell them my situation,[poverty and caring for the orphaned*

children] but no, I get nothing. The government is failing us and is so slow to do things for us." [P22; Age 72; Female]

"No, those people [the government officials] don't care. They only care about their vote." [P1; Age 61; Female]

4.8.1.2 *Identified problems*

1. There are procedural issues in social services.
2. A lack of clear communication exists between social services personnel and grandparents caring for AIDS orphans.
3. There is an issue of mistrust problem as grandparents caring for AIDS orphans do not trust government.

4.9 Discussion: Qualitative Findings

Qualitative findings showed that the grandparents caring for AIDS orphans experienced similar challenges related to caregiving in both urban areas and non-urban areas. A combination of all the results indicated that the act of caring for AIDS orphans affect grandparents at several levels. The following are the main themes extracted for the qualitative findings (see Table 4.2).

1. Theme One: Challenges experienced by grandparents.
2. Theme Two: Grandparents response to the experienced challenges.
3. Theme Three: Grandparent's motivation to be the primary caregiver of orphans.
4. Theme Four: Quality of health care services.
5. Theme Five: Quality of social services.

4.9.1 Challenges experienced by grandparents

Several interesting findings were drawn from this study. The fact that all grandparent caregivers to AIDS orphans were female (100%) as compared to no male caregivers (0%) concurs with previous research showing women's caregiving is essential in providing the backbone of care and support to AIDS orphans (Mestome & Madiba, 2013; Arilli, Ssewamala, & Ismayilova, 2012; Maundeni & Malinga-Musamba, 2012). The findings from this study revealed that grandparents caring for AIDS orphans are coupled with a series of biophysical, financial, social and emotional problems while being the primary caregivers of their AIDS orphans grandchildren.

Inadequate resources to support grandparents in their caring role is the main challenge. There was a severe financial dilemma as they battled to afford basic needs for themselves and orphans in their care. Findings showed that food insecurity is significantly associated with caregiver burden. Findings also suggested that households experienced food insecurity and other financial problems. This finding is supported by previous research conducted by Kidman and Thurman (2014) who found that lack of food was a major predictor of caregiver burden among caregivers of people affected by HIV and AIDS.

The dearth of stable income remains the leading cause of the dire poverty they are facing as most of the grandparents rely on their pension grant, which is further exacerbated if they are below the age of 60 years. The lack of formal and informal support thus contributed negatively to their overall health. The above findings are correlated with most studies conducted on grandparents caring for AIDS orphans in Sub-Saharan countries. The results from these studies highlighted the inadequacy of the grandparents in similar areas of their wellbeing, and that they

were prone to an increased risk of physical, social, and emotional problems (UNICEF, 2016; Matovu, Dawson-Rose, Weiss, & Wallhagen, 2019; Mtshali, 2016; Kalomo & Taukeni, 2020).

4.9.2 Grandparents response to the experienced challenges

As previously discussed, lack of support majorly contributes to the challenges grandparents faced while providing care to the orphans. The lack of support had a significant impact on the overall health of these grandparents. Findings from this study indicate that grandparents suffered from physical exhaustion due to the burden of increased responsibilities of caring for their AIDS orphaned children in their old age. The physical exhaustion was the outcome of running all the household chores associated with child care without rest. Grandparents reported being tired and developing chronic diseases such as high blood pressure. Similar findings of grandparents experiencing physical exhaustion were reported by Whitney and Fuller-Thomsen (2018) and Mendoza *et al.* (2017).

Grandparents minimised the severity of their health problems and neglected their health care needs and prioritised that of the grandchildren. Furthermore, grandparents delayed seeking medical attention when they were sick, and did not have sufficient time to relax, sleep, and eat properly. This had a significant negative impact on the overall quality of their lives. Similar results were found by Malaria and Muliira (2011) who concluded that raising grandchildren had a negative impact on grandparents' wellbeing due to lack of time and means to seek medical assistance as many of grandparent's health problems are left untreated. Dolbi-MacNab and Yancura (2018) also argued that similar findings were reported across global contexts in an analytic review on the needs, experiences, formal and informal support for grandparents raising grandchildren in China, New Zealand, Romania, and South Africa.

The above findings correlated with a study by Matovu, Dawson-Rose, Weiss and Wallhagen, (2019) conducted in Uganda. The study found that caregiving provided to AIDS orphans by sub-Saharan African grandparents had physical, financial, and emotional consequences (Matovu *et al.*, 2019). Social isolation was reported as another response from grandparents. In terms of reasons grandparents resorted to isolation, HIV and AIDS-related stigma, lack of socialization due to heavy responsibilities were mentioned by Matovu *et al.*, 2019.

Furthermore, parenting in their old age affected their lifestyle and relationships with family and friends. Grandparents isolated themselves from their social network, and no longer had time with their family and age mates who were free from parental responsibilities. Subsequently, this majorly impacted on their mental wellbeing. Similar findings were reported in a study by Kuo *et al.* (2012) which confirmed that caring for young children in the household increased depression among grandparent caregivers. Another study by Muliira and Muliira (2011) found that social isolation was a response employed by grandparents to cope with the challenges they faced.

HIV and AIDS related stigma also hindered their confidence. Grandparents believed that their neighbours were mocking them; hence, they preferred to keep their lives private from the rest of the community. As a result, they suffered from loneliness and emotional distress. Grandparents found it difficult to disclose their grandchildren's HIV status and the cause of their children's death due to the constant fear of being discriminated in the communities**.** Ogunmefun *et al*. (2011) and Mtshali (2016) reported similar findings in their studies confirming that grandparents who parent AIDS orphans triggered social problems amongst grandparents caring for AIDS orphans. This finding further corresponds to previous studies that confirmed that caregivers of AIDS orphans were victims of intense HIV/AIDS-related

stigma, to the point where the child's illness was kept secret (Demmer, 2011; Moore & Henry, 2005). This non-disclosure placed the child's physical health at risk (Demmer, 2011; Moore & Henry, 2005).

Emotional distress emanated as an essential response from all the constants worries and stress grandparents had to endure, which altered their emotional wellbeing. Their emotional anguish was related to several aspects ranging from mourning their children who died from HIV/AIDS-related complications in addition to the lack of formal and informal support in caring for the AIDS orphans left behind (Chazan, 2008). The study revealed that many grandparents caring for AIDS orphans were not prepared to care for the orphans at their age; however, the situation forced them to assume that role (Chazan, 2008). Grandparents were reported to feel helpless and depressed because they were unable to provide for the orphans, and worried about the future of their grandchildren in the event of their deaths. This finding corresponds to a study done by Kuo and Operario (2011) and Kalomo *et.al.* (2018) who found that psychological distress (anxiety and depression) among Black South African grandmothers raising orphaned grandchildren.

Rebellious teenage orphans and the frustration of dealing with them were also reported as sources of emotional stress suffered by grandparents. Some teenagers used drugs while others abused alcohol, which consequently fuels misbehaviour and poor school outcomes. Most of these teenage orphans displayed misbehaviour in their communities while others became rebellious. Unfortunately, their conduct was beyond the grandparent’s control, hence and had a negative impact on their psychological wellbeing. Findings from this study correlates with studies conducted by Hlabyago and Ogunbanjo (2009), Chazan (2008) and Cox (2018), who

reported that grandparents caring for orphans developed a series of health problems including hypertension, diabetes, and arthritis due to challenging parenting.

Unfortunately, there are currently no counselling services available for them. Findings from this study show that only a few grandparents reported receiving counselling from NGOs, and that the service stopped due to unavailability of funds. Regardless of these challenges, grandparents caring for AIDS orphans still found ways to cope. Grandmothers engaged in various robust processes such as crying, and accessed emotional support from friends, as well as extended family. They also focused on their responsibility to their grandchildren which kept them occupied and helped them forget about their misery. Findings from this study concurs with Dolbin-MacNab *et al*. (2016) who reported on the coping mechanisms employed by grandparents. The study found that grandparents depended on their spirituality, accessed sources of instrumental support, and sought emotional support and companionship from their grandchildren and broader communities (Dolbin-MacNab *et al*., 2016).

4.9.3 Grandparent's motivation to be the primary caregiver of orphans

Strengthening family bond and the undying love grandparents have for their grandchildren were found to be the main motivation for grandparents to become the primary caregivers for the orphans. Grandparents reported feeling a sense of reassurance and satisfaction that their grandchildren are being cared for properly. This finding corresponds with the study conducted by Winston (2006), who found that the main reason African-American grandmothers cared for their AIDS orphans was rooted in the belief that families come first and should stay together at all costs. Similar findings were reported in a research review by Sumo *et.al.* (2018). The research review concluded that primary caregiver grandparents maintained the connection within the family as it increased a sense of meaning in the orphans' lives (Sumo *et al.*, 2018).

Unreliability of some biological parents, and neglecting children due alcohol and drugs abuse, prompted grandparents to be the primary caregivers after the death of one of the parents. They struggled to locate the biological fathers after the death of their daughters. The absence of both parents forced grandparents to become the primary caregivers for the orphans left behind. Findings from this study also correlates with the previous studies done by Beegle *et al.* (2010), Preble (1990), Cox (2018) and Rutakumwa *et.al*. (2015). These studies found that there was a constant cultural expectation from grandmothers to be involved in the care of grandchildren in the absence of their biological parents regardless of the reason (Beegle *et al*., 2010; Preble, 1990; Cox, 2018; and Rutakumwa *et.al*., 2015).

4.9.4 Quality of health services

The Quality of public health care services was reported to be suitable and affordable for grandparents because they do not pay. However, disparity existed from the above findings as Lack of compassion from some healthcare professionals was denoted from the findings.

Grandparents faced the problem of accessing health services in rural areas. Grandparents had to cover long distances by foot before reaching the clinic as they battled with transport costs. The situation worsened in the winter months, more so if they were accompanied by the children.

Moreover, long waiting periods for non-club members was identified as another problem. Similar findings were reported by Mukumbang *et al.* (2019) who confirmed that belonging to an adherence club was advantageous, as it shifted most consultations and ART collections for stable patients into organised groups and had speedier processes.

Findings from this study also revealed that Multidisciplinary team (MDT) healthcare services did not have a professional practitioner dedicated to work and conduct home visits with grandparents caring for AIDS orphans both in rural and urban communities. A home-based intervention programme would improve coping skills and reduce stress levels amongst grandparents caring for AIDS orphans. Robitaille (2012) reported that the same service was offered in the US and that social workers and nurses would visit grandparents' homes once a month to provide ongoing health assessment and education on health concerns and medications (Robitalle, 2012).

Our findings found no counselling services available for both grandparents and their orphans in all clinical settings, which may affect grandparents psychologically, because counselling has been suggested as a specific psychological intervention as a coping mechanism for grandparents. Similar findings in terms of the unavailability of counselling services for grandparents caring for AIDS orphans were reported by previous research (Nyoni, Nabunya, & Ssewamala, 2019).

Previous research demonstrated that the wellbeing of grandparents caring for AIDS orphans was enhanced when adequate and appropriate social support was made available to them (Landry-Meyer, Gerard, & Guzell, 2005). Thus, community health care centres and clinics should design health promotion programmes that visit the elderly at home because they may be too overwhelmed by their caregiving responsibilities to go to the nearest clinic. Such programmes should cover health education on non-communicable diseases, in terms of both the prevention and management aspects. Also, programme co-ordinators should ensure that multidisciplinary teams (MDT) including social workers, psychologist, nutritionists, doctors, nurses are arranged to assist grandmothers with self-care activities. Support groups should also

be formed, which could be peer-led and include provision of respite when it is needed. Psychological support should be provided for both grandparents and orphans. In terms of nursing education, care of older people should be included in nursing curricula. Exposing students to clinical settings that give them the opportunity to work with caregiver grandmothers of AIDS orphans could make students more empathic and sensitive to the caregiver's needs.

4.9.5 Quality of social services

The responses of social services to the needs of grandparents caring for AIDS orphans involved several social assistance grants, such as old-age pensions, child support grants, and foster care grants. Findings from this study revealed that most grandparents received child support grants which provided income to financially eligible grandparents caring for AIDS orphans, although the grant appeared very meagre compared to the need of orphans. However, long application process and approval times, and other bureaucratic problems were noted as a hindrance for grandparents caring form AIDS orphans (Delany *et al*., 2008; Hlabyago & Ogunbanjo, 2009).

Foster care grants were regarded as a better solution to supplement grandparents' income, as it offered more financial assistance than the child support grant. However, it is only given to grandparents who are legally fostering AIDS orphans, and only a few grandparents qualified for foster care grant, due to complicated restrictions associated with its legibility criteria and its application process.

Old-age pension's grants are available to persons aged 60 years and older and was seen as the main source of financial income for grandparents caring for AIDS orphans. The findings showed that most grandparents over the age of 60 years received the grant. While pension

grants were designed to support grandparents, the grants were often utilised to benefit the orphans and meet their needs (Schatz & Ogunmefun, 2007; Chazan, 2008; Delany *et al*., 2008).

Despite needing general assistance, the finding found that some grandparents raising grandchildren may not be eligible for a couple of grants designed to be given to the orphans due to unavailability of documents such as birth certificates and ID, and because it was difficult for them to source these documents after the death of one/both of the biological parents.

Similarly, findings also indicated that most grants designed to benefit AIDS orphans has complicated eligibility criteria which exclude grandparents as they are regarded as family. As a result, they do not legally qualify to be foster parents for the AIDS orphans. This finding corresponds with Mzimela (2019) who confirmed that the foster care grant system is in a state of disarray and that social services are currently overburdened and unable to offer the necessary assistance required by grandparents.

The results from this study also showed that grandparents displayed a lack of knowledge about available supports for AIDS orphans. Additionally, they faced challenges of obtaining necessary documentation, long application and approval times, and other bureaucratic problems hindered them from getting speedy financial support from the social services (Delany *et al*., 2008; Hlabyago Ogunbanjo, 2009 and Delany *et al*., 2008).

4.10 Summary

The qualitative section presented the research findings and discussion for the qualitative part of the study, hence answering Objective one: To explore the experiences for grandparents caring for AIDS orphans in Western Cape Province of South Africa. The research findings

were obtained through individual semi-structured interviews. The results highlighted the experiences of the grandparents while caring for their grandchildren. The results showed that providing care to orphaned grandchildren affected grandparents in many aspects. The section has further revealed that caring for AIDS orphans without support impacts on many spheres of the grandparents' lives often leading to physical, psychological, financial, and social problems. The next section presents quantitative results derived from the study.

5 CHAPTER FIVE: QUANTITATIVE RESULTS AND DISCUSSION

5.1 Introduction

In this chapter, the interpretation and discussion of the quantitative data are presented. The data emerged from two sets of population namely: Population 2 which included the MDT and comprised of professional nurses, social workers, and psychologists; and Population 3 which was represented by the social development managers. The results are presented and structured in three sections. Section 1 describes the study results of the MDT, Section 2 describes the results of the managers in government and NGOs, and Section 3 describes the checklist results that were collected from the grandparents to evaluate the support given to them. The chapter ends with a discussion and integration of data from all three sources.

5.2 Section 1: Results of the Multidisciplinary Team (MDT)

The questionnaire was used to determine the available support (in terms of biophysical, psychological, social-economic, environmental, and health services) for grandparents caring for AIDS orphans in Western Cape Province of South Africa, thus answering Objective Two (2) of the study. Fifty (50) Multidisciplinary team (MDT) staff were identified using a stratified sampling method to select 13 community health centres (five clinics in Khayelitsha, five in Mitchell's plain and three in Grabouw), and within the clinics, an all-inclusive sampling method was used to select the members of MDT. The finding from the MDT team is presented and discussed in the subsequent paragraphs. The demographics profile is presented in Table 5.1.

5.2.1 Demographic profile of MDT

Most of the respondents were females 37 (74.0%). The age ranged from 23 to 59 with a mean age of 33.9 (±7.8) years. Most of the respondents (41; 82.0%) were located in the urban areas (Khayelitsha, Mitchell's Plain) with only nine (9; 18.0%) located in the rural area of Grabouw. More than half of the respondents were professional nurses (30; 60.0%), followed by social workers (13; 26.0%), and the least being psychologists (7; 14.0%). Most of the respondents had Honors (28; 56.0%), followed by those who had undergraduate degrees (16; 32.05), Masters 4 (8.0%) and only two respondents (2; 4.0%) had matric with an Enrolled Nursing Assistant (ENA) certificate. However, none of the respondents possessed a doctoral degree.

Table 5.1 Demographic profile of the respondents

Demographics	Total(N=50)	Percentage
Age in years(m±sd)	33.9	±7.8%
Gender		
Male	13	26.0%
Female	37	74.0%
Location of the organization		
Urban	41	82.0%
Rural	9	18.0%
Multidisciplinary team		
Social worker	13	26.0%
Professional nurse	30	60.0%
Psychologist	7	14.0%
Education level		
Matric (with ENA certificates)	2	4.0%
Degree	16	32.0%
Honors	28	56.0%
Masters	4	8.0%
Doctorate	0(	0.0%

5.2.2 Perceived support mechanisms given to grandparents caring for AIDS orphans

The perceived support mechanism given to grandparents caring for AIDS orphans was measured using various assessment which included ordinal agreement (Likert) scales with ordinal variables, fixed-response and open-ended items that incorporated skip patterns.

Table 5.2 below presents the perceived support mechanism given to grandparents caring for AIDS orphans using ordinal agreement (Likert scale). Twelve items were used in measuring the perceived support mechanisms given to grandparents caring for AIDS orphans and five items used to measure vulnerability to develop health problems amongst grandparents caring for AIDS orphans.

Table 5.2 the perceived support mechanisms given to grandparents caring for AIDS orphan

STATEMENT	TOTAL	AGREE	DON'T KNOW	DISAGREE
1. Lack of income for survival can be a contributing factor to health problem amongst grandparents caring for AIDS orphans.	50(100.0%)	50(100.0%)	0(0.0%)	0(0.0%)
2. No access to health services can exacerbate the already compromised health of grandparents caring for AIDS orphans.	50(100.0%)	50(100.0%)	0(0.0%)	0(0.0%)
3. Absence of basic needs may cause health problems amongst grandparents caring for AIDS orphans.	50(100.0%)	48(96.0%)	2(4.0%)	0(0.0%)
4. Lack of social security provision can be the major cause of stress experienced by grandparents caring for AIDS orphans.	50(100.0%)	48(96.0%)	2(4.0%)	0(0.0%)
5. I am aware of the health risk on the grandparents caring for AIDS orphans in general.	50(100.0%)	47(94.0%)	1(2.0%)	2(4.0%)
6. I can easily identify health problems amongst grandparent caregivers of AIDS orphans who make use of the clinic where I work.	50(100.0%)	40(80.0%)	4(8.0%)	6(12.0%)
7. I already encountered different categories of grandparents caring for AIDS orphans.	50(100.0%)	39(78.0%)	6(12.0%)	5(10.0%)
8. I am aware of urgent needs and problems grandparents caring for AIDS orphans are facing	50(100.0%)	37(74.0%)	9(18.0%)	4(8.0%)
9. The health problems of grandparents caring for AIDS orphans are escalating is in our communities?	50(100.0%)	32(64.0%)	18(36.0%)	0(0.0%)
10. I am aware of the impacts of HIV/AIDS on the welfare of grandparents caring for Aids orphans here in Western Province?	50(100.0%)	21(42.0%)	18(36.0%)	11(22.0%)
11. I am aware of the existing care plan and support services provided by my clinic, to the needy grandparents caring for AIDS orphans?	50(100.0%)	11(22.0%)	11(22.0%)	28(56.0%)

12. I am aware and actively involved in the roles the organization is playing in provision of support given to grandparents caring for AIDS orphan.	50(100.0%)	0(0.0%)	6(12.0%)	44(88.0%)

Respondents were asked if lack of income for survival could be a contributing factor to develop health problems amongst grandparents caring for AIDS orphans, and all the respondents (50; 100%) agreed with the statement. The respondent further was all in agreement that the inability to access health services can exacerbate the already compromised health of grandparents caring for AIDS orphans, (50,100%).

Question three assessed the consequences of the absence of basic needs to grandparents caring for AIDS orphans, and most of the respondents agreed that lack of basic needs might cause health problems amongst grandparents caring for AIDS orphans (48; 96.0%).

Question four sought respondents' views on the absence of income and social security, and the majority agreed that lack of income and social security provision to grandparents caring for AIDS orphans would cause major stress to grandparents caring for AIDS orphans (48; 96.0%).

Question five sought to establish grandparents' awareness about the health risks they are potentially exposed to while caring for the children. The majority were of aware of the health risk to their general wellbeing when caring for AIDS orphans in general (47; 94.0%).

Question six asked respondents to identify the health problems amongst grandparents caring for AIDS orphans who make use of their health facilities, and most (40; 80.0%) respondents could easily identify the health problems.

Question seven established if respondents encountered different categories of grandparents caring for AIDS orphans in their clinics., and the majority confirmed that they did (39; 78.0%).

Question eight assessed the respondent's awareness on the problems faced by grandparents caring for AIDS orphans, and the majority of respondents (37; 74.0%) were aware of the urgent needs and problems grandparents caring for AIDS orphans faced. However, only four (4:8.0%) respondents were not aware of the grandparent's needs, and nine (9; 18.05%) did not know about the grandparents' needs and the problems they faced in their communities.

Question nine sought to establish the grandparent's awareness of the escalation of the problems faced by grandparents caring for AIDS orphans in their communities. More than two-thirds of respondents 32(64.0%) agreed that it did. At the same time, no one disagreed with the statement, and regrettably, only eighteen (18; 36.0%) of health workers did not know if the health problems of grandparents are worsening or not.

Question ten established respondents' awareness on the impacts of HIV and AIDS on the welfare of grandparents caring for AIDS orphans. Slightly less than half of the respondents were aware of the impacts of HIV and AIDS on the welfare of grandparents caring for AIDS orphans (21; 42.0%), while eleven (11; 22.0%) respondents disagreed and eighteen (18; 36.0%) did not know.

Question eleven assessed if respondents are aware of an existing care plan and if there were any support services provided to needy grandparents caring for AIDS orphans by their perspective clinics directed. Unfortunately, only eleven (11; 22.0%) respondents were aware of the existing care plan and support services provided by their clinic, to the needy grandparents caring for AIDS orphans.

Question twelve asked respondents if they were actively involved in the roles their organizations (clinics/ communities health centres) were playing in the provision of support to grandparents caring for AIDS orphans. It is important to note that none of the respondents were aware and actively involved in the roles the organization in terms of providing support to grandparents caring for AIDS orphans.

5.2.3 Grandparents are vulnerable to various health problems

The respondents were asked to identify the most vulnerable grandparents prone to develop various health problems, and all the respondents (50; 100.0%) agreed that grandparents without support structures, grandparents who are head of the households and abandoned grandparents without extended family structures support are most vulnerable group of grandparents who are prone to develop various health problems. It was followed closely by those who agreed that grandparents caring for AIDS-affected orphans are vulnerable to various health problems. None of the respondents agreed that grandparents receiving psychological support are vulnerable to various health problems. Respondents further added the following as the groups of grandparents caring for AIDS orphans who are most vulnerable to various health problems:

a) Grandparents with no financial support;
b) Grandparents caring for babies and adolescents;
c) Grandparents who are living in poor housing conditions;
d) Grandparents who are taking care of physically challenged children and children with a behaviour disorder;
e) Grandparents who are still mourning their children and have to look after the grandchildren;
f) Grandparents with already poor or deteriorating health;
g) Grandparents caring for multiple orphans; and

h) Grandparents with emotional problems triggered by HIV stigma.

The respondents were also asked to provide recommendations that will improve and promote the wellbeing of the grandparents caring for AIDS orphans. Two-thirds of the respondents (32, 64.0%) suggested providing holistic support (social, emotional, psychological support; providing community support and appropriate social grants to grandparents caring for AIDS orphans; and offering counselling, check-ups and home visits to grandparents by social workers.

More than two-thirds of the respondents (21; 65.6%) highlighted that providing holistic support which includes social, emotional, psychological supports will improve the condition of grandparents while only eight respondents (8;25.0%) suggested "multidisciplinary counselling, check-ups and home visits especially social workers" and only four (4;12.5%) respondents suggested the provision of community and social grants.

5.2.4 Grandparents most vulnerable to various health problems

Table 5.3 Grandparents most vulnerable to various health problems

ITEMS	YES N (%)	NO N (%)
1. Grandparents without support structures	50(100.0%)	0(0.0%)
2. Grandparents who are head of the households	50(100.0%)	0(0.0%)
3. Abandoned grandparents without extended family support	50(100.0%)	0(0.0%)
4. Grandparents caring for AIDS affected orphans	48(96.0%)	2(4.0%)
5. Grandparents under psychological support	0(0.0%)	50(100.0%)

5.2.5 Identified problems

1. Lack of basic needs can be the main source of the health risk amongst grandparents caring for AIDS orphans
2. Lack of social security provision such as social grants can be the main cause of stress experienced by grandparents caring for AIDS orphans
3. The clinics and community health centres dearth the existing care plan to support grandparents caring for AIDS orphans who use their facilities.
4. There are no support structures in place to support grandparents caring for AIDS orphans in the clinics/CHC.
5. Unsupported grandparents caring for AIDS orphans are at risk of increased health problems.

5.2.6 Strategies to address the challenges faced by grandparents caring for AIDS orphans

Respondents were asked to identify strategies used by their healthcare facilities in addressing the challenges faced by grandparents caring for AIDS orphans, and just over a third (18; 36.0%) of the respondents reported that they had not tried any strategy. Another third of the respondents (16; 34.0%) reported that grandparents are provided with the emotional support in their clinics and less than a third (15; 30.0%) said that they are provided with a referral to formally established programmes and organizations, which target older persons and AIDS affected persons in their area. Unfortunately, only one respondent (1; 2.0%) indicated that grandparents are provided with social-economic support in their residential settings (Table 5.4).

Table 5.4 Strategies to address the challenges faced by grandparents caring for AIDS orphans

STRATEGIES TO ADDRESS THE PROBLEMS	N (%)
1. No strategies tried	18(36.0%)
2. Providing emotional support in your clinic	16 (34.0%)
3. Providing referral to formal established programs and organizations, which target older persons and AIDS affected person in your area	15 (30.0%)
4. Providing social economical support in their residential setting	1(2.0%)

5.2.6.1 *Identified problems*

1. Lack of strategies to support grandparents caring for AIDS orphans.
2. Inadequate support is given to grandparents caring for AIDS orphans

5.2.7 Existing functions or roles to support grandparents caring for AIDS orphans

All the respondents (50; 100.0%) reported that they have not predefined functions or roles in providing care and support to grandparents caring for AIDS orphans in their clinics (Table 5.5).

Table 5.5 Existing functions or roles

ITEM	YES N (%)	NO N (%)
1. Is there any existing functions or roles of professional nurses/social workers and/or psychologist in providing care and support to grandparents caring for AIDS orphans in your clinic?	0(0.0%)	50(100.0%)

5.2.8 Evaluation of the contributions of multidisciplinary team in providing holistic support to grandparents caring for AIDS orphans

Respondents were asked to evaluate the contributions of the multidisciplinary team in providing holistic support to grandparents caring for AIDS orphans in their clinics. More than half of the respondents (29; 58.0%) indicated not being aware of any of the holistic support offered to these grandparents. Just over a third of respondents (19; 38.0%) reported that holistic support offered to these grandparents was not adequate. Only two (2; 4.0%) respondents reported that adequate holistic support was provided (Table 5.6).

Table 5.6 Evaluation of the contributions of multidisciplinary team in providing holistic support to grandparent

ITEM	WELL DONE	SOMEWHAT GOOD	DON'T KNOW	NOT GOOD
1. How do you evaluate the contributions of multidisciplinary team in providing holistic support to grandparents caring for AIDS orphans in your clinic?	0(0.0%)	2 (4.0%)	29 (58.0%)	19 (38.0%)

5.2.8.1 *Identified problem on the role of MDT in providing holistic care to grandparents*

There appears to be a lack of involvement of MDT in providing holistic care and support to grandparents caring for AIDS orphans in various clinics

5.2.9 Coping rate of grandparents caring for AIDS orphans in various clinics

In rating how, grandparents caring for AIDS orphans cope with the impacts and the burdens associated with caregiving in their old age, the majority (35; 70.0%) of the respondents reported that they did not know how the grandparents coped with their caregiving duties. Almost a third (15; 30.0%) of respondents reported that these grandparents were not coping. None of the respondents reported that grandparents caring for AIDS orphans were coping well. Table 5.7 shows the coping rate of grandparents caring for AIDS orphans.

Table 5.7 Coping rate of grandparents caring for AIDS orphans

ITEM	COPING WELL	DON'T KNOW	NOT COPING
1. How do grandparents caring for AIDS orphans in your clinic cope with the impacts and the burdens associated with caregiving in their old age?	0 (0.0%)	35 (70.0%)	15 (30.0%)

5.2.9.1 *Identified problem on coping rate of grandparents caring for AIDS orphans*

Grandparents caring for AIDS orphans are not coping with caregiving duties

5.2.10 Additional recommendation from MDT team

The following were the recommendations from various MDT, which are related to grandparents caring for AIDS orphans and how they can be supported in their caregiving role while enhancing their overall health:

1. Social visits should be provided to grandparents caring for AIDS orphans and at their home homes to identify potential challenges.
2. MDT should initiate support protocol in their clinics.
3. The government should provide financial support and advocate for grandparents caring for AIDS orphans.
4. Grandparents caring for AIDS orphans should be equipped with the necessary knowledge and understanding of HIV and AIDS management, especially those taking care of children living with HIV.
5. Clinics and community health centres should start care planning and support services for grandparents caring for AIDS orphans and should include their health screening.

5.3 Section 2: The results of the managers in government and non-government organizations (NGOs)

In this section, the available support for grandparents caring for AIDS orphans from the perspective of managers in government and non-government organizations (NGOs) are presented. Fifteen persons were identified as managers in the three areas, on grounds of their knowledge on government response and planning on HIV and AIDS. The questionnaire (**Appendix 11)** was handed to 15 participants (Table 5.8) to determine the grandparent's perception of the availability of support given to them, thus answering objective 3 of the study. Of the Fifteen (15) participants, ten (10) held positions in government (Departments of social development), and Five (5) managed NGOs that served older persons. The data were analysed on the perceived knowledge on the support mechanisms given to grandparents caring for AIDS orphans. Opinions of the participants and issues which they identified that were prominent in the data, were analysed, and the finding are discussed.

5.3.1 Demographic profile of managers in government and non-government organizations (NGOs)

Out of 15 respondents, the majority (12; 80.0%) were females. The age of the respondents at the time of data collection ranged from 25 to 47 years with a mean age of 34.3 (±6.8) years. Most of the organizations (11; 73.3%) where the respondents are employed are located in the urban areas with only four (26.7%) located in the rural areas. Slightly more than half (8; 53.3%) of the respondents work in organizations focused on preventative social activities, which aiming to prevent and alleviate poverty in the event of life cycle risks such as loss of income due to unemployment, disability, old age, and death. One third (5; 33.3%) of the respondents work in organizations that focus on developments which primarily focus on strengthening the institutional capacity of civil society organizations that provide services to poor communities. Only two (2: 13.3%) respondents are in the rehabilitative services (tackling and preventing substance abuse). Almost half of the respondents (7; 46.7%) work in an organization targeting children whereas Four (4; 26.7%) of the respondents work in organizations that work with AIDS-affected persons. The last two pairs of participants work in organizations that deal with the elderly (2, 13.3%) and the youth (2, 13.3%). Again, less than half of the respondents possess a degree (8; 46.7%), followed by those who have honors (6; 40.0%) with only one respondent who has matric (1; 6.7%) and only one who has a master's degree (1; 6.7%). See Table 5.8 below.

Table 5.8 Demographic profile of managers in government and non-government organizations (NGOs)

Demographics	**Total(N=15)**
Age in years(m±sd)	34.3(±6.8)
Gender	**(N, %)**
Male	3 (20.0%)
Female	12 (80.0%)
Location of organization	
Urban	11 (73.3%)
Rural	4 (26.7%)
Organization's area of focus	
Preventative activities	8 (53.3%)
Rehabilitative services	2 (13.3%)
Development orientated	5 (33.3%)
Organization target group	
Children	7 (46.7%)
Elderly	2 (13.3%)
Youths	2(13.3%)
AIDS affected persons	4 (26.7%)
Education level	
Matric	1 (6.7%)
Degree	7 (46.7%)
Honours	6 (40.0%)
Masters	1 (6.7%)
Doctorate	0 (0.0%)

5.3.2 Perceived knowledge on support mechanisms given to grandparents caring for AIDS orphans

In measuring the perceived knowledge on support mechanisms given to grandparents caring for AIDS orphans, a nine-item questionnaire was used, whereby respondents were asked to rate their level of agreement with each statement.

Most of the respondents (14; 93.3%) agreed that organizations provided referral services for grandparents caring for AIDS orphans who are in need. The majority (14; 93.3%) also indicated that they were aware of urgent needs and problems grandparents caring for AIDS orphans fa ced and that they were aware of the impacts of HIV and AIDS on the welfare of grandparents caring for AIDS orphans here in Western Province (14; 93.3%). Only one (1; 6.7%) respondent was not aware of these issues (see Table 5.9). This was followed closely by most respondents (13; 86.7%) who agreed that they already encountered different categories of grandparents caring for AIDS orphans and only two (2; 13.3%) respondents indicated not knowing.

Most of the respondents (11; 73.3%) agreed that predominantly poor grandparents caring for AIDS orphans benefit from the support offered by various organizations with only three (3; 20.0%) respondents indicating disagreement and only one who indicated not knowing. Two-thirds of the respondents (10; 66.7%) agreed that the crisis of grandparents caring for AIDS orphans have affected the objectives and activities of the organization that their organization provides support to grandparents caring for AIDS orphans (10; 66.7%) and that they are aware and actively involved in the roles the organization is playing in provision of support given to grandparents caring for AIDS orphan (10; 66.7%). Less than two-thirds of the respondents suggested that they have the major strategies and intervention in place to address the problems

of grandparents caring for AIDS orphans. Nine (9; 60.0%) with three respondents disagreeing and three respondents who reported that they did not know.

Table 5.9 Perceived knowledge on support mechanisms given to grandparents caring for AIDS orphans

ITEM	AGREE	DON'T KNOW	DISAGREE
1. Organization provides referral services for grandparents caring for AIDS orphans in needs.	14 (93.3%)	1(6.7%)	0 (0.0%)
2. I am aware of urgent needs and problems grandparents caring for AIDS orphans are facing	14 (93.3%)	1(6.7%)	0 (0.0%)
3. I am aware of the impacts of HIV/AIDS on the welfare of grandparents caring for AIDS orphans here in Western Province?	14 (93.3%)	1(6.7%)	0 (0.0%)
4. I already encountered different categories of grandparents caring for AIDS orphans.	13 (86.7%)	2 (13.3)	0 (0.0%)
5. Most beneficiaries' grandparents caring for AIDS orphans are graded to be poor.	11(73.3%)	1(6.7%)	3 (20.0%)
6. The new crisis of grandparents caring for AIDS orphans have affected the objectives and activities of the organization	10 (66.7%)	2 (13.3%)	3 (20.0%)
7. This organization provides support to grandparents caring for AIDS orphans	10 (66.7%)	2 (13.3%)	3 (20.0%)
8. I am aware and actively involved in the roles the organization is playing in provision of support given to grandparents caring for AIDS orphan.	10 (66.7%)	1 (6.7%)	4 (26.7%)
9. I am certain that we have the major strategies and intervention in place to address the problems of grandparents caring for AIDS orphans.	9 (60.0%)	3 (20.0%)	3 (20.0%)

5.3.2.1 *Recommendation*

There is a need of putting in place the strategies specifically focusing on to supporting grandparents caring for AIDS orphans in various social services in Western Cape Province.

5.4 Section 3: Validation of findings with grandparents (results of the checklist)

This section compares the grandparent's perceptions of the available support with the actual available support for grandparents caring for AIDS orphans in the Western Cape Province of South Africa, thus answered objective 4 of the study. Twenty-five (25) participants who were previously engaged and interviewed to explore their experience were approached to complete the checklist. However, the NGO fieldworker added one person who missed the interview due to illness, adding the number of participants to twenty-six (26)]. The process was discussed in chapter 3, and the results are discussed below.

5.4.1 Quantitative findings of the biophysical, psychological factors, social cultural factors/, environmental dimension and health services dimension

The checklist table below shows the grandparents perceived available support vs the actual available support. The table demonstrates what the MDT said is available and the grandparent's and the perception of the grandparents about it.

Table 5.10 A checklist table for grandparents caring for AIDS orphans

Biophysical, psychological factors, social cultural factors, environmental dimension and health services dimension.	**Total (N=26)**	**Urban (n=18)**		**Rural(n=8)**		**Test**	***p*-value**
		Yes	No	Yes	No		
1. Do you get child support grant?	26(100.0%)	11(61.1%)	7(38.9%)	3 (37.5%)	5 (62.5%)	X^2=1.2	.265
2. Do you get counselling services from your clinic	26(100.0%)	0(0.0%)	18(100. %)	0(0.0%)	8(100.0%)		
3. Do you have running water and electricity in your household?	26(100.0%)	17(94.4%)	1(5.6%)	7 (87.5%)	1 (12.5%)	X^2=0.4	.540
4. Does your clinic provide referral services for you in case you need it.	26(100.0%)	5 (27.8%)	13(72.2%)	4(50.0%)	4(50.0%)	X^2=1.2	.272
5. Do you get any assistance (in cash or in other ways) other than your income? If yes, please respond to the following questions: From whom do you get assistance/support	26(100.0%)	11(68.8%)	5(31.3%)	4(50.0%)	4(50.0%)	X^2=0.8	.371
6. Government institutions	26(100.0%)	6 (33.3%)	12(66.7%)	4(50.0%)	4(50.0%)	X^2=0.6	.420
7. Non-government institutions	26(100.0%)	6(33.3%)	12(66.7%)	3(37.5%)	5(62.5%)	X^2=0.4	.837

8. Religious Institutions	26(100.0%)	6(33.3%)	12(66.7%)	1(12.5%)	7(87.5%)	X^2=1.2	.269
9. Family members	26(100.0%)	10(55.6%)	8(44.4%)	1(12.5%)	7(87.5%)	X^2=4.2	0.04*
10. Are you perhaps receiving foster care grant as a grandparent caring for AIDS orphans? If yes how is the accessibility of these grants?	26(100.0%)	1(5.6%)	17(94.4%)	0(0.0%)	8(100.0%)	X^2=0.4	.497
11. Easily accessible	26(100.0%)	1(5.6%)	17(94.4%)	1(12.5%)	7(87.5%)	X^2=0.3	.540
12. Experience difficult accessing foster care grant	26(100.0%)	16(88.9%)	2(11.1%)	6(75.0%)	2(25.5%)	X^2=0.8	.365
13. Do you get any support for education of your orphan's grand children?	26(100.0%)	5(27.8%)	13(72.2)	1(12.5%)	7(87.5%)	X^2=0.7	.393
14. Are you aware of different types of grand provided for your orphan's children	26(100.0%)	4(22.2%)	14(77.8)	4(50.0%)	4(50.0%)	X^2=2.0	.157
15. Are you the breadwinner in your family? If yes	26(100.0%)	18(100.)	0(0.0%)	6(75.0%)	2(25.5%)	X^2=4.8	0.03*
16. Are you working?	26(100.0%)	3(16.7%)	15(83.3)	1(12.5%)	7(87.5%)	X^2=0.1	.786
17. Do you experience any physical problems such as painful legs, back?	26(100.0%)	16(88.9)	2(11.1%)	8(100.0%)	0(0.0%)	X^2=0.9	.326

18. Do you experience difficulties in accessing your health facilities?	26(100.0%)	7(38.9%)	11(61.1)	5(62.5%)	3(37.5%)	X^2=1.2	.265
19. Are you satisfied with the health services that you are getting?	26(100.0%)	13(72.2)	5(27.8%)	4(50.0%)	4(50.0%)	X^2=1.2	.272
20. Do y you have access to electric power supply?	26(100.0%)	18(100.0%)	0(0.0%)	8(100.0%)	0(0.0%)		
21. Do you have access to clean water?	26(100.0%)	18(100.0%)	0(0.0%)	8(100.0%)	0(0.0%)		
22. Do you have access to bathrooms and toilet?	26(100.0%)	13(72.2%)	5(27.8%)	6(75.0%)	2(25.5%)	X^2=0.1	.883
23. Do you have access to telephone?	26(100.0%)	2(11.1%)	16(88.9%)	2(25.5%)	6(75.0%)	X^2=0.8	.563
24. Do you get a normal attitude from your community members (friends, neighbours)	26(100.0%)	10(55.6%)	8(44.4%)	4(50.0%)	4(50.0%)	X^2=0.1	.793
*Chi-square Test (or Fisher Exact Tests where appropriate), *Significant at p<.05*							

Over half of the urban grandparents (61.1%) receive child support grants whereas three (37.5%) of the rural grandparents had access to child support grants. Hence, a slight difference exists in the social and economic conditions between households of grandparents residing in rural areas compared to the urban areas. This was validated by the Managers in the social development services who agreed that the majority of grandparents caring for AIDS orphans in urban areas benefit from the child support grant. And also, the results from the MDT team (professional nurses, psychologists, and social workers) confirmed that lack of income and social security provision to grandparents caring for AIDS orphans would cause stress to grandparents caring for AIDS orphans (96.0%).

Caring for AIDS orphans without support comes with various emotional problems that need professional help. The comparative results show the lack of counselling services from their clinics in the rural (100.0%) and the urban area (100.0%) do not receive counselling support services from their clinics. The results are validated by the MDT (professional nurses, psychologists, and social workers) who agreed that grandparents caring for AIDS orphans do not receive the counselling service from their clinics. Furthermore, the results revealed the scarcity of the referral service for the grandparents caring for AIDS orphans. Grandparents in the urban area (27.8%) confirmed that their clinic provides referral services for them in case they need it, while half of those in the rural area (50.0%) agreed with this statement. This is validated by 93% of the managers in the social development and NGO organizations who confirmed the provision of the referral services to the grandparents in need. But, the service doesn't reach all the grandparents caring for AIDS orphans.

Grandparents caring for AIDS orphans possess different support needs, and the support given to them varies accordingly. The comparative results demonstrated that two-thirds (68.8%) of

the urban grandparents and a half (50.0%) of the rural grandparents receive assistance in cash from government institutions, non-governmental organizations, and religious institutions. More than half (55.6%) receive support from their family members. These results are validated by the results obtained from the managers in the social developments services in the government and NGOs (73.3%) who agreed that predominantly poor grandparents caring for AIDS orphans benefit from the support offered by the government and various organizations.

The majority of the grandparents (75%) in both rural and urban areas experienced difficulty accessing the foster care grant. This result corresponds to the results obtained from the majority of the managers from the social development (86.7%) who acknowledged the urgent need to solve the problems faced by grandparents caring for AIDS orphans. They further acknowledged the existence of different categories of grandparents caring for AIDS orphans who hold different needs.

The study results demonstrate the declining health of the grandparents caring for AIDS orphans, caused by various physical, emotional, social, and financial problems. From the results, it is evident that grandparents caring for AIDS orphans are not coping with their caregiving duties. The main problem was the inability to afford the basic needs for their grandchildren, such as food and educational support, which affect their emotional wellbeing. On this note, the checklist results demonstrated that few of the urban grandparents (27.8%) and only (12.5%) of the grandparents in the rural area receive educational support for their orphan grandchildren. The results correspond to the results obtained from the MDT results, who noticed the lack of involvement from the government side, hence recommended the government to provide financial support and play the advocate role for the grandparents.

The lack of knowledge on the availability of the different grants directed to grandparents caring for AIDS orphans is a hindrance to the grandparents to obtain, and benefit from the needed support. The results show that only a few of the urban grandparents (22.2%) and a half (50.0%) of the rural grandparents are aware of the different types of grants available for their orphan grandchildren. This contradicts the results obtained from 73.3% of the managers in social development services and NGOs who confirmed that most of the poor grandparents caring for AIDS orphans benefit from the support offered to them by the government and various organizations.

Grandparents caring for AIDS orphans are constantly occupied with intense caregiving duties. The checklist results show the positive connection between constant caregiving and physical problems amongst grandparents caring for AIDS orphans. The results demonstrated that the majority of the urban grandparents (88.9%) and all the grandparents from the rural area (100.0%) experienced physical problems such as painful legs and backache. This is validated by the MDT team, who agreed that unsupported grandparents caring for AIDS orphans are most vulnerable and prone to develop various health problems including physical problems.

Grandparents caring for AIDS orphans are old and receive chronic medications, and they have to take their grandchildren for checkups. The study results revealed that grandparents find it difficult to access the clinics. (38.9%) of urban grandparents and (62.5) from the rural areas experienced difficulties in accessing the health facilities. The above contradicts the findings obtained from the urban grandparents (72.2%) and half of the rural grandparents (50.0%) who reported being satisfied with the healthcare services that they are getting.

Negative attitudes and beliefs about HIV and AIDS were identified as the contributing factor to the emotional problem faced by some grandparents caring for AIDS orphans. The results show that over a half (55.5 %) of grandparents in the urban, and half (50.0%) of the grandparents in the rural area did not experience HIV and AIDS stigma, as their community members and neighbours demonstrated a positive attitude towards them, and their grandchildren, contributing positively to their overall health. The above corresponds to the MDT results confirming that HIV and AIDS stigma can trigger various emotional problems amongst grandparents caring for AIDS orphans.

The table below compares and shows the difference in the availability of the resources between grandparents caring for AIDS orphans in rural Vs urban areas.

Table 5.11 A comparative table on Perceived vs. available resources

URBAN RESOURCES			
Available resources (MDT)	**Perceived resources (Grandparents)**		**Comments/Gap**
Child support grant (CSG)	Yes		The resource is available but difficult to access to some grandparents caring for AIDS orphans.
Counselling services in the clinics		No	No counselling services available which exacerbate the emotional problems amongst grandparents caring for AIDS orphans and the children in their care.
Referral services	Yes		The referral services to the grandparents in need are available but the service doesn't reach all the grandparents caring for AIDS orphans.
Support (in cash) from the government institutions, non-governmental organizations, and religious institutions.	Yes		Assistance is available but not reliable, most of them depend on the availability of the funds.
Foster care grant (FCG)	YES		Available but not fully available to all grandparents, and difficult to access due to process issues.

Good health of the grandparents		No	Declining of health status due to various physical, emotional, social, and financial problems
Coping with caregiving duties		No	Grandparents are not coping due to inability to afford the basics need
Involvement of the Government		No	MDT recommended the government to provide financial support and play the advocate role for the grandparents.
knowledge on the available grants		No	Few grandparents are aware of the different types of grants directed to them which is a major hindrance to obtaining and benefiting from the needed support offered by the government and various organizations.
Presence of the physical problems such as painful legs, and backache.	Yes		Intense caregiving duties increase the vulnerability and the possibility to develop various health problems including physical problems.
Difficult accessing the healthcare facilities	Yes		Oppose the perceived positive satisfaction of the grandparents towards the healthcare services.
HIV and AIDS stigma	Yes		The stigma is present, and trigger various emotional problems amongst grandparents caring for AIDS orphans. However, only few of the grandparents experience it as most community members and neighbors possess a positive attitude towards HIV and AIDS, grandparents, and grandchildren in their care.
RURAL RESOURCES			
Available resources (MDT)	**Perceived resources (Grandparents)**		**Comments/Gap**
Child support grant (CSG	Yes		The child support is available but only few of the grandparents receive the child support grant.
Counselling services in the clinics		No	
the referral service for Grandparents	Yes		Of the referral services to the grandparents in need. But, the service doesn't reach all the grandparents caring for AIDS orphans.
Support (in cash) from the government institutions, non-	Yes		Assistance is available but not reliable, most of them depend on the availability of the funds.

governmental organizations, and religious institutions.			
Foster care grant (FCG)	YES		Available but difficult to access
Good health of the grandparents		No	Declining of health status due to various physical, emotional, social, and financial problems
Coping with caregiving duties		No	Grandparents are not coping due to inability to afford the basics need
Involvement of the Government		No	MDT recommended the government to provide financial support and play the advocate role for the grandparents.
knowledge on the available grants		No	Few grandparents are aware of the different types of grants directed to them which is a major hindrance to obtaining and benefiting from the needed support offered by the government and various organizations.
Presence of the physical problems such as painful legs, and backache.	Yes		Intense caregiving duties increase the vulnerability and the possibility to develop various health problems including physical problems.
Difficult accessing the healthcare facilities	Yes		Oppose the perceived positive satisfaction of the grandparents towards the healthcare services.
HIV and AIDS stigma	Yes		The stigma is present, and trigger various emotional problems amongst grandparents caring for AIDS orphans. However, only few of the grandparents experience it as most community members and neighbors possess a positive attitude towards HIV and AIDS, grandparents, and grandchildren in their care.

As is evident in Table 5.11, most of the grandparent's households were of low socio-economic status. Grandparents from rural areas and urban areas perceived that their households did not have enough money for basic needs, and they all depend on the state social security. the different types of social grants are available for them but very difficult to access, due to process issues or lack of documentations.

Both grandparents from the rural areas and urban areas are affected by HIV and AIDS on several levels: 1) Caregiving compromises their health status: 2) they all suffer emotionally, physical and financial problems; 4) they are all affected by HIV and AIDS stigma and discrimination in their communities; 5) they all experience lack of services such as counselling and referral services to deal with their emotional problem; 6) They all experience difficulties accessing healthcare facilities for their treatments and the children in their care; 7) Grandparents in rural and urban areas grandparents are not coping with the caregiving duties causing strain on the physical health.

5.5 Discussion and integration of the concurrent studies

The findings of the three sources of data reported similar problems. Grandparents experienced challenges relating to caregiving both in the urban area and rural areas. The findings revealed that HIV and AIDS affect grandparents caring for AIDS orphans on several levels as caregiving responsibilities compromised grandparents' health (biophysical, socio-economic, environmental, and psychological). The study findings concur with the findings of the study done in Uganda by Matovu, Dawson-Rose, Weiss and Wallhagen (2019), their study found that caregiving provided to HIV and AIDS orphans has physical, financial, and emotional consequences.

Caregiving duties not only harm grandparents' health but also affects their financial situation. Grandparents caring for AIDS and HIV orphans find themselves living in impoverished conditions and solely depend on the funds from pension grant, which may become a complicated process if grandparents are below retirement age. Thus, grandparents caring for HIV and AIDS orphans contend that the government should support them by providing financial support in addition to their old age grant. The study findings correspond with the study of Mashau and Tugli (2019), Kendall and Anglewicz's, (2018), Shaibu (2013) and Matovu and Wallhagen (2020). Grandparents in those studies disclosed difficulty in managing daily life and meeting basic needs for the orphans due to a lack of financial means, which consequently impact on their health.

The majority of grandparents reported that the strain of caregiving resulted in new ailments, such as sleep disorders, constant headaches, stress, and depression. Several suffered from biophysical ailments such as hypertension, arthritis, and diabetes. Some grandparents were

affected emotionally and feared antagonistic, or "harsh" treatment from their neighbours. Some of the health problems they suffered may be considered devastating and reduce their ability to cope and render appropriate care to the HIV and AIDS orphans in their care. These findings are consistent with current literature that caregiving affected the health of grandparents in various ways (Block, 2014; Kuo, Operario, & Cluver, 2012; Lee, & Blitz, 2020).

Grandparents caring for AIDS orphans fear stigma and discrimination in their communities, and the fear of HIV and AIDS stigma was shared among all the grandparents caring for AIDS orphans. Some of the reasons cited for fear of stigma were that people might gossip about the family due to the presence of a HIV and AIDS orphan child in the household. Moreso, the HIV and AIDS orphan may be discriminated against, put at risk, or may be victimised by other children or family members who might not interact with them, causing unnecessary misery for the children. Such fears indicated that HIV and AIDS-related stigma was not directed at the grandparents only but affected all household members. Similar findings were reported by Mohale (2013); Cluver, Orkin, Boyes, Gardner and Nikelo (2012); Demmer, (2011); and Kalomo and Liao (2018), who found that grandparents are constantly scared of being discriminated by their families, friends and the community.

Apart from encountering numerous financial problems, grandparents also faced difficulties in dealing with the educational aspect of the HIV and AIDS orphans, especially rebellious behaviours of the teenagers and the demands they placed on the grandparents which were beyond their capacity. The finding concurs with the results of Gordon (2016). However, Wood, Chase, and Aggleton (2006) reported that orphaned teenagers were more understanding to their grandparents and portrayed a positive commitment and attitude towards their schoolwork. The majority of grandparents used worship and prayer as a coping mechanism while others resorted

to sobbing and crying. These spiritual expressions may indicate a desperate need for emotional support and counselling. Similar findings were found in a number of literatures that indicated grandparents using spirituality and resilience coping strategies (Shaibu, 2013; Frood, & Purssell, 2020).

No visible differences were noted in caregiving patterns and problems between grandparents in urban settings and their rural counterparts. However, it was evident that the grandparents could not cope with the burden of caregiving on their own and needed formal support from the government, a finding which is consistent with the results of the study done by Kalomo and Taukeni (2020). In the absence of formal financial support, grandparents coped with their burden to the best of their ability. In terms of informal support, findings showed that they receipt thereof varied; however, the support that some received from NGOs was fairly considerable. The finding concurs with Wang, Beland and Zhang (2014) and Xie (2013) who reported similar findings. Grandparents believed that some form of formal financial support was necessary and should correspond with the caregiving demands they encounter. Thus, by implication, if grandparents are sufficiently supported in their caregiving role, they will be able to provide proper care to their HIV and AIDS grandchildren until they reach an independent age.

Grandparents interviewed in the qualitative study demonstrated by their actions that they were able to make a positive contribution in the fight against HIV and AIDS if they are adequately supported, and gain improved self-esteem and confidence. The grandparents caring for HIV and AIDS orphans demonstrated resilience and compassion, but appeared to be buckling under the strain of grieving their late children, providing care to the orphans left behind unsupported, as well as inability to provide adequately for their orphaned grandchildren. Nonetheless,

grandparents confirmed that NGOs did commendable work to ease their difficult situation: especially in providing information, assistance with parenting and applications of social grants, and supporting grandparents emotionally and materially. Sadly, such support is not consistent as it is not always available and is dependent on the availability of funds.

Phase One of the study provided data from the three sources namely, qualitative data using in-depth interviews from grandparents caring for AIDS orphans (1), Quantitative data using questionnaires from MDT team, social developments and NGOs personnel (2); and a comparative checklist from grandparents caring for AIDS orphans (3). The data were analysed and the results shown and discussed above. These results are now triangulated to provide a comprehensive picture and understanding of the situation of affected grandparents caring for AIDS orphans from both different perspectives.

Triangulation combines the results of analysed data gathered from multiple sources, possibly using multi-methods (Gibson, 2017). In the present study, both quantitative and qualitative research methods were used to gather data. Triangulation of the results of the analysed data indicate the magnitude of the problem, from the perceptions of various role players and stakeholders, and what solutions in the form of strategies development may be desirable and feasible. Also, triangulation in this study is used as a tool to confirm, cross-validate and corroborate results obtained from the different sources, and to strengthen overall findings (Gibson, 2017).

In the present study, information was obtained concurrently from both the quantitative and qualitative studies. In general, the information obtained from both sources produced information for an analysis of which served to enrich an understanding of the grandparent's

situations. The strength of the obtained data lies in its description of the magnitude of the difficulties that grandparents caring for AIDS orphans in the three areas, both urban and non-urban settings, face in day-to-day caregiving. The study demonstrated a wide range of activities in which the grandparents engage in rendering care to AIDS orphans. The analysed study data also yielded measures of the participants' health status and, objectively and subjectively, the extent to which they need to be supported to reduce their caregiving burden. However, the quantitative method of data collection was not able to provide a full understanding of the grandparents' experience of caregiving, nor how they cope with the challenges of caregiving; such understanding, then, was achieved in the analysis of the qualitative part of the study. That said, the qualitative study was only conducted in a single province (the Western Cape), and generalization of these findings to settings in other provinces may be limited.

The qualitative method elaborated the perceived greatest difficulties the grandparents' experience in caregiving. Rather than mere self-reports of the presence of a health condition, the in-depth study findings indicated the nature of the illnesses, complications, and new conditions that developed as a result of caregiving without support such as sleeplessness, crying and a worsening of their chronic illnesses such as diabetes and hypertension. The grandparents were able to express how they coped with caregiving responsibilities under difficult circumstances. The grandparents were also able to express themselves on matters relating to HIV and AIDS. The majority, for instance, elaborated on the effect of the lack of formal support on their health which findings concurred with the quantitative data from the MDT team.

Grandparents' support was acquired through NGOs. Also, some reported that they receive materials assistance and enjoy broad supports from an NGO on an ongoing basis. However, most respondents expressed frustration and a sense of helplessness due to the sudden stop of

some support of NGOs due to a lack of funds. The inconsistency of government not working with NGOs, which have first-hand information on and direct contact with grandparents caring for AIDS orphans, cuts across all three areas. The government's lack of consultation with NGOs in effect disempowers the organizations to render valuable support to grandparents caring for AIDS orphans. Similar frustration with the government's functioning was expressed by participants in the qualitative part of the study, who referred to the excessive time that government bureaucracy takes to process and approve grants applications.

Finally, the qualitative part of the study explored grandparents to voice their experience of AIDS-related stigma. For some, the fear of gossip, and discrimination against their families by some community members and neighbours was the main reason for not disclosing the status of an infected grandchild in their household. A contradictory finding in the analysis of the qualitative study data was that some grandparents feared "hostile treatment" from certain health professionals at public health service points. By contrast, the quantitative data analysis indicated a notably high level of satisfaction with services and treatment at these facilities.

The in-depth interviews, therefore, afforded the respondents an opportunity to verbalise some of their experiences more thoughtfully and frankly than by merely responding to fixed-response items in the survey questionnaire. Data obtained from the government and NGO personnel suggest that a major gap exists between the challenges and hardships that grandparent's face and the level of understanding of the government of their challenges and hardships. Consequently, the government's responses to grandparents caring for AIDS orphans' support needs have been inadequate or non-existent. The results from government personnel appeared to be aware of how desperate the situation and plight of grandparents caring for AIDS orphans are. However, in reality, it seems they expect that grandparents, triple burdened by caregiving,

poverty, and their poor health, should themselves take responsibility for making their voices heard. The government personnel overlooked the grandparents' vulnerability on several levels: one being the grandparents' low level of education and inability to articulate their needs and demands, and another being their lack of knowledge on how government structures work and how to access them.

The quantitative part of the study also measured the perceived support mechanisms given to grandparents caring for HIV and AIDS orphans and the analysis concluded that the government regard grandparents as unworthy of the governments' attention as shown in the survey results, there is an age discrimination attitude from the government side with the dearth of understanding, sympathy, and response toward grandparents caring for HIV and AIDS orphans. A lack of programmes targeting the older person compared to other programmes that are fully promoted and supported by the government is evidence of the age-based discrimination against grandparents caring for HIV and AIDS orphans.

Again, a lack of support from the government indicated by the grandparents caring for HIV and AIDS orphans respondents in the qualitative part is confirmed by a lack of knowledge about grandparents' needs acknowledged by some government personnel in the quantitative part. Another contradictory finding arose from the quantitative analysis which found that the government provides support, and affirmed their awareness of grandparents' needs and the active role played the government in the provision of support given to grandparents caring for AIDS orphans. By contrast, the findings from the qualitative data analysis oppose this as the results indicated a notably lack of support from the government side.

The third source of information was obtained from another quantitative survey of the MDT team in health care facilities. The respondents agreed that the lack of income for survival can be a contributing factor to health problems amongst grandparents caring for AIDS orphans and that no access to health services can exacerbate the already compromised health of grandparents caring for AIDS orphans. This finding correlates with the findings obtained from the qualitative analysis, grandparents reported not coping and being helpless in their caring roles which affect them emotionally and worsen their chronic illnesses such as diabetes and high blood pressure. Most grandparents also reported physical problems such as back pain and arthritis.

The respondents also agreed that the lack of social security provision can be the major cause of stress experienced by grandparents caring for AIDS orphans which also correlate with the finding of the qualitative analysis from grandparents affirming the helplessness feeling and depression caused by the inability to provide for their AIDS orphans accelerated by social grants scarcity.

Some minor difficulties encountered in interpreting the above triangulation of data and indication of how they were overcome: The first difficulty was combining and integrating three data sets of different proportions: The qualitative data with grandparents caring for AIDS orphans (n = 25), the quantitative data with government officials (n = 15) and MDT team survey (n =50). Moreover. The combination, comparison, and potential correlation of some data in three data sets could have been inherently problematic. However, this problem and other problems were solved as follows: A first problem was that of the researcher's subjectivity and consequent bias in the interpretation. Such bias could have entered through her disciplinary orientation and cultural experience, and her knowledge of the study context. In interpreting the

data, the researcher had to guard moreover against slipping from facts and data to conclude some inferences possibly unsupported by the data (Creswell, 2014b); therefore, the researcher endeavoured to cite the facts in respective data sets from which inferences were made. Similarly, the researcher endeavoured to genuinely represent the participants' views and circumstances and to not select issues of concern or interest to the researcher.

Additional steps that were taken to ensure that interpretation remained objective included engaging in self-reflection (Burns & Grove, 2014), in order to be aware of potential biases and avoid them, and presenting the triangulated data and the interpretations to the supervisors, as mentors, for scrutiny and affirmation. A related problem was how the researcher should provide an accurate account of the information and interpretation. In quantitative research, verification of the accuracy of such reporting may be conducted through "debriefing" between the researcher and the study participants (McMahon, & Winch, 2018).

In the present study, the researcher used a triangulation strategy to verify the accuracy of the reporting and interpretation. The strategy helped the researcher to identify instances of convergence and/or divergence in the data sets. Finally, the researcher together with the experienced research assistant conducted the qualitative interviews. The researcher documented the participants' experiences in the field, which provided a first hand and in-depth understanding of the phenomenon under study; the researcher was able therefore to communicate a detailed and credible account of the study settings and the grandparents' situations.

In summary, the evidence presented from the analysis of the data from the three sources validates the need for strategies development to improve the support given to grandparents

caring for AIDS orphans, to reduce the effects of the HIV and AIDS epidemic, and to ameliorate the care burden of the epidemic on the well-being of grandparents caring for AIDS orphans. Hence, the welfare and health of present and future cohorts of grandparents caring for AIDS orphans can be sustained, through the expanded provision of formal support from the government side, and support of the activities of NGOs.

5.6 Concluding Statements

The following paragraphs discuss the conclusion statements emerged from the study:

5.6.1 The current study evidenced that the majority of the grandparents may be vulnerable physically, socially, and economically. They experienced extreme poverty due to their low socio-economic status, lack of access to resources, little formal and informal support, limited living space, and the burden of care (Kalomo, & Taukeni, 2020; Hlabyago& Ogubanjo, 2009). The financial situation of the grandparents and their household was shocking; apart from income from a social pension in the majority of cases, and child support grants in some cases, no other support was forthcoming from the government for grandparents caring for AIDS orphans (Wang, Beland, & Zhang, 2014; Xie, 2013).

5.6.2 The findings demonstrated that grandparents are occupied continuously with their orphaned grandchildren, and are expected to carry out various household chores. This is a challenge to the grandparents who are already physically weak, fatigued and frail to assume so many responsibilities that include strenuous activities. Therefore, grandparents reported poor health generally, aggravated by chronic health conditions such as hypertension, diabetes, arthritis, and stress in particular

(Phetlhu, & Watson, 2014; Fourie, Mudavanhu, & Segalo, 2008; Mathilda, Mukombwe, Doreen, & Clara, 2015). Indeed, the health conditions may have been induced or exacerbated by the strain of caregiving responsibilities. Also, grandparents tend to minimise the severity of their health condition and delay seeking medical attention due to caregiving duties (Chazan, 2008; Makgato, 2010).

5.6.3 The South African government responded to the needs of all South Africans with several social assistance grants, including old-age pensions, child support grants, and foster child grants. The child support grants offer supplementary income to financially eligible grandparents caring for AIDS orphans; while foster child grants offer financial assistance for grandparents legally fostering a grandchild. Old-age pensions, which are available to those aged 60 years and older, support older South Africans (Chazan, 2008). However, while an old-age pension grant was planned to benefit grandparents, multiple family members often utilise the funds which are used to buy necessities for orphans' grandchildren instead (Schatz & Ogunmefun, 2007; Doblin-MacNab & Yancura, 2018) which demonstrate the significant lack of financial assistance that government grants provide to South African grandparents raising AIDS orphans (Dolbin-MacNab *et al.,* 2016).

5.6.4 Even though grandparents need assistance, some of them are below 60 years and are not eligible for the old-age pension (Dolbin-MacNab, & Yancura, 2018). There is also a lack of knowledge about available supports (Mzimela, 2019) and

other challenges including difficulty obtaining necessary documentation for the orphans, long application process and approval times, and other bureaucratic problems (Shaibu, 2013; Dolbin- MacNab, & Yancura, 2019; Delany, Jehoma, & Lake, 2016). Therefore, NGOs intervene to play a significant role in compensating the lack of assistance from the government side, and provide support to grandparents caring for AIDS orphans and their households, specifically assisting them with grants applications and follow up, providing information on HIV and AIDS, advice on day-to-day caregiving, skills development, and financial support (Frood, & Purssell, 2020; Delany, Jehoma, & Lake, 2016). The grandparents perceived that support from the government to help them with caregiving and related responsibilities was "non-existent." However, there are problems of NGOs that are no longer providing the same support due to scarcity of funds.

5.6.5 Fear of discrimination due to AIDS stigma were shared among grandparents caring for AIDS orphans. Majority of grandparents in this study had never talked about the HIV status of the orphans in their care or the cause of their children's death because they are scared to be treated differently by friends, family, and neighbours. Therefore, stigma relating to HIV and AIDS are problems with which grandparents are challenged with in their community. This finding is consistent with the majority of household studies carried out on HIV and AIDS (Mashegoane, & Mohale, 2016; Matovu, Dawson-Rose, Weiss, & Wallhagen, 2019).

5.6.6 Even though caring for HIV positive children with a high level of morbidity are eligible for a disability grant, none of the households received such a grant despite the effort made by grandparents to apply for such a grant. Disability grants could provide much-needed relief and a safety net for such households. Few grandparents were successfully granted the foster grants for their AIDS orphans with the help of NGO's, others are still struggling with the applications. The delays in processing their applications are mostly due to the inability to provide birth certificates and ID documents and for the orphans' children. On the other hand, few grandparents caring for AIDS orphans are not aware of the types of grants they can benefit from and ease their burden (Dolbin-MacNab, & Yancura, 2018; Hayslip, Hlabyago, & Ogunbanjo, 2009; Fruhauf, & Dolbin-MacNab, 2019).

5.6.7 Apart from food, the areas of need also include health and transport. Some grandparents in both urban and rural areas need transport facilitation for easy access to these services. Although the grandparents were making a valuable contribution by shouldering the burden of care in their household, assuming such responsibility often came at a great cost. Apart from the direct financial costs of caregiving, the burden of care adversely affected the grandparents' health. It is difficult for them to walk a long distance to the clinic, especially when they have to take the children (Nyasani, Sterberg, & Smith, 2009; Mtshali, 2016).

5.6.8 The consequences of increased responsibilities on the ageing grandparents without support exert tremendous pressure on them, causing them to live a lonely

life, and affect their overall health. Earlier studies have provided evidence of adverse physical and emotional disorders in grandparents as a result of caregiving stress (Kuo & Operario 2011; Shaibu, 2013; Mohale, 2013; Mtshali, 2016; Phetlhu, & Watson, 2014). Therefore, Grandparents caring for AIDS orphans merit special attention at health care facilities as grandparents who are not club members find it difficult to wait for a long time to get their chronic medications and see the doctor.

5.6.9 Grandparents caring for AIDS orphans have no other source of income except for their pension grants. They experience extreme poverty, and their poor socio-economic status undoubtedly makes caregiving more difficult for them. Their particular vulnerability was evident in several aspects in the analysis: socio-economic and health-related indicators, and a lack of support, in particular. This finding is supported by similar findings in other studies in Sub-Saharan African countries (Rutakumwa, Zalwango, Richards, & Seeley, 2015; 2009; Shaibu, 2013; and Mtshali, 2016). Additional findings showed that grandparents struggled to cope with parenting responsibilities and deal with teenagers' deviant behaviours (Nyoni, Nabunya, & Ssewamala, 2019)

5.6.10 Nonetheless, although the majority of grandparents received an old-age pension from the government, the financial situation of the grandparent's households was equally dire, and their pension grant was mostly used to take care of orphans in their care (Shaibu, 2013). Some few grandparents received little other support from the government, other than a child support grant. Financial support from

other family members living elsewhere was limited and not dependable. Grandparents are unable to engage in any income-generating activities because of caregiving responsibilities. The grandparents' dire financial situation has been reported in most of the previous studies done in South Africa (Hlabyago, & Ogunbanjo, 2009; Mohale, 2013).

5.6.11 The grandparents' experience of the significance of government support is considered insufficient. Non-profit organizations are playing a crucial role in supporting grandparents caring for AIDS orphans continuously. A high proportion of the grandparents reported receiving assistance from NGOs. The lead taken by NGOs in supporting affected grandparents has been reported by Nyasani Sterberg and Smith (2009) in South Africa. The lack of proper government support to grandparents caring for AIDS orphans in South Africa is reflected in the absence of appropriate policy and programme responses to meet the needs of grandparents caring for AIDS orphans (Schatz, Ogunmefun, 2007; Dolbin-MacNab & Yancura, 2018).

5.6.12 It was therefore agreed that the government's support is insufficient to alleviate the strain of caregiving; and it was indicated that grandparents needed "a lot" of support in the following areas: Money to buy food and other necessities; relief for physical assistance with daily activities, emotional support; and social support. The government does not offer help in any of these areas. Presumably, it relies on NGOs to do so (Phetlhu & Watson, 2014). Moreover, where the government does provide support to individuals and families affected by AIDS, none of them is

targeted at grandparents caring for AIDS orphans, which substantiates the grandparents' perception that they are excluded from support programmes.

5.6.13 The grandparents caring for AIDS orphans need "a lot" of emotional support as they are always worried and stressed about the future of their orphaned grandchildren. Not surprisingly, stigmatization of the disease was found to be a problem in most of the communities where the study was conducted, which is an obstacle for them in seeking help resources. More positively, some family members of grandparents were reported by the participants to be supportive of the orphans, which suggests that anti-AIDS stigma interventions may be accepted at a family level, which will help to strengthen family resilience against the stigma. However, some family members were still reported by grandparents, not help them, and have a hostile attitude toward AIDS-affected orphans

.

5.6.14 Studies conducted on caregiving to AIDS orphans have shown that caregiving is essentially a woman's responsibility and that males tend not to participate in caregiving directly (Orner, 2006; Karimli, Ssewamala, & Ismayilova, 2012). Men have typically been viewed as a family and household providers, or as a supportive role, but not as a primary carer. This correlates with the current study as only females were available to be interviewed as primary carers in the present study.

5.6.15 The study findings revealed that grandparents caring for AIDS orphans are doing their best to support the orphans. However, they provide support under harsh

conditions which in turn affect their life in the various sphere. Therefore, it is essential that grandparents are supported holistically (physically, emotionally and socio-economic) in their caregiving roles. Thus, the findings are certainly relevant to the development of comprehensive old-age support policies in South Africa, immensely to benefit grandparents caring for AIDS orphans. The need for the family and the community to collectively support the households affected by AIDS headed by grandparents should be included to benefit the wellbeing of grandparents caring for AIDS orphans (Matovu, Dawson-Rose, Weiss, & Wallhagen, 2019).

5.6. 16 Some children had been hospitalised numerous times, which took its toll on grandparents. All grandparents make use of public health care, and they found the health care providers to be helpful and affordable. However, few grandparents still find it difficult to walk a long distance to the health facility, especially in the winter months. Some grandparents experienced difficulties accessing their chronic medications which contributed to a reluctance to seek care at some health facilities from some of the grandparents. Unfriendly staff attitudes, long waiting periods are found to be another problem that some grandparents have to endure. The situation becomes worse when grandparents have cared for the AIDS-affected infants and bring them for check-ups. Therefore, healthcare facilities need to support grandparents and include grandparents in their care plans management.

5.7 Summary

The chapter presented data analysis from different sources and discussed the results with regards to the conceptual framework as well as the triangulation of the concurrent data. The chapter further provided the conclusion statement from the data which will be the key fundamental aspect in developing strategies that will improve the support given to grandparents caring for AIDS orphans in phase two of the study. The next chapter discuss phase two (2) of the study which is the development of strategies.

6 CHAPTER SIX: STRATEGIES TO IMPROVE THE SUPPORT GIVEN TO GRANDPARENTS CARING FOR AIDS ORPHANS

6.1 Introduction

The purpose of this chapter is to describe the development of strategies to improve the support given to grandparents caring for AIDS orphans in Western Cape Province of South Africa. The chapter is divided into three sections commencing with the introduction to strategies and strategic processes and reviews the basis for the strategy development in this study. The second section is the development of vision, mission, values, principles, assumptions, strategy objectives, and functional tactics of the strategy. The third section is the application of the Delphi technique to act as quality assurance to the developed strategies, and the results of each round of the Delphi will be presented systematically. The study concludes with a discussion of the strategic document for use in healthcare facilities to improve the support given to grandparents caring for AIDS orphans (which was acclaimed and approved through consensus agreement by the Delphi panellists) and a proposed model to enhance the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa.

6.2 Strategy development process

6.2.1 Description of strategies and strategic process

Strategies can be essential approaches management chooses for designing the action to solve a problem or accomplish a goal (Bryson, 2018). The strategic process is an organised procedure whereby an organization determines its oneness and motive and creates a vision and mission. It states its values and principles, identifies its direction, and develops a unified approach to its strategies. Moreover, the strategic process enables the organization to prioritise long-and short-

term objectives, decide on actions to achieve these objectives, assign accountability, and allocate financial resources (Esewe & Phetlhu, 2020). All of which are aligned to the environment to solve a problem or accomplish a goal (Ehlers & Lazenby, 2010; Bryson, 2018).

The strategic development approach supports the interaction of all stakeholders in an institution during the planning and implementation process of a programme. According to Leadership and governance (2000), to ensure that an organization succeeds in achieving its goals, it must incorporate an aligned strategy philosophy which encompasses all aspects of the organization at all levels of alignments from the leadership team on top to the bottom which will enhance the common goals and ensure that the entire organization is aligned with the vision and the strategy, hence everyone would know where the organization is going and how the organization will succeed in achieving its goals (Bryson, 2018).

This study purports to develop strategies that will improve the support given to grandparents caring for AIDS orphans. The organization refers to healthcare facilities (clinics and communities, health centres) and social development departments. A strategy is the purpose of the primary long-term goals and objectives of these facilities and departments and implementation of course of action and the allocation of resources necessary for the carrying out of these goals, which at the end will contribute in deciding where the above organizations would like to be, in terms of providing support to grandparents caring for AIDS orphans. The strategies were developed by means of the application of TQM Framework by Tenner and De Toro (1992), to work in partnership with all the key players (MDT, personnel in social services and NGO, and grandparents caring for AIDS orphans) using concluding statements and problems identified from phase one of the study.

6.3 Concluding Statements Forming the Basis of the Strategy Formulation

Sixteen (16) concluding statements formulated from thirty-two (32) Identified problems in phase one of the study, formed the evidence base for developing strategies to enhance the support given to grandparents caring for AIDS orphans in Western Cape Province. Table 6.1 presents Identified problems and related concluding statements grouped using the community health framework to facilitate the reader to form a link between the concluding statements and the conceptual framework that guided the study. The term GPCFAO stands for Grandparents caring for AIDS orphans, and Cs stands for concluding statement (see footnote).

Table 6.1. Identified problems and related concluding statements

BIOPHYSICAL	PSYCHOLOGICAL	SOCIO – ECONOMIC	BEHAVIOURAL	PHYSICAL ENVIRONMENT	HEALTH SYSTEM
1. GPCFAO are continuously rendering care to orphans without help, which is physically demanding and exhausting, hence increasing the risk of health problems. EP1 (**CS5.6.1; 5.6.2)**	4.Frustration and hopelessness from GPCFAO taking care of teenagers due to orphan's misbehaviours. Moreover, they lack the skills to deal with the teenager's deviant behaviours. EP4 **(CS 5.6.15)**	10. Inadequate formal financial support is given to GPCFAO, which makes it difficult for them to meet the basic needs of AIDS orphans in their care, and make it challenging to maintain good health for GPCFAO and for the infected children which might increase opportunistic infections amongst HIV/AIDS infected children. **EP10 (CS 5.6.3; 5.6.6; 5.6.8; 5.6.12)**	23. GPCFAO lack adequate skills to deal with orphan's deviant behaviours. No hope for the future amongst some orphans due to school dropout and using substance abuse. **EP 23 (CS 5.6.9)**	27. GPCFAOs and their families live in overcrowding and limited space which can lead to the infectious diseases**. EP27 (CS 5.6. 1)**	29.Healthcare services do not have care plans and support services to support GPCFAOs in their clinics and communities' health centres**. EP29 (CS 5.6.16)**
2.Poor health,[1] aggravated by chronic illnesses such as	5.There is a problem of stigma experienced by GPCFAO in their communities and their	**11.** There is a problem of NGO'S that are no longer assisting GPCFAO due to scarcity of funds EP11 (CS 5.6.3)	24. The irresponsibility of the biological parents who are still alive but abusing GPCFAO by not assisting	28.GPCFAOs struggle to get the transport fare to access the clinics,	30. The hostile attitude from some MDT healthcare workers prevents GPCFAO

[1] GPCFAO: Grandparents Caring For Aids Orphans
CS: Concluding statements

BIOPHYSICAL	PSYCHOLOGICAL	SOCIO – ECONOMIC	BEHAVIOURAL	PHYSICAL ENVIRONMENT	HEALTH SYSTEM
hypertension, arthritis, diabetes which are aggravated by the strain of caregiving responsibilities **EP 2 (CS 5.6.2)**	families, for having HIV and AIDS affected children in their care EP5 (**CS 5.6.5)**	12. The quality of social service is not adequate because of the delays in social grant applications and inconsistency in grant provision **EP12 (CS 5.6.6; 5.6.4).**	them in taking care of their children affects GPCFAOs holistically. **EP 24 (CS 5.6.15)**	causing them to walk a long distance (with children) to access the clinics**. EP28 (CS 5.6.16)**	from expressing themselves, making them reluctant to access the health service**. EP30 (CS:5.6.16)**
3.GPCFAO are not coping with caregiving duties, and are exhausted due to no physical support EP3 (**CS 5.6.1).**	6.GPCFAO experience fear of being discriminated which lead them to live a lonely life and they are scared to request help which affects the overall health **EP6CS 5.6.5; 5.6.13**).	13.There is a problem of NGO'S that are no longer assisting GPCFAO due to scarcity of funds **EP13 (CS 5.6.3)**	25.GPCFAOs do not trust the government; they think that the government does not care about their problems **EP 25 (CS 5.6.3.)**		31. MDT health workers do not go the extra mile to recognise and support GPCFAO in their diverse challenge of caring, concluding the lack of involvement of MDT in providing holistic care and support to GPCFAO in the clinics and CHS. EP31 **(CS 5.6.14)**
					32.Long waiting period before doctor consultation for GPCFAO who are not club members **EP32 (CS 5.6.16).**

BIOPHYSICAL	PSYCHOLOGICAL	SOCIO – ECONOMIC	BEHAVIOURAL	PHYSICAL ENVIRONMENT	HEALTH SYSTEM
	7.GCFAO experience negative attitude from the community **EP7 (5.6.5**)	14.GPCFAOs lack of knowledge of the rights of the children in their care and are not aware of different types of grants that they can apply for the orphans in their care. **EP14 (CS 5.6.4).**	26.Some GPCFAOs add non-related foster children to their existing AIDS orphans to qualify for the foster care grant, thus increasing their responsibilities to care for so many kids, which in turn affects their overall health EP **26 (CS 5.6.4).**		
	8.The rest of the community forgets GPCFAO; they live alone life without support, causing them to isolate themselves socially, resulting in an emotional breakdown. **EP 8 (CS 5.6.12).**	15. Lack of birth certificate for the orphans, which hinders the grant application process **EP15 (CS 5.6.4).**			
	9. Negative attitude from the neighbours towards grandchildren raised by	16. Pension grants allocated to GPCFAO to support their needs; instead, it takes care of			

	grandparents caring for AIDS orphans **9(CS 565)**	AIDS orphans. **EP16 (CS 5.6.3)**			
		17. Lack of formal and informal support from families, and the rest of the community **EP17 (CS 5.6.1; 5.6.10).**			
		18. Scarcity of the stable income from GPCFAO to sustain orphans' needs EP 18 **(CS 5.6.10)**			
		19. There are discrepancies in providing and qualifying for the foster care grants for the orphans fostered by GPCFAO. **EP 19 (CS 5.6.6)**			
		20. It is difficult for GPCFAOs to access social grants for AIDS orphans in their care, and for the ones who receive the social grant, it is inadequate to cover all the basic needs, including nutritious food for infected orphans. **EP 20 (CS 5.6.4)**			

		21.There are discrepancies in providing and qualifying for the foster care grants for the orphans fostered by GPCFAO. EP 21(CS 5.6.6)			
		22. It is difficult for GPCFAOs to access social grants for AIDS orphans in their care, and for the ones who receive the social grant, it is inadequate to cover all the basic needs, including nutritious food for infected orphans. **EP22 (CS 5.6.4)**			

6.3.1 Strategies formulation

The strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape province, South Africa was developed using a strategic process to develop a vision, mission, identify values, principles, and assumptions, and formulate strategy objective and functional tactics, based on the TQM Philosophy. Each step of the strategic process that followed in developing the strategy to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa, is explained in the subsequent paragraphs.

6.3.2 TQM Philosophy

Total quality management (TQM) is a set of opinions and ideas for improving the quality of products or services, which widely called "management philosophy", and its main aims are to satisfy customers and survive in the market (Neyestani, 2017). Historically, TQM was first emerged by the contributions of quality experts who developed this powerful management technique for improving business quality within the organizations. Ever since the creation of the concept, most types of organizations make use of it, including healthcare. The objective of TQM is to do things right the first time over and over again. The concept saved the organization the time needed to correct poor work and failed product and service implementations. The figure below (see Figure 3) shows the basic principles of TQM.

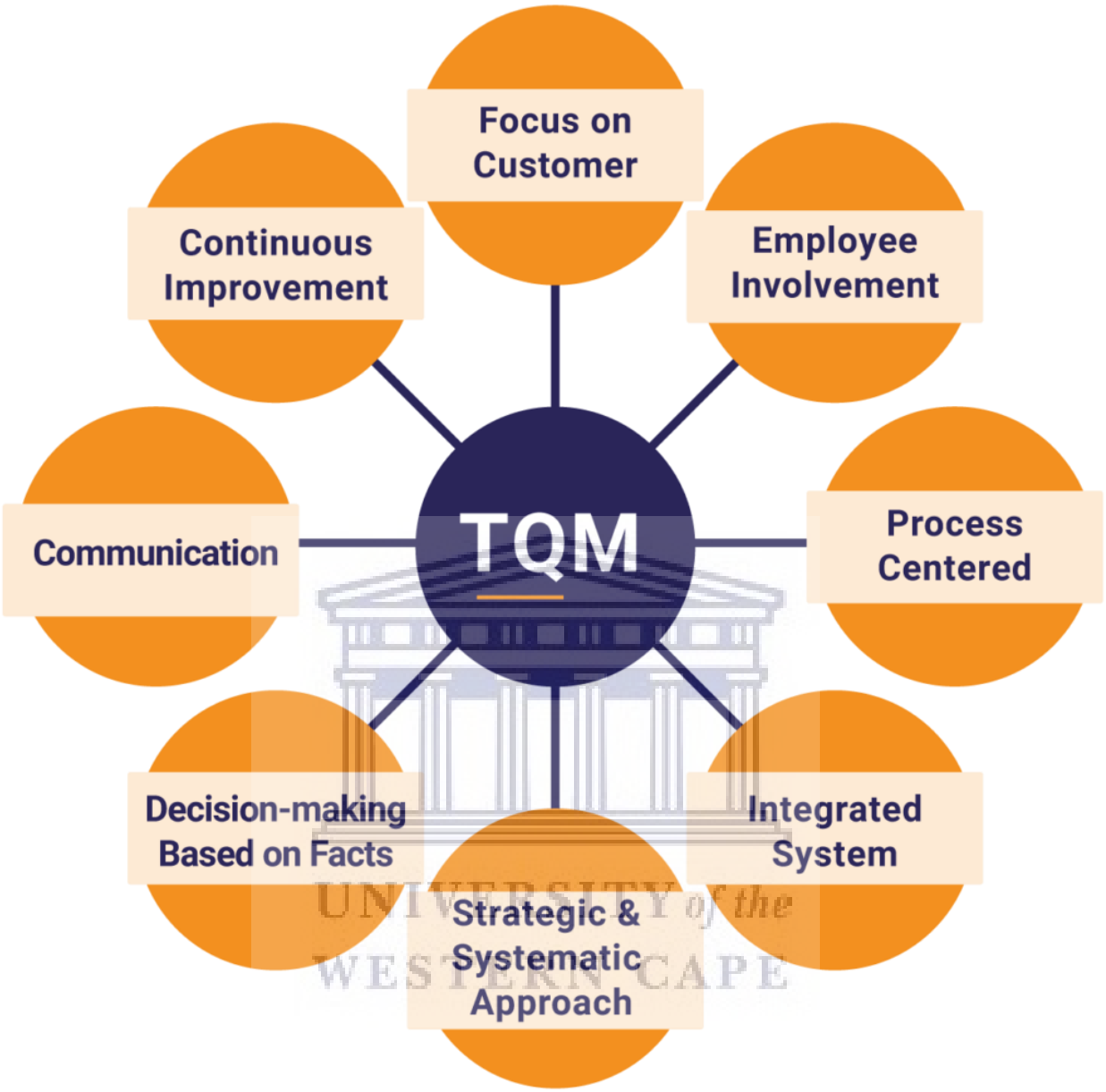


Figure 3 Total Quality Management principles (Source: Juran's Enterprise Excellence Management System)

6.3.3 Assumptions

The strategy to improve the support given to grandparents caring for AIDS orphans in the Western province, South Africa, is influenced by several assumptions. The precise statement

of these assumptions is essential as it presents a starting point for the understanding of the strategy to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa. The following assumptions influence the strategies:

- The strategies are developed for use within the healthcare and social services context of the Western Cape Province, South Africa.
- To improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, the strategy must be interpreted in terms of the philosophy of TQM. In this study, TQM's construction relies on the three fundamental principles that encompass its overall concept and, if efficiently administered, will promote the continuous improvement of the support given to grandparents caring for AIDS orphans in communities' healthcare and social services facilities.
- The three fundamental principles are the grandparents caring for AIDS orphans, Multidisciplinary team health workers (MDT) and government and NGOs personnel in social development services; using a collaborative process with eight components of TQM elements namely, 1) focus on custom; 2) employee involvement; 3) process centered, 4) integrated system; 5) systematic and strategic approach; 6) decision making based on fact; 7) communication and 8) continuous improvement. In this strategy, grandparents caring for AIDS orphans are the main focus of Multidisciplinary team health workers (MDT) health workers in various clinics, community health centres, government, and non-government (NGOs) personnel in social services.
- The strategies are viewed as "Active" because community nursing practice is active and rapidly growing, influencing, and to some degree, putting pressure on the quality of nursing practice in South Africa.

- Health facilities; must continually evaluate the quality of nursing practice using the Department of Health criteria concerning the nature of its mission aimed at the knowledge, practice, and attitude of health workers geared towards a comprehensive framework to improve the status of health through the anticipation of illnesses and health promotion and to continually improve the healthcare delivery system by focusing on access, equity, efficiency quality and sustainability
- Make use of the resources for the department of health and department of social development towards the achievement of the health promotion and caring for the healthcare users, as explained in the National Health act (National development plan: Vision 2030). This is necessary to change, revise, and renew the strategy and measurement objectives and functional policies to continuously improve the support given to grandparents caring for AIDS orphans in Western Cape Province, South Africa.
- The vision of the strategies gives rise to the mission that is driven by the values, principles, and assumptions of the strategy based on the TQM philosophy. Therefore, to change, revise, or renew the strategic objectives and functional policy of the strategy, all these fundamentals must be taken into consideration.

6.3.4 Context

The formulation of the strategies relates to support given to grandparents caring for AIDS orphans in all clinics, communities health, and social service in Western Cape Province, South Africa. The developed strategies are from the concluding statements from the empirical data derived from the investigation of grandparents caring for AIDS orphans, MDT in various clinics, community health centres, and government personnel in social development. Therefore, this cannot be generalised to other contexts but can be adapted to suit a particular situation.

6.3.5 Process

The focus of the strategies will be on the following aspects on the process of the strategy formulation: Vision, Mission, Values. Principles. Goals and objectives and Functional tactics.

6.3.5.1 *Vision*

A vision is a practical, credible, and attractive future of an organization in any organization (Hinton, 2012). A vision describes how to get to where you want to be. According to Dress, Lumpkin and Eisner (Taiwo, Lawal, & Agwu, 2016). Vision tends to be broad and is the mirror of the organization. Thus, the strategic planning process is the fundamental step to ascertain and develop a strategic vision for the organization because it is a motivating statement made by an organization that conveys what they would like to achieve. Therefore, the vision directs the direction of the organizations' efforts (Gulati, Mikhail, Morgan, & Sittig, 2016).

The vision statement responds to the questions: "What do we want to become?" and "Where do we want to go?" and concentrates on what the organization's long- term direction should be (Taiwo, Lawal, & Agwu, 2016). Therefore, it indicates the direction, the aim, the goal, and hopes of the organization and structures of its identity. According to Mishe (2000), the most compelling visions share six essential qualities:

- Conveys a sense of direction to the organization and gives a sense of direction, a goal and guide to a future state of its existence;
- Establishes a context for operating the organization. Contexts help to define and classify the environment in which the leader and the organization operate;

- Describes a future condition. Practical visions provide a future—state and condition that represents a “better” state than the ones of the past and that exists in the present;
- Motivates people. Leaders understand that useful and meaningful visions provide a high-value proposition to others. Those visions that appeal to the instincts, needs, and intelligence of people and touch their “soul” serve as a basis for systematic acceptance and motivation;
- Inspires people to work toward a shared state and a set of goals; and
- Serves as an axis point for organizational behaviour and performance and provides a central point for focusing the resources of the organization, developing strategy, and measuring progress towards the vision.

According to the National Development Plan (NDP) 2030, The Department of Health's vision is as follows: "*A long and healthy life for all South Africans*" and the mission to improve health status through the prevention of illness, disease and the promotion of healthy lifestyles, and to consistently improve the health care delivery system by focusing on access, equity, efficiency, quality, and sustainability. The vision of the social development department is: "*A caring, self-reliant society and has the mission to transform society by building conscious and capable citizens through the provision of comprehensive, integrated, and sustainable development services."*

Therefore, to develop a vision, the researcher inspected the two main collaborators in the provision of health and social services in the Western Cape Province, as represented by the Health Department (DOH), and the Social Development Department (DSD).

The Vision: *Acceptable lifestyle to all grandparents caring for AIDS orphans.*

6.3.5.2 *Mission*

A mission statement is a strong statement of the exceptional purpose of an organization, and that differentiates it from similar ones. It describes the general purpose for which an organization exists (Mas-Machuca, Ballesteros-Sola, & Guerrero, 2017). The mission identifies the present scope of the organizations' operations in terms of its present capabilities, customer focus, activities, makeup, product, market, and technology. It provides answers to the questions: "Who are we?" and "What do we do?" A mission statement embodies the philosophy, values, identity, character, and priorities of an organization, and also imitates the image the organization wants to project.

A mission statement is deemed to be a valuable strategic and communication tool in all types of organization (Cronin & Bolon, 2018) and is not about measurable targets but is instead a statement of intent, attitude, outlook, and orientation (Mas-Machuca, Ballesteros-Sola, & Guerrero, 2017). Thus, a good mission statement summarises an organization's unique and enduring reason for being and motivates stakeholders to pursue common goals, and answers the following questions:" What is our business?; Why do we exist?; and What are we trying to accomplish? (Cronin & Bolon, 2018).

Grandparents caring for AIDS orphans often experiencing the multiple burdens of poor living conditions, weak social network, and unhealthy lifestyles (Dolbin-MacNab, & Yancura, 2018), hence instigated the researcher to attempt developing strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province. The mission was then developed from the stakeholders' elements and from the research findings (refer to concluding statements and identified problems).

Mission: *To provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity from the participation of stakeholders and through excellence in multidisciplinary health care practice.*

6.3.5.3 *Value*

Values are the beliefs or an attitude towards a person, object, idea, or action. They represent a way of life, give direction to life, and form the basis of behaviour, especially behaviour based on decisions or choices (Mirvis, Googins, & Kinnicutt, 2010). Values dictate how decisions are made and embody what the organization stands for. Values influence the policies, the type of competitive advantage sought, the organization structure, systems of management, the strategies, and the organization's functional tactics (Aithal, 2016; Scott, & Mars, 2013). Therefore, it is important to understand the values common to the multidisciplinary team within the healthcare facilities (clinics and CHS) in the Western Cape Province, South Africa. To accomplish the above vision and mission, the following values were central and drive this strategy:

- Participation
- Respect and kindness
- Integrity in practical assistance
- Family and community-based care
- Strengthen existing resources
- Develop on locally appropriate practices
- Consideration of gender
- Strategic leverage and prevention
- Quality care

6.3.5.4 *Principles*

Principles indicate an accepted or fundamental basis of conduct, action, or management for application in action (Dictionary.com, 2004; Thesaurus, 2002). Therefore, to ensure that the formulated principles for the strategy are relevant and applicable, the researcher formulated the principles from identified problems in phase one of the study, together with the reference of the study framework. Thus, the formulated principles provide strategic direction for policies and programme formulation and develop special programmes for Grandparents caring for AIDS orphans (GPCFAO).

6.3.6 Formulated principles to improve the support given to grandparents caring for AIDS orphans (GCFAO)

According to the study results, grandparents caring for AIDS orphans (GPCFAOs) struggle to cope emotionally and socially (see concluding statements). Therefore, it is imperative to their wellbeing to have psychosocial support within families and communities, as these are the people who have regular interaction with them and the orphans under their care. Formulated principles that are applicable to the study include:

- Facilitate health, and social support system plans with GPCFAO and their families in order to assist them in finding connections with the rest of the community and their families.
- Develop community awareness programmes on the needs of GPCFAO

According to the identified problems, the support programmes may include a holistic focus on the training and skills development for teenagers; practical assistance (such as accessing

identity documents or social grants); counselling, HIV testing and treatment assistance and psychosocial support of infected children; nutritional support programmes and economic strengthening activities.

The following table (table 6.2) represents the application of the value and principles of health care workers and social services to the strategy to improve the support given to GPCFAO in the Western Cape province, South Africa.

Table 6.2 Formulated principles to improve the support given to grandparents caring for AIDS orphans (GCFAO)

VALUES	APPLICATION OF VALUES
Participation	All clinics and CHC (Communities health centres) must use participatory approach where grandparents caring for AIDS orphans are involved in identifying their needs, planning, facilitating, and evaluating interventions.
Respect and kindness	Support and care may be provided simply by changing how healthcare workers behave towards grandparents caring for AIDS orphans—showing respect and kindness at all times in a way that builds the dignity of grandparents caring for AIDS orphans.
Integrity in practical assistance	Integrity is the quality of a person who can be counted on to give precedence and adhere to moral values and ethical principles, even when there is strong inducement to pursue self-interest or personal desires (Dictionary.com, 2004; Shahriari, Mohammadi, Abbaszadeh, & Bahrami, 2013). Healthcare workers should possess the integrity to gain the confidence and trust from GPCFAO.
Family and community-based care	Encourage the use of the family and community approach, which supports GPCFAO within the context of their family and community environment.

PRINCIPLES OF HEALTH	APPLICATION
Strengthen existing resources	Develop skills from strengths by acknowledging the existing knowledge, skills, and expertise that the GPCFAO brings to each situation.
Develop on locally appropriate practices	Research and strengthen locally appropriate ways of supporting grandparents caring for AIDS orphans so that one is not encountering resistance to practices considered foreign. GPCFAO, in particular, may appreciate traditional approaches rather than unfamiliar ways of receiving support.
Strategic leverage and prevention	Influence the life of GPCFAO more broadly and focus on the prevention of suffering rather than just the alleviation of suffering. This principle must include consideration of the "Not harm" principles for every intervention with GPCFAO as foundational principles for all interventions.
Quality care	Healthcare workers in all clinics and CHC must maintain professional ethics through human dignity and human right, confidentiality, and cultural sensitivity.
Consideration of gender	Be gender-sensitive when providing support and recognise that the needs of grandparent's women may be different from those of grandparent's men.

6.3.6.1 *Goal /Aim*

Each strategy should have a goal and objectives to inform the functional plan. Therefore, in this study, the aim of the strategies is to improve the support given to grandparents caring for AIDS orphans in Western Cape Province, South Africa. The following is a discussion of the objectives for reaching the above set goal.

6.3.6.2 *Strategic objectives*

Objectives are plans aimed at achieving a goal (SUNO, 2010). Objectives can be classified as long-term or short-term. Long-term objectives are the statements which reflect the results that the programme seeks to achieve over a period of time (Pearce & Robinson, 2000). Furthermore, in the strategic process, strategic objectives are the long-term goals that are determined in line with the management's vision and reflect the organization's direction on a high level (SUNO, 2010).

In this study, the development of strategies aimed to improve the support given to GPCFAO in Western Cape Province, South Africa. The strategic objectives correlate with the vision, mission, value, principles, and assumptions of the strategy to improve the support given to grandparents caring for AIDS orphans in Western Cape Province, South Africa and were based on the thirty-two (32) identified problems from the empirical research and literature review in phase one of the study.

The development of five objectives includes problems clustered together using deductive and inductive logic. The long-term objectives focused on GPCFAO development, service delivery, and family and community responsibilities. These objectives had to be acceptable, flexible,

measurable, motivating, sustainable, achievable, and understandable. For easy tracking and monitoring, the strategic objectives are presented in the table below (see Table 6.3). Each strategic objective is stated with the identified problem/concluding statements from the empirical research serving as the evidence base. The implementation of a time frame is at least one year.

Table 6.3 Strategic objectives

OBJECTIVE	• GPCFAO who are taking care of affected teenagers are frustrated and hopeless due to teenagers' misbehaviours and GPCFAO lack skills to deal with their deviant behaviours **EP 23 (CS 5.6.9).** • There is a problem of stigma experienced by GPCFAO in their communities and their families, for having HIV and AIDS affected children in their care EP5 (**CS 5.6.5).** • GPCFAO are constantly worried and stressed about their grandchildren's future and they experience fear of being discriminated which lead them to live a lonely life and they are scared to request help which affect the overall health **EP6 (CS 5.6.13).** • GPCFAO are hopeless in their situation of caring for the orphans due to challenges they are faced with no resources **EP 10 (CS 5.6.12.)** • Inadequate access to essential social and health care services and experience lack of social and community support **EP 28 & EP11(CS: 5.6.14; 5.6.3)** • GPCFAO are facing extreme poverty and there is lack of strategies to support grandparents caring for AIDS orphans in both health care and social services EP 21 **(CS: 5.6.8).** • The quality of social service is not adequate because of slow process procedure for social grant application**. EP 12 (CS: 5.6.4)** GPCFAO lack of knowledge of the rights of the children in their care and are not aware of different types of grants that they can apply for the orphans in their care. Lack of birth certificate for the orphans which hinder the grant application process **EP 14 (CS:5.6.4).**

1. To strengthen the capacity for grandparents caring for affected AIDS orphans by developing more supportive relationship between them and the orphans in their care, and protect themselves against HIV. 2. To provide emotional support to GPCFAO through the grief process and stigma issues in their communities and promote their self-esteem. 3. To strengthen economic programmes that would protect GPCFAO against poverty, abuse, and exploitation.	• There are no counselling services available to help GPCFAO to cope with their emotional challenges. **EP9 (CS:5.6.13)** • Hostile attitude from health care workers preventing GPCFAO from expressing themselves **EP 30 (CS:5.6.16).** • Long waiting period before doctor consultation for GPCFAO who are not club members and difficulty accessing chronic medications **EP 32 (CS:5.6.16)**
4.To establish and enable health care and social services environment that focuses on the needs of GPCFAO and the orphans in their care through improving psychosocial services by involving and offering sensitive services to GPCFAO.	• GPCFAO are continuously rendering care to orphans without help which is physically demanding and exhausting, hence increasing risk of health problems **EP2 (CS 5.6.2).** • Due to caregiving duties, GPCFAO neglect their own health, and minimise the severity of their health conditions and delay seeking medical attention which affect their overall health. They are not coping with caregiving duties and are exhausted due to lack of physical support **EP1(CS: 5.6.2).** • GPCFAO are forgotten by the rest of the community, they are living alone life without support causing them to isolate themselves socially resulting in emotional breakdown EP8 **(CS: 5.6.8)**
5.To develop support programmes for GPCFAO that focuses on holistic care through locally appropriate community- and family-based psychosocial support programmes and through	• GPCFAO are continuously rendering care to orphans without help which is physically demanding and exhausting, hence increasing risk of health problems **(CS 5.6.2).**

promoting policy development in health care and social services that would maintain a focus on the holistic wellbeing of GPCFAO	• Due to caregiving duties, GPCFAO neglect their own health, and minimise the severity of their health conditions and delay seeking medical attention which affect their overall health **(CS: 5.6.2).** • GPCFAO are not coping with caregiving duties and are exhausted due to lack of physical support (**CS: 5.6.2).** • GPCFAO are forgotten by the rest of the community, they are living alone life without support causing them to isolate themselves socially resulting in emotional breakdown **(CS: 5.6.8)**

6.3.6.3 *Functional Strategies*

After developing objectives, it is vital to put measures in place for its implementation. The development of short-term objectives is one of the processes through which the strategies may be implemented, thus realizing the long-term objectives, as the day-to-day action plans and strategies arising from working to achieve the short-term objectives can be measured and monitored. Furthermore, creating short-term objectives assist in the implementation of policy through the process of operationalization of the long- term objectives and the identification of measurable outcomes of the functional actions.

In this study, the researcher developed an action plan and functional strategies from the strategic objectives, based on the thirty-two (32) problems identified from the empirical research to enable the operationalization and implementation of the strategic objectives. The functional tactics were further applied to the nine (9) principles and values to monitor and evaluate the strategic objectives. The functional tactics from a TQM theory, involve working in partnership amongst all the key players.

Table 6.4 Functional plans and Strategies

STRATEGIC OBJECTIVES	FUNCTIONAL STRATEGIES
1. To strengthen the capacity for grandparents caring for affected AIDS orphans by developing more supportive relationship between them and the orphans in their care, and protect themselves against HIV.	1.1 Studies show that children prefer to live with their grandparents after the death of their parents rather than with other relatives. They generally feel that their grandparents provide more love and affection than other relatives (Help age, 2004). In caring for their orphaned grandchildren, GPCFAOs ensure that their orphans' grandchildren grow up together as a family group, rather than in an institution or separated from each other in different families. However, as with all parenting relationships, this is not always easy. For some reason, including the vast generation gap, GPCFAOs struggle to bring harmony and understanding into their relationships with their orphans' grandchildren, and thus they must be supported in their caring roles 1.2 Start parenting skills programme and Programmes which can build a caring relationship between GPCFAO and the children in their care can be the best foundation for addressing such issues. Negotiations around behaviour arise from a foundation of care and respect, rather than the orphan's young person suddenly being treated like a child or having her freedom taken away
2. To provide emotional support to GPCFAO through the grief process and stigma issues in their communities and promote self - care amongst GPCFAO.	2.1 GPCFAOs suffer grief, shock, and sometimes trauma after the death of their adult children. It is especially hard for the GPCFAO if they have lost several children in a short space of time. The experiences of grief and the worries about the future make it difficult for the GPCFAO to cope with caring for the orphan's children left in their care. Grief is the emotional suffering that people feel when someone they love is taken away (Worden, 2018). As a response to loss, people may feel anger, sadness, shock, and guilt. While these feelings can be frightening and sometimes overwhelming, they are normal reactions to loss. Such reactions may last for a long time (sometimes many years), and it is essential not to rush the grief process. Providing emotional support to grieving GPCFAO is highly recommended as a key strategic focus area of any policies and programmes.

	Emotional support should be facilitated through: • Facilitation of support group • Facilitation of memory work • Facilitation of opportunities to say goodbye • Assistance with succession planning • provision of individual or family counselling • Pastoral care visits • Facilitation of traditional bereavement rituals. • It is also important to consult GPCFAO about what they would consider helpful in honouring the memory of their loved ones.
3. To strengthen economic programmes that would protect GPCFAO against abuse and exploitation.	3.1 Financial stress is the primary source of challenge that GPCFAO are facing in their caring role. Thus, the government and NGO programmes should include GPCFAOs in the planning. Economic programmes should include a focus on: • Pensions, childcare grants, school fee remission, and foster care grants; • Transport, health care and other subsidies for all older people; • Sustainable livelihoods and income-generating projects; • Encouraging the extended families of GPCFAO to support them financially; and offer them donations of material goods, such as school uniforms for orphaned children. • Access to identity documents and birth certificates to access resources such as social grants may be a challenge for GPCFAO, and investing in processes to overcome this challenge may make a sustainable difference to the psychosocial well-being of many GPCFAO and the orphans' children they support.

	3.2 Also, abuse and exploitation are often a result of extreme stress and poverty, and the study results show that GPCFAO faces a high level of poverty, hence categorised amongst the most vulnerable members of the society. Therefore, GPCFAO and children they have in their care have rights and entitlements that need to be protected. The study results show that they are often unaware of their rights, and even when they are informed, they often feel that they can do little to protect or realise their rights. Hence, to prevent GPCFAO against abuse, the following actions may be promoted : • Provide information about rights and entitlements, including knowledge of laws that provide protection, such as government funds, pensions, and child–care grants, and provide assistance with the procedures. • Secure correct documentation so that they can access the necessary support. • Inform GPCFAO about protective agencies that they may need to contact for specific assistance • Assist GPCFAO to protect the property rights of the children in their care by ensuring that they are well informed about their own and the children's rights and how to protect them. • Advocate for paralegal services so that GPCFAO and their orphaned children can access legal support and advice when necessary • Provide counseling and guidance to affected GPCFAO • Assist by accompanying GPCFAO to health facilities, social welfare offices • Assist GPCFAO who have experienced abuse to join support groups; • Facilitate community education and awareness on the needs of the GPCFAO, and children in their care. • Support access to education for AIDS orphans children, especially where policies for school fees exemptions exist • Social workers should visit families headed by GPCFAO to hear about their needs.

4.To establish and enable health care and social services environment that focuses on the needs of GPCFAO and the orphans in their care through improving psychosocial services by involving and offering sensitive services to GPCFAO.	4.1 Offering psychosocial support to GPCFAO must involve "seeing" or acknowledging their presence where they may have been neglected or invisible in their everyday actions of caring for HIV/AIDS orphans. 4.2 Also, it must involve recognizing their psychological and social needs where. Hence, healthcare and social service must ensure that GPCFAOs receive a continuum of care in a way that makes them feel included, valued, and supported in all aspects of their life. 4.3 It is crucial that GPCFAO feel appreciated and integral members of families, communities, and the larger society. It requires attention to psychosocial care and support in every interaction with GPCFAO. 4.4 Provide everyday psychosocial support by showing care and respect in each contact MDT health workers have with GPCFAO so that it builds their dignity, reduces their stress, and brings hope and appreciation even under challenging circumstances. Provide Everyday psychosocial support through the following ideas: • Listening respectfully to GPCFAO when they express their concerns, giving them a sense of being taken seriously. • Consult GPCFAO and those under their care about their needs and find ways to support them in meeting their needs. Follow up on their problems until they are resolved and refer the unresolved matters to other service providers. • Promote networks and circles of support around GPCFAO and include them to prevent feelings of loneliness and isolation 4.5 Promote psychosocial support with the general public, government service providers, and NGO 's who are dealing in any way with GPCFAO through: • Raising awareness about the value of treating GPCFAO with respect and kindness • Encourage respectful behaviour from all service-providers towards GPCFAO through establishing systems of accountability amongst the MDT healthcare workers and forcing them to interact with GPCFAO respectfully and compassionately. • Start a consultation process with GPCFAO about their local challenges regarding access to services and support.

	4.6 The results of the study show that GPCFAO neglects themselves due to a heavy load of responsibilities, which might affect their overall health. Therefore, programmes focusing on "care of the GPCFAO" may be valuable for them. Such programmes may involve the following: • Assist GPCFAO in being aware of their limitations and being honest with others when they cannot give certain types of help to orphans. • Help GPCFAO to structure their time, including rest periods and to explore safe local child-care options to relieve GPCFAO and encourage them to take time out to spend time with family and friends or do some fun activities • Instigate GPCFAO to ask for help from trusted friends and family members, and to invest in relationships with others who can become an ongoing source of strength and support. • When there are problems in the family or the community involving GPCFAO, encourage them to try to talk these through immediately so that they do not carry these additional stresses. • Encourage healthy eating as an essential part of their self-care and orphans in their care, especially affected orphans who are on ARV medications. Hence, GPCFAO can be supported in planning and cooking healthy meals using locally available and cost-effective food. • Promote regular exercise in the form of walks around their community and engaging in the work that they enjoy around their yard, such as starting vegetable gardening (this can provide good exercise for GPCFAO and be the source of healthy eating for them and their orphans.).
5. Develop a support programme for GPCFAO that focuses on holistic care through locally appropriate community- and family-based psychosocial support programmes and through promoting policy development in health care and social services that would maintain a focus on the holistic well-being of GPCFAO.	5.1 Holistic wellbeing of GPCFAO would be a sense of feeling complete or satisfied about their life and would include the physical, mental, economic, social, emotional, and spiritual parts of our lives, which then contribute to their total wellbeing. Therefore, developing their support means looking at each GPCFAO holistically, in terms of the different needs and rights that each person has to achieve overall wellbeing. 5.2 According to the study's findings, GPCFAOs are challenged with a variety of problems, prompting a need for holistic well-being support from their families, social units, and communities surrounding them. 5.3 Strengthen the circles of support surrounding GPCFAO through locally appropriate community- and family-based psychosocial support programs, and enhance the support and referrals for specialised care through focused programming. Therefore,

developing comprehensive programs that address the support needs in healthcare and social services will be crucial, and will have a significant and more sustained impact on the holistic wellbeing of GPCFAO and those under their care.

5.4 Providing psychosocial support to GPCFAO does not mean that each MDT health worker needs to become an expert in providing specialised psychosocial care. Instead, their priority will lie in recognition of the psychosocial needs amongst GPCFAOs and link them to the relevant service providers. Examples of grandparents caring for AIDS orphans who may require specialised psychosocial support include:

- GPCFAO who lost the social connection from their families and community support and struggling to cope with their emotional and social lives.
- GCFAO living in situations of abuse or potential harm.

Support may become possible through:

- A thorough identification of specialised psychosocial needs from vulnerable GPCFAO in need of more intensive psychosocial support, such as the examples listed above.
- Identify different types of specialised psychosocial support services and programmes that are already operating in the community, which might benefit GPCFAO and those under their care. It is, therefore, crucial promoting the referrals for specialised psychosocial support with the general public, government service providers, and NGO'S through:
- Awareness-raising about how to identify GPCFAO who may require specialised psychosocial support and,
- Campaign for the public relations and marketing of existing specialised psychosocial support services and programmes so that people are aware of the local referral resources.

Having outlined the importance of referral of GCFAO for specialised psychosocial support, it is worth emphasizing again that the best form of care is everyday support from a family and community context. The practice of support from family may help prevent severe distress and may be more effective in alleviating suffering than referrals for expert psychological or social assistance. Therefore, where possible, the family and community support surrounding all GCFAO should be strengthened. The focus of holistic well-being for GPCFAO should be done at the community level, and the national level and the focus on community-level should be:

5.5 To encourage the community to give support to all GPCFAO in their community. For example, community leadership could encourage positive attitudes and challenge discrimination. Also, youth groups or churches could organise childcare projects to assist GPCFAO in having time to do their shopping and attend church meetings

	• Whereas at the national level, the laws and policies, are challenged to include providing support to all GCFAO in terms of pensions and individual grants, school fee exemptions, and priority health care 5.6 Healthcare facilities should develop an organizational holistic support policy for GPCFAO and post it on their notice.

6.4 Application of the Delphi practice

6.4.1 Introduction

The previous section developed the draft strategies from conclusion statements derived from identified problems and transformed into performance objectives. This section presents the steps followed in carrying out a Delphi study and consensus reached on components and strategies to include in the document for use in the healthcare in the Western Cape Province, South Africa. The section will further describe the methodology, procedures, and results of each round of the Delphi.

6.4.2 Background

Grandparents are the primary caregivers of AIDS orphans, and they experience problems while providing care to these children (Tanyi, Pelser, & Okeibunor, 2018) Such problems include physical (such as body pains and backache), socio-cultural (such as stigma and discrimination), psychological (such as anxiety and depression, stress and feeling of inferiority), physical environment (lack of houses) and inadequate financial resources to meet orphans' needs (Wang, Hayslip, Sun, & Zhu, 2019; Wild & Gaibie, 2014).

In South Africa, there is insufficient documented evidence of an available sustainable approach to supporting grandparents caring for AIDS orphans in all the health dimensions (biophysical, socio-cultural, psychological, physical environment and health system), despite the efforts made by some researchers worldwide and in South Africa (Kidman & Thurman, 2016; Dolbin-MacNab, & Yancura, 2018). This study aims to develop strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province.

Previous chapters outlined the different results that informed the development of the strategies. The strategies target the healthcare facilities (PHC level) as well as government/legislative levels. The content of the developed strategies is quality assured, and a consensus of opinions from a group of experts reached through a Delphi study.

6.4.3 The Delphi technique

This study employed the classic Delphi technique because the researcher believes that adopting a physical meeting contradicts the basic rules of the classical Delphi procedure, which is an avoidance of situations that might cause some of the panel members to control the consensus process (Boulkedid, Abdoul, Loustau, Sibony & Alberti, 2011). Similarly, some other advantages inherent in this technique are the anonymity of panellists, which enhances the probability that opinions are not influenced by the person who expressed it (Mozuni & Jonas, 2017). Furthermore, the development of strategies that would be acceptable and feasible for use in all health facilities in the Western Cape Province is considered a project that should be thoughtfully handled by experienced persons to add to the credibility of the study outcome. A consensus was assumed in this study by a 75% agreement obtained from the results of the questionnaire presented.

6.4.3.1 *Design of the Delphi study*

The study employed a two-round Delphi technique. The draft strategies developed by the researcher in Phase One transformed into performance objectives. Experts in community nursing and public health were then approached for their opinions to standardise the content of the strategic document.

6.4.3.2 *The procedure followed*

The researcher sent an invitation to participate in the study via email to all identified individuals, included a Delphi Information Sheet (**Appendix12**) to outline the purpose of the study and a Delphi

Consent Form (Appendix 13). Informed consent was requested via-email from fifteen (15) experts that fit the inclusion criteria to participate in the Delphi study. Twelve (12) of the invited experts consented to the study marking an initial response rate of 80%. The approach employed the use of a self-administered questionnaire to the experts without any physical contact with each other.

A questionnaire was developed and reviewed by two (2) independent researchers for the applicability of the questions (**Appendix 13**). The first section requested demographic information of participants, including age, gender, current profession, county of residence, number of years' experience in their field.

6.4.3.2.1 Sampling and study population

The purposive sampling and snowball technique was used in this study to achieve the aim, as mentioned above. The sampling technique used assisted the researcher in selecting participants who possess the knowledge and experience in the field of the research question, hence provided rich information.

6.4.3.2.2 Inclusion criteria and exclusion criteria

As the Delphi procedure rests on the adequate identification of experts and their participation, an initial task was to operationalise the concept of 'expert'; hence, the researcher used the following indicators of expertise in health and social services:

i. Publications in the field of social development and public health policy and HIV and AIDS, especially grandparents caring for AIDS orphans.
ii. Involvement in elderly and HIV and AIDS based research, ideally over an extended period (5 years and more.)

iii. Professional nurses (head of units) with an extended work experience period(5 years and more) of services in the field of community nursing

iv. Involvement in the teaching for an extended period (more than five years) in the field of community nursing in the tertiary academic environment

v. Management staff in social development with work experience of more than five years.

vi. An operational Multidisciplinary team in any managerial or decision-making

vii. Management of NGO's for more than five years in the field of HIV and AIDS

viii. A Multidisciplinary operational team in any managerial or decision-making position.

6.4.3.2.3 The exclusion criteria

The study excluded those who do not fit into any of the above criteria.

6.4.4 Data collection tool

The researcher used a self-administered questionnaire for data collection. The process of the development and application of the questionnaire is discussed below.

A summary of concluding statements from the problems identified in phase one leads to the development of five objectives through inductive and deductive logical reasoning (see attached draft objectives, functional and tactical actions). Then, the researcher translated them into aims and performance objectives backed by the six TQM principles that served as a framework to guide the development of the strategies.

The researcher developed a 65-item questionnaire from the performance objectives. The researcher developed the vision and mission statements for the healthcare facilities by means of inductive and deductive reasoning to develop performance objectives derived from the data analysis in phase one.

The formulated aims and objectives set the basis of the questions posed in the questionnaire to the panellists.

The researcher divided the preliminary questionnaire into two documents. The first document contained the draft overview of the research background, research problem, findings, and the draft strategies based on deductive and inductive logic. The second document comprised of two sections: Section A-1 asked questions about panellists' demography such as age, area of specialization and work experience, and Section B-1, which asked panellists' input to the developed strategy in a quantitative and open-ended question format.

Furthermore, panellists supposed to comment on the draft strategies in terms of its applicability, feasibility, acceptability, and measurability. The questionnaire concluded each section by asking the panellists to make contributions or state reasons for their ratings briefly. Hence, they served as baseline for the next part that was formulated in the form of close-ended questions by a Likert scale of 5 and its ratings as 5= strongly agreed, 4 = Agree, 3= strongly disagree, 2= Disagree and 1= Neutral.

6.4.4.1 *Pre-test*

The researcher conducted a pre-test with three experts that were not part of the study. They contributed enormously to the draft document and the technicality of framing the questions. Their suggestions included simplifying and explaining the document in simple language, and they suggested the inclusion of additional references in the document. Their input was utilised in the final draft to refine and revise the questionnaire.

6.4.4.2 *Data collection process*

As a Delphi technique does not require the physical presence of the group members, the invitations to participate (voluntarily and without remuneration) were emailed together with an explanation of what the Delphi procedure entails and a questionnaire (**Appendix13**). The researcher obtained the panellists' addresses and contact details, such as their emails, cell phone numbers, and official physical contact addresses. The researcher ascertained their availability and willingness to serve on the panel and administered an Information sheet (**Appendix 12**)) and Consent Form (**Appendix 2**) before starting the study.

The panellists also indicated the preferred method to receive their questionnaire, which facilitated the process and reduced dropout rates. It is worth mentioning that the panellists had a maximum of two to four weeks to respond to the questionnaire. However, in instances of lack of immediate response, follow-up phone calls were made to the panellists to remind them of the task ahead.

The preliminary draft copy of a detailed description of the research problem that informed the study was sent together with the study vision, mission, value statement, and principles developed for the healthcare facilities **(Appendix 15)**. The problem identified and concluding statements of the empirical research, objectives, and functional strategies developed inductively/deductively were explained in detail to enable the understanding of the panellists and their part of the study. Also, it enabled the panellists to make informed judgment and suggestions which enriched the study.

6.4.5 Delphi rounds

Delphi rounds refer to the use of "experts", and use of a series of multiple questionnaires combined with controlled feedbacks that provides information on the opinion (Trevelyan & Robinson, 2015). Data collection employed the following rounds:

6.4.5.1 *Round One*

This procedure started with an open-ended questionnaire (**Appendix 13**), which served as the foundation of seeking specific information from the experts/panellists. The researcher requested input and opinions regarding the authenticity, applicability, and measurability of the objectives. The researcher analysed the data from the first round using SPSS (26) and arranges the suggestions according to the themes that resulted from each panellist's suggestions and categorised quantitatively for content analysis techniques (Toronto, 2017). The use of the quantitative analysis allowed the discovery for median and mode answers. Also, the researcher grouped some different terms whereby they appeared to be the same issue, grouped them to provide one universal description. The first-round consensus defined 75% or more of the respondents to be in agreement with a statement.

6.4.5.2 *Round Two*

This was the second phase of data collection. Only the Delphi participants whose responses did not meet the predetermined acceptance criteria of 75% received a second questionnaire (**Appendix 14)** for review of the items summarised by the researcher based on the information provided in the first round.

Ascertaining the level of collective opinion was determined with the use of descriptive and inferential statistics. The researcher obtained data from the ratings of the analysed items by producing statistical summaries for each item. The researcher then computed Central tendencies (means, medians, and

mode), and levels of dispersion (standard deviation and the inter-quartile range) to provide participants with information about collected opinions, enabling participants to see where their response stands with that of the group.

6.4.5.3 *Round Three*

Round three was the final round in which all the items achieved consensus, hence providing a final opportunity for participants to revise their judgments. A consensus agreement of 75% formed the basis for accepting the panellists' opinion as none of the panellists reviewed their responses further (Keeney, McKenna, & Hasson, 2011).

6.4.5.4 *Response Rate*

There was only one panellist out of the initial twelve (12) experts who could not serve on the panel as planned. However, he did not respond to his emails, phone calls, or text messages after the first meeting with the researcher. The response rate was thus 92 %.

6.4.6 Results and interpretation of Delphi findings

6.4.6.1 *Overview of the section*

This section presents the result and interpretation of each round of the Delphi questionnaires. It commences with the returned number of questionnaires and the panellists‘rating of the domains in the questions presented.

6.4.6.1.1 Result and interpretation of Round One

The researcher analysed the data using SPSS (version 26). The questionnaires from the panellists were first given a code number for ease identification before entry into Microsoft. Thus, assisted in correcting the noted discrepancies. The researcher employed descriptive statistics to describe the data

and reported in measures of central tendencies e.g., frequencies (f), median, and mode (Brink, Van Der Walt, & Van Rensburg, 2010). Furthermore, content analysis was employed on the qualitative aspect to discover categories and themes that arose from each document.

6.4.6.2 *Demography of Delphi Panellists*

Table 6.5 below shows that only 4 (40%) of the panellist are males, while the remaining 7 (70%) are females. The area of specialty of the panellist is displayed in the same table as follows: 3 (27%) of the panellist are lecturers from tertiary institutions, 1(9%) of the panellist social development staff, 1(9%) of the panellist is public health consultant, 4 (36%) were nursing managers in community health centres and clinics, 2(18%) were in a HIV/AIDS non-government organization (NGO), and 1 (10%) in public health. The work experience of the panellist further reflected that only 1(9%) of the panellist has work experience of fewer than ten (10) years while 2 (18%) of the panellist have work experience of between 20 and 29 years, 3(27%) of the panellists have work for more than 30 years, and the remaining majority of the panellist has experience of 10 to 19 years. Out of 12 experts, two (2) experts are international in the field of public health (consultants). However, one of them did not complete due to work pressure.

Table 6.5 Demography of Delphi panellists

DEMOGRAPHICS		Frequency	Percentage
Gender	Female	7	64
	Male	4	36
Area of speciality	Lecturer	3	27
	NGO management	2	18
	Nursing(CHC/Clinic management)	4	36
	Public health	1	9
	Social development	1	9

Working experience	10-19 years	5	45
	20-29 years	2	18
	30 years and above	3	27
	Below 10 years	1	9
Total		**11**	**100.0**

6.4.6.2.1 The rating score

The panellists' ratings on the vision, mission, values, and principles, as well as the objectives, are displayed in table 6.6 It indicates five panellists scored all the items above 75% (P_3, 4,6,10 and 11), as highlighted below.

Table 6.6 Rating score for each respond panellists Scores on Each domain of Questionnaire

Respond	Vision	Mission	Value	Principle	Objective 1	Objective 2	Objective 3	Objective 4	Objective 5
1	62.50	60.71	65.00	75.00	68.75	68.75	56.25	75.00	62.50
2	75.00	57.14	75.00	75.00	68.75	75.00	75.00	100.00	100.00
3	81.25	82.14	85.00	81.25	75.00	81.25	75.00	75.00	68.75
4	81.25	82.14	85.00	81.25	75.00	81.25	87.50	81.25	68.75
5	68.75	42.86	70.00	43.75	50.00	50.00	50.00	50.00	50.00
6	81.25	75.00	75.00	75.00	75.00	75.00	75.00	75.00	68.75
7	62.50	60.71	75.00	50.00	68.75	56.25	56.25	56.25	56.25
8	81.25	75.00	75.00	68.75	68.75	68.75	68.75	68.75	68.75
9	75.00	75.00	75.00	68.75	68.75	68.75	68.75	68.75	68.75
10	87.50	75.00	75.00	81.25	75.00	81.25	75.00	75.00	81.25
11	93.75	78.57	75.00	75.00	75.00	75.00	75.00	75.00	75.00

6.4.6.2.2 Measures of Central Tendencies

Table 6.7 indicates that the panellists' mean score on the vision statement was 77.27 %, the median 68.75%, and the maximum 93.75% with SD of 9.79. The mission statement has a mean score of 69.48%, a median score of 75.00 %, and a minimum score of 42.86%, maximum, 82.14% and an SD of 12.41while the range was 39.29. The value statement and principles had a minimum score of 25% each, but a maximum score assigned was 100%. The interpretation of the table can thus be seen at a glance as described. The panellists, whose scores did not meet the predetermined criteria of 75% in each domain, were sent a second questionnaire after a review of the panellists' recommendations. The phase 2 questionnaire showed their position or score against the other participant's score.

Table 6.7 Measures of Central Tendencies

	Mean	Std. Deviation	Median	Minimum	Maximum	Variance	Range	Percentiles		
								25	50	75
VISION STATEMENT	77.27	9.79	81.25	62.50	93.75	95.88	31.25	68.75	81.25	81.25
MISSION STATEMENT	69.48	12.41	75.00	42.86	82.14	153.99	39.29	60.71	75.00	78.57
VALUE STATEMENT	75.45	5.68	75.00	65.00	85.00	32.27	20.00	75.00	75.00	75.00
PRINCIPLES	70.45	12.53	75.00	43.75	81.25	156.96	37.50	68.75	75.00	81.25
OBJECTIVE 1	69.89	7.30	68.75	50.00	75.00	53.27	25.00	68.75	68.75	75.00
OBJECTIVE 2	71.02	10.18	75.00	50.00	81.25	103.69	31.25	68.75	75.00	81.25
OBJECTIVE 3	69.32	10.99	75.00	50.00	87.50	120.74	37.50	56.25	75.00	75.00
OBJECTIVE4	72.73	12.89	75.00	50.00	100.00	166.19	50.00	68.75	75.00	75.00
OBJECTIVE 5	69.89	13.06	68.75	50.00	100.00	170.45	50.00	62.50	68.75	75.00

6.4.6.3 *Results: Round Two*

6.4.6.3.1 Rating score

This round entailed sending a questionnaire to the panellist who scored below 75% in round one. Thus, Seven (7) expert participated in round 2 Delphi study and the consensus of opinion from the experts was set to 75% or more (Keeney, McKenna, & Hasson, 2011).

The results of the seven participants' scores are displayed below. The table shows that all participants scored each variable above 75%. Table 6.8 below highlights the results of the second questionnaire (**Appendix 16**) sent to the panellists.

Table 6.8 Round two rating score

Respond	Vision	Mission	Value	Principle	Objective1	Objective2	Objective3	Objective4	Objective5
1	88.24	96.43	90.00	75.00	100.00	87.50	87.50	75.00	87.50
2	76.47	89.29	75.00	75.00	93.75	75.00	75.00	100.00	100.00
3	81.25	82.14	85.00	81.25	75.00	81.25	75.00	75.00	93.75
4	81.25	82.14	85.00	81.25	75.00	81.25	87.50	81.25	100.00
5	82.35	92.86	90.00	87.50	93.75	93.75	93.75	93.75	93.75
6	76.47	75.00	75.00	75.00	75.00	75.00	75.00	75.00	93.75
7	88.24	96.43	75.00	100.00	87.50	81.25	100.00	100.00	100.00
8	76.47	75.00	75.00	93.75	93.75	87.50	100.00	87.50	93.75
9	76.47	75.00	75.00	75.00	100.00	100.00	100.00	87.50	100.00
10	87.50	75.00	75.00	81.25	75.00	81.25	75.00	75.00	81.25
11	93.75	78.57	75.00	75.00	75.00	75.00	75.00	75.00	75.00

6.4.6.4 *Results: Round Three*

Round (3) of Delphi involved compiling all the participants' scores against their identities and sending it to them for acceptance and final review. Since no further changes from the participants, the vision, mission, value statement, principles, and objectives regarded as authentic, applicable, verifiable, and measurable, therefore, and no further analysis is done. The results were accepted to enable the strategy development to improve the support given to grandparents caring for AIDS orphans in healthcare facilities in the Western Cape Province, South Africa.

Table 6. 9 Results of Round Three

VISION:

- To deliver a long and healthy life for all grandparents caring for AIDS orphans through a comprehensive, integrated, and sustainable healthcare delivery system focusing on access, support, equity, efficiency, and quality.

Participants	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**
Percentage	88.24	76.47	76.47	76.47	82.35	76.47	88.24	76.47	76.47	82.35	88.24

MISSION:

- To provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity and excellence in community health care practice.

Participants	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**
Percentage	96.43	89.29	82.14	82.14	92.86	75.00	96.43	75.00	75.00	75.00	88.24

VALUE STATEMENT:

- Maintenance of professional ethics through Participation, Respect, and kindness, Integrity in practical assistance.
- Involving Family and community-based care, strengthening existing resources, developing on locally appropriate practices, Consideration of gender, and providing quality care.

Participants	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**
Percentage	90.00	75.00	85.00	85.00	90.00	75.00	75.00	75.00	75.00	75.00	75.00

PRINCIPLES:

- To facilitate community support system plans involving families and the rest of the community.
- To develop community awareness support programmes focusing on the training and skills development, Practical assistance, providing psychosocial support, and strengthening economic activities.

Participants	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**	**P11**
Percentage	75.00	75.00	81.25	81.25	87.50	75.00	100.00	93.75	75.00	81.25	75.00
OBJECTIVE 1	100.0	93.75	75.00	75.00	93.75	75.00	87.50	93.75	100.0	75.00	75.00
OBJECTIVE 2	87.50	75.00	81.25	81.25	93.75	75.00	81.25	87.50	100.0	81.25	75.00
OBJECTIVE 3	87.50	75.00	75.00	87.50	93.75	75.00	100.00	100.0	100.0	75.00	75.00
OBJECTIVE 4	75.00	100.00	75.00	81.25	93.75	75.00	100.00	87.50	87.50	75.00	75.00
OBJECTIVE 5	87.50	100.00	93.75	100.\0	93.75	93,75	100.00	93.75	100.0	81.25	75.00

6.5 Application of strategies to improve support given to GPCFAO in healthcare services in the Western Cape Province, South Africa.

As mentioned at the beginning of this chapter, this is the last section in the strategic development process that will improve the support given to grandparents caring for AIDS orphans in Western Cape Province.

The Vision for strategies to improve the support given to GPCFAO in health care services is:" to provide a long and healthy life for all GPCFAO through comprehensive, integrated and sustainable primary healthcare service delivery system focusing on access, support, equity, efficiency, and quality' 'The vision give rise to the Mission of the strategy.

The mission of the strategies is: to provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity and excellence in community and healthcare facilities support and legislative support.

The values guided the mission and vision and universal health coverage (WHO, 2019) of achieving quality community nursing healthcare to improve the overall health of Grandparents caring for AIDS orphans (GPCFAO) through professional ethics, participation, respect, kindness, accountability, and integrity. Also, involving the family and community, strengthening existing government and NGOs resources, and developing locally appropriate practices will contribute to providing quality care to GPCFAO.

The strategies to improve the support given to GPCFAO in Western Cape Province, South Africa, is based on TQM philosophy. TQM is based on three fundamental principles that encompass its overall

concept and, if efficiently administered, will promote the continuous improvement of the support given to GPCFAO. The three fundamental principles of TQM are: focus on the customers, internal and external; process improvement and total involvement along with six supporting elements, namely: leadership, communication, teamwork, continuous improvement, employee involvement education, and training.

The strategic objectives are in line with the vision, mission, values, principles, and assumptions of the strategy and the philosophy of TQM, and from the problems identified that compromised the support given to GCFAO. The functional tactics are developed from the strategic objectives to enable the operationalization and implementation of the strategic objectives and ensure that strategic objectives can be measured and evaluated.

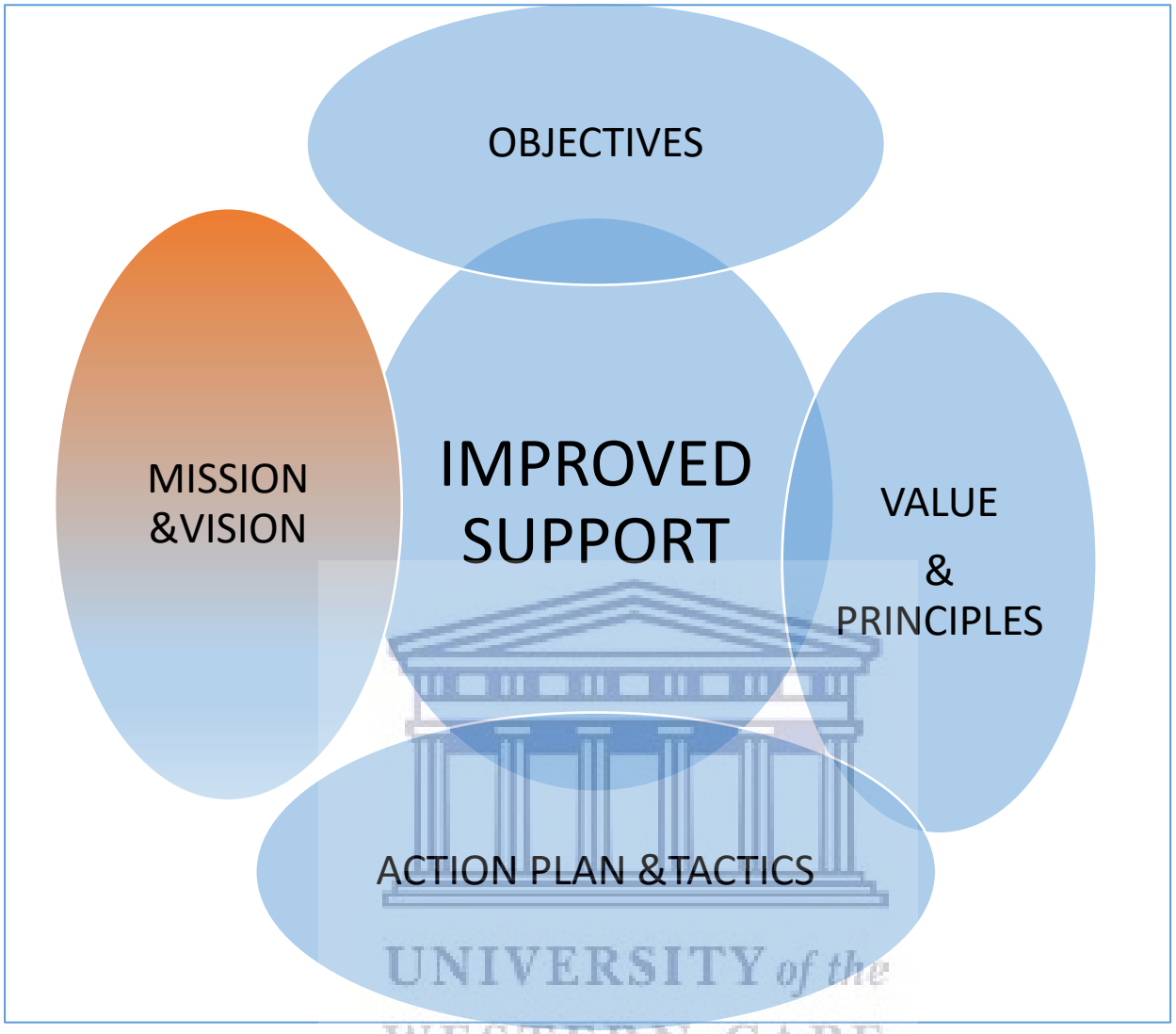


Figure 4 Model of the strategies

6.6 The Strategic Document (SD)

The section presents the final strategic document for Multidisciplinary health workers for use in primary healthcare facilities in the Western Cape Province, South Africa.

6.6.1 Purpose of the Strategic Document (SD)

The researcher developed the document from a need for primary healthcare facilities to have a document based on the problems of a dearth of holistic support given to grandparents caring for AIDS orphans. The use of the strategies document, if successfully implemented, it can improve the support given to grandparents caring for AIDS orphans and reduce their hardship. The author carefully created it as part of her Ph.D. Dissertation in the school of Nursing at the University of the Western Cape, South Africa.

6.6.2 Basis for strategies development

The researcher followed each step of the strategic process to develop the strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa. The strategic objectives are based on Total Quality Management (TQM) philosophy with the (32) identified problems from the empirical results.

The goal is the continuous improvement of the quality of the primary health care system in partnership with social development in the Western Cape Province, which will positively impact the health of grandparents caring for AIDS orphans. As a result, grandparents caring for AIDS orphans will reduce emotional worries, physical complications, and reduce socio-economics problems which ascertained as the core challenges that they confronted with in their caring roles.

6.6.2.1 *Presentation of TQM elements and Problem identified*

1. Key: IDENTIFIED PROBLEMS: (IP)IP 1- 32
2. Key: TOTAL QUALITY MANAGEMENT: (TQMe)

- Leadership
- Team work
- Communication
- Continuous improvement
- Employee involvement
- Education and training

6.6.3 Strategic planning process

A Strategic Plan is a vision of the organization's future and the needed steps to achieve it. A good strategic plan should include goals and objectives, desired outcomes, metrics for measuring progress, timelines, and budgets (Richardson, 2004). It is crucial to have a strategic plan when developing a comprehensive plan for the organization, which would include both long-range and strategic elements. The plan outlined in this document is straightforward, clear, and is based on the real current situation. The Strategic Plan assists an organization in establishing priorities and refining the needs of its constituency. A strategic plan must be flexible, feasible and yet serve as a guide to implementing programmes, evaluating how these programmes are doing, and making adjustments when necessary.

A strategic plan should contain the thoughts, feelings, ideas, and wants of the developers and carry them along with the organization's purpose, mission, and regulations into an integrated document. The development plan requires much probing, discussion, and examination of the leaders' views who are responsible for the plan's preparation. However, more often than not, the plan's development is less

complicated than the implementation. Efficient implementation of a plan should involve all involved all in its implementation, and they must function as a whole, or the plan is destined for failure**.**

6.6.3.1 *Action plans*

The goal of action plans is to describe the implementation process of the strategies to attain the objectives. They refer to community and system changes to be sought and specific action steps to be taken to bring about changes in all relevant sectors of the community. Action plans focus on ways to select changes in programmes, policies, and practices. They also describe action steps, the agents involved, the timing, resources, the support needed, potential barriers or resistance, and the communication channel about this plan of action.

Action plans also include those whose action (or inaction) contributes to the problem (and its solution), such as healthcare providers and broader agents and potential allies from faith communities, businesses, schools, community and cultural organizations, and government. Potential agents of change include all those in a position to work towards the solution, such as residents, healthcare providers, family members, and neighbours. They also include previously identified targets of change who have a responsibility to contribute to the solution, and cultural organizations, and government.

6.6.3.2 *Gathering of background information*

The Strategic Planning Committee uses background information for its review. By shifting through that information, the Committee would be able to develop a sound basis to continue their work. After gathering existing information, another information gathering activity should take place. Develop a survey questionnaire to poll all members for their viewpoints on the organization or unit's directions. After the information has been synthesised from the questionnaires and information already gathered, move to the second step.

6.6.3.3 *Planning workshop (s)*

The organization needs to gather information on five basic questions. These are, 1) "Where are we now? (The Situation); 2) "How did we get there?" (Our Momentum); 3) "Where are we going?"(The Direction); 4) "Where should we be going?" (Desired Direction); 5) "How will we get there?" (The Strategic Plan).

The example below outlined using two half-day working sessions. The overall process comprised a productive action planning session that allows a diverse group of participants to:

- Clarify common purpose: Listening, gathering and reviewing data, and building a shared vision and mission.
- Generate and critique options: to achieve the mission, the group identifies particular changes in communities and systems and sought (i.e., new or modified programmes, policies, and practices) to achieve the mission.
- Obtain consensus about community and system changes to be sought through ballot voting about the importance and feasibility of proposed changes, or by having participants use "dots" to register preferences for changes to be sought.
- Decide how to proceed as a group through open discussion, the group identifies action steps (i.e., who will do what by when) to bring about the identified changes.

6.6.3.4 *Background Work before the Session/Workshop*

The background work includes having sessions with various people, including those most affected GPCFAO, and documenting the issue or problem in the community. The goal for the session number one is to assess the present situation, and how arrived at that present condition, whereas the following

activity of this first workshop purports to fathom the desired direction. Identify priority changes to be sought:

a) by specific strategy (i.e., providing information and enhancing skills, modifying access, barriers, and opportunities, improving services and support, altering incentives and disincentives, and modifying policies) and

b) By community sector (e.g., Health Organizations, Faith Communities, Government).

6.6.3.5 *Planning a Workbook*

Designing of the Workbook will combine all of the information collected through the Planning Workshop, and scrutinise them across the presented ideas, then arrange them into an essential body for evaluation by organizing the workshop audiences and other interested parties in the organization.

6.6.3.6 *Second Planning Workshop*

After gathering information into a workbook, there is a need to plan another workshop immediately after the first one and will accomplish quite a few things. In the first half-day, a Mission Statement should be adopted and reviewed for the organization. The Mission Statement will include what the organization (health care facilities) intends to stand for; what it hopes to contribute to GPCFAO at large. It should set goals for the healthcare facility and then, having set the goals, fulfil the Mission Statement by translating each goal into a specific objective, meaning that the Mission Statement will be carried forth into a strategic plan.

The second workshop's product should also include a set of community and system changes (i.e., new or modified programmes, policies, and practices) required in each relevant sector of the community (e.g., Health Organizations, Faith Communities, Government) for each objective.

6.6.3.7 *The Committee Structure*

The constitution of the Strategic Planning Committee should be the people who understand the organization and who have a constant feel for the organization and where it is moving. The Committee should be made a permanent standing committee within the organization with a rotating membership to encourage constant review and updating.

6.6.4 Strategies to improve support given to grandparents caring for aids orphans

6.6.4.1 *Introduction*

Together with their MDT staff, community healthcare facilities should provide efficient sound services that promote and provide holistic support to grandparents caring for AIDS orphans to their highest level and offer them an excellent professional service that is of high quality. The strategic plan's foundation is developed upon the mission, vision, core values, and principles of the healthcare facilities (see Table 6.10 below).

Table 6.10 Strategic Plan's foundation

Mission:	To provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity and excellence in community health care practice.
Vision:	To deliver a long and healthy life for all grandparents caring for AIDS orphans through a comprehensive, integrated, and sustainable healthcare delivery system focusing on access, support, equity, efficiency, and quality.
Core values:	Maintenance of professional ethics through Participation, Respect, and kindness, Integrity in practical assistance. Involving Family and community-based care, strengthening existing resources, developing locally appropriate practices, Considering gender, and providing quality care.
Principles:	To facilitate community support system plans involving families and the rest of the community. To develop community awareness support programmes focusing on the training and skills development, Practical assistance, providing psychosocial support, and strengthening economic activities

6.6.4.2 *Institutional background*

This study's context was Community healthcare centres and clinics located in two districts, which are the City of Cape Town Metropolitan municipality (Khayelitsha and Mitchell's plain) located in the urban area of Cape Town and Overberg municipality (Grabouw) which is a rural area.

6.6.4.3 *Planning Context*

In order to have a basis of information regarding the current challenges faced by GPCFAO, the researcher conducted an assessment of strengths, weakness, opportunities, and threats (SWOT) by the application of the health policy analysis triangle of Walt and Gibson (1994) to explore the key players (MDT health workers, the government, non-government organizations, and grandparents caring for AIDS orphans) regarding the objectives of the study (Developing strategies to improve the support given to grandparents caring for AIDS orphans), and the knowledge possessed by the MDT health workers.

These key players are viewed as both internal and external customers as the researcher considers MDT health workers who provide services to clinics and community health centres as external (Peace & Robinson, 2000). The strengths for the communities' health care centres and clinics lies in them being the Primary health care institutions with a high level of specialised MDT personnel. Furthermore, they are government facilities centrally located across the Western Cape Province and receive funding directly from the Department of health, thus making its services to be affordable when compared to the private health institutions.

The researcher developed the strategies in line with TQM principles, and experts assured its authenticity through the Delphi process. The information gained from the empirical study in Phase

One and a review of the relevant literature describes the magnitude of HIV and AIDS effects on grandparents caring for AIDS orphans and their support needs. The findings indicate how various affected grandparents caring for AIDS orphans might benefit from developed strategies.

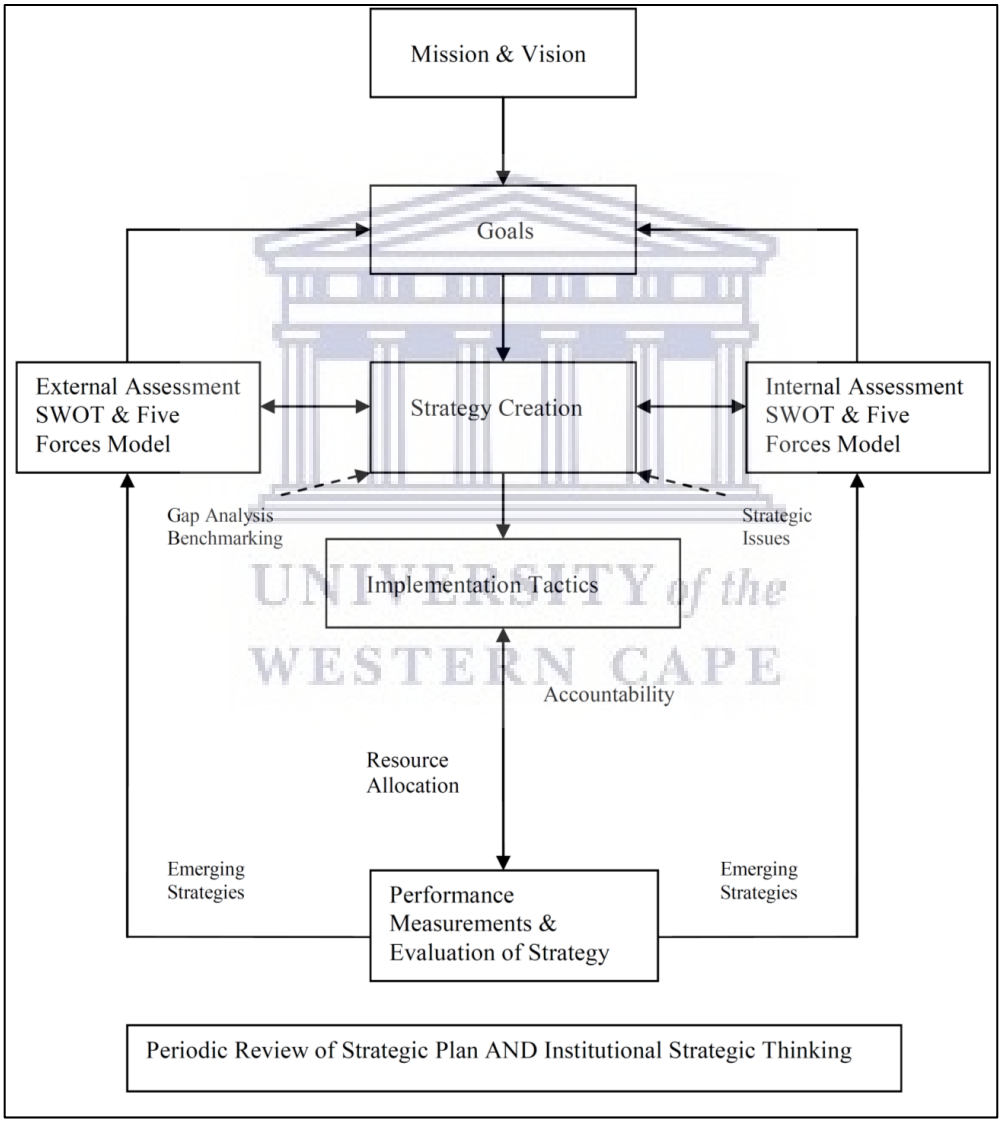


Figure 5 Strategies process

6.6.4.4 *Strategic goal*

The strategic goal was to develop a strategy aimed at improving the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa.

6.7 Objective One: To strengthen the capacity for grandparents caring for infected and affected AIDS orphans by developing more supportive relationship between them and the orphans in their care and protect themselves against HIV.

6.7.1 Basis for Objective One

The first strategy calls for the improvement of grandparents' capability to carry out their caregiving responsibilities optimally and with the least strain on themselves and protect themselves from contracting HIV infection through caregiving duties.

Evidence shows that grandparents caring for AIDS orphans need to support on multiple levels. Due to the massive generation gap, grandparents struggle to bring harmony and understanding into their relationships with their orphans' grandchildren especially teenagers, and they must be supported in their caring roles. Furthermore, some grandparents have to care for HIV infected orphans; thus, they need to have access to information and resources on how to care for the infected for AIDS orphans and how to protect themselves from HIV infection and contain the spread of the disease.

The essential resources required in this regard include protective material, emotional support (counselling), and financial support. However, grandparents should not be viewed as passive recipients of the available resources to support them, but as active participants and stakeholders in the planning and implementation of the appropriate programmes. Hence, improving the cognition of their contribution and improve their self-esteem and ability to cope and contribute. Therefore, grandparents

caring for AIDS orphans can become full partners in the fight against HIV and AIDS and manage the effects of the epidemic.

6.7.2 Strategies for Objective One

Develop parenting skills programme which can build a caring relationship between grandparents and the orphans in their care.

- Initiate home visits from social workers for situation analysis and identification of caregiving problems in the home headed by grandparents caring for AIDS orphans and address the identified problems.
- Develop counselling programmes to educate and support both grandparents and the Orphans in their care.
- Government should provide information, develop counselling programmes, support, and life skills training for grandparents caring for AIDS orphans to empower them and improve their caregiving duties. Joint efforts between the government and NGO to mitigate the effects of the disease in communities should provide age-group appropriate information and counselling services for older persons.
- Develop community plans which Provide supportive and developmental programmes targeting adolescent orphans children (between 12 and 18 years). Such programmes include adolescent development programmes, parenting programmes and behaviour management programmes.
- Commence afterschool programmes, child care services, after school, and holiday programmes to support orphans with their homework and stimulate their mental development, thus assisting in reducing the number of orphans failing and dropping out of school.
- Instigate youth programmes that teach children about the influence of peer pressure, hence deterring them from drug and alcohol abuse and engaging in gang activities in their area.

- Government should provide essential personal protective equipment (PPE) to grandparents caring for AIDS orphans for their universal protection (latex gloves, plastic aprons, disposable napkins, and sanitary containers).
- Complement grandparents' level of knowledge on the sexual transmission of HIV.

6.7.3 Performance Measure /Tactics

- Do an Annual review of objectives in forms of workshop presentations on the programme intervention on HIV and AIDS to ensure grandparents 'inclusion and make provision to address their specific needs.
- Include MDT in the community health centres and clinics to provide grandparents with information, counselling support, and life skills training to empower them and enhance their caregiving responsibilities.
- Do a quarterly conference for MDT health workers and include grandparents caring for AIDS in the presentations.

6.8 Objective Two: To provide emotional support to grandparents caring for AIDS orphans by supporting them in the grief process and avoiding stigma and discrimination in their communities.

6.8.1 Basis for Objective Two

Grief, shock, and trauma after the death of their children, coupled with stigma and discrimination in their communities, is a cause for concern and calls for collaborative efforts by all concerned to address and overcome them. The worries experience about the future of the orphans make it difficult for the grandparents to cope with caring responsibilities.

6.8.2 Strategies for Objective Two

Provide emotional support to help grandparents caring for AIDS orphans to deal with the loss, stigma, and discrimination through:

- Strengthening Community system and enforce community leaders to talk openly about HIV and AIDS and on behalf of the affected grandparents caring for AIDS orphans, in order to bring their plight to the public's attention and to generate broad support.
- Encourage the identification of affected grandparents caring for AIDS orphans households and help to mobilise community responses.
- Destigmatise HIV and AIDS within families by targeting information campaigns and providing counselling to all family members
- Develop comprehensive intervention programmes developed jointly by the government and NGOs aiming at including grandparents caring for AIDS orphans in the services provided.

6.8.3 Performance Measure /Tactics

- Do annual workshops, public meetings, and campaigns organised by the community leaders through government and NGOs to address issues of HIV and AIDS stigma and discrimination. Leaders may include the clinic managers, representatives of community newspapers, religious leaders, youth leaders, community-based organization managers, and others.
- Community meetings and workshops educate and encourage community leaders to understand problems of stigma and discrimination with which grandparents caring for AIDS orphans must contend. Such campaigns may help to obviate discrimination on all levels.
- Encourage the nursing care plans in the communities' health centres and clinics aiming at holistically supporting grandparents caring for AIDS orphans, which will also include holistic

screening. It is also essential to consult grandparents about what they would consider helpful in honouring their loved ones' memory.

- Raising awareness about HIV and AIDS in the local communities in order to reduce and stop HIV and AIDS-related stigma through the production of radio programmes, dramas, booklets, and posters and involving grandparents by training them to become community educators.
- Invite grandparents in the workshops caring for AIDS orphans to relate the first-hand experience of discrimination against them in their community, health service points, and other public institutions.
- Social workers should provide and facilitate the opportunities to say goodbye to their deceased children by supporting them with the funeral arrangement. Furthermore, encourage Community leaders and the church leader to arrange and provide spiritual support and facilitate with their traditional bereavement rituals if necessary.
- Non- Government organizations (NGOs), religious bodies, and other relevant community structures should help to identify, but not single out, grandparents households made vulnerable by HIV and AIDS, and help to mobilise community response to support such households.
- Community organizations working against HIV and AIDS should promote de-stigmatization of HIV and AIDS within communities by providing counselling for all grandparents caring for AIDS orphans, including the orphans.
- Social service should initiate and facilitate support groups of grandparents caring for AIDS orphans in the communities where they can open up and share their experiences and concern.

6.9 Objective Three: To identify and assist GPCFAO with their need for adequate shelter and strengthen economic programs that would protect them against extreme poverty.

6.9.1 Basis of the Objective Three

GPCFAO stated the need for adequate shelter featured prominently in outcomes of the qualitative results in this dissertation and warrants urgent attention from the government. Furthermore, financial stress, poverty, abuse, and exploitation (often resulting from extreme anxiety and poverty) are the challenges grandparents face. The study results show that they are often unaware of their rights, and even when they are informed, they often feel that they can do little to protect or realise their rights. Therefore, the following strategies may be essential to protect their rights and entitlements.

6.9.2 Strategies for Objective Three

- Establish economic programs that focus on the Provision of Pensions, childcare grants, school fee remission, and foster care grants; transport, health care, and other subsidies for grandparents caring for AIDS orphans.
- Encourage and support sustainable livelihoods and income-generating projects for GPCFAO such as funding small business in their communities
- Encourage extended families of GPCFAO to support them financially; and offer them donations of material goods, such as school uniforms and clothing for orphaned children.
- Address vulnerability associated with lack of access to identity documents and birth certificates for the orphans and access resources such as social grants that will support GPCFAO to meet household costs.
- Establish an outreach committee comprised of health promoters and social workers targeting GPCFAO, identify vulnerable GCFAO, and involve them.

- GPCFAO are not only at risk of infection with the HIV virus, but are exposed to opportunistic infections such as pulmonary tuberculosis. The provision of more spacious and better ventilated houses will help to reduce the spread of contagious opportunistic infections in this sub-population. Indoor piped water and flush toilets are crucial for optimal hygiene and facilitating caregiving.

6.9.3 Performance Measure /Tactics

- Provide transport from and to the clinics to care for sick children.
- Provide information about rights and entitlements, including knowledge of laws that provide protection, such as government funds, pensions, and childcare grants, and assist with the procedures.
- Secure correct documentation so that they can access the necessary support.
- Inform GPCFAO about protective agencies that they may need to contact for specific assistance.
- Assist GPCFAO to protect the property rights of the children in their care by ensuring that they are well informed about their own and the children's rights and how to protect them.
- Advocate for paralegal services so that GPCFAO and their orphaned children can access legal support and advice when necessary.
- Provide counselling and guidance to affected GPCFAO.
- Assist by accompanying GPCFAO to health facilities and social welfare offices.
- Assist GPCFAO who have experienced abuse to join support groups.
- Facilitate community education and awareness on the needs of the GPCFAO, and children in their care.
- Support access to education for orphaned AIDS children, especially where policies for school fees exemptions exist.

- Provincial government should give directives to high-ranking officials, who with the assistance of NGOs should draw up a plan of action to speed up housing delivery for GPCFAOs households.

6.10 Objective Four: To establish and enable health care and social services environment that focuses on the needs of GPCFAO and the orphans in their care through improving psychosocial services by involving and offering and improving access essential services

6.10.1 Basis of Objective Four

The results of the study show that GPCFAO neglects themselves due to a heavy load of responsibilities. Therefore, offering psychosocial support to GPCFAO must involve "seeing" or acknowledging their presence where they may have been neglected or invisible in their everyday actions of caring for HIV and AIDS orphans. Also, it must involve recognizing their psychological and social needs where. Healthcare, in partnership with the social service, must ensure that GPCFAOs receive a continuum of care that includes, value, and supports GPCFAO in all aspects of their lives. It is crucial that GPCFAO feel appreciated and integral members of families, communities, and the larger society.

6.10.2 Strategies for Objective Four

- Provide everyday psychosocial support by showing care and respect in each contact MDT health workers have with GPCFAO so that it builds their dignity, reduces their stress, and brings hope and appreciation even under challenging circumstances.
- Promote psychosocial support with the general public, government service providers, and NGO's who are dealing in any way with GPCFAO.
- Strengthen the circles of support surrounding GPCFAO through locally appropriate community- and family-based psychosocial support programmes.

- Enhance the support and referrals for specialised care through focused programming.
- Develop comprehensive programmes that address the Psychosocial support needs in healthcare and social services

6.10.3 Performance Measure /Tactics

- Encourage respectful behaviour from all service-providers towards GPCFAO through establishing systems of accountability amongst the MDT healthcare workers and forcing them to interact with GPCFAO respectfully and compassionately.
- Raise an awareness about the value of treating GPCFAO with respect and kindness
- Social workers should start a consultation process with GPCFAO about their local challenges regarding access to services and support.
- Assist GPCFAO in being aware of their limitations and being honest with others when they cannot give certain types of help to orphans.
- Help GPCFAO to structure their time, including rest periods and to explore safe local child-care options to relieve GPCFAO and encourage them to take time out to spend time with family and friends or do some fun activities
- Instigate GPCFAO to ask for help from trusted friends and family members, and to invest in relationships with others who can become an ongoing source of strength and support.
- Encourage healthy eating as an essential part of their self-care and orphans in their care, especially affected orphans who are on ARV medications. Hence, GPCFAO can be supported in planning and cooking healthy meals using locally available and cost-effective food.
- Promote regular exercise in the form of walks around their community and engaging in the work that they enjoy around their yard, such as starting vegetable gardening (this can provide good exercise for GPCFAO and be the source of healthy eating for them and their orphans.).

6.11 Objective Five: To develop a support programme for GPCFAO that focuses on holistic care of GPCFAO through promoting age-friendly district health service points and through policy development that would maintain a focus on the holistic well-being of GPCFAO.

6.11.1 Basis for Objective Five

While the government makes special provision for health care services to specific population age groups, such as the youth, children, and expectant mothers, at the district level, it provides no dedicated geriatrics services for older clients who are desirable. Older persons have specific healthcare needs, especially relating to chronic ailments, and have physical and cognitive impairments. Grandparents caring for AIDS orphans 'health is severely compromised through the strain of caregiving. The national and provincial government thus needs to plan, in consultation with NGOs and district health managers provide dedicated health care services to older clients, with specific consideration given to the chronic health conditions and vulnerabilities of grandparents caring for AIDS orphans. Such needs embrace primary health care, nutritional services, welfare services, dental care, eye care, and other essential services. The services should be delivered in age-friendly environments. District-level managers should commit to policies that sustain grandparent's' capacity to support themselves and others in their household.

6.11.2 Strategies for Objective Five

- The national and provincial governments should promote age-friendly health service points at the district level. Features of such environments may include accessible seating, signage in large lettering, and local languages indicating facilities such as the pharmacy, dressing room, social worker, psychologist, nutritionist, and separate appointment and referral systems for older clients.

- Provincial government should discourage age discrimination in vital services such as primary health care services, voluntary counselling and testing (VCT), and education on HIV and AIDS at community health centres.
- National and provincial governments should train health care providers at the district level in the management and prevention of age-related physical health conditions, such as hypertension and arthritis, and mental illnesses such as depression and stress.
- Provincial and district government should improve the availability and supply of medicines to treat health conditions commonly found in older persons at district-level health service points.
- GPCFAOs' health support groups need to be established at district health service points to provide co-counselling with treatment use and adherence, especially in chronic conditions.

6.11.3 Performances measures and tactics

- Establish health service points with age-friendly environments per district regarding the accessibility of health service points for older persons within districts.
- Identify all health service points that meet the above criteria within the district. Obtain data from the infrastructure design reports of the health service point infrastructure and physical inspection of the facilities.
- Establish health service points with effective referral and appointment systems for older patients per district.
- Include measures systems performance and assess whether the referral and appointment systems benefit GPCFAO patients.
- Ensure services at the receiving health facility are readily available, and older patients/clients have not turned away due to unavailability of services, incorrect appointment times, and incorrect or inappropriate referrals.

- Conduct interviews with the health service providers on how to adequately manage the referral or appointment system for GPCFAO. It is, therefore, crucial promoting the referrals for specialised psychosocial support with the general public, government service providers, and NGO'S through an awareness-raising about how to identify GPCFAO who may require specialised psychosocial support and, campaign for the public relations and marketing of existing specialised psychosocial support services and programmes to make people aware of the local referral resources.
- Identify different types of specialised psychosocial support services and programmes that are already operating in the community, which might benefit GPCFAO and those under their care.
- Having outlined the importance of referral of GCFAO for specialised psychosocial support, it is worth emphasizing again that the best form of care is everyday support from a family and community context. The practice of support from family may help prevent severe distress and may be more effective in alleviating suffering than referrals for expert psychological or social assistance. Therefore, where possible, the family and community support surrounding all GCFAO should be strengthened.
- The focus of holistic well-being for GPCFAO should be done at the community level, and the national level and the focus on community-level should be to encourage the community to give support to all GPCFAO in their community. For example, community leadership could encourage positive attitudes and challenge discrimination. Youth groups or churches could also organise childcare projects to assist GPCFAO in having time to do their shopping and attend church meetings. Whereas at the national level, the laws and policies, are challenged to include providing support to all GCFAO in terms of pensions and individual grants, school fee exemptions, and priority health care.

However, the use of the proposed strategies will rely on role players to gather and record activities throughout the year, so that performance and trends of service point activities can be measured. A plan of action to guide the use of the strategies is proposed below.

6.12 Plan of action to guide the use of the proposed strategies

The strategies outlined above provides a basis to improve the support given to grandparents caring for AIDS orphans (GPCFAO). Hence, policy-makers may scrutinise the strategies, and after consultation with relevant role-players may take decisions to:

- Review existing relevant policies and programmes to ascertain the gaps in supporting grandparents caring for AIDS orphans and their dependents.
- Engage with stakeholders in the formation of a working group to design the best strategies to address or alleviate the grandparent's predicament.
- Re-assess the situations of grandparents and their households, primary responsibility for NGOs, determine the support needed, and evaluate the scope and effectiveness of existing responses.
- Consider how the support needs of grandparents caring for AIDS orphans could be mainstreamed in existing policies and programmes, or whether there is a need for new dedicated policy and programmes to support the grandparents and their households.
- Design comprehensive strategies to address the gaps in government policy and programmes and grandparents 'needs and how such strategies could or should involve grandparents or their representative organizations.
- Identify resources required by various role players: budgets, time, staff, volunteers, infrastructure, etc., to implement policy actions and achieve desired outcomes. A realistic assessment of role players' capacity will help them focus their energy and resources on what is achievable within a specific time frame.

The following are the NGO's whose input will be potentially crucial in the various processes:

- Grandmothers Against Poverty and Aids (GAPA),
- Neighbourhood Old Age Homes (NOAH),
- The South African Older Persons' Forum (SAOPF),
- The South African Red Cross Society and the Methane Society for the Aged (MUSA).
- Another NGO is Catholic Welfare and Development (CWD), whose focus is on community development in general, and deals with women empowerment and provides services to the vulnerable and marginalised sections of society, among whom are the poor, homeless and unemployed within the Western Cape Province.
- CWD works to empower the youth, women, refugees, the elderly, and those living with HIV and AIDS, and
- Nelson Mandela Children's Fund and the Desmond Bishop Tutu HIV Foundation.

6.12.1 The roles and tasks of various stakeholders and role players

The roles, functions and tasks of various stakeholders and role players may include the following:

- Appointment of a working group by the government who work in consultation with stakeholders, to identify a role player(s) to drive one or more desired outcomes proposed in the developed strategies.
- The compilation of examples of successful, relevant community responses to the epidemic, such as community health home-based care programme by NGOs that serve older clients as best practices for replication by relevant role players.
- Consultation with the private sector on roles it might play and contributions it could make. Commercial banks could be approached to revise discriminatory home loan and credit policies that exclude older persons who wish to improve their dwelling conditions. Grandparents may want to borrow money from a bank to buy a new and bigger house for their family.

- Associations of government departments at the provincial level and other stakeholders could mobilise and ensure optimal utilization of resources (financial, human, infrastructural, and knowledge related) to achieve desired outcomes. Ways in which role players may be involved in resource mobilization could include :
  - i) The government facilitating and coordinating other role players' activities, and various government departments providing budgetary allocations to support the realization of the plan;
  - ii) Non-profit organizations (NPOs)) offering dedicated support programmes for grandparents caring for AIDS orphans, such as income generation skills development and food gardening programmes; and
  - iii) Religious bodies offering emotional counseling, and providing physical space for support group meetings, training, and skills development activities (e.g., income generation; budgeting and networking).

6.12.2 Evaluation of the appropriateness and feasibility of the developed strategies.

The strategies developed is designed to assist role players in supporting grandparents caring for AIDS orphans in the Western Cape Province, South Africa. The strategies highlight the central role that government must play at all levels in facilitating and coordinating the activities of different role players at the district level.

The strength of the strategies lies in its inclusive approach, which involves all role players (government, NGOs, communities, organizations, and grandparents themselves), aiming to build bridges within and across formal and informal sectors of society, and within and outside of government departments.

The limitation may be its reliance on the government's political willingness to adopt the strategies and implement its recommendations. The adoption of the developed strategies as a guiding tool will, therefore, depend on the willingness of politicians and policymakers to recognise the extent of grandparents ' plight and the urgency of their needs.

The developed recommendations are not a solution for all problems of service inaccessibility experienced by grandparents caring for AIDS orphans. The recommendations are made rather than to strengthen or improve what infrastructure and services are already in place. It is not disputed that the South African government already does a great deal for indigent older citizens through the grant system (Satumba, Bayat, & Mohamed, 2017).

However, insufficient or poor accessibility of services for grandparents, because of barriers such as a lack of affordable transport to access health care, prevails in non-urban areas especially. Moreover, research indicates that entry points to health services points must be barrier-free (Cavalieri, 2013). Physical and service delivery barriers need to be removed to enable grandparents to access needed care and maintain health and independence. Also, age-friendly public health facilities at the district level can help inform and educate health providers about the specific needs of grandparents caring for AIDS orphans.

7 CHAPTER SEVEN: EVALUATION OF THE STUDY, LIMITATIONS, REFLECTIONS AND RECOMMENDATIONS

7.1 Introduction

The previous chapters discussed the research methodology, research findings and the strategies formulation process. Conclusions were arrived at in line with the set objectives which were systematically attended to until it culminated into the formulation of a strategy to improve the support given to grandparents caring for AIDS orphans, which is the hallmark of this study.

In this chapter, the study is evaluated, and recommendations are made for future policy and research in the subject area and recommendations to address grandparents' support needs.

7.2 Evaluation of study

The study aimed at developing strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa. The researcher functions within the constructivist paradigm as it considers the participants' voice and acknowledges the multiple realities about the topic of the study. Constructivists believe that knowledge is individually constructed; hence the viewpoint of each participant was considered when exploring the aspects being investigated (Denzin and Lincoln, 2003).

This study adopted the dimensions model of community health nursing framework by Clark (2003), and information was obtained concurrently from both the quantitative and qualitative studies. In general, the information obtained from both sources produced the report for an analysis of which

served to enrich an understanding of the grandparent's situations. The researcher clearly outlined the research objectives as the findings of the study were to be the basis upon which the strategies were to be formulated.

The first objective was to explore the experiences of grandparents caring for AIDS orphans in Western Cape Province of South Africa. Semi-structured interviews were conducted to grandparents caring for AIDS orphans to gather information from them in this regards.

The focus was on the challenges encountered while caring for AIDS orphans, and concluding statements were made based on the findings in this section. The concluding statements highlighted the fact that grandparents caring for AIDS orphans displayed various challenges, they lacked formal and informal support which influence many spheres of their lives leading to physical, psychological, socioeconomic and behavioural problems.

The second objective was to determine the available support (in terms of biophysical, psychological, and health services) for grandparents caring for AIDS orphans in the Western Cape Province of South Africa. Self-administered questionnaires were distributed to the MDT team in different health care facilities. Information obtained from them measured the perceived holistic support mechanisms given to grandparents caring for AIDS orphans. The results agreed that the lack of support and difficulty accessing the health care services is a contributing factor to health problems amongst grandparents caring for AIDS orphans and exacerbate their already compromised health and worsen their chronic illnesses such as diabetes and high blood pressure.

The third objective was to determine the grandparents' perception of the availability of support given to them in the Western Cape Province of South Africa. Self-administered questionnaires were

distributed to social development managers and NGOs personnel. Information obtained from them measured the perceived support mechanisms (in terms of social-economic and environmental) from the government. The analysis concluded that the government regard grandparents as unworthy of the governments' attention as shown in the results, there is an ageist attitude from the government side with the dearth of understanding, sympathy, and response toward grandparents caring for AIDS orphans.

The finding arose from the study confirmed a notable lack of support and a lack of acknowledgement of grandparents' needs from the government level, community level and the family level. Hence, there is no available support to grandparents caring for AIDS orphans, and the government is not playing an active role in the provision of support to grandparents caring for AIDS orphans.

Objective four was to compare the grandparents' perceptions of available support with the available support for grandparents caring for AIDS orphans in the Western Cape Province of South Africa. A comparative checklist was employed to obtain information from grandparents caring for AIDS orphans. The finding confirmed the lack of formal support except the support acquired through NGOs which still not reliable; the inconsistency to process and approve grants applications also was the main challenge for both rural and urban grandparents. Grandparents experience health problems due to intense caregiving duties. The study also found that the rural areas grandparents experience difficulties in accessing the health facilities.

The findings revealed no visible differences in caregiving patterns and problems between grandparents in urban settings and their non-urban based counterparts. In general, both rural and urban grandparents could not cope with the burden of caregiving on their own and needed formal support from the government.

Finally, conclusions were drawn, a strategy was then formulated using the concluding statements as a yardstick. As a result, the respondents in conjunction with the researcher had constructed new knowledge by using inductive and deductive logic. The respondents'role was that of informing the strategy through their input in the study. This implies that objective five, which was to develop strategies to improve the support given to grandparents caring for AIDS orphans in the Western Cape Province, South Africa was successfully achieved. The following paragraphs provide a discussion on the different contributions the study achieved.

7.3 Contributions of the study

7.3.1 Contribution to knowledge and grandparents

The study has contributed to knowledge in the subject area through its review and synthesis of the literature as well as the evidence generated in the empirical study. A key outcome of this review and study is the documentation of empirical evidence on the effects of the HIV and AIDS epidemic on grandparents, as caregivers and how they cope with limited support from NGOs and a lack of formal support. Another contribution is the identification of gaps in the extant literature, policy instruments and documents reviewed, and the specific attempts made in the dissertation to fill some of these gaps.

Overall, it has been argued that grandparents' issues and concerns have thus far largely been overlooked in all policy development and intervention. Highlighting this gap may contribute to future policy formulation and reform. Thus, the study and its outcomes can help to put grandparents and their support needs on centre stage, especially regarding issues relating to their capacity and need for support to be able to render care optimally and cope, and to sustain their own health.

7.3.2 Contribution to community nursing and public health care

The study brings a unique contribution to community nursing knowledge because a strategy, which had not been previously formulated, was co-constructed. The greater part of the literature on health provision indicates that state health systems do not cater adequately for the health care needs of grandparents caring for AIDS orphans. The study has made a strong case for opportunities to deliver appropriate and optimal health care to this population and thus support them at the primary health care level. The developed strategies (see Chapter Six) in this regard identifies a set of potential health plans to guide and measure successful implementation of appropriate, inclusive primary health care programmes.

The study also highlighted an apparent reluctance of grandparents caring for AIDS orphans to access health care services, hence purporting a need for improved health care services for grandparents caring for AIDS orphans. In addition, the study has highlighted the lack of grandparents' involvement in the HIV and AIDS policy provisions. Practical steps that may be taken to involve grandparents in such activities could include development of a standardised protocol for their inclusion and participation in such policy processes. Such a practical tool may serve as a guide to district health managers on how to work with grandparents caring for AIDS orphans.

Identification of the health care needs of grandparents caring for AIDS orphans in communities and recognition that they render home care in their community may be a valuable entry point for public health care programmes to support grandparents. The developed strategies in Chapter 6 can serve as a tool to be consulted by various role players at the district level to identify and act on issues relating to the needs of grandparents in general: for example, improve their accessibility to health services, and change the hostile attitude towards them.

The study promotes the principles of primary health care, such as PHC as a collaborative effort between all relevant Multidisciplinary role players, which can help to build links with other support services and facilitate timely referrals of grandparents caring for AIDS orphans to other levels of care within a continuum of health care. However, while the study and dissertation conceivably achieved the objectives that were set, areas in need of further research were identified in the course of the work, which are outlined in sub-section below.

7.4 Recommendations for further studies

In view of the findings from this study, the twenty-six grandparents who participated in the study constitute only a small number in the picture that they provided of the immense suffering and vulnerability. Numerous recommendations to improve their situation and reduce their burden were made within developed strategies proposed and outlined in Chapter 6. Additional recommendations, of a broader or more specific nature, are made below:

7.4.1 Towards improving grandparents' quality of life

Grandparents' situations must be improved through support from the government and other role players. With regards to improve their health, the study has demonstrated that strategies to achieve this goal may be best effected through public health agencies at the district level. Improved quality of life for grandparents caring for AIDS orphans can serve indirectly to improve the health and well-being of those in their care. Specifically, grandparents' quality of life may be enhanced by improving their access to essential services, such as health care, and the removal of bureaucratic barriers for example, where they need to obtain legal documents and ease their grants application process.

Although the majority of the grandparents caring for AIDS orphans surveyed received an old age grant, the amount of the benefit was shown to be insufficient to provide for the needs of multiple household members. Thus, the government might investigate the feasibility of providing care grants to grandparents caring for AIDS orphans. Such measures, taken together, would go a long way towards improving grandparent's quality of life, especially through improved physical health, financial, emotional and psychosocial well-being.

Also, it is important that grandparents themselves are enabled to become actively involved in addressing socio-economic, development and health issues that affect their lives.

7.4.2 Towards providing appropriate Primary Health Care (PHC) responses

Results from this study demonstrated that grandparents caring for AIDS orphans suffer from poor health generally, which is manifested in chronic conditions such as hypertension, diabetes, arthritis and depression. Thus, grandparents require better access to health care services that can manage the above disease conditions common to older people. Such measures should include the establishment of age-friendly health service points at the clinics, and the encouragement of vital services such as counselling.

This study has shown that some health personnel at the clinics have very little understanding of how to relate to grandparents and provide health services that meet their needs. Hence, additional measures should include improved referral and appointment systems for grandparents caring for AIDS orphans, to enable them to conserve limited time and financial resources. Also, Multidisciplinary health care providers at the clinics need specific training in the treatment of age-related health conditions, as well as providing HIV and AIDS necessary information to grandparents caring for AIDS orphans.

7.5 Identification of further research needed

Further research is indicated on the needs and roles of grandparents caring for AIDS orphans, to inform the design of appropriate HIV and AIDS interventions inclusive of grandparents and their needs. The impact of poverty on HIV and AIDS-related caregiving, as it affects grandparents, need to be linked to national poverty monitoring and evaluation systems by the government, so that an understanding may be achieved of how the two phenomena reinforce one another in affected grandparents' households. Moreover, a better understanding is needed of the health-seeking behaviour of involved grandparents caring for AIDS orphans, and to what extent AIDS-related caregiving duties is a causative factor of their ailments.

The findings of the study demonstrated that social protection, in the form of grants, is inadequate and doesn't meet the multiple expenses that grandparents must bear due a lack of other formal support. A review of the formula used to calculate the nature and amount of grants, and whom they are targeted at and for what purposes, is strongly indicated.

7.6 Study limitations

A significant limitation in this study was the problem of the time both in the first and the second phase of the study. In the first phase, the researcher struggled to get access to government personnel. The researcher had to present the study to the research committee in the social service and various clinics and communities health centre and waited for a long time to get the permission from the social services and Department of Health. In the second phase of the study, which involved the Delphi process. The panellists were not easy to track, and some of them did not respond on time to the questionnaires due to their busy work schedule, hence reducing the time the researcher dedicated to other aspects of the study and prolong the duration of the study and resulting in having another academic year added to the

programme. However, the slow response of the panellists did not in any way impact on the study outcome. Also, due to limited time and funds, the study was limited into the Western Cape Province only.

7.7 The researcher's reflection

The reflection is purely subjective because it is based on the researcher's experiences during the course of the study.

Firstly, research participation among multidisciplinary health workers and managers in social development was meagre. Although they are supposed to have a better understanding of the role of research and involvement of all concerned in developing healthcare delivery, instead they shy away from participating in studies concerning their services. The staff from the social development service Hold a feeling of protecting the government policy resulting in false recommendations. The grandparents caring for AIDS orphans were more open and happy to participate, unlike the MDT team and the management staff in the social developments.

Secondly, the bureaucratic nature of getting permission to research the various clinics was challenging. The researcher had to go through a process of getting ethics clearance from Department of Health and social development which took nearly six months as I supposed to present my study to almost ten clinics and three social developments offices.

The research journey has broadened the researcher's growth as a novice researcher. The researcher learnt many lessons through day-to-day interactions with experienced researchers and those who demonstrated knowledge about the concept under investigation. However, she encountered lots of challenges. These ranged from financial, juggling family and work pressure and the work has refused

to give study leave to ease the pressure, hence causing immense frustration, at the time the researcher considered to quit the programme but and my husband was always there to encourage and remind me to persevere.

However, despite all the challenges faced, the researcher met the aim and objective of the study, the researcher developed strategies to improve the support given to grandparents caring for AIDS orphans. The researcher adequately used both conceptual frameworks (Community nursing and TQM frameworks) throughout the study.

7.8 Concluding Remarks

It was the researcher's intention that gaps in knowledge identified in the research problem, and the identification of a need for empirical evidence in the problem area, should be filled to a large extent by the evidence generated in the study. The study has contributed in a large measure to filling such gaps, but more information is still needed in different settings in all of South Africa's provinces.

8 REFERENCES

Aithal, P. S. (2016). Creating innovators through setting up organisational vision, mission and core values: a strategic model in higher education. *International Journal of Management, IT and Engineering*, *6*(1), 310-324.

Ajmal, M. M., Tuomi, V., Helo, P. T., & Sandhu, M. A. (2020). TQM practices in public sector: case of Finnish healthcare organisations. In *Hospital Management and Emergency Medicine: Breakthroughs in Research and Practice* (pp. 536-549). IGI Global.

Albejaidi, F. (2018). An investigation into the challenges towards implementation of total quality management under the Saudi Healthcare National Transformation Program–2020. *J Health Med Nurs*, *46*, 1-12.

Albers, M. J. (2017). *Introduction to quantitative data analysis in the behavioral and social sciences*. John Wiley & Sons.

Al-Hyari, K., Abu Hammour, S., Abu Zaid, M.S. and Haffar, M. (2016), "The impact of lean bundles on hospital performance, does size matter?", International Journal of Health Care Quality Assurance, Vol. 29 No. 8, pp. 877-894.

Alotaibi, G. B. G., Yusoff, R. Z., Mokhtar, S. S. M., & Taib, C. A. (2020). Total Quality Management: Perspective of Saudi Healthcare Organisations. *Journal of Business Management and Accounting*, *9*(1), 89-93.Alderslade, L. (2019). https://www.agedcareguide.com.au/talking-aged-care/what-age-is-considered-old Accessed in November 2020.

Ashmore, J., & Gilson, L. (2015). Conceptualizing the impacts of dual practice on the retention of public sector specialists-evidence from South Africa. *Human Resources for Health*, *13*(1), 1-9.

Avella, J. R. (2016). Delphi panels: Research design, procedures, advantages, and challenges. *International Journal of Doctoral Studies*, *11*(1), 305-321.

Babbie, E., & Mouton, J. (2012). The practice of social research. Fourteenth impression. Cape Town.

Baidoun, S. D., Salem, M. Z., & Omran, O. A. (2018). Assessment of TQM implementation level in Palestinian healthcare organisations. *The TQM Journal*

Bartlett, L. (2019). Promoting Permanency and Human Rights. *Forthcoming*, *23*.

Basson, Y. (2017). Selected developments in South African labour legislation related to persons with disabilities. *Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad*, *20*(1).

Beegle, K., De Weerdt, J., & Dercon, S. (2010). Orphanhood and human capital destruction: Is there persistence into adulthood?. *Demography*, *47*(1), 163-180.

Beer, M. (2020). *Fit to Compete: Why Honest Conversations about Your Company's Capabilities are the Key to a Winning Strategy*. Harvard Business Press.

Block, E. (2014). Flexible kinship: caring for AIDS orphans in rural L Lesotho. *Journal of the Royal Anthropological Institute*, *20*(4), 711-727.

Block, E. (2016). Reconsidering the orphan problem: The emergence of male caregivers in Lesotho. *AIDS care*, *28*(sup4), 30-40.

Block, E. (2018). Living, dying, after death: Achieving a "good" death in the time of AIDS orphan care. *Death studies*, *42*(5), 275-281.

Brady, S. R. (2015). Utilizing and adapting the Delphi method for use in qualitative research. *International Journal of Qualitative Methods*, *14*(5), 1609406915621381.

Brady, S. R., Jason, L. A., & Glenwick, D. S. (2015). The Delphi Method. *Handbook of methodological approaches to community-based research: Qualitative, quantitative, and mixed methods*, 61-67.

Brannen, J. (Ed.). (2017). *Mixing methods: Qualitative and quantitative research*. Routledge.

Breckenridge, T. A., Black-Hughes, C., Rautenbach, J., & McKinley, M. (2019). HIV/AIDS orphans in South Africa: NGO interventions supporting transitions to alternative care. *International Social Work*, *62*(2), 502-517.

Brink, H., Van der Walt, C., & Van Rensburg, G. (2006). *Fundamentals of research methodology for health care professionals*. Juta and Company Ltd.

Brittain, S., Ibbett, H., de Lange, E., Dorward, L., Hoyte, S., Marino, A., ... & Lewis, J. (2020). Ethical considerations when conservation research involves people. *Conservation Biology*.

Brodie, I., & Pearce, J. (2017). Violence and alternative care: a rapid review of the evidence. *Psychology, Health & Medicine*, *22*(sup1), 254-265.

Brown, J. D. (2000). What is construct validity. *Available at jalt. org/test/bro_8. htm (accessed 10 June 2013)*.

Bryman, A. (2017). Quantitative and qualitative research: further reflections on their integration. In *Mixing methods: Qualitative and quantitative research* (pp. 57-78). Routledge.

Bryson, J. M. (2018). *Strategic planning for public and non-profit organisations: A guide to strengthening and sustaining organisational achievement*. John Wiley & Sons.

Buckley, R. (2018). Simultaneous analysis of qualitative and quantitative social science data in conservation. *Society & Natural Resources*, *31*(7), 865-870.

Burns, E., & Groove, W. (2014). Research method. *Ergonomics*, *32*(3), 237-248.

Buschle, C., Reiter, H., & Bethmann, A. (2020). Introducing the Qualitative Pre-test Interview (QPI) for questionnaire development.

Castleberry, A., & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds?. *Currents in Pharmacy Teaching and Learning*, *10*(6), 807-815.

Cavalieri, M. (2013). Geographical variation of unmet medical needs in Italy: a multivariate logistic regression analysis. *International Journal of Health Geographics, 12*(27). doi:10.1186/1476-072X-12-27.

Centres for Disease Control and Prevention. (2020). Interim guidance for healthcare facilities: preparing for community transmission of COVID-19 in the United States. *Page last reviewed February*, *29*.

Chaitkin, S., Cantwell, N., Gale, C., Milligan, I., Flagothier, C., O'Kane, C., & Connelly, G. (2017). Towards the Right Care for Children: Orientations for Reforming Alternative Care Systems-Africa, Asia, Latin America.

Chazan, M. (2014). Everyday mobilisations among grandmothers in South Africa: Survival, support and social change in the era of HIV/AIDS. *Ageing and Society*, *34*(10), 1641.

Chazan, M. (2015).The grandmothers' movement: Solidarity and survival in the time of AIDS. Montreal, Canada: McGill-Queen's University Press.

Cherry, K. (2013). What is a cross-sectional study. *Retrieved November, 15*, 2020.

Chiarini, A., & Vagnoni, E. (2017). TQM implementation for the healthcare sector. *Leadership in Health Services*.

Chinyoka, I. (2018). *How and why do states provide for children? Comparing social grants for families with children in Southern Africa* (Doctoral dissertation, University of Cape Town).

Chu, X., & Ilyas, I. F. (2016). Qualitative data cleaning. *Proceedings of the VLDB Endowment*, *9*(13), 1605-1608.

Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, *25*(6), 435-437.

Corbin, J. H. (2017). Health promotion, partnership and intersectoral action.

Cortopassi, A. C., Driver, R., Eaton, L. A., & Kalichman, S. C. (2019). A new era of HIV risk: it's not what you know, it's who you know (and how infectious). *Annual review of psychology*, *70*, 673-701.

Cortopassi, A. C., Driver, R., Eaton, L. A., & Kalichman, S. C. (2019). A new era of HIV risk: it's not what you know, it's who you know (and how infectious). *Annual review of psychology*, *70*, 673-701.

Council, S. A. N. A. (2017). National Strategic Plan on HIV, TB and STIs 2017–2022. *SANAC Pretoria*.

Cox, C. (2018). Cultural diversity among grandparent caregivers: Implications for interventions and policy. *Educational Gerontology*, *44*(8), 484-491.

Cram, F., & Mertens, D. M. (2015). Transformative and indigenous frameworks for multimethod and mixed methods research. In *The Oxford handbook of multimethod and mixed methods research inquiry*.

Creswell, J. W. (2014b). *A concise introduction to mixed methods research*. SAGE publications.

Creswell, J.W. & Creswell, J.D. 2018. Research design: qualitative, quantitative and mixed methods approaches. 5thed. Los Angeles: Sage publication

Creswell, J.W. (2014a). Research design: qualitative, quantitative and mixed methods approaches 4thed.Califonia: Sage publication.

Cronin, C. E., & Bolon, D. S. (2018). Comparing hospital mission statement content in a changing healthcare field. *Hospital topics*, *96*(1), 28-34.

Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, *36*(4), 253-263.

Daniel, B. K. (2019). What constitutes a good qualitative research study? Fundamental dimensions and indicators of rigour in qualitative research: The TACT framework. In *Proceedings of the European Conference of Research Methods for Business & Management Studies* (pp. 101-108).

Delany, A., & Jehoma, S. (2016). Implementation of social grants: Improving delivery and increasing access. *ChildGauge*, 60.

Delany, A., Jehoma, S., & Lake, L. (2016). *South African child gauge 2016: Children and social assistance*. Children's Institute, University of Cape Town.

Demmer, C. (2011). Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: an exploratory study. *AIDS care*, *23*(7), 873-879.

Denzin, N. K., & Lincoln, Y. S. (2018). *The SAGE Handbook of Qualitative Research*. SAGE.

Department of Health(2016). South African National AIDS Council. South African HIV and TB Investment Case: Reference report Phase 1. Pretoria, South Africa

Di Gessa, G., Glaser, K., & Tinker, A. (2016). The impact of caring for grandchildren on the health of grandparents in Europe: A life course approach. *Social Science & Medicine*, *152*, 166-175.

Dolbin-MacNab, M. L., & Few-Demo, A. L. (2020). Grand families in the United States: an intersectional analysis. *Grandparenting Practices Around the World*, 189.

Dolbin-MacNab, M. L., & Yancura, L. A. (2018). International perspectives on grandparents raising grandchildren: Contextual considerations for advancing global discourse. *The International Journal of Aging and Human Development*, *86*(1), 3-33.

Dolbin-MacNab, M. L., & Yancura, L. A. (2018). International perspectives on grandparents raising grandchildren: Contextual considerations for advancing global discourse. *The International Journal of Aging and Human Development*, *86*(1), 3-33.

DOLBIN-MACNAB, M. L., & YANCURA, L. A. (2019). Global perspectives on grandparenting: A conceptual metaframework. *Grandparenting: Influences on the Dynamics of Family Relationships*, 347.

Dolbin-MacNab, M. L., Jarrott, S. E., Moore, L. E., O'HORA, K. A., Vrugt, M. D. C., & Erasmus, M. (2016). Dumela Mma: an examination of resilience among South African grandmothers raising grandchildren. *Ageing & Society*, *36*(10), 2182-2212.

Dunham, C. C., & Flores-Yeffal, N. Y. (2019). The effect of stress proliferation on depression in South African grandparent caregivers. *International Social Work*, 0020872819842926.

Dwyer-Lindgren, L., Cork, M. A., Sligar, A., Steuben, K. M., Wilson, K. F., Provost, N. R., ... & Biehl, M. H. (2019). Mapping HIV prevalence in sub-Saharan Africa between 2000 and 2017. *Nature*, *570*(7760), 189-193.

Farrugia, L. (2019). WASP (write a scientific paper): The ongoing process of ethical decision-making in qualitative research: Ethical principles and their application to the research process. *Early human development*, *133*, 48-51.

Fauk, N. K., Mwakinyali, S. E., Putra, S., & Mwanri, L. (2017). The socio-economic impacts of AIDS on families caring for AIDS-orphaned children in Mbeya rural district, Tanzania. *International Journal of Human Rights in Healthcare*

Friedland, B. A., Gottert, A., Hows, J., Baral, S. D., Sprague, L., Nyblade, L., ... & Tamoufe, U. (2020). The People Living with HIV Stigma Index 2.0: generating critical evidence for change worldwide.

Friedland, B. A., Sprague, L., Nyblade, L., Baral, S. D., Pulerwitz, J., Gottert, A., ... & Jackson, A. (2018). Measuring intersecting stigma among key populations living with HIV: implementing the people living with HIV Stigma Index 2.0. *Journal of the International AIDS Society*, *21*(Suppl 5).

Fuertes, G., Alfaro, M., Vargas, M., Gutierrez, S., Ternero, R., & Sabattin, J. (2020). Conceptual Framework for the Strategic Management: A Literature Review—Descriptive. *Journal of Engineering*, *2020*.

Fusheini, A., Eyles, J., & Goudge, J. (2016). The social determinants of health and the role of the health care system: a case study of the significance of good governance in public hospitals in South Africa. *Health*, *8*(12), 1288-1306

Geiselhart, K., Gwebu, T. D., & Krüger, F. (2008). Children, adolescents and the HIV and AIDS pandemic: changing inter-generational relationships and intra-family communication patterns in Botswana. *Children Youth and Environments*, *18*(1), 99-125.

Ginter, P. M., Duncan, W. J., & Swayne, L. E. (2018). *The strategic management of health care organisations*. John Wiley & Sons.

Goldberg, R. E., & Short, S. E. (2016). What do we know about children living with HIV-infected or AIDS-ill adults in Sub-Saharan Africa? A systematic review of the literature. *AIDS care*, *28*(sup2), 130-141.

Goodwin, D., Mays, N., & Pope, C. (2020). Ethical Issues in Qualitative Research. *Qualitative Research in Health Care*, 27-41.

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse education today*, *56*, 29-34.

Granlund, S., & Hochfeld, T. (2020). 'That Child Support Grant Gives Me Powers'–Exploring Social and Relational Aspects of Cash Transfers in South Africa in Times of Livelihood Change. *The Journal of Development Studies*, *56*(6), 1230-1244.

Gray, J. R., Grove, S. K., & Sutherland, S. (2016). *Burns and Grove's The Practice of Nursing Research-E-Book: Appraisal, Synthesis, and Generation of Evidence*. Elsevier Health Sciences.

Gulati, R., Mikhail, O., Morgan, R. O., & Sittig, D. F. (2016). Vision statement quality and organisational performance in US hospitals. *Journal of Healthcare Management*, *61*(5), 335-350.

Haber, D. (2019). *Health promotion and aging: Practical applications for health professionals*. Springer Publishing Company.

Hall, K., Richter, L., Mokomane, Z., & Lake, L. (Eds.). (2018). *South African child gauge 2018*. Children's Institute, University of Cape Tow

Hall, K., Skelton, A., & Sibanda, S. (2016). Social assistance for orphaned children living with family. *South African Child Gauge*.

Hall, K., Skelton, A., & Sibanda, S. (2016). Social assistance for orphaned children living with family. *South African Child Gauge*.

Hansen, E. C. (2020). *Successful qualitative health research: a practical introduction*. Routledge.

Harley, D. A., & Teaster, P. B. (Eds.). (2015). *Handbook of LGBT elders: An interdisciplinary approach to principles, practices, and policies*. Springer.

Harris, L. M., Wilfong, J., Thang, N. D., & Kim, B. J. (2017). Guardianship Planning Among Grandparents Raising Grandchildren Orphaned by HIV/AIDS in Northern Vietnam. *Grand Families: The Contemporary Journal of Research, Practice and Policy*, *4*(1), 7.

Hayslip Jr, B., Fruhauf, C. A., & Dolbin-MacNab, M. L. (2019). Grandparents raising grandchildren: What have we learned over the past decade?. *The Gerontologist*, *59*(3), e152-e163.

Hennink, M., Hutter, I., & Bailey, A. (2020). *Qualitative research methods*. SAGE Publications Limited.

Hinton, K. E. (2012). *A practical guide to strategic planning in higher education* (Vol. 7). USA: Society for College and University Planning.

Hlabyago, K. E., & Ogunbanjo, G. A. (2009). The experiences of family caregivers concerning their care of HIV/AIDS orphans. *South African Family Practice*, *51*(6), 506-511.

Hlongwane, N., & Madiba, S. (2020). Navigating Life with HIV as an Older Adult in South African Communities: A Phenomenological Study. *International Journal of Environmental Research and Public Health*, *17*(16), 5797.

Hoffman, J. (2018). Second-parenthood realities, third-age ideals:(grand) parenthood in the context of poverty and HIV/AIDS. *Grandparenting Practices Around the World: Reshaping family*, 89.

Hughes, A. S. (2016). Mixed methods research. *APS Observer*, *29* (5).

Human Sciences Research Council Annual (HSRC) Report 2018/2019

Ingelsson, P., Bäckström, I., & Snyder, K. (2018). Strengthening quality culture in private sector and health care. *Leadership in Health Services*.

J Visser, M. (2018). Change in HIV-related stigma in South Africa between 2004 and 2016: a cross-sectional community study. *AIDS care*, *30*(6), 734-738.

Jarrett, J. E. (2015). Total quality management (TQM) movement in public health. *International journal of quality & reliability management*. Vol. 33 No. 1, pp. 25-41, available at: http://dx.doi.org/10.1108/IJQRM-12-2013-0193

Johnson LF, Dorrington RE, Moolla H. Modelling the impact of HIV in South Africa's provinces. [homepage on the Internet]. University of Cape Town; 2016 [cited 2016Aug 24]. Available from: http://www.thembisa.org/content/downloadPage/Provinces2016

Johnson, L. F., Dorrington, R. E., & Moolla, H. (2017). Progress towards the 2020 targets for HIV diagnosis and antiretroviral treatment in South Africa. *Southern African journal of HIV medicine*, *18*(1).

Kadungure, T. P. (2017). *Experiences of caregivers caring for children with different special needs in a cluster foster care village in KwaZulu-Natal* (Doctoral dissertation).

Kalomo, E. N., & Liao, M. (2018). Burden of care among caregivers of persons living with HIV/AIDS in rural Namibia: Correlates and outcomes. *Social work in public health*, *33*(1), 70-84.

Kalomo, E. N., & Taukeni, S. G. (2020). Elderly Grandparents as Caregivers of Children Affected or Infected by HIV and AIDS in Namibia. In *Biopsychosocial Perspectives and Practices for Addressing Communicable and Non-Communicable Diseases* (pp. 68-83). IGI Global.

Kalomo, E. N., & Taukeni, S. G. (2020). Elderly Grandparents as Caregivers of Children Affected or Infected by HIV and AIDS in Namibia. In *Biopsychosocial Perspectives and*

Kalomo, E. N., Lee, K. H., Lightfoot, E., & Freeman, R. (2018). Resilience among older caregivers in rural Namibia: The role of financial status, social support and health. *Journal of gerontological social work*, *61*(6), 605-622.

Kalomo, E. N., Lee, K. H., Lightfoot, E., & Freeman, R. (2018). Resilience among older caregivers in rural Namibia: The role of financial status, social support and health. *Journal of gerontological social work*, *61*(6), 605-622.

Karimli, L., Ssewamala, F. M., & Ismayilova, L. (2012). Extended families and perceived caregiver support to AIDS orphans in Rakai district of Uganda. *Children and youth services review*, *34*(7), 1351-1358.

Keeney, S., McKenna, H., & Hasson, F. (2011). *The Delphi technique in nursing and health research*. John Wiley & Sons

Kelly, G. (2019). Disability, cash transfers and family practices in South Africa. *Critical Social Policy*, *39*(4), 541-559.

Khosa, P., & Kaseke, E. (2017). The utilisation of the child support grant by caregivers: the case of Ba-Phalaborwa municipality in Limpopo Province. *Social work*, *53*(3), 356-367.

Kidman, R., & Heymann, J. (2016). Caregiver supportive policies to improve child outcomes in the wake of the HIV/AIDS epidemic: an analysis of the gap between what is needed and what is available in 25 high prevalence countries. *AIDS care*, *28*(sup2), 142-152.

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, *24*(1), 120-124.

Kuo, C., & Operario, D. (2011). Health of adults caring for orphaned children in an HIV-endemic community in South Africa. *AIDS care*, *23*(9), 1128-1135.

Kuo, C., Cluver, L., Casale, M., & Lane, T. (2014). Cumulative effects of HIV illness and caring for children orphaned by AIDS on anxiety symptoms among adults caring for children in HIV-endemic South Africa. *AIDS Patient Care and STDs*, *28*(6), 318-326.

Lee, Y., & Blitz, L. (2018). experiences of grandparents raising grandchildren in Malawi. *Innovation in Aging*, *2*(suppl_1), 658-658.

Lee, Y., & Blitz, L. (2020). 'Kufunika kwa mtundu/fuko'(Family circle): Understanding experiences of grandparents raising grandchildren in Malawi. *International Social Work*, 0020872820959360.

Lee, Y., & Blitz, L. V. (2016). We're GRAND: A qualitative design and development pilot project addressing the needs and strengths of grandparents raising grandchildren. *Child & Family Social Work*, *21*(4), 381-390.

Martin, F. S., & Zulaika, G. (2016). Who cares for children? A descriptive study of care-related data available through global household surveys and how these could be better mined to inform policies and services to strengthen family care. *Global social welfare*, *3*(2), 51-74.

Mashau, N. S., & Tugli, A. K. (2019). Experiences of grandmothers raising their grandchildren in Vhembe District, South Africa. *Journal of Gender, Information and Development in Africa (JGIDA)*, *8*(Special Issue 1), 139-153.

Mashegoane, S., & Mohale, N. F. (2016). Parenting AIDS-orphaned grandchildren: experiences from Lephalale, South Africa. *Gender and Behaviour*, *14*(1), 6931-6943.

Mas-Machuca, M., Ballesteros-Sola, M., & Guerrero, A. (2017). Unveiling the mission statements in social enterprises: a comparative content analysis of US-vs. Spanish-based organisations. *Journal of Social Entrepreneurship*, *8*(2), 186-200.

N, Barron P, Day C, Ndlovu N, Padarath A, editors. District Health Barometer 2018/19. Durban: Health Systems Trust; February 2020

Mathilda, Z., Mukombwe, O., Doreen, M., & Clara, H. (2015). Coping Strategies of Caregivers of HIV/AIDS Orphans in Ward 15 Bikita District, Masvingo Province, Zimbabwe. *Money*, *12*, 57.

Matovu, S. N., & Wallhagen, M. I. (2020). Perceived Caregiver Stress, Coping, and Quality of Life of Older Ugandan Grandparent-Caregivers. *Journal of cross-cultural gerontology*, *35*(3), 311-328.

Matovu, S., Rankin, S., & Wallhagen, M. (2020). Ugandan Jajjas: Antecedents and rewards of caring for grandchildren in the context of HIV. *International Journal of Older People Nursing*, *15*(2), e12304.

Maxwell, J. A. (2020). Why qualitative methods are necessary for generalization. *Qualitative Psychology*.

Melis, T., Fikadu, Y., & Lemma, L. (2020). Perceived Stigma and Associated Factors Among HIV Positive Adult Patients Attending Antiretroviral Therapy Clinics at Public Facilities of Butajira Town, Southern Ethiopia, 2020. *HIV/AIDS (Auckland, NZ)*, *12*, 717.

Mendoza, A., Fruhauf, C., Bundy-Fazioli, K., & Weil, J. (2017). Understanding Latino grandparents raising grandchildren through a bioecological lens. *The International Journal of Aging and Human Development*, 86, 281–305.

Messner, D. A., Al Naber, J., Koay, P., Cook-Deegan, R., Majumder, M., Javitt, G., & Chandrasekharan, S. (2016). Barriers to clinical adoption of next generation sequencing: Perspectives of a policy Delphi panel. *Applied & translational genomics*, *10*, 19-24.

Mhaka-Mutepfa, M. (2018). Sociodemographic factors and health-related characteristics that influence the quality of life of grandparent caregivers in Zimbabwe. *Gerontology and Geriatric Medicine*, *4*, 2333721418756995.

Mhaka-Mutepfa, M., Mpofu, E., & Cumming, R. (2015). Impact of protective factors on resilience of grandparent carers fostering orphans and non-orphans in Zimbabwe. *Journal of Aging and Health*, *27*(3), 454-479.

Mhaka-Mutepfa, M., Mpofu, E., & Cumming, R. (2015). Impact of protective factors on resilience of grandparent carers fostering orphans and non-orphans in Zimbabwe. *Journal of Aging and Health*, *27*(3), 454-479.

Mirvis, P., Googins, B., & Kinnicutt, S. (2010). Vision, mission, values. *Organisational Dynamics*, *39*(4), 316.

Moore, A. R., & Henry, D. (2005). Experiences of older informal caregivers to people with HIV/AIDS in Lome, Togo. *Ageing International*, *30*(2), 147-166.

Moosa, M., & Patel, J. (2020). South Africans support social grants, but say work at any wage beats unemployment.

Morse, J. M. (2016). *Mixed method design: Principles and procedures* (Vol. 4). Routledge.

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, *24*(1), 9-18.

Motsoaledi, A. (2014). Health budget vote speech by the Minister of Health. Cape Town, South Africa.RetrievedonJuly30,2019,from http://www.health.gov.za/docs/media/MinisterHealthBudgetVoteSpeech24July2014.p df.

Mozuni, M., & Jonas, W. (2017). An introduction to the morphological Delphi Method for design: A tool for future-oriented design research. *She Ji: The Journal of Design, Economics, and Innovation*, *3*(4), 303-318.

Mtshali, M. N. G. (2016). Role reversal of rural black grandparents in South Africa. *Journal of Comparative Family Studies*, *47*(3), 369-377.

Mtshali, M. N. G. (2016). Role reversal of rural black grandparents in South Africa. *Journal of Comparative Family Studies*, *47*(3), 369-377.

Mukumbang, F. C., van Wyk, B., Van Belle, S., & Marchal, B. (2019). Unravelling how and why the Antiretroviral Adherence Club Intervention works (or not) in a public health facility: A realist explanatory theory-building case study. *PloS one*, *14*(1), e0210565.

Muruganantham, G., Vinodh, S., Arun, C. S., & Ramesh, K. (2018). Application of interpretive structural modelling for analysing barriers to total quality management practices implementation in the automotive sector. *Total Quality Management & Business Excellence*, *29*(5-6), 524-545.

Mzimela, P. M. (2019). *Child and youth care workers' support of grandparents raising orphaned grandchildren* (Doctoral dissertation).

Mzimela, P. M. (2019). *Child and youth care workers' support of grandparents raising orphaned grandchildren* (Doctoral dissertation).

Nasim, K. (2018). Role of internal and external organisational factors in TQM implementation. *International Journal of Quality & Reliability Management*.

Neyestani, B. (2017). Principles and Contributions of Total Quality Management (TQM) Gurus on Business Quality Improvement. *Available at SSRN 2950981*.

Niehaus, I. (2017). Marriage, kinship and childcare in the aftermath of AIDS: rethinking "orphanhood" in the South African lowveld. *Anthropology Southern Africa*, *40*(1), 42-55.

Nnama-Okechukwu, C. U., & Okoye, U. O. (2019). Rethinking institutional care using family-based alternative child care system for orphans and vulnerable children in Nigeria. *Journal of Social Work in Developing Societies*, *1*(3).

Nyasani, E., Sterberg, E., & Smith, H. (2009). Fostering children affected by AIDS in Richards Bay, South Africa: A qualitative study of grandparents' experiences. *African Journal of AIDS Research*, *8*(2), 181-192.

Nyoni, T., Nabunya, P., & Ssewamala, F. M. (2019). Perceived social support and psychological wellbeing of children orphaned by HIV/AIDS in Southwestern Uganda. *Vulnerable Children and Youth Studies*, *14*(4), 351-363.

O'Neill, P., Sohal, A., & Teng, C. W. (2016). Quality management approaches and their impact on firms′ financial performance – An Australian study. *International Journal of Production Economics*, *171*, 381–393. doi: 10.1016/j.ijpe.2015.07.015 [Crossref], [Web of Science ®], [Google Scholar]

Oduaran, A., & Oduaran, C. (2018). Grandparents functional capacity in mitigating challenges experienced by children orphaned by HIV and AIDS in sub-Saharan Africa. *Ubuntu: Journal of Conflict and Social Transformation*, *7*(Special Issue 1), 203-216.

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*(1), 85-102.

Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS care*, *18*(3), 236-240.

Osafo, J., Knizek, B. L., Mugisha, J., & Kinyanda, E. (2017). The experiences of caregivers of children living with HIV and AIDS in Uganda: a qualitative study. *Globalization and Health*, *13*(1), 1-13.

Palmer, R., & Gasman, M. (2008). "It Takes a Village to Raise a Child": The Role of Social Capital in Promoting Academic Success for African American Men at a Black College. *Journal of College Student Development 49*(1), 52-70. doi:10.1353/csd.2008.0002.

Patel, L., & Plagerson, S. (2016). The evolution of the child support grant. ChildGauge, 39

Phelanyane, F., Boulle, A., & Kalk, E. (2020, July). Prevention of mother-to-child-transmission (PMTCT) of HIV in Khayelitsha, South Africa: A contemporary review of the service 20 years later. in *journal of the international aids society* (vol. 23, pp. 48-48). the atrium, southern gate, Chichester po19 8sq, w Sussex, England: john Wiley & sons ltd.

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*, *20*(Supplement 1), 348-359.

Polit, D. F., & Beck, C.T. (2018). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. (9th Ed). Philadelphia: Lippincott Williams, & Wilkins.

Polit, D.F., & Beck, C.T. (2012). *Nursing research: Generating and assessing evidence for nursing practice*.(9th ed.). Philadelphia, PA: Wolters Kluwer.

Polit, D.F., & Beck, C.T. (2014). *Essentials of nursing research: Appraising evidence for nursing practice*.(8th ed.). Philadelphia, PA: Wolters Kluwer.

Practices for Addressing Communicable and Non-Communicable Diseases (pp. 68-83). IGI Global.

Preble, E. A. (1990). Impact of HIV/AIDS on African children. *Social science & medicine*, *31*(6), 671-680.

Ravitch, S. M., & Carl, N. M. (2019). *Qualitative research: Bridging the conceptual, theoretical, and methodological*. SAGE Publications, Incorporated.

Reed, M. L. (2018). *Grandparents cry twice: Help for bereaved grandparents*. Routledge.

Republic of South Africa. (2005). Children's Act, No. 38 of 2005. *Government Gazette*, *492*(28944).

Robitaille, K. Y. (2012). The health of rural grandparents raising grandchildren.

Rutakumwa, R., Zalwango, F., Richards, E., & Seeley, J. (2015). Exploring the care relationship between grandparents/older carers and children infected with HIV in south-western Uganda: Implications for care for both the children and their older carers. *International journal of environmental research and public health*, *12*(2), 2120-2134.

Saldulker, H., & South Gauteng High Court. (2012). Children's Court Case No: 14/1/4-206/10. *A3056/11*.

Salunke, S., & Lal, D. K. (2017). Multisectoral approach for promoting public health. *Indian Journal of Public Health*, *61*(3), 163.

Samuel, P. S., Marsack, C. N., Johnson, L. A., LeRoy, B. W., Lysack, C. L., & Lichtenberg, P. A. (2017). Impact of grandchild caregiving on African American grandparents. *Occupational therapy in health care*, *31*(1), 1-19.

Satumba, T., Bayat, A., & Mohamed, S. (2017). The impact of social grants on poverty reduction in South Africa. *Journal of Economics*, *8*(1), 33-49.

Satumba, T., Bayat, A., & Mohamed, S. (2017). The impact of social grants on poverty reduction in South Africa. *Journal of Economics*, *8*(1), 33-49.

Schatz, E., Ogunmefun, C. (2007) Caring and contributing: The role of older women in rural South African multigenerational households in the HIV/AIDS era. World Development 35: 1390–1403. doi:10.1016/j.worlddev.2007.04.004.

Scott, R. E., & Mars, M. (2013). Principles and framework for eHealth strategy development. *Journal of medical Internet research*, *15*(7), e155.

Sekayi, D., & Kennedy, A. (2017). Qualitative Delphi method: A four round process with a worked example. *The Qualitative Report*, *22*(10), 2755-2763.

Shafiq, M., Lasrado, F., & Hafeez, K. (2019). The effect of TQM on organisational performance: empirical evidence from the textile sector of a developing country using SEM. *Total Quality Management & Business Excellence*, *30*(1-2), 31-52.

Shaibu, S. (2016). Caring for HIV-positive orphans in the context of HIV and AIDS: perspectives of Botswana grandmothers. *International journal of older people nursing*, *11*(4), 315-323.

Sidpra, J., Chhabda, S., Gaier, C., Alwis, A., Kumar, N., & Mankad, K. (2020). Virtual multidisciplinary team meetings in the age of COVID-19: an effective and pragmatic alternative. *Quantitative imaging in medicine and surgery*, *10*(6), 1204.

Simbayi, L., Zuma, K., Zungu, N., Moyo, S., Marinda, E., Jooste, S., ... & Mohlabane, N. (2019). South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017: towards achieving the UNAIDS 90-90-90 targets.

Simelela, N., Venter, W. F., Pillay, Y., & Barron, P. (2015). A political and social history of HIV in South Africa. *Current HIV/AIDS Reports*, *12*(2), 256-261.

Sitienei, E. C., & Pillay, J. (2019). Psycho-educational and social interventions provided for orphans and vulnerable children at a community-based organisation in Soweto, South Africa. *African journal of AIDS research*, *18*(1), 1-8.

Small, J., Aldwin, C., Kowal, P., & Chatterji, S. (2019). Aging and HIV-related caregiving in sub-Saharan Africa: a social ecological approach. *The Gerontologist*, *59*(3), e223-e240.

Smith, B., & McGannon, K. R. (2018). Developing rigor in qualitative research: Problems and opportunities within sport and exercise psychology. *International review of sport and exercise psychology*, *11*(1), 101-121.

Souza, A. C. D., Alexandre, N. M. C., & Guirardello, E. D. B. (2017). Psychometric properties in instruments evaluation of reliability and validity. *Epidemiologia e Serviços de Saúde*, *26*, 649-659.

Stats, S. A. (2019). Statistical Publications, July 2019

Sumo, J. N., Wilbur, J., Julion, W., Buchholz, S., & Schoeny, M. (2018). Interventions to improve grandparent caregivers' mental and physical health: an integrative review. *Western journal of nursing research*, *40*(8), 1236-1264.

Tadesse, S., Dereje, F., & Belay, M. (2014). Psychosocial wellbeing of orphan and vulnerable children at orphanages in Gondar Town, North West Ethiopia. *Journal of public health and epidemiology*, *6*(10), 293-301.

Taiwo, A. A., Lawal, F. A., & Agwu, P. E. (2016). Vision and Mission in Organisation: Myth or Heuristic Device?. *The International Journal of Business & Management*, *4*(3).

Tamasane, T., & Head, J. (2010). The quality of material care provided by grandparents for their orphaned grandchildren in the context of HIV/AIDS and poverty: A study of Kopanong municipality, Free State. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *7*(2).

Tanyi, P. L., Pelser, A., & Okeibunor, J. (2018). HIV/AIDS and older adults in Cameroon: Emerging issues and implications for caregiving and policy-making. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *15*(1), 7-19.

Thepthien, B. O., & Srivanichakorn, S. (2016). Societal awareness of stigma and discrimination against persons living with Human Immunodeficiency Virus (HIV)(PLHIV): Experience of clinicians, PLHIV, general population, and persons who are vulnerable to HIV. *Journal of AIDS and HIV Research*, *8*(4), 25-37.

Thomas, T., Tan, M., Ahmed, Y., & Grigorenko, E. L. (2020). A Systematic Review and Meta-Analysis of Interventions for Orphans and Vulnerable Children Affected by HIV/AIDS Worldwide. *Annals of Behavioral Medicine*.

Tonjang, Suebsakul, and Natcha Thawesaengskulthai. "A systematic literature review of TQM and innovation in healthcare." *ISPIM Conference Proceedings*. The International Society for Professional Innovation Management (ISPIM), 2020.

Toronto, C. (2017). Considerations when conducting e-Delphi research: A case study. *Nurse Researcher*, *25*(1).

Tracy, S. J. (2019). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. John Wiley & Sons.

Treasury, N. Z. (2019). Budget Speech 2019.

Trevelyan, E. G., & Robinson, N. (2015). Delphi methodology in health research: how to do it?. *European Journal of Integrative Medicine*, *7*(4), 423-428.

UNAIDS (2018a) Science Panel. Making the end of AIDS real: consensus building around what we mean by "epidemic control."Geneva:(http://www.unaids.org/sites/default/files/media_asset/glion_oct2017_meeting_report_en.pdf, accessed 4 July 2019).

UNAIDS, D. (2018b). Disponível em: http://www. unaids. org/sites/default/files/media_asset/20170720_Data_book_2017_en. pdf. *Acesso em*, *1*.

UNAIDS, U. (2019). Factsheet: global AIDS update. 2019.

UNAIDS, W. (2017). UNAIDS. *WHO Epidemiological Fact Sheets on HIV and AIDS*,

UNAIDS. (2015). On the fast-track to end AIDS by 2030: Focus on location and population. Retrievedfromhttp://www.unaids.org/sites/default/files/media_asset/WAD2015_report_en_part01.pdf (accessed August 2019).

UNAIDS.(2019). Global HIV Statistics, Fact Sheet November; 2020. Available from: https://www.google.com/search?client=firefox-b-d&q=hiv+aids+statitsics(Last accessed on November 2020).

United Nations. (2016). International migration report 2015 (Report No. ST/ESA/SER.A/384). New York, NY: Department of Economic and Social Affairs Population Division. Retrieved from http://www.un.org/en/development/desa/population/migration/publications/migrationreport/docs/MigrationReport2015.pdf

Upton, R. L. (2003). "Women Have No Tribe" Connecting Carework, Gender, and Migration in an Era of HIV/AIDS in Botswana. *Gender & Society*, *17*(2), 314-322.

Van Heerden, A., & Wild, L. G. (2018). Grandparent support and mental and behavioural health in middle childhood. *Social Development*, *27*(2), 366-380.

van Schoten, S., de Blok, C., Spreeuwenberg, P., Groenewegen, P., & Wagner, C. (2016). The EFQM Model as a framework for total quality management in healthcare. *International journal of operations & production management*.

Velloza, J., Kemp, C. G., Aunon, F. M., Ramaiya, M. K., Creegan, E., & Simoni, J. M. (2020). Alcohol Use and Antiretroviral Therapy Non-Adherence Among Adults Living with HIV/AIDS in Sub-Saharan Africa: A Systematic Review and Meta-Analysis. *AIDS and Behavior*, *24*(6), 1727-1742.

Wang, C. D., Hayslip Jr, B., Sun, Q., & Zhu, W. (2019). Grandparents as the primary care providers for their grandchildren: A cross-cultural comparison of Chinese and US samples. *The International Journal of Aging and Human Development*, *89*(4), 331-355.

Watkins, D. A., Nugent, R., Saxenian, H., Yamey, G., Danforth, K., González-Pier, E., ... & Jamison, D. T. (2017). Intersectoral policy priorities for health.

Wicks, D. (2017). The coding manual for qualitative researchers. *Qualitative research in organisations and management: an international journal*.

Wild, L. G. (2018). Grandparental involvement and South African adolescents' emotional and behavioural health: a summary of research findings. *Contemporary Social Science*, *13*(2), 232-245.

Wild, L. G., & Gaibie, F. (2014). Grandparental involvement and South African adolescents' psychological well-being. *Journal of Intergenerational Relationships*, *12*(4), 425-441.

Wild, L. G., & Gaibie, F. (2014). Grandparental involvement and South African adolescents' psychological well-being. *Journal of Intergenerational Relationships*, *12*(4), 425-441.

Winston, C. A. (2006). African American grandmothers parenting AIDS orphans: Grieving and coping. *Qualitative Social Work*, *5*(1), 33-43.

Worden, J. W. (2018). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. springer publishing Company.

World Health Organisation (2016).Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations – 2016 update. Geneva

APPENDIX 1 : TRANSLATED INTERVIEW GUIDE

IYUNIVESITI YENTSHONA KOLONI

Private Bag X 17, Bellville 7535, South Africa
Umnxeba: ***+27 21-959 3244 Fax: 27 21-959 2679***
Imeyili**: fakimanimpaye@uwc.ac.za**

UHLELO LODLIWANONDLEBE

IKHOWUDI NOMBOLO YOMTHATHI-NXAXHEBA#
.....UMHLA.....

Isihloko seprojekthi yophando nzulu: Ukwakha iindlela zokuphucula inkxaso koomakhulu abanakekela iinkedama zengculaza eNtshona Koloni
Olu phando lucaciswe kum ngolwimi endiluqondayo. Imibuzo yam malunga noluphando iphenduliwe. Ndiyakuqonda ukuba ukuthatha kwam inxaxheba kuqulathe ntoni kwaye ndiyavuma ukuthatha inxaxheba ngokuzithandela. Ndiyayiqonda into yokuba ukuba ndingubani ayizukuxelelwa nabani na. Ndiyaqonda ukuba ndingarhoxa koluphando nanini na ndingakhange ndinike sizathu, futhi ngaphandle kokoyikaukuba kungakhona imiphumela emibi okanye ukuphulukana namalungelo.
Utyikityo lomthathi nxaxheba .....
Kumbuzo ngamnye kule ilandelayo, uyacelwa ukuba uphendule ngokuthe ngqo nangokunyaniseka. Lilungelo lakho ukuba ungavumi okanye uyeke ukuthatha inxaxheba kolu phando.

Iimpendulo zakho zibaluleke kakhulu. Ndingathanda ukukuthembisa ukuba zonke iimpendulo zakho zizakugcinwa ziyimfihlo kwaye zisetyenziselwe iinjongo zoluphando

ICANDELO A

Ulwazi ngcaciso: Bonakalisa ngo X apho kufaneleke khona kuwe

Iminyaka	Isini	Isimo somtshato	Umgangatho wemfundo	Umsebenzi	Ingingqi yokuhlala

ICANDELO B

Ingeniso nenkcitho yekhaya

1.1 Bangaphi abantwana abaphantsi konakekelo lwakho?

2. Ngubani obeka isonka etafileni kweli khaya?

ICANDELO C

Iimeko zengqondo

3. Unexesha elingakanani uhlala nabazukulwana bakho abaziinkedama?
4. Yintoni eyakukhuthaza ukuba uthathe isigqibo sokuba uhlale nabazukulwana bakho abazinkedama njengomakhulu?
5. Yaba yintoni unobangela wokusweleka kwabazali babazukulwana bakho?
6. Kwaye ubunexesha elingakanani umnakekela phambi kokuba asweleke?
7. Ingaba wenza njani ukumelana nendlela oziva ngayo kwimo yonxunguphalo?
8. Ingaba ikhona inkxaso oyifumanayo ekuhlaleni?
9. Ingaba bukhona ubunzima ojongene nabo apha ekuhlaleni malunga nokukhulisa umzukulwana wakho oyinkedama yengculaza?
10. Ingaba ukhe uzive uneentloni, unomsindo kwaye ungakwazi kuzenzela nto?
11. Loluphi uhlobo lokumelana nengxaki othe walusebenzisa ukwenza ngcono iingxaki zakho kungoku nje? Ingaba zikhona iinkonzo zabacebisi ezifumanekayo kwingingqi ohlala kuyo?
12. Ingaba ikhona inkxaso oyifumanayo (ngemali okanye ezinye iindlela) ngaphandle komvuzo wakho? ukuba ikhona nceda uphendule lemibuzo ilandelayo:
13. Uyifumana kubani inkxaso? (kwimibutho karhulumente {GO's}, kwimibutho engeyiyo ekarhulumente{NGO's}, kumaziko ezokholo, ekuhlaleni, okanye ezinye?)
14. Loluphi uhlobo loncedo osele ulufumene?

15. Zeziphi ezona ntlobo zenkxaso osele uzifumene ezingundoqo?
16. Ungakhe undichazele ukuba umelana njani nokuphila kwesisimo sangoku?
17. Zinjani izimo nengqwalasela yasekuhlaleni malunga noomakhulu abanakekela iinkedama zengculaza?

ICANDELO D
IIMEKO ZOKUHLALA

1. Ingaba mhlawumbi ufumana imali yesibonelelo yokuba ngumgcini wabantwana njengomakhulu onakekela iinkedama zengculaza?
2. Ukuba kunjalo, kunjani ukufikeleleka kwezizibonelelo?
3. Ingaba uyazi ngeentlobo ezahlukeneyo zezibonelelo zabantwana abazinkedama?
4. Wenza njani ukukhusela ukutya kuhlale kukhona? Uyifumana phi imali eyingeniso?
5. Ingaba uyayifumana inkxaso kwamanye amalungu osapho ekukhuliseni abazukulwana bakho abazinkedama?
6. Ingaba bukhona ubunzima okhe wadibana nabo ekufumaneni imali yesibonelelo karhulumente yakho okanye yabazukulwana bakho abazinkedama? Ukuba kunjalo cacisa?
7. Zeziphi ezona zidingo zakho njengoyena mnakekeli wenkedama zengculaza? Kwaye uzama kangakanani ukufezekisa ezizidingo?
8. Zeziphi iindlela eziyingeniso yemali kusapho lwakho?
9. Yimalini oyisebenzisa kwimfundo, ukutya nezinye izinto ezingundoqo zabantwana abazinkedama?
10. Ukusweleka kwelungu losapho kwikhaya lakho kuyichaphazela kangakanani inkcitho yengeniso?

ICANDELO E
OKUCHAPHAZELA UMZIMBA/ISIQU

1. Ingaba uneendawo ezibuhlungu ozivayo (njengentloko, umzimba obuhlungu)?

2. Ukuba kunjalo, uqale nini ukuva ezi ngxaki?
3. Khawucacise impilo yakho?

ICANDELO F
OKUCHAPHAZELA INDALO / OKUSINGQONGILEYO

1. Luhlobo olunjani lwezindlu ohlala kuzo?
2. Unako oku kulandelayo:
    - Umbane
    - Umnxeba
    - Amagumbi okuhlambela
    - Amanzi acocekileyo
    - Igumbi langasese

ICANDELO G
OKUCHAPHAZELA IINKONZO ZEZEMPILO

1. Uzifumana phi iinkonzo zezempilo?
2. Ungahlomla uthini ngokusebenza, umgangatho nokufikeleleka kwezi nkonzo?
3. Ingaba uyoneliseka zezinkonzo zezempilo uzifumanayo? Ukuba kunjalo, kangakanani? Ukuba akunjalo, ngoba?
4. Ungathini xa uhlomla ngokuba zingadlala ndima ithini ezi arhente(agents) ukusombulula ezingxaki zomakhulu abanakekela iinkedama zengculaza kule ndawo uhlala kuyo?
    - Urhulumente
    - Imibutho engeyiyo ekarhulumente
    - Oomakhulu ngokwabo
5. Ingaba zikhona iingxaki othe wazifumana ngenxa yalozwelonke? Ukuba kunjalo nceda ubonise ukuba njani kwaye ikuchaphazele kangakanani wena nosapho lwakho?
6. Ungandixelela ukuba wazi ntoni nge HIV/AIDS?

7. Ngokoluvo lwakho nangamava wakho, zinto zini ezimbi eziziziphumo zokunakekela iinkedama zengculaza koomakhulu?
8. Ukuba unezinto ofuna ukuzihlomla okanye iinkcukacha ofuna ukuzongeza malunga nentlalontle yoomakhulu abanakekela iinkedama zengculaza ngokubanzi, nendlela esebenzayo yenkxaso, ungazongeza.
9. Ungandixelela ukuba wazi ntoni nge HIV/AIDS?
10. Zeziphi ezona ngxaki zokupila ojongene nazo ekunakekeleni abazukulwana bakho abazinkedama zengculaza?

Enkosi.

APPENDIX 2: CONSENT FORM

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 3244 3244 Fax: 27 21-959 2679
E-mail: E-mail:fakimanimpaye@uwc.ac.za

CONSENT FORM

Title of Research Project: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name……..

Participant's signature…….

Date……

APPENDIX 3: TRANSLATED INFORMATION SHEET

IYUNIVESITI YENTSHONA KOLONI

Private bag X17 Bellville 7535, South Africa
Umnxeba: +27 21-959 3244 iFax: 27 21-959 2679
Imeyili: fakimanimpaye@uwc.ac.za

IPHEPHA LENKCUKACHA ZODLIWANONDLEBE OLULUNGISELELWE OOMAKHULU ABANAKEKELA IINKEDAMA ZENGCULAZA

Isihloko seprojekthi: Ukwakha iindlela zokuphucula inkxaso koomakhulu abanakekela iinkedama zengculaza eNtshona Koloni

Lungantoni oluphando?
Igama lam ndingu Furaha Akimanimpaye. Kungoku nje ndibhaliselwe inkqubo yobugqirha ebunesini kwiUnivesiti yeNtshona Koloni. Ndiyakumema ukuba uthathe inxaxheba koluphando kuba ubandakanyeka ekunakekeleni iinkedama zengculaza. Injongo kukuvelisa iindlela zokuphucula inkxaso koomakhulu abanzoluphando akekela iinkedama zengculaza kwiphondo laseNtshona Koloni kwiRiphabliki yoMzantsi Afrika.

Kuzakuthiwa mandenze ntoni ukuba ndiyavuma ukuthatha inxaxheba?
Ukuba uyavuma ukuthatha inxaxheba koluphando, uzakucelwa ukuba wenze udliwanondlebe kwaye lungathatha malunga nemizuzu engamashumi amathandathu (60) yexesha lakho. Udliwanondlebe luzakufuna ingcombolo ngolwazi lwakho nengxaki ojongene nazo ekunakekeleni iinkedama zengculaza, neengcebiso zakho zokuba zingasombululeka njani ezingxaki uzikhankanyileyo. Kananjalo izakuquka ne inkxaso ngenkcubeko nokuhlala, inkxaso ngokwasengqondweni, inkxaso ngokwenyama/emzimbeni nenkxaso ngemali oyifumanayo njengo makhulu onakekela iinkedama zengculaza kwanemiceli-mngeni onayo.

Ingaba ukuthatha kwam inxaxheba koluphando luzakugcinwa luyimfihlo?
Zonke iinkcukacha zakho neempendulo zemibuzo noshicilelo lweteyiphu(tape) zizakugcinwa kwindawo ekhuselekileyo iminyaka emihlanu emva kokuba iziphumo zophando zipapashiwe. Ushicilelo lweteyiphu luyakuhlala lungabhalwanga umnikazi walo, ukukhusela ukuba kungabinaku nxulunyaniswa iimpendulo kunye neenkcukacha zakho ezikuchazayo. Ukuze sikwazi ukugcina ukungaziwa, umphandi akazukuwabiza amagama wenu okanye igama leziko/nkampani kupapasho lweziphumo zophando.

Zintoni ezibubungozi koluphando?
Akukho bungozi baziwayo okanye bulindelekileyo bunxulumene nokuba yinxalenye yaleprojekthi yoluphando. Kodwa ke ukuba uziva ungakhululekanga phambi, ngethuba okanye emva kokuthatha inxaxheba, ukhululekile ukuba ungarhoxa ekuthatheni inxaxheba ngokuthi wazise umphandi, kwaye esisigqibo siyakuhlonitshwa, kungekho kwantlokoma/ngxolo eza kuwe.

Zintoni eziyinzuzo zoluphando?
Ukuthatha kwakho inxaxheba kusenokungabina nzuzo kuwe buqu, kuba akukho sibonelelo semali, kodwa izinto ezizakuthi zifunyaniswe zingaba yinzuzo kuwe nanjengoko ingakhokelela ekuphuhlisweni kweendlela ezinokunceda kwinkxaso enikwa oomakhulu abanakekela iinkedama zengculaza kwiPhondo lweNtshona Koloni.

Ingaba ndinyanzelekile ukuba ndithathe inxaxheba koluphando, kwaye ndingayeka ukuthatha inxaxheba nanini na?
Ukuthatha kwakho inxaxheba koluphando kukuzithandela kwaye ukhululekile ukuba ungarhoxa nakwesiphi na isigaba soluphando ngaphandle kwesohlwayo okanye ukunikezela ngesimo sakho njengomsebenzi wezempilo okanye umzali. Ungakhetha ukungathathi nxaxheba kwaphela koluphando, kungabikho ntlokoma.

Ndingenza njani ukuze imibuzo yam iphenduleke?
Ukhululekile ukuba ungabuza nawuphina umbuzo omayela noluphando okanye intatho nxaxheba yakho. Olu phando luqhutyelwa kwi Univesiti yeNtshona Koloni, eMzantsi Afrika. Ukuba unemibuzo malunga nobuqu bophando, nceda uqhakamshelane nam kwezi nkcukacha zoqhakamshelwano zilandelayo.
University of the Western Cape

School of Nursing
Private Bag X17, Bellville 7535, South Africa
Umnxeba: 021 9593244 iFax: 9592679
Imeyile: fakimanimpaye@uwc.ac.za
iselula: 0737083908
Unelungelo njengomthathi nxaxheba lokuba ubuze nawuphi na umbuzo onxulumene noluphando okanye nayiphi na ingxaki odibene nayo ngexesha loluphando. Ngoko ke, ukuba uthe wanombuzo okanye ingxaki edinga ukuhoywa, sukulibazisa ungatsalela nawuphi na kwaba balandelayo:
uNkosikazi F Akimanimpaye, 0219593244 imeyile: fakimanimpaye@uwc.ac.za
School of Nursing, University of the Western Cape
Private Bag X17, Bellville
Cape Town, Republic of South Africa

Head of Department: Dr.Arunachallam
Umnxeba: +27-(21)-9592523
imeyile: sarunachallam@uwc.ac.za

Dean of the Faculty of Community and Health Sciences
Prof Jose Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
Umnxeba: 021 9592631
imeyile: chs-deansoffice@uwc.ac.za
Oluphando luvunywe yiSenate Research Committee ne Ethics Commiittee kwiYunivesiti yaseNtshona Kol

APPENDIX 4: INERVIEW GUIDE (ENGLISH)

UNIVERSITY OF THE WESTERN CAP

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 3244 Fax: 27 21-959 2679
E-mail: fakimanimpaye@uwc.ac.za

INTERVIEW SCHEDULE

CODE NUMBER OF THE INTERVIEWEE # …….. .. DATE ……..

Title of Research Project: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve, and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's signature ……..

For each of the following questions, you are requested to provide precise and true response. It is your right to refuse or discontinue from participating in this study.

Your answers are very important. I would like to promise you that all your responses will be kept confidential and used only for the purpose of this study

SECTION A

Biographical information: Indicate with an 'X' where it is applicable to you.

Age	Gender	Marital Status	Education Level	Occupation	Area of residence

SECTION B

Household Income and Expenditure

1. 1. How many children under your care?
2. Who is the breadwinner of the family?

SECTION C

Psychological factors

3. How long have you been living with your orphan grandchildren?
4. What motivated you to take the decision to live with your orphan grandchildren as a grandparent
5. What are the causes of death of your grandchildren's parents?
6. And for how long have you been caring for him/her before his/her death?
7. How do you cope in terms of emotional well- being?
8. Do you get any other support from your community?
9. Is there any difficulties do you experience in raising your AIDS orphans grandchildren in your community?
10. Do you ever feel ashamed, angry and helpless?
11. What coping mechanisms that you have used to improve your problems so far? Is there any counselling service available in your community?
12. Do you get any support (in cash or in other ways) other than your income? If yes, please respond to the following questions:
13. From whom do you get support? (GOs, NGOs, religious Institutions, the local community or others?)
14. What kind of assistance have you received so far?
15. What are the main support services you are receiving?
16. May you tell me as to how you are managing to survive in the current situation?
17. What is the attitude and perceptions of the community towards grandparents caring for AIDS orphans?

SECTION D

SOCIAL FACTORS

1. Are you perhaps receiving foster care grant as a grandparent caring for AIDS orphans?
2. If yes how is the accessibility of these grants?
3. Are you aware of different types of grand provided for orphan's children?
4. What do you do to maintain food security? Where do you get an income?
5. Do you get any support from the extended families in raising your orphan grandchildren?
6. Have you ever had any difficult experiences in accessing government grant for yourself or your orphan grandchild? If yes explain?
7. What are your basic needs as the main caregivers of AIDS orphan? And to what extent do you manage to meet these needs?
8. What are the sources of income for your family?
9. How much do you spend for education, foods and other basic need for orphans children?
10. To what extent does the death of a family member in your household affected your income/ expenditure?

SECTION E

PHYSICAL FACTORS

1. Do you experience any physical problems (such as backache, painful body)?
2. If yes when did you start experiencing these problems?
3. Describe your health?

SECTION F

ENVIRONMENTAL FACTORS

1. What types of the households do you live in?
2. Do you have the followings:
    - Electric power supply
    - Telephone
    - Bathrooms
    - Clean water
    - Toilet

SECTION G

HEALTH SERVICES FACTORS

1. Where do you get the health services?

2. What do you comment on the adequacy, quality and accessibility and affordability of these services?
3. Are you satisfied with the health services that you are getting? If yes, to what Extent? If not why?
4. How do you comment with regards of what should be the roles of the following agents to address the problems of grandparents caring for AIDS orphans in your community?
    - The government
    - NGOs
    - Grandparents themselves
5. Is there any problem that you have encountered due to the pandemic? If yes, Please indicate how & to what extent it has affected you and your family?
6. Can you tell me what do you know about HIV/AIDS?
7. In your opinion and from your own experience, what are the negative consequences of caring for AIDS orphans on grandparents?
8. If you have any comments or additional information regarding the welfare of grandparents caring for AIDS orphans in general and support mechanisms you may add.
9. Can you tell me what do you know about HIV/AIDS?
10. What are the major survival problems that you are facing in taking care of your AIDS grandchildren?

Thank you.

APPENDIX 5: UNIVERSITY OF THE WESTERN CAPE PERMISSION

ETHICAL APPROVAL

UNIVERSITY of the WESTERN CAPE

OFFICE OF THE DIRECTOR: RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 753
South Africa
T: +27 21 959 4111/2948
F: +27 21 959 3170
E: research- ethics
@uwc.ac.za www.uwc.ac.za

27 March 2018

Ms F Akimanimpaye
School of Nursing
Faculty of Community and Health Science

Ethics Reference Number: HS 16/5/31

Project Title: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape.

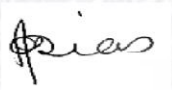
Approval Period: 16 March 2018 – 16 March 2019

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of



PROVISIONAL REC NUMBER - 13

APPENDIX 6: INFORMATION SHEET

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

8.1 Tel: +27 21-959 3244 3244 Fax: 27 21-959 2679

8.2 =E-mail: E-mail:fakimanimpaye@uwc.ac.za

INFORMATION SHEET

Project Title: Project Title: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape

What is this study about?

This is a research project being conducted by Furaha Akimanimpaye at the University of the Western Cape. We are inviting you to participate in this research project because you are involved in taking care of AIDS orphans. The purpose of this study is to develop strategies to improve support for grandparents caring for AIDS orphans in the Western Cape Province, Republic of South Africa.

What will I be asked to do if I agree to participate?

You will be asked to be interviewed and it will take approximately 30 minutes to one hour of your own time at work, or at home. The interview will seek information on your knowledge, and challenges you face in taking care of AIDS orphans and your suggestions on how to solve these issues you so identify. It will also cover the socio-cultural support, psychological support, physical and financial support given to you as a grandparent caring for Aids orphans as well as the challenges you have.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, all the personal information and responses in the questionnaire and audio tapes will be kept in a secure place for five years after the results of the research have been published. The audio tapes will remain anonymously labeled to prevent linking the responses with your personal identification

during data collection process a code will be placed on the collected data; through the use of identification key and only the researcher will have access to the identification key**.** To ensure the confidentiality of the data, the researcher will keep all the data in a locked filing cabinets using identification codes only on data forms, and using password-protected computer files. If we write a report or article about this research project, your identity will be protected. The researcher will not mention your names or the name of the institution in the publication of the research findings.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the support given to grandparents caring for AIDS orphans. We hope that, in the future, other people might benefit from this study through improved strategies that might enhance the support given to grandparents caring for Aids orphans in the Western Cape Province.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify

What if I have questions?

This research is being conducted by *Furaha Akimanimpaye, school of nursing **at*** the University of the Western Cape. If you have any questions about the research study itself, please contact Prof. D. Phetlhu at: (021)9599532, *e mail:* dphetlhu@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Dr Arunachallam Luke

Head of Department

University of the Western Cape

Private Bag X1Bellville 7535

Sarunachallam@uwc.ac.za

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535chs-deansoffice@uwc.ac.za
This research has been approved by the University of the Western Cape's Senate Research Committee.
(REFERENCE NUMBER: *to be inserted on receipt thereof from SR*)

APPENDIX 7: QUESTIONNAIRE FOR MULTIDISCIPLINARY TEAM.

SURVEY:

For each of the following questions, you are requested to provide precise and true response. It is your right to refuse or discontinue from participating in this study.

Your answers are very important. I would like to promise you that all your responses will be kept confidential and used only for the purpose of this study.

Thank you for your participation!

SECTION A

Demographic profile

Please indicate the appropriate response to each item as it applies to you

1. **Gender**

Male	Female

2. **Age** _____ years
3. **Location of the organization**

Urban	Rural

4. **Multidisciplinary team**

Social worker	Professional nurse	Psychologist

5. **Education level of participant**

Matric		Degree		Honors		Masters		Doctorate	

SECTION B

Indicate with an 'X' the extent to which you agree or disagree with each STATEMENT in the right hand column

Perceived support mechanisms given to grandparents caring for Aids orphans

.

Statement	Strongly agree	Agree	Don't know	Disagree	Strongly Disagree
13. I am aware of the health risk on the grandparents caring for AIDS orphans in general.					
14. I can easily identify health problems amongst grandparent caregivers of AIDS orphans who make use of the clinic where I work.					
15. I am aware of the existing care plan and support services provided by my clinic, to the needy grandparents caring for AIDS orphans?					
16. Absence of basic needs may cause health problems amongst grandparents caring for AIDS orphans.					
17. Lack of income for survival can be a contributing factor to health problem amongst grandparents caring for AIDS orphans.					
18. No access to health services can exacerbate the already compromised health of grandparents caring for AIDS orphans.					

19. Lack of social security provision can be the major cause of stress experienced by grandparents caring for AIDS orphans.					
20. The health problems of grandparents caring for AIDS orphans are escalating is in our ‘’communities?					
21. I am aware of urgent needs and problems grandparents caring for AIDS orphans are facing					
22. I already encountered different categories of grandparents caring for AIDS orphans.					
23. I am aware and actively involved in the roles the organization is playing in provision of support given to grandparents caring for AIDS orphan.					
24. I am aware of the impacts of HIV/AIDS on the welfare of grandparents caring for Aids orphans here in Western Province?					

2.Which one of the following group of grandparents caring for aids orphans do you feel are most vulnerable to various health problems? (Please indicate in rank order)

A) Grandparents under psychological support

YES		NO	

B) Grandparents without support structures

YES		NO	

C) Grandparents who are head of the households

YES		NO	

D) Grandparents caring for AIDS affected orphans

YES		NO	

E) Abandoned grandparents without extended family structures support

YES		NO	

3. If any other, please indicate

.....

.....

.....

4. What do you suggest that will make the optimum health of grandparents caring for AIDS orphan's life better?

……

…….

5. As a health care provider, what strategies have you tried to address these Problems?

A) Providing social economical support in their residential setting

B) Providing referral to formal established programs and organizations, which target older persons and AIDS affected person in your area.

C) Providing emotional support in your clinic.

D) No strategies tried

6. Is there any existing functions or roles of professional nurses/social workers and/or psychologist in providing care and support to grandparents caring for AIDS orphans in your clinic?

Yes	No

7. If yes please identify these roles/functions…….

8. How do you evaluate the contributions of multidisciplinary team in providing holistic support to grandparents caring for AIDS orphans in your clinic.

Well done	Somewhat good	Don't know	Not good

9. How do grandparents caring for AIDS orphans in your clinic cope with the impacts and the burdens associated with caregiving in their old age?

Coping well	Don't know	Not coping

10. If you have any additional comments, which are related to HIV/AIDS and its Impacts on the health support networks of grandparents caring for Aids orphans, you can add.

……

……

……..

Thank you.

/

APPENDIX 8: QUESTIONNAIRE FOR SOCIAL SERVICES

SURVEY:

For each of the following questions, you are requested to provide precise and true response. It is your right to refuse or discontinue from participating in this study.

Your answers are very important. I would like to promise you that all your responses will be kept confidential and used only for the purpose of this study.

Thank you for your participation!

SECTION A

Demographic profile

Please indicate the appropriate response to each item as it applies to you

6. **Gender**

Male	Female

7. **Age** _____ years
8. **Location of the organization**

Urban	Rural

9. **Multidisciplinary team**

Social worker	Professional nurse	Psychologist

10. Education level of participant

Matric		Degree		Honors		Masters		Doctorate	

SECTION B

Indicate with an 'X' the extent to which you agree or disagree with each STATEMENT in the right hand column

Perceived support mechanisms given to grandparents caring for Aids orphans

.

Statement	Strongly agree	Agree	Don't know	Disagree	Strongly Disagree
25. I am aware of the health risk on the grandparents caring for AIDS orphans in general.					
26. I can easily identify health problems amongst grandparent caregivers of AIDS orphans who make use of the clinic where I work.					
27. I am aware of the existing care plan and support services provided by my clinic, to the needy grandparents caring for AIDS orphans?					
28. Absence of basic needs may cause health problems amongst grandparents caring for AIDS orphans.					
29. Lack of income for survival can be a contributing factor to health problem amongst grandparents caring for AIDS orphans.					

30. No access to health services can exacerbate the already compromised health of grandparents caring for AIDS orphans.					
31. Lack of social security provision can be the major cause of stress experienced by grandparents caring for AIDS orphans.					
32. The health problems of grandparents caring for AIDS orphans are escalating is in our communities?					
33. I am aware of urgent needs and problems grandparents caring for AIDS orphans are facing					
34. I already encountered different categories of grandparents caring for AIDS orphans.					
35. I am aware and actively involved in the roles the organization is playing in provision of support given to grandparents caring for AIDS orphan.					
36. I am aware of the impacts of HIV/AIDS on the welfare of grandparents caring for Aids orphans here in Western Province?					

2.Which one of the following group of grandparents caring for aids orphans do you feel are most vulnerable to various health problems? (Please indicate in rank order)

F) Grandparents under psychological support

YES		NO	

G) Grandparents without support structures

YES		NO	

H) Grandparents who are head of the households

YES		NO	

I) Grandparents caring for AIDS affected orphans

YES		NO	

J) Abandoned grandparents without extended family structures support

YES		NO	

3. If any other, please indicate

.....

.....

.....

4. What do you suggest that will make the optimum health of grandparents caring for AIDS orphan's life better?

……

…….

5. As a health care provider, what strategies have you tried to address these Problems?

E) Providing social economical support in their residential setting

F) Providing referral to formal established programs and organizations, which target older persons and AIDS affected person in your area.

G) Providing emotional support in your clinic.

H) No strategies tried

6. Is there any existing functions or roles of professional nurses/social workers and/or psychologist in providing care and support to grandparents caring for AIDS orphans in your clinic?

Yes	No

7. If yes please identify these roles/functions…….

8. How do you evaluate the contributions of multidisciplinary team in providing holistic support to grandparents caring for AIDS orphans in your clinic.

Well done	Somewhat good	Don't know	Not good

9. How do grandparents caring for AIDS orphans in your clinic cope with the impacts and the burdens associated with caregiving in their old age?

Coping well	Don't know	Not coping

10. If you have any additional comments, which are related to HIV/AIDS and its Impacts on the health support networks of grandparents caring for Aids orphans, you can add.

……

……

……..

Thank you.

APPENDIX 9: WESTERN CAPE DEPARTMENT OF HEALTH PERMISSIONS

Proposal Details: WC_201710_019

WESTERN CAPE HEALTH RESEARCH COMMITTEE

APPLICATION DETAILS

TITLE OF RESEARCH PROJECT

Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape Province.

TYPE OF STUDY

Academic

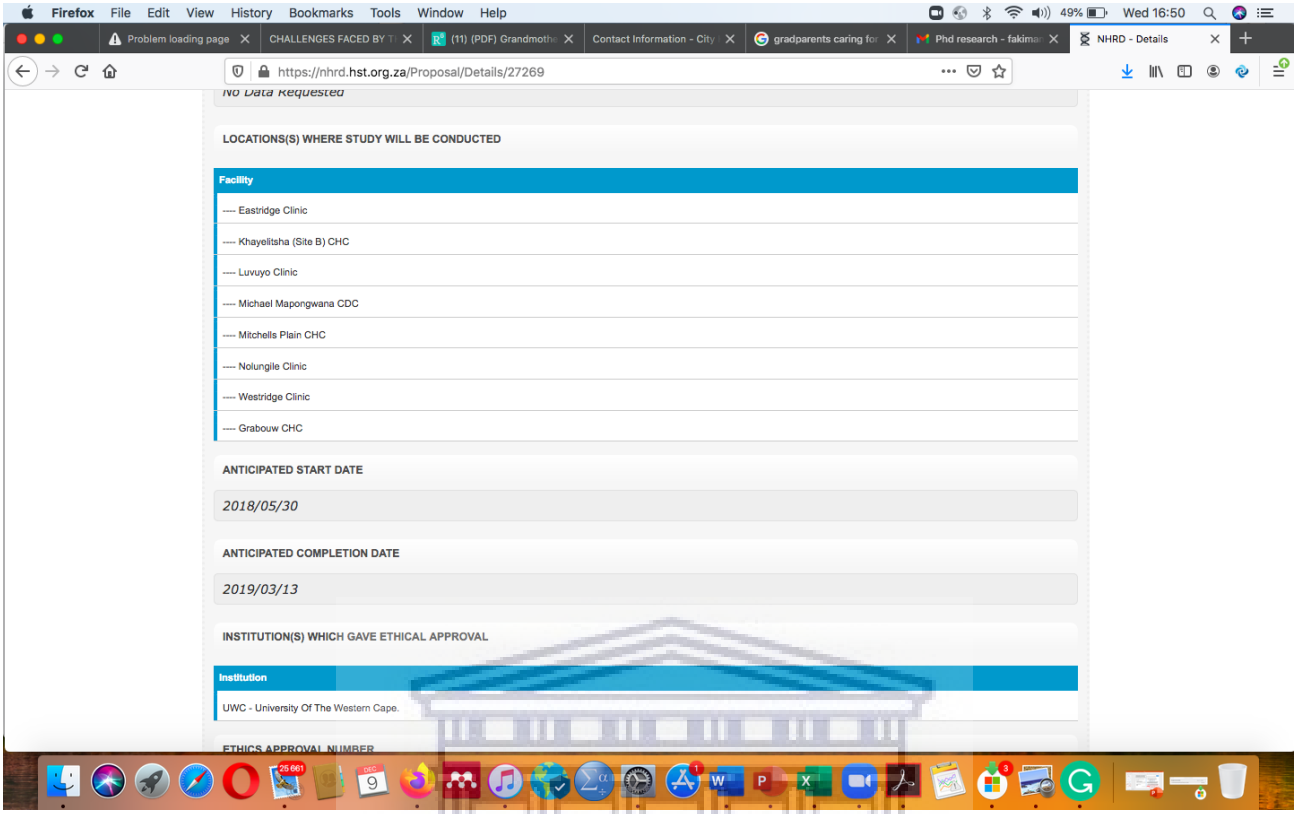
STATUS OF APPLICATION

Approved

STATUS OF PROJECT

On-Going

PROPOSAL SUBMISSION DATE



CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

CITY HEAL
Dr Natacha Berkow

Epidemiologist: Specialised Heal

T: 021 400 6864 F: 021 421 4894
E: Natacha.Berkowitz@capetown.gov.

2018-06-05

Re: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape 7943

Dear Furaha Akimanimpaye

Your research has been approved to interview staff and grandparents of AIDS orphans at the following City Facilities:

Eastern & Khayelitsha: **Town Two CDC, Nolungile Youth Clinic**
Luvuyo CDC, Kuyasa CDC

Contact Person: Dr Virginia De Azevedo (Area 2 Manager)
Tel/Cell: 021 360 1258/083 629 3344

Please note the following:

1. So as not to burden the staff the following facilities were selected for your proposal.
2. All individual patient information obtained must be kept confidential.
3. Access to the clinics and clients must be arranged with the relevant Managers such that normal activities are not disrupted.
4. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 6 months of its completion (which is currently scheduled for March 2019) and feedback must also be given to the clinics involved.
5. Your project has been given an ID Number (7943): please use this in any future correspondence with us.
6. No monetary incentives to be paid to clients on the City Health premises
7. If this research gives rise to a publication, please submit a draft before publication for City Health comment and include a disclaimer in the publication that "the research findings and recommendations do not represent an official view of the City of Cape Town".

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR N BERKOWITZ
Epidemiologist: SPECIALISED HEALTH

Western Cape Government
Health

Health impact assessment
Health research sub directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201710_019
ENQUIRIES: Dr Sabela Petros

University of the Western Cape

Robert Sobukwe Road

Bellville

Cape Town

7535

For attention: Mrs Furaha Akimanimpaye

Re: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape Province.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

Mitchells Plain CHC	**Dr Neal David**	**021 391 5899**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report

(**Annexure 8**) to the provincial Research Co-ordinator

(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR J EVANS

ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 01/06/2018

CC: **P OLCKERS** **DIRECTOR: KLIPFONTEIN/ MITCHELLS PLAIN**

Western Cape Government
Health

Health impact assessment
Health research sub directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201710_019
ENQUIRIES: Dr Sabela Petros

University of the Western Cape

Robert Sobukwe Road

Bellville

Cape Town

7535

For attention: Mrs Furaha Akimanimpaye

Re: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape Province.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

Khayelitsha (Site B) CHC	**Mr David Binza**	**021 360 5207**
Michael Mapongwana CDC	**Dr Germarie Fouche**	**021 361 3353**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR J EVANS

ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 17/04/2018

CC: **M PHILLIPS** **DIRECTOR: KESS**

APPENDIX 10. WESTERN CAPE DEPARTMENT OF SOCIAL SERVICES PERMISSION

Western Cape Government
Social Development

Research, Population and Knowledge Management
tel: +27 21 483 4512 fax: +27 21 483 5602
48 Queen Victoria Street, Cape Town, 8000

Reference: 12/1/2/4

Enquiries: Clinton Daniels

Tel: 021 483 8658/483 4512

Ms F. Akimanimpaye

13 Victoria Street

Bellville

7530

Dear Ms Akimanimpaye

RE: APPROVAL TO UNDERTAKE RESEARCH IN THE WESTERN CAPE DEPARTMENT OF SOCIAL DEVELOPMENT

1. Your request for ethical approval to undertake research in respect of *'Developing strategies to improve support given to grandparents caring for AIDS orphans in the Western Cape'* refers.
2. It is a pleasure to inform you that your request has been approved by the Research Ethics Committee (REC) of the Department, subject to the following conditions:

- That the Secretariat of the Research Ethics Committee be informed in writing of any changes made to your proposal after approval has been granted and be given the opportunity to respond to these changes.
- That ethical standards and practices as contained in the Department's Research Ethics Policy be maintained throughout the research study, in particular that written informed consent be obtained from participants.
- The confidentiality and anonymity of participants, who agree to participate in the research, should be maintained throughout the research process and should not be named in your research report or any other publications that may emanate from your research.

- The Department should have the opportunity to respond to the findings of the research. In view of this, the final draft of your research report should be send to the Secretariat of the REC for comment before further dissemination.
- That the Department be informed of any publications and presentations (at conferences and otherwise) of the research findings. This should be done in writing to the Secretariat of the REC.
- Please note that the Department supports the undertaking of research in order to contribute to the development of the body of knowledge as well as the publication and dissemination of the results of research. However, the manner in which research is undertaken and the findings of research reported should not result in the stigmatisation, labelling and/or victimisation of beneficiaries of its services.
- The Department should receive a copy of the final research report and any subsequent publications resulting from the research.
- The Department should be acknowledged in all research reports and products that result from the data collected in the Department.
- Please note that the Department cannot guarantee that the intended sample size as described in your proposal will be realised. Furthermore, this approval relates ONLY to the participation of officials of this Department and NOT any beneficiaries of its services.
- Logistical arrangements for the research must be made through the office of the relevant Regional Managers, subject to the operational requirements and service delivery priorities of the Department.
- Failure to comply with these conditions can result in this approval being revoked.

Yours sincerely

Ms M. Johnson

Chairperson: Research Ethics Committee

Date: 11/5/17

APPENDIX 11: CHECKLIST QUESTIONNAIRE

For each of the following questions, you are requested to provide precise and
True response. It is your right to refuse or discontinue from participating in this study.
Your answers are very important. I would like to promise you that all your responses will be kept confidential and used only for the purpose of this study.

Thank you for your participation!

SECTION A

Demographic profile

Please indicate the appropriate response to each item as it applies to you

1. Gender

Male	Female

2. **Age** _____ years

3. **Residential area**

Urban	**Rural**

4.Biophysical, psychological factors, social cultural factors, environmental dimension and health services dimension.

Statement	Yes	No	%
1. DO you get child support grant?			
2. Do you get counselling services from your clinic			
3. Do you have running water and electricity in your household?			
4. Does your clinic provide referral services for you in case you need it.			
5. Do you get any assistance (in cash or in other ways) other than your income? If yes, please respond to the following questions: From whom do you get assistance/support			
6. Government institutions			
7. Non-government institutions			
8. Religious Institutions			
9. Family members			
10. Are you perhaps receiving foster care grant as a grandparent caring for AIDS orphans? If yes how is the accessibility of these grants?			
11. Easily accessible			
12. Experience difficult accessing foster care grant			

13. Do you get any support for education of your orphans grand children?			
Statement	**Yes**	**No**	%
13.Are you aware of different types of grand provided for your orphan's children			
14.Are you the breadwinner in your family? If yes			
15.Are you working?			
16.Do you experience any physical problems such as painful legs, back?			
17. Do you experience difficulties in accessing your health facilities?			
18.Are you satisfied with the health services that you are getting?			
19.Do y you have access to electric power supply?			
20.Do you have access to clean water?			
21.Do you have access to bathrooms and toilet?			
22.Do you have access to telephone?			
23.Do you get a normal attitude from your community members(friends, neighbours)			

APPENDIX 12: DELPHI INFORMATION SHEET

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa Tel: +2721-9592271 Fax: 27219592679

E-mail:www.uwc.ac.za

INFORMATION SHEET

Title of Research: Developing Strategies to improve support given to grandparents caring for AIDS orphans in Western Cape Province, South Africa.

What is this study about?

This is a research project being conducted by Furaha Akimanimpaye ,a PhD student at the University of the Western Cape. We are inviting you to participate in this research project because you are a public health nurse/social worker, psychologist , a manager in government or NGO social services, or an academic staff in community and health sciences . The purpose of this research is to develop strategies to improve support given to grandparents caring for AIDS orphans in social and

health care facilities in Western Cape province ,South Africa. The Delphi method is intended as the final phase to refine the strategy.

A Delphi is a systematic forecasting method that involves structured interaction among a group of experts on a subject. Thus, it may be referred to as an expert brainstorm

What will I be asked to do if I agree to participate?

You will be asked to:

1. Read through an initial draft strategy document developed by the researcher which is attached to this document and assist in refining it by your honest opinions and suggestions.

2. Assist by acting as quality assurer in refining a strategic document which is acceptable and feasible and shall lead to the support strategies for use in all communities health facilities /clinics and social services across Western Cape .

3. Complete three to four rounds involving a series of questionnaires, each building on the results of the previous one. The results of each round shall be compiled and returned to you. Over successive iterations, you will be able to re-evaluate your responses in light of the complied responses of other panellists.

4. The first round of the questionnaire may take up to one hour while subsequent ones could last for approximately 30-45 minutes of your time at home or at work.

5. You will return the completed questionnaire in a closed envelope that shall be provided or you will send it back to the researcher via her e-mail address.

6. The questions will seek information on whether the draft strategy is acceptable and additional inputs from you as an expert/ panellist. The focus will be on improving support given to grandparents caring for AIDS orphans (GPCFAO) based on the conclusion statements and problems identified in the first phase of the study that explored grandparents caring for AIDS orphans, Multidisciplinary personnel in Communities health centre ; and social developments personnel .

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, your names will not be required in the questionnaires, rather code numbers will be attached to the returned questionnaires to ensure they are not traced to you.

All the personal information and responses in the questionnaires shall be kept in a secure place for five years after the results of the research have been published. The questionnaires shall remain anonymously labelled to prevent linking the responses with your personal identification through the use of identification key. Only the researchers will be able to link the survey to your identity.

To ensure your confidentiality, data shall be locked in secured filling cabinets using identification codes only on data forms and pass word protected computer files known only to the researcher and supervisor during and the data analysis. These shall be kept for at least five years before they are destroyed. If we write a report or article about this research project, your identity will be protected. The researchers will not mention your names or the name of the institution in the publication of the research findings.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about challenges faced by grandparents caring for AIDS orphans , and thereafter develop strategies to enhance support given to them . We hope that, in the future, other people might benefit from this study through understanding of these strategies.

The strategies to enhance support given to grandparents caring for AIDS orphans that shall be developed will also contribute to the knowledge base of multidisciplinary team especially nursing practice and social workers in the sense that they will serve as a reference point for nurses in the care of grandparents caring for AIDS orphans and children in their care and may throw more light and

inform research on fears and hindrances faced by grandparents caring for AIDS orphans in their caring roles.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, no resentment shall be held against you.

What if I have questions?

This research is being conducted by Furaha Akimanimpaye from the School of Nursing at the University of the Western Cape, South Africa. If you have any questions about the research study itself, please contact Furaha Akimanimpaye at:

School of nursing

University of The Western Cape ,
South Africa .
Cell Phone: 0737083908; (027)9593244 Email: fakimanimpaye@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department/Project Supervisor:

Professor Deliwe Phetlhu
School of Nursing, University of the Western Cape
Private Bag X17, Belville 7535
Cape Town. Republic of South Africa
Telephone: +27(21)-9593003
Dean of the Faculty of Community and Health Sciences:
Prof Anthea Rhoda
UNIVERSITY OF THE WESTERN CAPE Private Bag X17

Bellville 7535
chs-deansoffice@uwc.ac.za
This research has been approved by the University of the Western Cape's Senate Research Committee.

Private Bag X 17, Bellville 7535, South Africa
Tel: +271-9592271 Fax: 2721 9592679

www.uwc.ac.za

APPENDIX 13: DELPHI CONSENT FORM

CONSENT FORM

Title of Research Project: Developing strategies to improve support for grandparents caring for AIDS orphans in the Western Cape

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I

may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

8.3

8.4 Participant's name……..

8.5 Participant's signature…….

8.6 Date……

APPENDIX 14: Delphi Round 1 Questionnaire

ROUND ONE DELPHI PANELLIST QUESTIONNAIRE

Dear Sir/ Madam/Dr /Prof,

Thank you for agreeing to participate in this Delphi survey on the development of strategies to enhance support given to grandparents caring for AIDS orphans in Western Cape Province ,South Africa. This study forms part of a two-phased PHD Thesis being undertaken in the University of the Western Cape, South Africa.

This questionnaire round is the first of up to three rounds of the survey. Please try to answer all the questions as we expect you to have in-depth knowledge of all of them. You will have the opportunity to revise your answers with subsequent rounds of the survey.

In these surveys, you will be asked to act as quality assurers to help refine strategies in terms of its authenticity, usability and relevance. The draft strategy was developed by the researcher from a list

of conclusion statements and problems identified in the first phase of the study that investigated grandparents caring for AIDS orphans ,multidisciplinary health workers, and social development personnel on the knowledge, challenges encountered by grandparents caring for AIDS orphans in their caring role.

Instructions: The questions can be answered with only a single selection, a space is also provided for you to comment on the underlying reasons for your responses. In formulating your responses, you are not expected to assess the feasibility or cost of data collection for the indicators.

Once l have received responses from all panellists, I will collate and summarise the findings and formulate the second questionnaire. You should receive this in the next two weeks. I assure you that your participation in the survey and your individual responses will be strictly confidential to the research team (supervisor and statistician) and will not be divulged to any outside party, including other panellists.

SECTION A

1. This section asks questions about your social demographics. Mark X on the appropriate column on the right hand side. 1. Area of Specialty

Public health	
Nursing (CHC/ Clinic Management)	
Social development management	
NGO management	
Lecturer	
Other	

2. Gender

Male	
Female	

3. Working experience

Below 10 years	

10 -19 years	
20- 29 years	
30 years and above	

……

……

SECTION B

This section seeks your input on the ways to enhance support given to grandparents caring for AIDS orphans in Western Cape . Kindly assess the vision, mission and value statements, as well as the objectives and functional tactics for their relevance, authenticity, and usability.

Choose from the response indicators on a Likert scale of four where: 4= Excellent; 3= Very good; 2= Good; 1=Poor.

B.1: This section asks questions about the vision statement for the strategy

Vision Statement: "Vision : — A healthy lifestyle to all grandparents caring for AIDS orphans

Variable	Excellent	Very good	Good	Poor
1. Is the vision statement logic and convey a sense of direction to members of the organisation.				
2. It is extensive enough to serve as an axis point for the organization				
3. It is inspiring and uplifting to everyone involved to work toward a common state and a set of goals				
4. It is easy to communicate and motivates members of the organization				

Use the section below to kindly answer the following questions on vision statement.

5. Give reasons for your scores in the section on vision statement just completed

---

---

6. What would you want included in the section?

---

7. Why do you want item 6 above included?

B2: This section asks your opinion on the mission statement for the Multidisciplinary team

Mission Statement: “To provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity from participation of stakeholders and through excellence in multidisciplinary health care practice .

A mission statement is a durable statement of the exceptional purpose of an organization that differentiates it from similar ones. It describes the comprehensive purpose for which an organization exists. (Pearce & Robinson, 2000). The mission identifies the present scope of the organization's operations in terms of its present capabilities, customer focus, activities, makeup, product, market, and technology. It provides answers to the questions: "Who are we?" and "What do we do?" A mission statement embodies the philosophy, values, identity, character and priorities of an organization, and also reflects the image the organization wants to project. A mission statement is not about measurable targets, but is rather a statement or intent, attitude, outlook and orientation (Ehlers & Lozengy, 2010; Peace & Robinson, 2000).

Furthermore , good mission statement summarises an organization’s unique and enduring reason for being and motivates stakeholders to pursue common goals. The mission statement answer the

following questions:" What is our business? ; Why do we exist? ; and What are we trying to accomplish? (Suno, 2010).)

Variable	Excellent	Very good	Good	Poor
8. It is unique to the statements on grandparents caring for AIDS orphans and multidisciplinary team.				
9. It is realistic: describe the comprehensive purpose of which the organization exists				
10. It is current and does not have to be changed often.				
11. It is clear and focused.				
12. It is concise: short, snappy and possible.				
13. It is short and has emotional appeal				
14. It is memorable: People can see and remember it.				

Use the section below to kindly answer the following questions on mission statement.

15. Motivate for your scores in the section on mission statement just completed.

16. What would you want included in the mission statement?

---

17. Why do you want item 16 above included?

This section asks questions about the value statement for the multidisciplinary team

- B.3: Value Statement: "Maintenance of professional ethics through Participation, Respect and kindness, Integrity in practical assistance ,involving Family and

community-based care, Strengthening existing resources, Developing on locally appropriate practices ,Consideration of gender and providing Quality care.

Variable	Excellent	Very good	Good	Poor
18. It captures the culture of the organization in terms of ethics and non- discrimination based on race culture or gender.				
19. It describes the guiding principles.				
20.It contains organizational culture.				
21. It describes expectation of staff				
22. It describes the ethics and morality and integrity, trust and excellence in practice				

Use the section below to kindly answer the following questions in your own words.

23. Give reasons for your scores in the section on value statement just completed.

---

24. What would you want included in the section on value statement?

---

25. Why do you want item 24 above included?

B.4: This section asks questions about the principles of the multidisciplinary team health workers .

- ❖ Principles: Facilitate health and social support system plans with GPCFAO and their families in order to assist them in finding connections with the rest of the community and their families.
- ❖ Develop community awareness programmes on the needs of GPCFAO

According to the identified problems, the support programmes may include a holistic focus on:

- ❖ Training and skills development for teenagers
- ❖ Practical assistance (such as accessing identity documents or social grants)
- ❖ Counselling, HIV testing and treatment assistance and psychosocial support of GPCFAO and infected children
- ❖ Nutritional support programmes
- ❖ Economic strengthening activities

Variable	Excellent	Very Good	Good	Poor
26. It meets the target satisfaction.				
27. It Involves all concerned (grandparents caring for AIDS orphans and MDT staff).				
28. It is multi-sectoral (able to sustain partnership coordinate care).				
29. The method of governance is transparent, accountable to all concerned.				

Use the section below to kindly answer the following questions in your own words.

30. Give reasons for your scores in the section on principles just completed.

---

31. What would you want included in the section on principles?

---

32. Why do you want item 31 above included?

B.5: This section asks questions about the objectives, functional strategies developed to improve support given to grandparents caring for AIDS orphans by the multidisciplinary team.

To answer the following questions, kindly refer to page 21-38 of the draft strategic document sent to you. This is to reduce the bulky nature of the questionnaire.

Objective 1	Functional strategies			
Variable	Excellent	Very good	Good	Poor
33.It is specific, concrete, detailed and well defined.				
34.It is measurable in terms of numbers and quantity				
35. It is achievable: feasible and actionable				
36.It is realistic considering resources.				

Use the section below to kindly answer the following questions in your own words.

37. Give reasons for your scores in the section on objective 1 just completed.

---

38. What would you want included in the section on objective 1?

---

39. Why do you want item 38 above included?

Objective 2	Functional strategies			
Variable	Excellent	Very good	Good	Poor
40. It is specific: concrete, detailed, well defined.				
41. It is measurable: in terms of numbers & quantity.				
42. It is achievable: feasible & actionable.				
43. It is realistic: considering resources available.				

Use the section below to kindly answer the following questions in your own words.

44. Give reasons for your scores in the section on objective 2 just completed.

Objective 3	Functional strategies			
Variable	Excellent	Very good	Good	Poor
45. It is specific: concrete, detailed, well defined.				
46. It is measurable: in terms of numbers & quantity.				

47. It is achievable: feasible & actionable.				
48. It is realistic: considering resources available.				

Use the section below to kindly answerer the following questions in your own words on objective 3.

49. Give reasons for your scores in the section on objective 3 just completed.

---

50. What would you want included in the section on objective 3?

---

51. Why do you want item 50 above included?

Objective 4	Functional strategies			
Variable	Excellent	Very good	Good	Poor
52. It is specific: concrete, detailed, well defined.				

53. It is measurable: in terms of numbers & quantity.				
54. It is achievable: feasible & actionable.				
55. It is realistic: considering resources available.				

Use the section below to kindly answer the following questions in your own words.

56. Give reasons for your scores in the section on objective 4 just completed.

---

57. What would you want included in this section on objective 4?

---

58. Why do you want item 57 above included?

Objective 5	Functional strategies			
Variable	Excellent	Very good	Good	Poor
59. It is specific: concrete, detailed, well defined.				
60. It is measurable: in terms of numbers & quantity.				
61. It is achievable: feasible & actionable.				

62. It is realistic: considering resources available.				

Kindly use the section below to answer the following questions in your own words.

63. Give reasons for your scores in the section on objectives just completed.

---

64. What would you want included in the section on objectives?

---

65. Why do you want item 64 above included?

THANK YOU FOR YOUR QUICK RESPONSE TO THIS QUESTIONNAIRE

APPENDIX 15: ROUND 2 QUESTIONNAIRE

Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Senate Research Committee.

ROUND TWO DELPHI PANELLIST QUESTIONNAIRE

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +271-9592271 Fax: 2721 9592679

www.uwc.ac.za

Dear Sir/ Madam/Dr /Prof,

Thank you for agreeing to participate in this Delphi survey on the development of strategies to enhance support given to grandparents caring for AIDS orphans in Western Cape Province ,South Africa. This study forms part of a two-phased PHD Thesis being undertaken in the University of the Western Cape, South Africa.

This questionnaire round is the second of up to three rounds of the survey. Please try to answer all the questions as we expect you to have in-depth knowledge of all of them. The aim of this round is to revise your answers with round one of the survey

In these surveys, you will be asked to act as quality assurers to help refine strategies in terms of its authenticity, usability and relevance. The draft strategy was developed by the researcher from a list of conclusion statements and problems identified in the first phase of the study that investigated grandparents caring for AIDS orphans ,multidisciplinary health workers, and social development personnel on the knowledge, challenges encountered by grandparents caring for AIDS orphans in their caring role.

Instructions: The questions can be answered with only a single selection, a space is also provided for you to comment on the underlying reasons for your responses. In formulating your responses, you are not expected to assess the feasibility or cost of data collection for the indicators.

Once l have received responses from all panellists, I will collate and summarise the findings and formulate the second questionnaire. You should receive this in the next two weeks. I assure you that your participation in the survey and your individual responses will be strictly confidential to the research team (supervisor and statistician) and will not be divulged to any outside party, including other panellists.

SECTION A

4. This section asks questions about your social demographics. Mark X on the appropriate column on the right hand side. 1. Area of Specialty

Public health	
Nursing (CHC/ Clinic Management)	
Social development management	
NGO management	
Lecturer	
Other	

5. Gender

Male	
Female	

6. Working experience

Below 10 years	
10 -19 years	
20- 29 years	
30 years and above	

……

SECTION B

This section seeks your input on the ways to enhance support given to grandparents caring for AIDS orphans in Western Cape . Kindly assess the vision, mission and value statements, as well as the objectives and functional tactics for their relevance, authenticity, and usability.

Choose from the response indicators on a Likert scale of four where: 4= Excellent; 3= Very good; 2= Good; 1=Poor.

B.1: This section asks questions about the vision statement for the strategy

Previous Vision Statement: “Vision : — A healthy lifestyle to all grandparents caring for AIDS orphans

New vision statement : A healthy lifestyle to all grandparents caring for AIDS orphans through a holistic care and support .

Variable	Excellent	Very good	Good	Poor
1. Is the vision statement logic and convey a sense of direction to members of the organization.				
2. It is extensive enough to serve as an axis point for the organization				
3. It is inspiring and uplifting to everyone involved to work toward a common state and a set of goals				
4. It is easy to communicate and motivates members of the organization				

Use the section below to kindly answer the following questions on vision statement.

5. Give reasons for your scores in the section on vision statement just completed

---

---

6. What would you want included in the section?

---

7. Why do you want item 6 above included?

B2: This section asks your opinion on the mission statement for the Multidisciplinary team

Mission Statement: “To provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity from participation of stakeholders and through excellence in multidisciplinary health care practice .

A mission statement is a durable statement of the exceptional purpose of an organization that differentiates it from similar ones. It describes the comprehensive purpose for which an organization exists. (Pearce & Robinson, 2000). The mission identifies the present scope of the organization's operations in terms of its present capabilities, customer focus, activities, makeup, product, market, and technology. It provides answers to the questions: "Who are we?" and "What do we do?" A mission statement embodies the philosophy, values, identity, character and priorities of an organization, and also reflects the image the organization wants to project. A mission statement is not about measurable targets, but is rather a statement or intent, attitude, outlook and orientation (Ehlers & Lozengy, 2010; Peace & Robinson, 2000).

Furthermore , good mission statement summarises an organization’s unique and enduring reason for being and motivates stakeholders to pursue common goals. The mission statement answer the following questions:” What is our business? ; Why do we exist? ; and What are we trying to accomplish? (Suno, 2010).)

Variable	Excellent	Very good	Good	Poor
8. It is unique to the statements on grandparents caring for AIDS orphans and multidisciplinary team.				
9. It is realistic: describe the comprehensive purpose of which the organization exists				
10. It is current and does not have to be changed often.				
11. It is clear and focused.				
12. It is concise: short, snappy and possible.				
13. It is short and has emotional appeal				
14. It is memorable: People can see and remember it.				

Use the section below to kindly answer the following questions on mission statement.

15. Motivate for your scores in the section on mission statement just completed.

16. What would you want included in the mission statement?

---

17. Why do you want item 16 above included?

This section asks questions about the value statement for the multidisciplinary team

- PREVIOUS VALUESTATEMENT : "Maintenance of professional ethics through Participation, Respect and kindness, Integrity in practical assistance ,involving Family and community-based care, Strengthening existing resources, Developing on locally appropriate practices ,Consideration of gender and providing Quality care.
- CURRENT VALUE STATEMENT :Maintenance of professional ethics through participation , respect and kindness, integrity in practical assistance ,involving family and community based- care ,strengthening existing resources, developing on local appropriate practices, consideration of gender ,providing quality care through empath and advocacy .

Variable	Excellent	Very good	Good	Poor
18. It captures the culture of the organization in terms of ethics and non- discrimination based on race culture or gender.				
19. It describes the guiding principles.				
20.It contains organizational culture.				
21. It describes expectation of staff				

22. It describes the ethics and morality and integrity, trust and excellence in practice				

Use the section below to kindly answer the following questions in your own words.

23. Give reasons for your scores in the section on value statement just completed.

---

24. What would you want included in the section on value statement?

---

25. Why do you want item 24 above included?

B.4: This section asks questions about the principles of the multidisciplinary team health workers .

- ❖ Principles: Facilitate health and social support system plans with GPCFAO and their families in order to assist them in finding connections with the rest of the community and their families.
- ❖ Develop community awareness programmes on the needs of GPCFAO

According to the identified problems, the support programmes may include a holistic focus on:

- ❖ Training and skills development for teenagers
- ❖ Practical assistance (such as accessing identity documents or social grants)

- Counselling, HIV testing and treatment assistance and psychosocial support of GPCFAO and infected children
- Nutritional support programmes
- Economic strengthening activities

Variable	Excellent	Very Good	Good	Poor
26. It meets the target satisfaction.				
27. It Involves all concerned (grandparents caring for AIDS orphans and MDT staff).				
28. It is multi-sectoral (able to sustain partnership coordinate care).				
29. The method of governance is transparent, accountable to all concerned.				

Use the section below to kindly answer the following questions in your own words.

30. Give reasons for your scores in the section on principles just completed.

---

31. What would you want included in the section on principles?

---

32. Why do you want item 31 above included?

B.5: This section asks questions about the objectives, functional strategies developed to improve support given to grandparents caring for AIDS orphans by the multidisciplinary team.

To answer the following questions, kindly refer to page 21-38 of the draft strategic document sent to you. This is to reduce the bulky nature of the questionnaire.

Objective 1	Functional strategies			
Variable	Excellent	Very good	Good	Poor
33.It is specific, concrete, detailed and well defined.				
34.It is measurable in terms of numbers and quantity				
35. It is achievable: feasible and actionable				
36.It is realistic considering resources.				

Use the section below to kindly answer the following questions in your own words.

37. Give reasons for your scores in the section on objective 1 just completed.

---

38. What would you want included in the section on objective 1?

---

39. Why do you want item 38 above included?

Objective 2	Functional strategies			
Variable	Excellent	Very good	Good	Poor

40. It is specific: concrete, detailed, well defined.				
41. It is measurable: in terms of numbers & quantity.				
42. It is achievable: feasible & actionable.				
43. It is realistic: considering resources available.				

Use the section below to kindly answer the following questions in your own words.

44. Give reasons for your scores in the section on objective 2 just completed.

Objective 3	Functional strategies			
Variable	Excellent	Very good	Good	Poor
45. It is specific: concrete, detailed, well defined.				
46. It is measurable: in terms of numbers & quantity.				
47. It is achievable: feasible & actionable.				
48. It is realistic: considering resources available.				

Use the section below to kindly answerer the following questions in your own words on objective 3.

49. Give reasons for your scores in the section on objective 3 just completed.

---

50. What would you want included in the section on objective 3?

---

51. Why do you want item 50 above included?

Objective 4	Functional strategies			
Variable	Excellent	Very good	Good	Poor
52. It is specific: concrete, detailed, well defined.				
53. It is measurable: in terms of numbers & quantity.				
54. It is achievable: feasible & actionable.				
55. It is realistic: considering resources available.				

Use the section below to kindly answer the following questions in your own words.

56. Give reasons for your scores in the section on objective 4 just completed.

---

57. What would you want included in this section on objective 4?

---

58. Why do you want item 57 above included?

Objective 5	Functional strategies			
Variable	Excellent	Very good	Good	Poor
59. It is specific: concrete, detailed, well defined.				
60. It is measurable: in terms of numbers & quantity.				
61. It is achievable: feasible & actionable.				
62. It is realistic: considering resources available.				

Kindly use the section below to answer the following questions in your own words.

63. Give reasons for your scores in the section on objectives just completed.

---

64. What would you want included in the section on objectives?

---

65. Why do you want item 64 above included?

THANK YOU FOR YOUR QUICK RESPONSE TO THIS QUESTIONNAIRE

APPENDIX 16: DAFT STRATEGIC DOCUMENT

DRAFT STRATEGIC DOCUMENT TO DELPHI PANELLIST ON STRATEGIES TO IMPROVE SUPPORT GIVEN TO GRANDPARENTS CARING FOR AIDS ORPHANS IN THE WESTERN CAPE PROVINCE, SOUTH AFRICA.

BY

STUDENT : FURAHA AKIMANIMPAYE

STUDENT NUMBER : 2414761

SUPERVISOR: PROF D. PHETLHU

CO – SUPERVISOR :DR M.BEMEREW

Table of Contents

9 BACKGROUND OF THE STUDY

AIDS is amongst the leading causes of death in the world especially in Sub-Saharan countries, with South Africa amongst the highest burdened country reaching 7.52 millions of people living with HIV (SA stats, 2018). One of the dire consequences is that young people are dying leaving behind elderly people to care for their children with limited resources, hence impacting on their economic, social, physical and psychological health (Embleton et al.2014).

This is mainly caused by the fact that elderly themselves may have developed care needs from the aging progression and also associated with depletion of their resources (Mutepfa, Mpofu &Cumming, 2015). In response to the needs and rights of AIDS orphans in the world and in South Africa, support systems have shifted from its initial focus of orphanages to foster families as primary caretakers of AIDS orphans (Kidman &Thurman, 2014).

However, most research conducted on this topic argues that caring for AIDS-orphaned children adds serious strain on caregivers and households due to higher dependency burdens (Kidman & Thurman, 2014; Casale et al.2015 & Shaibu, 2013).

Amongst others, caring for a dependent child comprise a variety of undertakings, including attending to their medical, financial and emotional needs. Essentially, AIDS orphans often have special needs that intensify demands on the caregiver , they are more likely to be HIV infected, to experience bereavement and AIDS-related stigma and to have emotional and behavioural problems (Kidman

&Thurman,2014) This situation can be even worse when caregivers are grandparents who in most cases are in their twilight years.

In South Africa, although the prevalence of HIV is low amongst older persons, their homes, physical, mental and social wellbeing are being affected by the increased AIDS related morbidity and mortality in their family (Nyberg et al.,2012 & Sherr et al.,2014). This is caused by the alarming increasing morbidity and mortality rate of AIDS associated illnesses amongst the younger generation, leaving older people to provide care to the orphans left behind instead of being cared for themselves (Munthree & Maharaj 2010). It is more so crucial since the country has an advanced HIV and AIDS epidemic contributing to the continued rising orphans' rates in communities, prompting the country to be counted amongst the highest burdened countries in the world (Embleton et al., 2014).

Evidence shows that grandparents are becoming the main bearers of the burden of caring for those infected and affected by AIDS, leading to them becoming the most suitable primary caretakers of the sick and orphaned grandchildren (Backhouse & Graham, 2013). Besides, raising grandchildren on a full-time basis is expected from most grandparents after the death of their children. However, grandparents are not afforded the time to adjust to this transition and to deal with their own emotions due to their own loss prior to assuming the role of caregiver, therefore this can result in emotional strain (Phetlhu & Watson, 2014).

Literature shows that caregiving duties add pressure to the over-burdened grandparents with emotional, physical and nutritional stresses, limited resources, limited support and their already compromised health due to old age (Ogunmefun, Gilbert, & Schatz 2011). Furthermore, this responsibility increases tension to their general wellbeing, thus triggering a growing need to improve the support given to them when caring for AIDS orphaned children.

Therefore government working in the cooperative commitment of and Non-Government Organizations (NGO's) seeks to strengthen the existing commitments and efforts to create a supportive environment for the affected orphans. Hence, government developed a system of social assistance which includes a

number of social grants aimed at supporting households in caring for AIDS orphans, and included foster families in the policy because they were identified as the most effective and appropriate support system (Hearle & Ruwanpura, 2009).

However, the current policy, particularly in South Africa (The Children's Act 38 of 2005), is not supportive to the grandparents' plight as they cannot be compensated as foster parents, but rather they are considered as the natural parents who possess the duty of caring after orphans following death of their parents.

The primary reason is that there are stringent eligibility requirements placed on these foster grants and this problem is embedded in the legal obligation for a grandparent as sole parent after the death of their own child (Children's Act 38 of 2005). According to the policy, a primary caregiver is a person who has formal or informal parental responsibility or the right to care for AIDS orphans and who exercises that responsibility and right (Goodman, 2012 , Tshoose, 2010).

According to Saldulker (2012), the government placed stricter judgement and more explicit boundaries for which kinds of relatives should be eligible to receive state support to provide care to children through the foster care system.

In order for a child to be eligible to receive a foster care grant, the government stated that it is compulsory to ensure that the child's caregivers doesn't already have a legal "duty of support" to the child. The government interprets South African law relating to the duty of support thus:

Biological parents of children, whether married or unmarried, have a duty of support.

Adoptive parents are considered the parents of a child once the adoption is concluded, and have a duty of support. Both maternal and paternal grandparents, regardless of whether the mother and father were married, have a duty of support. Siblings have a duty of support but Aunts and uncles bear no responsibility to support their nieces and nephews (Saldulker, 2012).

According to the South African law since 2012, qualified families caring for AIDS orphans are entitled to a foster care grant (Hall, Skelton & Sibanda, 2016). The budget speech (2019) from Finance Minister Tito Mboweni confirms that foster families are provided with a grant of R 1000 per month which is usually paid out until the child turns 18 years old. However, if the child is living with a disability, the foster family can get an additional care dependency grant of R1780. This is in spite of the fact that these foster parents are often at the age where they are economically active and gainfully employed.

Grandparents caring for AIDS orphans only qualify to receive the child support grant of R 425 and not a foster grant. Hence, the grandparent's old age pension money of R1695 per month (Budget speech, 2019) intended for their own personal wellbeing is then used to care for their grandchildren as the child support grant is little as compared to the foster grant. The scenario is worse when the grandparent caring for AIDS orphan is under the age of 60 and unemployed, as they only qualify for the child grant and not the pension grant.

Child Support Grants may alleviate some of the burden associated with caring for an orphaned child, yet to compound the matter further, grandparents may be eligible for this child support grants but It may be difficult to obtain the grant due to the need to supply the child's birth certificate, the caregiver's identification documents, or the parents' death certificates, which may not be readily available if they were not registered with the government's Department of Home Affairs (South African Government Services ,2013).

It is argued that grandparents caring for their grandchildren experience complicated administrative procedures which make it difficult for them to access the above mentioned social grant allocated to foster families (Breckenridge et al.,2019)

Although , one of the Government key strategy is to reinforce and support the capacity of families caring for AIDS orphans by developing comprehensive, integrated and a quality response for AIDS orphans , grandparents caring for AIDS orphans remain invisible in despite them being the major primary caregivers to most AIDS orphans, which consequently hinders their holistic wellbeing.

According to Mutemwa and Adejumo (2014),

there is evidence that grandparents are trying hard to gain access to services provided by government and NGO's, however, misguided beliefs and attitudes serve to exclude older people from developmental programmes that could help them and the children they support.

Therefore , this implicate heavily their health, causing long term complications on their health system (Wild & Gaibie ,2014) .Thus ,since it is imperative for the grandparents to have a good quality of health, the researcher investigated their experiences when dealing with AIDS orphans, their needs and how they deal with the challenges of caring for these orphans. Consequently, the researcher explored the biophysical, psychological, physical, environmental and sociocultural impact on grandparents caring for AIDS orphans in the Western Cape Province.the study focused mainly on this growing phenomenon of families headed by grandparents with little or no support in most South African communities since most of them are often dependent on pension pay-outs for their livelihood.

6. Research problem

Grandparents are often the primary caregivers of AIDS orphans and they experience problems while providing care to these children. Such problems include physical (such as body pains and backache), socio- cultural (such as stigma and discrimination), psychological (such as anxiety and depression, stress and feeling of inferiority), physical environment (lack of houses) and inadequate financial resources to meet orphans' needs (Boon, James, Ruiter, van den Borne, Williams, & Reddy, 2010; Wild & Gaibie ,2014).

In South Africa, there is insufficient documented evidence of available sustainable approach to support grandparents caring for AIDS orphans in all the health dimensions (biophysical, socio- cultural, psychological, physical environment and health system) despite the effort made by some researchers worldwide and in South Africa (Kidman & Thurman, 2014).

Hence there is a need to conduct a study focusing on their experiences so as to understand their needs, challenges and their coping mechanisms as they care for AIDS orphans. Although a support structure has been put in place with regards to foster care, it is not attainable by all grandparents who often experience complicated administrative processes and are seen as natural parents who do not qualify to access the foster care grant. There are no strategies available to assist in ensuring that grandparents are adequately supported in their role as primary caregivers.

7. Purpose of the study

The purpose of the proposed research is to develop strategies to improve support given to grandparents caring for AIDS orphans in the Western Cape Province of South Africa. dimensions model of community health nursing which is a revision of the previously titled epidemiologic prevention process model (Clark 2003) was used as a framework to explore the experience of grandparents caring for AIDS orphans ,to determine the available support for them as well as their perception on the availability of the support given to them and to compare their perception of availability of support with the available support for them. Based on the findings of this phase ,conclusion statements were developed based on the identified problems. Five objectives were developed through this method ,this was followed by functional strategies aimed at addressing the objectives. These strategies if accepted as good enough by the panellist selected for this second phase, then they will have ability to improve support given to grandparents caring for AIDS orphans in Western Cape Province ,South Africa.

8. Summary of Phase One

This is the second of a two phase study aimed at developing strategies to improve support given to grandparents caring for AIDS orphans in Western Cape Province. The first phase explored the experienced of grandparents caring for AIDS orphans and determined the support given to them .

ninety (90) respondents that comprised of 25 grandparents caring for AIDS orphans , 50 multidisciplinary team (professional nurses ,social workers and psychologists) , and 15 social development personnel were explored using a mix-method approach.

The empirical findings are reported in the table below in the form of problem identified and concluding statements.

Table 1: Problem identified and conclusion statements

Biophysical	**Psychological**	**Social cultural**	**Behavioural**	**Physical environm**
1.GPCFAO are continuously rendering care to orphans without help which is physically demanding and exhausting, hence increasing risk of health problems. (CS:6.1.4) 2. Due to caregiving duties, GPCFAO neglect their own health, and minimise the severity of their health conditions and	1.Frustration and hopelessness from GPCFAO who are taking care of teenagers for teenagers due to orphan's misbehaviours. And they lack skills to deal with teenager's deviant behaviours. (CS:6.1.6.1, Paragraph 1) 2.. GPCFAO are facing stigma problems in their communities and in their families affecting them emotionally. 3.PostTraumatic Depression (PTD) to GPCFAO who cared for their terminal ill children and witnessed	1.Inadequate financial support given to GPCFAO which make it difficult for them to meet the basic needs for AIDS orphans in their care, and make it difficult to maintain good health for GPCFAO and for infected children which might increase opportunistic infections amongst HIV/AIDS infected children. (CS 6.1.1.). 2.There is a problem of NGO'S that are no longer providing assistance to GPCFAO due to scarcity of funds (CS:6.1.6.5)	1.GPCFAO lack adequate skills to deal with orphan's deviant behaviours (CS 6.1.6.2) 2.Irresponsibility of the biological parents who are still alive but abusing GPCFAO by not assisting them to take care of their own children which affect GPCFAO holistically. (CS: 6.1.6.4) 3. GPCFAO don't trust government, they think that government doesn't care about their problems. 4. No hope for the future amongst some	1.Overcrowding in which can lead infectious diseases (CS :6.1.3) 2.Lack of transport problematic for gra access clinics (CS:

delay seeking medical attention which affect their overall health (CS :6.1.5, Paragraph 2). 3. GPCFAO are not coping with caregiving duties, and are exhausted due to no physical support (CS 6.1.4)	their death and have to care for their AIDS orphans. (CS 6.1.6. Paragraph one) 4. GPCFAO are constantly worried and stressed about their grandchildren's future 5. GPCFAO experience fear of being discriminated which lead them to live a lonely life and they are scared to request help which affect the overall health (CS:6.1.5.3). 6. GPCFAO are forgotten by the rest of the community, they are living alone life without support causing them to isolate themselves socially resulting in emotional breakdown. (CS 6.1.5) 7. GPCFAO are hopeless in their situation of caring for the orphans due to challenges they are faced with no resources. (CS:6.1.6; Paragraph 2; CS 6.1.6.1) 8. There is a problem of stigma experienced by GPCFAO for having HIV/AIDS	3.There is a problem of GPCFAO who are isolated from the rest of the community and families, affecting their social health. (CS:6.1.5, Paragraph 1) 4.No clear communication between social service personnel and GPCFAO. (6.1.1.1 paragraph 2). 5.GPCFAO are facing extreme poverty and there is lack of strategies to support grandparents caring for AIDS orphans in both health care and social services. 6. The quality of social service is not adequate because of slow process procedure for social grant application. (CS: 6.1.1.1, paragraph 1.) 7. GPCFAO lack of knowledge of the rights of the children in their care and are not aware of	orphans due to school dropout and using substance abuse. (CS 6.1.6.2) 5. GPCFAO a add foster children to their existing AIDS orphans in order to qualify for the foster care grant, thus increasing their responsibilities to care for so many kids which in turn affect their overall health. (6.1.1.1, Paragraph 5)	

	affected children in their care (CS 6.1.6.3)	different types of grants that they can apply for the orphans in their care. (CS:6.1.1.1 paragraph 5) 8. Lack of birth certificate for the orphans which hinder the grant application process. (CS:6.1.1.1 Paragraph 3) 9.Due to intense caregiving duties, GPCFAO are not having social life with their age mate friends and family members, affecting their social health. 10. Pension grant allocated to GPCFAO is not used for its purpose, it used instead to take care of AIDS orphans (CS: 6.1.7) 11. It is very difficult for GPCFAO below 60 years as they don't receive pension grant and		

		most of them are not working (CS :6.1.1.1 Paragraph 1) 12.GPCFAO lack of good wellbeing and support from family members, community churches and social services which affects their overall health. (CS:6.1.2; Paragraph 1) 13. Scarcity of the stable income from GPCFAO to sustain orphans' needs (CS :6.1.7) 14. There is discrepancies in providing foster care grant to GPCFAO in different organizations of social services (CS: 6.1.1.1 Paragraph 5) The grants received by GPCFAO is inadequate to cover all the basic needs including nutritious food for infected orphans, (CS 6.1.1). 15.It is difficult for GPCFAO to access		

		social grants for AIDS orphans in their care (CS 6.1.1.1).		

9. Strategy Development

The strategy to improve the support given to grandparents caring for AIDS orphans (GPCFAO) in Western Cape province , South Africa was developed using a strategic process to develop a vision and mission, identify values, principles and assumptions, and formulate strategic objectives and functional tactics, based on Bryson's (2011) philosophy. Each step of the strategic process that was followed in the development of the strategy to improve support given to grandparents caring for AIDS orphans in Western Cape Province ,South Africa is discussed in this section

9.1 **5.1 Vision**

According to Dess, Lumkin and eisner (2007) ,vision tend to be broad and can be viewed as what the organization could and should look like ,thus , the first step of strategic planning process is to ascertain and develop a strategic vision for the organization because it is an aspirational statement made by an organization that articulates what they would like to achieve ,therefore ,the vision guides the direction of the organization's efforts (Wright ,2014) .

The vision statement responds to the questions :"What do we want to become ?" and "Where do we want to go?" and concentrate on what the organization's long- term direction should be (Suno, 2010).

Therefore , it indicates the direction ; the aim ;the goal and hopes of the organization and structures the organization's identity.

According to Mishe (2000), the most effective visions share six essential qualities:

- Conveys a sense of direction to the organization and gives a sense of direction, a goal and guide to a future state of its existence;
- Establishes a context for operating the organization . Contexts help to define and classify the environment in which the leader and the organization operate;
- Describes a future condition. Effective visions provide a future—state and condition that represents a "better" state than the ones of the past and that exists in the present;
- Motivates people. Leaders understand that effective and meaningful visions provide a high value proposition to others. Those visions that appeal to the instincts, needs and intelligence of people and touch their "soul" serve as a basis for systematic acceptance and motivation;
- Inspires people to work toward a common state and a set of goals; and
- Serves as an axis point for organizational behaviour and performance and provide a central point for focusing the resources of the organization, developing strategy and measuring progress towards the vision.

9.2 5.2 Mission

A mission statement is a durable statement of the exceptional purpose of an organization that differentiates it from similar ones. It describes the comprehensive purpose for which an organization exists. (Pearce & Robinson, 2000). The mission identifies the present scope of the organization's operations in terms of its present capabilities, customer focus, activities, makeup, product, market, and technology. It provides answers to the questions: "Who are we?" and "What do we do?" A mission statement embodies the philosophy, values, identity, character and priorities of an organization, and

also reflects the image the organization wants to project. A mission statement is not about measurable targets, but is rather a statement or intent, attitude, outlook and orientation (Ehlers & Lazenby, 2010; Peace & Robinson, 2000).

Furthermore , good mission statement summarises an organization's unique and enduring reason for being and motivates stakeholders to pursue common goals. The mission statement answer the following questions:" What is our business? ; Why do we exist? ; and What are we trying to accomplish? (Suno, 2010).)

Therefore ,to develop a vision and mission for the Multidisciplinary health workers in the Western Cape Province , the researcher inspected the two main stakeholders in the provision of health and social services in Western Cape Province, as represented by the health department (DOH), and the social development department .

The vision of the Department of Health is: A long and healthy life for all South Africans and the mission to improve health status through the prevention of illness, disease and the promotion of healthy lifestyles, and to consistently improve the health care delivery system by focusing on access, equity, efficiency, quality and sustainability.

The vision of social development department is :A caring and self-reliant society and has the mission to transform the society by building conscious and capable citizens through the provision of comprehensive ,integrated and sustainable development services.

Considering that grandparents caring for AIDS orphans are considered amongst disadvantaged group ,often experiencing the multiple burden of poor living conditions, weak social network and unhealthy lifestyle (refers to concluding statements) instigated the researcher to make an attempt of developing a strategy to enhance the support given to grandparents caring for AIDS orphans in the Western Cape

province , thus ,the following vision was formulated as stated in the subsequent paragraph. The vision for the multidisciplinary health workers in the clinics and communities health centre of western cape province , South Africa was developed from elements of each of the above-mentioned stakeholders' vision , as well as from the research findings (refer to concluding statements).

Vision : — A healthy lifestyle to all grandparents caring for AIDS orphans

Mission :To provide holistic care and support to grandparents caring for AIDS orphans through strengthening their caring capacity from participation of stakeholders and through excellence in multidisciplinary health care practice .

9.3 5.3 Values

Values are freely chosen, enduring beliefs or an attitude towards a person, object, idea or action. It represent a way of life, give direction to life, and form the basis of behaviour, especially behaviour that is based on decisions or choices (Burns & Grove, 2014). In an organization, values dictate the way that decisions are made and embody what the organization stands for. Values influence the policies, the type of competitive advantage sought, the organization structure, systems of management, the strategies and the functional tactics of the organization (Thompson & Strickland, 2001). It is therefore important to attempt to understand the values that are common to the multidisciplinary team within the clinics and communities health centre in Western cape province ,South Africa. Hence, in order to accomplish the above vision and mission the following values are central and drive this strategy:

- Participation
- Respect and kindness
- Integrity in practical assistance
- Family and community-based care

- Strengthen existing resources
- Develop on locally appropriate practices
- Consideration of gender
- Strategic leverage and prevention
- Quality care

9.4 5.4 Principles

Principles refer to an accepted or fundamental basis of conduct, action or management for application in action (Dictionary.com, 2004; Thesarus, 2002). Therefore, for the assurance purpose that the principles for the strategy to enhance support given to GPCFAO are common and applicable to their need, in order to provide a holistic support for GPCFAO, the researcher formulated her own principles from identified problems in phase one of the study, together with the reference of the study framework. Thus, they provide strategic direction for policy and programme formulation as well as developing special programmes for GPCFAO. Hence, the focus areas are aligned with the study framework which have been outlined in the previous sections.

9.4.1 5.4.1 Formulated principles to enhance support given to GPCFAO

According to the study results, GPCFAO are struggling to cope emotionally and socially (see concluding statements). Therefore, it is extremely important to their wellbeing to be provided with psychosocial support within families and communities, as these are the people who have regular and direct contact with the GPCFAO and the orphans under their care.

Formulated principles that are applicable to the study includes:

- Facilitate health and social support system plans with GPCFAO and their families in order to assist them in finding connections with the rest of the community and their families.

- ❖ Develop community awareness programmes on the needs of GPCFAO

According to the identified problems, the support programmes may include a holistic focus on:

- ❖ Training and skills development for teenagers
- ❖ Practical assistance (such as accessing identity documents or social grants)
- ❖ Counselling, HIV testing and treatment assistance and psychosocial support of infected children
- ❖ Nutritional support programmes
- ❖ Economic strengthening activities

The following table represents the application of the value and principles of health care workers and social services to the strategy to enhance support given to GPCFAO in the Western Cape province, South Africa.

Values	**Application of values**
Participation	All clinics and CHC (Communities health centres) must use MDT participatory appr for AIDS orphans are involved in identifying their needs, planning, facilitating and
Respect and kindness	Support and care may be provided simply by changing the way MDT health grandparents caring for AIDS orphans. This is about showing respect and kindness the dignity of grandparents caring for AIDS orphans
Integrity in practical assistance	Integrity is the quality of a person who can be counted on to give precedence and adl principles, even when there is strong inducement to pursue self-interest or personal Shahriari, Mohammadi, Abbaszadeh, & Bahrami, 2013). It is therefore expected tha social services personnel possess integrity so as to gain the confidence and trust fro

Family and community-based care	Encourage the use of the family and community approach which supports GPCF family and their community environment.
Strengthen existing resources	Develop skills but from strengths, by acknowledging the existing knowledge, skills a brings to each situation.
Develop on locally appropriate practices	Research and strengthen locally appropriate ways of supporting grandparents caring is not encountering resistance to practices which are considered foreign. GPCFA traditional approaches rather than unfamiliar ways of receiving support.
Strategic leverage and prevention	Influence the live of GPCFAO more broadly and include a focus on prevention o alleviation of suffering. This principle must include consideration of the "Do n intervention with GPCFAO as foundational principles for all interventions.
Quality care	MDT team in all clinics and CHC must maintain professional ethics through hu confidentiality, and cultural sensitivity.
Consideration of gender	Be gender sensitive when providing support and recognise that the needs of grandpa from those of grandparent's men.

9.5 **5.5 Strategic objectives**

Objectives are plans aimed at achieving a goal (SUNO,2010).objectives can be classified as long term and short term objectives .the long objectives are the statements that are made to indicate the results that the programme seek to achieve over a period of time (Pearce & Robinson ,2000).furthermore , in strategic process ,strategic objectives are the long term goals that are determined in line with the managements' vision and reflect the organization's direction on a high level (SUNO,2010).

In this study, the aim for development of a strategy was to enhance the support given to GPCFAO in Western Cape province, South Africa. The strategic objectives were determined in line with the vision, Mission, value, principles and assumptions of the strategy to enhance support given to grandparents caring for AIDS orphans in Western Cape Province, South Africa and were based on the forty (40) identified problems from the empirical research and literature review in phase one of the study.

These problems were clustered together to develop six strategic objectives through deductive and inductive logic, to enhance support given to GPCFAO in Western Cape Province, South Africa.

The long-term objectives focused on GPCFAO development, Service delivery and family and community responsibilities. These objectives had to be acceptable, flexible, measurable, motivating, sustainable, achievable and understandable. A table was developed to place these factors in Matrix for ease of tracing and monitoring over a period of time. A time frame is set, in that a marked improvement in supporting GPCFAO in at least one year of the implementation of the strategy is expected.

The five strategic objectives to enhance support given to GPCFAO in Western Cape Province, South Africa are presented in table below , each strategy objective is stated with the identified problem/concluding statements(se e table 7.1.6) from the empirical research serving as the evidence base.

Objective	Problem identified/Evidence
1. To Develop more supportive relationships between GPCFAO and AIDS orphans in their care.	GPCFAO who are taking care of teenagers are frustrated and hopeless due to teenagers' misbehaviours and GPCFAO lack skills to deal with their deviant behaviours. (CS:6.1.6.1, Paragraph 1)
2. To provide emotional support to GPCFAO through the grief process and stigma issues in their communities and promote self - care amongst GPCFAO.	❖ GPCFAO who cared for their terminal ill children and witnessed their death suffer from Posttraumatic Depression (PTD).CS 6.1.6. Paragraph one ❖ GPCFAO are facing stigma problems in their communities and in their families affecting them emotionally. ❖ Posttraumatic Depression (PTD) to GPCFAO who cared for their terminal ill children and witnessed their death and have to care for their AIDS orphans. (CS 6.1.6. Paragraph one) ❖ GPCFAO are constantly worried and stressed about their grandchildren's future. ❖ GPCFAO experience fear of being discriminated which lead them to live a lonely life and they are scared to request help which affect the overall health (CS:6.1.5.3).

3.To Strengthen economic programmes that would protect GPCFAO against abuse and exploitation.	❖ GPCFAO are hopeless in their situation of caring for the orphans due to challenges they are faced with no resources. (CS:6.1.6; Paragraph 2; CS 6.1.6.1) ❖ There is a problem of stigma experienced by GPCFAO for having HIV/AIDS affected children in their care (CS 6.1.6 ❖ Inadequate access to essential social and health care services and experience lack of social and community support ❖ GPCFAO are facing extreme poverty and there is lack of strategies to support grandparents caring for AIDS orphans in both health care and social services. ❖ The quality of social service is not adequate because of slow process procedure for social grant application. (CS: 6.1.1.1, paragraph 1.) ❖ GPCFAO lack of knowledge of the rights of the children in their care and are not aware of different types of grants that they can apply for the orphans in their care. (CS:6.1.1.1 paragraph 5) ❖ Lack of birth certificate for the orphans which hinder the grant application process. (CS:6.1.1.1 Paragraph 3)
4.To establish and enabling health care and social services environment that focuses on the needs of GPCFAO and the orphans in their care through improving psychosocial services by involving and offering sensitive services to GPCFAO.	❖ There are no counselling services available to help GPCFAO to cope with their emotional challenges. (CS:6.1.6.5) ❖ There is a problem of accessibility to the clinics for the GPCFAO who stays far from the clinics, they have to walk far with children which is tiring for them and affect their health.CS:6.1.8) ❖ Hostile attitude from health care workers preventing GPCFAO from expressing themselves. (CS: 6.1.8) ❖ MDT don't go extra mile in recognizing and supporting GPCFAO.

	❖ Lack of involvement of MDT in providing holistic care and support to GPCFAO in the clinics (CS:6.1.8) ❖ Long waiting period before doctor consultation for GPCFAO who are not club members (CS: 6.1.8)
5.To develop support programme for GPCFAO that focuses on holistic care through locally appropriate community- and family-based psychosocial support programmes and through promoting policy development in health care and social services that would maintain a focus on the holistic wellbeing of GPCFAO.	❖ GPCFAO are continuously rendering care to orphans without help which is physically demanding and exhausting, hence increasing risk of health problems. (CS:6.1.4) ❖ Due to caregiving duties, GPCFAO neglect their own health, and minimise the severity of their health conditions and delay seeking medical attention which affect their overall health (CS :6.1.5, Paragraph 2). ❖ GPCFAO are not coping with caregiving duties and are exhausted due to no physical support (CS 6.1.4) ❖ GPCFAO are forgotten by the rest of the community, they are living alone life without support causing them to isolate themselves socially resulting in emotional breakdown. (CS 6.1.5)

9.5.1 **5.5.1 Functional Strategies**

After developing objectives, it is important to put measure in place for its implementation. The development of short-term objectives is one of the process through which a strategy may be implemented thus realising the long- term objectives, as the day to day action plans and strategies arising from working to achieve the short-terms objectives can be measured and monitored.

Furthermore, creating short-term objectives assist in implementation of policy through the process of operationalisation of the long- term objectives and the identification of measurable outcomes of the functional actions

In this study, the action plan and functional strategies were developed from the strategic objectives which were based on the forty-one (41) problems identified from the empirical research in order to enable operationalisation and implementation of the strategic objectives. The functional tactics were further applied to the six (9) principles and values to allow monitoring and evaluation of the strategic objectives. Furthermore, the functional tactics were also based on comprehensive theory of collaboration (CTC), which involve working in partnership amongst all the key players.

Table … Functional plans and Strategies

STRATEGIC OBJECTIVES	FUNCTIONAL STRATEGIES
1. To Develop more supportive relationships between GPCFAO and AIDS orphans in their care.	the results show that grandparents are the main caregivers of AIDS prefer to live with their them after the death of their parents rather as they generally feel that their grandparents provide more love relatives (Help age ,2004).In caring for their orphaned grandchildre their orphans grandchildren grow up together as a family group, rat or separated from each other in different families. However, as with all parenting relationships, this is not always reasons, including the large generation gap, GPCFAO struggle understanding into their relationships with their orphans' grandchil be supported in their caring roles. The support would include the fo ❖ Social services should start parenting skills programme and build a caring relationship between GPCFAO and the child the best foundation for addressing such issues.

	❖ Social workers must visit the homes of GPCFAO for s identification of caregiving problems and address the proble ❖ Develop counselling programs to educate and support both Orphans in their care. ❖ Start funded child care services, after school and holidays p orphans to socialise with others children and stimulate their ❖ Start afterschool programs to support orphans with their hor to reduce the number of orphans failing and dropping out o ❖ youth programs that would teach them the influence of pee them away from using drugs and alcohol as well as gang ac
2. To provide emotional support to GPCFAO through the grief process and stigma issues in their communities and promote self - care amongst GPCFAO.	2.1 GPCFAO suffer grief, shock and sometimes trauma after t children. It is especially difficult for the GPCFAO if they have lost s short space of time. The experiences of grief and the worries al difficult for the GPCFAO to cope with caring for the orphan's child Grief is the normal and necessary emotional reaction to the death emotional suffering that people feel when someone that they (Thogomelo,2009). As a response to loss, GPCFAO feel frightening sadness, shock, and guilt. While these feelings can be frigh overwhelming, they are normal reactions to loss. Also , such react time (sometimes many years), and it is important not to rus Thogomelo,2009)

Therefore, providing emotional support to grieving GPCFAO is hi
key strategic focus area of any policies and programmes.

- Emotional support to help GPCFAO deal with the loss ,st
  should be facilitated through:
- Raising an awareness about HIV/AIDS in the local commu
  and stop the stigma associated with it through the producti
  ,dramas ,booklets and posters and also involve GPCFAO by
  community educators.
- Social service should initiate and facilitate support groups o
  communities where they can open up and share their experi
- Healthcare centres should start care plans aiming to sup
  will include holistic screening
- Provide counselling to GPCFAO and the orphans left behin
- Provide and facilitate the opportunities to say goodbye to
  by supporting them with the funeral arrangement .
- Provide and encourage spiritual support
- Facilitate with t their traditional bereavement rituals if nece
- It is also important to consult GPCFAO about what they w
  honouring the memory of their loved ones.

3.1 Financial stress was labelled as the main source of challenge th
in their caring role. Therefore, GPCFAO should be included in gov
planning programmes.

3. To strengthen economic programmes that would protect GPCFAO against abuse and exploitation.	Economic programmes should include a focus on: ❖ Pensions, childcare grants, school fee remission and foster c ❖ Transport, health care and other subsidies for all older peop ❖ Encourage and support sustainable livelihoods and incom GPCFAO such as funding small business in their communit ❖ Encouraging the extended families of GPCFAO to suppo offer them donations of material goods, such as school uni orphaned children. ❖ Support GPCFAO to access identity documents and b orphans in order to access resources such as social g GPCFAO to meet households cost including food . ❖ Involve GPCFAO by starting an outreach committee compr promoters and social workers targeting GPCFAO and ensu GPCFAO are identified and supported. ❖ Provide transport from and to the clinics to care for sick ch 3.2 Also, Abuse and exploitation are often a result of extreme stress study results shows that GPCFAO faces high level of poverty, henc the most vulnerable members of the society. Therefore, GPCFAO, in their care have rights and entitlements that need to be protected. that they are often not aware of their rights, and even when they are feel that they can do little to protect or realise their rights. Hence, t may be promoted to prevent GPCFAO from being exposed to abus for them in situations of abuse: ❖ Provide information about rights and entitlements, including that provide protection, such as government funds, pensions and provide assistance with the procedures. ❖ Secure correct documentation so that they can access the ne ❖ Inform GPCFAO about protective agencies that they may n specific assistance

4. To establish and enabling health care and social services environment that focuses on the needs of GPCFAO and the orphans in their care through improving psychosocial services by involving and offering sensitive services to GPCFAO.	❖ Assist GPCFAO to protect the property rights of the childre ensuring that they are well informed about their own and th how to protect them. ❖ Advocate for paralegal services so that GPCFAO and their access legal support and advice when necessary ❖ Provide counselling and guidance to affected t GPCFAO ❖ Assist by accompanying GPCFAO to health facilities, socia ❖ Assist GPCFAO who have experienced abuse to join suppo ❖ Facilitate community education and awareness on the need children in their care. ❖ Support access to education for AIDS orphans children, esp for school fees exemptions exist ❖ Social workers should visit families headed by GPCFAO to 4.1 Offering psychosocial support to GPCFAO must involve "see their presence where they may have been neglected or invisible i of caring after HIV/AIDS orphans. 4.2 Also, it must involve recognising their psychological and soc healthcare and social service must ensure that GPCFAO receive a way that makes them feel included, valued and supported in all asp 4.3 It is important that GPCFAO feel that they are appreciated and families, communities and the larger society. This requires attentio and support in every interaction with GPCFAO 4.4. Provide everyday psychosocial support by showing care and re MDT heath workers have with GPCFAO so that it builds their dign and brings hope and appreciation even in difficult circumstances. Therefore, the following would be some ideas about how everyda may be provided to GPCFAO:

- ❖ Listening respectfully to GPCFAO when they express their sense of being taken seriously
- ❖ Consulting GPCFAO and those under their care about their ways to support them in having their needs met. This may i their problems until they are resolved and remembering to r dealt with to other service providers.
- ❖ Promoting networks and circles of support around GPCFA are not excluded so as to prevent feelings of loneliness and

4.5 It is also recommended that psychosocial care and support of G with the general public, government service providers and NGO 's way with GPCFAO through:

- ❖ Raising an awareness about the value of treating GPCFAO kindness
- ❖ Encouraging respectful behaviour from all service-provider through the establishment of systems of accountability amo enforce them to interact with GPCFAO in a respectful and
- ❖ Start a consultation processes with GPCFAO about their loc access to services and support.

the results of the study show that GPCFAO neglect themselves due responsibilities which might affect their overall health.

Therefore, Programmes focusing on "care of the GPCFAO" ma Such programmes may involve the following:

- ❖ Assisting GPCFAO to be aware of their limitations and t when they cannot give certain types of help.
- ❖ Helping GPCFAO to structure their time, including rest pe
- ❖ Exploring safe local child-care options to relieve GPCFAC take time out to do leisure or fun activities and to spend quali and their friends.

- ❖ Instigate GPCFAO to ask for help from trusted friends and invest in relationships with others who can become an ong and support.
- ❖ When there are problems in the family or in the communi encourage them to try to talk these through immediately so t these additional stresses.
- ❖ Encourage healthy eating as an important part of their self-c care especially affected orphans who are on ARV medication be supported in how to plan and cook healthy meals using lo effective food.
- ❖ Promote regular exercise in the form of walks in and arou engaging in work that they enjoy around their yard, suc gardening - this can provide good exercise for GPCFAO and eating for them and their orphans.

Furthermore, Self-care programmes may utilise grandparents self-care and healthy living, and enable them to identify locally factors that can be used to strengthen the care of grandparents c

5.1 Holistic wellbeing of GPCFAO would be a sense of feeling con their life and would include the physical, mental, economic, social, parts of our lives which then contribute to their total wellbeing. The support means looking at each GPCFAO holistically, in terms of th rights that each person has in order to achieve overall wellbeing.

5.2 The study results in phase one revealed that GPCFAO are strug problems (see identified problems…), Therefore, if holistic wellbei their lives, it is important not just to focus on grandparents as indiv families, social units and the communities that surround them, and needs are met.

5.3 The circles of support surrounding GPCFAO may be streng appropriate community- and family-based psychosocial support pr an important aspect of holistic care to GPCFAO. And can be done b

support and referrals for specialised care are made possible and en
programming. Therefore, healthcare and social services mu
complement each other to improve the service delivery to G
comprehensive programmes that address different needs and conc
will have a significant and more sustained impact on the holistic we
those under their care.

5.4 Providing psychosocial support to GPCFAO does not mean tha
become an expert in the provision of specialised psychosocial care.
about recognising the psychosocial needs of GPCFAO and linking
other service providers. Examples of grandparents caring for AIDS
require specialised psychosocial support include:

- GPCFAO who are not well connected socially, and who are
  their emotional and social lives because of being disconnect
  and community support.
- GPCFAO who are struggling with multiple losses, for exam
  own children
- GPCFAO who show signs of psychological distress, such as
  anxiety
- Grandparents living with chronic illnesses such as diabetes,
- Grandparents caring for AIDS orphans living in situations o
  harm.

However, the referral of GPCFAO for specialised psychosocial sup
possible through:

- A thorough identification of specialised psychosocial needs
  particularly vulnerable and in need of more intensive psych
  the examples listed above.
- Identify different types of specialised psychosocial support
  programmes which are already operating in the community
  benefit the GPCFAO and those under their care.

	❖ Referring GPCFAO for specialised psychosocial care and fo care. It is therefore recommended that referrals of GPCFAO for special support be promoted with the general public, government service p through: ❖ Awareness-raising about how to identify GPCFAO who ma psychosocial support ❖ Promoting public relations and marketing of existing specia support services and programmes so that people are aware o resources.
5. To develop support programme for GPCFAO that focuses on holistic care through locally appropriate community- and family-based psychosocial support programmes and through promoting policy development in health care and social services that would maintain a focus on the holistic wellbeing of GPCFAO.	Having outlined the importance of referral of grandparents caring f specialised psychosocial support, it is worth emphasising again tha everyday support from a family and community context. This may severe distress, and may be more effective in alleviating suffering t psychological or social assistance. Therefore, where possible, the fa support surrounding all grandparents caring for AIDS orphans shou 5.5 The focus of holistic wellbeing for GPCFAO also should be d and at the national level and the focus on community level should b ❖ To encourage the community to give support to all GPCF For example, the community leadership could encourage challenge discrimination. Also, youth groups or churches c projects to assist GPCFAO to have time to do their shop meetings. ❖ Whereas at national level the laws, policies and programm to include provision of support to all GPCFAO. This may provision of pensions, special grants, school fee exemptions for GPCFAO 5.5. Healthcare (mostly clinics and CHC) and social services shoul organizational holistic support policy for GPCFAO and post it on t

following is a drafted potential organization's policy around holisti
caring for AIDS orphans in Western Cape Province, South Africa:

Organizational policy of holistic care and support for grandpa
orphans

Our organization recognises the valuable role that grandparents car
are playing in caring for orphaned children.

We would like to provide care and support for grandparents caring
the following ways:

- Treating grandparents caring for AIDS orphans with respec
  times
- Listening to their ideas, experiences and needs
- Designing projects together with grandparents caring for AI
  their stress and meet their needs
- Arranging childcare so that grandparents caring for AIDS o
  participate in the activities of our organization
- Visit grandparents caring for AIDS orphans who have lost f
  offering a donation towards the costs of the funeral expense
  funeral programme.
- Setting aside a portion of our annual budget specifically for
  support work of grandparents caring for AIDS orphans
- Prioritising grandparents caring for AIDS orphans when it
  resources that we may have to offer our community partner
- Involve grandparents caring for AIDS orphans in evaluatin
  work on their holistic wellbeing.
- When common issues are expressed by several grandparent
  orphans, we will take these suggestions forward to the relev
  departments to promote change.

REFERENCES

Backhouse, J.,& Graham, A. (2013). Grandparents raising their grandchildren: Acknowledging the experience of grief. *Australian Social Work*, *66*(3), 440-454.

Boon, H., James, S., Ruiter, R. A., Van den Borne, B., Williams, E., & Reddy, P. (2010). Explaining perceived ability among older people to provide care as a result of HIV and AIDS in South Africa. *AIDS care*, *22*(4), 399-408.

Breckenridge, T. A., Black-Hughes, C., Rautenbach, J., & McKinley, M. (2019). HIV/AIDS orphans in South Africa: NGO interventions supporting transitions to alternative care. *International Social Work*, *62*(2), 502-517.

Bryson, J. M., & Alston, F. K. (2011). *Creating your strategic plan: A workbook for public and non-profit organizations* (Vol. 3). John Wiley & Sons.

Casale, M., & Gibbs, A. (2015). Gender differences in sources and availability of social support among South African caregivers of children. *South African Review of Sociology*, *46*(4), 100-125.

Dess, G. G., Lumpkin, G. T., Eisner, A. B., & Vujić, J. (2007). *Strategijski menadžment: teorija i slučajevi*. Data status.

Embleton, L., Ayuku, D., Kamanda, A., Atwoli, L., Ayaya, S., Vreeman, R., ... & Braitstein, P. (2014). Models of care for orphaned and separated children and upholding children's rights: cross-sectional evidence from western Kenya. *BMC international health and human rights*, *14*(1), 9.

Goodman, C. C. (2012). Caregiving grandmothers and their grandchildren: Well-being nine years later. *Children and Youth Services Review*, *34*(4), 648-654.

Hall, K., Skelton, A., & Sibanda, S. (2016). Social assistance for orphaned children living with family. *South African Child Gauge*.

Hearle, C., & Ruwanpura, K. N. (2009). Contentious care: Foster care grants and the caregiver–orphan relationship in KwaZulu-Natal Province, South Africa. *Oxford Development Studies*, *37*(4), 423-437.

Kidman, R., & Thurman, T. R. (2014). Caregiver burden among adults caring for orphaned children in rural South Africa. *Vulnerable children and youth studies*, *9*(3), 234-246.

Mhaka-Mutepfa, M., Mpofu, E., Moore, A., & Ingman, S. (2017). Carer Grandparents of Sub-Saharan Africa. *Grandparents in Cultural Context*, 40.

Munthree, C., & Maharaj, P. (2010). Growing old in the era of a high prevalence of HIV/AIDS: The impact of AIDS on older men and women in Kwazulu-Natal, South Africa. *Research on Aging*, *32*(2), 155-174.

Mishe, M. A. (2000). *Strategic renewal: Becoming a high-performance organization.* New Jersey: Prentice Hall.

Mutemwa, M., & Adejumo, O. (2014). Health challenges of elderly people caring for children orphaned by AIDS in a community setting in South Africa: HIV/AIDS management and care. *African Journal for Physical Health Education, Recreation and Dance*, *20*(Supplement 1), 336-347.

Nyberg, L., Lövdén, M., Riklund, K., Lindenberger, U., & Bäckman, L. (2012). Memory aging and brain maintenance. *Trends in cognitive sciences*, *16*(5), 292-305.

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*(1), 85-102.

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*, *20*(Supplement 1), 348-359.

Saldulker, H., & South Gauteng High Court. (2012). Children's Court Case No: 14/1/4-206/10. *A3056/11*.

Shaibu, S. (2013). Experiences of grandmothers caring for orphan grandchildren in Botswana. *Journal of Nursing Scholarship*, *45*(4), 363-370.

Sherr, L., Cluver, L. D., Betancourt, T. S., Kellerman, S. E., Richter, L. M., & Desmond, C. (2014). Evidence of impact: health, psychological and social effects of adult HIV on children. *Aids*, *28*, S251-S259.

SUNO. (2010). Strategic Planning Handbook and Managers Implementation Tools (Revised). New Orleans.

Tshoose, C. (2010). The impact of HIV/AIDS regarding informal social security: issues and perspectives from a South African context. *Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad*, *13*(3).

Wild, L. G., & Gaibie, F. (2014). Grandparental involvement and South African adolescents' psychological well-being. *Journal of Intergenerational Relationships*, *12*(4), 425-441.

Wright, R. (2014). A cultured vision: an organization's guiding principles can influence the effectiveness of governance activities. *Internal Auditor*, *71*(4), 65-68.

APPENDIX 17: EDIITNG CERTIFICATEI

I & L Editing Services

Exactly what you need

Professional Editing
(37205 certified)

Date: 17 December 2020

CERTIFICATE OF ENGLISH EDITING

This is to certify that the paper with the provisional title "**Developing strategies to improve support for Grandparents caring for AIDS Orphans in the Western Cape Province**", to be submitted by **Furaha Akimanimpaye** (Student Number: 2414761) of the **University of the Western Cape (South Africa)**, has been edited for language by a professional copy editor. Neither the research content nor the author's intentions were altered in any way during the editing process.

I & L Editing Services guarantee the quality of English language in the abovementioned paper, provided our editor's changes are accepted and further changes made to the paper are checked by our editor.

W. Martin
Copy editor

Cape Town, South Africa

ileditingservices@gmail.com /wmartin.trans@gmail.com (+27 82 074 7306)