CARING FOR ADOLESCENTS BY OLDER CARERS IN THE CONTEXT OF HIV COMBINATION PREVENTION INTERVENTIONS IN RURAL KWAZULU-NATAL: AN ETHNOGRAPHIC APPROACH

A thesis submitted in fulfilment of the requirements for the degree of Doctor of

Philosophy (Health Promotion) in the School of Applied Human Sciences
(Discipline of Psychology),

College of Humanities,

University of KwaZulu-Natal

By

Dumile Olivia Gumede

941355344

Supervisor
Prof Anna Meyer-Weitz

January 2021

DECLARATION

I, Dumile Olivia Gumede declare that:

i. The research reported in this thesis is my original work except where indicated.

ii. This research has never been submitted to any other educational institution for a similar purpose.

iii. All information contained herein has been appropriately referenced, including all identifying information, which has been given the utmost ethical consideration.

iv. This dissertation does not contain any work or writings by any other person;

    a) Where any words have been used: they have been properly referenced to indicate their origin, and

    b) Where verbatim quotations have been used: proper referencing has been adhered to, to indicate their source and has been placed in quotation marks to indicate this fact.

v. All other works such as tables and figures, which have been adapted for use in the study, have been properly referenced to indicate their original source and authors.

vi. To my best knowledge and of my conscience, I have done all I can to reference properly and correctly all sources I used to produce the research outcome as required.

vii. I bear sole responsibility for errors of omission that may unintentionally occur and are due to human limitations although maximum accuracy was aspired for in all possible respects.

Signature: [redacted]

Date: 27/07/2021

DEDICATION

This work is dedicated to the memory of my late parents who could not be physically here to see me complete this thesis. I thank both my parents for the great job that they did raising a daughter like me. Finishing this work was a commitment I made to honour their names. My father, my hero, Banguthuli Mkhwanazi, was someone who unconditionally loved me and believed in my capabilities beyond myself. He was an indigenous philosopher who role-modelled leadership and fearlessness. His belief in me kept me working every day even when I wanted to give up. My mother, Hilda Mkhwanazi, was a cheerful and hard-working woman who taught resilience, self-reliance and me multi-tasking. She drew strength from singing. As such, I composed a song that I sang to her before she died and she gave me the most beautiful smile, which remained in my heart and motivated me to finish this work.

Rest in peace.

ACKNOWLEDGEMENTS

I would first like to thank God for giving me the strength to complete this project. May His Grace keep on locating me forever and ever. I thank Him for giving me this life and entrusting me with the ability to conduct this study and for assigning the angels that guided me. I am grateful to God for making this happen: it has been a dream, a journey and finally a reality.

Then, I would like to express my sincere gratitude to the following people for their contribution toward this study:

My heartfelt thanks goes to my supervisor, Professor Anna Meyer-Weitz, for her direction, guidance, encouragement and advice she has given me throughout the duration of this study.

My mentors, Professors Janet Seeley, Kobus Herbst and Sioux McKenna for your academic and emotional support. You have inspired me, encouraged me, and always been so kind, patient and knowledgeable. I thank you from the bottom of my heart for all your effort in getting me across the finish line. I am more grateful than words can express.

I would also like to thank my former and current colleagues from the Africa Health for Research Institute, the South African Medical Research Council and the Durban University of Technology for constantly supporting me in every way throughout this study and for giving me courage.

A special thank you my friends, who are too many to mention, but have each impacted me in a special way. In particular, a very grateful thank you to my spiritual family for their prayers.

As I moved towards the finalisation of this work, I encountered Nikki Watkins, who thoroughly edited and reviewed this work. I am indebted to her for editing this document and for ensuring that it reaches the required academic standard.

Last, but definitely not the least, I would like to thank the people whose love keep me going and focused: my husband, Siphiwe, and children (Lindelwa, Ntombinkulu and Khethelo). Their extraordinary love and care is so inspiring. Thank you for praying for me. I am so grateful for their support in making this dream a reality, as I remember the sacrifices they have made which have all contributed to this study’s completion.

Finally, to the participants, I extend my gratitude and appreciation for your participation in this study.

ACKNOWLEDGEMENT OF FINANCIAL AID

This study was funded by the National Research Foundation (NRF) of South Africa (Grant number: 128945). The financial assistance of the University of KwaZulu-Natal (UKZN), the South African Medical Research Council (SAMRC), and the Durban University of Technology (DUT) is also acknowledged. Their contributions removed the financial burden of embarking on such a journey. Opinions, findings and conclusions or recommendations expressed are those of the author and are not necessarily to be attributed to the NRF, the SAMRC, the DUT or the UKZN.

ABSTRACT

In South Africa and in many other developing countries, grandparents/older carers have taken the role of caring for children, even where the older carers themselves have no steady source of income and are suffering from chronic illnesses. While previous studies have documented the experiences of older carers who are raising young children, few researchers have examined the caring of adolescents and the care relationships from the perspectives of both the older carers and adolescents in South Africa. The study examined the caring of adolescents by older carers in a rural KwaZulu-Natal district in which HIV prevention interventions called DREAMS were implemented.

Following an ethnographic approach, this study used repeat in-depth interviews, key informant interviews, and observations to elicit information from six adolescents aged 13 to 19, six older carers aged 50 and above, and two HIV programme facilitators (n=14) over 12 months, from October 2017 to September 2018, in the uMkhanyakude district, KwaZulu-Natal. Written informed consent was obtained from all individuals before participation. All data were collected in isiZulu and audio-recorded, transcribed, and translated into English. The researcher combined both thematic and dyadic analysis approaches to understand care relationships and the lives of adolescents and their older carers in order to add a deeper understanding of the data. A multi-theoretical approach including the life course perspective, the social-ecological model, and the self-management framework was applied to examine and interpret data.

The findings of the study indicated a dynamic process which influenced how older carers ended up taking the primary care responsibility of their grandchildren. The factors that positively or negatively affected the quality of relationships between adolescents and their older carers were adolescents' difficult behaviours and carers' behaviours (positive and negative). Gender was also used to frame the labels ascribed to the adolescents. The consequences of stigmatised labelling of adolescents negatively affected the adolescents in older carer families. Additionally, generational perspectives between adolescents and their older carers of romantic sexual relationships were highlighted. Further, the motivators and barriers to participation in DREAMS interventions of adolescents in older carer families were influenced by the four levels of the socio-ecological model namely individual, interpersonal, organisational, and community levels. The motivating factors included obtaining HIV and sexual and reproductive health information, perceived changes in risky behaviours, and improved care relationships and communication between adolescents and the older carers. The barriers to participation in DREAMS interventions included internalized stigma, negative peer pressure, and caregivers' lack of information about the HIV prevention interventions as well as challenges related to the organisation responsible for implementing DREAMS interventions. Lastly, the older carers employed a range of self-management practices for chronic conditions to promote health and well-being; while, sometimes, putting their lives at risk.

In conclusion, the adolescents and their older carers were emotionally distressed, thereby impacting their well-being and the quality of the care relationships. Furthermore, adolescents faced challenges as they explored their sexuality and transit to adulthood. The strenuous relationships with the adolescents, rather than chronic conditions, were the main stressors that undermined the older carers' ability to self-manage chronic illnesses. Further studies are required to understand the impact of COVID-19 on older carer families and its influence on self-management of chronic illnesses and caring for adolescents.

Key words: *Caring, adolescents, older carers, HIV prevention interventions, risky behaviours, self-management, chronic conditions*

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS AND ABBREVIATIONS

ABYM : Adolescent Boys and Young Men

AGYW : Adolescent Girls and Young Women

AHRI : Africa Health Research Institute

AIDS : Acquired Immune Deficiency Syndrome

ART : Antiretroviral Therapy

CAB : Community Advisory Board

CDC : Centers for Disease Control and Prevention

CHW : Community Health Worker

COVID-19 : Coronavirus Disease 2019

DBE : Department of Basic Education

DOH : Department of Health

DREAMS : Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe

DSD : Department of Social Development

DUT : Durban University of Technology

FP : Family Planning

GBV : Gender-based Violence

HIV : Human Immunodeficiency Virus

HSSREC : Humanities and Social Sciences Research Ethics Committee

HST : HIV Testing Services

HTC : HIV Testing and Counselling

IP : Implementing Partner

NRF : National Research Foundation

PEPFAR : President’s Emergency Plan for AIDS Relief

SAMRC : South African Medical Research Council

SEM : Social Ecological Model

SRH	: Sexual and Reproductive Health
SSA	: Sub-Saharan Africa
STI	: Sexually Transmitted Infection
TB	: Tuberculosis
UKZN	: University of KwaZulu-Natal
UNAIDS	: Joint United Nations Program on HIV/AIDS
UNICEF	: United Nations International Children's Emergency Fund
WHO	: World Health Organization
WBOT	: Ward-based Outreach Teams

DEFINITION OF TERMS

Adolescents	Persons between the ages of 10-19 are in the phase known as adolescence, which is a marked transition period between childhood and adulthood (WHO, 2013). In this study, it will refer to persons between the ages of 13 and 19 years.
HIV Combination Prevention Interventions	A holistic approach whereby HIV prevention is not a single intervention (such as condom distribution) but the simultaneous use of complementary behavioural, biomedical, and structural prevention strategies (UNAIDS, 2010).
Older Carer	An older carer is a woman or a man who is over 50 years old and is the sole caregiver of a child under 18 (HelpAge International, 2011a). Often the older carer is a grandfather or grandmother to the child but not always – great grandparents and older aunts and uncles are also older carers. In this study, the researcher used the terms older carer, older caregiver, and grandparent interchangeably.
Self-management	Refers to an individual's ability to manage symptoms, treatment, and consequences of living with a chronic condition, with the purpose of achieving or maintaining a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

CHAPTER ONE

INTRODUCTION

1.1 Introduction

The purpose of this thesis is to investigate the caring of adolescents by older carers in the context of Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS) interventions in rural KwaZulu-Natal, South Africa. It is an interpretive inquiry using an ethnographic approach. The study seeks firstly to understand the pathways into the caring for adolescents by older caregivers and the health circumstances of the older caregivers; secondly, the study investigates how adolescents are perceived by the carers and the nature of communication on sexual and reproductive health (SRH) in these relationships. Lastly, the study explores the experiences of participating in DREAMS interventions from the perspectives of adolescents, older carers, and HIV programme facilitators. In pursuing these research interests, I explore the lived experiences of six dyads of adolescents and their older caregivers in the uMkhanyakude district, KwaZulu-Natal. To further assist in the investigation, I also examined how HIV programme facilitators position adolescents and their grandparent caregivers’ relationships and behaviours.

The chapter begins with the background to the study and provides a broad context for the seeming emergence of increasing numbers of children and adolescents being raised by grandparent caregivers. Next, the chapter outlines the ways children come into the care of their grandparents as well as the challenges of caring for the young and being cared for by older caregivers. Next, the impetus and justification for the study are discussed and the research aims and objectives are presented. The chapter concludes with the structure of the thesis.

1.2 Background and Rationale To The Study

The Human Immunodeficiency Virus (HIV) pandemic in sub-Saharan Africa (SSA) has provided significant opportunities for orphaned and vulnerable children to be cared for by older carers (grandparents) (Mugisha et al., 2013). According to the Joint United

Nations Programme on HIV/AIDS (UNAIDS), about 14.9 million children have lost parents to Acquired Immune Deficiency Syndrome (AIDS) (UNAIDS, 2018). While HIV care and antiretroviral therapy (ART) services have reduced AIDS-related deaths (UNAIDS, 2016b), large numbers of orphaned and vulnerable children are still cared for by older caregivers in SSA (Kasedde, Doyle, Seeley, & Ross, 2014). This trend suggests that these children are transitioning from childhood into adolescence in the context of receiving care from older caregivers. The role of older carers is more significant in adolescents' lives (Attar-Schwartz & Buchanan, 2018).

Adolescents are defined as individuals aged 10-19 years by the World Health Organisation (WHO) (WHO, 2013). It is generally assumed that adolescents engage in risky behaviours including sexual behaviours that may place them at risk for unplanned pregnancies, sexually transmitted infections (STIs) and HIV (Bukenya et al., 2020; Landor, Simons, Simons, Brody, & Gibbons, 2011). Risky sexual behaviours, including unprotected sex, early sexual debut, multiple sex-partners, and inconsistent use of condoms and other contraceptive methods are often reported among adolescents (Ssewanyana et al., 2018; Wamoyi, Stobeanau, Bobrova, Abramsky, & Watts, 2016), often compromising their health and future aspirations. According to the United Nations Children's Fund (UNICEF) (2020), only one in three adolescent girls aged 15-19 years with multiple partners use condoms in SSA. Engaging in unprotected sex may increase the risk of unplanned pregnancy, HIV infection, and other STIs among adolescents (Mcgrath, Nyirenda, Hosegood, & Newell, 2009; Zuma, Mzolo, & Makonko, 2011). Condom use among young people continues to be low in South Africa (Muchiri, Odimegwu, & De Wet, 2017). A South African study reported that about 30% of sexually active adolescents indicated low or inconsistent condom use (Dietrich et al., 2013).

Pregnancy in adolescence has declined globally but remains high in SSA (UNICEF, 2020). A systematic review in 2018 showed that the prevalence of adolescent pregnancy in SSA countries was 19.3% (Kassa, Arowojolu, Odukogbe, & Yalew, 2018). Pregnancy during adolescence impact negatively on the health and well-being of both girls and boys, with girls often having to bear most of the consequences (Karp et al., 2020). It can bring about stigma, social isolation, school dropout, forced marriage, and in some cases, violence and suicide for the adolescent girls (UNICEF, 2020).

Moreover, it is during adolescence that gender differences in the HIV epidemic begin to occur (UNICEF, 2020). In 2015, there were approximately 1.8 million adolescents (10-19 years old) living with HIV in SSA (UNICEF, 2016). However, more adolescent girls carry the burden of HIV as more are infected than adolescent boys (UNICEF, 2020). The gender disparities are explained by a wide range of inequalities namely early sexual debut, forced sex, gender-based violence (GBV), early and forced marriage, unequal access to services and information about SRH including sexual health knowledge; unequal gender power relationships; inability to negotiate safer sex and lack of economic independence (UNICEF, 2020). In addition, more adolescent girls lack knowledge of HIV than boys (UNICEF, 2020). According to UNAIDS (2016b), about 36% of boys and 30% of girls did not report a complete knowledge of HIV prevention.

While HIV and SRH healthcare needs of adolescents have recently gained considerable attention world-wide, many of their needs for information on HIV and SRH among adolescents remain unmet (Okawa et al., 2018). Stigma is one of the main barriers for adolescents' use of HIV and SRH services in SSA (Hall et al., 2018). Moreover, adolescents experience barriers to access and use of SRH services including poor knowledge of contraceptive methods, little support from male partners and other health system related challenges (Jonas et al., 2020). To counteract these barriers and improve access to HIV and SRH services by adolescents, a multi-sectoral HIV prevention programme – the DREAMS (Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe lives) Partnership – was implemented between April 2016 − September 2018 in SSA, including South Africa (Chimbindi et al., 2018). Condom promotion, family planning (FP) counselling and education, parenting/caregiving, violence prevention, HIV testing and counselling (HTC) and linkage, and community mobilisation were among the DREAMS interventions (Saul et al., 2018).

Despite increased coverage of HIV prevention interventions like DREAMS, the current services do not address the challenges and needs of adolescents adequately.

Particularly, very few interventions are sensitive to adolescents in older carer families. Caregiver social support is a protective factor for adolescents' psychosocial well-being and caregiver mental health (Casale et al., 2015). However, many older carer families lack adequate support from family members, communities, and government structures (HelpAge International, 2011b).

While older carers play an important role in supporting adolescents, they have many responsibilities and challenges associated with caring for the young. The responsibilities of older carers include providing shelter, food and clothing for themselves and for adolescents under their care; socialising adolescents; providing protection to adolescents and also love and affection; and comforting adolescents on the death of their parents (HelpAge International, 2011b). However, the caring responsibilities during the life course occur when older carers are likely to need support from adult children and their families, but are confronted with the need to care for the adolescents and increased responsibilities (HelpAge International, 2011b). This may be physically, economically, psychologically, and socially a burden for the older carers. In addition, older carers experience challenges in providing care for adolescents which include parenting challenges; difficulty in communicating with the adolescents about SRH issues; being largely excluded by family interventions which tend to target mothers of children rather than older carers (HelpAge International, 2011b); lack of financial resources; and health-problems which are further compromised by living with chronic illnesses (Kasedde et al., 2014; Kuo & Operario, 2011). Previous research has found that caregivers living with chronic illnesses are more likely to be socially isolated, experience greater relationship problems, have worse mental health, and use authoritarian, harsh parenting practices (Conger, Conger, & Martin, 2010; Lachman, Cluver, Boyes, Kuo, & Casale, 2014). This may impact the quality of caring they provide for the adolescents and may disrupt adolescents' healthy development. However, older carers living with chronic illnesses have received little or no attention in the literature. It is, therefore, critical that this aspect needs exploration.

Furthermore, being raised by an older carer can also be difficult for adolescents. It can occur suddenly or after a long illness period with biological parents (Kelley, Whitley, & Campos, 2011). Thus, adolescents raised by older carers experience multiple adverse events such as loss of educational and social opportunities (Kasedde et al., 2014; Skovdal, Ogutu, Aoro, & Campbell, 2009a). In a systematic review of SSA studies, adolescents who are cared for by older carers are at particularly high risk of engaging in risky sexual behaviours and are vulnerable to HIV infection due to poverty (Gillespie, Kadiyala, & Greener, 2007). Of the limited studies available, findings suggest that adolescents raised by older carers, primarily grandmothers, are more likely than others to engage in unprotected sexual activities (Hayslip & Kaminski, 2005). Furthermore, because of past traumatic events and issues with their biological parents, these young people are at risk for alcohol and substance abuse, low self-esteem, and rape (McGuigan & Pratt, 2001). These challenges place adolescents at increased risk for emotional and behavioural problems (Kelley et al., 2011). Despite a body of research showing that adolescents experience increased emotional and behavioural problems (Johnson & Wolke, 2013; Petersen et al., 2010), few studies are focusing on adolescents raised by older carers.

The multiple challenges faced by both older carers and the young people they care for can have a negative impact on the care relationship and the quality of care provided to adolescents. Evidence shows that positive, warm, and nurturing caregiver-child relationships support the transition from adolescence into adulthood and prevent risky behaviours that can derail a smooth transition (Richter et al., 2009). However, much less is known about caring behaviours and family dynamics in older carer families, and how these factors may influence risk-taking behaviours of adolescents being raised in these contexts. To reduce new HIV infections among adolescents, it is important to understand the unique issues faced by adolescents in the care of older people. HIV prevention interventions that are sensitive to older carer family arrangements and its influences on the sexual behaviour of adolescents are likely to offer a more effective intervention. The findings of this study give clear insight into the adolescents' experiences in order to inform adolescent and family-focused interventions to circumvent some of the challenges they might experience.

While previous studies have described the experiences of older carers who are raising young children, few researchers have examined the caring of adolescents and the care relationships from the perspectives of both the older carers and adolescents in South Africa. Also, Attar-Schwartz and Buchanan (2018) suggest that most research still focuses on adolescent-parent relationships, while the care relationships between adolescents and grandparents (older carers) remains poorly studied.

1.3 Aims

The primary aim of this study is to understand the caring of adolescent girls and boys (aged 13 to 19) by older carers (aged 50 and older) in a rural KwaZulu-Natal district in which DREAMS interventions were implemented. The study will provide insights from adolescents, older carers, and HIV programme facilitators.

1.4 Research Objectives

The objectives of the study are:

- To explore the factors that shape the caring of adolescents by older carers and the nature of relationships between adolescents and their older carers.
- To explore the labelling of adolescents by their older carers and its impact on transitions and adolescent life trajectories.
- To explore the generational perspectives of adolescents and their older carers on romantic sexual relationships.
- To examine the motivators and barriers to participation in DREAMS interventions of adolescents in older carer families.
- To explore the older carers' experiences of self-management of chronic conditions and its influence on caring for adolescents.

1.5 The Outline of the Thesis

This thesis is divided into nine chapters. The various aspects that are discussed in each chapter are presented below:

Chapter One: Introduction

The current chapter is an introductory chapter and offered both the background to the study and the rationale for examining the caring for adolescents by older caregivers.

It also presented the research aims, objectives, and an outline of the remainder of the thesis.

Chapter Two: Literature Review

In this chapter, a literature review is presented related to the research topic addressed in the study. It therefore begins with a historical background of caregiving and in the African and South African contexts in order to demonstrate how the conceptualisation of caring of children has evolved over time. This is followed by the gendered nature of caregiving and the reasons why older carers decide on taking caring responsibilities. The challenges facing older caregivers are presented. Since the study focus mainly on caring for adolescents in the context of HIV prevention interventions, a focus on adolescent sexuality, risky behaviours, and HIV was a necessary inclusion. This is followed by issues concerning caregiver-adolescent communication regarding HIV and SRH. Furthermore, equally important was a focus on HIV prevention interventions targeting adolescents and their families. The final section of this chapter is the theoretical framework that informed the study.

Chapter Three: Methodology

Chapter Three offers an account of the detailed methodology followed throughout this research. This chapter begins with an overview of the philosophical assumptions underpinning this research, followed by the research strategy and design as well as the empirical techniques applied for data collection and analysis. Ethical considerations of the study and how the researcher addressed these are also presented in this chapter. Lastly, the criteria to measure the rigour of this study are outlined.

Chapter Four: Factors shaping caregiving by older carers and relationships with adolescents

This is the first of four chapters that present the findings and discussion of the key themes identified in the study. It is subdivided into three parts. The first part begins with the demographic characteristics of the research participants. The second part concentrates on the factors shaping caring for adolescents by older caregivers. In the final part, I will then discuss the findings in relation to the social ecological model and the life course theory.

Chapter Five: Labelling of adolescents in older carer families

This is the second chapter of the findings, which is subdivided into three sections. It focuses on how the adolescents in older carer families are labelled. It starts by presenting the labels ascribed to adolescents and the behaviours associated with the labels. This is followed by gender and labelling. Then, the chapter concentrates on factors influencing the stigmatised labelling of adolescents. The chapter is concluded by a discussion of the findings in relation to the literature reviewed.

Chapter Six: Exploring generational perspectives of adolescents and older carers on romantic sexual relations

Chapter Six is the third chapter of the findings. The first section covers the views of adolescents and their older carers on the meaning of romantic sexual relationships. This will be followed by presenting their perspectives on the appropriate timing for engaging in sexual activities. Then, the chapter covers the views of adolescents and older carers on the places to meet romantic sexual partners and the desired characteristics of ideal romantic sexual partners. I then critically discuss the presented results and the implications of the results in relation to the literature reviewed.

Chapter Seven: Motivators and barriers to participation in DREAMS interventions of adolescents in older carer families

This chapter is subdivided into three parts and provides the experiences of participating in DREAMS interventions of adolescents in older carer families. Part 1 focuses on the socio-ecological factors facilitating their participation in interventions, and part 2 focuses on the socio-ecological factors hindering the participation of adolescents in HIV interventions. The final part is a discussion of the findings by drawing on the literature reviewed.

Chapter Eight: Older carers' experiences of self-management of chronic conditions and its influence on caring for adolescents

This is the final chapter of the findings, which is subdivided into three sections. The first section presents the participants' characteristics and chronic conditions. This is followed by the themes of the self-management processes: focusing on illness needs, activating resources, and living with a chronic illness (recognising that some degree of overlap exists across the themes). The chapter is concluded by a discussion of the findings in relation to the older carers' experiences of self-management of chronic conditions and its influence on caring for adolescents.

Chapter Nine: Synthesis of the findings, recommendations, and conclusions

The aim of this chapter is to present the summary and conclusions drawn from the results of the analysis of interviews and observations, and then make recommendations in an effort to further improve the caring for adolescents by older carers in South Africa. This is important because it is envisaged that the findings of this study will inform policy and achieve improved health and overall well-being for the adolescents and older carers. The chapter is concluded by highlighting the limitations faced in the process of the research project, the recommendations for interventions, and the suggestions for future research into the subject under investigation.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

A significant focus in this chapter is on engaging with existing studies surrounding the experiences of older carers raising adolescents, so as to identify the gaps in knowledge that constitute the basis of this current study. The chapter begins by analysing grandparent caregiving in the African context, and documents how gender has influenced the caregiving role. This is followed by a discussion of the reasons why an increasing number of grandparents are taking on the caring role of their grandchildren. The next section explores the health challenges facing grandparent caregivers. Further, this chapter focuses on adolescent sexuality, risky behaviours and HIV including caregiver-adolescent communication on SRH issues. In addition, it explores HIV and SRH services in the South African context and factors influencing adolescent participation in HIV interventions. This chapter concludes by presenting a theoretical framework chosen to underpin the study.

2.2 The African Context of Caregiving

Historically, kinship care is an important form of care and support within the social structure of families in African societies and elsewhere. In the pre-colonisation era, Black African families provided informal kinship care for the common interest and corporate function of the family (Ince, 2009). Such support was largely unpaid and voluntary but regulated by cultural norms and values (Assim, 2013). The forced separation of Black South African families in the apartheid era resulted in the formation of vulnerable family structures in the rural areas, with a high level of disconnect between generations (Makiwane, 2010). Families engaged in a mutual exchange where older people enabled the economic migration of younger adults by taking on the caring of the grandchildren and maintaining the family land and protecting the assets (Hosegood & Timaeus, 2006). In the post-colonial and apartheid eras, the primary purpose of kinship care among Black South African families was to promote family survival under difficult social and economic conditions which was linked to their context and living arrangements (Ince, 2009).

2.3 Caregiving Context in South Africa

In 2018, there were 2.7 million orphans in South Africa (Statistics South Africa, 2019). This refers to children without a living biological mother, father or both parents, and comprised of 14% of all children in South Africa. The majority (63%) of all orphans in South Africa are paternal orphans but have living mothers. The high number of paternal orphans is seen to be the result of the higher mortality rates of men in South Africa, as well as the frequent absence of fathers in their children's lives (Hall, 2019). However, extended families play a critical role in the care of children in South Africa, as the majority of children that are not living with their parents live with their grandparents or other relatives (Mkhwanazi et al., 2018).

2.4 Gender and Caregiving

Among older people, gender differences shape caregiving within families (Mugisha, Schatz, Seeley, & Kowal, 2015). The literature pertaining grandparent caregiving shows that caregiving role is performed predominantly by women (Kasedde et al., 2014; Matovu & Wallhagen, 2018; Rutakumwa, Zalwango, Richards, & Seeley, 2015). A study in Uganda among older carers reported that the majority of carers of children aged 13-17 years were 50 years and older and predominantly female (Rutakumwa et al., 2015). Similarly in an earlier study, Wave 1 of the Well-being of Older People Survey among people of 50 years and older who are affected or infected by HIV/AIDS conducted in 2009/2010 in Uganda, it was reported that more children under 18 years were living with women (231 of the 312 - 74%) (Mugisha et al., 2015). Despite recent data, in South Africa, households with a woman over the age of 60 resident (as opposed to those without) are twice as likely to have a fostered child living in the household and three times as likely to have an orphaned child in the household (Schatz, 2007). While some men in South Africa may be older carers, men are often employed or live away from home for employment reasons, and this further contributes to gendered caregiving (Mugisha et al., 2015).

Women’s decision to provide care “aligns with narratives about older women being altruistic and selfless caregivers” (Schatz & Seeley, 2015, p. 9). The feminisation of caring has long been facilitated by women’s socialisation into nurturing roles (Hooyman & Gonyea, 1995) which has led to assumptions that women are responsible for caring for the young and sick. Gilligan’s study on gender-role socialisation stated that gender roles are internalised from a young age and are reinforced throughout the life course (Gillan, 1982). Little is known about the influence of historical gender experiences in caregiving, considering older carers may have been exposed to different constraints and opportunities in childhood. An exploration of the historical time in which older carers lived in and its influence in gender differences and caregiving is needed.

2.5 Reasons Why Grandparents are Caring for Children

Grandparents raising grandchildren have gained public attention as being critical in providing care for vulnerable children in times of need (Goodman, 2012). Different situations exist which explain why grandparents are taking caring responsibilities of their grandchildren. The historical consequence of labour migration and non-marital childbearing has resulted in grandparents being the primary caregivers of their grandchildren (Statistics South Africa, 2018). The HIV epidemic further aggravated the responsibility of grandparents for the grandchildren due to the increased adult morbidity and mortality. Despite the massive antiretroviral therapy (ART) roll-out in the country many grandparents remain responsible for the care of grandchildren (Statistics South Africa, 2018). South Africa still has the highest number of HIV infections in the world and has seen dramatic increase in AIDS-related deaths which peaked around 2007 (Statistics South Africa, 2018). For instance, about 61% of double and single orphans in Namibia, South Africa, and Zimbabwe and over 50% in Botswana, Malawi, and Tanzania are living with their grandparents (Mudege & Ezeh, 2009). While HIV care and antiretroviral therapy (ART) services have significantly reduced AIDS-related deaths (UNAIDS, 2016b), large numbers of orphaned and vulnerable children are still cared for by older caregivers in SSA (Kasedde et al., 2014). This trend suggests that these children are transitioning from childhood into adolescence while receiving care from older caregivers. The role of older carers is more significant in adolescents’ lives (Attar-Schwartz & Buchanan, 2018).

Abebe and Aase (2007) report that some caregivers may be motivated to care for the children because of the benefits that children can offer to the caregivers. They argue that one of the motivating factors to care for the children, especially boys, is the "immensely valuable labour contribution of children, which is required in agricultural and domestic activities" (Abebe & Aase, 2007, p. 2066). This could be true in certain circumstances in South Africa. But as grandparents usually take on caring responsibility for their grandchildren from an early age when the children are unable to perform housework, the uptake of the caring responsibility is better understood from a cultural and life course perspective. Findings from the present study address this deficit in the research by presenting the life course pathways and cultural practices to caring for adolescents.

Historically, caring for children has always been common for grandparents, and these older carers have been identified as a key family support system in ensuring a critical safety net for children to experience a good quality of life (Schatz, Madhavan, Collinson, Gomez-Olive, & Ralston, 2015). Providing care can be fulfilling for the older carer as it strengthens the relationships between the older carer and the child. Furthermore, older carers have reported emotional fulfilment, new meaning and purpose to life by offering care to the young ones. Nevertheless, older carers often provide care alongside health and financial challenges and this may place the older carer in a situation where difficult choices have to be made whether they should provide care or not. While previous studies have reported on the reasons influencing grandparents to assume caring responsibilities for young people in their family, little is known about factors influencing grandparental caregiving from a life course perspective.

2.6 Health Challenges Faced by Older Caregivers

Health challenges facing grandparents who are caring for their grandchildren have received adequate research attention. Chronic conditions are common in older people and affect their functioning (Mugisha et al., 2016; Solanki, Kelly, Cornell, Daviaud, & Geffen, 2019) and the number of older people suffering from one or more chronic conditions (known as multi-morbidity) continues to rise rapidly (Chang et al., 2019). Chronic conditions refer to health problems that need continuous management for at least six months including cancer, hypertension, diabetes, and HIV (WHO, 2002). With the availability of ART, HIV is considered a chronic condition as it has been shown to increase life expectancy (Deeks, Lewin, & Havlir, 2013). Of the 25.4 million people globally receiving ART, about 5.2 million live in South Africa (UNAIDS, 2020b). Population ageing will increase the disease burden of chronic diseases, and consequently increase demands on the healthcare system (Solanki et al., 2019). However, the healthcare services in SSA are already overburdened by communicable and non-communicable diseases (Herbst et al., 2015).

Older people aged 50 years and older often have one or more chronic diseases (Chang et al., 2019). An earlier study in South Africa showed that 518 older people aged 50 and older (73%) reported one or more chronic diseases (Westaway, 2009). Hypertension alone (25%), followed by hypertension and diabetes mellitus (8%), hypertension and arthritis (8%), arthritis alone (8%), and diabetes mellitus alone (5%), were the most frequently mentioned chronic diseases (Westaway, 2009). A recent study showed that diabetes is the seventh leading cause of morbidity and mortality in South Africa, due to trends of poor diet, obesity, high fasting blood glucose, and low physical activity levels (Werfalli et al., 2018).

HIV remains a major public health challenge in sub-Saharan Africa, with South Africa among the worst affected. South Africa has 7.5 million people living with HIV, with nearly 5.2 million on ART (UNAIDS, 2020b). Data suggests that with ART, more individuals are living into old age with HIV in South Africa (Chang et al., 2019).

Access to healthcare services and lack of financial resources are some of the issues reported as challenges for older people with chronic conditions in SSA (Kasedde et al., 2014; Rutakumwa et al., 2015). Also, these older people provide care at a time when their health is also declining because of old age and additional complications such as chronic conditions (Mudege & Ezeh, 2009), and are in need of care themselves (Mugisha et al., 2015).

While chronic conditions such as HIV, high blood pressure, diabetes, and strokes are burdening older South Africans' health (Mayosi et al., 2009; Solanki et al., 2019; Westaway, 2009), the responsibilities of caring for orphaned and vulnerable grandchildren further impact their wellbeing (Kasedde et al., 2014; Munthree &

Maharaj, 2010). South African older people, and others elsewhere in Africa, often live in multi-generational households with their adult children and grandchildren (Schatz, Madhavan, Collinson, Gomez-Olive, & Ralston, 2015). Older carers in Uganda reported chronic pain and stress as major challenges in their role as carers, thereby limiting their ability to execute caring duties (Rutakumwa et al., 2015), and likely limiting their time for self-care. Traditionally, older people have relied on their children for support in old age and sickness (Mudege & Ezeh, 2009). However, navigating self-management of chronic conditions while at the same time taking on the added responsibility of caring for their grandchildren is not fully known. This makes it particularly important to understand how chronic disease impacts the lives of older carers. It is therefore important to understand the psychosocial impact of caring for the adolescents while living with chronic illness. Understanding self-management experiences of older carers could provide a framework within which to develop health promotion interventions to support older carers with chronic conditions in South Africa and elsewhere, and strengthen their relationships with the adolescents they are caring for. Adolescence is a time of profound changes in behaviour and social relationships (Suleiman, Galván, Harden, & Dahl, 2017). Given that adolescence is a critical period of romantic and sexual identity development (Suleiman et al., 2017), we need a better understanding of the caring of adolescents in older carer families.

2.7 Adolescent Sexuality, Risky Behaviours, and HIV

Adolescents are defined as individuals aged 10-19 years by the World Health Organisation (WHO) (WHO, 2013). Adolescence is a period of development during which many youths become aware of their identity as sexual beings (Ritchwood, Penn, Peasant, & Albritton, 2017). They, in general, tend to engage in risky sexual behaviours that eventually put them at risk for unwanted pregnancies, STIs, and HIV amongst others (Bukenya et al., 2020; Landor et al., 2011). Risky sexual behaviours, including early sexual debut, unprotected sex, multiple sex-partners, and low and inconsistent contraceptive use are common among adolescents (Ssewanyana et al., 2018; Wamoyi et al., 2016), often compromising their health and future aspirations.

Adolescent pregnancy has declined globally but remains high in SSA (UNICEF, 2020). A systematic review in 2018 showed that the prevalence of adolescent pregnancy in

SSA countries is 19.3% (Kassa et al., 2018). A population-based study conducted in uMkhanyakude district in rural KwaZulu-Natal showed that the incidence of teenage pregnancy is 6.4% (5.7-8.6) and adolescents start using contraception after their first pregnancy (Chimbindi et al., 2018). Adolescent pregnancy can have many negative consequences for the health and well-being of girls. It can result in stigma, social isolation, school dropout, forced marriage, and in some cases, violence and suicide for the adolescent girls (UNICEF, 2020). Research has reported the severe negative health, education, social, and economic consequences of early and unintended pregnancies among adolescents (Christofides et al., 2014; Kanku & Mash, 2010; Kaye, 2008). Girls' secondary education has been found to be a protective factor to becoming pregnant in adolescence (UNICEF, 2020).

According to the UNICEF (2020) only one in three adolescent girls aged 15-19 years with multiple partners use condoms in SSA. Engaging in unprotected sex may increase the risk of unintended pregnancy, HIV infection, and other sexually transmitted infections (STIs) among adolescents (Mcgrath et al., 2009; Zuma et al., 2011). Condom use among young people continues to be low in South Africa (Muchiri et al., 2017). A South African study reported that a third of sexually active adolescents reported low or inconsistent condom use (Dietrich et al., 2013).

However, most of these studies have focused on adolescents in general. There is limited work on adolescents in older carer families. Gaining an understanding of adolescents in these families is important in identifying factors that impact sexual decision making regarding initiating sexual activity and preventing pregnancy. Studying adolescents in older carer families could assist in providing guidelines on the capacity and needs of adolescents in older carer families, which, in turn, guides the development of intervention goals and content.

HIV remains one of the world's most serious public health challenges. There were approximately 38 million people living with HIV across the globe in 2019 (UNAIDS, 2020a). SSA remains the worst affected region by HIV in the world, with 25.7 million people living with HIV (UNAIDS, 2020b). South Africa has 7.5 million people living with HIV (UNAIDS, 2020b). In 2015, there were approximately 1.8 million adolescents (10-19 years old) living with HIV in SSA (UNICEF, 2016). The greatest burden of HIV remains among adolescents. It is during adolescence that gender disparities in the HIV epidemic begin to emerge (UNICEF, 2020). More adolescent girls are infected with HIV than adolescent boys ((UNICEF, 2020). Gender and unequal power relations play a key role in the sexual wellbeing of adolescents (Muhanguzi, 2011). As mentioned earlier, the gender disparities are influenced by various inequalities ranging from gender based violence, early and forced marriage, inequitable access to services and information regarding SRH services and knowledge as well as a lack of negotiating power and little economic independence (UNICEF, 2020). Various studies have shown that unequal gender power relationships and gender norms make girls and women vulnerable for HIV infection, pregnancy, sexual violence and early marriage (Muhanguzi, 2011). In addition, more adolescent girls lack knowledge of HIV than boys (UNICEF, 2020). According to the UNAIDS (2016), about 36% of boys and 30% of girls have no comprehensive knowledge of HIV prevention. It is important to note that knowledge might not necessarily influence sexual decision-making of girls and boys as these may be influenced by social contexts and interpersonal relationships (Van de Bongardt, Reitz, Sandfort, & Deković, 2015). The socialisation in childhood influences how girls and boys think and behave during adolescence (Basu, Zuo, Lou, Acharya, & Lundgren, 2017). The traditional norms that view girls subservient (Ngabaza, Shefer, & Macleod, 2016) and constructions of female sexuality as passive, lack of desire, and subordinate to male sexual needs or desires (Tolman, 2012), make condom negotiation for girls nearly impossible.

2.8 Relationships between Adolescents and Older Carers

The grandparent-grandchild relationship is one of the three relationships between parent-child, parent-grandparent, and grandparent-grandchild relationships that has been historically reported to represent the basic intergenerational triangle of the family (Monserud, 2008). This relationship develops in the context of the family and changes throughout the life course of individuals (Monserud, 2008). Closeness in the grandchild-grandparent relationship early on minimizes challenges with the grandchild’s behaviour problems during early school years (Goodman, 2012). In modern society, children’s exposure to education and media as significant external influences have altered their relationships with adult generations (Tafere, 2015).

Other studies of grandparent-grandchild relationship quality have shown an association with caregiver role satisfaction (Hayslip & Kaminski, 2005) and physical health (Goodman, 2012). However, these studies have focused on young children rather than adolescents and conducted in high-income settings. Understanding changing relationships requires the study of intergenerational relationships through the life course (Tafere, 2015). Therefore, an understanding of relationships between adolescents and their older carers needs further exploration in the South African context.

2.9 Caregiver-adolescent Communication on Sexual and Reproductive Health

The family is one of the key factors that can contribute to reducing the negative consequences of adolescent risky sexual behaviour (Faludi & Rada, 2019). Evidence shows that adolescents who engage in conversations with their caregivers about sexual matters are more likely to delay sexual activity, have fewer sexual partners, and are more likely to use condoms and contraceptive methods (Kirby, Laris, & Rolleri, 2007; Rogers, Ha, Stormshak, & Dishion, 2015). However, there has been extensive research that has demonstrated that family plays an important role in sexual socialisation among adolescents in higher-income settings (Bleakley, Khurana, Hennessy, & Ellithorpe, 2018; Hutchinson & Cederbaum, 2011; Widman, Bradley-Choukas, Noar, Nesi, & Garrett, 2017) and to a lesser extent in SSA (Seif, Thecla, & Moshiro, 2018; Tsala Dimbuene & Kuate Defo, 2011). While this has positive adolescent outcomes, previous research in South Africa has indicated that most communication between adolescents and caregivers is limited and fear based (Soon et al., 2013; Vilanculos & Nduna, 2017). Parents and other caregivers use indirect communication strategies to communicate with their adolescents about sex while more direct strategies are used when warnings are given around sexual matters (Bastien, Kajula, & Muhwezi, 2011). The communication focus primarily on abstinence and the consequences of unintended pregnancy and HIV and AIDS while safer sex and condom use are often avoided (Kajula, Sheon, Vries, Kaaya, & Aarø, 2014). A study conducted in three South African provinces reported gender differences between parents and adolescents made it difficult for caregivers to talk to their adolescents about sex and its consequences (Vilanculos & Nduna, 2017). With both boys and girls, male caregivers communicated less about sexual topics than female caregivers did (Evans, Widman, Kamke, & Stewart, 2020; Wilson & Koo, 2010).

Although studies on caregiver-adolescent communication on SRH are increasing in SSA (Bastien et al., 2011; Seif, Kohi, & Moshiro, 2019; Wamoyi, Fenwick, Urassa, Zaba, & Stones, 2010), this area has not been well studied in the context of older carers and adolescents. Most of these studies have focused on adolescents and parents. There is limited work on SRH communication between adolescents and older carers. Gaining an understanding of generational perspectives between adolescents and their older carers can play an important role in identifying factors that influence sexual decision making regarding initiating sexual activity and ideal sexual partners.

Also, while previous research has studied this phenomenon from the perspective of either caregivers or adolescents, researchers suggest caregiver-adolescent communication about sex would be best examined using dyadic data with both caregiver and adolescent perspectives to compare if similar or different communication patterns emerge (Evans et al., 2020). Findings from this study will provide us with deeper understanding of both caregivers and adolescents' needs and attitudes about SRH communication, key aspects for developing effective interventions aimed at increasing communication about SRH matters between caregivers and adolescents.

2.10 HIV and SRH Services in South Africa

The National Strategic Plan for HIV and AIDS (2017-2022) launched in 2011 refers to prevention, treatment, care, and support components targeting adolescents who are considered a priority in the national AIDS response (South African National Department of Health, 2017). Universal access to HTC and treatment are key goals of the plan. The strategy embraces a multi-sectoral approach to adolescent health, involving inter-departmental collaboration between the Departments of Health, Basic Education, and Social Development, to better respond to the vulnerability of adolescents. For example, in 2012, these departments launched an Integrated School Health Programme (ISHP) to provide SRH information and services either in schools, through healthcare facilities, or through community-based service providers. In addition, each department has created its own adolescent health strategies or policies.

One of the South African government HIV campaigns is ‘She Conquers’. The ‘She Conquers’ campaign delivers biomedical, socio-behavioural, and structural interventions to increase access to information, services, and support for adolescent girls and young women (South African National Department of Health, 2017). The biomedical interventions seek to increase access to SRH information and services through adolescent and youth-friendly clinics and the ISHP. Socio-behavioural interventions are aimed at improving community mobilisation and support, ensuring girls stay in school, and improve access to peer groups and clubs. They also provide opportunities for improved awareness and knowledge on GBV, substance use and abuse, and stigma and discrimination. Attempts to improve access to parenting programmes for adolescents and young parents are also made available. Structural interventions focus on greater access to grants and general social assistance, bursaries, and opportunities to post-school education, employment, mentorship, and internships.

In addition to government-led campaigns, the DREAMS Partnership was implemented between April 2016 − September 2018 in SSA, including South Africa (Chimbindi et al., 2018). Condom promotion, family planning counselling and education, parenting/caregiving, violence prevention, HTC and linkage, and community mobilisation were among the DREAMS interventions (Saul et al., 2018). Little is known about the experience of participation in DREAMS interventions by young people.

2.11 Factors influencing adolescent participation in HIV and SRH interventions

Adolescents in South Africa and elsewhere in the world need access to interventions to prevent and manage HIV and unwanted pregnancies (Appollis et al., 2020). They possess unique characteristics that differentiate them from other population groups, hence, their health needs are unique and need special attention. While HIV and SRH healthcare needs of adolescents have recently gained attention in the global sphere, adolescents face multiple factors affecting their access to HIV and SRH interventions at different levels.

At an individual level, the need for information on HIV and SRH among adolescents remains unmet (Okawa et al., 2018). Studies in South Africa identified poor knowledge of health services (Jonas et al., 2020; Schriver, Meagley, Norris, Geary, & Stein, 2014) as barriers for adolescents to access health services. Another study reported that adolescents who had their sexual debut before baseline had a lower rate of session attendance in an after-school SRH education programme compared with those who had not (Mathews et al., 2015). At an interpersonal level, lack of support from male partners (Jonas et al., 2020) and domestic responsibilities (Appollis et al., 2020; Mathews et al., 2015) hinder adolescents' participation in interventions. Also, a study in rural KwaZulu-Natal reported that adolescents lack guidance from their immediate families and their parents were opposed to them accessing SRH services as it was seen to be an indication that they were sexually active (Zuma et al., 2020). Other researchers reported health systems related challenges including dissatisfaction with local public clinics (Schriver et al., 2014), distances to health facilities, transportation costs, and long waiting queues (Mathews et al., 2015; Nkosi et al., 2019) as barriers to accessing health interventions by adolescents. At societal level, stigma is one of the main challenges for adolescents' use of HIV and SRH services (Hall et al., 2018; Nkosi et al., 2019).

Given the importance of multilevel factors that influence behaviours in uptake of HIV prevention interventions, this study sought to elucidate factors influencing participation in DREAMS interventions among adolescents in older carer families.

2.12 Theoretical Framework

The theoretical framework chosen to underpin the study therefore draws on ideas from a number of theories or models. The life course theory was the main theoretical framework of this study, while the Social Ecological Model (SEM) and the self-management processes was used to explain particular aspects within the life course theory.

2.12.1 Life course theory

Caregiving and receiving involves people who are at different life stages (Roos, Silvestre, & De Jager, 2017). The two age groups that are relevant in this study are older carers (aged 50 and above) and adolescents (aged between 13 and 19 years). The caring relationship is dependent on their subjective life course experiences (Vorster, Roos, & Beukes, 2013). This study draws on the life course perspective as a theoretical framework that orients scholarly attention to the caring relationship between older carers and adolescents.

The life course perspective is a theoretical model that has emerged across several disciplines including sociology, anthropology, psychology, and demography. Glen Elder (1994), a sociologist, was one of the early authors to write about a life course perspective, and he continues to be one of the driving forces behind its development. At its core, a life course perspective contends that human development is a lifelong process and that no life stage can be understood in isolation from others (Johnson, Crosnoe, & Elder, 2011). It looks at how biological, psychological, and social factors act together to influence people's lives from birth to death, and across generations (Hutchison, 2010).

This approach makes use of four dominant and interrelated themes: (1) historical time, (2) timing of lives, (3) linked lives, and (4) human agency (Elder, Johnson, & Crosnoe, 2003; Elder, 1994). The meaning of these themes are discussed below.

Historical time: The first of these themes that Elder suggests is the interplay of human lives and historical time. He observed that people born in different generations face different possibilities and restrictions within their different historical worlds or generations. Social changes that occur in one group or generation impact the other generation differently (Elder et al., 2003). In the context of this study, older carers were born and exposed to constraints and opportunities which may be different from the adolescents, as both the older carers and the adolescents are from different generations. Historical time means the period of time one lives in. This explains the context and the setting within which lived experiences are understood.

Timing of lives: In this theme, when taking up a role such as older carer, how long the role would last and the sequencing of role all influence the life course of a person and others that are connected to them (Elder et al., 2003).

Linked lives: The concept of linked lives highlights the inter-relationships that influence experiences and events across the life course (Elder et al., 2003). Previous research shows that parents/caregivers and children influence each other over the life course, and the events and transitions in the lives of one generation have consequences for the other generation (Umberson, Pudrovska, & Reczek, 2010). As individuals navigate their life journeys, the relationships with people close to them influence the direction and quality of their lives. The lives of adolescents and their older carers are uniquely linked, shaping and being shaped by each other while they navigate their life journeys. The concept of linked lives in the life course perspective is especially important in this study focusing on adolescents and their older carers. The lives of adolescents and their older carers are embedded and this has a profound effect on their experiences of the caring relationship. Caregiving is an example of linked lives that includes not only an intersection of time and place, but also an influence on relational experiences.

Human agency: Agency is based on the assumption that humans are not passive recipients of a predetermined life course but make purposeful and informed decisions that determine the shape of their lives (Black, Holditch-Davis, & Miles, 2009). However, this idea has been contested as it is viewed as a rather westernised conceptualisation of agency that depends on individualistic ideas of choice and autonomy (Dutta & Basu, 2008). Some scholars argue individual agency is a relational process in which individuals exercise their agency through interactions with the wider social-cultural context (Dutta & Basu, 2008; Schoon & Heckhausen, 2019). Social and cultural environments can be hampering or facilitating individual agency (Hutchison, 2010). In addition to individual characteristics, the influence of the wider social-cultural context has to be considered as well as the interaction of individuals in this context (Schoon & Heckhausen, 2019). Agency has particular significant salience in the context of intergenerational care relationships. Older carers make life-changing decisions for themselves and their adolescent grandchildren. Also, adolescents make choices for themselves that may impact their older carers.

The application of life course theory is relevant to the study of intergenerational relationships. Life course themes are important in understanding the caring of adolescents by older carers because the life course theory views events, context, and timing as forces that shape and intersect with experience (Hutchison, 2010). Other scholars (Kasedde et al., 2014; Tafere, 2015) have used the life course perspective to examine relationships between younger and older generations. The life course perspective remains a strong tool for documenting changes in the nature of relationships as influenced by individuals, family, or other external factors (Tafere, 2015).

2.12.2 Social Ecological Model (SEM)

The socio-ecological model (SEM) was first introduced as a conceptual model for understanding human development by Urie Bronfenbrenner in the 1970s and later formalised as a theory in the 1980s (Kilanowski, 2017). The Centers for Disease Control and Prevention (CDC) have adapted the SEM for various health promotion endeavours. The SEM is a theory-based framework to help the understanding of multifaceted and interactive effects of personal and contextual factors that determine behaviours, and for identifying behavioural and organisational intervention points and mediators for health promotion within organisations (CDC, 2015).

The SEM include five hierarchical levels (individual, interpersonal, community, organisational, and societal (Figure 2.1) (CDC, 2015). The first level is the individual, which includes the characteristics that influence behaviour such as knowledge, attitudes, skills, and beliefs. The second level is interpersonal, which includes formal (and informal) social networks and social support systems that can influence individual behaviours, such as family, friends, and peers. The third level is the community, which is about relationships among organisations, institutions, and informational networks within defined boundaries, including associations, community leaders, and businesses in which social relationships occur and seek to identify the characteristics of these settings. The fourth level is the organisational, which refers to organisations or social institutions with rules and regulations for operations that affect how, or how well, services are provided to an individual or group. The fifth level is the policy/enabling environment which includes the broad cultural context and policies across different spheres of government which help create a climate in which behaviour is encouraged or inhibited.

This study is based on the SEM, which recognises the intertwined relationship existing between an individual and their environment (Gombachika et al., 2012). It recognises that while individuals are responsible for initiating and maintaining the required life style changes to reduce risk and improve health, individual behaviour is influenced by various factors at different levels (Elder et al., 2007).

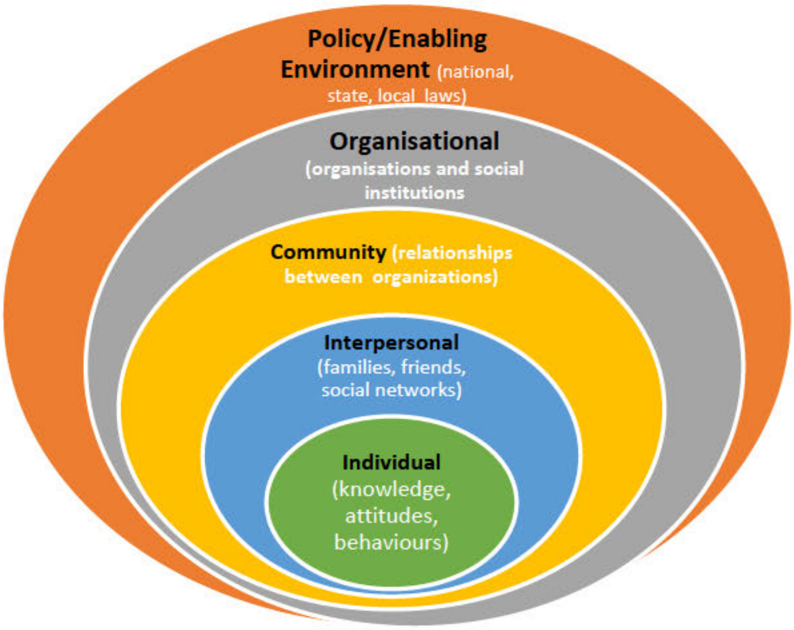


Figure 2.1: Social ecological model

Source: Adapted from the Centre for Disease Control and Prevention (CDC), The Social Ecological Model: A Framework for Prevention, http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html (Retrieved 16 November 2020).

The SEM has practical limitations. It has been reported that the incorporation of multilevel analyses can be cumbersome and complex (Gombachika et al., 2012).

However, a major strength of the SEM for this study is that it was possible to explain how factors at different levels influenced adolescents' participation in DREAMS interventions. Adopting the SEM to understand the experiences of adolescents' participation in HIV interventions could provide opportunities for interventions that focus not only on the biophysical being, but also to contextual factors. This is an important aspect as health intervention implementers often neglect to recognise the contexts in which young people live (Mburu et al., 2014).

Applied to adolescents cared for by older carers, a social-ecological assessment has important consequences for health practitioners. For example, adolescents' ability to initiate HIV and SRH services in South Africa is strongly dependent on their family relations (Kuo et al., 2016) and lack of adequate space in health facilities (Nkosi et al., 2019), as well as by community stigma (Ngwenya et al., 2020). Therefore, interventions for adolescents at risk of HIV should involve not only the youth but their families as well as the broader organisational and societal domains.

2.12.3 Self-management processes

The health of people living with chronic conditions depends on both the health care available, their motivation and ability to self-regulate their conditions (Russell et al., 2016). The work of Schulman-Green and colleagues (Schulman-Green et al., 2012) informs the study's theoretical framework. Self-management processes focus on three broad domains namely, illness needs, enabling access to resources, and the everyday living with a chronic illness.

Focusing on illness needs involves the necessary self-management tasks and skills for individuals to take care of their bodies and illness-specific concerns of a chronic condition (for example, adherence to treatment) (Schulman-Green et al., 2012). As part of this process, individuals gain knowledge about the chronic illness, take personal responsibility of their health needs, and engage in health promotion activities (Schulman-Green et al., 2012). The engagement illness needs can be performed by the individual or in cooperation with family members and healthcare providers depending on the individual's needs, level of motivation, values, and resources (Schulman-Green et al., 2012).

Activating resources include mobilising integral resources to assist individuals in managing various aspects of their chronic condition (for example, support from important others, healthcare workers, and family members) (Schulman-Green et al., 2012). The tasks and skills that are linked to enabling resources include communicating with healthcare service providers, coordinating services, identifying and gaining support from psychological resources, being involved in a spiritual community, seeking and managing social support, and addressing various challenges of a social and environmental nature (Schulman-Green et al., 2012).

Living with a chronic illness requires tasks and skills linked to coping with the illness and growing as a person, as well as to move from a focus on the illness needs to a better integration of the illness into everyday living (Schulman-Green et al., 2012). In living with a chronic illness, individuals engage in four overlapping and interrelated tasks, namely, managing of emotions, adjusting to the illness and new healthy lifestyle, integrating illness into everyday living, and a meaning-making process (Schulman-Green et al., 2012).

Addressing emotions is an important aspect of self-management (Schulman-Green et al., 2012). Chronic illness is a disruptive event (Bury, 1982) and may be a traumatic experience (Russell & Seeley, 2010), resulting in disruptions to the physical capabilities, social identities, and life trajectories of sufferers (Bury, 1982). A study on experiences of diabetes in Ghana showed that depression characterised individual experiences (De-Graft Aikins, 2005). Therefore, emotional processing involves understanding and sharing various emotions as well as to grieve the loss of health or functioning (Schulman-Green et al., 2012). In the process to adjusting to a chronic illness, different regulatory tasks and skills are required to accept the changes in daily living and to the self as a result of the illness (Schulman-Green et al., 2012). Integrating the illness into everyday living involves the tasks and skills of changing one’s lifestyle and seeking to integrate this into normal living by engaging in meaningful activities without ignoring to the illness needs (Schulman-Green et al., 2012). A study of people living with HIV and on ART in Uganda reported that participants adjusted to the new self and integrated HIV by reconceptualising HIV as a normal disease, for example going back to work and getting back to their life routines (Russell & Seeley, 2010). Meaning-making requires the individuals to reflect on the meaning of the illness in their lives and reassess their values for personal growth and fulfillment (Schulman-Green et al., 2012). Some participants decided to support others with HIV at the clinic or as ‘experts and advisers’ in their community, while others gave more weight and meaning to religion in their life (Russell & Seeley, 2010).

The concept of linked lives is important in the context of older carer-grandchild relationships. It refers to the reciprocal interactions of social relationships, and acknowledges how others influence the life course pathways and personal changes of the individual (Elder, 1994). The lives are linked through life course occurrences and pathways that influence the life course of others. The processes of self-management are influenced by the person and others, for example, healthcare professionals, family, and society (Luttik, Jaarsma, Moser, Sanderman, & Van

Veldhuisen, 2005; Udlis, 2011). While patients' families can provide support in self-management behaviours, they can also hamper the self-management behaviours (Jones et al., 2008; Rosland, Heisler, Choi, Silveira, & Piette, 2010). Understanding self-management in a context where the lives of those living with chronic conditions are interconnected with those they care for is important.

2.13 Conclusion

This chapter highlighted the different social factors that have contributed to the care provided by grandparents, as well as the intergenerational implications on the health of the older caregivers and behaviours of the adolescents. The chapter has also examined a number of theories which have implicitly and explicitly informed research, policy, and practice regarding caregiving and care relationships, and which have the potential to further inform the meanings older caregivers and adolescents attach to their experiences of the care relationship. The chapter concludes by arguing that while existing studies highlighted the impact on grandparents by assuming the role of carer and on adolescents of being cared for by grandparents, further research is needed to explore this influence in more depth.

The following chapter outlines the methodology adopted for the study.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter of the thesis addresses the methodology adopted for the study to explore caring of adolescents by older carers in the context of HIV combination prevention interventions in rural KwaZulu-Natal. Firstly, an overview of the philosophical assumptions underpinning this research is presented, followed by the research strategy and design as well as the empirical techniques applied for data collection and analysis. The socio-demographic information for the study participants is also included in this chapter as this background provides critical information for the following five chapters. The chapter concludes with the criteria to measure the rigour of this study and the strengths of the methodology.

3.2 Interpretivism as Philosophical Paradigm

The philosophical assumptions underlying this research come from the interpretive tradition. A paradigm is a set of assumptions or beliefs and practices that standardise an inquiry by providing lenses, frames, and processes which reflect a specific world view (Merriam & Tisdell, 2016; Weaver & Olson, 2006). It addresses beliefs about the nature of reality (known as an ontology), nature of knowledge (known as epistemology) (Merriam & Tisdell, 2016), and ethics and value systems (known as axiology) (Ponterotto, 2005). A paradigm further requires us to ask particular questions and use relevant approaches in the process of systematic inquiry (Merriam & Tisdell, 2016).

The interpretive perspective argues that reality is socially constructed and that there is no single, observable reality; but multiple realities or interpretations of a particular occurrence (Merriam & Tisdell, 2016). This implies that the social world is what people perceive it to be. It emphasises better insight into the reasons individuals give for their actions and the reactions of others (Weaver & Olson, 2006). Interpretivism is often used interchangeably with constructivism as researchers do not find knowledge but construct it (Merriam & Tisdell, 2016). In this study, the researcher sought to gain an in-depth understanding of the experiences of the care relationships between adolescents and their older carers and ways in which they make sense of and give meaning to their daily experiences.

The next section presents related assumptions on ontology, epistemology, axiology, and methodology in the context of the interpretive paradigm.

Ontology relates to whether we believe there is a common, shared reality or whether there exists multiple, socially constructed realities (Maree, 2016). It also addresses the questions: What is the form and nature of reality, and what can be known about that reality? (Ponterotto, 2005). If a “real” world is assumed, then what can be known about it is “how things really are” and “how things really work” (Guba & Lincoln, 1994, p. 108). Interpretivists and constructivists believe there exist multiple constructed realities, rather than a single true reality, as mentioned above (Merriam & Tisdell, 2016; Ponterotto, 2005; Weaver & Olson, 2006). The constructivist position are views that reality is subjective, contextual and situational, therefore reflects the individual’s perspectives and experience, the social context, and the interaction between the individual and the researcher (Ponterotto, 2005).

Epistemology seeks the nature of knowledge and truth (Merriam & Tisdell, 2016). It asks the following questions: What is the nature of the relationship between the knower (the research participant) or would-be knower (the researcher)? and what can be known? (Guba & Lincoln, 1994; Ponterotto, 2005). What are the sources of knowledge? How reliable are these sources? How does one know if something is true? Guba and Lincoln (1994, p. 108) argue that if a “real” reality is assumed, then the position of the knower must be one of objective detachment or value free in order to to discover “how things really are” and “how things really work”. Constructivists “advocate a transactional and subjectivist stance that maintains that reality is socially constructed and, therefore, the dynamic interaction between researcher and participant is central to capturing and describing the “lived experience” of the participant” (Ponterotto, 2005, p. 129). The researcher and the participant engage in a close and interactive relationship, therefore the findings can be seen to be created within this interactive relationship (Guba & Lincoln, 1994). For example, in this study, the researcher spent many hours with the same adolescents and older carers and interviewed them at length. The assumption is that through the process of deep interaction and dialogue, both the participants and the researcher will come to deeper understanding of the lived experience of being an adolescent cared for by an older carer or an older carer, caring for an adolescent.

Axiology refers to the part of the researcher's values in the scientific process (Ponterotto, 2005). Constructivists argue that the researcher's values and lived experiences are strongly linked to the research process (Ponterotto, 2005). The researcher should acknowledge, describe, and bracket their values, but not totally ignore them (Ponterotto, 2005). As previously mentioned, epistemology underlying a constructivist position requires an interaction between the researcher and the participants in order to construct and express the "lived experience" being studied. Therefore, the researcher cannot deny their value biases in this close interactive relationship with the participants (Ponterotto, 2005). However, constructivist researchers will also need to bracket their biases (Merriam & Tisdell, 2016; Patton, 2015; Ponterotto, 2005). This implies the researcher should investigate the different aspects of the interaction with the participants and gain insight into personal prejudices, viewpoints, and assumptions (Merriam & Tisdell, 2016). These assumptions and prejudices are then bracketed or suspended so that full attention is given to the phenomenon that is currently appearing in the researcher's consciousness (Merriam & Tisdell, 2016; Patton, 2015). However, Ponterotto (2005) states that researchers should see their biases as opportunities for dialogue with the participants. For example, the researcher has some experience in being an adolescent, and then used her experience to enhance rapport and dialogue with the adolescents.

Methodology refers to the process and procedures of the research (Merriam & Tisdell, 2016; Ponterotto, 2005). It asks the question: How can the researcher go about finding out whatever they believe can be known? (Guba & Lincoln, 1994). Deciding on a methodology flows from one's position on ontology, epistemology, and axiology, and is guided by the theoretical framework that informs understanding, the selection of literature, and research methodology on a particular study topic and the interpretation of findings (Ponterotto, 2005). Given a constructivists' position on the centrality of intense researcher-participant interaction (Guba & Lincoln, 1994; Ponterotto, 2005) and on the need to be immersed over longer periods of time in the participants' world (Ponterotto, 2005), they often embrace naturalistic designs. The aim of a naturalistic design is for the researcher to be embedded in the day-to-day lives of the research participants (Ponterotto, 2005). In other words, naturalistic inquiry studies real-world situations as they unfold (Patton, 2015) using a variety of approaches and strategies in order to develop better insights into peoples' perspectives and their social realities.

3.3 Qualitative Research Methodology

A qualitative research methodology was adopted in this study. Maree (2016) defines qualitative research as a process of naturalistic inquiry that seeks an in-depth understanding of social phenomena within their natural setting. Qualitative research is grounded in the interpretivist perspective as it involves the way the social world is described, understood, experienced, interpreted or produced.

Qualitative researchers are interested in how people arrange themselves and their settings and how they make sense of their surroundings through symbols, rituals, social structures, social roles, and so forth (Maree, 2016). This view was also described by other authors that at the heart of qualitative research is how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences (Denzin & Lincoln, 1994; Merriam & Tisdell, 2016).

Most researchers define qualitative research according to its characteristics namely the focus on meaning and understanding; researcher as a primary instrument; the inductive process; thick or rich description (Merriam & Tisdell, 2016); and contextualisation (Newman, 2014; Patton, 2015).

The researcher is the primary instrument for data collection and analysis (Merriam & Tisdell, 2016; Patton, 2015). However, with the researcher being the primary instrument, their shortcomings and biases can affect the study. As previously mentioned, for the researchers to deal with their own biases, they need to acknowledge them and monitor them according to the theoretical framework that is used. Furthermore, the researcher should be critically aware of their own interests and biases that may influence the data collection and meaning making of the data (Merriam & Tisdell, 2016).

Qualitative research places great emphasis on the understanding of phenomena, by taking the ‘emic’ perspective rather than some outside perspective (Maree, 2016; Merriam & Tisdell, 2016). As Hesse-Biber and Leavy (2011) point out, qualitative research extracts meaning from data about people’s experiences, circumstances, and situations. The process of qualitative research is inductive, meaning that researchers collect data to build concepts, hypotheses or theories, rather than deductively as used for research in the positivist paradigm (Merriam & Tisdell, 2016). Data collected from interviews, observations, or documents are integrated and categorised into major themes and sub-themes as the researcher works from the specific to the general (Merriam & Tisdell, 2016).

The outcome of a qualitative study is a rich description of the phenomenon or think descriptions (Geertz, 1973; Merriam & Tisdell, 2016). Words and pictures rather than numbers are used to convey what the researcher has learned about a phenomenon (Merriam & Tisdell, 2016). The descriptions are of the context, the participants involved, and the activities of interest (Merriam & Tisdell, 2016). Also, data in the form of quotations from interviews, field notes, and documents are used as evidence for the findings of the study (Merriam & Tisdell, 2016).

Qualitative research emphasises the social context of the research (Patton, 2015) because the meaning of social actions, events, or statements depends on the context in which they occur (Newman, 2014). The context of people’s lives affects their behaviours and the meanings they attach to their actions. Context has multiple layers and is dynamic, changing over time (Patton, 2015). It includes a time context when the time something occurs, location of the context, feelings involved regarding the occurrence, and socio-cultural context of the occurrence (Newman, 2014). Researchers need to shape data gathering methods and the overall research approach to the context (Patton, 2015).

3.4 Research Design

This study selected an ethnographic research design to understand caring of adolescents by older carers in the context of HIV combination prevention interventions. A research design is a plan or strategy that is underpinned by a particular research paradigm that guides the selection of participants, the formulation of research questions, the methods used in data collection method, and the way data should be analysed (Maree, 2016). Therefore, the selection of a particular research design refers to the researcher's ontological and epistemological perspective that determine the methodological approach (Maree, 2016).

3.4.1 Ethnographic approach

Ethnography refers to a qualitative design in which the researcher studies the shared and learned patterns of values, beliefs, behaviours, and language of a culture-sharing group (Creswell, 2007). It focuses on the study of culture (Wagner, Kawulich, & Garner, 2012) by describing and interpreting the cultural or social group (Maree, 2016). Although there are many definitions of culture, it essentially refers to the beliefs, values, and attitudes that structure the behaviour patterns of a specific group of people (Merriam & Tisdell, 2016). Ethnography is also called naturalistic research because it emphasises observing the details of everyday life as they naturally unfold in the real world (Rubin & Babbie, 1993). The roots of ethnography can be traced back to the early 1900s when small anthropological studies by researchers such as Bronislaw Malinowski were conducted in rural societies over extended periods of time by documenting their social arrangements and belief systems (Reeves, Kuper, & Hodges, 2008). Understanding people's culture requires an investigation of the setting to better understand a particular culture group's views, values, and practices (Wagner et al., 2012). Anthropologist Clifford Geertz (1973) pronounced that an ethnographer's task is to explore and explain culture through thick descriptions that gives detailed insight into peoples' perceptions, feelings, imaginations, and perceptions of their world. He emphasises the need for a long term immersion of the researcher in the naturalistic settings and to provide thick and rich description of the culture in all its dimensions (Geertz, 1973). Ethnographers therefore spend a significant amount of time in the field to study the lives of the people from within their naturalistic setting (Maree, 2016; Merriam & Tisdell, 2016). This requires an understanding of the language spoken in that setting, engagement in some of the activities taking place in that setting, and reliance on intensive fieldwork with a select group of participants from the setting (Merriam & Tisdell, 2016).

According to Maree (2016), ethnography argues that all human behaviour is intentional and observable and the researcher should, therefore focus on understanding the reasons for people's behaviours. People are seen to display the culture through behaviours in specific social contexts, however the display of behaviour do not give meaning but meaning is rather inferred (Newman, 1997). This requires an ethnographer to move from what is heard or observed to its meaning. Meaning of behaviour can only be known through the immersion of the researcher in the setting to observe and experience the culture and its detailed descriptions, and to provide descriptions thereof (Merriam & Tisdell, 2016). The data set may constitute formal and informal interviews, records, documents, and artefacts as well as a fieldwork diary of each day happenings as well as personal reflections and insights of those events (Merriam & Tisdell, 2016).

An ethnographic approach offers several advantages to this study in understanding the caring for adolescents by older carers and how these experience affects their lives over time. First, an ethnographic approach provides a deeper understanding of the participants' experiences over time, which cross-sectional methods may not provide. It provides the nuanced understanding of phenomena, which evolve through time. Second, the use of participant observation enabled the researcher to become immersed in the setting, thereby generating a rich understanding of the social setting (environment in which care relationships took place). Participant observation also gave the researcher opportunities to gather empirical insights into practices and behaviours which are normally hidden from the public as outlined by authors (Reeves et al., 2008).

3.4.2 Dyadic approach

The current study adopted a dyadic approach to explore care relationships between older carer-adolescent dyads. A dyadic approach is used to study relationships (Caldwell, 2014; Maguire, 1999; Wittenborn, Dolbin-MacNab, & Keiley, 2013). One's life is shared in different personal relationships with family members, friends, romantic partners, and co-workers in the workplace (Wittenborn et al., 2013). In this case, adolescents and their older carers are in a care relationship. Family researchers have long recognised the linked nature of human lives and have used the dyadic approach to obtain data about individual and relationship characteristics from multiple members of a relationship to address a relationally focused research question (Wittenborn et al., 2013). This approach also enables researchers to examine the dyadic views of reality, dyadic meaning, and dyadic everyday living as well as the nature of the relationship (Eisikovits & Koren, 2010).

3.5 Data Collection Techniques

Ethnography aims to provide thick, holistic insights into people's views and actions, as well as the setting they inhibit through the collection of data (Reeves et al., 2008). Ethnographers employ a combination of data collection techniques over extended periods. The primary data collection techniques in ethnography are participant observation, interviews, and document analysis (Patton, 2015). The use of multiple data collection techniques is called data source triangulation (Merriam & Tisdell, 2016). Triangulation serves to reduce bias and ensure the integrity of the participants' responses. A study in Tanzania collected data from various sources using participant observation, in-depth interviews, and focus group discussions to increase their understanding of complex issues related to young people's sexual behaviours (Wamoyi, Fenwick, Urassa, Zaba, & Stones, 2011). This section will discuss three techniques which were used to collect and record data in this study.

3.5.1 Participant observation

Through participant observation, learning occurs about how people behave and interact with others in their everyday natural context (Skovdal & Cornish, 2015). It involves simultaneously being part of the everyday life and observe the actions of others in their everyday living (Kawulich, 2005). Participant observation is used to have a better understanding of what is important in this community; the norms and habits, the social relationships and hierarchies, the support that is available, the power dynamics among people and relationships with institutions, and the context in which they live (Skovdal & Cornish, 2015). Participant observation method was utilised in this research because it provided direct access to behaviour in its natural context (Skovdal & Cornish, 2015). The researcher spent a period of 12 months with adolescents and their older carers, thus accessing what they do in daily life, and participating in the ordinary course of their activities. The object of interest such as behaviours modelled by older carers arose in the course of everyday activities, and the researcher had the opportunity to understand them in context. By spending time in the homes of adolescent-older carer families, the aim was to gain a concrete understanding of what it is like to be cared for by an older carer or to care for an adolescent for the participants, and of their experience of HIV interventions.

3.5.2 Key informant interviews

Key informant interviews are used to scope out basic information or to do a rapid appraisal of the situation in a particular setting through key informants (Skovdal & Cornish, 2015). Key informants are those individuals who possess rich and concrete knowledge or first-hand knowledge of the phenomena (Skovdal & Cornish, 2015) and who are willing to share that knowledge with the researcher (LeCompte & Goetz, 2008; Marshall, 1996). Key informants are able to provide detailed, objective information, clarity and a deeper insight into the happenings around them (Ponterotto, 2006) . With this kind of interview, researchers are particularly keen to gain objective information about different situations (Skovdal & Cornish, 2015).

3.5.3 In-depth interviews

An in-depth interview is a conversation between the researcher and the participant, where the researcher seeks knowledge from the participant's point of view (Hesse-Biber & Leavy, 2011) in order to make meaning about a particular phenomenon. In-depth interviews are suitable for collecting data on individuals' personal histories, perspectives, and experiences. In-depth interviews are essential for understanding how participants view their worlds. Researchers who conduct in-depth interviews look for patterns that occur in the thick descriptions of social life as explained by the participants (Hesse-Biber & Leavy, 2011).

a) *Repeat interviews*

It is common to interview participants on multiple occasions in ethnography (Vincent, 2013). Ethnography is longitudinal as it is conducted over extended periods. Multiple (repeat) interviews are used to collect data with research participants. For example, an ethnographic study in Tanzania conducted repeat interviews with participants to elicit a more detailed understanding on parental control and monitoring and the implications of this on young people's sexual decision making (Wamoyi et al., 2011).

Repeat interviews allow researchers to study individual lives over time, noting the factors that influence individual life trajectories (Hutchison, 2010). Vincent (2013) suggests that repeat interviews offer unique advantages over single interviews. Repeat interviews are useful for documenting participants' lived experiences over time (Vincent, 2013) and allow participants to reflect on their lived experiences as they are happening (Saldana, 2003). Qualitative researchers are interested in the lived experience of change, or sometimes stability, over time (Calman, Brunton, & Molassiotis, 2013). It is through the immersion of the researcher in the natural setting over time that knowledge can be gained of the nature of social change, the way it occurs and strategies that individuals use to enable and manage change in their personal lives (Neale & Flowerdew, 2003). This will also enable knowledge into how structural change influence the lives of individuals (Neale & Flowerdew, 2003). Therefore, repeat interviews allow researchers to make connections operating at individual and societal levels (Neale & Flowerdew, 2003). Repeat interviews allow researchers to ask follow-up questions and can be tailored for each individual (Vincent, 2013). Experiences since the last interview can be shared (Murray et al., 2009). Ethnography requires the researcher to establish and maintain contact with the research participants over time (Vincent, 2013). As a result, repeat interviews provide natural opportunities to develop deeper relationships between participants and the researcher that will impact the trust between then which in turn will ease the discussion of sensitive and personal topics and allow for a deeper insight into phenomena (Murray et al., 2009). These advantages of repeat interviews offer a powerful alternative to single interviews.

b) *Separate interviews*

The large body of research on adolescent-older carer relationships spring from research carried out with older carers exclusively, with few investigating the adolescents' perspective (Triado, Feliciano, Sole, Osuna, & Pinazo, 2005). There is a need to conduct research with dyads (pairs) because the carer and the cared for both have their own individual perspectives of the relationship and experience of HIV interventions. Interviews with dyads can be conducted separately, jointly, or in combination (Caldwell, 2014; Ummel & Achille, 2016) and have been primarily used to study relationships between patients and their older carers, patients and nurses, parents and children (Phillips, Comeau, Pisa, Stein, & Norris, 2016), and couples (Wittenborn et al., 2013). Separate interviews are conducted with each dyad member to allow them to respond from their perspective, whereas joint interviews are carried out with both dyad members simultaneously to produce a shared narrative (Polak & Green, 2016; Seale, Charteris-Black, Dumelow, Locock, & Ziebland, 2008; Zarhin, 2018). Scholars have identified several advantages and disadvantages of both joint and separate interviews. Several concerns have been raised about joint interviewing in that dyad members may alter their responses to please the other dyad member (Morris, 2001) by providing answers which are acceptable to the partner (Taylor & de Vocht, 2011). One member may dominate the interview (Forbat & Henderson, 2003) or silence the other member (Polak & Green, 2016; Zarhin, 2018). Individual perspectives of dyads may be harder to separate in joint interviews (Taylor & de Vocht, 2011). Joint interviews may also create tensions among dyad members, trigger conflicts, and harm the quality of relationships (Zarhin, 2018).

In contrast, separate interviews could help to overcome some of the disadvantages of joint interviews with dyads. Each partner is free to tell the story from their own perspective without having to be concerned about the reaction of the other person when providing criticism or sharing sensitive topics (Morris, 2001). This does not mean that an individual should be interviewed without their partner’s knowledge or consent; it only brings awareness that an individual might not necessarily share the same experiences and views of their partner and thus capturing these unique perspectives might be easier in separate interviews (Taylor & de Vocht, 2011). The researcher was aware of possible power dynamics between adolescents and their older carers; hence a separate interviewing approach was adopted in this study, with each participant being interviewed separately.

3.6 Instruments

Participant observation data were recorded in field notes, following an observation guide (see Appendix 12). Field notes provide a written record of the researcher’s observations and experiences during data collection and fieldwork (Skovdal & Cornish, 2015). Writing good field notes should begin by drawing a map of the setting in which the researcher is conducting the observation (Kawulich, 2005), followed by a description of the setting in the field notes (Wagner et al., 2012). Field notes include records of what is observed, including informal conversations with participants, records of activities and ceremonies (Kawulich, 2005), discussions between research participants, and participants’ nonverbal and verbal communication (Wagner et al., 2012).

An interview guide is a set of topics and questions that the researcher will cover during the interview (Hesse-Biber & Leavy, 2011). The researcher can adapt the sequencing and wording of the questions to each interview (Rubin & Babbie, 1993). In this study, the researcher used interview guides (see Appendix 13-15) to elicit information from adolescents, older carers, and HIV programme facilitators during interviews. The interview guides consisted of a series of open-ended semi-structured questions and were tailored for each category of the study participants. The open-ended questions for the older carers were designed to allow the participant to “tell their story” of their family history, circumstances of caring for the adolescent, and experiences of HIV interventions in order to capture the qualitative nature of the data. The interview guide also allowed adolescents to describe their experiences of being in the care of older carers and their experiences of HIV interventions. Additionally, the interview guide for the HIV programme facilitators focused on the description of HIV interventions and the experiences of the programme facilitators on working with the older carers and their adolescent grandchildren.

3.7 Study Setting

This study was conducted in the uMkhanyakude district, northern KwaZulu-Natal in South Africa. The district is predominately rural with high rates of poverty and unemployment (Herbst et al., 2015). There are high mobility patterns of the population in this district and frequent changes in the populations’ living arrangements (Tanser et al., 2008). The district is characterised by people living in predominantly multi-generational families consisting of grandparents, adult children, and grandchildren. In this setting, orphaned and vulnerable children live with extended families (Tanser et al., 2008). The number of AIDS-orphans increased between 2000 and 2005 in this district (Knight, Hosegood, & Timaeus, 2016). The district has a high HIV prevalence and incidence (Chimbindi et al., 2018). About 19% of adolescent girls and young women (AGYW) and 5.6% of adolescent boys and young men (ABYM) are living with HIV (Francis et al., 2018). Also, the area has a high prevalence of STIs among young people aged 15 to 24 years (Francis et al., 2018). Free HIV testing, treatment, and care services are available from the public healthcare facilities, in accordance with South African Department of Health (DoH) guidelines in this setting.

Within this context, a multi-sectoral HIV combination prevention programme – the DREAMS Partnership was implemented between April 2016 − September 2018 to reduce HIV infection in AGYW (and their male sexual partners) through evidence-based health, and educational and social interventions (Chimbindi et al., 2018). The DREAMS Partnership is an investment by the U.S. Government President's Emergency Plan for AIDS Relief (PEPFAR) office, Bill and Melinda Gates Foundation, Girl Effect (formerly the Nike Foundation), and other private sector partners, announced in 2014 (Saul et al., 2018). The overall aim of DREAMS is to reduce HIV incidence in AGYW through a combination of interventions that target community, family, male partners, and AGYW to promote safer sexual relations, social protection, biological protection, and empower AGYW. The DREAMS core package, aimed at addressing HIV risk behaviours; HIV transmission; socio-economic vulnerabilities; and gender-based violence is delivered by five main implementing partners (IPs) and five sub-contracted community based organisations. They work closely with government departments including the DoH, the Department of Social Development (DSD), and the Department of Basic Education (DBE), as well as the local municipality (Birdthistle et al., 2018). A fuller description of the DREAMS interventions and the list of IPs delivering the interventions are provided in Chimbindi et al. (2018).

The researcher chose the uMkhanyakude district as a research site because the district is one of the sites in which the DREAMS programme (herein referred to as HIV combination prevention interventions) was implemented in South Africa (Chimbindi et al., 2018).

3.8 Sampling and Study Populations

By its very nature, qualitative research is not prescriptive (Wagner et al., 2012). Owing to the intense and in-depth nature of qualitative studies, sample sizes tend to be small (Wagner et al., 2012). The sample of participants for this research was primarily recruited using purposive sampling. The purposive sampling technique is the deliberate choice of a participant due to the qualities the participant possesses. In purposive sampling, the researcher uses specific selection criteria to identify and select the information-rich cases (Patton, 2015; Wagner et al., 2012). Members of a sample are chosen with a ‘purpose’ to represent a phenomenon or group (Maree, 2016).

As mentioned previously, a large body of research on adolescent-older carer relationships springs from research carried out with older carers exclusively, with few investigating the adolescents’ perspective (Triado et al., 2005). The most precise way to approach this issue would be to use samples consisting of older carer-adolescent dyads. By examining and confronting this double-sided perspective, the researcher could get a deeper understanding of the caring context. Also, knowing both perspectives may help work out better ways to optimise such a relationship.

A purposive sample was used to select adolescents and their older carers (n=12) and HIV programme facilitators (n=2) to understand the experiences of caring for adolescents by older carers in the context of DREAMS interventions, according to the following selection criteria:

Adolescents

- An adolescent (boy or girl aged) aged 13-19 years whose primary caregiver was an older carer (man or woman) aged 50 years and above in uMkhanyakude district.
- An adolescent who was the recipient of DREAMS intervention.

Older carers

- An older carer (man or woman) aged 50 years and above who was the primary caregiver for an adolescent (girl or boy) aged 13-19 years who was the recipient of DREAMS intervention.

HIV programme facilitators

- Individuals (men or women) working for the organisation responsible for the implementation of DREAMS interventions in the uMkhanyakude district and involved in delivering interventions to adolescents.

3.9 Procedures

The following section outlines the procedures that were followed in the study. It begins with an explanation of how entry into the research sites was gained, followed by recruitment of study participants. Finally, the specific data collection methods and techniques used to analyse the data are also presented in this section.

3.9.1 Gatekeepers' permission and ethical clearance

The study first obtained permission from the Africa Health Research Institute (AHRI) (see Appendix 2), the DREAMS Programme (see Appendix 3), and the Community Advisory Board (CAB) of the AHRI (see Appendix 4). The CAB is made up of members of the tribal and civil councils in the local uMkhanyakude district. Secondly, the study received ethical clearance from the University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee (HSS/1109/017D). Details pertaining to the ethical clearance required in this study are discussed later in this chapter under ethical considerations. An ethical clearance letter is attached as Appendix 1. Lastly, the researcher obtained permission from the DREAMS IP (that is, DREAMS implementing organisation) in the community to conduct the study.

3.9.2 Recruitment of study participants

The researcher first recruited HIV programme facilitators as key informants to participate in the study. The programme facilitators also assisted the researcher in identifying adolescents who met the selection criteria to be invited to participate in the study. The programme facilitator and the researcher arranged to visit the adolescents and their older carers to introduce the study and to build rapport. Both the programme facilitator and the researcher visited the individuals at home for the introductory meeting. Thereafter, in subsequent visits, the researcher visited the individuals on her own to discuss the study in detail and to invite the individuals to participate in the study.

For dyads who were interested in participating, arrangements were made to visit them at home to do participant observations and to arrange individual interviews at convenient times for the participants. Also, interested programme facilitators were interviewed at convenient times and places.

3.9.3 Data collection

The researcher obtained written informed consent from all participants (key informants, adolescent-older carer dyads) in the study, using participant information sheets (PIS) (see Appendix 5-7), informed consent forms (see Appendix 8-10), and child assent forms (see Appendix 11). Consent to audio record interviews was also requested from the participants, and this was included in the informed consent form and child assent form. The PIS and consent forms were translated into isiZulu by a qualified translator.

To ensure informed consent of participants, individuals were first informed again of the aims and objectives of the study. An informed consent was obtained by explaining the study information as indicated in the PIS, which covered the following:

- Voluntary nature of study participation and that the participant may decline or withdraw participation during any stage of the interview without any negative consequences.
- Participation and data obtained would be confidential, and data would only be used for research purposes.
- Data would be anonymous as no name would be used to link information obtained to the particular participant. Any information collected would be identified on forms and computer files only by a study participant number, not the participant’s name.
- The information obtained would be reported in a research report and published in accordance with ethical guidelines.
- No monetary or any other benefits would result from participation in the study, but participants were offered a light snack at the end of the interview.

The participants were given copies of PIS and consent forms, and the researcher retained the original copies of the consent forms. The researcher treated informed consent as a process, reminding participants at each phase what the study was about, answering any related questions, providing information, and reiterating that participants could withdraw from the interview and/or study at any time.

Data collection was done in three phases over 12 months from October 2017 to September 2018 in order to elicit rich qualitative data, as shown in Table 3.1. All the interviews were conducted in isiZulu by a single interviewer, who is also the PhD candidate. Additionally, she kept a reflective journal in which she noted her experiences of the whole research process. The journal contained concrete descriptions of the interviewer's experiences.

Table 3.1: Summary of data collection phases and activities

Phases	**Period**	**Key informant interviews**	**Interviews with adolescents**	**Interviews with older carers**	**Observations**
Phase 1*	October 2017 – January 2018	2	4	5	9
Phase 2	February – May 2018	-	6	6	11
Phase 3**	June – September 2018	2	7	8	8
Total		4	17	19	28

*Two adolescents and one older carer were not interviewed as they were absent.
**One adolescent and two older carers were interviewed twice.

Phase 1: This was the first phase of data collection over four months from October 2017 to January 2018. The researcher first conducted two key informant interviews with HIV programme facilitators to get an insight into the DREAMS interventions and circumstances facing adolescents in the care of grandparents. After that, nine separate interviews with adolescents and their older carers were conducted. Conducting the interviews in privacy was a priority. Even if the other individual in the dyad was also at home, the interview was conducted in a private space without anyone else being able to overhear. The initial interviews focused on the participants' life history, family composition, dyad relationship, and experiences with HIV interventions. The researcher asked open-ended questions to capture how each individual understood their own past and experiences. As Newman points out, exact accuracy in the story is less critical than the story itself. In other words, the objective was to arrive at how the participants recalled their past rather than the objective truth (Newman, 2014). All the interviews were audio recorded, and each lasted between 30 and 120 minutes depending on how much a participant wished to talk at the particular interview. Dyads were also visited at home for participant observation at different times of the day. These data were recorded in field notes focusing on what was observed, informal conversations with participants, records of activities, conversations between participants, and participants' nonverbal and verbal behaviours.

Phase 2: Before the second phase, data were analysed to identify emerging themes and issues to follow up with each individual in the next phase of interviews. Therefore, the second phase of data collection was conducted from February 2018 to May 2018 using repeat interviews and observations. The interviews focused on the concrete details of participants' experiences in the topic area.

Phase 3: The last phase of data collection was conducted from June 2018 to September 2018. The final interviews enabled participants to consider the meaning of their experiences. The multiple-interview approach also allowed the researcher and the participants to explore any additional thoughts and feelings about the topic.

Table 3.2 provides the socio-demographic information for the adolescent-older carer dyads as this background is critical across the next five chapters of this thesis.

Table 3.2: Socio-demographic characteristics of adolescent-older carer dyads

Older carers (n=6)				**Adolescents (n=6)**					
Name and age (years) in 2017	**Sex (F/M)**	**Relationship**	**Number of children in care**	**Name and age (years) in 2017**	**Sex (F/M)**	**Number of years with older carer**	**In school (Y/N)**	**Biological mother alive (Y/N)**	**Biological father alive (Y/N)**
MaNdawo (76)	F	Paternal grandmother	3	Thabani (15)	M	3	Y	Y	Y
MaZulu (64)	F	Maternal grandmother	15	Neli (14)	F	**10**	Y	Y	N
MaNgubo (80)	F	Maternal grandmother	6	Zama (15)	F	15	N	Y	Y
MaDube (58)	F	Maternal grandmother	11	Sane (13)	F	3	Y	Y	N
MaJali (56)	F	Maternal grandmother	2	Thandi (13)	F	13	Y	Y	N
MaKhoza (64)	F	Paternal grandmother	**9**	Mpume (19)	F	6	N	Y	N

Notes: All names are pseudonyms. F=Female M=Male N=No Y=Yes

3.10 Data Management and Analysis

Anthropologist Clifford Geertz (1973) uses the term thick and rich description and emphasises the need to study of human social behaviour through interpretive approaches. Ethnography focuses on understanding and describing meaning in social life. It involves thick participation whereby a researcher spends sustained time with participants and thick description by describing the phenomenon in as much detail as possible including its complexity (Geertz, 1973; Maree, 2016). Ethnography also uses thick analysis or multiple strategies of data analysis (Evers, 2016). The concept of thick analysis was introduced in 2010 by Evers and Van Staa to indicate the purposeful and creative combination of analysis methods to analyse a set of qualitative data (Evers, 2016). Thick analysis deals with the complexity of social phenomena more comprehensively than the use of just one analysis method (Evers, 2016). The researcher combined both thematic and dyadic analysis approaches to understand care relationships and the lives of adolescents and their older carers in order to add a deeper understanding of the data as suggested by Evers (2016).

Data analysis was done using four steps for conducting qualitative data analysis as devised by Babchuk (2019). The steps are illustrated below:

Step 1: Assembling materials for analysis

In the first step of qualitative data analysis, the researcher transcribed interviews and laid out other forms of data to be analysed including observational notes and memos. Data was clearly labelled and stored in a password-protected computer and locked in a filing cabinet. The interviews were transcribed verbatim, translated into English and managed using Atlas.ti 8.

Step 2: Re-familiarising oneself with the data

This step constituted an initial read through the transcripts and notes from participant observations in order to bring the researcher increasingly closer to the data as guided by Babchuk (2019). The entire transcribed text and field notes were thoroughly read to obtain an overall and comprehensive impression of the content and context. The researcher began to write personal reflective field notes, a technique developed by

Glaser and Strauss (1967) called memoing. Memos can be used to enable the researchers to immerse themselves in the data, and to explore the meanings that the data bring, maintain continuity, and sustain momentum in conducting the research (Birks, Chapman, & Francis, 2008).

Step 3: Coding, generating categories and themes

Coding is about identifying and naming sections of data with a label that helps to categorise, summarise, and account for each section of data and normally consists of at least two phases: initial coding (also known as open coding) and focused coding (also known as selective coding) (Charmaz, 2006). According to Babchuk (2019), in initial coding, the researcher assigns codes to text segments or passages. When researchers conduct initial coding, they compare data with data and stay close and remain open to exploring what they interpret is happening in the data (Charmaz, 2006). In this study, the researcher conducted a second read through the transcripts, observational notes, and memos to begin initial coding procedures. While coding, the researcher used the constant comparative method, which Glaser and Strauss (1967) define as comparing data with data, data with code, and code with code, to find similarities and differences. In focused coding, the researcher condenses initial codes into manageable categories (Babchuk, 2019; Merriam & Tisdell, 2016) through inductive data analysis (Thomas, 2006). As previously mentioned an inductive analysis enables the researcher to derive concepts, themes, or a model by interpreting the raw data after detailed readings of the data (Thomas, 2006). The researcher derived names of categories and used participants’ phrases as well as research literature. This was followed by the process of generating themes from the categories. According to Babchuk (2019) this process involves comparing categories and looking for the story to tell.

Step 4: Interpreting findings

Interpretation of findings is described by Patton (2015) as the final phase of the data analysis process which involves an explanation of the findings, answering why questions, attaching significance to particular results, and putting patterns into an analytic framework. It is a discussion of findings in which the researcher situates the findings in the context of literature and theory (Babchuk, 2019).

Moreover, the study followed the procedure of dyadic analysis as guided by Eisikovits and Koren (2010). The first level of the dyadic analysis procedure is described as similar to that performed in qualitative studies on the individual level. Data should initially be divided into significant statements in a process called horizontalisation (Merriam & Tisdell, 2016) including quotes that provide an understanding of how the participants experienced the phenomenon (Eisikovits & Koren, 2010). This process allows for categories of data to be developed where responses are clustered together to create themes within the data. The second level is unique to dyadic analysis which is the examination of the themes emerging from the narratives of each dyad individual, and the assessment of contrasts and overlaps between the individual versions (Eisikovits & Koren, 2010).

3.11 Ethical Considerations

Ethical considerations are highly significant in any research. The ethical considerations of the current research were largely influenced by the basic philosophies underlying research codes relevant to research with human subjects. In particular, principles that provide a coherent framework for evaluating the ethics of research studies proposed by the Belmont Report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979) guided the researcher in guaranteeing ethical conduct in this study. The major, well established and accepted principles of ethics in research include: ensuring informed consent of participants, avoiding harm to participants, and respecting the privacy of participants (Gray, 2009).

3.11.1 Ensuring informed consent of participants

The principle of informed consent implies that research participants are given adequate and accessible information about the study to enable them to either make an informed decision about participation in the study or not (Gray, 2009). Before participating in this study, all participants were made aware of the aims and objectives of the study, the duration of the study, the number of repeat interviews, and the time the researcher has to spend with the participant during data collection as per the PIS. It was made clear that participation was voluntary and they could withdraw from participation in this study at any point in the study without suffering negative consequences.

To ensure the informed consent of the participants, the researcher adhered to the following:

- Informed of the nature and purpose of the study;
- Asked whether they wanted to participate in the research;
- Asked if they agreed to be recorded;
- Assured of confidentiality and anonymity;
- Advised that they could withdraw at any stage of the interview without giving a reason and refrain from answering any questions with no negative consequences;
- Asked to sign a written consent form confirming their consent to the above.

In subsequent interviews, participants were reminded about the study; however, only oral informed consent was requested during follow up interviews.

3.11.2 Avoiding harm to participants

The Belmont Report emphasises beneficence. The principle of beneficence refers to the obligation of researchers to ensure in a way that benefits the health and well-being of participants in scientific investigations; conversely, the principle of non-maleficence refers to their obligation to do no harm (Marshall, 2007). Therefore, the principles of beneficence and non-maleficence emphasise the importance of maximising benefits and minimising potential harm. Ethically sound research requires appropriate steps to ensure that participants will not suffer undue medical, social, and psychological harm during research (Gray, 2009). The participants were given the participant information sheet which explained the purpose of the study. No direct physical or psychological harm was envisaged to occur through the process of taking part in this study. However, it was acknowledged that some participants might recall memories that could cause discomfort or distress during the interviews. In response to this anticipation, information on support groups and welfare services for people experiencing psychosocial and relationship and family problems was provided to all participants.

3.11.3 Respecting the privacy of participants

Participant confidentiality is an ethical requirement of research (Creswell, 2007). This requires the use of pseudonyms or false names to preserve anonymity (Surmiak, 2018). The practice of anonymising research participants is common in qualitative studies by using pseudonyms to protect participant identity (Gumede, Young-Hauser, & Coetzee, 2017; Knight et al., 2016; Ngwenya et al., 2018; Skovdal, Ogutu, Aoro, & Campbell, 2009b). In this study, to ensure anonymity, even for the storage of data, pseudonyms were assigned to each participant. The assigned pseudonyms were the names that were also be used during the presentation and discussion of the data in this study. The pseudonyms were chosen following cultural norms of respect that were observed in the study area between addressing an older person and younger person. Older people are not called by their first name but a prefix ‘Ma’ is used before their maiden name. Therefore, older carers were assigned pseudonyms with the prefix ‘Ma’.

3.12 Establishing Trustworthiness

Without rigour, research becomes fiction and loses its worth (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Positivist and interpretivist researchers have different views on how research rigour can be assessed. Reliability and validity are the key measures in quantitative research (Wagner et al., 2012). The work by Lincoln and Guba discusses the concept of trustworthiness to establish rigour in qualitative research. Trustworthiness is achieved when findings, as closely as possible, reflect the meanings as described by the participants (Lincoln & Guba, 1985). They suggest that four criteria may be used by qualitative researchers to ensure trustworthiness of a study: credibility, transferability, dependability, and confirmability instead of internal validity, external validity, reliability, and objectivity, respectively.

3.12.1 Internal validity or credibility

In quantitative research, validity (or internal validity) refers to the degree to which research findings match reality or the degree to which research findings are congruent with reality (Merriam & Tisdell, 2016). However, as previously mentioned, in a qualitative inquiry, internal validity is replaced with credibility (Lincoln & Guba, 1985). Credibility is defined as the confidence that can be placed in the truth of the research findings (Lincoln & Guba, 1985). According to Maree (2016, p. 123), credibility deals with the questions, “how congruent are the findings with reality?” and “how do I ensure that the reader will believe my findings?” Credibility is used to address activities that make it more credible that the findings were derived from the data (Wagner et al., 2012). Lincoln and Guba (1985) describe a series of techniques that can be used for establishing credibility: prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member-checking.

3.12.2 External validity or transferability

Unlike generalisability in quantitative research, transferability refers to the extent to which the results of qualitative research can be transferred to other contexts with other participants (Lincoln & Guba, 1985). Transferability invites readers of research to make links between elements of the study and their own experience or research (Maree, 2016). To increase transferability, participants should be typical of the phenomenon being studied and the researcher should provide sufficient descriptive data of the context being studied (Lincoln & Guba, 1985). It is from this premise that readers can explore and determine if the research is transferrable to their context. Merriam and Tisdell (2016) offer strategies which qualitative researchers can use to enhance transferability including rich, thick description (Geertz, 1973), and the use of maximum variation sampling as pioneered by Glaser and Strauss (1967).

3.12.3 Reliability or consistency (dependability)

Qualitative researchers are concerned with dependability between their explanations and how participants’ view the phenomenon of inquiry (Lincoln & Guba, 1985). Dependability is achieved through the research design and its rigour in implementation; the operational detail of data gathering; and the reflective appraisal of the study (Maree, 2016). Merriam and Tisdell (2016) suggest that strategies to achieve dependability are triangulation, reflexivity, peer review, and the audit trail.

3.12.4 Objectivity or confirmability

Confirmability means ensuring that the findings are grounded in the data or shaped by the participants and not by researcher bias or constructions (Lincoln & Guba, 1985; Wagner et al., 2012). It is the degree to which the study findings can be confirmed or corroborated by other researchers (Anney, 2014). To increase confirmability, Lincoln and Guba (1985) suggest an audit trail, triangulation, and reflexivity.

3.13 Methodological Strategies Employed to Increase Trustworthiness

The next section will present how the researcher established rigour in the inquiry by adopting the following methodological strategies in this study: triangulation, prolonged engagement, thick description, reflexivity, and peer review or debriefing shown in Table 3.3.

3.13.1 Triangulation

The best-known strategy to increase internal validity or credibility is triangulation. It involves the use of different methods, sources, and theories to confirm emerging themes (Merriam & Tisdell, 2016). Triangulation assist in reducing bias as it cross verifies the integrity of participants' responses (Anney, 2014). Four measure triangulation techniques are used (Lincoln & Guba, 1985). The first triangulation technique involves the use of multiple investigators to study the same problem, which brings the different views of the inquiry and helps to strengthen the integrity of the findings. The second is data source triangulation that uses different sources of data or research instruments such as interviews, focus group discussion, participant observation, participatory methods, or that utilises different informants to enhance the quality of the data from the different sources. The third method is triangulation that uses different research methods and lastly, theory triangulation that uses multiple theoretical perspectives to examine and interpret the data. Morse (2015) suggests that triangulation increases the scope or depth of the study, because different data sets or different methods may each elicit different data, different participants, or perspectives.

This study used methods triangulation, data source triangulation, and theory triangulation. Firstly, the study combined participant observation, in-depth interviews, and key informant interviews to provide richer and more comprehensive data. Observing situations that participants discussed with the researcher during in-depth interviews, allowed the researcher to verify her understanding and to ensure correct interpretation of the data. Methods triangulation involved checking out the consistency of findings generated by different data collection methods. Secondly, the data sources, which were used in this study were adolescents, their older carers, and HIV programme facilitators. These sources provided multiple perspectives on the phenomenon. Thirdly, for theory triangulation, the study applied the life course perspective, the social-ecological model, and the self-management processes model to examine and interpret data.

3.13.2 Prolonged engagement

Ethnography requires the researcher to be immersed in the participants' world in order to establish a relationship of trust with the participants and to gain insight into the context of the study (Geertz, 1973; Lincoln & Guba, 1985). This involves spending extended time in the field to observe various aspects of the setting, speaking with a range of people, and developing relationships and rapport with members of the community. Morse (2015) suggests that prolonged engagement is necessary for producing thick, rich data.

In this study, the researcher walked around the study site to familiarise herself with the environment, observing infrastructures and people. Thereafter, she conducted fieldwork over 12 months in the study site with the same group of participants. The extended period was important because as rapport increased, participants volunteered different and often more sensitive information than they did at the beginning of the research project. Also, spending more time on data collection in the study site provided time for trust to be established with participants. With increased trust, the researcher obtained better, richer data.

3.13.3 Thick description

To increase credibility, transferability, and confirmability, qualitative researchers use a thick description of the phenomenon under study (Geertz, 1973; Merriam & Tisdell, 2016). Thick descriptions mean that the researcher provides the reader with a full and detailed account of the context of the study, participants, research design, participant views, and data (Anney, 2014; Geertz, 1973). A thick description of study participants entails describing the participants of the study fully without compromising anonymity (Ponterotto, 2006). In other words, a thickly described sample facilitates the reader's ability to visualise the sample with the relevant demographic and psychological characteristics (Ponterotto, 2006). In this study, the researcher reports demographic characteristics of the participants such as age, gender, marital status and so on.

Describing the setting and procedures in sufficient detail provides a context for understanding the findings of the study as suggested by Ponterotto (2006). A thick description of results provides a clear voice of participants by using long quotations from the participants or excerpts of interviewer-interviewee dialogue as mentioned by Ponterotto (2006).

3.13.4 Reflexivity

Credibility is further enhanced through the application of reflexivity which refers to the researcher’s insight of how the researcher affects and is affected by the research process (Merriam & Tisdell, 2016). Researchers are required to disclose their assumptions, biases, and experiences in relation to the study at hand. This implies that the researcher should reflect on self to recognise and take accountability for one’s own situatedness within the research and the influence it may have on the setting and people that are being studied, the particular questions that are being asked, the data that are being collected and its interpretation (Berger, 2015). This disclosure helps the reader to understand better how the researcher arrived at the interpretation of the data (Merriam & Tisdell, 2016). Within research reports, reflexivity is normally presented as a description of the ethnographer’s ideas and experiences, which can be used by readers to assess the possible impact of these influences on a study (Reeves et al., 2008). In this study, the researcher engaged in reflexivity through a reflexive journal to record her thoughts, decisions, and experiences during the research process. This will help others to follow the researcher’s reasoning and how the researcher arrived at the interpretations.

Table 3.3: Strategies used in this study to ensure trustworthiness

Criteria	Strategies	Actions taken
Credibility	Methods triangulation	Used multiple methods: observations, key informant interviews, and in-depth interviews.
	Data sources triangulation	Used multiple data sources: adolescents, older carers, HIV programme facilitators.
	Theory triangulation	Applied multiple theories: life course theory, social ecological model, and self-management processes model.
	Prolonged engagement	Conducted fieldwork for 12 months doing 40 repeat interviews and 28 observations.
	Thick description	Provided a full description of the setting, participants, research design, participant views, and data.
	Reflexivity	Reflexive journal about self and methods.
	Peer review or debriefing	Regular reviews or debriefs with supervisors, colleagues, and other scholars.
	Member checks	Verified data gathered in earlier interviews
Transferability	Thick description	A full description of the setting, participants, research design, participant views, and data.
Consistency	Reflexivity	Reflexive journal about self and methods.
	Triangulation	Methods triangulation (observations, key informant interviews, and in-depth interviews).
	Peer review or debriefing	Regular reviews or debriefs with supervisors, colleagues, and other scholars.

Confirmability	Triangulation	Methods triangulation (observations, key informant interviews, and in-depth interviews), data source triangulation (adolescents, older carers, HIV programme facilitators) and theory triangulation (life course theory, social ecological model, and self-management processes model).
	Reflexivity	Used participants' quotes to support findings. Reflexive journal about self and methods.

3.13.5 Peer review or debriefing

Peer review or debriefing is a process which exposes researchers to exploring research processes and insights with peers (Lincoln & Guba, 1985). Researchers seek support from other professionals to provide scholarly guidance such as academic staff (Anney, 2014). This is aimed to prevent bias and help the conceptual development of the study (Morse, 2015). Feedback from peers allow the researcher to improve the quality of the study findings (Anney, 2014). In this study, the researcher sought scientific support from her doctoral supervisor, workplace mentors, other professionals, and colleagues. The researcher sent her analysis to the supervisor and workplace mentors to engage in further dialogue regarding the credibility of the analysis. Some preliminary findings of the study were presented in peer-reviewed local and international conferences where some delegates provided comments to the researcher to enhance the writing up. For example, the researcher attended and presented in the 2nd International Workshop on HIV Adolescence in Cape Town (South Africa) held in October 2018 and the 20th International Conference on AIDS and STIs in Africa in Kigali (Rwanda) held in December 2019. The comments and feedback also helped the researcher to synthesise and see new patterns in the data (Morse, 2015).

3.13.6 Member checking

Member checks or participant validation is the process of soliciting feedback on preliminary or emerging findings with some of the study participants in order to rule out misinterpretations (Merriam & Tisdell, 2016). It means interpretations and findings are sent back to the participants for them to verify the interpretations made by the researcher and to suggest changes if they are unhappy with it or because they had been misreported (Anney, 2014). In this study, during subsequent interviews, the researcher asked some participants to verify the data gathered in earlier interviews. The purpose of member checks is to eliminate researcher bias in the analysis and interpretation of findings (Anney, 2014).

3.14 Reflections on the Strengths of the Study Methods

This section discusses the researcher's reflections on the strengths of the study methods used in this study to investigate caring of adolescents by older carers in the context of HIV interventions in the uMkhanyakude district, South Africa. The study used the ethnographic research design to conduct in-depth interviews, key informant interviews, and observations with participants.

3.14.1 Strengths of the study methods

a) *Repeat interviews*

Repeat interviews were useful and facilitated rapport building with the study participants. As multiple visits to the homes of study participants were conducted, the researcher established trusting relationships with the study participants. The degree of trust was important, and this trust increased over time during fieldwork. This was particularly observed with adolescents who were reluctant at the beginning of fieldwork. The repeat interviews created the opportunity for the participants to know the researcher and to better understand the study.

Moreover, repeat interviews enabled participants to provide detailed and in-depth accounts. Listening to the audio recordings or reading the interview summaries before undertaking the following one provided opportunities to follow up lines of enquiry missed in the previous interview. Discussing and following up issues that the study participants raised in the previous interviews not only generated interest from the study participants, it also enhanced trust between the researcher and the study participants. They recognised that the researcher had listened to their stories. Repeat interviews also provided opportunities for the researcher to do member checks on her interpretation of data. Some participants were excited to learn that the researcher remembered what they had said previously. Subsequent interviews were tailor-made, based on what the participant said in the previous interview.

Repeat interviews were also appropriate to produce information about changes experienced by the participants over time and gave the researcher the flexibility to explore new ideas and follow-up issues in subsequent interviews.

b) Separate interviews with dyads

The researcher established that the separate interviews were the best approach for this study involving pairs of adolescents and their older carers for two reasons: conflicting intergenerational family relationships due to differences in social and cultural values between generations (Silva et al., 2015), and sensitivity of topics. Because of the ethical considerations involved in ensuring that existing relationships are not jeopardised, some researchers choose to interview each member of a dyad separately as outlined by Voltelen, Konradsen and Ostergaard (2017). Using joint interviews could have risked overpowering the voice of adolescents. Therefore, it would have been a challenge for this study to put the two together in a joint interview based on cultural customs of *ukuhlonipha* (Chappell, 2016) that limit young people from talking openly in the presence of their caregivers to maintain peaceful family relationships.

Separate interviews also allow more privacy for discussing relationship ‘secrets’ and for individuals to express their perspectives in the absence of their partner (Hertz, 1995; Taylor & De Vocht, 2011; Valentine, 1999).

Separate interviews allowed the participants to express dissatisfactions with the relationship without necessarily inducing conflict between the dyads; for example, older carers expressed how unhappy they were about their adolescent grandchildren’s sexual behaviours. Interviewing dyads separately helped minimise or reduce confrontation or conflicts between dyad members. It also allowed each individual to openly share their views and feelings.

Separate interviews enhanced understanding of care relationships and dynamics between adolescents and their older carers, from the perspective of each individual member of the pair (dyad). The separate interviews also allowed comparison of perceptions and experiences between adolescents and their carers. Interview data pointed to both issues of congruence in the adolescent-older carer dyads and issues entailing distinctive discrepancies in perceptions.

c) *Separate interviews by the same interviewer*

A decision about how many interviewers will be involved in conducting separate interviews is important in a dyad study. In this study, separate interviews with adolescent-older carer dyads were conducted by one interviewer focusing on their experiences of care relationships and their respective involvement in HIV interventions. The strength of having one interviewer conducting separate interviews enhanced the interviewer-participant relationship.

3.15 Conclusion

This study aimed to understand the caring for adolescents by older carers in the context of HIV combination prevention interventions in rural KwaZulu-Natal. The research strategy adopted was qualitative research using ethnographic and dyadic approaches to understand care relationships between adolescents and their older carers. The primary data collection techniques used in this study were participant observation, repeat in-depth interviews, and key informant interviews. Trustworthiness of the study was enhanced using reflexivity, triangulation, peer review or debriefing, prolonged engagement, thick description, and member checking. Lastly, the strengths of the study methods were discussed. The next five chapters describe and discuss the findings of the research.

CHAPTER FOUR

FACTORS SHAPING CAREGIVING BY OLDER CARERS AND RELATIONSHIPS WITH ADOLESCENTS

4.1 Introduction

Many older carers are caring for adolescents and a better understanding of the lives of older carers and that of adolescents in their care is necessary for appropriate support. Although research on grandparents caring for orphaned children by HIV and AIDS has proliferated in recent years, our understanding of the pathways that shape caring of adolescents by older carers and the nature of relationships between adolescents and their older carers are underdeveloped.

This chapter extends the knowledge generated through repeat in-depth interviews with adolescents and their older carers by presenting and discussing stories of six dyads when asked how older carers became involved in raising the adolescent grandchildren. The first section presents the socio-demographic characteristics of adolescent-older dyads. This is followed by a section focusing on factors influencing pathways into grandparent caregiving. The third section concentrates on the nature of relationships between adolescents and their older carers. Lastly, the findings are discussed aligned to the factors of the socio-ecological model (SEM), and the relevant themes of the life course perspective that emerged as potential influences on the pathways to grandparental caregiving and the nature of relationships between adolescents and older carers.

4.2 Results

4.2.1 Socio-demographic characteristics of grandparent-adolescent dyads

A total of 12 participants (six adolescents and six older carers) participated in the study. All the older carers for the adolescents were older women aged 56 to 80 years. They were primary caregivers for between two and 15 children. Four were maternal grandmothers and two paternal grandmothers to the focal adolescents. This reflects the nature of caregiving common in this setting that it was predominantly women who were primary caregivers to the adolescents. Some older carers started caring for the focal adolescent grandchildren since their grandchildren were born, while others assumed caring responsibilities when the grandchildren in-migrated to their households. The number of years the grandparents had been caring for their focal adolescent grandchildren ranged between three and 15 years. Four grandmothers were widowed, and two were unmarried. Of the two unmarried older carers, one was in a cohabiting relationship. Only two older carers had attended primary school, while others had no formal education. Although not questioned directly about their HIV status, two older carers disclosed that they were living with HIV and were on ART. In the following chapters, all participants will be noted as follows – name, carer / girl, boy / facilitator, age; for example – MaZulu, older carer, 64.

With regard to the adolescents, the study sample included five adolescent girls and one adolescent boy aged between 13 and 19 years. Four adolescents were in secondary school while the other two had dropped out of school due to pregnancy and academic difficulties, respectively. The biological mothers of all six adolescents in the care of grandparents were still alive, but only two were living in the same household with the adolescents. Four adolescents were paternal orphans.

4.2.2 Factors shaping caregiving by older carers

Repeat in-depth interviews with adolescents and their older carers (n=12) described a dynamic process which shaped how older carers ended up taking the primary caring responsibility of their grandchildren. This process involved five interconnected aspects as follows: factors related to adolescents' biological parents; factors related to older carers; factors related to family living arrangements; factors related to cultural norms; and factors related to grandchildren. Participants narrated stories which included all the aspects woven together, concurrently shaping pathways for older carers to assume caring responsibilities (See Figure 4.1 on the following page).

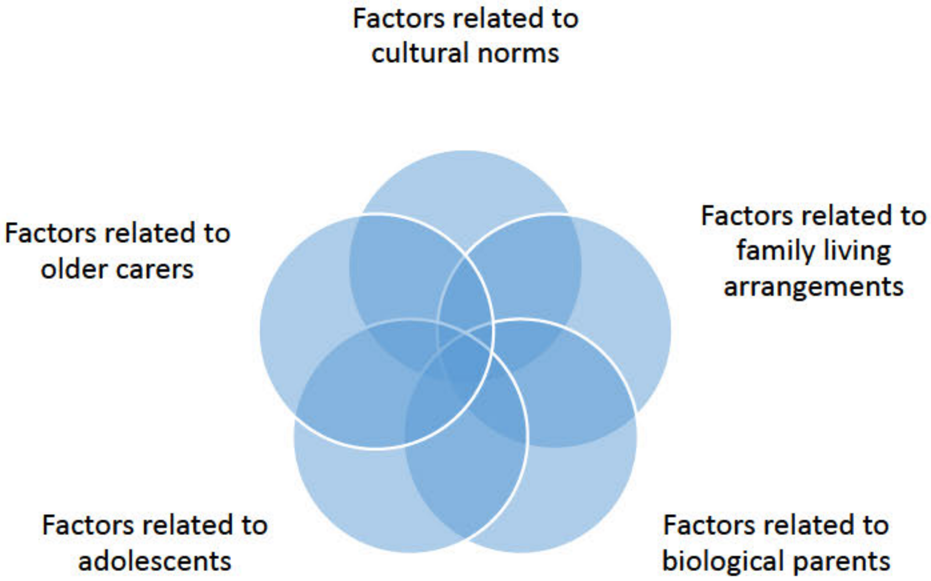


Figure 4.1: Factors shaping caregiving by older carers

4.2.2.1 Factors related to cultural norms

Cultural norms that regulate caring of children born out of wedlock were mentioned by four older carers as reasons why they took on the caring responsibility of their grandchildren. They stated that adhering to cultural norms was the primary motivator in this regard. The older carers explained that according to cultural expectations and rules, a child born out of wedlock remains in the custody of a maternal family unless the paternal family pays *inhlawulo* [a fine to the maternal family to claim rights to the child]. To illustrate, one of the maternal grandmothers, MaZulu, shared her story of how her husband reinforced this cultural norm within their family:

> *My late husband left me an instruction. He never wanted grandchildren to live with paternal families. He often said their biological fathers had not paid inhlawulo* [a fine to claim custody]; *therefore, grandchildren belonged to him. It is for that reason I have decided to take this burden* [caring for grandchildren]. *(MaZulu, older carer, 64)*

Apart from her husband's instruction, MaZulu also had a child before she married her husband. She mentioned that she left her child with her parents when she got married as she was not allowed to bring the child into the marriage with a man who was not the father of the child.

In contrast, two paternal grandmothers did not abide by this preconditional norm as they were caring for adolescents without any fine being paid to maternal families. Although they knew about the norm regarding children born out of wedlock, they disregarded the cultural norm due to lack of financial resources. One stated:

> *Culturally, we should have paid inhlawulo but we ignored it because* [name of father] *died and we can't afford. This thing needs money, which I don't have… but, I know we still have a debt to settle with* [granddaughter's maternal family]. *(MaKhoza, older carer, 64)*

However, the other paternal grandmother was in the process of adhering to the norm of paying a fine to her grandson's maternal family. She said:

> *My grandson is registered in his maternal surname. It's not right. He should be registered as* [paternal surname]. *He also wants to change to [paternal surname]. … In order for him to change the surname, we first need to pay inhlawulo to get permission from* [maternal surname] *to change his surname. … We are waiting for school holidays, then we will do it. He cannot take an identity document while using her maternal surname. (MaNdawo, older carer, 76)*

It was clear that paying the fine was also linked to the grandchild's sense of identity.

4.2.2.2 Factors related to living arrangements

Multigenerational co-residences, whereby grandparents, their adult children, and grandchildren lived together influenced the process of adolescent grandchildren being in the care of their grandparents. Of the six families of older caregivers, five consisted of grandparents, their adult children, and grandchildren living together. Older carers mentioned that when their adult children (biological parents) moved away from home, in many instances in search of employment, or were unable to care for their children, the grandchildren were left in their care as they were all living together as a family. One said: *“We all live together as a family. My children and grandchildren are here with me”* (MaNgubo, older carer, 80). Another one stated: *“None of my children got married. They live with me, except those who are away to look for jobs. But, I’m caring for their children while they are away”* (MaDube, older carer, 58).

The older carers took the caring responsibility as they lived together with their children.

4.2.2.3 Factors related to adolescents’ biological parents

Four themes were clearly expressed regarding the reasons why adolescents’ biological parents were unable to provide care for their children, leading to the need for grandparental caregiving. The themes were identified as paternal death, parental alcohol abuse, parental neglect, and parental unemployment. Each theme emerged in both the dyad interviews; that is with the adolescents and their respective grandmothers, except for parental unemployment, which was only mentioned by the grandmothers.

Firstly, **paternal death** emerged across four dyad cases as a reason the biological mothers were unable to care for their adolescent children. Participants described that the adolescents’ fathers died after a long illness, the nature of which was apparently not known by the participants. In all cases, death occurred however during a time when the respective adolescents were too young to recall the circumstances leading to their fathers’ death:

> *I came to live with my grandmother when I was 10 years old. The reason was my father died and my mother moved back with us to live here. (Sane, girl, 13)*
>
> *My father died, then we moved to live here. I can’t recall the year but I was still very young such that I don’t have any memory of my father. I don’t even know the name of the place where we lived with him. I was just told he was sick and he died. Thereafter, we moved to live here. (Neli, girl, 14)*

> *My father died, then I moved to live here with my grandmother. At that time, my grandmother was living alone. She requested me to come and live with her. (Mpume, girl, 19)*

Some older carers mentioned that paternal death left their grandchildren without financial resources and the mothers could not cope without the financial support provided by the fathers while they were still alive. The historical narratives showed that all the adolescents in this study were born in the context of non-marital relationships with some parents cohabiting. However, when their fathers died, their mothers moved back to their parents' home together with the children. One older carer said:

> *When the father of my grandchildren died, my daughter was simply depending on him for financial support. She couldn't cope to support the children, then I told her come back home with the children … they were not married and there was no reason for her to continue living with that family* [in-laws]. *(MaDube, older carer, 58)*

Another one stated:

> *My daughter and her partner were not married at the time of his death, although they were living together. But it was difficult for her to support the children as she was not working and depending on her partner for financial support. She did not have food and children were just hungry, that's why she had to come back with the children. (MaZulu, older carer, 64)*

It was clear that the loss of fathers disrupted the living arrangements of children and had a financial impact on the lives of the young ones.

Secondly, of the six dyads, only one dyad, MaNgubo and Zama, narrated **parental alcohol abuse** as a reason that Zama's mother was unable to care for Zama and her siblings. Zama's mother lived in the same household with MaNgubo and Zama. During the interviews, both Zama and MaNgubo mentioned that Zama's mother had no time for her children and did not support them financially due to alcohol abuse. This compelled MaNgubo to take the responsibility to care for her grandchildren. Zama mentioned that:

> *My grandmother is the one taking care for all us. … My mother is a person who is usually drunk ... sometimes she earns extra money, but it finishes off quickly. She only thinks of alcohol once she has money. (Zama, girl, 15)*

While Zama's mother was the one receiving the child support grant, MaNgubo also complained that Zama's mother abused alcohol and used the child support grant to buy alcohol instead of supporting her children: "*She* [Zama's mother] *drinks alcohol and wastes her money on alcohol including the child grant"* (MaNgubo, older carer, 80).

Thirdly, **parental neglect** was also referred to as a reason why older carers sheltered their grandchildren because adolescents' parents had abandoned their children and thus were not fulfilling their responsibilities. This was highlighted in Mpume's story as she had not seen her mother for approximately three years and had received no financial support from her:

> *My mother is alive, but I can't even remember when I last I saw her. I cannot say she died. It's just that it's been long since I saw her. They say she lives in* [name of place] *where she works as a farmworker. I last saw her in December 2016. It meant nothing for me to see her. I feel bad that I don't see her. It really hurts me. She should be supporting my grandmother to provide me with things that I need. But she's not supportive. I don't know how to reach her because she doesn't care for me. (Mpume, girl, 19)*

While Zama had been seeing her father, she shared that her father was not supporting her financially and mentioned that her father's behaviour had caused her to act with violence when she saw him:

> *My father lives there* [pointing direction], *yet I don't know him. They say he's my father. I only know him by face. He also knows that I'm his daughter, yet he doesn't know that I eat. Sometimes I deny him that he's my father. I don't even greet him when we meet in town. He calls me, but I don't go to him because he doesn't know that I need food and clothes. One night he came here, and he was drunk. He pronounced himself as my father. I shouted at and chased him away. (Zama, girl, 15)*

It was clear that the adolescents were emotionally negatively affected by their unmet needs and absence of parents, both physically and emotionally.

Some participants mentioned that parental neglect was perpetuated by new sexual partners after parental separation. They shared that their biological parents lived away cohabitating with their sexual partners, hence leaving their adolescent children behind in the care of grandmothers.

One said: *"My mother is living in* [name of place] *with my stepfather. She last visited us three years ago"* (Neli, girl, 14). Another one shared a painful story about her mother, who was living with her sexual partner and had abandoned them:

> *She* [mother] *doesn't live here. She lives at* [name of place]. *She's on casual employment. There at* [name of place], *she lives with my stepfather, and they have one child together. … Mostly, my mother and I don't communicate. She rarely comes back home. She doesn't visit to spend time with us* [Sane and siblings]*, even just for a few days when she is off at work. Never! Sometimes, she comes by the end of the month, but she never spends a night with us. She goes back on the same day … I don't feel happy about this because, sometimes, I miss my mother. Sometimes, I just want to be closer to her and spend time with her. Whenever I miss her, I just go to sit alone and not talk to anyone. (Sane, girl, 13)*

Even Sane's grandmother, MaDube, also complained about her daughter (Sane's mother) as she believed that Sane's mother was prioritising her new sexual partner and had limited time to spend with Sane:

> *I'm not happy with [*Sane's mother] *because she's just deserting her children and caring for a man regardless of the difficulties I'm now having with Sane. Sane is now problematic. She* [Sane's mother] *needs to come home to see it for herself. It's very difficult to raise someone else's child. (MaDube, older carer, 58)*

When trying to understand how parents' new sexual relationships resulted in neglecting their children, the story of MaNdawo explained that a new sexual partner might not care about the child that was not theirs and therefore influence the biological parent from not fulfilling parental responsibilities. MaNdawo spoke with disappointment about Thabani’s father who lived away with his new partner. She blamed her son’s girlfriend for being a barrier to Thabani getting support from his father. She had expected her son’s partner to champion Thabani to get his needs met like a mother would do for her child. This was despite the fact that Thabani’s father was employed and capable of meeting Thabani’s needs.

> *He* [Thabani’s father] *is not responsible. He is employed yet not financially supporting Thabani. Look, Thabani is struggling. He doesn’t have school uniform and his father is not sending us money. It hurts me to see my grandson struggling like this when there is a woman in his father’s life. This woman is the reason* [Thabani’s father] *is not financially supporting Thabani. She should be like a mother to Thabani and ensure that* [Thabani’s father] *is a responsible father. (MaNdawo, older carer, 76)*

It seemed that MaNdawo blamed another person for the actions of her son who neglected his parental responsibility.

Lastly, as stated before, **parental unemployment** was another reason they were unable to care for their children. For instance, one older carer was looking after 15 grandchildren and explained that her adult children were either unemployed or in informal jobs. As she said: *“My daughters are unemployed. Sometimes, they get temporary jobs”* (MaZulu, older carer, 64).

Similarly, MaDube also mentioned that her adult children were living away from home in search of employment opportunities.

4.2.2.4 Factors related to grandchildren

The two themes that emerged during the interviews that related to the grandchildren were biological ties with grandchildren and expectation for reciprocal care from grandchildren.

Grandmothers described that **biological ties with grandchildren** compelled them to assume caring responsibilities for their adolescent grandchildren. During the interviews, grandmothers expressed rhetorical questions to the interviewer such as

"*What should I do – they are my blood*", "*Who else will care for them?*" and "*Where am I supposed to dump them?*" These expressions indicated how grandmothers felt that the biological ties they had with the grandchildren obligated them to take up the responsibility to care for their grandchildren.

Grandmothers mentioned that they were motivated to care for their adolescent grandchildren in the hope that their grandchildren would also care for them. The **expectation for reciprocal care from grandchildren** was a recurrent theme in the interviews with all individual grandmothers. This expectation was influenced by their views of being old and sick. They felt they also needed someone to care for them as they were not able to fulfil some everyday housework such as cooking, fetching water, and cleaning and therefore the expectation that while they care for their grandchildren, they would in turn receive some form of care and support from their grandchildren as well.

One said: *"I'm now old and hope that my grandson will also take care of me in future. … I don't want to go an old-aged home"* (MaNdawo, older carer, 76). Another one stated:

> *I'm old and sick yet caring for so many grandchildren. Doing household work makes me tired and there are tasks such fetching water that I'm unable to do. I pray that at least one of them will have a good heart to return the help that I have offered them. (MaNgubo, older carer, 80)*

It seemed some adolescents had internalised the expectation to provide future care to their grandmothers. They stated:

> *I hope to get a job in future to help my grandmother as she has done to me. (Mpume, girl, 19).*
>
> *My grandmother deserves better, that's why I wish to return the help one day. (Neli, girl, 14)*

However, other adolescents did not seem to have plans to care for their grandmothers in the future as they did not mention it.

4.2.2.5 Factors related to older carers

The four pathway themes that were identified as factors related to the older carers were fear of being labelled as discriminating against other grandchildren; past experience of being raised by a grandmother; feeling unsafe living alone as an older woman; and self-perceived role of grandmothers.

One older carer, MaDube (58) stated that she **feared being labelled as discriminating against other grandchildren** if she refused to take caring responsibilities for all her grandchildren who needed care. She explained that once an older carer starts caring for one grandchild, she was bound to continue caring for others to avoid conflicts within the family. Refusing to care for others could be regarded as discrimination between grandchildren and could lead to tensions within the family. To avoid being labelled as discriminating, MaDube stated that she was caring for 11 grandchildren:

> *It's not easy for me not to care for all my grandchildren because, you see, I started caring for my eldest grandson. How can I refuse to care for others when I had cared for my grandson? Doing that will create divisions with my family and they will think as if I'm discriminating against other grandchildren. So, I am just continuing with what I started with the first one. (MaDube, older carer, 58)*

Two older carers mentioned **past experience of being raised by their grandmothers** when they were young. They felt that it was difficult for them to refuse to care for their grandchildren when they themselves had been raised by their grandmothers. One older carer said:

> *My father died when I was still young, and my mother left us with our grandmother as she went to* [name of place] *for employment. I'm raising my grandchildren because I was also raised by my grandmother. If it was not for my grandmother, who would have taken care of my sister and I? (MaJali, older carer, 56)*

Feeling unsafe living alone as older women was mentioned by two older carers. They stated after the death of their husbands, they felt unsafe living alone as older women who were widows and decided to take in their grandchildren. They believed that living with grandchildren made them feel safer from criminals and keep them company. One said:

> *My husband died in* [year]. *It was just the two of us here at home because my children don't live with us. They live away for employment reasons. I was not comfortable as I lived alone after my husband had died. I was scared of criminals and needed someone to be around in case I need help like when I get sick and to avoid criminals from attacking me if I lived alone. So, I requested my son to bring my grandson to live with me while I care for him. (MaNdawo, older carer, 76)*

Another one stated:

> *When I became a widow, I was scared to live alone. There are criminals here and we sometimes hear that older women are robbed by the criminals. … My children were all away from home and needed someone to help me with housekeeping and to keep me company. (MaKhoza, older carer, 64)*

It seems being widowed influenced the caring responsibility for these older carers.

Self-perceived roles of grandmothers emerged during the interviews with the older carers. They viewed themselves as care providers as they were grandmothers within their families. For them, being a grandmother meant being present at home to perform caring responsibilities and to support their families. An interview with MaNdawo revealed how she perceived her role as a grandmother. She viewed herself as available to care for her grandchildren while her adult children were away from home for employment. She described herself as the anchor of her family and explained that she was the only who could perform the role of being the anchor, otherwise, her family would dissolve if she was not available. This is what she said during the interview:

> *Who will care for the grandchildren? Who will remain at home? This home will be dissolved if I could leave. I am the only one looking after this home. A home is a home with a person who lives and looks after it. I love my grandchildren, and my role is to look after them. (MaNdawo, older carer, 76)*

Other older carers shared the same view:

> *Looking at my grandchildren makes me realise that I have reached the stage in life to care for my grandchildren. I feel so happy to see them playing in the yard. (MaJali, older carer, 56)*
>
> *My role as a grandmother is to support my family. Caring for my grandchildren is part of supporting my family. Grandmothers in the community are expected to look after the grandchildren. (MaZulu, older carer, 64)*

4.3 Relationships Between Adolescents and their Older Carers

In this section the nature of relationships between adolescents and their older carers and the factors that influence the relationships are explored. When adolescents and their older carers were asked about the nature of the caring relationship, their responses were mixed. Adolescents reported both positive and negative relationships with their older carers, whereas older carers viewed the relationships as mostly difficult. This is illustrated by interviews drawn from two dyads:

One adolescent said:

> *I consider my grandmother as a mother and a father in my life. She's open and approachable, but, sometimes, she delays in expressing things she doesn't like. … For example, when I've done wrong, I prefer to be told instantly when I've done wrong. (Thabani, boy, 15)*

This perspective is different from that of his grandmother who stated: *"He's lazy, rebellious and doesn't want to listen to me. He wants to do as he pleases. He doesn't talk to me"* (MaNdawo, older carer, 76).

In the same way, another dyad also expressed contrasting perspectives about their relationship:

> *I like her but she shouts a lot. Sometimes, I think she's mad. (Zama, girl, 15)*
>
> *She's defiant. She doesn't want to listen to me. She doesn't know who I am. She has no respect for me. (MaNgubo, older carer, 80)*

In exploring the factors that positively or negatively affect the quality of relationships between adolescents and their older carers, adolescents' difficult behaviour and carers' behaviours were identified.

4.3.1 Adolescents' difficult behaviours

Older carers mentioned adolescents' difficult behaviours that negatively affected the nature of their relationships. The behaviours that were mentioned as difficult were unwillingness to do household chores and engaging in risky behaviours. The older carers stated that these behaviours were frustrating for them as, despite their attempts to discourage unacceptable behaviours, they met resistance from the adolescents.

Some older carers complained that the adolescents were **unwilling to perform the household chores**. One older carer said:

> *He doesn't want to listen to me. As a child, he's supposed to help me with household chores like washing dishes and fetching water. He's lazy and refuses. He would say he's tired too. Then I end up doing chores for myself as I cannot force him. He's very lazy. I told him to plant banana trees and he never did it. You see that flower tree, he should have trimmed it but he hasn't because he's lazy. He does chores when he feels like doing it. He cooks only when he likes … he doesn't want to clean his bedroom. I'm the one who cleans it for him … it hurts me when he refuses to take my instructions. I would like us to have a mutual relationship. (MaNdawo, older carer, 76)*

Another one stated:

> *She is not helping me with housework. Dishes are always dirty and the house is a mess. I always tell her to tidy up but she doesn't want to listen to me … when she has done work, it's not complete or not done properly. For example, there is a pot she hasn't washed for three days. She soaked it and left it like that. (MaNgubo, older carer, 80)*

Further, older carers mentioned that their adolescent grandchildren were **engaging in risky behaviours**, including sleeping away from home, falling pregnant, drinking alcohol, engaging in sexual relations with older men, and dropping out of school.

One older carer said:

> *As today, she left on the previous day and never came back home. She has a tendency to go away and to come back home midnight. Sometimes, she goes away for several days … now she's pregnant. (MaNgubo, older carer, 80)*

Similarly, another older carer was feeling distressed and annoyed that her adolescent granddaughter was pregnant:

> *My granddaughter is pregnant, and I'm annoyed as I don't know what will happen. … Nonetheless, even my adult children did the same thing, that's why I'm taking care of so many grandchildren. I've counselled myself that my adult children did it, so I should forgive Mpume. Let me just accept it. So, I've accepted the situation. (MaKhoza, older carer, 64)*

While MaKhoza was annoyed that Mpume was pregnant, Mpume, on the other hand, was also distressed that her grandmother had refused to let her be with her boyfriend who had made her pregnant:

> *Now that I'm pregnant, my grandmother does not allow me to leave the house. She's refusing me to see my boyfriend. I only phone him if I need us to talk. Our communication is only via the phone. I last saw him in* [four months ago]. *Sometimes, I miss to be with him but I've accepted that I can't see him. (Mpume, girl, 19)*

It was clear that Mpume's pregnancy had negatively affected her relationship with her grandmother and it also impacted on her being allowed to spend time with her boyfriend.

Consistent with other older carers, MaDube was annoyed about her granddaughter's risky behaviour of **sleeping away from home**. She also mentioned that her granddaughter was **drinking alcohol** and **engaging in sexual relations** with an older man:

> *I am tired and enough of Sane. Of late she sleeps away from home, and sometimes she's away for several days without anyone knowing her*

> *whereabouts. … Last night, she didn’t sleep at home … sometimes I stay awake for the whole night because I fear she might be killed. Girls are being killed by boyfriends. … Yes, she has a boyfriend and he’s older than her … I heard they met in a tavern. … Can you believe that she now drinks alcohol? (MaDube, older carer, 58)*

In a separate interview with Sane, she indicated that she was not happy about their home environment where she lived with her older carer:

> *I want to go back to my father’s family in* [name of place] *but my grandmother is refusing. I no longer want to stay here because my step-grandfather is cheating on my grandmother. He’s not buying us food anymore. He has a girlfriend from church … my grandmother nearly chopped him with an axe; fortunately, we were there to take it away. … I’ve been telling my grandmother that we should move out, but she keeps on saying we will move when she gets land to build a house. … Also, here, they* [step-grandfather’s family] *gossip about us … I’m going to fail at school if I continue staying here. (Sane, girl, 13)*

Furthermore, a concern about adolescents **dropping out of school** was also raised by two older carers. One said:

> *She didn’t like school and ended up dropping out school … I’m not at peace. What will she be in future without education? Even her younger sister has advanced into an upper class than her … she’s after men … I tried to talk to her to go back to school but refused as she didn’t want to be in a lower class than her younger sister. I even asked her to go to an adult school but she didn’t want to. … It’s worse now that she’s pregnant. (MaNgubo, older carer, 80)*

While Zama’s grandmother was concerned that Zama dropped out of school because she engaged in sexual activities, Zama said:

> *I do wish to go back to school. I’m blame myself that I dropped out of school. It is sad to see other children coming back from school during the day while I’m just at home. Sometimes, I think of buying a school report so I can go back*

> *to school next year* [2018]. *But I cannot go back to Grade 4 … I can't be in the same class with younger girls. I'll be the only one older than other girls in class. … Life is boring here at home yet I don't want to wander out the streets. (Zama, girl, 15)*

Similarly, another older carer was also concerned about the future of her granddaughter. She was also distressed about the burden of caring for her granddaughter's baby:

> *The teachers at school usually don't recommend for girls to attend school while pregnant because they feel it motivates other girls to fall pregnant at school. Suspending a pregnant girl from school is a harsh decision. However, we, as caregivers, feel that a pregnant girl must be suspended from school because we don't send them to school to get pregnant. The girl must babysit and breastfeed the baby because teenage mothers who continue schooling don't breastfeed. Now, I should drop off everything and babysit the baby. It would be unfair for her to go back to school while I'm busy babysitting the baby for her. I didn't send her to school to find a baby for me to babysit … I feel very sad because I had planned for Mpume to finish school as I've been caring for her. (MaKhoza, older carer, 64)*

On the other side, Mpume felt ashamed for falling pregnant. However, she was hopeful of going back to school once she had given birth:

> *At the moment I've dropped out school. It was a mistake to get pregnant and I feel bad that I'm pregnant and no longer at school. It was not my intention. … Pregnant girls are allowed to continue schooling but they refuse when girls are towards giving birth. I dropped out of school because I wouldn't have been able to write the final exam. My expected date of delivery is around exam time. Dropping out was a better option for me because in any way I wouldn't have been able to write the final exam. I will go back to school after giving birth provided if I get someone to babysit. (Mpume, girl, 19)*

The results suggested that Mpume was distressed by her pregnancy and dropping out of school.

4.3.2 Carers' behaviours

Adolescents reported both positive and negative caring behaviours by their older carers with perceived negative caring behaviours as posing some challenges for the adolescents with consequent impacts on their relationships with their carers. Adolescents, however, indicated that they at times display behaviours in response to the way they are treated by their older carers. Some adolescents indicated that they did not relate well with their older carers as they made them do too many household chores, used physical punishment, denied them opportunities to visit paternal or maternal families, and were unable to provide them with their basic needs.

Some adolescents raised complaints about being **overloaded with household chores** by their older carers. They mentioned the household tasks that their older carers expected them to perform in the family:

> *I cook on weekends. During the week after school, I do the washing and fetch water from the community tap until the drum is full. Every weekend, I also go to the forest to fetch firewood. (Neli, girl, 14)*
>
> *I fetch water and firewood from the forest. In the past, I used to go with my grandmother to the forest to fetch firewood but she's no longer able to walk to the forest because she is old and suffering from her knees. I'm the only one going to the forest to fetch firewood. I also do the laundry, cook and make tea for* [step-grandfather]. *(Sane, girl, 13)*
>
> *I wash dishes every day and cook during weekends. Sometimes, I help my grandmother when she's sick by feeding her and give her medication when it's time for her to take the medication. (Thandi, girl, 13)*
>
> *After school, I fetch water, do the laundry, wash the dishes, clean the house, and study. My grandmother is unable to do a lot* [of household tasks] *because during the day she babysits the babies* [younger grandchildren]. *I also boil water for my grandmother to bath in the evening. (Mpume, girl, 19)*

In discussion with the older carers, they gave some reasons for assigning household chores to the adolescents, as seen in the interviews below. One carer stated that it was meant to train adolescents to acquire working skills and be self-reliant when they leave home or when the grandparent died.

> *The reason I am assigning Neli and others with housework is because I want them to do learn to things for themselves. I don't want them to grow up not having acquired skills to work. In future, they must be able to help themselves and not say 'we don't know how to work'. (MaZulu, older carer, 64)*
>
> *It's important for Thabani to do tasks here at home to keep himself busy; instead of roaming around the streets. (MaNdawo, older carer, 76)*

Thabani's grandmother looked at household chores as a form of communal responsibility, and considered performing household chores as part of physical activity that kept him busy instead of roaming around the streets.

Further, all the adolescent girls mentioned that their older carers used **physical punishment** to discipline them. One adolescent shared her story:

> *Oh, my grandmother! She often pinches me. I don't know where she gets the strength but she beats us. You see, she has once bitten me on my arm and it left a dark mark where she had bitten me. If she has nothing to beat you with, she bits you or pinches you. One time she pinched me on my shoulder. You can still see that I was pinched. If she bites me, I cry a lot because it hurts me. (Zama, girl, 15)*

In the same way others said:

> *My grandmother beats me up when I have done something wrong. For example, when I have not gone to fetch water or washed dishes. (Sane, girl, 13)*
>
> *I get beaten with a stick for misbehaving. Sometimes, my grandmother instructs my uncle to hit me. It is better if my grandmother is one beating me because it does not hurt so much, but it is worse if it my uncle. He, even, uses a sjambok* [plastic or leather whip]. *(Mpume, girl, 19)*

It appeared that some older carers delegated other family members to use physical punishment to discipline the adolescents.

However, one older carer blamed the democratic government that had given rights to children, thus influencing the adolescents to misbehave, as she said:

> *Isn't that the government said children have rights? Children should not be punished because they have rights. That's why things are like this! Some families have dissolved because children have rights, and they do as they like. Our forefathers and parents never gave us rights. A child was a child. A child obeyed adults. The government is giving children so many rights. Right now, children have babies. The government says 'go and fall pregnant and I will give you money to support your babies'. The government is indeed giving them support. They get money from the government. They get pregnant in order to get government money. (MaNgubo, older carer, 80)*

Lastly, their carers seemed not able to provide the adolescents with their **basic needs**. During the first interview, one adolescent, who later in the study fell pregnant and dropped out of school, mentioned her grandmother was not able to buy her learning equipment and school uniform:

> *While I'm happy to live with my grandmother, I don't have sufficient uniform items. My school uniform is not enough. Right now, I do have shoes but short of other things. I don't have enough learning equipment like a calculator and Maths instruments. As such I'm unable to concentrate at school when I don't have these things. It would be much better if I had everything. I would learn without problems at school. My grandmother says she doesn't have money. This year, she didn't buy me my full uniform items. She bought me only one shirt because the one I used last year was torn apart. (Mpume, girl, 19)*

Likewise, another adolescent indicated that sometimes her grandmother could not afford to provide her with food:

> *It's very difficult when there is no food. My grandmother would send us to school without food. At least, during the week, we get food from school* [school feeding scheme]. *On weekends it can be difficult when we don't have food. It*

> *becomes to talk to her* [older carer] *or to tell her we are hungry because I can see the situation. There is nothing I can do. I simply keep quiet or sleep to forget about the hunger. (Sane, girl, 13)*

While the perceived negative caring behaviours of older carers made it difficult for the adolescents to relate well to their older carers, adolescents also mentioned some positive caring behaviours by older carers. These included the provision of food and clothes as well as assistance with household tasks which were mentioned by the adolescents as positively affecting the relationships:

> *My grandmother buys food for us to eat. She really feeds us. I think the day she dies will be the end of my sister and I. She's the one who cares for us. Unlike my mother who drinks alcohol. My grandmother ensures that we have food as her grandchildren. (Zama, girl, 15)*
>
> *My grandmother provides me with things I need. She washes my uniform, cooks and dishes for me, and buys clothes for me. (Neli, girl, 14)*

In addition, some adolescents mentioned how grandmothers guided their social behaviours and motivated them to successfully complete their schooling:

> *I'm happy to have a grandmother who cares for my future. She regularly emphasises the importance of education. (Thandi, girl, 13)*
>
> *I also like it that my grandmother advises me about how to behave as a girl and motivates me to finish school. (Neli, girl, 14)*

Furthermore, some adolescents mentioned that their carers shared historical stories with them and these stories seemed to create positive bonds between the adolescents and their carers:

> *It's so nice when my grandmother tells me how she grew up and the games they used to play when they were young. They played games in a different and funny way from us. For example, one day she told me they used charcoal stones to play 'umagenda'* [tossing the charcoal stone in the air whilst picking one or two or three on the circle] *and used grass ropes to play 'inqgathu'* [rope

> skipping]. *We use rock stones to play ‘umagenda’ and nylon rope for skipping. (Sane, girl, 13)*
>
> *I appreciate when my grandmother shares family history and things that happened during apartheid in the country. Sometimes, I use the information she shares with me for my school projects. (Thabani, boy, 15)*

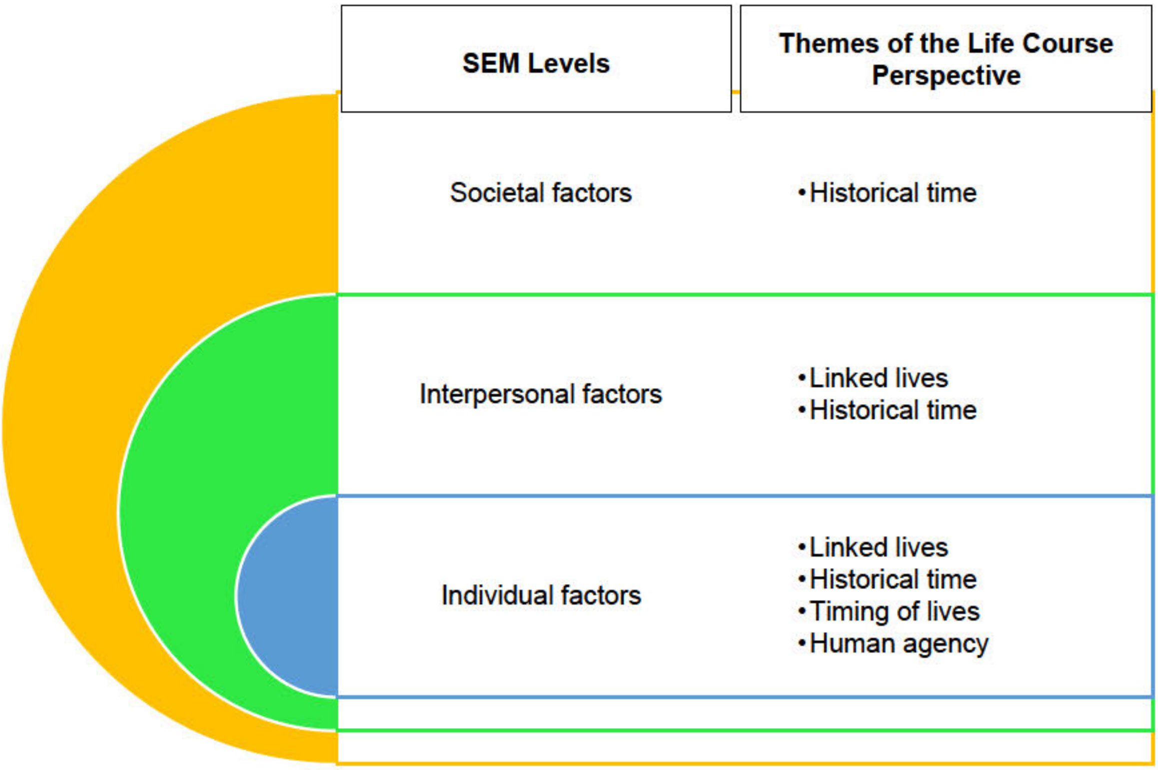
The adolescents found historical information valuable in understanding the indigenous life that the older carers were exposed to and, sometimes, benefited from the information when they applied it to their schoolwork.

4.4 Discussion

Firstly, the study explored factors that influenced caring of adolescents by their grandparents/older carers in rural South Africa, using a multi-theoretical approach. I applied the SEM and the life course perspective to understand overlapping factors influenced by the levels of the SEM and the themes of the life course perspective.

The findings showed a dynamic process, which influenced how older carers assumed the caring responsibilities of their adolescent grandchildren. This process involved five interconnected factors namely, factors related to cultural norms, factors related to family living arrangements, factors related to biological parents, factors related to adolescent grandchildren, and factors related to older carers.

The three factors of the SEM: individual, interpersonal, and societal and the four themes of the life course perspective: historical time, linked lives, the timing of lives, and human agency are used to frame the categories of the findings as shown in Figure 4.2.



SEM Levels	Themes of the Life Course Perspective
Societal factors	•Historical time
Interpersonal factors	•Linked lives •Historical time
Individual factors	•Linked lives •Historical time •Timing of lives •Human agency

Figure 4.2: Factors of SEM with associated themes of the life course perspective

At an individual level of the SEM, the themes of the life course that influenced caring of adolescents by grandparents were historical time, linked lives, the timing of lives, and human agency. Related to historical time, the findings of this study illustrate that grandparental caregiving must be understood in the historical context of the individuals (Hutchison, 2010). One interesting finding is that past experience of being raised by a grandmother influenced the pathways to grandparental caregiving. Older carers who traced this pattern of caregiving back to their own grandparents evidenced grandparental caregiving as a norm. These older carers valued their past experiences, and they shaped their life course trajectories and those of their adolescent grandchildren. An implication of this is the possibility that older carers may assume the grandparental caregiving role because they have been socialised into thinking of grandparental caregiving as a norm, and, therefore, will not use their agency in the decision to care for their grandchildren. However, life course perspectives suggest that our decisions are shaped and informed by history that is in essence the study of context (Elder et al., 2003).

The timing of grandparenthood was also an important factor in the lives of older carers as they associated grandparent identity with caring for their grandchildren. It is well documented that grandparents play a vital role in providing grandchild care to families in sub-Saharan Africa (Mugisha et al., 2015; Rutakumwa et al., 2015). The findings of this study indicate that the grandparents perceive themselves as carers. A possible explanation for this might be that grandparents are socially constructed as carers. The notion of grandparent caregiving as normative was perhaps best illustrated when one of the older carers in this study mentioned that the community expected grandmothers to care for the grandchildren. These findings are in agreement with those obtained by previous studies in other countries such as Kenya that caring for grandchildren is a cultural expectation (Breheny, Stephens, & Spilsbury, 2013; Ingersoll-Dayton, Punpuing, Tangchonlatip, & Yakas, 2018; Skovdal, 2010). However, the present study raises the possibility that cultural expectations may influence grandparents and they might find it difficult to refuse to care for their grandchildren. This has implications for grandparents who may not have viewed themselves as carers and desire to assume other roles instead of caring for their grandchildren. They may find themselves stuck in the caring role, which may have negative implications on the quality of relationships with their grandchildren, and on the well-being of both the grandchildren and the older carers.

Older carers also used their agency by negotiating mutually beneficial arrangements of caring for and being cared for by adolescent grandchildren. Their agency was seen when they felt unsafe living alone as older women and deciding to take on caring responsibilities so that their need for security, companionship, and general housekeeping assistance could be addressed. The findings that of the older carers who talked about the benefits of companionship by their grandchildren were similar to the findings in previous studies of grandparents caring for grandchildren (Ingersoll-Dayton et al., 2018). In this study the benefits of such arrangements for the grandparents were also mentioned. The findings of this study show that the older carers expected reciprocal care from grandchildren. In line with studies in Uganda and Ethiopia, they demonstrated that older carers and children were simultaneously caregivers and care recipients (Abebe & Aase, 2007; Rutakumwa et al., 2015). These findings are in line with the interpersonal level of the SEM and life course theory as they emphasise the ways in which family members reciprocally influence each other.

This study shows that interpersonal factors also overlap with linked lives and historical time in influencing the care provided by grandparents. The findings of this study show that links to adult children influenced grandparents to play a role in raising grandchildren. Grandparents embraced the caregiving role when their grandchildren lost parents, or when their adult children were unemployed or abused alcohol and thus were not able to take care of their own children. This is consistent with previous research which has shown that parental death played an important role in grandparents taking up the caregiving of their grandchildren (Kuo & Operario, 2010; Mudege & Ezeh, 2009). In this study it is possible that the death of biological parents, specifically fathers, is related to AIDS as at the time, ARVs were not widely available in South Africa. However, the fact that adolescents and the older carers were also not informed about the cause of death might be related to stigma. Some African studies found that families who lost an adult member to HIV were subjected to different forms of stigma including physical, social, and verbal stigma (Hosegood, Preston-Whyte, Busza, Moitse, & Timaeus, 2007; Ogunmefun, Gilbert, & Schatz, 2011).

Another finding is that parental neglect was perpetuated by new sexual partners of parents after separation. It may be possible that this form of parental neglect perpetuated by new sexual partners of parents is related to gender power differences in sexual relationships, as suggested in previous studies (Clüver, Elkonin, & Young, 2013; Jewkes & Morrell, 2012). Biological parents could experience limited agency to provide care and support to their children from previous relationships in the context of new sexual partnerships. Other researchers suggest that gender norms shape parents’ spousal relationships and influence relationships between parents and the children, for instance in the attention given to the children (Wamoyi, Wight, & Remes, 2015). This has important implications on adolescent psychological well-being and their transitions into adulthood. The findings of this study indicate that adolescents were emotionally distressed by parental neglect. Consequently, experiencing parental neglect can become a traumatic life event for the adolescents (Heim, Shugart, Craighead, & Nemeroff, 2010).

Biological ties between adolescents and their older carers can also be understood from the principle of linked lives as a result of family ties in that the adolescents are the children of the older carers' adult children. The older carers feel obliged to care for their adolescent grandchildren due to family ties. The moral obligation to care for family members is characterised by exchanges with others related by blood (Knight et al., 2016). In addition to the influence of biological ties influenced by linked lives between adolescents and their older carers, older carers expressed an expectation that their adolescent grandchildren would reciprocate care. Moreover, the principle of historical time shaped grandparent caregiving as family living arrangements increased the opportunities for grandparent caregiving when they co-resided with adult children in the family.

At the societal level of the SEM, this study identified historical time as playing a role in influencing grandparents to take on the responsibility of caring for their grandchildren. Cultural norms detecting that children born out of wedlock should remain in the custody of maternal grandparents contributed to caring of adolescents by grandparents. This study found that grandparent caregiving is a practice that was deeply ingrained in the culture of people for children born out of wedlock. These findings are consistent with previous studies in Africa that caregiving of children born out of wedlock were raised by the grandparents (Kasedde et al., 2014; Wamoyi et al., 2015). These cultural norms that define grandparent caregiving for children born out of wedlock may exacerbate separation, emotional distress and social distance between children and their parents, as demonstrated in a study in China (Zhao, Wang, Zhou, Jiang, & Hesketh, 2018).

While the older carers used their agency to take on the responsibility of caring for the adolescent children at an individual level, their agency was limited or silent at interpersonal and societal levels of the SEM. At the interpersonal and societal levels, the older carers did not have the agency to make independent choices. This finding suggests that older carers may be obliged to accept the responsibility of caring for their grandchildren even when they are not willing to do so. A possible explanation for this might be that older carers use their agency within the framework of social norms, values, sanctions, and relationships (Dutta & Basu, 2008). Interpersonal relationships and cultural norms may be constraining agency of older carers in caring for adolescents.

Secondly, the study explored the nature of the relationship between adolescents and their older carers, and interrogated individual and structural factors that both negatively and positively affect the quality of relationships between the two. The influential factors identified were adolescent behaviours and caring behaviours by older carers.

The findings of this study highlight that there were both protective behaviour and risks within the care relationships for adolescents influenced by interpersonal and structural factors of the SEM. Protective factors are associated with a reduction of negative outcomes and decrease the severity of the consequences, while factors that increase the likelihood of experiencing an adverse health outcome are risks (WHO, 2007). In this study, some adolescents perceived their older carers as good people and this perception was rooted in their experience that their lives were better because of their older carers' efforts. For instance, some adolescents expressed their gratitude for the supportive role played by their older carers such as providing food. The WHO suggests that behaviours that show adolescents that they are loved and accepted are protective factors to healthy adolescent development (WHO, 2007). The study findings are consistent with those of previous studies on the relationships between grandparents and their grandchildren (Attar-Schwartz & Buchanan, 2018; Attar-Schwartz, Tan, & Buchanan, 2009; Dolbin-MacNab & Keiley, 2009). However, it was surprising in the findings that when adolescents described their care relationships with their grandparents, they did not mention love and affection for their grandparents; instead, they emphasised deep gratitude for their grandparents' efforts in providing food and clothes as well as sharing historical information.

In contrast, other adolescents experienced difficulties in the care relationship with their older carers. These difficulties stemmed from physical punishment, the amount of household chores, and the lack of basic needs. A Tanzanian study found that young women's poverty and the lack of basic material needs motivated young women to engage in transactional sex (Wamoyi, Wight, Plummer, Mshana, & Ross, 2010). These may be risk factors in the care relationships between adolescents and their older carers which could influence risky behaviours of adolescents. The risk factors including poverty, parental separation, and parental death have been identified as having a negative impact on adolescents (Tan, 2018). Adolescence is a transitional time between childhood and adulthood that involves significant physical, cognitive, and social changes (Dolbin-MacNab & Keiley, 2009). Adolescents' desire for autonomy may contribute to adolescent-older carer conflicts. For instance, one older carer mentioned that her grandson refused to do household chores upon her instructions and wanted to do chores when he chose to. This may suggest the need for autonomy in adolescence.

The findings of the study indicate that adolescents and their older carers reported changing perspectives about the caring relationships. For example, in the beginning of fieldwork, some reported smooth relationships but data from later fieldwork showed complaints about each other, as demonstrated by Gumede et al. (2019) about the challenges of using separate interviews with individuals in dyads. The life course perspective captures the changing relationships in the context of wider social changes and life events happening between adolescents and their older carers. For example, adolescent pregnancy shaped the relationships. With the life course perspective, it sheds light on the impacts of life events and the agency of adolescents and their older carers demonstrated over time. As Hutchison (2010) points out, the life course perspective is helpful in explaining how people change and stay the same as they make their journey in life.

4.5 Conclusion

This chapter has provided insight on the pathways into caring for the adolescent grandchildren by the older carers. The findings of this study show individual, interpersonal, and social factors combined with linked lives and historical time were the main factors driving pathways to grandparent caregiving in this study.

The major advantage of this study is that a multi-theoretical approach to understanding factors influencing caring of adolescents by grandparents/older carers has been used. Older women continue to provide care for children within the family and continue to care for the children made vulnerable by parental death or neglect. Urgent efforts and investment are required to provide for the future care needs of these older people. Grandparents may be overly optimistic about the care they will receive from their grandchildren and may be at risk of not having their future care needs met. Adult children and grandchildren may not be there to care for older people. Programmes should prioritise these older people who are already caregivers. To improve the nature of relationships between adolescents and their older carers, interventions and family support systems have to understand the experiences and needs of all concerned. The next chapter explores the labels used for adolescents in caring relationships and how the labels impacted adolescents' lives.

CHAPTER FIVE

LABELLING OF ADOLESCENTS IN OLDER CARER FAMILIES

5.1 Introduction

Adolescence is a critical period of rapid physical and psychosocial changes (WHO, 2017). It is during adolescence that behavioural gender patterns begin to emerge (Igras, Macieira, Murphy, & Lundgren, 2014). While socialisation starts at birth, adolescence is a critical point of intensification in personal gender attitudes as puberty reshapes gender self-perception, as well as social expectations from others (e.g. family members) (Kagesten et al., 2016). It is during adolescence that gender roles are solidified (Igras et al., 2014).

This chapter reports findings of interviews with adolescents, their older carers, and HIV programme facilitators. After the grandparents and their adolescent grandchildren had told their stories of how the grandchildren came into their care, they were asked to relate their experiences of how the adolescent grandchildren were perceived in these relationships. The researcher explored how the labelling of adolescents by their older carers impacts transitions and adolescent life trajectories in a community where HIV combination prevention interventions are implemented.

5.2 Results

5.2.1 Labels ascribed to adolescents and behaviours associated with labels

In the accounts with young people, their older carers, and key informants, labelling occurred when the behaviour of young people was deemed acceptable or unacceptable. Two categories were used to label young people: ‘well-behaved’ and ‘badly-behaved’. ‘Well-behaved’ young people were those who acted in an acceptable and approved manner within their families and in the community by following the rules and expectations set for them. Older carers used terms such as ‘collected’ and ‘handle-able’ to describe ‘well-behaved’ young people. In contrast, ‘badly-behaved’ young people were perceived as those who conducted themselves against the rules and expectations. They were perceived as the opposite of ‘well-behaved’, and the terms and phrases used to refer to them were ‘defiant’, ‘mischievous’, ‘do as they like’, and ‘misbehaving’.

Participants were asked to list behaviours which were associated with the labels ascribed to the adolescents. Several themes emerged, as summarised in Table 5.1. These behaviours were related to (a) peer networking, (b) mobility, (c) sexuality, (d) schooling, and (f) religiosity.

Table 5.1: Labels ascribed to adolescents and the associated behaviours

	Peer networking	**Mobility**	**Sexuality**	**Schooling**	**Religiosity**
Well-behaved	Have no or few close friends Establish friends at church	Seek ‘mobility license’ (permission to go outside home range) Limit movements outside home range	Not sexually active or delay sexual intercourse until completion of secondary school or marriage Practice regular virginity testing Not using contraceptive methods	Attend and complete school Compliant with school rules	Attend church services Compliant with church rules
Badly-behaved	Have many friends Bully	Wander the streets Frequent delays to return home Sneak out in the night	Sexually active Pregnant Have premarital children Engage in concurrent or multiple sexual partnerships	Drop out of school Defiant to school rules	Not attending church services Noncompliant with church rules

5.2.2 Gender and labelling

Three themes emerged which indicated that gender appeared to frame how adolescents were perceived and expected to behave. These themes were: (a) control of sexual desire by girls, (b) virginity testing for girls, and (c) restricted freedom of movements of girls.

a) Control of sexual desire by girls

During the interviews, some participants expressed that girls were expected to control their sexual desire by not engaging in sexual activities. A sexually active girl was perceived as ‘badly-behaved’. One older carer used three phrases to refer to a sexually active girl. Those phrases were “*uhubha abafana”*, “*uthanda abafana”* and “*ushintsha abafana”*. The direct translations of these phrases are ‘*she runs after boys*’, ‘*she loves boys*’, and ‘*she changes boys*’, respectively. She said:

> *A badly-behaved girl runs after boys … she loves boys before time. She changes boys. Today she is with this one boy and tomorrow she is with another one. (MaNgubo, older carer, 80).*

She further explained the contextual meaning of these phrases that they meant a girl who is sexually active and has concurrent sexual partners.

Another older carer explained that: *“A ‘well-behaved’ girl is expected to control her sexual desire and not to show interest in sexual intercourse”* (MaZulu, older carer, 64). This was reinforced by one adolescent boy as he said: *“I simply walk away if my girlfriend presents sexual appetite when I don’t intend to do sexual intercourse”* (Thabani, boy, 15). He preferred to take the lead in initiating sexual intercourse as a boy. One of the older carers further explained that: *“A girl who is unable to control her sexual desire lacks sexual morals”* (MaNgubo, older carer, 80).

b) Virginity testing for girls

Both adolescents and older carers emphasised virginity as a symbol of well-behaved girls. Girls’ virginity was frequently monitored through a method of virginity testing. Below is the explanation of virginity testing given by one adolescent girl:

> *Virginity testing is a process whereby a girl lies on her back with her legs open for a tester to look at the vagina to determine if the girl had sex or not. It's done at church and in the camp within the community. … In the camp, virginity testing is conducted in privacy between the girl who is being tested and the virginity tester, and the results are communicated immediately to the girl being tested. Whereas, in church, virginity testing is conducted in front of other girls and parents. Individual results are publicised to everyone present if the girl is still a virgin or not. In both the camp and church, a girl who is found to be a virgin is issued a certificate for being a virgin. (Thandi, girl, 13)*

She further described her experience of virginity testing:

> *I regularly test either in church or in the camp. There are around 40 girls aged between nine and 21 years who come for virginity testing in the camp. It's held once a month, overnight. So, every month transport is organised to collect girls in the community to go to the camp for testing. When we get there, we sing and dance* [traditional dance] *for the whole night. Then, testing is done early morning. … I like to be tested and choose to be tested because it helps me to abstain from sex. I've received many virginity certificates* [meaning that she's a virgin]. *(Thandi, girl, 13)*

According to one of the older carers, she uses the phrase *"she is damaged"* to refer to a girl whose virginity test results were negative and the negative virginity test results were understood to mean that a girl has had sexual intercourse: *"In our church, girls are tested for virginity. … If the results show that she is damaged, it means that she has slept with a boy"* (MaKhoza, older carer, 64).

While girls' virginity was monitored through 'virginity testing', one adolescent commented that this practice was not done for boys: *"Virginity testing is only for girls. Boys are not tested for virginity in church … I don't know why. … It's done on girls to ensure they are virgins before marriage"* (Mpume, girl, 19).

However, other adolescents had lost confidence and trust in the practice of virginity testing. They doubted the effectiveness of virginity testing due to the perceived high rate of pregnancy among those girls who went for virginity testing and were found to be “virgins”. Below is the story of Neli (girl, 14).

In the first interview with Neli, she was eager and looking forward to going for virginity testing. Her grandmother, MaZulu, supported the idea of Neli going to the overnight camp for virginity testing. She believed, “*it’s good for girls to go to the camp as they are taught on how to behave* [meaning not to engage in sexual intercourse]”. She also believed “*if young girls underwent virginity testing, they would have a fear of engaging in sexual intercourse and not fall pregnant*”. On the other hand, Neli said that she liked the idea of meeting with other girls to sing, dance, and to get a virginity certificate. Surprisingly, in the third interview, she had changed her mind about going for virginity testing.

> *Oh, no! Those girls who go for virginity testing engage in sex. You see, pregnant girls at school are those who go to the camps for virginity testing. Other girls tell us that ‘yes! We went to the camp, and after that, we went with our boyfriends’. You see, today, girls are going for camping. You will see boys going to the camp to look for girls. Boys will be flocking to the camp. They stand along the fence, and the girls will sneak out to go with their boyfriends. Some girls will come only to sing and dance, and after that leave early in the morning before they are tested for virginity. Others will test and go home after testing. But in the night, they say things are happening. At school, pregnant girls are those who attend camps. I don’t want to go to for virginity testing anymore. I’m okay staying at home. In the end, I know myself that I’m a virgin. (*Neli, girl, 14)

While Neli was concerned about the effectiveness of virginity testing to reduce pregnancy, Thabani pointed out corruption in the practice of virginity testing, as he said: “*There is corruption! Those women who test girls for virginity are bribed to issue virginity certificates as if a girl is still a virgin when she is not*” (boy, 15). He strongly believed that the results of virginity testing were not reliable as the results were subject to fabrication.

c) Restricted freedom of movements of girls

Mobility was one of the characteristics used by older carers to frame adolescents as ‘well-behaved’ or ‘badly behaved’. It appeared that girls were expected to have more restricted freedom of movement than boys. One older carer commented:

> *Sometimes, he* [Thabani aged 15] *comes back home later than the stipulated time. … Although, I’m not happy when he is not obeying my instructions, it would have been worse if he was a girl. A ‘well-behaved’ girl should never delay coming home after school. (MaNdawo, older carer, 76)*

Another older carer placed less restrictions for movement on her grandsons when compared to her granddaughter:

> *I allow boys to go out to play soccer but, I want her* [Neli aged 14] *in front of my eyes … because she is a girl and should not be wandering outside the streets. A girl child who wanders in the street can fall pregnant with a child whose father is unknown. I don’t want her to be away from home. She will end up having a boyfriend. Having a boyfriend will lead to a child whose father is unknown because the boyfriend will deny making her pregnant. … I restrict her movements so that she can be collected and for me to monitor her closely. (MaZulu, older carer, 64)*

Furthermore, some girls had also internalised the gender norm in that they described freedom of movement as ‘badly behaved’ and felt bad for moving outside the home. One said: *“I’m now ‘well-behaved’ these days. I don’t go out anymore”* (Zama, girl, 15). Another one stated: *“I don’t go out to roaming around the street like badly behaved girls. My grandmother doesn’t allow me to go out unless it’s necessary, like going to school or to fetch firewood”* (Neli, girl, 14).

5.2.3 Factors shaping stigmatised labelling of adolescents

Four themes were identified in how stigmatised labelling of adolescents was used in a way to direct young people’s behaviours by themselves and by older carers: regulated association, self-exclusion from HIV and SRH services, exclusion from religious activities, and stereotypes towards adolescents in older carer families.

a) Regulated association

The labels ascribed to the adolescents were mentioned as a criterion to regulate association by adolescents themselves and by older carers. Some adolescents stated their grandparents restricted them from choosing their own friends, particularly those labelled as ‘bad behaved’. According to one adolescent: *“My grandmother doesn’t want my friends because she knows they are not good … they drink alcohol and smoke dagga”* (Zama, girl, 15).

Older carers affirmed that they did not want their grandchildren to associate with other young people in the community whom the older carers perceived as ‘bad behaved’. They controlled relationships between their adolescent grandchildren and peers and feared ‘bad behaved’ young people were risky to their adolescent grandchildren. One older carer stated:

> *She* [Neli] *will learn many wrong things if she meets with bad friends. A bad friend will tempt her about joys of having a boyfriend, and then she will be tempted. Having a boyfriend will result in pregnancy and having a child. The child will end up being mine. A bad friend will also show her alcohol and drugs. … I want her to tell me who her friends are. It’s better if I know her friends and their parents as well as if the parents are good people who can see if children are starting to misbehave. If she mixes with a bad child from the neighbour’s house, I try by all means to separate them. I sit her down and caution her to be careful and not allow a friend to put her into doing bad things, like engaging in sexual relationships. (MaZulu, older carer, 64)*

Being an older carer of a badly-behaved adolescent grandchild was perceived as creating a bad reputation for older carers. When adolescents were not well-behaved, some older carers saw themselves as a source of blame for not raising the adolescents appropriately. One older carer said:

> *Now that she* [Sane] *badly behaves, she must do things alone and leave* [name of neighbour’s child]. *How am I supposed to live in the community with* [name of neighbour] *when my child has turned my neighbour’s child into a rotten child? People are going to accuse me. (MaDube, older carer, 58)*

Some adolescents distanced themselves from peers whom they perceived were less like themselves. Instead, they associated with those who were like them:

> *I don't want 'badly-behaved' friends … those who are always moving up and down the streets … those who are not doing household chores at home … all my friends are well-behaved. (Thandi, girl, 13)*

b) Self-exclusion from HIV and SRH services

Being framed as badly behaved was stated as a barrier to accessing HIV and SRH services by young people. HIV programme facilitators mentioned that some adolescent mothers in the community self-excluded themselves from participating in the HIV interventions in fear of being labelled as bad examples amid other adolescents. According to one of the HIV programme facilitators, there was a misperception in the community that the HIV interventions were targeting the well-behaved:

> *Some adolescents were unable to join group sessions in fear that others knew about their history of sexual life. They excluded themselves, thinking they will be pointed out as a bad example among other adolescents, especially those adolescents who have had babies. They told themselves they do not deserve to join the programme because it was too late for them since they already had babies; whereas the programme was not like that. (Female facilitator, 41)*

c) Exclusion from religious activities

Both adolescents and their older carers mentioned that girls who were found to have lost their virginity, were engaging in premarital sexual intercourse, or who fell pregnant were excluded from church. This was illustrated in the story of Mpume, who fell pregnant and lost her church status:

> *Before* [falling pregnant], *I was known that I'm a virgin because we regularly test from the church. In our church, we sit in front and wear white clothes* [church uniform] *to indicate that we are virgins … only virgins sit there. If you are no longer a virgin, they remove you. In fact, you don't even go there. So,*

> *I haven't been going to church now. … All my friends are there in front, and I cannot join them. (Mpume, girl, 19)*

Her grandmother affirmed Mpume's story: *"She has embarrassed us for becoming bad behaved … she can't sit with girls* [virgins]. *She can't sit with women too because she's not married"* (MaKhoza, older carer, 64).

d) Stereotypes of adolescents in older carer families

The labels generated stereotypes of adolescents in older carer families. Adolescents who are cared for by grandparents were regarded as badly behaved in the community. This was illustrated by one adolescent: *"Some say children living with grandmothers lack respect, and they love boys* [meaning engaging in sexual activities] *since they know they live with grandmothers"* (Neli, girl, 14).

It appears that there was a perception in the community that older carers were too old to monitor young people's behaviour. Nevertheless, the very same adolescent disputed this perception: *"I'm well behaved and don't have a boyfriend. Although my grandmother is very old, she's very strict, and I don't do anyhow. I respect her"* (Neli, girl, 14).

5.3 Discussion

The findings show two labels communicated by older carers and sometimes adolescents themselves that can impede adolescents from engaging with healthcare services, attending school, participating in HIV interventions, or developing positive relationships with their caregivers. These labels are 'well-behaved' and 'badly-behaved', based on behaviours deemed acceptable or unacceptable. These findings concur with a study conducted in rural Uganda that reported young people's behaviours were categorised according to those who were well-behaved and those who were engaged in deviant behaviours (Bernays, Bukenya, Thompson, Ssembajja, & Seeley, 2017). Findings presented here show that this categorisation of adolescent behaviours between good and bad is based on stereotypes that are stigmatising. This becomes a binary morality of right versus wrong (Kolling, Rasmussen, & Oxlund, 2017).

The effects of labelling and stigma have largely been studied from the experiences of people living with HIV (Pantelic, Casale, Cluver, Toska, & Moshabela, 2020) and mental illness (Huggett et al., 2018). Research has shown that the labels given to people become the primary means of identification of the person by others (Goffman, 1963). Adolescents in this study responded to these labels in several ways, including internalising them, modifying their behaviours, or resisting them. The study highlights that labelling in the context of care relationships, in part to reinforce acceptable or discourage unacceptable behaviours, weighs heavily on adolescents' life trajectories and decisions for participation in healthcare services and HIV interventions. This is particularly important because HIV and sexual communication is often interlinked with relationships between adolescents and their caregivers (Bastien et al., 2011; Chappell, 2016).

The findings also illustrate the masculine power of boys taking the lead in initiating sexual intercourse. Boys do not view girls as equal sexual partners in the sexual relationships, but rather as tools for their sexual enjoyment linked to their constructions of hegemonic masculinity discussed in older studies as well (Dahlbäck, Makelele, Yamba, Bergström, & Ransjö-Arvidson, 2006). On the other hand, conceptions of female sexuality seems to be passive, devoid of desire, and subordinate to the needs or desires of males aligned to the previous research (Tolman, 2012). This makes the negotiation of safer sex difficult for the girls (Ninsiima et al., 2018). Ninsiima et al. (2018) stated that girls who show sexual agency are considered to be abnormal. Older carers also encouraged masculine behaviour among boys and promoted passivity among girls regarding their sexuality in this study. This is consistent with previous findings that abstinence from sex was emphasised to female adolescents by caregivers (Seif et al., 2018). It should however be noted that older carers may be socialising adolescents in the way they were socialised when they themselves were young as an indication of how historical experiences impact their values and practices mentioned in the previous chapter. As reported by other scholars, caregivers' views regarding sexuality are influenced by cultural norms and traditions that have also shaped the experiences of the older carers (Jerves et al., 2013).

Furthermore, the study shows how gendered/intersectional identities affect labelling. Control of female sexuality through virginity testing is another important finding of this study. This has also been reported by other scholars that girls are expected to not lose their virginity while it was different for boys (Nyanzi, Pool, & Kinsman, 2001) Societal expectations by older carers that adolescent girls should stay virgins until marriage, make it difficult for the girls to explore their sexuality. This echoes the findings of other researchers that male virginity was not a major issue for the boys. More emphasis was put on girls remaining virgins and the practice of virginity testing applied to girls only (Dahlbäck et al., 2006). Even when some girls are not virgins, they are supposed to pretend that they are in order to be accepted and regarded as ‘well-behaved’. When girls express their sexuality, it is considered a violation of their gendered norms, which is to be sexually inactive. The norms that dictate that girls behave like girls (Ngabaza et al., 2016) and phrases such as ‘she likes boys’ and ‘she runs after boys’ were used to express sexuality of girls in a negative light. These findings highlight the challenge that adolescent girls face as they explore their sexuality and transit to adulthood.

The study also shows that in some cases, deviating from the norm and breaking the rules on acceptable behaviours endorsed by older carers led to rejection within the family and community. For example, Mpume was excluded from church activities due to pregnancy. It is evident that the stigma associated with her pregnancy, and failure to maintain a gendered label for a ‘well-behaved’ girl, led Mpume to adopt an ‘outsider’ status. Stigma, as Goffman (1963) describes, deeply shames and changes individuals from whole individuals to discounted ones. This is similar to what Ruzibiza (2020) found in her study, that adolescent mothers who reported feeling very stigmatised, were lonely and isolated. The impact of labelling pregnant girls has severe consequences for adolescent girls’ sexual and reproductive health experiences. A study in South Africa reported that adolescents shared narratives of stress, emotional isolation, feelings of depression, and suicidal ideation, linked to HIV and pregnancy (Duby et al., 2020). Adolescent mothers may not fully utilise or not access SRH services for fear of stigmatisation (Duby et al., 2020; Gyan, 2018). Internalised stigma, or self-stigma, has been conceptualised as the subjective perception of being devalued and marginalised, which directly affects a person’s sense of self-esteem (Kalichman et al., 2009). In this study, some adolescents excluded themselves from HIV prevention interventions as a result of internalised stigma. It was interesting to note that internalised stigmatised labelling was used as a way of self-exclusion from

HIV interventions. These findings contribute to qualitative evidence suggesting that multi-faceted discrimination and internalised stigma that young people face pose a significant barrier to engage with HIV services in South Africa, similar to a finding by Pantelic et al. (2020).

Restricted freedom of movements of girls was another important finding of this study that shapes the experiences of adolescents as young people. Findings presented here mirror those of previous findings that girls' freedom needs to be restricted because girls have more to lose in a relationship than boys (Ninsiima et al., 2018). Older carers were concerned that the freedom of movement of girls created pregnancy risks for girls. This is similar to what Kolling et al. (2017) found in their study in Burundi that participants talked about how hanging out in the street can lead to a lot of "bad things", and this was connected to the influence of "bad friends" and socialising with "bad groups". In the context of the global Coronavirus Diseases 2019 (COVID-19) pandemic, it may be necessary for the older carers to restrict movements of adolescents. The risk of dying from COVID-19 has been reported to increase with age, and most of the deaths observed have been in people older than 60, especially those with chronic conditions such as hypertension (HelpAge International, 2020; United Nations, 2020). This has important implications for the older carer families. Their caregiving role provides an added risk of exposure for older carers as it makes it impossible for them to self-quarantine (Lloyd-Sherlock, Ebrahim, Geffen, & McKee, 2020). It is of concern that should the older carers become ill with COVID-19 or, worse, die, the implications for the children and adolescents they care for will be profound, as from experiencing grief and bereavement to a lack of care.

The striking findings of this study are that adolescent girls not only have to cope with the effects of gendered labels but also experience the secondary impact of stigma by association. According to Goffman (1963), stigma by association occurs when a person is devalued, rejected, or victimised based on a relationship with a stigmatised individual. The interpretation of this finding is that older carers are stigmatised on the basis of ageism, and the adolescents in older carer families are stigmatised on the basis of being raised by older carers. The concept of linked lives can provide understanding in which stigma experienced by one member of the dyad can affect the other member (Elder, 1998).

5.4 Conclusion

This study highlights how labelling emerged as the key to influencing the experiences of adolescents living with older carers in KwaZulu-Natal, South Africa. An understanding of how young people are described and perceived is vital for HIV interventions. This research has described labels placed on adolescents living with older carers and the impact this had on their experiences. Negative labelling may weaken a sense of self, family relationships and create barriers to accessing HIV interventions and therefore, further increasing HIV risks among adolescents. HIV interventions aimed at supporting adolescents need to consider these labels and how they are internalised or resisted by adolescents. Interventions should focus on working together with carers and healthcare providers to address the stigma attached to the labels and support adolescents to achieve a healthy transition to adulthood. Creating psychologically safe environments for adolescents and greater awareness of the negative consequences of labelling on the life course trajectories of these young people are fundamental.

The next chapter presents generational perspectives between adolescents and their older carers of ideal romantic relationships.

CHAPTER SIX

EXPLORING GENERATIONAL PERSPECTIVES OF ADOLESCENTS AND OLDER CARERS ON ROMANTIC SEXUAL RELATIONSHIPS

6.1 Introduction

Adolescence is a period of transition from childhood to adulthood where greater independence and romantic sexual relationships begin to emerge (Maina, Orindi, Sikweyiya, & Kabiru, 2020). Romantic sexual relationships are influenced by the age, culture, and socialisation of the individual (Kaye, 2008). The quality of family relationships and interactions can promote or cause a barrier to the development of necessary skills needed to participate in successful romantic sexual relationships during adolescence and adulthood. Perspectives about romantic sexual relationships vary among different cultures and generations. Parents and other carers of adolescents may have views on romantic relationships shaped by different norms and expectations from the young people in their care. Understanding adolescents' and their carers' views of romantic sexual relationships is key to HIV preventive interventions aimed at improving the health and well-being of adolescents. In this chapter the exploration of generational perspectives between adolescents and their older carers of romantic sexual relationships are presented.

6.2 Results

This section presents four themes that emerged in the exploration of generational perspectives between adolescents and older carers of romantic sexual relationships: meaning of romantic sexual relationships, appropriate timing for engaging in sexual activities, places to meet romantic sexual partners, and desired characteristics of preferred romantic sexual partners.

6.2.1 Meaning of romantic sexual relationships

When adolescents and older carers discussed romantic sexual partnerships, they categorised these partnerships as sexual, romantic, and combination of romantic and sexual. Also, their understandings were limited to heterosexual groups.

> *It's a relationship between a boy and a girl in which they have sex … they kiss and touch each other. (Thabani, boy, 15)*
>
> *It's when a boy and a girl sleep together* [sex]. *(Sane, girl, 13)*
>
> *It means having a boyfriend … sharing love, gifts, spending time together, and sleeping together. (Zama, girl, 15)*
>
> *It is when there is both love and sleeping together* [sex] *between a boy and a girl … even if I fall in love with a boy but I will not have sex with him. I will tell him right at the beginning that 'we can have a relationship but no sex'. (Neli, girl, 15)*
>
> *A boy and a girl play together* [sex] *with their private body parts. (MaNdawo, older carer, 76)*
>
> *We grew up when a boy and girl who loved each other were not allowed to have physical contact until marriage but things change. It can be anything now. (MaJali, older carer, 56)*
>
> *It's love between a boy and a girl* [ukuthandana]. *During our times, it didn't include sleeping together* [sex] *but these days they sleep together* [sex]. *(MaNgubo, older carer, 80)*

6.2.2 Appropriate timing for engaging in sexual activities

Both adolescents and older carers identified and described life events which marked acceptable and appropriate timing for young people to engage in sexual activities. However, it was clear that different views were held about the life events marking appropriate times for young people to be sexually active. The identified life events mentioned were completing secondary school education, reaching the age of 19, and marriage.

Mostly older carers mentioned they expected young people to complete secondary school before engaging in sexual activities: *"Young people must first finish school before they sleep* [have sex]*"* (MaJali, older carer, 56). Another older carer said: "*The mind of a young person should have reached maturity after finishing school and ready to know about love and sleeping* [having sex]*"* (MaNdawo, older carer, 76).

However, her grandson did not agree with young people being prohibited from sex, and found it unrealistic and contrary to the reality of young people:

> *Young people must not be prohibited from sex; it's not wrong to be in a sexual relationship before finishing school. It helps to engage in sex at a young age for one to be able to control himself/herself. It's not wrong to have a boyfriend or a girlfriend as long as it involves protected sex. (Thabani, boy, 15)*

While one dyad had opposing views, only one dyad agreed on the expectation for young people to first complete secondary school before engaging in sexual activities. An adolescent girl said: *"The right time to sleep with a boy* [to have sex] *is when one has finished high school"* (Neli, girl, 15). Her grandmother stated: *"My granddaughter* [Neli] *must first complete Standard 10, thereafter it would be the best time for her to have a boyfriend"* (MaZulu, older carer, 64).

Reaching the age of 19 was also mentioned by older carers as their expectation for when young people can be involved in sexual activities. The age of 19 was linked to an assumption that young people would have finished school at the age of 19. One older carer related to her personal past experience:

> *I had a boyfriend for the first time at the age of 19 because I was no longer in school and not committed with anything at home, that's why I expect her* [Neli] *to find a partner when she's 19 and no longer in school. (MaZulu, older carer, 64)*

However, the assumption that young people aged 19 have finished school was not true for Mpume. In the first interview with her, she had a dilemma about the expected age to engage in a sexual relationship and completing secondary schooling:

> *My grandmother tells me that I must not have a boyfriend. I must wait for the right time when I am over 18 years old… although I am now 19 years old but the time is still not right for me because I'm still in school … it would have been better if I had already finished school. (Mpume, girl, 19)*

In subsequent interviews, Mpume mentioned she was pregnant and had dropped out of school.

Furthermore, marriage was also mentioned as the appropriate time for young people to engage in sex. One older carer repeatedly emphasised that marriage was the appropriate time to initiate sex in accordance with the church rules. As she said in one of the interviews:

> *Our church rule says a young man proposes a young woman in church for marriage, but they should not have sex until they get married. They can meet or communicate through cellphones but no sexual intercourse. (MaKhoza, older carer, 64)*

However, one adolescent who was a member of the same church opposed the notion of excluding sex in romantic relationships. He confirmed that his church rules prohibited sex before marriage:

> *Boys and young men are not allowed to engage in sexual intercourse before marriage. Girls and young women should not engage in sexual intercourse before marriage. … However, in my view, sexual relationships help one to prepare himself/herself for serious relationships in future. It helps one to learn things at a young age such as preferences for a potential marriage partner in future, and to understand yourself as an individual in a relationship. (Thabani, boy, 15)*

6.2.3 Places to meet romantic sexual partners

When exploring the formation of romantic sexual relationships, it was clear that different socialising spaces were mentioned. Some spaces were viewed as more desirable than others between the perspectives of adolescents and their older carers. Schools and churches were identified as safe and normal environments where young people were expected to meet age appropriate romantic sexual partners. However, alcohol-serving establishments were concerning places among older carers.

The schools were mentioned by both adolescents and older carers as an important context for educational achievement. However, some adolescents saw opportunities for age appropriate romantic sexual relationships while older carers viewed schools as centres for education alone. According to some adolescents, young people spent time in schools and thought schools were safe spaces for young people to meet other age appropriate romantic sexual partners to develop relationship skills:

> *We spend most of our time in school, from Monday to Friday, and even during weekends. It's just us. Although there are teachers, but we young people play and talk together most of the time. I feel that schools are a good place for us as young people to meet other young people, like us, for love relationships. (Thabani, boy, 15)*
>
> *Many girls at school have boyfriends. It's common that girls meet boys at school and get involved in love relationships whilst at school. (Neli, girl, 14)*

In contrast, their older carers were totally against romantic sexual relationships among school-going youth. They stated:

> *No, no, no. Young people are supposed to go to school to obtain education. Love, sex and studying cannot simply go hand-in-hand. These things cannot just be combined. Children lose focus from education if they think about love while still in school. It's a distraction. (MaNdawo, older carer, 76)*
>
> *Schools are a learning space not for young people to meet there for sexual relationships. It disturbs a young person from concentrating to schoolwork. (MaZulu, older carer, 64)*

In addition to the schools, some adolescents and older carers mentioned that the churches were spaces for young people to meet potential romantic sexual partners:

> *It's better for him to find a future wife in church … when he has completed school. (MaNdawo, older carer, 76)*

> *Church is a place where we teach young girls to become wives for tomorrow. We have sessions every week to teach girls to wait for the right men … it's where a man can get a trained wife. (MaZulu, older carer, 64)*

The churches were also mentioned as spaces in which arranged marriages were facilitated. One older carer said:

> *In our church, men choose young women for marriage. It's such a big achievement for the family if their child is chosen. Marriage is a big thing because the family gets ilobolo* [bride wealth] *from the man for choosing their child. (MaKhoza, older carer, 64)*

Mpume confirmed her grandmother's story about arranged marriages within their church and narrated the process laid down by the church to be followed by a man to choose a young woman for marriage:

> *Our church rule is that any man* [church members and non-church members] *can propose a young woman for marriage during a church seminar. He can send someone to tell a young woman that 'I want to meet with your parents to request you for marriage'. Then the young woman would inform her parents. Or else, a man can propose a young woman for marriage in front of all the church members including the church leader during a church conference. (Mpume, girl, 19)*

Mpume further explained that a young woman was not forced to marry the man proposing marriage in church. However, refusing to accept the proposal for marriage jeopardised any future marriage opportunity for the young woman:

> *If you don't want to, you may refuse. But you end up having never married in your lifetime if you refuse a marriage proposal … you become cursed for refusing a marriage proposal … for you will never get married. (Mpume, girl, 19)*

Furthermore, participants reported that there were many alcohol-serving venues such as taverns, bars, and shebeens in the local community, where young people commute to for entertainment and alcohol. Observation data showed four visible alcohol-serving venues within the study site. These alcohol venues were also mentioned as spaces where young people meet romantic sexual partners. Only one adolescent spoke about going to the tavern with her friends to meet men, however, she mentioned that the intention was not to develop romantic sexual partnerships but to obtain money:

> *I used to go the tavern and return home around 2am … I just wanted money … I went to rip off money from men! I wanted money. I would bring back R300. I ripped them off by asking 'could you please buy me fried chips?' One would give me R50, and say 'we will go to my house* [to have sex], *isn't?' I would say 'yes'. … We spent the money on buying fried chips and useless stuff. Sometimes, I bought groceries for our family and cosmetics and underwear for myself. (Zama, girl, 15)*

In contrast, her grandmother was convinced that Zama went to the tavern to meet men for sex and money:

> *She goes to the tavern all night to find men. They give her money. … They cannot give her money without sex. It's obvious that she sleeps with men for money. (MaNgubo, older carer, 80)*

Another older carer disclosed her adolescent grandchild's romantic sexual relationship with an older man that she met in a tavern:

> *I've heard she met a man in a tavern. She goes with her friend at night to the tavern. Apparently, she has lied to this older man that she has completed school. (MaDube, older carer, 58)*

6.2.4 Desired characteristics of ideal romantic sexual partners

In understanding the preferred characteristics of the ideal romantic sexual partners, older carers and youth had both similar and different views. Four themes emerged when older caregivers and their adolescents described desired characteristics of an ideal romantic partner. These were: (a) ability to provide financial security, (b) similarity on values and interests, (c) commitment to finding a marriage mate, and (d) educational achievements. The older caregivers expressed their perspectives in relation to their adolescent grandchildren, while the adolescents thought of themselves.

a) Ability to provide financial security

Both adolescents and their older carers stated that a man who has the ability to provide financial security was desirable as a partner. Older carers' views were that having money meant that a man would be able to afford to pay *ilobolo* [bride wealth] to care for his family. As one older carer emphasised: *"A man cannot tell a woman that he loves her, only. He must be having money before he proposes"* (MaZulu, older carer, 64).

Similarly, the previously mentioned story of Zama also showed that she wanted men to provide money to her when she went to the tavern.

Interestingly, older carers had negative attitudes towards poor men who had no money like schoolboys. The main reason was that schoolboys were still in school hence did not have money as they were still dependent on their parents for financial support. As such, older carers did not prefer their granddaughters to have relationships with school going boys. In interviews with MaKhoza, she repeatedly expressed her opinions against sexual relationships between girls and schoolboys:

> *When you want a partner, don't go for a schoolboy. Look for an employed man. A schoolboy relies on his parents for money. So, what are you going to do with a schoolboy? What is a schoolboy going to do for you? A schoolboy receives pocket money from his parents as he is still in school. So, a schoolboy cannot help you, financially. (MaKhoza, older carer, 64)*

Another older carer seconded this perspective: *"A school going boy is not in a position to have money. What if she* [Neli] *gets pregnant? Who will pay for the baby's basic needs?"* (MaZulu, older carer, 64).

It seemed Mpume had internalised the messaging she received from her grandmother, MaKhoza, about the preference for a man who was able to provide financial security, as she said: *"It's even better to find an employed man, so he can help me with my financial needs"* (Mpume, girl, 19).

b) Similarity on values and interests

The perception of similarities influenced individuals' desirability for a potential partner. Participants, carers and adolescents, recommended shared religious values and interests in potential partners. There were no restrictions for membership in the same church. Thus, older carers and adolescents preferred men who had religious backgrounds:

> *As we are religious people, it's better for my granddaughter* [Neli] *to find a religious man. Non-religious men do things and behave in any way, whereas religious men are educated on how to care for a woman. So, a non-religious man will influence my granddaughter to do things against religious values. He will impregnate her and after that dump her. Non-religious go all over the place; they are not collected. … I don't mind even if he comes from a different church as long as he is religious. (MaZulu, older carer, 64)*
>
> *He may belong to a different church than mine, provided that he is not a criminal. I'll be comfortable with a churchgoer. (Mpume, girl, 19)*
>
> *I prefer a girl who has religious values. She knows how to respect and care for older people. … They will also pray together. (MaNdawo, older carer, 76)*

c) Commitment to finding a marriage mate

There were narratives between one dyad that a man who looks for a marriage partnership can be characterised as an ideal partner for young women. Both MaKhoza and Mpume shared a similar view about marriage.

MaKhoza mentioned that she emphasised to Mpume by saying: *"I regularly tell her [Mpume], 'you must finish school and find a proper man who has intensions of taking you to be his wife* [marrying]*''* (MaKhoza, older carer, 64). It seems Mpume supported this opinion as she also said: *"An ideal man is the one who will ask me for marriage"* (Mpume, girl, 19).

While MaKhoza and Mpume (dyad) desired marriage partners, MaNgubo and Zama (dyad) had contrasting views about marriage. MaNgubo viewed men as having power to control women in marriage as she stated:

> *I wish for Zama to find a man to marry her so that she has someone to control her. She needs a husband to control her, otherwise she'll continue moving from one man [sexual partner] to another. She'll continue wandering the streets instead of taking care of a husband. A husband will keep her under his control*. (MaNgubo, older carer, 80)

Zama however feared married life as she associated marriage with excessive household labour work for women. She also pointed out that her character was not suitable for marriage as she perceived herself to be too outspoken and stubborn to the point of being considered as rude:

> *I don't want to get married. I don't want to go to live with another person's family* [in-laws]. *I will suffer there! You will find that I will have to fetch water far away. Here, I fetch water close by. You will find that I will have to climb the mountain before I reach water! No! ... I'm hot headed! I don't qualify* [for marriage]. *I argue until I'm the last one talking. (Zama, girl, 15)*

d) Educational achievements

Only one dyad mentioned educational achievements as a preferred characteristic for the ideal romantic sexual partner:

> *It has to be someone with education background. I want someone who completed school so that we can read together. Education is very important to me. It brings employment opportunities in life. (Thabani, boy, 15)*

His grandmother seconded the importance of attaining education for women:

> *It's unlike our times. Education was not important for a girl child. Girls were raised to get married and to become housewives like myself. Nowadays, young women are educated, employed and financially supporting their families. (MaNdawo, older carer, 76)*

6.3 Discussion

This study aimed to get a better understanding of how adolescents and their older carers viewed romantic sexual relationships. The older carers were both pragmatic and traditional in their views while the adolescents were often idealistic.

The study makes a unique contribution by showing that older carers constructed their perspectives with close reference to their own life course experiences, particularly when they considered the appropriate timing for engaging in sexual activities. For example, one older carer expected her adolescent granddaughter to engage in sexual activities at the age of 19 years based on her previous experience in life.

The life events that were considered as marking the appropriate time for sex placed the adolescents in the ‘waiting period’. Being in the waiting period was confusing and risky for the adolescents. For example, Mpume was 19 years old and still in school, and therefore prohibited from sex. While she was in the waiting period, it is possible that she will have been conflicted with the waiting period and the reality of her life as she fell pregnant and dropped out of school. This finding is congruent with those of Mgwaba and Maharaj (2018) who report that young people, especially school-going youth hide their sexual relationships from parents or elders of the family since they are forbidden from engaging in sexual activities. Furthermore, it is suggested that if young people are prohibited from sex, they may also not prepare for it and fail to access contraception (McKee, Watson, & Dore, 2014).

The study reveals that adolescents engaged in romantic sexual relationships at a school level to experiment with and build relationship skills. However, the older carers viewed this experimentation as risky to academic performance for the adolescents.

In this study, participants identified schools, churches, and alcohol-serving establishments as places where young people meet romantic sexual partners. These findings echo those of previous studies (Kalichman, Simbayi, Kaufman, Cain, & Jooste, 2007; Reynolds et al., 2018). Using the Priorities for Local AIDS Control Efforts (PLACE) methodology, a study in eSwatini identified 182 venues where adolescent girls and young women (AGYW) met sexual partners (Reynolds et al., 2018). These types of venues included drinking spots/‘shebeens’ (31%), kiosk/stores/shops (16%), bars/clubs (15%), parks (8%), bottle stores (4%), shisanyammas (barbeque restaurants) (3%), and places of worship (3%). A South African study found that shebeens are often the places in which people meet new sexual partners (Weir et al., 2003). Attending alcohol-serving venues may expose adolescents to HIV risk and sexual exploitation regardless of alcohol consumption. The physical attributes of the setting such as number of patrons, music, dancing, amount of alcohol sold, lack of HIV prevention messages, and access to free condoms could contribute to HIV risk behaviours (Cain et al., 2012).

The practice of arranged marriages facilitated through the church emerged in this study. Before marriage both individuals may not know each other, and even when they know each other, there is no love and emotional bond between them (Yadav & Srivastava, 2019). The practice of arranged marriages may contribute to early marriages, also referred to as child marriages. Walker (2012) reports that approximately 40% of young women aged 20-24 worldwide who were married before the age of 18 live in SSA, thus resulting in early marriage being largely prevalent in this area. Several authors argue that early marriage is influenced by poverty, gender inequality, cultural taboos against premarital sex for girls, religious beliefs, and patriarchal predisposition for controlling female sexuality (Petroni, Steinhaus, Fenn, Stoebenau, & Gregowski, 2017; Walker, 2012). Child marriages make girls vulnerable to early pregnancy and STIs, because these girls have limited agency to influence decision-making about safer sex, particularly condom use or contraceptive use (Petroni et al., 2017).

In this study, one adolescent explained that young women are not forced to accept proposals in arranged marriages; however, young women may feel coerced into marriage in fear of being stigmatised for refusing a marriage proposal. Their agency may be compromised by the belief that they will never get married in the future if they refuse the marriage proposal. These organised marriages may also place young women at the risk of human trafficking for sexual exploitation and abuse, particularly when a man outside of church comes to propose to a young woman, who has no background available of the young woman and vice versa. In addition, older men who can afford to pay ilobolo [bride wealth] may propose to young women. Evidence shows that partnerships with older men facilitate gendered power imbalances within the relationship and older men tend to dominate sexual decision-making such as whether to use a condom (Biello, Sipsma, Ickovics, & Kershaw, 2010; Leclerc-Madlala, 2008; Luke, 2005). Age-disparate sexual relationships in the context of arranged marriages may increase the young women's vulnerability to HIV.

Previous studies in South Africa have reported that many adolescents feel pressurised to become involved in sexual relationships in order to 'fit in' with and gain social status among their peers (Gevers, Jewkes, Mathews, & Flisher, 2012; Mgwaba & Maharaj, 2018; Selikow, Ahmed, Flisher, Mathews, & Mukoma, 2009). Sexual relationships that involve the exchange of money is widely reported in the literature (Stephenson, Winter, & Elfstrom, 2013; Wamoyi et al., 2016). What is unique about the findings in this study is the insight that sexual relationships based on money can be a result of motivations of a generational influence between adolescents and their caregivers or socialization of adolescents within their families. In this study, for example, one adolescent was motivated by her older carer to target a man who can provide financial security in a romantic relationship. A desire for men with money, together with women's unequal access to economic resources and livelihood opportunities, means that sexual relationships are one of the possible ways that adolescent girls can access money (Petroni et al., 2017). These findings complement those of previous studies reported in South Africa and Kenya that poor young women seek out sexual partnerships to increase their economic and social capital (Jennings et al., 2017; Kaufman & Stavrou, 2004). The desire for men with money in sexual relationships can place girls at higher risk of pregnancy and HIV. Evidence shows that transactional sex relationships is a risky behaviour that has been linked to HIV and gender-based violence (Adjei & Saewyc, 2017; Stephenson et al., 2013) due to age and unequal power differences between partners and limited agency to negotiate condom use (Cluver, Orkin, Boyes, Gardner, & Meinck, 2011). In addition, the findings of this study show that older carers did not prefer sexual relationships between adolescent girls and school-going boys. Reliance on parents for financial support placed school-going boys at the risk of being rejected by their female peers for sexual relationships. Thus, the school-going boys could be trapped into engaging in sexual relationships with older women and criminal activities to obtain money. Other authors have noted that about 4% of adolescent boys had engaged in transactional sex in SSA (Adjei & Saewyc, 2017). These findings suggest that adolescent boys are confronted with similar risks such as HIV and sexual exploitation that adolescent girls face. Adolescent boys are likely to be facing difficult choices between the need for money to attract adolescent girls and the threat of engaging in risky behaviours.

The study findings also highlight gender norms, depicting masculinity of men and marriage as a tool to oppress women. For example, one older carer viewed men as having power and control over women and wished for her granddaughter to get married in order to be controlled by a man. Her granddaughter feared control of women in marriage unions and had internalised that outspoken women are rude, and therefore not suitable for marriage. Findings presented here mirror those of previous findings that women are socially expected to be nice and submissive (Ninsiima et al., 2018). Endorsement and attitudinal acceptance of stereotypical masculinity norms prescribing male dominance and toughness have been associated with violence (Ali et al., 2017; Courtenay, 2000). A study undertaken in South Africa shows that about 65% of women aged 18-30 years have experienced intimate partner violence (Gibbs, Jewkes, Willan, & Washington, 2018). Despite being a fundamental violation of girls' and women's human rights (Ellsberg et al., 2015), violence against girls and women is often rooted in socially accepted gender inequalities and is therefore condoned (UNAIDS, 2016a). A study conducted in Nigeria and Tanzania highlights that married girls are more likely to exhibit attitudinal acceptance of intimate partner violence, compared with their unmarried peers (Meinhart, Seff, Darmstadt, Weber, & Stark, 2020). Family socialisation is critical for adolescent development and a source of risk and protection related to youth violence (Garthe, Sullivan, & Gorman-Smith, 2019). Older carers supporting non-violent responses to conflict and non-masculinity of men may protect adolescents from the risk of intimate partner violence in romantic relationships. Relationships that adolescents have with their caregivers are essential in shaping their norms and behaviours in romantic relationships (Garthe et al., 2019).

6.4 Conclusion

The insights into the perspectives of adolescents and older carers about romantic sexual relationships were surprising and valuable in building a nuanced understanding of how individual, interpersonal, and cultural factors can shape adolescent transition into adulthood. Incorporating the perspective of adolescents and older carers is essential to the development of health promotion interventions.

The next chapter presents factors that facilitate and hinder the participation of adolescents in older carer families in HIV combination prevention interventions.

CHAPTER SEVEN

MOTIVATORS AND BARRIERS TO PARTICIPATION IN DREAMS INTERVENTIONS OF ADOLESCENTS IN OLDER CARER FAMILIES

7.1 Introduction

HIV remains the greatest burden in the world. There were approximately 38 million people living with HIV across the globe in 2019 (UNAIDS, 2020a). SSA remains the worst affected region by HIV in the world, with 25.7 million people living with HIV (UNAIDS, 2020b). AGYW aged between 15 and 24 years are the most affected contributing to 71% of all new reported HIV infections in the region (UNAIDS, 2016b). South Africa has 7.5 million people living with HIV (UNAIDS, 2020b). Despite widespread availability of ART in South Africa, the risk of HIV infection is particularly high among the AGYW, and they are at disproportionately higher risk of HIV than their male peers (UNAIDS, 2016b). In 2015, there were approximately 1.8 million adolescents (10-19 years old) living with HIV in SSA (UNICEF, 2016).

Adolescents have been an underserved group in global and national responses to the HIV epidemic (Ferrand et al., 2010; Mafigiri et al., 2017). Adolescents in older carer families are among such high-risk groups that have not received adequate attention. While in recent years, there has been increased public health interest in offering HIV prevention interventions for adolescents, their participation in HIV interventions is especially pertinent. General studies have been conducted on the factors that facilitate or hinder the uptake of HIV services by adolescents (Jonas et al., 2020; Ngwenya et al., 2020). However, little is known about views of adolescents living with older caregivers regarding their experiences of participation in HIV prevention interventions. The researcher examined socio-ecological motivators and barriers that influence participation in DREAMS interventions of adolescents in older carer families from the perspectives of adolescents, their older carers and HIV programme facilitators responsible for the implementation of DREAMS interventions. Exploring the multiple perspectives can bring light to individual, interpersonal, organizational, and societal dynamics that influence the participation of adolescents in HIV prevention interventions.

7.2 Results

As noted in Chapter 3 of this thesis, the researcher conducted key informant interviews with two HIV programme facilitators (one male aged 30 and one female aged 41) to get an insight into the DREAMS interventions, their experiences of the interventions and the participation of adolescents in older carer families. The HIV programme facilitators were employed by the selected organisation responsible for implementing DREAMS interventions in the uMkhanyakude district. Their role was to recruit DREAMS recipients and facilitate DREAMS programme sessions. It was critical to hear their views on DREAMS interventions as they possessed rich knowledge of the interventions and had interacted with adolescents in older carers. The socio-demographic information for the adolescents and their older carers is presented in Table 3.2 of Chapter 3.

7.2.1 Motivators of participation in DREAMS interventions

The motivators of participation in DREAMS interventions are organised into four levels of the socio-ecological model (SEM) namely individual, interpersonal, organisational, and community levels, as indicated in Figure 7.1. For each level, themes are supported by illustrative quotes from the interviews.

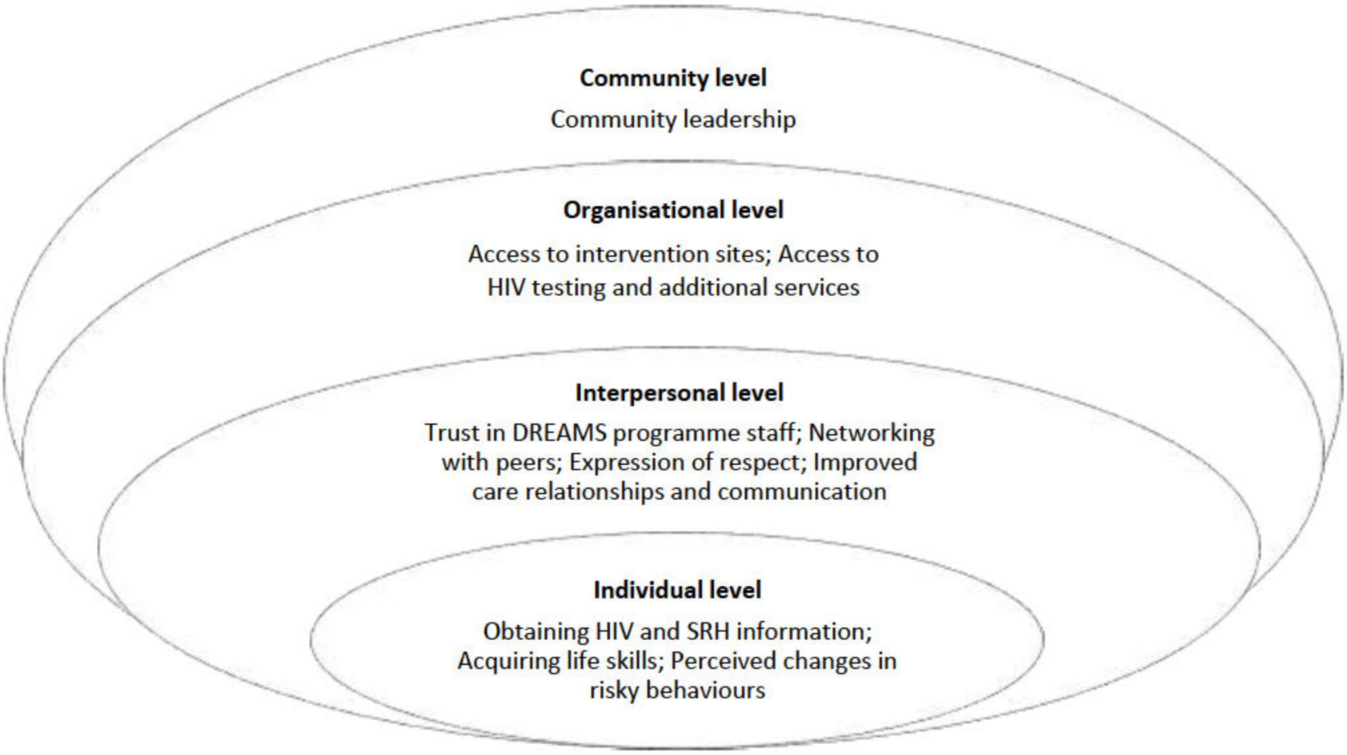


Figure 7.1: Motivators of participation in DREAMS interventions

7.2.1.1 Individual level

A number of individual factors positively influenced the participation in DREAMS interventions among adolescents in older carer families. The motivating factors mentioned were obtaining HIV and SRH information, acquiring life skills, and perceived changes in risky behaviours.

a) Obtaining HIV and SRH information

Some adolescents mentioned that obtaining relevant information regarding HIV and SRH issues motivated them to participate in the HIV interventions. They listed topics which were discussed. These topics included HIV, STIs, Tuberculosis (TB), condoms, contraceptives, communication, anger management, and career planning. An adolescent boy shared what he learnt from the intervention and his motivation to participate as follows:

> *We learnt a lot. We learnt about many STIs, names of STIs, contracting STIs, and link between STIs and HIV … I discovered that there are many diseases besides TB and HIV. … We learnt about families with financial problems, relationships with other people, and people to contact for help. The programme taught us real life issues faced by young people, family relationships, and handling family conflicts. Often, the topics were important. They taught us about things I have seen and experienced. Like, I've asked myself what do I want for my future? What steps do I need to follow? … I believed that I will learn something new in each session to change my life for the better hence I encouraged myself to continue participating in the intervention. (Thabani, boy, 15)*

Thabani's story showed that he was driven by a quest for more information to change his life and to plan for his future. He looked at information from the perspective of real-life issues hence he related with the discussions. He found the topics relevant to his needs for information.

The HIV programme facilitators explained topics which the adolescents enjoyed during the interventions. These topics included condom use, sexual relationships, and future planning.

> *…topics on condom use and sexual relationships. They* [adolescents] *liked those topics! And the session about gossiping and proper communication. An effective session but which brought up anger amongst the adolescents, was the anger management session. When they narrated stories, anger got out. Oh, they have anger issues! You find a mother thinking that everything is*

> *alright with her daughter whereas the daughter is angry with the mother because the daughter feels the mother loves the son more than the daughter. There are things that mothers do to their girls but not to the boys. There are things that boys do knowingly that the mother will not be harsh to them like when it comes to girls. Anger and frustration start building up inside a girl's mind. Another source of anger is a mother who has a relationship with another man* [stepfather] *… the child becomes jealous, angry and full of hatred. (Female facilitator, 41)*

b) Acquiring life skills

Apart from obtaining information, acquiring life skills motivated adolescents to participate in the interventions. One adolescent explained participating in DREAMS interventions assisted her to redefine friendships and to set relationship boundaries with peers:

> *I used to have bad friends who enjoyed wandering in the streets, not doing household chores and being disrespectful towards adults. In group sessions, we were taught how to choose good friends for us. At first, it was difficult to drop off my old friends because I realised they were not good for me and no longer fitted my new criteria of friends. I was bored and lonely without my old friends. But, gradually, I learnt new skills to find good friends. Now, I surround myself with friends who do household chores in their homes and who respect adults … it's very important to learn to be surrounded by good friends otherwise I would have changed to be as bad as my old friends. (Thandi, girl, 13)*

c) Perceived changes in risky behaviours

Some adolescents mentioned they believed they had changed risky behaviours as a result of participation in the interventions. They reflected on how they behaved prior and during their participation in the interventions. From their reflections, it showed that some had been engaging in risky behaviours. The perceived behaviour changes motivated their participation in the interventions. As raised above by Thandi, she mentioned that she had stopped associating with negative friends and found new ones, as she felt her association with them increased her vulnerability to engage in risky behaviours.

However, dyadic analysis revealed some similarities and differences of perspectives between adolescents and their carers regarding whether adolescents had adopted positive behaviours or not. One adolescent stated that she used to seduce men for money in the tavern and slept away from home but had managed to modify her risky behaviours through participation in a group learning intervention:

> *In beginning* [of the intervention], *there was no difference from my behaviour. In the end, there was because they taught us how to behave as young people. Here at home, I changed into a new person, I became a well-behaved person! I used to travel a lot and return at night. Sometimes I didn't come back home. I went with my friends to the tavern to rip off money from men. ... My friends were rippers. They smoked dagga and drank alcohol. … Oh, I no longer do that. Even, my friends were complaining and saying, 'you bore us now that you no longer go with us to the tavern'. I think the reason, I no longer do it, is the lessons from the classes* [intervention]. *(Zama, girl, 15)*

In a separate interview with Zama's grandmother, her story confirmed that there was a big difference in Zama's behaviour at the time she participated in the intervention. She refrained from travelling a lot and spent more time at home with the family. This change of behaviour made MaNgubo happy to be with her granddaughter at home instead of feeling distressed about Zama:

> *I can say those classes were helpful. She stopped wandering out and stayed with me here at home. She became useful with household chores. I was also at peace to see her at home rather than not knowing where she was at night. I could sleep peacefully at night knowing that she is safe (MaNgubo, older carer, 80)*

Both agreed that Zama had changed her going out behaviour. However, as seen earlier, Zama shared more details about where she was and what she was doing when she was away from home, which MaNgubo did not know about. Also, for Zama, the nights away at the tavern were exciting for her as she made money from those men she lured. This happened while her grandmother worried during those nights that she was away as she did not know the whereabouts of her granddaughter. She stayed awake at night wondering where Zama was. The interventions came at a time when their relationship was tense due to Zama’s behaviour. However, the changes in Zama’s behaviour improved their relationship as they were able to spend time together.

On the other side, one dyad did not agree about the occurrences of positive behaviour changes. An adolescent boy shared his experience of developing the ability to control his negative emotions and attitudes:

> *We did a session about financial problems within families. I used to be angry when my father and I could not communicate about my needs and which he refused to do for me. I would be upset and angry and took my anger out on my parents. But I needed to be humble and accept the way things are. It didn’t mean that I was not going pass my exams at school for not getting money for a school trip. (Thabani, boy, 15)*

In contrast to Thabani’s view, his grandmother said: “*Nothing has changed with Thabani. He is still the same as he was. Of course, he doesn’t go out in the night as he never did. But he still goes out where he likes, as he likes, during the day”* (MaNdawo, older carer, 76).

Thabani’s perceptions were that he had changed as an individual during participation in the programme. He expressed appreciation that he learnt about anger management and communication. Prior to enrolment in the programme, he mentioned that he had anger and communication issues with his father. He had to confront these issues and apply new skills learnt from the programme. From his perspective, he saw improvement in the way he communicated with his father and in the way he dealt with negative emotions. In contrast, his grandmother did not have enough information about the intervention. From her perspective, she was worried about Thabani’s going-out behaviour and felt the intervention had not made an impact on Thabani as he was still roaming the streets during the day. It was clear that Thabani perceived that he had changed at a deeper personal level not necessarily noticeable while on the surface he seemed to be going on with risky behaviour. Of importance, is that adolescent risky behaviour caused relationship tension between the adolescents and their older carers.

7.2.1.2 Interpersonal level

At an interpersonal level, the motivators of participation in DREAMS interventions that were mentioned included trust in DREAMS programme staff, networking with peers, and improved care relationships and communication, as described below.

a) Trust in DREAMS programme staff

Some older carers also discussed trust and positive qualities exhibited by the DREAMS staff that facilitated the older carers in supporting participation of their adolescent grandchildren in the interventions. One of the HIV programme facilitators was mentioned as a respected community member, a local pastor's wife, and a co-founding member of a community crèche. In her different roles, she had interacted with many people, young and old, in the community, hence she was called '*mother of the nation*'. The community approached her to play the part of mediator when families encountered conflicts. Many older carers regarded the facilitator as trustworthy and a reliable source of information. This trust was displayed in interviews with the older carers:

> [HIV programme facilitator] *will never mislead me! I trusted that she will not tell us lies about the classes will help my granddaughter. She lives with us in the community. We respect her as a pastor's wife … that's why I had no problem for Sane to attend the classes. (MaDube, older carer, 58)*
>
> *We knew* [name of staff] *long time ago. She looks after young children at the crèche. Sometimes, when we have family problems, she comes in to help us resolve our issues. … She told me about the classes and asked for my granddaughter to join. I agreed because* [name of staff] *is active in community development projects. (MaJali, older carer, 56)*

On the other hand, while the adolescents did not mention trusting the programme facilitators, they knew that their older carers trusted the facilitator hence they ensured that they participated in the interventions:

> *My grandmother knows [name of staff] and they get along well. So, I went to attend the classes because she requested permission from my grandmother to join the classes and my grandmother allowed me. (Thandi, girl, 13)*

> [Name of staff] *visited my grandmother here at home and told her about the classes, then I joined the classes. (Mpume, girl, 19)*

In addition, the relationships that developed between adolescent participants and the DREAMS programme staff over the course of the interventions positively contributed to retention. One programme facilitator shared his experience that being able to build rapport with adolescents made them more willing to attend and actively participate in the sessions:

> *We talked after every session and motivated the young people to continue participation in the programme. We engaged with them until we became friends. Building friendships with these young people was our strategy to motivate them to remain in the programme. They were open with us. Even when we meet in the community, they asked 'when are we meeting for a learning session?' Truth be told, we discussed things which are not included in the school curriculum. And the sessions were facilitated by young people. They took us as their equals. (Male facilitator, 30)*

b) Networking with peers

Participants mentioned that participation in interventions provided an opportunity for the young people to network with peers and friends. According to the programme facilitators, the interventions were delivered in a group format and were conducted either in schools or community venues. Depending on the intervention, groups ranged from 15 to 20 participants. Many adolescents came along with their friends to participate in the interventions.

> *I liked it because my friends were there. We talked and ate biscuits together. (Sane, girl aged 13)*

> *It was nice to meet with my friends during the classes. I really enjoyed attending the classes with my friends. We played and had fun. (Neli, girl, 15)*

> *I loved to come because my friends were there. We would talk and laugh. (Mpume, girl, 19)*

Thus, participation in the interventions created a friendly space for the adolescents to enjoy themselves away from home. It is important to note that these adolescents came from an environment in which their older carers restricted adolescents' movements and selection of friends. These adolescents had limited opportunities to socialise with their peers as they had responsibilities at home helping older carers. As a result, participating in the activities brought an opportunity to get away from the home environment and be with friends to have fun, to play games, and to enjoy refreshments.

The programme facilitators also shared similar sentiments that adolescents were motivated to participate in the interventions in order to meet with friends:

> *They enjoyed being together as peers to play and learn about different topics. They were fascinated by games, role plays and condom demonstrations; hence they didn't want to be absent for sessions. (Male facilitator, 30)*

c) Improved care relationships and communication

One of the main factors facilitating participation in HIV interventions was that it improved care relationships and communication between adolescents and their older carers. The parenting/caregiver programme seemed to facilitate communication between some adolescents and their older carers. This was illustrated by one adolescent:

> *There was a difference in our communication. She used to shout at me and not listening to what I needed to say. I can say my grandmother was able to listen to me until I finished when talking to her … sometimes older people don't want to listen to the young ones and it's difficult to talk when they don't want to listen. It's like you don't respect them and you are badly-behaved … although, we still talk but I feel we talked a lot during DREAMS. (Mpume, girl, 19)*

It seemed communication between adolescents and their older carers was limited by the age-gap between them. Adolescents feared to express their feelings to avoid being labelled as ‘badly-behaved’. Participating in the interventions enabled dyads to discuss issues openly and to share their feelings on different aspects.

The parenting/caregiver programme delivered separate sessions for adolescents and for caregivers as well as joint sessions for both adolescents and their caregivers. Some adolescents in this study participated in the programme with their older carers.

During the first interview, one dyad shared how the intervention improved their communication and care provided by the older carer. The older carer said that participating in the parenting/caregiver programme taught her to see things from the adolescent’s perspective, leading to improved communication and a better relationship:

> *They taught us about rules of parenting, which say we must not act like lions towards our grandchildren. We must not shout at our grandchildren when they go out with their friends. We must not lockdown our grandchildren at home. … Do I mean my granddaughter* [Sane] *must not relate with other children? Who will she relate with? She is young and I am old. I can’t play with her. … We learnt those lessons. Be polite to a child even when he/she has done a mistake. Sit down with the child and talk politely, not yelling at the child. In future, the child might fail to talk to you as a caregiver when he/she encounters a problem. The child would be scared for being shouted at … I realised that it is a mistake to act like a lion towards my grandchildren. You may think you are old yet there are things which you don’t know. Old ways are an enemy to a child, nowadays … I had talked to my granddaughter after we had been taught there* [programme]. *I said: ‘HIV is found through sex. Pregnancy is found through sex. There is no need for an unplanned child, which will end up being a burden to me’. She said: ‘I will never fall pregnant’ ... I last talked with her after we had finished the programme. Now, it’s difficult to talk her because she doesn’t want to listen. As I’ve told you she’s sleeps away from home and misbehaving. (MaDube, older carer, 58)*

In the same way as MaDube, Sane stated:

> *We used to talk as we were taught there* [programme]. *We talked about HIV and how it is passed from one person to another. Attending the programme helped us* [grandmother and granddaughter] *to know information which we didn't about how diseases spread. Talking to my grandmother helped to not to do it* [sex] ... *we don't talk a lot now. We were talking a lot when we attended DREAMS. (Sane, girl, 13)*

As a result of participation in the interventions, it seems communication about sex and HIV between some adolescents and their older carers was enhanced and resulted in more positive caring relationships. However, it seems communication lapsed after attendance to DREAMS programmes stopped.

Additionally, the programme facilitator dealt with several communication session between adolescents and their older carers regarding HIV testing and condoms. She narrated a story that one carer had misinterpreted that her adolescent child was engaging in sexual activities when she found condoms in his bag:

> *We had a session about condoms. One of the caregivers disclosed that she had bitten her son because she found condoms in his school bag as she was looking for a pen. She found two condoms, one open and one closed. Immediately, she concluded that her son was having sex. Whereas her son brought condoms after they were taught at school about condoms. She was fighting over the fact that she found condoms in his bag. She didn't care that the condom was open* [meaning he may have had protected sex]. *This case made us realise that* [name of programme] *is effective in problem solving. During the joint session, caregivers shared their experiences about behaviours they don't like from their children, and young people did the same about what they don't like from their caregivers. Young people said, 'I don't want my mother to open my bag and judge me about what she found inside my bag. I would appreciate if my mother could ask me when she found something she did not understand in my bag, rather than to shout at me'. This caregiver asked for apology from her son. We were so excited that they were learning how to communicate with children. (Female facilitator, 41)*

Further, adolescents shared that participation in DREAMS interventions resulted in them being more obedient and respectful towards adult authority. Across the dyads, older carers emphasised respect when raising their adolescent grandchildren. Adolescents' common understanding of respect was that it implied only obeying adults and doing as instructed. The older carers expected their adolescent grandchildren to obey authority as a symbol of being respectful. Failure and resistance to authority were unacceptable and likely to be met with negative consequences for the adolescents such as physical punishment. One adolescent illustrated that her participation in the interventions was influenced by the expectation to respect adult authority:

> *One day I was just lazy to attend group session but the thought of facing discipline made me to go. I went because I knew my aunt would ask* [the facilitator] *if I attended the session. If I had not gone, she would have shouted at me and would have told my grandmother about it. I hate being yelled at. (Zama, girl, 15)*

It was clear that Zama continued participating in DREAMS interventions to avoid conflict and to maintain a positive relationship with her grandmother.

7.2.1.3 Organisational level (DREAMS implementing organisation)

The organisation level motivators identified by the study participants referred to access to intervention sites and HIV testing as well as additional services.

a) Access to intervention sites

Easy access to intervention sites was mentioned as facilitating participation of adolescents in DREAMS interventions. Venues were located within the community to improve adolescents' access to the programme. The adolescents were grouped according to their area of residence to minimise travelling time and distance to the venue. An average time to and from the venues ranged from five minutes to 20 minutes on foot. One programme facilitator explained:

> *We delivered sessions in local venues in the community. The venues were closer to programme recipients. Our recruitment strategy was to recruit young people from schools, homesteads, and other community structures such as*

> *churches. We also grouped young people based on their place of residence so that they didn't have to travel long distances from their homes to the venues. It's us, facilitators, who travelled to the venues to reach the young people. The young people were enthusiastic to walk short distances to the venues to attend group sessions. And, most of them, attended all group sessions. (Male facilitator, 30)*

> *We attended classes at* [name of venue]*. It took me few minutes to get there from home. I was never late because it's very close to my home. (Neli, girl, 14)*

Older carers were also comfortable knowing that their adolescent grandchildren were close to home as they were concerned with the safety of the adolescents, as one stated: *"I'm happy that the classes were delivered closer to my house. It was safer for Thandi to get there"* (MaJali, older carer, 56).

b) Access to HIV testing and additional services

Access to HIV testing and additional services which were offered by the organisation implementing DREAMS interventions, facilitated the uptake of HIV interventions by the adolescents. The HIV programme facilitators explained that their organisation used a referral system for the participating adolescents to obtain additional services within the organisation and through other external service providers. One of the facilitators explained that sometimes they found some adolescents who were not ready to exit the programme and transferred them to another programme within the organisation. The implementing organisation also collaborated with other organisations to refer young people for additional services. Some of the services mentioned were HIV Testing Services (HTS), TB screening and testing, and contraceptives.

One adolescent said: "*We were referred* to [name of organisation] *for HIV testing. … I did go and was tested for HIV"* (Sane, girl, 13). Another one stated: *"I've always wanted to know my HIV status. They told us that we could go to* [name of organisation] *if we want to test for HIV. I went with other girls to test"* (Neli, girl, 14).

The organisation also linked adolescents with government departments who had problems with birth certificates and child support grants. One adolescent stated:

> *They helped me to get the child support grant because my grandmother had struggled for a long time to apply for the grant since my mother is nowhere to be found. (Mpume, girl, 19)*

The HIV testing and additional services generated interest and motivated adolescents to take part in the interventions and they found value from the services provided by the implementing organisation.

7.2.1.4 Community level

a) Support of community leadership

Community leaders were supportive of the organisation responsible for the implementation of DREAMS interventions in the different communities. According to the HIV programme facilitators, their organisation had engaged with community leaders to introduce the HIV interventions and first obtained support from community leaders before implementation. This was evident when community leaders, through community meetings, informed and mobilised communities to participate in the interventions. Additionally, community leaders reached an agreement with the implementing organisation to hire local people in order to increase employment opportunities for local people. Apart from securing employment opportunities for local people, community leaders felt that employing local people would facilitate better links with the organisation, especially in cases when problems arise, as one HIV programme facilitator explained:

> *They wanted local people whom they can contact when there are problems with the programme. If you are not a local person, then you must be accompanied by a local person so that the community can come to the local person when there are problems. (Female facilitator, 41)*

7.2.2 Barriers to participation in DREAMS interventions

The interviews with adolescents, their older carers, and HIV programme facilitators revealed several factors hindering participation in HIV interventions by adolescents.

Similar to the previous section, the factors are organised according to the individual, interpersonal, organisational, and community levels of the socio-ecological model (SEM) as indicated in Figure 7.2.

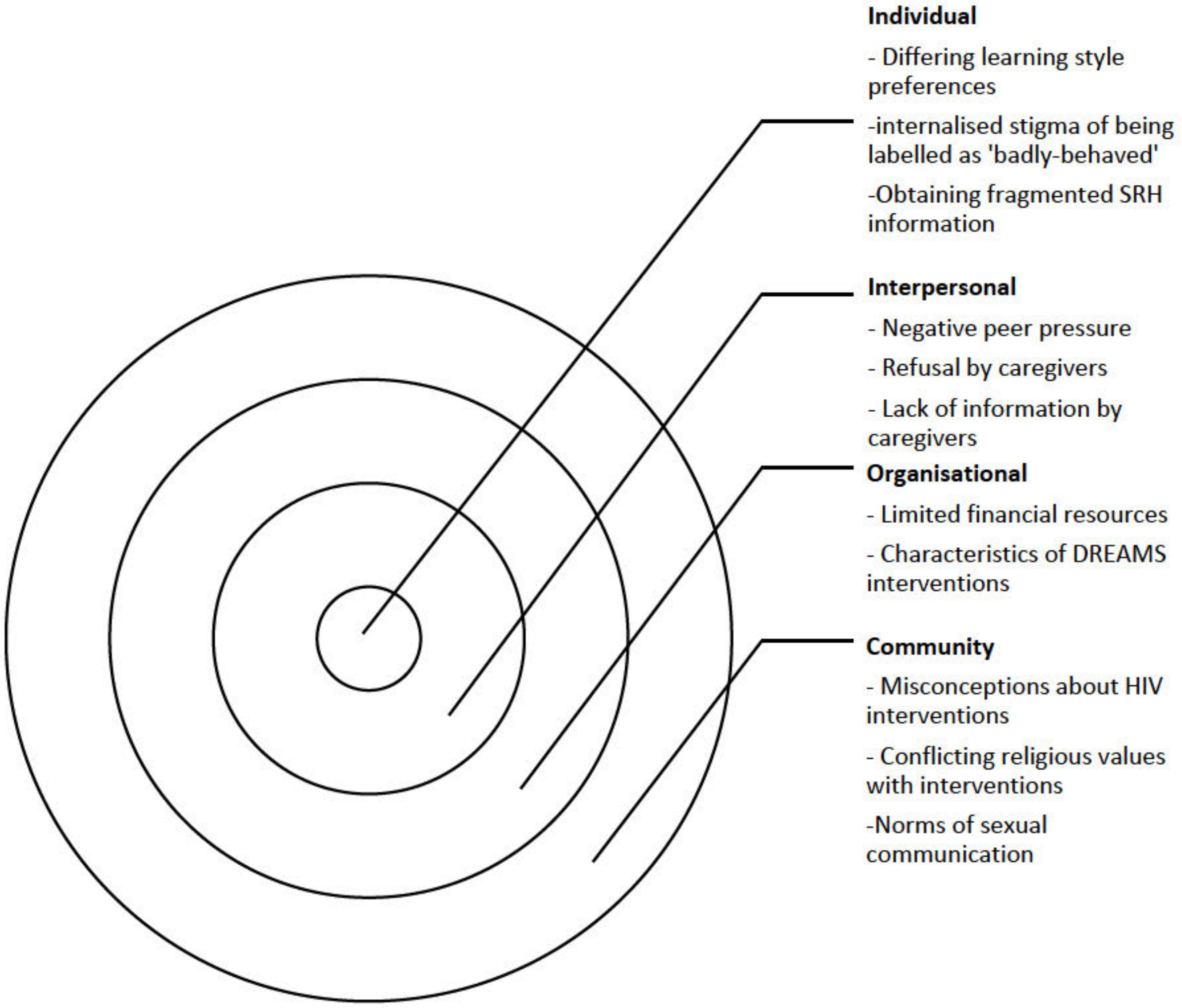


Figure 7.2: Barriers to participation in DREAMS interventions

7.2.2.1 Individual level

The study participants identified differing learning style preferences, internalised stigma of being labelled as 'badly-behaved', and obtaining fragmented SRH information as barriers to adolescents' participation in DREAMS interventions.

a) *Differing learning style preferences*

Adolescents participated in group-level interventions which comprised of oral and written activities, games, and role play. Differing learning style preferences among adolescents hindered learning in the behavioural interventions for HIV prevention. Two adolescents expressed challenges they faced due to learning methods which they did not like. Firstly, Thabani was a shy boy who participated in a gender-based violence (GBV) programme. He spoke with a soft voice about his struggles to participate in a role play scenario depicting GBV, and to share his personal experiences about body parts in group sessions:

> *There is something I was not comfortable with and it scared me. I am known as a person who does not like talking. However, there* [group sessions for the GBV programme]*, I had to talk in order to relate with other people. I was not free to talk about things like male body parts in a group setting. … I also didn't like doing role plays about violence against women and girls … I don't like violence and it felt like I was being violent. (Thabani, boy, 15)*

On the other side, Thandi was a loud spoken girl, and she was frustrated by written learning activities. She preferred listening to and participating in speeches, discussions, and question-answer sessions. As she said:

> *I liked it when there were no written tasks. I preferred group discussions … I get tired of writing. Sometimes, I felt like not attending group sessions to avoid writing activities. (Thandi, girl, 13)*

It was clear that writing activities created barriers and thus affected her willingness to actively engage in a meaningful way.

b) Internalised stigma of being labelled as ‘badly-behaved’

As stated before, internalised stigma of being labelled as ‘badly-behaved’ hindered participation in the HIV interventions by adolescents. Being a sexually active adolescent was labelled as bad behaviour. Even at school, adolescents tended to mock girls who had fallen pregnant. One adolescent explained that other girls laughed at pregnant girls and would utter statements like: “‘*You said you would never fall pregnant, but look at you now. You are pregnant!*’” (Neli, girl, 14).

Some pregnant adolescents dropped out of school and others who were teenage mothers did not participate in DREAMS interventions to avoid being labelled as ‘badly-behaved’. These adolescents struggled to fit in with their peers due to their personal experiences and feared rejection for not having been ‘well-behaved’. There was a misconception that DREAMS interventions were for the ‘well-behaved’. However, the facilitator emphasised that:

> *We enrolled and accepted both adolescents who had babies and those who did not have babies. We told those who had babies on how to prevent pregnancy so that they do not fall pregnant again. (Female facilitator, 41)*

c) Obtaining fragmented SRH information

Some adolescents mentioned that they received fragmented SRH information from their churches and the HIV intervention programmes. They reported that they were taught about contraceptives and different types of contraceptives to prevent pregnancy and HIV during programme sessions. In contrast, their churches prohibited premarital sex and thus the use of contraceptives by youth. One adolescent narrated teachings from his church:

> *They say men should not have sex before marriage. Women should also not, and they should ensure they do not have sex before marriage. In church, they make it clear that if you fail* [to abstain], *come to church for prayers … but in DREAMS, they told us about condoms. (Thabani, boy, 15)*

Some adolescents also indicated that their churches were silent about HIV. One adolescent said: *“In church, we are taught about abstinence … nothing is said about*

HIV and contraceptives … yet we learnt about HIV from DREAMS but not from church" (Thandi, girl, 13). Another one stated: *"No, in church they don't teach us about HIV"* (Neli, girl, 14).

Further, church messages were also advocated at home by the older carers. It was clear that adolescents were conflicted with messages they received from their church, home, and DREAMS.

7.2.2.2 Interpersonal level

The study participants identified negative peer pressure, refusal by caregivers, and lack of information about DREAMS as interpersonal factors hindering adolescents' participation in the HIV interventions.

a) Negative peer pressure

Negative peer pressure served as a barrier to participation for some adolescents. This was illustrated by one adolescent as she discussed that she experienced negative peer pressure as her friends demotivated her from participation:

> *My friends decided to withdraw from participating in DREAMS. They said that they felt bored during group sessions. Then, they expected me to give up participating in the programme. I simply ignored them. Sometimes, they stopped me on the way to attend classes. (Zama, girl, 15)*

As stated before, the experience was different for adolescents who attended DREAMS programmes together with their friends.

b) Refusal by caregivers

The HIV programme facilitators reported that some adolescents in the community were not allowed by their caregivers to participate in the HIV interventions. Two reasons were mentioned for refusals. Firstly, some adolescents were not allowed to attend programme sessions as a punishment for not carrying out household chores. Some caregivers wanted the young people to prioritise household chores before attending DREAMS group sessions. When household chores were not performed, the caregivers refused to allow the young people to attend the DREAMS group sessions.

The HIV programme facilitators reported that some caregivers made restrictions that adolescents were only allowed to attend programme sessions once they had completed the household chores:

> *Sometimes household chores commitments prevented them from attending group sessions. Some young people came to attend sessions when they had not properly completed their assigned chores at homes. We would tell young people 'you should do 1, 2, and 3* [meaning household chores] *because your parents expect you to do that before you come for group sessions'. (Male facilitator, 30)*

Secondly, another facilitator mentioned that some adolescents left their home as if they were going to attend programme sessions, but instead went to hang out elsewhere. In other words, some adolescents used participation in programme sessions as an excuse to leave the house. When caregivers learnt about these lies, they immediately refused to allow the adolescents to continue with participating in order to punish them for lying.

c) Caregivers' lack of information

Lack of information by older caregivers about DREAMS interventions affected young people's participation in the interventions. This was illustrated by two older caregivers, MaNdawo and MaZulu, as they reported that they saw their grandchildren going to attend the sessions regularly, and were concerned about not having information about the HIV interventions. These two older carers narrated their frustrations about the need for information and how they demanded their adolescent grandchildren to provide them with information. However, both older carers reported that their adolescent grandchildren ignored them and provided less information than what they expected. One older carer said:

> *One day, he told me that he attends classes, but I didn't know what they taught to him. Whenever he came back from school, he would say 'they are calling me, I'm going there. There is something we are learning'. He would not say what it was that they were learning. In the end, he said they were learning about HIV after I had asked for several times 'what are you learning about?'*

> *He said, 'we are taught about HIV'. I then kept quiet because he usually goes out. (MaNdawo, older carer, 76)*

Another one said:

> *They did not give me an explanation. … One day I asked, 'what are they teaching you because you do not explain anything to me'? I was worried that I didn't have detailed information about conversations Sane was part of.* (MaZulu, older carer, 64)

Lack of information limited the support the older carers gave to the adolescents who were participating in DREAMS interventions and affected their relationships with them.

7.2.2.3 Organisational level (DREAMS implementing organisation)

At the level of the organisation responsible for implementing DREAMS interventions, the study participants identified limited financial resources and specific characteristics of DREAMS interventions as barriers to successful participation of adolescents.

a) Limited financial resources

HIV programme facilitators reported that their organisation had limited financial resources to reach the many adolescents who needed the HIV interventions. They stated limited financial resources as the main challenge for their organisation in delivering the HIV interventions. This is reflected in the explanation of a programme facilitator:

> *Enrolling 20 adolescents in this ward does not mean that only 20 adolescents are living in this ward. They are many who could not receive the interventions because each group was limited to 20 adolescents. (Male facilitator, 30)*

He pointed out that some adolescents were excluded from the interventions as the organisation limited the areas where it operated due to financial constraints.

Further, limited funding constrained the organisation from hiring sufficient HIV programme facilitators to facilitate planned programme sessions in the various venues. The HIV programme facilitator indicated they were overwhelmed by the demand to facilitate the number of groups in the different venues. The facilitators felt that the workload and pressure to meet targets, sometimes made it difficult for them to be punctual for the planned group sessions with the adolescents. Disruption of the group sessions frustrated the adolescents, especially when there was no communication about delays or cancellations of the programme sessions. One adolescent expressed her frustration:

> *I didn't like waiting for the facilitators because, sometimes, they arrived late and not send any communication. I also didn't like when the sessions were cancelled, but I appreciate that they would apologise for being late to start the sessions or for making late cancellations. (Sane, girl, 13)*

Lastly, at the beginning of the interventions, some adolescents were provided with transport fare as an incentive to participate in DREAMS interventions. Many adolescents were motivated to participate as they were informed during recruitment about the incentive money. However, the organisation discontinued the transport fare due to limited financial resources and upon realising that adolescents did not have to incur transport costs for participation in the programme sessions as community venues were used. The facilitator explained:

> *In the beginning, there was a transport allowance. Later, it was realised that we do group sessions in the community where they live. Therefore, there was no need for a transport allowance. So, the allowance was never paid to some adolescents. … There was noise about this in the community … since young people were recruited on the premise that they will receive money which some did not get. (Female facilitator, 41)*

Some adolescents who did not receive the transport fare were not happy about it. They expressed their feelings:

> *Ay, there, they lied to us, there! Oh, my goodness, they lied to us! They said we must join the classes; they will give us money. Each day of attending will accumulate R10. We never received our money until now! (Zama, girl, 15)*

> *Oh, there! They told us we would get money for attending classes. … They played us. You see, people are saying 'they will not go to attend if the classes start again' because they were told lies'. (Sane, girl, 13)*

It was clear that the adolescents were unhappy about not receiving the transport fare as promised and regarded it as dishonesty on the part of the organisation implementing the DREAMS interventions.

b) Characteristics of DREAMS interventions

Some aspects of the DREAMS interventions were identified as hindering successful adolescent participation in the HIV interventions. Six intervention characteristics were reported. The first one regarded **DREAMS interventions that were school-based** and required the participation of adolescents within selected schools. One adolescent mentioned that her school was selected for a DREAMS programme while other neighbouring schools were not. It affected her when she walked alone without the company of other girls from the neighbouring school because their school was not included for the school-based intervention. Also, attending the school-based DREAMS intervention meant less time to spend with her other friends from the neighbouring school, as she said:

> *After school, I had to remain to attend DREAMS sessions, while other girls from* [neighbouring school] *walked back home. We walked together after school. So, I had to walk alone back home because their school was not part of DREAMS. Some are my friends and I lost time to be with them. (Thandi, girl, 13)*

The second characteristic that was a major barrier to adolescent participation was the **exclusion of adolescent boys in the parenting/caregiver programme**. The programme was only for adolescent girls and their parents/caregivers. One facilitators stated that the exclusion of boys in the programme influenced HIV risk for adolescent girls:

> *The programme was not supposed to include girls and their caregivers only, but it should have been the caregivers and their children, both boys and girls.*

> *The HIV statistics in KwaZulu-Natal shows that the HIV rate is not decreasing. I realised that, even though we were fighting HIV, but we fought on the side. In actual fact, boys needed the intervention that the girls received. Girls were taught about the programme. They were taught about how they can protect themselves from HIV. They were taught about teenage pregnancy. The problem is, a girl does not impregnate another girl. A girl does not acquire HIV from another girl, unless through sores. A girl gets pregnant due to having sex with a boy. A girl acquires HIV from having sex with a boy. A girl does not have powers over a boy, but the boy has powers over the girl. … If a girl refuses sex, the boy will force a girl until she has sex with him. … Girls were taught how to behave, but boys were not. In the programme, we talked with girls and their caregivers whereas boys were not there. Teaching boys will protect girls. If both boys and girls are taught, they will know how to build love relationships without sex. By so doing, teenage pregnancy and the spread of HIV can be prevented. (Female facilitator, 41)*

The third barrier was the **exclusion of adolescents with disabilities** in the HIV prevention interventions. One facilitator mentioned that adolescents with disabilities were overlooked for participation in DREAMS interventions. None of the adolescents with disabilities were reached by the implementing organisation to receive the HIV interventions. Reasons cited for the exclusion were that these adolescents lived in boarding facilities and returned home during school holidays when it was also a recess for DREAMS intervention activities. One facilitator said:

> *I did not have* [adolescents with disabilities] *in my groups … most of them live in boarding schools for learners with disabilities. … It was not noticeable that they are not receiving the interventions because we delivered programmes during school days, while they come back home over school holidays. We were not active during the school holidays. (Female facilitator, 41)*

Another facilitator stated:

> *Honestly, we did not pay attention on recruiting young people with disabilities. Of all the groups I facilitated, I did not have any young person with disability. We do have them in the community but we did not make any effort to include*

> *them. Even when reporting, we were not asked about reporting recipients with disabilities. (Male facilitator, 30)*

The issue of exclusion of adolescents with disabilities from DREAMS interventions was also raised by some older carers. One said:

> *I have a grandson who has mental health disorders as result he dropped out of school. My problem is that he is just sitting here at home without anything to do. I wanted him to join the classes* [DREAMS] *but they did not take him. (MaNgubo, older carer, 80)*

Another one stated:

> *My younger granddaughter has a hearing disability and no longer attending school. She is also not earning a child support grant because I don't have money to take her to the doctor for assessment in order to apply for the grant … she did not attend the classes* [DREAMS]. *How was she supposed to go there when she can't hear? I don't think they were going to allow her. I don't think they took children with disabilities. But, I wished they could have helped me get the doctor's letter to apply for the child support grant. (MaJali, older carer, 56)*

The fourth barrier associated with characteristics of DREAMS interventions was the **exclusion of older carers in the parenting/caregiver programme**. Some older caregivers were concerned that they were excluded from participating in the parenting/caregiver programme with their adolescent grandchildren due to age and physical abilities. One said:

> *I did not attend the classes with my granddaughter. She* [programme facilitator] *preferred my daughter* [Neli's aunt] *to come with Neli. I even asked her* [programme facilitator], *'how does it happen that I don't go with my granddaughter yet I'm the one caring for her?' She simply said 'I thought you would not afford to attend every session because you are also looking after the house and the young babies'. Then, I did not attend the classes. (MaZulu, older carer, 64)*

Another one stated: *“I could not attend the classes because she* [programme facilitator] *said ‘I’m too old’. They took my daughter* [Zama’s aunt] *instead of me to go with Zama”* (MaNgubo, older carer, 80).

One facilitator explained that they excluded older caregivers to save them from the strain of walking to the venues:

> *We excused older caregivers, especially those who are too old and unable to walk … we decided that their adolescent grandchildren must attend the sessions with someone who is still physically active and able to walk to the venues. We also thought it was going to be too hectic for the older people to abandon their housework and come to attend the sessions. (Female facilitator, 41)*

Fifth, **timing of programme sessions** was not convenient for some adolescents to attend the DREAMS interventions. Participants reported that DREAMS sessions that were scheduled for late afternoons conflicted with adolescents’ housework commitments.

> *Sometimes, the young people could not come for sessions that were held in the late afternoon. This is the time most of them are busy with household work such as cooking. (Male facilitator, 30)*

> *I missed a few sessions because they were late afternoon. … I was unable to attend the late afternoon sessions because I need to cook before it gets dark. (Mpume, girl, 19)*

Lastly, **recruitment strategies** employed by the implementing organisation combined with the targeted age group of young people hindered participation of some adolescents in the HIV interventions. The HIV programme facilitator explained that the organisation used various strategies to recruit adolescents for participation in the interventions. Each programme had its recruitment strategy targeting the same age group of adolescents. These strategies included sending letters to the caregivers, conducting door-to-door visits in the community, and recruiting young people in schools. The caregiver/parenting programme was community-based and used a door-to-door recruitment strategy whereby caregivers with adolescents aged 13-19 were recruited first. Often, these adolescents were in school while their caregivers were recruited. On the other hand, the school-based programme recruited adolescents aged 10-14 directly in schools. The HIV programme facilitator explained that the caregiver/parenting programme was unable to meet its target as some adolescents were already committed and participating in the school-based programme.

7.2.2.4 Community level

At community level, two factors were identified that hindered adolescents' participation in the DREAMS interventions. These factors were misconceptions about the interventions and norms of sexual communication.

a) Misconceptions about interventions

Participants stated that community misconceptions about the HIV prevention interventions created barriers for adolescents to participate in the DREAMS interventions. One facilitator mentioned that some community members perceived the interventions as 'a thing for women' and others labelled the interventions as a campaign to teach young people to control adults. She said:

> *It was sometimes difficult to recruit young people in the community to participate in DREAMS. We met resistance from some people, especially men. Some men in the community called DREAMS as a thing for women and didn't want to listen to us. Others said, 'Your women thing annoys us because you teach children to control us'. They felt DREAMS came to teach young people to be disrespectful towards adults. (Female facilitator, 41)*

b) Norms of sexual communication

Norms of sexual communication in the community was identified by the HIV programme facilitators as affecting their ability to facilitate some sexual health topics with the adolescents. One programme facilitator indicated that it was unacceptable for her as a pastor's wife to talk about sex in public spaces:

> *Sex topic! The reason it was difficult (laughing) for me is my church position. I am a pastor's wife. Many people create a wrong picture that since I am a*

> *Christian, I do not talk about that* [sex]. *It was difficult to utter sex-related words. When I said those words, all participants closed their mouths* [indication of surprise] *and said 'even you can utter such a word!' Sometimes I felt uncomfortable after talking about sex and regretted discussing the sex topic. However, I ignored the feelings because it was my job and I, as a facilitator, was required to talk about sex with young people and their caregivers. (Female facilitator, 41)*

Another facilitator shared his challenges as a man when talking about menstruation:

> *You see, the topic which was difficult for me to facilitate, is the topic about menstruation. It's the only one. I tried as I was expected to facilitate it. I was not familiar with facilitating it. … I never thought I would find myself facilitating this topic. The topic was difficult for me as man to talk about menstruation in the midst of girls … it's not common for a man to talk about menstruation in the presence of women because we, as men, don't menstruate. People think it's not our topic to discuss. (Male facilitator, 30)*

It was clear that norms of sexual communication challenged the programme facilitators when discussing sex and sexual development with young people. However, the young people did not express any problems with the programme facilitators discussing sex topics, except, as stated before, one adolescent boy who was not comfortable talking about his sexual organs during the sessions.

7.3 Discussion

This study explored the factors that facilitate and hinder participation in HIV combination preventions by adolescents living with older caregivers. Findings depicted here provide insights into individual, interpersonal, organisational, and community motivators and barriers that played a role in adolescents' participation in the HIV interventions.

The study findings highlight that DREAMS interventions strengthened the life skills of adolescents in older carer families, particularly interpersonal relationship skills, and coping with emotions. One adolescent girl reflected on her experience of redefining and recognising healthy peer relationships.

Family, peers, and HIV programme facilitators were instrumental in supporting the participation in HIV intervention by creating an enabling environment for adolescents to participate. These aspects are at the interpersonal level of the SEM. This is consistent with other studies showing that support from significant others has a positive impact on adolescents' uptake of health promotion interventions (Dunbar et al., 2010). The support that adolescents received from their peers and older carers motivated the adolescents to participate in DREAMS interventions. However, refusal by caregivers and lack of information given to caregivers negatively influenced adolescents' participation in HIV interventions. The results show that relationships with caregivers played an important role in the participation of adolescents in HIV interventions. Disapproval and lack of support from significant others such as caregivers and peers may limit access to HIV interventions by adolescents. Families are well positioned to reinforce motivation, decision-making, and adolescent protective behaviours (Kuo et al., 2016). HIV interventions need to consider the influence of caregivers and therefore promote communication between adolescents and their caregivers. In addition, it is imperative to involve and empower older carers with knowledge about SRH, HIV, and AIDS.

As stated before, domestic work seems to influence care relationships between adolescents and their older carers. In addition, domestic work responsibilities also influenced participation of young people in DREAMS interventions. These findings mirror those of other researchers that domestic responsibilities were barriers for adolescents in accessing HIV interventions (Mathews et al., 2015). In this study, the older carers expected young people to prioritise domestic chores over participation in HIV interventions. Refusing to let them attend DREAMS sessions was used as a punishment for not performing domestic chores. While it may be important for young people to perform their domestic responsibilities, this may give the impression that HIV interventions are less important than domestic work. A study in Uganda reported that children from older carer families were often late coming to school as a result of domestic chores (Rutakumwa et al., 2015). These findings show that domestic tasks are a burden for the adolescents in older carer families and this needs attention as it may compromise their health and well-being.

Moreover, in this study, improved care relationships and communication between adolescents and their older caregivers as a result of the exposure to DREAMS programme components generated interest in the interventions and motivated adolescents to participate in the HIV interventions. According to study participants, DREAMS interventions provided a specific and critically important experience of improved care relationships between adolescents and their older carers. As participants described these, they reflected on connections and bonds that are critical to adolescents' well-being. The DREAMS parenting/caregiver programme mitigated communication barriers between adolescents and their older carers. Other studies in South Africa have similarly found that a caregiver/parenting programme improved interactions between adolescents and their primary caregivers and facilitated important conversations about sensitive topics (Bhana et al., 2014; Bogart et al., 2013; Thurman, Nice, Visser, & Luckett, 2020). It seems the DREAMS parenting/caregiver programme promoted sexual health communication between adolescents and their older carers and reduced adolescents' behavioural risks. For example, one adolescent reported delaying sexual debut as a result of communication with her older carer that the programme facilitated. However, the study raises important issues about lack of sustainable communication between adolescents and older carers after completion of the DREAMS programme. The question of how the communication between adolescents and older carers can be sustained after interventions have come to an end is a matter of great concern.

This study found that the implementing organisation was important in creating greater access to other services in addition to HIV prevention interventions. For example, the programme facilitators assisted and linked the older carer families with other social services to obtain birth certificates and to apply for child support grants. These findings showed that offering a combination of services which adolescents need, motivated their participation in HIV prevention interventions. Also, the findings of this study highlight the utilisation of lay facilitators to deliver HIV prevention interventions. The utilisation of lay facilitators is common in low-income settings (Bhana, McKay, Mellins, Petersen, & Bell, 2010; Rochat, Mitchell, Stein, Mkwanazi, & Bland, 2016; Van Rooyen et al., 2016). While utilisation of lay facilitators promotes employment opportunities for local community members, they may lack competent skills and self-efficacy to challenge community norms of sexual communication.

Moreover, conflicting sexual health messages and information between different structures confused the adolescents. The research reveals that adolescents obtained conflicting SRH information from their churches, homes, and DREAMS organisation. The contradictory information undermined the HIV prevention initiatives, promoted by a fragmented and uncoordinated approach between different social structures in fighting HIV. This study shows that confusion about conflicting SRH information may be influenced by aspects that occur at the interpersonal, community, and organisational levels of the SEM. Also, their beliefs about whether to use contraceptives and condoms or not were shaped by sources of information they obtained from their families, churches, and HIV implementers. This had important implications on the young people's desire to participate in HIV interventions as attitudes and beliefs play an important role in the intention to carry out a behaviour (Ngwenya et al., 2020). These findings have implications for the design of HIV prevention interventions. The authors suggest that interventions that focus on the individual level of SEM can be addressed by changing the current negative beliefs and attitudes that young people have about themselves as recipients of the information. A study in Ibaden Nigeria by Sylvester (2014) reported that the best predictors for risky sexual behaviour are a low self-esteem and low monitoring practices of parents or carers while lower levels of authoritative parenting was found to be associated with risky sexual behaviours. Furthermore the quality of collaboration between information providers and adolescents are also important to bring about positive change.

Further, adolescents' attitudes towards participation in the HIV interventions were influenced by how they were being labelled by peers, family, and in the community. Being labelled as 'badly-behaved' and internalisation of this label created significant barriers to adolescents' participation in HIV interventions. It also led to internalised stigma. This is consistent with previous research in South Africa which has shown self-stigmatisation to be a barrier to engaging in HIV and health services by adolescents (Nkosi et al., 2019; Pantelic et al., 2020). Moreover, internalised stigma compromised adolescents' self-esteem as they avoided engaging in HIV interventions with their peers. These findings add to the body of qualitative research, which has suggested that internalized stigma contributes to anti-social behaviours and mental health problems (Huggett et al., 2018; Mason & Sultzman, 2019).

At an organisational level, exclusion of boys in the DREAMS caregiver/parenting programme was a major barrier to the participation of adolescent boys in the programme. While excluding adolescent boys in the programme may affect family communication with their caregivers, it also placed adolescent girls at increased risk of HIV infection and unwanted pregnancies. Public health researchers have long noted that adolescent girls are disproportionately affected by HIV in sub-Saharan Africa (UNAIDS, 2016b). While more interventions are now in place to reduce HIV infections among adolescent girls, it seems adolescent boys are not prioritised. These findings corroborate with those reported in South Africa that exclusion of adolescent boys and young men in HIV prevention interventions is counter-productive, inequitable, and did not play a major role in reducing HIV incidence among AGYW (Zuma, Seeley, Sibiya, & Chimbindi, 2019). Being left out from certain HIV prevention interventions may have detrimental effects on sexual behaviours for the adolescent boys. Consequently, adolescent boys may have the belief that they are not at risk, therefore, are less affected by HIV and AIDS. This may further reinforce gender stereotypes that women are responsible for SRH. Maharaj (2000) argued in earlier work that males view women responsible to seek reproductive services such as contraceptives while they have little negotiating power regarding their own reproductive health. Moreover, adolescent males may be ignorant of reproductive health matters and engage in risky sexual behaviours, making them susceptible to HIV infection and other STIs. Therefore, the findings of this study highlight the need for inclusion of boys in HIV interventions.

The study findings raise the important issue of exclusion of adolescents with disabilities in DREAMS interventions, education, and social welfare services. This is important because disability is often associated with stigma (WHO, 2011). The DREAMS implementing organisation in this study had difficulty recruiting and enrolling adolescents with disabilities as recipients of HIV prevention interventions. Consistent with previous reports, adolescents with disabilities are often excluded from HIV interventions (UNAIDS, 2017; UNICEF, 2012). The exclusion of adolescents with disabilities might also imply, among other things, that the DREAMS implementing organisation did not appreciate and acknowledge disabled young people as beings. Interacting with other young people may provide comfort to young people with disabilities. Being marginalised from participation in HIV prevention interventions may have detrimental effects on the sense of self-worth for the adolescents with disabilities. Consequently, adolescents with disabilities may have the belief that they are asexual beings, therefore, unaffected by HIV and AIDS. Moreover, they may engage in risky sexual behaviours as a mechanism of self-esteem validation to overcome the belief of being asexual (UNAIDS, 2017), making them prone to HIV infection and other STIs as well as pregnancy. A study in South Africa reported that 11.8 % of adolescent girls aged 15-18 years with a reported disability were HIV positive compared with 3.3% of girls with no reported disabilities (Mejia-Pailles, Berrington, Seeley, McGrath, & Hosegood, 2017). These results are worrisome considering that DREAMS interventions were implemented in the same district in which this study found marginalisation of adolescents with disabilities.

Staying in the house all the time or not attending school may reinforce the social exclusion of these young people as they may have limited opportunities for education and for interactions with their non-disabled peers. The uMkhanyakude District, where the study was conducted, is the poorest rural district of the KwaZulu-Natal province. In 2016, the Section 27 study reported that there were 14 registered schools for children and adolescents with disabilities in the district, and of these, only one was a high school (Hodgson & Khumalo, 2016). Furthermore, another study in the district reported that disabled children and adolescents aged 7-18 years showed higher proportions of not attending school (8.7%) compared with children and adolescents without reported disabilities (4.1%) (Mejia-Pailles et al., 2017). The findings of this study add depth, in that some of these adolescents with disabilities are also in older carer families which raises a need to focus on adolescents in older carer families.

In addition, economic factors may also make adolescents with disabilities vulnerable to poverty. While the monthly disability social grant provided by the South African government makes young people living with disabilities financially better off, the findings of this study showed that older carers caring for young people with disabilities had challenges in accessing social grants. Findings presented here complement those reported in South Africa that only 5.6% of children and adolescents with a reported disability were recipients of disability or care dependency grants, while 21.9% were not receiving any support at all, despite having a reported disability (Mejia-Pailles et al., 2017). These findings highlight the need to focus on adolescents in older carer families.

7.4 Conclusion

The findings of this study demonstrate that adolescents in older carer families face motivators and barriers to participation in HIV preventions across the four levels specified in the SEM: individual, interpersonal, organisational, and community. By integrating the influencing factors of these levels the motivators and the barriers to participation in HIV interventions by adolescents cared for by grandparents were better understood.

The chapter that follows presents older carers’ experiences of self-management of chronic conditions and its influence on caring for adolescents.

CHAPTER EIGHT

OLDER CARERS' SELF-MANAGEMENT OF CHRONIC CONDITIONS AND ITS INFLUENCE ON CARING FOR ADOLESCENTS

8.1 Introduction

Health challenges experienced by grandparents who are raising their grandchildren have received research attention. Chronic diseases are common in older people and affect older peoples' ability to function (Mugisha et al., 2016; Solanki et al., 2019). The number of older people suffering from one or more chronic conditions (known as multi-morbidity) continues to rise rapidly (Chang et al., 2019). Older people aged 50 years and older often have one or more chronic diseases (Chang et al., 2019). A study in South Africa reported that among 250 women aged 50 and above, 72.4 % (n = 181) had at least one chronic illness, and of the 181 who reported having chronic illnesses, 46.1 % (n = 83) reported having one chronic illness, while 53.9 % (n = 98) reported multi-morbidities (Aboyade, Beauclair, Mbamalu, Puoane, & Hughes, 2016). Previous research has established that diabetes and hypertension are prevalent among older women living in South Africa, placing a heavy burden on the healthcare system (Herbst et al., 2015; Solanki et al., 2019). The South African Statistics reported that hypertension/high blood pressure (43.4%), followed by diabetes mellitus (15.6%) and then arthritis (13.1%) were the most frequently mentioned chronic diseases among older people (Stats SA, 2015). Regarding HIV, South Africa has 7.5 million people living with HIV, with nearly 5.2 million on ART (UNAIDS, 2020b). Data suggest that with ART, more individuals with HIV are living to old age in South Africa (Chang et al., 2019).

While chronic conditions such as HIV, high blood pressure and diabetes are major health burdens of older South Africans (Mayosi et al., 2009; Westaway, 2009), the responsibilities of caring for grandchildren may further impact their health and wellbeing (Munthree & Maharaj, 2010; Schatz, 2007). Older carers in Uganda reported chronic pains and stress as major challenges in their role as carers, thereby limiting their ability to effectively execute caring duties (Rutakumwa et al., 2015), and likely experience less time for their self-care. Understanding how older carers of adolescents navigate the self-management of chronic conditions while at the same time taking on the added responsibility of caring for their grandchildren is an under research area. The personal health and wellbeing challenges of older carers are likely to take its toll not only at a personal level, but also impact the caring process of adolescents in different ways. Therefore, the researcher explored the carers' self-management experiences of their chronic conditions and its influence on caring for adolescent grandchildren. Understanding self-management experiences of older carers provides a framework for the development of interventions to support older carers of young people who live with chronic conditions.

8.2 Results

8.2.1 Participants' characteristics and chronic conditions

The characteristics of the participants, including health conditions, are presented in Table 8.1. All six older carers were women aged between 56 and 80 years and caring for between two to 15 grandchildren. Two were paternal grandmothers, and four were maternal grandmothers of the index adolescents. Of the six older carers, only one was cohabiting with a sexual partner while others were widowed. All participants were provided with a pseudonym to ensure confidentiality. Among the six grandmothers who participated in the study, all reported managing between one and four chronic health conditions. Arthritis, hypertension, HIV, vision impairment, chronic pain, and stomach ulcers were the conditions reported.

Table 8.1: Participants' characteristics and chronic conditions

Name*	Sex	Age	Marital status	Education	Number of children in care	Source of income	Chronic conditions
MaNdawo	F	76	Widow	None	3	Old age pension, cash or in-kind remittances	Arthritis, chronic pain
MaZulu	F	64	Widow	Secondary	15	Old age pension, child support grant	Arthritis, hypertension, chronic pain
MaNgubo	F	80	Widow	None	6	Old age pension, informal micro-enterprising	Arthritis, hypertension, stomach ulcers, chronic pain
MaDube	F	58	Unmarried, living with partner	None	11	Child support grant, informal micro-enterprising	Chronic pain
MaJali	F	56	Unmarried	None	2	Farm work, informal micro-enterprising	HIV, epilepsy, chronic pain
MaKhoza	F	64	Widow	Primary	9	Old age pension, child support grant	HIV, hypertension, vision impairment, chronic pain

*Pseudonyms F= Female

The findings are structured according to the themes drawn from the self-management framework by Schulman-Green and colleagues (Schulman-Green et al., 2012), namely focusing on illness needs, activating resources, and living with a chronic illness (recognising that some degree of overlap exists across the themes).

8.2.2 Theme 1: Focusing on illness needs

In exploring how the older carers focused on their chronic illness needs, they indicated a range of activities including following instructions from the healthcare workers, completing health tasks, and performing health promotion activities.

Firstly, the older carers mentioned that they were **following instructions from the healthcare workers** about the management of the chronic conditions. These instructions were related to treatment adherence, healthy diet, and regular clinic attendance for routine check-ups, as seen in the interview below:

> *At first, I was diagnosed with TB and was taking pills for six months. I never missed taking my pills until the end. Now, I'm taking HIV pills and am making sure that I always have my pills. (MaJali, older carer, 56)*

Fear of being reprimanded by the nurses for not adhering to these instructions appeared to motivate the older carers to follow the instructions as shared by an older carer:

> *We are told to eat healthy foods at the clinic. The nurses make us choose food to eat. They say, 'don't use cooking oil. Eat boiled food'. They make us choose so that we become healthy. They say, 'salt makes us sick'. We now eat food that is not tasty. Nonetheless, I do follow the instructions from the clinic because nurses can see if you don't follow the instructions, and would shout at you. (MaNgubo, older carer, 80)*

The ability of some older carers to take ownership of their health needs by following appropriate meal plans as instructed by the healthcare workers was limited by their adolescent grandchildren refusing to cook healthier meals. Some older carers related their challenges in eating a healthy diet and how they occasionally used their agency to focus on their illness needs:

> *It’s sometimes difficult to maintain a healthy diet when you don’t cook for yourself. Thandi doesn’t want to boil food. She likes frying food with excessive cooking oil. Fried food is not good for me. The nurses educate us to eat boiled vegetables instead of frying them … I would eat it though because I have no choice. Sometimes, I cook my own food with a small pot so that I don’t keep on eating unhealthy food … I normally avoid cooking because of epilepsy. I don’t want to have seizures while I’m next to the stove. (MaJali, older carer, 56)*

> *I have a vegetable garden at the backyard, where I plant pumpkins, mealies, cabbages, nuts, and beans. I need to eat fresh vegetables to get energy. Fresh vegetables are healthy unlike those that we buy from the shops. My problem is Thabani. He refuses to go and fetch water for me to water the garden. If there is no rain, my vegetables get destroyed for not getting water. Sometimes, I hire* [name of person] *to fetch water for me because I cannot push a wheelbarrow nor carry 25L bucket on top of my head. (MaNdawo, older carer, 76)*

In the same way, another older carer related her barriers to eating a healthy diet and how the chronic condition limited her agency:

> *I’m taking my treatment after eating food as advised by the nurses and visit the clinic for my appointments. The problem is that I can’t see properly. So, I no longer cook otherwise I will simply burn the food. Mpume and others are the ones cooking. The problem is that they don’t like cooking traditional food like ‘amadumbe’ and samp with crushed nuts. I like traditional food because it’s healthy and the nurses encourage us to eat healthy. (MaKhoza, older carer, 64)*

Rather than supporting their older carers’ efforts to eat healthily, it seemed that the adolescent grandchildren appeared to be quite dismissive of the health concerns of their older carers.

Secondly, older carers mentioned **completing health tasks** in their effort to self-manage chronic conditions. Attending regular medical appointments, collecting treatment from the facilities, and adhering to treatment were key in the management of their illnesses. One older carer said:

> *Since I have BP* [high blood pressure]*, I regularly go to the clinic to collect medication so that I can remain healthy*. (MaZulu, older carer, 64)

Some older carers indicated that they performed these health tasks independently while others relied on the support of their adolescent grandchildren as seen from the interview below:

> *I'm on treatment for high blood pressure and HIV. I was first on treatment for BP and later started ARVs in 2011. I take my pills at seven in the evening. However, before I take my pills, Mpume needs to first give me food. After I had eaten, then she gives me my pills. … I recently went to the clinic* [accompanied by Mpume, her granddaughter] *for blood tests and they told me my blood results are excellent! (MaKhoza, older carer, 64)*

Lastly, older carers mentioned that they **performed health promotion activities** to minimise the impact of chronic conditions and engaged in self-initiated treatment like using home remedies, traditional medicine, and alternative therapy for their conditions.

Older carers mentioned that they used home remedies to self-manage the treatment of chronic illnesses and minor ailments including fever, heartburn, body pains, and skin rashes. Salt was a common commodity for bathing, steaming, and soaking that the older carers mentioned that they used to cope with these minor ailments as seen from the interviews below:

> *My feet, ankles and knees are often painful and swollen because I have arthritis. To care for myself, mostly I walk barefoot and soak my feet in warm salt water. Salt has anti-inflammatory properties that help reduce swelling. I also have some oil that I use to rub my feet. (MaNdawo, older carer, 76)*

> *Salt is my number one defence! I use it to steam and soak my body whenever it is painful or if I have symptoms of fever. Milk is another thing that I*

> *occasionally use for heartburn. It's just that I'm able to get cow milk if my son's cow has given birth … I warm and drink cow milk for heartburn. (MaNgubo, older carer, 80).*

Apart from home remedies to treat physical aching, older carers often reported anxiety and emotional distress related to living with chronic conditions and socio-economic problems such as a lack of finances and strenuous relationships with their adolescent grandchildren. A common traditional medicine to cope with emotional 'pains' which some older carers mentioned was '*impepho*', an indigenous African plant. This was illustrated from the interviews below:

> *My heart is sometimes painful, especially when I don't have money and thinking about living with HIV. I would simply take 'impepho' and burn it inside my bedroom. Smoking the flames of 'impepho' calms me. (MaJali, older carer, 56)*

> *I burn 'impepho' to manage with emotional pains … Sane is making me angry with the way she's behaving. 'Impepho' helps me a lot otherwise my heart is just going to stop beating* [dying]. *(MaDube, older carer, 58)*

Further, some older carers stated that they sometimes used alternative therapies to cope with chronic conditions and mental distress. The use of alternative therapies was motivated by factors including a lack of access to medication at healthcare facilities and standard healthcare treatments which the older carers perceived as ineffective. This was illustrated in the interviews below with older carers:

> *I wasn't alright yesterday. I become sick once something upsets me. I ended up getting herbal tea from a certain woman in the community because I was just not feeling alright at all. ... It's herbal medicinal tea for drinking. The woman sells it. Remember, I take pills for BP and arthritis, but sometimes I don't get arthritis medication and painkillers at the clinic. ... The nurses said they don't have pills for arthritis and painkillers … BP pills are for BP; they are not painkillers. Yesterday, I was literally bedridden but I feel better today. The herbal tea helped me! They say it runs through the veins and gives you*

> *energy! I cooked it in the morning and I already feel better. It also relieves pain. (MaNgubo, older carer, 80)*

> *The nurses at the clinic used to give me pills for epilepsy but those pills were not effective. I felt like they were making worse. … After taking the pills, I would just get seizures. Then I decided to take the herbal tea for a while until the seizures stopped. (MaJali, older carer, 56)*

It appears that apart from the chronic illnesses, the older carers seemed to suffer from mental distress and they treated this predominantly by traditional medicine and alternative therapies.

In addition, the older carers engaged in physical activities to improve musculoskeletal function and mobility. Improving musculoskeletal function and mobility through performing physical activities was shared by all the older carers. They referred to physical activity as '*ukunyakazisa igazi*' meaning 'an act of moving one's body for blood circulation in the body system'. Walking, dancing in church, and doing household chores such as gardening, washing clothes and dishes by hand, and cleaning (sweeping) the yard and house were the main daily physical activities which they performed to promote their health. Some older carers said:

> *Once Thabani and my younger granddaughter has left for school, I start cleaning the yard and the house. (MaNdawo, older carer, 76)*

> *I dance in church to keep myself physically fit. (MaKhoza, older carer, 64)*

Interestingly, one older carer mentioned how she had changed a negative experience into something positive by thinking differently about it:

> *I do garden work every morning. It's just that the chickens destroy my garden because it's not fenced and I don't have a chicken house to secure the chickens. Nonetheless, chasing the chickens from destroying my garden keeps me fit. (MaJali, older carer, 56)*

During fieldwork, the researcher observed that mornings were very busy for the older carers once their grandchildren had gone to school. As they were left behind at home, they started the household tasks.

8.2.3 Theme 2: Activating resources

In exploring the resources that the older carers activated, they mentioned healthcare resources, spiritual resources, family resources, and community resources to manage various aspects of their chronic illnesses.

With regards to **healthcare resources** that were important for the older carers to self-manage the chronic illnesses, community healthcare workers (CHWs) and healthcare facilities were mentioned. The older carers stated that they regularly interacted with CHWs who provided the older carers with home-based care and health education as seen from the interviews below:

> *We have community health workers visiting us at our homes. They tell us not to sit down for too long as we are elderly people who are also sick. We need to make the blood flow through the body by being active as elderly people. So, although my eyes cannot see anymore, I make my blood flow by working in the garden. … One day I was very sick, she assisted me to sit up in bed and to walk to the toilet. (MaKhoza, older carer, 64)*

> *The community health workers sit down with us when they visit our homes. They would advise us that no matter how difficult life is, we must make things easier for ourselves and take things lightly … by not thinking too much* [a phrase that is often use to describe depression or when one is keen on mulling through issues] *… As elderly people, our hearts are weak, thus, we must avoid thinking too much about our problems, and otherwise, we will be attacked by a stroke. (MaZulu, older carer, 64)*

Older carers also mentioned that they found CHWs easily accessible in case of emergency as they lived in the community unlike going to the clinic to consult the nurses. Interestingly, some older carers indicated that they also made use of the services of the CHWs even for healthcare needs related to their adolescent grandchildren. The interviews below illustrate how the older carers sought reproductive healthcare services from the CHWs regarding their adolescent grandchildren:

> *I asked the CHW to test Mpume for pregnancy. I was worried because she had missed her menstrual period for two months and wanted to know whether she was pregnant or not. The CHW came to my house to see Mpume and she did the pregnancy test. She, then referred her to the clinic* [for antenatal care]. *(MaKhoza, older carer, 64)*

> *The CHW helped me with a referral letter, which she gave to Zama to go to the clinic for contraception. (MaNgubo, older carer, 80)*

Further, some older carers mentioned seeking care from multiple healthcare facilities. There were two primary healthcare facilities or clinics within the community. One healthcare facility is managed by the provincial government and the other is managed by the local government. The older carers indicated that they utilised both the provincial and the local government clinics interchangeably for different chronic illnesses:

> *For BP, I go to* [provincial government clinic] *to collect my medication, whereas for arthritis I prefer to go to* [local government clinic]. *There at* [provincial government clinic], *sometimes, the nurses tell you that the pills are out of stock. (MaNgubo, older carer, 80)*

> *I normally go to* [provincial government clinic] *because it's closer to us than* [local government clinic]. *(MaJali, older carer, 56)*

> *The nurses at* [local government clinic] *are very rude. They have no respect for older people, that's why I use* [provincial government clinic]. *There is this nurse at* [provincial government clinic] *who is caring whenever she attends an older person. If she is not on duty, I sometimes return home and go another day when she's back at work. She is such a caring nurse and gives you all the pills that you need. … Others simply tell you that the pills are out of stock or give you insufficient pills. (MaDube, older carer, 58)*

It was clear that the quality of patient care, distance to the healthcare facility, and availability of medication influenced the older carers when choosing the healthcare facilities to use for their chronic illnesses.

Moreover, **spiritual resources** were an important component of health and well-being that the older carers mentioned that sustained them. This was noted as they were all active members of churches in the community. The researcher observed that some older carers belonged to the same churches and those who belonged to the same church appeared to share a spiritual relationship. During fieldwork, the researcher had seen MaNdawo (76) walking together with MaKhoza (64) to church. In the same way, the researcher found MaDube (58) at MaZulu's (64) house on several occasions. In addition, it appeared praying was a source of strength for these older carers as some reported that they received some spiritual counselling about managing illnesses and stressful conditions through their churches:

> *They* [pastors] *preach to us that we mustn't overburden our hearts with worries to prevent stroke. (MaZulu, older carer, 64)*
>
> *Whenever I am at church, I become alive again. I forget about all the illnesses and all the problems that Zama bring to my life. (MaNgubo, older carer, 80)*

It was clear that the older carers' churches provided them with the spiritual support to manage the chronic illnesses and difficult relationships with their adolescent grandchildren.

Furthermore, some older carers mentioned that they obtained **family support** from their adult children to buy food and to pay for the costs related to healthcare such as transport to go to healthcare facilities, as seen in the interview below:

> *My daughters send money every month to buy food. I also use the money to pay for transport to go the clinic. (MaNdawo, older carer, 76)*
>
> *My eldest daughter is helpful. She is Thandi's mother. Although she is unemployed, she sells meat in town. Selling meat provides her with money to afford to buy us food. (MaJali, older carer, 56)*

In contrast, getting financial support emerged as a challenge for the older carers whose adult children were unemployed and unable to offer support to them. These older carers struggled financially to self-manage as their old age pension could not cover the costs to self-manage their chronic illnesses and to meet the basic needs of their grandchildren:

> *None of my daughters is employed. I rely on my old age pension and the child support grant to care for myself and 15 grandchildren. Their fathers are not paying maintenance because some are also unemployed. Others are unknown where they are. Even if I want to search for them, I wouldn't find them. (MaZulu, older carer, 64)*

With regards to household chores, all the older carers mentioned that they sought assistance with performing household tasks from their adolescent grandchildren. The older carers had assigned household chores to the grandchildren such as cooking, cleaning, fetching water and wood as they were often sick and physically unable to carry out the housework themselves. One older carer stated that she was suffering from visionary impairment and was unable to see properly to do things for herself: *"Mpume does my laundry. I can't do it … I can no longer cook. She makes tea for me; cook food for me because I'm no longer able to do these things"* (MaKhoza, older carer, 64).

Similarly, another older carer further reinforced this theme from another perspective in that she wanted her grandchildren to do household chores such as fetching firewood as she could not afford to pay for electricity:

> *I don't usually cook anymore. My grandchildren do the cooking. We don't use an electric stove but we use firewood for cooking because electricity is expensive, and I'm financially struggling. The grandchildren go out to fetch firewood from the forest. They are so helpful. Having grandchildren means that I can point where I need help and they would help me. (MaZulu, older carer, 64)*

Apart from mobilising assistance with domestic work, it also emerged that some older carers obtained healthcare support from their adolescent grandchildren. This was raised by two older carers living with HIV and on ART as they explained that their adolescent grandchildren supported them in taking medication, as seen in the interviews below and noted in the previous chapter:

> *I told Mpume that I have HIV and BP. She knows that I'm taking pills every day after dinner. At seven in the evening, I simply call her to give me the pills. She would give me, then I would just take my pills and go to bed. (MaKhoza, older carer, 64)*
>
> *I've been taking ARVs for the past seven years. It's Thandi who reminds me every day that it's time to take my pills. (MaJali, older carer, 56)*

While the older carers received support from their adolescent grandchildren, some mentioned that they were not satisfied as seen in the interviews below:

> *A child must be sent to do things for the adults at home. Thabani must wash dishes for me. He must fetch water for me. But, he is very lazy. (MaNdawo, older carer, 76)*
>
> *I no longer have physical strength. I find myself crawling on my knees to prepare food, while Zama has gone out. Yet, she would want food when she comes back at night … then I have to cook because there are younger grandchildren who need food to eat, just like myself. So, I make fire and cook. (MaNgubo, older carer, 80)*

It seemed that the older carers were distressed when their adolescent grandchildren did not meet their expectations.

Lastly, mobilising **community resources** through participation in community saving clubs including burial schemes, grocery schemes, and loan schemes was also mentioned by the older carers. A major reason driving older carers to choose these savings clubs was because they made funds easily accessible and often at a better interest rate. These groups provided quick cash loans to the older carers to meet their needs to manage chronic illnesses and to care for their grandchildren, as seen in the interviews below:

> *I borrow money from the loan scheme to buy food, to go to a doctor or to buy clothes for the grandchildren. (MaZulu, older carer, 64)*
>
> *I'm a member of a burial scheme with the hope that if I die or my family member dies, the burial scheme will cover the funeral costs. We also borrow money from the burial scheme and pay it with interest. I prefer borrowing from our scheme because the interest rate is very low. It is much quicker to get money from the scheme because we need quick cash to buy food. (MaNgubo, older carer, 80)*

It appeared that community savings clubs facilitated access to micro-finances for the older carers to support their self-care practices.

8.2.4 Theme 3: Living with a chronic illness

Four tasks were identified by the older carers in relation to how they lived with chronic illness. These tasks were processing emotions, adjusting to illness and to a new self, integrating illness into daily life, and meaning making.

Firstly, the participants narrated stories about the diagnosis of their chronic illness(es) and how they **processed the emotions** of living with a chronic illness. Living with a chronic condition brought up emotions of shock, confusion, sadness, and anger among the older carers, as expressed in the interview below:

> *Apart from persistent eyes, I don't feel well. Sometimes I say 'oh hee!'* [an exclamation of yelping] *and then tell myself to accept the situation … the eye doctor said 'your eyes are dirty inside the eyeball. There are dark marks'. I said 'please wipe those dirty marks' as I've heard that doctors can wipe eyes. The doctor said, 'it's not going to make any difference even if we can try to wipe your eyes because it's inside. You must just go home and expect to die like this. (MaKhoza, older carer, 64)*

It seemed that MaKhoza was shocked and confused because she could not understand the explanation that there was no treatment to restore her vision. In addition, the thought of eating 'boiled and unsalted' food was difficult for one older carers, as stated below:

> *If I think of eating boiled and unsalted food, I simply lose appetite. Unsalted food is tasteless. But, what can I do because I have BP and the nurses are preaching us to boil food and not to use salt. (MaNgubo, older carer, 80)*

While one older carer was sad about living with HIV and lacking financial resources to self-manage, she also blamed herself for acquiring HIV infection:

> *I didn’t know that involving myself with men was a problem. I thought I was just having a good time; whereas I took a burden upon my shoulders. (MaJali, older carer, 56)*

Another older carer complained about living with arthritis:

> *As it is now a cold season, I'm unable to wake up early morning. My joints are stiff and painful. I'm horribly inactive in the morning and would take time to recoup. (MaZulu, older carer, 64)*

It was clear that living with these chronic illnesses was mentally distressing to the older carers.

Secondly, during the interviews, some participants shared their initial experiences of facing a changed life and personal losses related to **adjusting to the illness and to their 'new self'**. Adjusting to the illness and their new self was an emotional process for the older carers. It involved thinking about themselves as a new person and trying to make sense of the new person. Participants identified two strategies which they used to adjust to the illness and their new self, namely accepting and embracing the illness as part of ageing and comparing themselves to others as a way of fostering self-motivation.

A narrative of accepting and embracing the illness as part of ageing was shared by one older carer. She talked about how she had expected that, at some point, her life would deteriorate because of ageing and the illness. It seemed that she had conceptualised that illnesses are inherent to ageing, as seen in the interview below:

> *I've heard that when you are old, you go back to becoming a baby* [meaning dependent]. *I can feel that I am getting closer to becoming a baby. My grandparents and my mother went through this stage, which means I am approaching my mother's stage. … They used to say to me 'one day you will get old and become sick'. … When I see things changing, I realise they knew this would come. My life is now weakening, and I tell myself that it's because I'm aging. I can feel my body is unlike the one I had during my early days. I feel it when doing chores; I am not strong as I was. … Even walking, I cannot walk like a fit person. I limp when walking. (MaKhoza, older carer, 64)*

Another older carer compared herself to other people living with HIV as a way of fostering self-motivation, as she stated:

> *There was a woman at* [name of place] *who stopped taking ARVs and eventually died. I don't want to die like her, that's why I'm taking my pills every day. The reason I'm still alive is because I'm taking my pills. (MaJali, older carer, 56)*

Thirdly, one older carer mentioned she employed certain strategies to **integrate illness into her daily life** by reorganising her everyday life in order to adapt to living with arthritis:

> *In winter, I don't touch cold water because they make my bones sore. I also don't do handwashing of clothes when it's very cold. I only do the washing when the sun is warmer. Also, I wear warm clothes like warm jackets, so that my skin would not feel cold. If I feel cold; my bones become sore. (MaZulu, older carer, 64)*

Lastly, **meaning making** about the chronic illnesses emerged during the interviews. One older carer described the meaning of illness as a pathway to death, as seen in the interview below:

> *I often tell Mpume that she must be prepared that I might die soon because I am old and sick. Living with all these diseases* [HIV, vision impairment, hypertension, and chronic pains] *means my life will be shorter than others. (MaKhoza, older carer, 64)*

Others mentioned that they found a greater sense of purpose in life through caring for their grandchildren. When they talked about the chronic illnesses, caring for their grandchildren was more important than going to an old age home to receive better care, as seen in the interviews below:

> *I may be sick but I'm still looking after my grandchildren. It gives me a reason to wake up in the morning. I don't want an old-age home. Who will look after my grandchildren if I go the old age home? Being sick doesn't mean I cannot talk. I can still talk and guide them about life. (MaNdawo, older carer, 76)*

> *Sometimes I tell them [grandchildren], 'I'm going to leave you and find an old age home for myself to get some fresh air'* [meaning relief from caring for the

> grandchildren]. *But I can’t. Who am I going to leave them with? It’s better to suffer with them. (MaNgubo, older carer, 80)*

The older carers also indicated that they opted to prioritise the needs of their grandchildren instead of focusing on managing their chronic illnesses and their need for a better life, as seen in the interviews below:

> *Although my years have gone by, I do care for myself; however, I’m unable to do this well because I have so many grandchildren. I wish I could eat nice things; but I can’t. I wish I could go to doctors to get boosting injections so that I could live a healthy life. I can’t get to eat nice things like other older people. I can’t afford to stock things like apples, bananas, yoghurts, and meat all the time. No, I can’t because I have so many grandchildren. We use a big pot for cooking food which gets finished in no time. I’m unable to care for myself properly because of the large number of grandparents. I’m not eating enough food. (MaZulu, older carer, 64)*

> *They are still young; they deserve to eat as much they like. I’m about to die. Even if I sleep with an empty stomach, I am fine knowing that they have eaten. (MaNgubo, older carer, 80)*

> *Now that Mpume is pregnant, I will be looking after her baby so that she goes back to school. When am I am to rest? I need to rest too but who will look after Mpume’s baby because her mother disappeared. (MaKhoza, older carer, 64)*

It was clear that the older carers valued meeting the needs of their grandchildren instead of self-managing their chronic conditions.

8.3 Discussion

This study explored the experiences of meaning making and self-management of chronic conditions among older carers and the influence of self-management on the caring for grandchildren in rural South Africa. The framework of Schulman-Green et al. (Schulman-Green et al., 2012) was useful to enhance the theoretical understanding of the self-management processes employed by the older carers with chronic conditions.

Evidence from this study points to a range of self-management practices used by the older carers which were often influenced by the nature of care relationships between the older carers and their adolescent grandchildren. Because self-management of chronic conditions emerged in the context of older people, it is easy to perceive it as one in which it is influenced by ageing. However, the findings show that self-management was influenced by caring for the grandchildren.

Previous studies have reported HIV infection among older people aged 50 and above (Chang et al., 2019; Nyirenda et al., 2013; Scholten et al., 2011). This study expands on previous studies by contributing to knowledge on the subject of caregiving experiences of older carers living with HIV and the intersection of meaning making of illness and caring. With the advent of ART, older carers are navigating the self-management of HIV and other chronic conditions while at the same time taking on the added responsibility of caring for their grandchildren. Having older carers with chronic illnesses could have a significant impact on the adolescents and the care that the adolescents receive from their older carers. HIV stigma by association is one of the challenges that may face adolescents who are being raised by older carers living with HIV. Studies in high-income settings reported that adolescents with HIV positive parents perceived themselves as different from their peers or feared they would be discriminated if their parents' HIV status is disclosed (Cree, Kay, Tisdall, & Wallace, 2004; Murphy, Roberts, & Hoffman, 2002; Reyland, Higgins-D'Alessandro, & McMahon, 2002). The adolescents in this study did not mention their older carers' HIV status. In a South African study, adolescents with HIV positive caregivers were reported to have increased risks of poor educational outcomes, mental health problems, stigma, and isolation from peers (Cluver, 2011). While some older carers reported their HIV status in this study, it is likely that, with ARVs, HIV have become more normalised and accepted as a chronic condition. A review in the Lancet in 2013 by Deeks, Lewin and Havlir (2013) argued that HIV can be seen as a chronic illness due to ART.

The findings indicate that all the older carers experienced chronic pain and engaged in physical activities to manage chronic pain. It is critical for older people to engage in physical activity to prevent diseases, maintain independence and improve quality of life (Sun, Norman, & While, 2013). Other authors have noted that physical activity programmes target more younger people than older people and it is also less accessible for older people due to smaller incomes (Burton et al., 2018). Findings presented in this study show that older people can use minimal resources to meaningfully engage in physical activities without financial costs and within their home environments. Consistent with previous studies, working around the house as part of domestic responsibilities was viewed as a form of exercise (Phillips et al., 2016). Apart from engaging in physical activities to prevent immobility as noted by the older carers in this study, it is possible that it also improved their mental health as they were often distressed by living with chronic diseases and caring for grandchildren. The findings of this study show that the impact of living with chronic illness(es) and caring for adolescent grandchildren had a toll on the health and well-being of the older carers. The older carers indicated mental distress in relation to living with chronic illnesses, lack of finances, and strenuous relationships with their adolescent grandchildren. Consistent with previous studies, HIV positive caregivers and caregivers of orphaned and vulnerable adolescents are vulnerable to mental health problems (Kuo & Operario, 2011; Rochat, Bland, Coovadia, Stein, & Newell, 2011).

Mental distress is likely to impact their self-management of chronic illness(es). Self-management involves the tasks that people living with a chronic illness must master to gain control of their condition and to live successfully with the chronic disease (Schulman-Green et al., 2012). Problems experienced in everyday living have been reported to negatively impact the self-care of chronic illness (Van Houtum, Rijken, & Groenewegen, 2015). A striking finding in this study was that strenuous relationships with their adolescent grandchildren, rather than chronic conditions, were the main stressors that often undermined the older carers' ability to self-manage. This finding differs from a study conducted in the United States, where older adults with chronic conditions often did not want to burden their children with the responsibilities of caring for them (Cahill, Lewis, Barg, & Bogner, 2009). In this study, older carers expected their adolescent grandchildren to care and support them. The United States and other high-income countries are, however, very different from the African context. It is possible that the carers' expectations determined the relationships between older carers and their adolescent grandchildren.

Consistent with the literature, family support is critical in sustaining self-management behaviours and addressing the barriers among people living with chronic illnesses (Pamungkas, Chamroonsawasdi, & Vatanasomboon, 2017; Rochat, Mkwanazi, & Bland, 2013; Schulman-Green et al., 2020). Adolescent grandchildren provided support to their older carers in executing self-management tasks such as treatment adherence, regular healthcare attendance, and cooking food. In this study, the older carers emphasised the important role that the emotional and physical support from their adolescent grandchildren played in self-managing their chronic conditions. Obtaining support from their adolescent grandchildren facilitated the older carers in self-managing chronic conditions. This finding is supported by other studies (Dolbin-MacNab et al., 2016; Rutakumwa et al., 2015) who reported that the older carers counted on their grandchildren to perform household chores that were too physically demanding for the older carers to perform. They emphasised the important role of social support not only in helping them to take their medication but also in helping them to find a sense of purpose in caring for their grandchildren. A study in Uganda found that adolescents supported caregivers' adherence to HIV treatment through reminding them to take ARVs and honour clinic appointments (Nalugya, Russell, Zalwango, & Seeley, 2018). Consistent with a study in South Africa (Dolbin-MacNab et al., 2016), older carers also believed that focusing on their grandchildren contributed to their sense of resilience and living with the chronic illnesses.

On the other hand, adolescent grandchildren can also pose barriers to self-management behaviours for the older carers. Dietary changes are commonly used as essential strategies to improve the self-management of chronic illnesses (Guilleminault et al., 2017). While adolescent grandchildren played an important role in cooking for their grandparents, the older carers in this study reported that grandchildren usually provided the older carers with unhealthy food. Rather than supporting their older carers' efforts to eat healthily, the adolescent grandchildren were dismissive of the health concerns of the older carers. The findings of this study fill an important knowledge gap about the influence of adolescent grandchildren on dietary modifications for older carers with chronic illnesses. Previous studies have focused on the caregiver influence in relation to their children's eating behaviours (Begen et al., 2017; Scaglioni et al., 2018).

The global COVID-19 pandemic has brought new health challenges for older carers with chronic conditions. Firstly, the risk of serious illness and dying from COVID-19 has been reported to increase with age, and most of the deaths observed have been in people older than 60, especially those with chronic conditions such as hypertension (HelpAge International, 2020; Lloyd-Sherlock et al., 2020; United Nations, 2020). As mentioned earlier, a South African study reports that the majority (72.4 %) of women aged 50 and above had at least one chronic illness (Aboyade et al., 2016). Considering that grandparent caregiving is mainly provided by older women (Casale, 2011; Kasedde et al., 2014; Rutakumwa et al., 2015), as also shown in this study, it is likely that the older women who are caring for their grandchildren are also living with chronic illnesses, and thus at risk of contracting COVID-19. Secondly, chronic illnesses among older carers are not just the only risk factor to COVID-19, they also have few economic resources to protect themselves. For instance, lack of finances negatively impacted the older carers in self-managing their chronic illnesses in this study. The specific resources that the older carers chose to mobilise were influenced by their human agency and the nature of relationship with their adolescent grandchildren. For instance, participating in micro-finance activities was influenced by the carers' agency and the need to provide the adolescent grandchildren with food.

Thirdly, physical distancing is crucial in the prevention of COVID-19 transmission (United Nations, 2020). However, physical distancing may be impossible for older carers who depend on their adolescent grandchildren, as noted in this study, for care and support such as cooking and cleaning. The older carers may face challenges in obtaining food if their adolescent grandchildren are infected with COVID-19. Lastly, timely linkage to care could be hindered during the COVID-19 pandemic (Jiang, Zhou, & Tang, 2020). Older carers with chronic illnesses who should be attending routine healthcare check-ups might be deterred or delayed because of fear of contracting COVID-19 while travelling by public transport and while visiting healthcare facilities. Also, the clinical symptoms of COVID-19 include fever, cough, and shortness of breath (Garba, Lubuma, & Tsanou, 2020). Therefore, the use of home remedies and alternative therapies to treat fever, as noted in this study, is a potential risk to healthcare seeking in the context of COVID-19. For instance, the findings of this study indicate that older carers used alternative therapies, specifically herbal tea, to treat flulike symptoms. The older carers may delay seeking healthcare while they are using the alternative therapies at home.

The findings of this study add depth to previous research relating to the role of CHWs in society and particularly in supporting older carers with the self-management of chronic illnesses. Previous studies have shown that the role of CHWs include health education, home-based care, and supporting adherence to treatment (Loeliger, Niccolai, Mtungwa, Moll, & Shenoi, 2016; Mottiar & Lodge, 2018). This study also reveals their role in facilitating access to and utilisation of sexual and reproductive (SRH) services by adolescents in older carer families. For instance, it was reported that the CHWs conducted pregnancy testing, referrals for antenatal care (ANC), and referrals for contraception, thus promoting healthcare service utilisation by adolescents in older carer families. Home visits by CHWs seemed to be effective in identifying pregnant adolescents and those needing contraceptives in older carer families. A study in South Africa showed that healthcare providers or nurses tended to impose their values upon adolescents regarding contraceptives and posed challenges for adolescents' uptake of SRH services (Nkosi et al., 2019). It is possible that home visits by CHWs and the relationships they have with the older carers could positively influence adolescents' uptake of SRH services.

The findings provide a framework within which services and interventions can support older carers. Caring for grandchildren while suffering from a chronic illness can be draining and the older carers may need a combination of support to self-manage these conditions and strengthen relationships with their grandchildren.

8.4 Conclusion

This study provides needed information for planning primary healthcare needs and chronic care health services that will increasingly have to support older people with chronic illnesses. The findings demonstrate that self-management of chronic conditions by older caregivers and caring for grandchildren are inextricably linked. Health promotion researchers and health providers cannot view self-management of chronic conditions by older carers as a single issue and hope to attain optimal health and well-being for older populations. Optimal self-management of chronic diseases must be seen within a larger context that simultaneously addresses chronic diseases, while paying attention to the intersection of social and cultural factors on older caregivers' self-management strategies. Understanding the role played by grandchildren in supporting their older carers' self-management practices can assist in developing an intervention in which young people are involved in self-management education and support for older carers living with chronic conditions.

The next chapter summarises the key findings of this thesis and presents recommendations for interventions and for future research.

CHAPTER NINE

SYNTHESIS OF THE FINDINGS, CONCLUSION AND RECOMMENDATIONS

9.1 Introduction

This chapter provides a synthesis of key findings and conclusion of this doctoral thesis in order to address the overall aim of the study which was to understand caring of adolescent girls and boys (aged 13 to 19) by older carers (aged 50 and older) in a rural KwaZulu-Natal district in which DREAMS interventions were implemented. In addition, the study also explored the participation in DREAMS interventions by adolescents in older carer families and the influence of DREAMS interventions on caring attitudes and behaviours of older carers as well as risk-taking behaviours of adolescents. The study provided insights from adolescents, older carers, and HIV programme facilitators.

This is a consolidation chapter, which is aimed at amalgamating the individual aspects of the study to reach conclusions and make recommendations for the caring of adolescents by grandparents/older carers in the context of combination HIV prevention interventions. The unique contribution of this study stems from its dyadic approach in understanding caring of adolescents by older carers and the deeper insight into the challenges of older carers living with chronic illness living in a rural area. The study used an ethnographic approach where separate, in-depth interviews were conducted with adolescents, older carers, and HIV programme facilitators. Limitations of the overall thesis are also outlined in this chapter. This chapter concludes with recommendations for interventions as well as suggestions for future research.

9.2 Synthesis of Key Findings and Conclusions

The overall synthesis of the study findings and conclusions is presented in Table 9.1. The summary of findings of this doctoral thesis is grouped according to the five objectives of the study.

Table 9.1: Synthesis of research findings and conclusions

Objectives	**Data utilised**	**Key findings**	**Key conclusions**
Objective 1: To explore the factors that shape the caring of adolescents by older carers and the nature of relationships between adolescents and their older carers.	Results presented in Chapter Four	Factors shaping caring for adolescents by older caregivers • Factors related to adolescents' biological parents ○ Paternal death ○ Parental alcohol abuse ○ Parental neglect ○ Parental unemployment • Factors related to older carers • Factors related to family living arrangements ○ Multigenerational co-residence • Factors related to cultural norms ○ Cultural norms regulating caring of children born out of wedlock • Factors related to adolescents ○ Biological ties with older carers ○ Providing reciprocal care to older carers	• The three factors of the Socio-Ecological Model (SEM) that influence caring of adolescents by older carers are individual, interpersonal, and societal. • The themes of the life course theory that shape caring of adolescents by older carers are historical time, linked lives, the timing of lives, and human agency. • Older carers use their agency to take the responsibility of caring for the adolescents at an individual level of the SEM; their agency is limited at interpersonal and societal levels of the SEM. • Grandparent caregiving is socially constructed as a norm. • The adolescents are emotionally distressed by parental neglect. • There are both protective behaviours and risks within the care relationships.

		Factors that positively or negatively affect the quality of relationships between adolescents and their older carers • Adolescents’ difficult behaviours ○ Unwillingness to do household chores ○ Engaging in risky behaviours, namely sleeping away from home, falling pregnant, drinking alcohol, engaging in sexual relations with older men, and dropping out of school) • Older carers’ negative behaviours ○ Overloading adolescents with household chores ○ Using physical punishment ○ Denying adolescents opportunities to visit paternal or maternal families ○ Unable to provide adolescents with basic needs • Older carers’ positive behaviours ○ Providing food and clothes as well as assistance with household tasks ○ Guiding adolescents’ social behaviours ○ Motivating adolescents to successfully complete schooling ○ Sharing historical stories	• The risk factors in the care relationships between adolescents and their older carers could be influencing risky behaviours of adolescents.

Objective 2: To explore the labelling of adolescents by their older carers and its impact on transitions and adolescent life trajectories	Results presented in Chapter Five	Labels ascribed to adolescents • Well-behaved • Badly-behaved Behaviours associated with the labels • Peer networking • Movements of adolescents • Adolescent sexuality • Schooling • Religiosity Gender and labelling • Control of sexual desire by girls • Virginity testing for girls • Restricted freedom of movements of girls Factors shaping stigmatised labelling of adolescents • Regulated association • Self-exclusion from HIV and SRH services • Exclusion from religious activities • Stereotypes towards adolescents in older carer families	Adolescent girls face challenges as they explore their sexuality and transit to adulthood. Labelling in the context of care relationships, in part to reinforce acceptable or discourage unacceptable behaviours, weighs heavily on adolescents' life trajectories and decisions for participation in healthcare services and HIV interventions. In the context of the COVID-19 pandemic, it is necessary for the older carers to restrict movements of adolescents.
Objective 3: To explore the generational perspectives between adolescents and their older carers of romantic sexual relationships	Results presented in Chapter Six	Meaning of romantic sexual relationships Appropriate timing for engaging in sexual activities • Completing secondary school education • Reaching age of 19yrs • Marriage	Waiting for the appropriate time to engage in sexual activities caused anxiety and vulnerability to engage in adolescent risky behaviours. Arranged marriages place young women at the risk of human trafficking for sexual exploitation and abuse.

		Places to meet romantic sexual partners • Schools • Churches • Alcohol-serving establishments Desired characteristics of ideal romantic sexual partners • Ability to provide financial security • Similarity of values and interests • Commitment to marriage • Education achievement.	Sexual relationships based on money can be a result of motivations of generational influences between adolescents and their caregivers.
Objective 4: To examine the motivators and barriers to participation in DREAMS interventions of adolescents in older carer families.	Results presented in Chapter Seven	Motivators of participation in DREAMS interventions • Individual level ○ Obtaining HIV and SRH information ○ Acquiring life skills ○ Perceived changes in risky behaviours • Interpersonal level ○ Trust in DREAMS programme staff ○ Networking with peers ○ Improved care relationships and communication	Exclusion of boys in the DREAMS caregiver/parenting programme played a major barrier in the participation of adolescent boys and places adolescent girls at increased risk of HIV infection and unwanted pregnancies. Exclusion of adolescents with disabilities implies that the DREAMS implementing organisation did not appreciate and acknowledge young people living with disabilities as sexual human beings. Exclusion of older carers in DREAMS interventions negatively affects relationships between adolescents and older carers.

		• Organisational level (DREAMS implementing organisation) ○ Access to intervention sites ○ Access to HIV testing and additional services • Community level ○ Support of community leadership Barriers to participation in DREAMS interventions • Individual level ○ Differing learning style preferences ○ Internalised stigma of being labelled as ‘badly-behaved’ ○ Obtaining disintegrated SRH information • Interpersonal level ○ Negative peer pressure ○ Refusal by caregivers ○ Caregivers’ lack of information • Organisational level (DREAMS implementing organisation) ○ Limited financial resources ○ Characteristics of DREAMS interventions	

		- Community level ○ Misconceptions about HIV interventions ○ Conflicting religious values with interventions ○ Norms of sexual communication	
Objective 5: To explore the older carers' experiences of self-management of chronic conditions and its influence on caring for adolescents	Results presented in Chapter Eight	Focusing on illness needs - Following instructions from the healthcare workers - Completing health tasks - Performing health promotion activities - Engaging in self-treatment regimes Activating resources - Healthcare resources - Spiritual resources - Family resources - Community resources Living with a chronic illness - Processing emotions - Adjusting to illness and to new self - Integrating illness into daily life - Meaning making	Older carers are mentally distressed by living with chronic illnesses, lack of finances, and strenuous relationships with adolescents. Strenuous relationships with the adolescents, rather than chronic conditions, are the main stressors that undermined the older carers' ability to self-manage chronic illnesses. Older carers are living with chronic illnesses, and thus are at risk of COVID-19. Community health workers (CHWs) also facilitate access to and utilisation of sexual and reproductive (SRH) services by adolescents in older carer families.

Objective 1: To explore the factors that shape the caring of adolescents by older carers and the nature of relationships between adolescents and their older carers

This is the first objective of the study that explored the factors that shape the caring of adolescents by older carers and the nature of relationships between adolescents and their older carers.

Findings indicate a dynamic process which influenced how older carers ended up taking the primary caring responsibility of their grandchildren. This process involved five interconnected aspects namely factors related to adolescents' biological parents, factors related to older carers, factors related to family living arrangements, factors related to cultural norms, and factors related to grandchildren. These aspects were woven together, concurrently shaping pathways for older carers to assume caring responsibilities. Firstly, cultural norms that regulate caring of children born out of wedlock were the reason why older carers took on the responsibility of their grandchildren's caring. Secondly, family living arrangements that included multigenerational co-residence was another source of grandparent caregiving. With regards to the reasons why adolescents' biological parents were unable to provide care for their children leading to the need for grandparent caregiving, the findings show paternal death, parental alcohol abuse, parental neglect, and parental unemployment. Another finding is that parental neglect was perpetuated by new sexual partners of parents after separation. Other authors in SSA have reported that stepparents are perceived as being more punitive and abusive than biological parents (Hoenayi & Yendork, 2018). It may be possible that this form of parental neglect perpetuated by new sexual partners of parents is related to gender power differences in sexual relationships. Biological parents could be experiencing limited agency to provide care and support to their children from previous relationships in the context of new sexual partnerships. Further, biological ties between adolescents and older carers and the reciprocal care between adolescents and older carers were the factors influencing grandparent caregiving. Lastly, fear of being labelled as discriminating against other grandchildren, past experience of being raised by a grandmother, feeling unsafe when living alone as an older woman, and the self-perceived role of a grandmother were the factors related to the older carers that influenced grandparent caregiving.

In exploring the factors that positively or negatively affected the quality of relationships between adolescents and their older carers, adolescents' difficult behaviours and carers' behaviours (positive and negative) were the findings indicated in this study. With regards to adolescents' difficult behaviours that negatively affected the nature of their relationships, unwillingness to do household chores and engaging in risky behaviours (including sleeping away from home, falling pregnant, drinking alcohol, engaging in sexual relations with older men, and dropping out of school) were the sources of strained relationships between adolescents and older carers.

In addition, the findings show that there were both positive and negative caring behaviours by the older carers. The negative caring behaviours posed some challenges for the adolescents with consequent impacts on their relationships with their carers. The negative caring behaviours included overloading the adolescents with household chores, using physical punishment to discipline the adolescents, denying the adolescents opportunities to visit paternal or maternal families, and being unable to provide the adolescents with their basic needs.

While the negative caring behaviours of older carers made it difficult for the adolescents to relate well with their older carers, some caring behaviours by older carers positively affected the relationships. These included the provision of food and clothes as well as assistance with household tasks, guiding the adolescents' social behaviours, motivating the adolescents to successfully complete their schooling, and sharing historical stories.

In conclusion, the three factors of the Socio-Ecological Model (SEM) that influenced caring of adolescents by older carers were individual, interpersonal, and societal, while the themes of the life course theory that influenced caring of adolescents by older carers were historical time, linked lives, the timing of lives, and human agency. Older carers used their agency to take on the responsibility of caring for the adolescents at an individual level of the SEM, however, their agency was limited at interpersonal and societal levels of the SEM. A possible explanation for this is that grandparent caregiving is socially constructed as a norm. This has negative implications as the older carers may assume the grandparent caregiving role because they have been socialised into thinking of grandparent caregiving as a norm, and, therefore, not using their agency in the decision to care for the grandchildren. They may find themselves stuck in the caring role. This may have negative implications on the quality of relationships with their grandchildren, and on the well-being of both the grandchildren and the older carers.

The adolescents were emotionally distressed by parental neglect and the caring behaviours of the older carers. Similarly, the older carers were emotionally distressed by the adolescents' difficult behaviours. This had negative implications on the well-being of both the adolescents and the older carers. It risked the quality of relationships between adolescents and their older carers which could influence the risky behaviours of adolescents and the health and well-being of the older carers.

This study suggests a need to improve the nature of relationships between adolescents and their older carers.

Objective 2: To explore the labelling of adolescents by their older carers and its impact on transitions and adolescent life trajectories

This is the second objective of the study that explored the labelling of adolescents by their older carers and its impact on transitions and adolescent life trajectories.

Two categories were used to label young people: 'well-behaved' and 'badly-behaved'. 'Well-behaved' young people were those who acted in an acceptable and approved manner within their families and in the community by following the rules and expectations set for them. In contrast, 'badly-behaved' young people were those who conducted themselves against the rules and expectations. The behaviours associated with the labels ascribed to the adolescents were related to peer networking, mobility, sexuality, schooling, and religiosity. Gender was used to frame the labels ascribed to the adolescents. Girls were expected to control their sexual desire, virginity testing was used to monitor girls' sexuality, and girls were restricted freedom of movement. The findings show that consequences of stigmatised labelling of adolescents were regulated association, self-exclusion from HIV and SRH services, exclusion from religious activities, and stereotypes towards adolescents in older carer families.

The study draws the conclusion that adolescent girls face challenges as they explore their sexuality and transit to adulthood. Also, labelling in the context of care relationships, in part to reinforce acceptable or discourage unacceptable behaviours, weighs heavily on adolescents' life trajectories and decisions for participation in healthcare services and HIV interventions. Lastly, in the context of the COVID-19 pandemic, it may be necessary for the older carers to restrict movements of adolescents in order to protect both the adolescents and the older carers from contracting COVID-19.

Objective 3: To explore the generational perspectives between adolescents and their older carers of romantic sexual relationships

This is the third objective of the study that explored generational perspectives between adolescents and their older carers of romantic sexual relationships.

Romantic sexual partnerships were conceptualised as relationships involving sex (sexual), non-sexual relationships (romantic) and a combination of romantic and sexual between heterosexual groups. The appropriate timing for engaging in sexual activities is associated with life events including completing secondary school education, reaching age of 19yrs, and marriage. In exploring the formation of romantic sexual relationships, spaces for the adolescents to meet romantic sexual partners are schools, churches, and alcohol-serving establishments.

In understanding the preferred characteristics of the ideal romantic sexual partners, the desired characteristics of an ideal romantic partner included the ability to provide financial security, similarity on values and interests, commitment to finding a marriage mate, and education achievements.

The study concludes that waiting for the appropriate time to engage in sexual activities caused anxiety and vulnerability for the adolescents. Also, arranged marriages placed young women at the risk of human trafficking for sexual exploitation and abuse. Lastly, sexual relationships based on money could be a result of motivations of generational influence between adolescents and their caregivers.

Objective 4: To examine the motivators and barriers to participation in DREAMS interventions of adolescents in older carer families

This is the fourth objective of the study that examined the motivators and barriers to participation in DREAMS interventions of adolescents in older carer families.

In order to arrive at a fuller understanding of specific factors that shaped participation in DREAMS interventions, the adolescents, their older carers and DREAMS programme staff were asked about both motivators and barriers to adolescents' participation in DREAMS interventions.

The motivators for participation in DREAMS interventions of adolescents in older carer families were influenced by four levels of the socio-ecological model (SEM) namely individual, interpersonal, organisational, and community levels. At an individual level, the motivating factors were obtaining HIV and SRH information, acquiring life skills, and perceived changes in risky behaviours. At the interpersonal level, the motivators of participation in DREAMS interventions included trust in DREAMS programme staff, networking with peers, and improved care relationships and communication between adolescents and the older carers. At the level of the organisation responsible for implementing DREAMS interventions, access to intervention sites and access to HIV testing and additional services were motivators that influenced participation in DREAMS intervention of adolescents in older carer families. Lastly, at community level, support of community leadership enabled adolescents to participate in HIV prevention interventions.

On the other hand, the four levels of the socio-ecological model (SEM), namely individual, interpersonal, organisational, and community levels of influence also shaped the barriers to participation in DREAMS interventions. At an individual level, differing learning style preferences, internalised stigma of being labelled as 'badly-behaved', and obtaining disintegrated SRH information were the barriers to adolescents' participation in DREAMS interventions. At the interpersonal level, the adolescents were hindered to participate in DREAMS interventions due to negative peer pressure, refusal by caregivers, and caregivers' lack of information about the HIV prevention interventions. At the level of the organisation responsible for implementing DREAMS interventions, limited financial resources and characteristics of DREAMS interventions were the major barriers to successful participation of adolescents. There were six DREAMS intervention characteristics contributing to the barriers to the uptake of HIV prevention interventions. The first one regards DREAMS interventions that were school-based and required the participation of adolescents within selected schools. The second characteristic of DREAMS interventions that was a major barrier to adolescent participation was the exclusion of adolescent boys in the parenting/caregiver programme. This was followed by the exclusion of adolescents with disabilities in the HIV prevention interventions. The DREAMS implementing organisation overlooked the adolescents with disabilities when targeting adolescents to participate in HIV prevention interventions. Another barrier associated with the characteristics of DREAMS interventions was the exclusion of older carers in the parenting/caregiver programme. The older caregivers were excluded as participants in the parenting/caregiver programme due to their age and physical abilities. Also, timing of programme sessions in the late afternoon posed challenges for the adolescents to attend the group sessions for the DREAMS interventions. Lastly, recruitment strategies employed by the implementing organisation combined with the targeted age group of young people hindered the participation of adolescents in the HIV interventions. At community level, misconceptions about the interventions and norms of sexual communication were the barriers to adolescents' participation in the DREAMS interventions.

The study draws the conclusion that exclusion of boys in the DREAMS caregiver/parenting programme played a major barrier in the participation of adolescent boys and, thus places adolescent girls at increased risk of HIV infection and unwanted pregnancies. Further, exclusion of adolescents with disabilities implies that the DREAMS implementing organisation does not appreciate and acknowledge young people living with disabilities as sexual human beings. Lastly, exclusion of older carers in DREAMS interventions can negatively affect relationships between adolescents and older carers.

Objective 5: To explore the older carers' experiences of self-management of chronic conditions and its influence on caring for adolescents

This is the last objective of the study that explored the older carers' experiences of self-management of chronic conditions and its influence on caring for adolescents.

In exploring how the older carers focused on their chronic illness needs, they used a range of activities including following instructions from the healthcare workers, completing health tasks, and performing health promotion activities. Concerning the resources that the older carers activated in the self-management of chronic conditions, they mobilised healthcare, spiritual, family, and community resources. Four tasks were executed by the older carers in relation to how they lived with chronic illness. These tasks included processing emotions, adjusting to illness and to their new self, integrating illness into daily life and meaning making.

The study concludes that older carers were mentally distressed by living with chronic illnesses, lack of finances, and strenuous relationships with adolescents. The strenuous relationships with the adolescents, rather than chronic conditions, were the main stressors that undermined the older carers' ability to self-manage chronic illnesses. In addition, older carers living with chronic illnesses are at risk of COVID-19. Lastly, community health workers (CHWs) also facilitated access to and utilisation of sexual and reproductive (SRH) services by adolescents in older families.

9.3 Limitations of the Study

Every study has its limitations as researchers often experience challenges in participant selection, data collection and analysis (Maree, 2016). Stating these challenges upfront allows the reader to understand better the conclusions made. The limitations of the study are discussed below.

Firstly, this study was designed to provide in-depth understanding around factors that influence intergenerational care of adolescents by their grandparents/older carers. The ethnographic approach focused on a limited number of participants. While this approach is likely to have been effective in providing a comprehensive understanding of the dynamics influencing caring of adolescents by their grandparents, it is important to note that the small sample may limit the generalisability of the findings. Moreover, the small sample consisting of women older carers only, does not tell us anything about men who are primary older carers. Factors shaping older men caregivers are likely to be different, as there is a considerable difference in gender roles affecting the motivations of providing care. However, this reflects the gendered nature of caregiving of grandchildren by older women.

Moreover, although the older carers readily agreed to participate in the study, the practical aspects of conducting research (repeat in-depth interviews) in this environment presented a unique set of challenges. It was difficult to interview the older carers as they often experienced pain, fatigue, and suffered from hearing or visual problems. Cognitive impairment amongst some older carers impacted them recalling details of historical events, and answering questions about their perceptions. Strategies such as speaking louder and slowly were used to miminise the limitations.

In addition, data collection took place just after the implementation of the HIV interventions were completed. As a result, the researcher could not conduct participant observations during the delivery of the interventions. At the time of data collection, some participants struggled to recall detailed information about their experiences with the interventions. In addition, the programme facilitators interviewed were already out of a job and no longer employees of the organisation. From a research point of view, this meant that detailed data on experiences during the implementation were not available. However, valuable insights into the experiences with the HIV interventions were nevertheless gained.

Another important limitation of this study was that adolescents were not asked to provide their perspective on their cooking behaviours and the factors impacting their choices when preparing meals for the older carers.

Lastly, the study sample comprised of one adolescent boy. This was due to the fact that adolescents were recruited through the DREAMS implementing organisation and the researcher found one adolescent boy who was an intervention recipient and being cared for by an older carer.

9.4 Recommendations for Interventions

Based on the findings of this study, the following strategies are recommended for improving caring of adolescents by older carers and interventions targeting adolescents in older carer families.

9.4.1 Inclusion of adolescent boys in parenting/caregiver programmes

The importance of caregivers in the prevention of HIV among adolescents has received a growing amount of attention in the literature. Interventions focused on strengthening relationships between adolescents and their caregivers as a protective factor for HIV prevention among adolescents, should consider incorporating adolescent boys too. While HIV disproportionately affects adolescent girls and HIV incidence continues to disproportionately affect adolescent girls compared to adolescent boys, addressing it requires working with both adolescent girls and adolescent boys as well as their caregivers.

9.4.2 Inclusion of adolescents with disabilities in HIV and health interventions

Disability among children and adolescents is a relevant issue in high HIV burdened contexts. It is of paramount importance to involve adolescents with disabilities in HIV prevention interventions as they are equally vulnerable to HIV, STIs, and pregnancy as adolescents not living with disabilities.

9.4.3 Involvement of adolescents in planning, designing, and delivering HIV prevention interventions

Adolescents are targeted by HIV prevention interventions such as DREAMS. Involving adolescents as partners in HIV prevention interventions could offer many benefits for the adolescents and the implementers. Given the barriers experienced by adolescents in participating in HIV prevention interventions such as negative peer pressure and internalised stigma, there is an urgent need to involve the adolescents in planning, designing and delivering HIV prevention interventions so that the barriers can be removed. Involving adolescents in programme design could counteract the internalisation of negative labels about adolescents and mitigate challenges that young people face in participating in HIV interventions.

9.4.4 Involvement of older carers in HIV prevention interventions

As stated before, the importance of caregivers in the prevention of HIV among adolescents is a protective factor for adolescents. Interventions focused on strengthening relationships between adolescents and their caregivers, should consider involving older carers too. Older carers are playing an important role in providing a safety net for their grandchildren and in shaping their life trajectories. Therefore, HIV prevention interventions would be strengthened by the increased involvement of older carers, and their involvement would enhance caring relationships. In addition to older carers, community leaders such as pastors, should be included in HIV prevention strategies and be provided with skills and accurate information to further communicate HIV and sexual health information.

Furthermore, this study has important implications in the design of parenting/caregiver programmes or other services aimed at optimising intergenerational relationships, particularly inside the family. Knowing both perspectives of the relationship and the factors influencing relationships between adolescents and their older carers, should be incorporated by professionals who develop such programmes. Also, considering factors that positively and negatively impact relationships between adolescents and older carers can indicate topics to be included in such programmes, skills to develop, or resources that can be used to improve the relationship. The adolescents and their older carers' mutual caring relationship calls for adolescents to assist their older carers due to age and chronic illnesses. Therefore, the adolescents in older carer families need to be capacitated with some background to the ageing process and best ways to care for their elderly caregivers.

9.4.5 Prioritisation of older carers for COVID-19 vaccination

As countries prepare to implement their respective COVID-19 immunisation programmes, older carers should be prioritised for COVID-19 vaccination, particularly while supply is limited. A number of factors make older carers a high risk population that should be allocated the COVID-19 vaccination. These factors include their caring responsibilities for younger generations, living with chronic conditions, living situations such as inability to physically distance, and reliance on grandchildren for care and support.

9.4.6 Training and support of lay HIV programme facilitators

The findings of this study add to previous research relating to the utilisation of lay facilitators to deliver HIV prevention interventions. However, lay HIV programme facilitators need to be trained and supported to handle sexual communication with young people as they may face challenges related to cultural norms of sexual communication. Lack of confidence by lay facilitators may hinder young people's participation in HIV interventions. Therefore, the lay facilitators should be supported and supervised by professionals such as psychologists and health promotion specialists to increase access to HIV interventions in low-resourced settings of adolescents. Also, the selection and training of facilitators for SRH and youth sexuality programmes should focus on people who would be at ease to talk about sexual matters and provide them with the relevant training to become competent in this role.

9.4.7 Strengthening community engagement to increase acceptance of HIV prevention interventions

Community acceptability and understanding of HIV prevention interventions plays an important role in the success of interventions, and mostly in the participation of targeted populations such as adolescents in the interventions. Community members form part of the adolescents' socio-ecological system and play a significant role in adolescents' participation in the interventions. The study findings highlight community misconceptions about DREAMS interventions that the interventions were perceived as 'a thing for women' and 'a campaign to teach adolescents to control adults'. Therefore, for the success of combination HIV prevention interventions, strengthening community engagement to increase their acceptance and understanding of the interventions is important for the participation of adolescents in the interventions.

9.4.8 Supporting older carer families with housework and psychosocial support

Both adolescents and their older carers are suffering with the burden of housework. Therefore, there is a need for these families to be supported with housework such as cleaning, cooking, and laundry so that adolescents and older carers are relieved from the responsibilities of performing housework. In the context of South Africa, the services of ward-based outreach teams (WBOTs) should incorporate support of older carer families with housework. This in turn would relieve some of the adolescents from various chores that may impact their school work and participation in important health related interventions.

Further, a concerning issue raised in the study is the lack of sustainability in the communication between adolescents and older carers after the DREAMS interventions have come to an end. WBOTs should provide psychosocial support to older carer families. However, this suggests a need to strengthen the WBOTs with therapists trained in family relationships to support older carer families sustain communication and family relationships.

9.4.9 Clustering of schools for HIV interventions

School-based programmes should consider clustering schools for HIV interventions particularly schools that are geographically in close proximity. This would promote diversity between learners from different schools. When interacting with young people from a variety of backgrounds, experiences, abilities and cultures, young people would gain a more comprehensive understanding of the phenomenon. It would also capacitate young people on how to articulate and use their own strengths and points of view to contribute in a diverse working environment, and to learn from one another. In addition to diversity, it may be possible that young people in schools that are geographically in close proximity, live in the same neighbourhood and may be friends, as one adolescents mentioned in this study. The findings of this study show that young people were motivated to attend HIV interventions with their friends. Therefore, clustering of schools may also provide young people the opportunity to participate in HIV interventions with their friends.

9.4.10 Nutrition campaigns for older carer families

The findings of the study show that adolescents can play a critical role in undermining healthy eating for their older carers. Rather than supporting their older carers’ efforts to healthy eating, the older carers complained that the adolescent grandchildren were dismissive of the health concerns of the older carers. These findings are useful to nutrition campaigns aimed at promoting healthy eating behaviours. The WBOTs could educate families, particularly older carer families, about a healthy diet. Health education could be packaged into a tailored campaign to educate older carer families about the potential harm of unhealthy eating practices. The campaign could also recommend that adolescents become champions of healthy eating and encourage and support adolescents' attempts to improve their older carers' diets. Another approach would be to facilitate the role of older carers as coaches of traditional food cooking skills to the adolescent grandchildren so that these skills are maintained in the contemporary society. Lastly, older carers could also coach the adolescents on how to grow a vegetable garden. These activities could be a valuable approach to improving older carers' diets and the relationships between adolescents and their older carers.

9.5 Suggestions for Further Research

More research is needed on the experiences of adolescents with disabilities regarding their participation in HIV prevention interventions, considering a broader spectrum of disability.

Future research could focus specifically on adolescents in older carer families to investigate their knowledge and attitudes towards healthy eating as well as the barriers and facilitators affecting the preparation of healthy foods for their older carers. Such an approach may also yield interesting findings relating to adolescents' views of healthy eating.

The findings highlighted in this study suggest that transactional sex could be motivated by adolescents' socialisation in older carer families. The role of interpersonal level factors (adolescent-caregiver relationships) in shaping participation in transactional sex relationships has not been fully examined in SSA. Further studies are needed to examine how adolescent-caregiver relationships shape young women's participation in transactional sex relationships.

Lastly, in the context of COVID-19, it is likely that the pandemic will disrupt the lives of older carers with chronic illnesses and their grandchildren. Further studies are required to understand the impact of COVID-19 on older carer families and its influence on self-management of chronic illnesses and caring for adolescents.

9.6 Reflections on the PhD journey

As an emerging scholar, my journey in conducting and finally completing this study was both challenging and rewarding. My participation as both the insider and outsider in this prolonged engagement research has taught me a number of scientific lessons related to my research. Beyond that, this study taught me lessons applicable to my journey as a PhD candidate.

This study made me realise the influence of the life course on a person’s PhD journey. During the trajectory of my PhD journey, I learned that linked lives and human agency are important for one to transition from no university qualification to PhD, despite many social circumstances. When I look back, I realise I would not have reached this point if it were not for the inter-relationships or linked lives and my ability to exercise my agency to shape my PhD journey. I have realised that the decision I took to go back to work for my first employer (Africa Health Research Institute) and to leave my family behind was a life-changing decision for me. I believed that being in the environment of my first employer was going to create a conducive opportunity for me to connect with the established and renowned researchers to support me. Indeed, they provided me with necessary support that I required as a PhD candidate. The environment was motivating and the support from my colleagues included reviewing my PhD proposal and offering me resources to do the study. It is from this experience that I realised the importance of linked lives and individual agency for postgraduate student support and a smooth transition to completing PhD studies. From this journey, I have learnt that supporting PhD students whose lives are linked to mine can mitigate the problem of postgraduate students dropping out of their studies and attaining triumph despite their challenges.

Even though working for my employer put me in a privileged position to work with renowned researchers, I possess critical skills that allowed me to use my agency such as being able to set boundaries, being self-motivated, self-regulated, and able to make decisions. PhD students also need to be empowered to cultivate human agency skills in order to have a successful PhD journey.

9.7 Overall conclusion

A multi-theoretical approach including the life course perspective, the social-ecological model, and the self-management framework was applied to explore the caring of adolescents by older carers in the context of HIV combination prevention interventions in a rural district of South Africa. The study provided insights from adolescents, older carers, and HIV programme facilitators.

The study highlights interdependence and the mutual caring relationship between adolescents and their older carers. The lives of adolescents and older carers are uniquely linked, shaping and being shaped by each other in their life course. However, the intersection of living with a chronic disease and being old complicates the grandparents' caring behaviours to adolescents. The self-management of chronic diseases burdens the older carers in addition to caring for adolescents. While older carers employ a range of self-management practices to promote health and well-being; they, sometimes, put their lives at risk. Lack of socio-economic resources combined with adolescents' challenging behaviours places the older carers at higher risk for mental health problems.

Additionally, being raised by an older carer who is living with a chronic disease affects the adolescent's sense of self and how the relationship is maintained. Similarly, adolescents in older carer families confront challenges as they explore their sexuality and transit to adulthood. The consequences of stigmatised labelling of adolescents negatively affect the adolescents in older carer families and their participation in HIV interventions. The adolescents in older carers are vulnerable to risky behaviours and mental health problems.

This study contributes to understanding the context of adolescent-older carer relationships, the factors influencing this relationship, and its linkage to young people's risks and the older carers' self-management of chronic illnesses. The findings are uniquely valuable in that as both the perspectives of the adolescents and the older carers themselves are presented.

Lastly, the adolescents and older carers' linked lives require interventions to recognise that both the adolescents and older carers exert relational influence, thereby impacting their well-being and the quality of the care relationships throughout the life course. Therefore, no intervention should focus on neither adolescents nor older carers at the exclusion of the other.

REFERENCES

Abebe, T., & Aase, A. (2007). Children, AIDS and the politics of orphan care in Ethiopia: The extended family revisited. *Social Science and Medicine*, *64*, 2058–2069. https://doi.org/10.1016/j.socscimed.2007.02.004

Aboyade, O. M., Beauclair, R., Mbamalu, O. N., Puoane, T. R., & Hughes, G. D. (2016). Health-seeking behaviours of older black women living with non-communicable diseases in an urban township in South Africa. *BMC Complementary and Alternative Medicine*, *16*(410), 1–9. https://doi.org/10.1186/s12906-016-1378-4

Adjei, J. K., & Saewyc, E. M. (2017). Boys are not exempt: Sexual exploitation of adolescents in sub-Saharan Africa. *Child Abuse and Neglect*, *65*, 14–23. https://doi.org/10.1016/j.chiabu.2017.01.001

Ali, T. S., Karmaliani, R., Mcfarlane, J., Khuwaja, H. M. A., Somani, Y., Chirwa, E. D., & Jewkes, R. (2017). Attitude towards gender roles and violence against women and girls (VAWG): Baseline findings from an RCT of 1752 youths in Pakistan. *Global Health Action*, *10*(1), 1–10. https://doi.org/10.1080/16549716.2017.1342454

Anney, V. N. (2014). Ensuring quality of the findings of qualitative research: Looking at trustworthiness. *Journal of Emerging Trends in Educational Research and Policy Studies*, *5*(2), 272–281.

Appollis, T. M., Duby, Z., Jonas, K., Dietrich, J., Maruping, K., & Mathews, C. (2020). Factors influencing Adolescent Girls and Young Women's participation in a Combination HIV Prevention Intervention in South Africa. *Research Square*, 1–31. https://doi.org/10.21203/rs.3.rs-60050/v3

Assim, U. M. (2013). *Understanding kinship care of children in Africa: A family environment or an alternative care option?* University of the Western Cape.

Attar-Schwartz, S., & Buchanan, A. (2018). Grandparenting and adolescent well-being: evidence from the UK and Israel. *Contemporary Social Science*, *13*(2), 219–231. https://doi.org/10.1080/21582041.2018.1465200

Attar-Schwartz, S., Tan, J. P., & Buchanan, A. (2009). Adolescents' perspectives on relationships with grandparents: The contribution of adolescent, grandparent, and parent-grandparent relationship variables. *Children and Youth Services Review*, *31*(9), 1057–1066. https://doi.org/10.1016/j.childyouth.2009.05.007

Babchuk, W. A. (2019). Fundamentals of qualitative analysis in family medicine. *Family Medicine and Community Health*, *7*(e000040), 1–10. https://doi.org/10.1136/fmch-2018-000040

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic illness: A review. *Patient Education and Counseling*, *48*, 177–187. https://doi.org/10.1016/S0738-3991(02)00032-0

Bastien, S., Kajula, L., & Muhwezi, W. (2011). A review of studies of parent-child communication about sexuality and HIV/AIDS in sub-Saharan Africa. *Reproductive Health*, *8*(25). https://doi.org/10.1186/1742-4755-8-25

Basu, S., Zuo, X., Lou, C., Acharya, R., & Lundgren, R. (2017). Learning to Be Gendered: Gender Socialization in Early Adolescence Among Urban Poor in Delhi, India, and Shanghai, China. *Journal of Adolescent Health*, *61*(4), S24–S29. https://doi.org/10.1016/j.jadohealth.2017.03.012

Begen, F. M., Barnett, J., Barber, M., Payne, R., Gowland, M. H., & Lucas, J. S. (2017). Parents' and caregivers' experiences and behaviours when eating out with children with a food hypersensitivity. *BMC Public Health*, *18*(1), 1–10. https://doi.org/10.1186/s12889-017-4594-z

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Bernays, S., Bukenya, D., Thompson, C., Ssembajja, F., & Seeley, J. (2017). Being an ‘adolescent’: The consequences of gendered risks for young people in rural. *Childhood*, 1–15. https://doi.org/10.1177/0907568217732119

Bhana, A., McKay, M. M., Mellins, C., Petersen, I., & Bell, C. (2010). Family-based HIV prevention and intervention services for youth living in poverty-affected contexts: The CHAMP model of collaborative, evidence-informed programme development. *Journal of the International AIDS Society*, *13*(Suppl 2: S8), 1–8. https://doi.org/10.1186/1758-2652-13-S2-S8

Bhana, A., Mellins, C. A., Petersen, I., Alicea, S., Myeza, N., Holst, H., … McKay, M. (2014). The VUKA family program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS Care*, *26*(1), 1–11. https://doi.org/10.1080/09540121.2013.806770

Biello, K. B., Sipsma, H. L., Ickovics, J. R., & Kershaw, T. (2010). Economic dependence and unprotected sex: The role of sexual assertiveness among young urban mothers. *Journal of Urban Health*, *87*(3), 416–425. https://doi.org/10.1007/s11524-010-9449-1

Birdthistle, I., Schaffnit, S. B., Kwaro, D., Shahmanesh, M., Ziraba, A., Kabiru, C. W., … Floyd, S. (2018). Evaluating the impact of the DREAMS partnership to reduce HIV incidence among adolescent girls and young women in four settings: A study protocol. *BMC Public Health*, *18*(1), 1–15. https://doi.org/10.1186/s12889-018-5789-7

Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, *13*(1), 68–75. https://doi.org/10.1177/1744987107081254

Black, B. P., Holditch-Davis, D., & Miles, M. S. (2009). Life course theory as a framework to examine becoming a mother of a medically fragile preterm infant. *Research in Nursing and Health*, *32*(1), 38–49. https://doi.org/10.1002/nur.20298

Bleakley, A., Khurana, A., Hennessy, M., & Ellithorpe, M. (2018). How Patterns of Learning About Sexual Information Among Adolescents Are Related to Sexual

Behaviors. *Perspectives on Sexual and Reproductive Health*, *50*(1), 15–23. https://doi.org/10.1363/psrh.12053

Bogart, L. M., Skinner, D., Thurston, I. B., Toefy, Y., Klein, D. J., Hu, C. H., & Schuster, M. A. (2013). Let's Talk!, A South African Worksite-Based HIV Prevention Parenting Program. *J Adolesc Health*, *53*(5), 602–608. https://doi.org/10.1016/j.jadohealth.2013.01.014.

Breheny, M., Stephens, C., & Spilsbury, L. (2013). Involvement without interference: How grandparents negotiate intergenerational expectations in relationships with grandchildren. *Journal of Family Studies*, *19*(2), 174–184. https://doi.org/10.5172/jfs.2013.19.2.174

Bukenya, J. N., Nakafeero, M., Ssekamatte, T., Isabirye, N., Guwatudde, D., & Fawzi, W. W. (2020). Sexual behaviours among adolescents in a rural setting in eastern Uganda: a cross-sectional study. *Tropical Medicine & International Health*, *25*(1), 81–88. https://doi.org/10.1111/tmi.13329

Burton, E., Farrier, K., Hill, K. D., Codde, J., Airey, P., & Hill, A. M. (2018). Effectiveness of peers in delivering programs or motivating older people to increase their participation in physical activity: Systematic review and meta-analysis. *Journal of Sports Sciences*, *36*(6), 666–678. https://doi.org/10.1080/02640414.2017.1329549

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*(2), 167–183. https://doi.org/10.1155/1998/97416

Cahill, E., Lewis, L. M., Barg, F. K., & Bogner, H. R. (2009). You Don't Want to Burden Them: Older Adults' Views on Family Involvement in Care. *J Fam Nurs*, *15*(3), 295–317. https://doi.org/10.1177/1074840709337247

Cain, D., Pare, V., Kalichman, S. C., Harel, O., Mthembu, J., Carey, M. P., … Mwaba, K. (2012). HIV Risks Associated with Patronizing Alcohol Serving Establishments in South African Townships, Cape Town. *Prevention Science*, *13*(6), 627–634. https://doi.org/10.1007/s11121-012-0290-5

Caldwell, K. (2014). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, *14*(4), 488–507. https://doi.org/10.1177/1468794113490718

Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Medical Research Methodology*, *13*(1), 14. https://doi.org/10.1186/1471-2288-13-14

Casale, M. (2011). “I am living a peaceful life with my grandchildren. Nothing else”. Stories of adversity and “resilience” of older women caring for children in the context of HIV/AIDS and other stressors. *Ageing and Society*, *31*(8), 1265–1288. https://doi.org/10.1017/S0144686X10001303

Casale, M., Cluver, L., Crankshaw, T., Kuo, C., Lachman, J. M., & Wild, L. G. (2015). Direct and Indirect Effects of Caregiver Social Support on Adolescent Psychological Outcomes in Two South African AIDS-Affected Communities. *American Journal of Community Psychology*, *55*(3–4), 336–346. https://doi.org/10.1007/s10464-015-9705-3

CDC. (2015). The Social-Ecological Model: A Framework for Prevention. Retrieved November 16, 2020, from https://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html

Chang, A. Y., Gómez-Olivé, F. X., Payne, C., Rohr, J. K., Manne-Goehler, J., Wade, A. N., … Salomon, J. A. (2019). Chronic multimorbidity among older adults in rural South Africa. *BMJ Global Health*, *4*(e001386). https://doi.org/10.1136/bmjgh-2018-001386

Chappell, P. (2016). Secret languages of sex: disabled youth’s experiences of sexual and HIV communication with their parents/caregivers in KwaZulu-Natal, South Africa. *Sex Education*, *16*(4), 405–417. https://doi.org/10.1080/14681811.2015.1092432

Charmaz, K. (2006). *Constructing Grounded Theory*. London: Sage.

Chimbindi, N., Mthiyane, N., Birdthistle, I., Floyd, S., McGrath, N., Pillay, D., … Shahmanesh, M. (2018). Persistently high incidence of HIV and poor service uptake in adolescent girls and young women in rural KwaZulu-Natal, South Africa prior to DREAMS. *PLoS ONE*, *13*(10), 1–17. https://doi.org/10.1371/journal.pone.0203193

Christofides, N. J., Jewkes, R. K., Dunkle, K. L., Nduna, M., Shai, N. J., & Sterk, C. (2014). Early adolescent pregnancy increases risk of incident HIV infection in the eastern cape, south africa: A longitudinal study. *Journal of the International AIDS Society*, *17*, 1–7. https://doi.org/10.7448/IAS.17.1.18585

Clüver, F., Elkonin, D., & Young, C. (2013). Experiences of sexual relationships of young black women in an atmosphere of coercion. *Journal of Social Aspects of HIV/AIDS*, *10*(1), 8–16. https://doi.org/10.1080/17290376.2013.807055

Cluver, L. (2011). Children of the AIDS pandemic. *Nature*, *474*, 27–29. https://doi.org/10.1038/474027a

Cluver, L., Orkin, M., Boyes, M., Gardner, F., & Meinck, F. (2011). Transactional Sex Amongst AIDS-Orphaned and AIDS-Affected Adolescents Predicted by Abuse and Extreme Poverty. *Journal of Acquired Immune Deficiency Syndromes*, *58*(3), 336–343. https://doi.org/10.1097/QAI.0b013e31822f0d82

Conger, R. D., Conger, K. J., & Martin, M. J. (2010). Socioeconomic status, family processes,and individual development. *Journal of Marriage and Family*, *72*(3), 685–704. https://doi.org/10.1111/j.1741-3737.2010.00725.x

Courtenay, W. H. (2000). Constructions of masculinity and their influence on men’s well-being: a theory of gender and health. *Social Science & Medicine*, *50*, 1385–1401. Retrieved from http://www.postpartummen.com/pdfs/SS&M.PDF

Cree, V. E., Kay, H., Tisdall, K., & Wallace, J. (2004). Stigma and Parental HIV. *Qualitative Social Work*, *3*(1), 7–25. https://doi.org/10.1177/1473325004041129

Creswell, J. W. (2007). *Qualitative inquiry and research design: choosing among five approaches* (2nd ed.). Thousand Oaks: Sage.

Dahlbäck, E., Makelele, P., Yamba, C. B., Bergström, S., & Ransjö-Arvidson, A. B. (2006). Zambian male adolescents' perceptions about premarital sexual relationships. *African Journal of AIDS Research*, *5*(3), 257–264. https://doi.org/10.2989/16085900609490387

de-Graft Aikins, A. (2005). Healer shopping in Africa: new evidence from rural-urban qualitative study of Ghanaian diabetes experiences. *British Medical Journal*, *331*, 737. https://doi.org/10.1136/bmj.331.7519.737

Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *The Lancet*, *382*, 1525–1533. https://doi.org/10.1016/S0140-6736(13)61809-7

Denzin, N. K., & Lincoln, Y. S. (1994). *The SAGE Handbook of Qualitative Research*. Thousand Oaks: SAGE.

Dietrich, J., Sikkema, K., Otwombe, K. N., Sanchez, A., Nkala, B., de Bruyn, G., … Gray, G. E. (2013). Multiple levels of influence in predicting sexual activity and condom use among adolescents in Soweto, Johannesburg, South Africa. *J HIV AIDS Soc Serv.*, *12*(3–4), 404–423. https://doi.org/10.1080/15381501.2013.819312

Dolbin-MacNab, M. L., Jarrott, S. E., Moore, L. E., O'Hora, K. A., Vrugt, M. D. C., Erasmus, M., & Erasmus, M. (2016). Dumela Mma : an examination of resilience among South African grandmothers raising grandchildren. *Ageing & Society*, *36*, 2182–2212. https://doi.org/10.1017/S0144686X15001014

Dolbin-MacNab, M. L., & Keiley, M. K. (2009). Navigating interdependence: How adolescents raised-solely by grandparents experience their family relationships. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, *58*(2), 162–175. https://doi.org/10.1111/j.1741-3729.2008.00544.x

Duby, Z., McClinton Appollis, T., Jonas, K., Maruping, K., Dietrich, J., LoVette, A., … Mathews, C. (2020). "As a Young Pregnant Girl… The Challenges You Face": Exploring the Intersection Between Mental Health and Sexual and Reproductive Health Amongst Adolescent Girls and Young Women in South Africa. *AIDS and*

Behavior, 1–10. https://doi.org/10.1007/s10461-020-02974-3

Dunbar, M. S., Maternowska, M. C., Kang, M.-S. J., Laver, S. M., Mudekunye-Mahaka, I., & Padian, N. S. (2010). Findings from SHAZ!: A Feasibility Study of a Microcredit and Life-Skills HIV Prevention Intervention to Reduce Risk Among Adolescent Female Orphans in Zimbabwe. *Journal of Prevention & Intervention in the Community*, *38*(2), 147–161. https://doi.org/10.1080/10852351003640849

Dutta, M. J., & Basu, A. (2008). Meanings of health: Interrogating structure and culture. *Health Communication*, *23*(6), 560–572. https://doi.org/10.1080/10410230802465266

Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, *20*(12), 1642–1655. https://doi.org/10.1177/1049732310376520

Elder, G. H. (1998). The Life Course as Developmental Theory. *Child Development*, *69*(1), 1–12. https://doi.org/10.1111/j.1467-8624.1998.tb06128.x

Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). The Emergence and Development of Life Course Theory. *Handbook of the Life Course*, 3–19. https://doi.org/10.1007/978-0-306-48247-2_1

Elder, J. P., Lytle, L., Sallis, J. F., Young, D. R., Steckler, A., Simons-Morton, D., … Ribisl, K. (2007). A description of the social-ecological framework used in the trial of activity for adolescent girls (TAAG). *Health Education Research*, *22*(2), 155–165. https://doi.org/10.1093/her/cyl059

Elder Jr., G. H. (1994). Time, human agency, and social change : Perspectives on the Life Course. *Social Psychology Quarterly*, *57*(1), 4–15.

Ellsberg, M., Arango, D. J., Morton, M., Gennari, F., Kiplesund, S., Contreras, M., & Watts, C. (2015). Prevention of violence against women and girls: What does the evidence say? *The Lancet*, *385*(9978), 1555–1566. https://doi.org/10.1016/S0140-6736(14)61703-7

Evans, R., Widman, L., Kamke, K., & Stewart, J. L. (2020). Gender Differences in

Parents' Communication With Their Adolescent Children about Sexual Risk and Sex-Positive Topics. *Journal of Sex Research*, *57*(2), 177–188. https://doi.org/10.1080/00224499.2019.1661345

Evers, J. C. (2016). Elaborating on Thick Analysis: About Thoroughness and Creativity in Qualitative Analysis. *Forum: Qualitative Social Research*, *1*(Art 6).

Faludi, C., & Rada, C. (2019). Gender differences in sexual and reproductive health education in the family: A mixed methods study on Romanian young people. *BMC Public Health*, *19*(1103), 1–13. https://doi.org/10.1186/s12889-019-7321-0

Ferrand, R. A., Munaiwa, L., Matsekete, J., Bandason, T., Nathoo, K., Ndhlovu, C. E., … Corbett, E. L. (2010). Undiagnosed HIV infection among adolescents seeking primary health care in Zimbabwe. *Clinical Infectious Diseases*, *51*, 844–851. https://doi.org/10.1086/656361

Forbat, L., & Henderson, J. (2003). "Stuck in the middle with you": The ethics and process of qualitative research with two people in an intimate relationship. *Qualitative Health Research*, *13*(10), 1453–1462. https://doi.org/10.1177/1049732303255836

Francis, S. C., Mthiyane, T. N., Baisley, K., Mchunu, S. L., Ferguson, J. B., Smit, T., … Shahmanesh, M. (2018). Prevalence of sexually transmitted infections among young people in South Africa: A nested survey in a health and demographic surveillance site. *PLoS Medicine*, *15*(2), 1–25. https://doi.org/10.1371/journal.pmed.1002512

Garba, S. M., Lubuma, J. M. S., & Tsanou, B. (2020). Modeling the transmission dynamics of the COVID-19 Pandemic in South Africa. *Mathematical Biosciences*, *328*(108441), 1–14. https://doi.org/10.1016/j.mbs.2020.108441

Garthe, R. C., Sullivan, T. N., & Gorman-Smith, D. (2019). The Family Context and Adolescent Dating Violence: A Latent Class Analysis of Family Relationships and Parenting Behaviors. *Journal of Youth and Adolescence*, *48*, 1418–1432. https://doi.org/10.1007/s10964-019-01051-w

Geertz, C. (1973). *The interpretation of cultures: selected essays*. New York: Basic Books Inc. https://doi.org/10.4324/9781912128310

Gevers, A., Jewkes, R., Mathews, C., & Flisher, A. (2012). “I think it’s about experiencing, like, life”: A qualitative exploration of contemporary adolescent intimate relationships in South Africa. *Culture, Health and Sexuality*, *14*(10), 1125–1137. https://doi.org/10.1080/13691058.2012.723752

Gibbs, A., Jewkes, R., Willan, S., & Washington, L. (2018). Associations between poverty, mental health and substance use, gender power, and intimate partner violence amongst young (18-30) women and men in urban informal settlements in South Africa: A cross-sectional study and structural equation model. *PLoS ONE*, *13*(10), 1–19. https://doi.org/10.1371/journal.pone.0204956

Gillespie, S., Kadiyala, S., & Greener, R. (2007). Is poverty or wealth driving HIV transmission? *Aids*, *21*(Suppl 7), S5–S16. https://doi.org/10.1097/01.aids.0000300531.74730.72

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster inc.

Gombachika, B. C., Fjeld, H., Chirwa, E., Sundby, J., Malata, A., & Maluwa, A. (2012). A Social Ecological Approach to Exploring Barriers to Accessing Sexual and Reproductive Health Services among Couples Living with HIV in Southern Malawi. *ISRN Public Health*, *2012*, 1–13. https://doi.org/10.5402/2012/825459

Goodman, C. C. (2012). Caregiving grandmothers and their grandchildren: Well-being nine years later. *Children and Youth Services Review*, *34*(4), 648–654. https://doi.org/10.1016/j.childyouth.2011.12.009

Gray, D. E. (2009). *Doing Research in the Real World* (2nd Editio). Thousand Oaks: SAGE Publications Inc. https://doi.org/10.1177/1350507607083204

Guba, E. ., & Lincoln, Y. . (1994). *Competing Paradigms in Qualitative Research. In N.K. Denzin & Y.S. Lincoln (Eds.), Handbook of qualitative research*. Thousand

Oaks: Sage.

Guilleminault, L., Williams, E. J., Scott, H. A., Berthon, B. S., Jensen, M., & Wood, L. G. (2017). Diet and asthma: Is it time to adapt our message? *Nutrients*, *9*(1227), 1–25. https://doi.org/10.3390/nu9111227

Gumede, D., Ngwenya, N. B., Namukwaya, S., Bernays, S., & Seeley, J. (2019). A reflection on ethical and methodological challenges of using separate interviews with adolescent-older carer dyads in rural South Africa. *BMC Medical Ethics*, *20*(47), 1–12. https://doi.org/10.1186/s12910-019-0383-9

Gumede, N. A., Young-Hauser, A. M., & Coetzee, J. K. (2017). Mother-daughter communication on intimate relationships: Voices from a township in Bloemfontein, South Africa. *Qualitative Sociology Review*, *13*(1), 228–244.

Gyan, S. E. (2018). Passing as “Normal”: Adolescent Girls’ Strategies for Escaping Stigma of Premarital Sex and Childbearing in Ghana. *SAGE Open*, 1–8. https://doi.org/10.1177/2158244018801421

Hall, K. (2019). *Demography of South Africa’s children. In South African Child Gauge*.

Hall, K. S., Manu, A., Morhe, E., Dalton, V. K., Challa, S., Loll, D., … Harris, L. H. (2018). Bad girl and unmet family planning need among Sub-Saharan African adolescents: the role of sexual and reproductive health stigma. *Qual Res Med Healthc*, *2*(1), 55–64. https://doi.org/10.4081/qrmh.2018.7062

Hayslip, B., & Kaminski, P. L. (2005). Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist*, *45*(2), 262–269. https://doi.org/10.1093/geront/45.2.262

Heim, C., Shugart, M., Craighead, W. E., & Nemeroff, C. B. (2010). Neurobiological and psychiatric consequences of child abuse and neglect. *Developmental Psychobiology*, *52*(7), 671–690. https://doi.org/10.1002/dev.20494

HelpAge International. (2011a). *Intergenerational issues between older caregivers and children in the context of AIDS in eastern and southern Africa*.

HelpAge International. (2011b). *Psychosocial care and support for older carers of orphaned and vulnerable children: Policy guidelines*. Nairobi. Retrieved from www.helpage.org

HelpAge International. (2020). *Social protection for older people during COVID-19 and beyond*. London.

Herbst, K., Law, M., Geldsetzer, P., Tanser, F., Harling, G., & Bärnighausen, T. (2015). Innovations in health and demographic surveillance systems to establish the causal impacts of HIV policies. *Current Opinion in HIV and AIDS*, *10*(6), 483–494. https://doi.org/10.1097/COH.0000000000000203

Hertz, R. (1995). Separate But Simultaneous Interviewing of Husbands and Wives: Making Sense of Their Stories. *Qualitative Inquiry*, *1*(4), 429–451. https://doi.org/10.1177/107780049500100404

Hesse-Biber, S. J., & Leavy, P. L. (2011). *The practice of qualitative research* (2nd ed.). Thousand Oaks: Sage.

Hodgson, T. F., & Khumalo, S. (2016). *Too many children left behind: Exclusion in the South African Inclusive Education System With a focus on the Umkhanyakude District, KwaZulu-Natal*. Durban.

Hoenayi, R. K., & Yendork, J. S. (2018). “I Wouldn’t Say We Were Treated Equally”: Experiences of Young Adult Stepchildren in the Ghanaian Context. https://doi.org/10.1080/10502556.2018.1466250

Hosegood, V., Preston-Whyte, E., Busza, J., Moitse, S., & Timaeus, I. M. (2007). Revealing the full extent of households’ experiences of HIV and AIDS in rural South Africa. *Social Science and Medicine*, *65*(6), 1249–1259. https://doi.org/10.1016/j.socscimed.2007.05.002

Huggett, C., Birtel, M. D., Awenat, Y. F., Fleming, P., Wilkes, S., Williams, S., & Haddock, G. (2018). A qualitative study: experiences of stigma by people with mental health problems. *Psychology and Psychotherapy: Theory, Research and Practice*, *91*(3), 380–397. https://doi.org/10.1111/papt.12167

Hutchinson, M. K., & Cederbaum, J. A. (2011). Talking to daddy's little girl about sex: Daughters' reports of sexual communication and support from fathers. *Journal of Family Issues*, *32*(4), 550–572. https://doi.org/10.1177/0192513X10384222

Hutchison, E. D. (2010). A Life Course Perspective. *Dimensions of Human Behavior: The Changing Life Course*, 1–38. https://doi.org/10.1016/j.socscimed.2011.09.014

Igras, S. M., Macieira, M., Murphy, E., & Lundgren, R. (2014). Investing in very young adolescents' sexual and reproductive health. *Global Public Health*, *9*(5), 555–569. https://doi.org/10.1080/17441692.2014.908230

Ince, L. (2009). Kinship care : an afrocentric perspective, (April).

Ingersoll-Dayton, B., Punpuing, S., Tangchonlatip, K., & Yakas, L. (2018). Pathways to grandparents' provision of care in skipped-generation households in Thailand. *Ageing and Society*, *38*(7), 1429–1452. https://doi.org/10.1017/S0144686X17000058

Jennings, L., Mathai, M., Linnemayr, S., Trujillo, A., Mak'anyengo, M., Montgomery, B. E. E., & Kerrigan, D. L. (2017). Economic Context and HIV Vulnerability in Adolescents and Young Adults Living in Urban Slums in Kenya: A Qualitative Analysis Based on Scarcity Theory. *AIDS and Behavior*, *21*(9), 2784–2798. https://doi.org/10.1007/s10461-017-1676-y

Jerves, E., López, S., Castro, C., Ortiz, W., Palacios, M., Rober, P., & Enzlin, P. (2014). Understanding parental views of adolescent sexuality and sex education in Ecuador: A qualitative study. *Sex Education*. Taylor & Francis. https://doi.org/10.1080/14681811.2013.814034

Jewkes, R., & Morrell, R. (2012). Sexuality and the limits of agency among South African teenage women: Theorising femininities and their connections to HIV risk practises. *Social Science and Medicine*, *74*(11), 1729–1737. https://doi.org/10.1016/j.socscimed.2011.05.020

Jiang, H., Zhou, Y., & Tang, W. (2020). Maintaining HIV care during the COVID-19 pandemic. *The Lancet HIV*, 1–2. https://doi.org/10.1016/S2352-3018(20)30105-3

Johnson, M. K., Crosnoe, R., & Elder Jr., G. H. (2011). Insights on adolescence from a life course perspective. *J Res Adolesc*, *21*(1), 273–280. https://doi.org/10.1111/j.1532-7795.2010.00728.x.

Johnson, S., & Wolke, D. (2013). Behavioural outcomes and psychopathology during adolescence. *Early Human Development*, *89*, 199–207. https://doi.org/10.1016/j.earlhumdev.2013.01.014

Jonas, K., Duby, Z., Maruping, K., Dietrich, J., Slingers, N., Harries, J., … Mathews, C. (2020). Perceptions of contraception services among recipients of a combination HIV-prevention interventions for adolescent girls and young women in South Africa: A qualitative study. *Reproductive Health*, *17*(1), 1–14. https://doi.org/10.1186/s12978-020-00970-3

Jones, R. A., Utz, S. W., Williams, I. C., Hinton, I., Alexander, G., Moore, C., … Oliver, N. (2008). Family interactions among African Americans diagnosed with Type 2 Diabetes. *Diabetes Educ*, *34*(2), 318–326. https://doi.org/10.1177/0145721708314485.

Kagesten, A., Gibbs, S., Blum, R. W., Moreau, C., Chandra-Mouli, V., & Amin, A. (2016). Understanding Factors that Shape Gender Attitudes in Early Adolescence Globally: A Mixed-Methods Systematic Review. *PLoS ONE*, *11*(6), 1–36. https://doi.org/10.1371/journal.pone.0157805

Kajula, L. J., Sheon, N., Vries, H. De, Kaaya, S. F., & Aarø, L. E. (2014). Dynamics of parent-adolescent Communication on sexual health and HIV/AIDS in Tanzania. *AIDS and Behavior*, *18*(SUPPL. 1). https://doi.org/10.1007/s10461-013-0634-6

Kalichman, S. C., Simbayi, L. C., Cloete, A., Mthembu, P. P., Mkhonta, R. N., & Ginindza, T. (2009). Measuring AIDS stigmas in people living with HIV/AIDS: The Internalized AIDS-Related Stigma Scale. *AIDS Care*, *21*(1), 87–93. https://doi.org/10.1080/09540120802032627

Kalichman, S. C., Simbayi, L. C., Kaufman, M., Cain, D., & Jooste, S. (2007). Alcohol use and sexual risks for HIV/AIDS in Sub-Saharan Africa: Systematic review of empirical findings. *Prevention Science*, *8*, 141–151. https://doi.org/10.1007/s11121-006-0061-2

Kanku, T., & Mash, R. (2010). Attitudes, perceptions and understanding amongst teenagers regarding teenage pregnancy, sexuality and contraception in Taung. *South African Family Practice*, *52*(6), 563–572. https://doi.org/10.1080/20786204.2010.10874048

Karp, C., Wood, S. N., Galadanci, H., Kibira, S. P. S., Makumbi, F., Omoluabi, E., … Moreau, C. (2020). ‘I am the master key that opens and locks’: Presentation and application of a conceptual framework for women’s and girls’ empowerment in reproductive health. *Social Science and Medicine*, *258*(113086), 1–11. https://doi.org/10.1016/j.socscimed.2020.113086

Kasedde, S., Doyle, A. M., Seeley, J. A., & Ross, D. A. (2014). They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic. *Social Science & Medicine*, *113*, 161–168. https://doi.org/10.1016/j.socscimed.2014.05.002

Kassa, G. M., Arowojolu, A. O., Odukogbe, A. A., & Yalew, A. W. (2018). Prevalence and determinants of adolescent pregnancy in Africa: a systematic review and Meta-analysis. *Reproductive Health*, *15*(195), 1–17. https://doi.org/10.1186/s12978-018-0640-2

Kaufman, C. E., & Stavrou, S. E. (2004). “Bus fare please”: The economics of sex and gifts among young people in urban South Africa. *Culture, Health and Sexuality*, *6*(5), 377–391. https://doi.org/10.1080/13691050410001680492

Kawulich, B. B. (2005). Participant Observation as a Data Collection Method. *Forum: Qualitative Social Research*, *6*(2).

Kaye, D. K. (2008). Negotiating the transition from adolescence to motherhood: Coping with prenatal and parenting stress in teenage mothers in Mulago hospital, Uganda. *BMC Public Health*, *8*(1), 83. https://doi.org/10.1186/1471-2458-8-83

Kelley, S. J., Whitley, D. M., & Campos, P. E. (2011). Behavior problems in children raised by grandmothers: The role of caregiver distress, family resources, and the home environment. *Children and Youth Services Review*, *33*, 2138–2145. https://doi.org/10.1016/j.childyouth.2011.06.021

Kilanowski, J. F. (2017). Breadth of the Socio-Ecological Model. *Journal of Agromedicine*, *22*(4), 295–297. https://doi.org/10.1080/1059924X.2017.1358971

Kirby, D. B., Laris, B. A., & Rolleri, L. A. (2007). Sex and HIV Education Programs: Their Impact on Sexual Behaviors of Young People Throughout the World. *Journal of Adolescent Health*, *40*, 206–217. https://doi.org/10.1016/j.jadohealth.2006.11.143

Knight, L., Hosegood, V., & Timaeus, I. M. (2016). Obligation to family during times of transition: care, support and the response to HIV and AIDS in rural South Africa. *AIDS Care*, *28*(Sup4), 18–29. https://doi.org/10.1080/09540121.2016.1195486

Kolling, M., Rasmussen, T., & Oxlund, B. (2017). Of “bad behaviour” and “dangerous sex”: moral responses to the threat of HIV/AIDS among children and youth in rural Burundi. *MOJ Public Health*, *5*(4), 122–130. https://doi.org/10.15406/mojph.2017.05.00136

Kuo, C., Atujuna, M., Mathews, C., Stein, D. J., Hoare, J., Beardslee, W., … K Brown, L. (2016). Developing family interventions for adolescent HIV prevention in South Africa. *AIDS Care*, *28*(sup1), 106–110. https://doi.org/10.1080/09540121.2016.1146396

Kuo, C., & Operario, D. (2010). Caring for AIDS-orphaned children: an exploratory study of challenges faced by carers in KwaZulu-Natal, South Africa. *Vulnerable Children Youth Studies*, *5*(4), 344–352. https://doi.org/10.1080/17450128.2010.516372

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. https://doi.org/10.1080/09540121.2011.554527

Lachman, J., Cluver, L., Boyes, M., Kuo, C., & Casale, M. (2014). Positive parenting for positive parents: HIV/AIDS, poverty, caregiver depression, child behavior and parenting in South Africa. *AIDS Care*, *26*(3), 304–313. https://doi.org/10.1080/09540121.2013.825368.Positive

Landor, A., Simons, L. G., Simons, R. L., Brody, G. H., & Gibbons, F. X. (2011). The Role of Religiosity in the Relationship Between Parents, Peers, and Adolescent Risky Sexual Behavior. *Journal of Youth and Adolescence*, *40*(3), 296–309. https://doi.org/10.1007/s10964-010-9598-2

Leclerc-Madlala, S. (2008). Age-disparate and intergenerational sex in southern Africa: The dynamics of hypervulnerability. *Aids*, *22*(Suppl 4), S17–S25. https://doi.org/10.1097/01.aids.0000341774.86500.53

LeCompte, M. D., & Goetz, J. P. (2008). Ethnographic Data Collection in Evaluation Research. *Educational Evaluation and Policy Analysis*, *4*(3), 387–400. https://doi.org/10.3102/01623737004003387

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park: Sage Publications.

Lloyd-Sherlock, P., Ebrahim, S., Geffen, L., & McKee, M. (2020). Bearing the brunt of covid-19: Older people in low and middle income countries. *The BMJ*, *368*, 1–2. https://doi.org/10.1136/bmj.m1052

Loeliger, K. B., Niccolai, L. M., Mtungwa, L. N., Moll, A., & Shenoi, S. V. (2016). “I have to push him with a wheelbarrow to the clinic”: Community health workers’ roles, needs, and strategies to improve HIV care in rural South Africa. *AIDS Patient Care and STDs*, *30*(8), 385–394. https://doi.org/10.1089/apc.2016.0096

Luke, N. (2005). Confronting the “Sugar Daddy” Stereotype : Age and Economic Asymmetries and Risky Sexual Behavior in Urban Kenya. *International Family Planning Perspectives*, *31*(1), 6–14.

Luttik, M. L., Jaarsma, T., Moser, D., Sanderman, R., & van Veldhuisen, D. J. (2005). The importance and impact of social support on outcomes in patients with heart failure: An overview of the literature. *Journal of Cardiovascular Nursing*, *20*(3), 162–169. https://doi.org/10.1097/00005082-200505000-00007

Mafigiri, R., Matovu, J. K. B., Makumbi, F. E., Ndyanabo, A., Nabukalu, D., Sakor, M., … Wanyenze, R. K. (2017). HIV prevalence and uptake of HIV/AIDS services among youths (15-24 Years) in fishing and neighboring communities of Kasensero, Rakai District, South Western Uganda. *BMC Public Health*, *17*(1), 1–10. https://doi.org/10.1186/s12889-017-4166-2

Maguire, M. C. (1999). Treating the Dyad as the Unit of Analysis: A Primer on Three Analytic Approaches. *Journal of Marriage and the Family*, *61*(1), 213–223. https://doi.org/10.2307/353895

Maharaj, P. (2000). Promoting male involvement in reproductive health. *Agenda*, *16*(44), 37–47. https://doi.org/10.2307/4066433

Maina, B. W., Orindi, B. O., Sikweyiya, Y., & Kabiru, C. W. (2020). Gender norms about romantic relationships and sexual experiences among very young male adolescents in Korogocho slum in Kenya. *International Journal of Public Health*, *65*(4), 497–506. https://doi.org/10.1007/s00038-020-01364-9

Makiwane, M. (2010). *The changing patterns of Intergenerational Relations in South Africa*.

Maree, K. (2016). *First steps in research* (2nd ed.). Pretoria: Van Schaik.

Marshall, M. (1996). The key informant technique. *Family Practice*, *13*(1), 92–97.

Marshall, P. A. (2007). *Ethical challenges in study design and informed consent for health research in resource-poor settings*.

Mason, S., & Sultzman, V. O. (2019). Stigma as experienced by children of HIV-positive parents: a narrative review. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *31*(9), 1049–1060. https://doi.org/10.1080/09540121.2019.1573968

Mathews, C., Eggers, S. M., De Vries, P. J., Mason-Jones, A. J., Townsend, L., Aarø,

L. E., & De Vries, H. (2015). Reaching the hard to reach: longitudinal investigation of adolescents’ attendance at an after-school sexual and reproductive health programme in Western Cape, South Africa. *BMC Public Health*, *15*(608), 1–12. https://doi.org/10.1186/s12889-015-1963-3

Matovu, S., & Wallhagen, M. (2018). Loss as Experienced by Ugandan Grandparent-Caregivers of Children Affected by HIV/AIDS. *Journal of Loss and Trauma*, *23*(6), 502–515. https://doi.org/10.1080/15325024.2018.1482105

Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M., & Bradshaw, D. (2009). The burden of non-communicable diseases in South Africa. *The Lancet*, *374*(9693), 934–947. https://doi.org/10.1016/S0140-6736(09)61087-4

Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Iorpenda, K., & Ferguson, L. (2014). Responding to adolescents living with HIV in Zambia: A social-ecological approach. *Children and Youth Services Review*. https://doi.org/10.1016/j.childyouth.2014.03.033

Mcgrath, N., Nyirenda, M., Hosegood, V., & Newell, M.-L. (2009). Age at first sex in rural South Africa. *Sex Transm Infect*, *85*(Suppl 1), i49–i55. https://doi.org/10.1136/sti.2008.033324

McGuigan, W. M., & Pratt, C. C. (2001). The predictive impact of domestic violence on three types of child maltreatment. *Child Abuse and Neglect*, *25*(7), 869–883. https://doi.org/10.1016/S0145-2134(01)00244-7

McKee, A., Watson, A.-F., & Dore, J. (2014). ‘It‘s all scientific to me’: focus group insights into why young people do not apply safe-sex knowledge. *Sex Education*, *14*(6), 652–665. https://doi.org/10.1080/14681811.2014.917622

Meinhart, M., Seff, I., Darmstadt, G. L., Weber, A. M., & Stark, L. (2020). Attitudinal Acceptance of Intimate Partner Violence Among Adolescents and Young Adults in Nigeria and Tanzania: An Exploration Into Target Reference Groups Order and Affiliation of Authorship. *Journal of Adolescent Health*, *66*, S3–S8. https://doi.org/10.1016/j.jadohealth.2019.10.006

Mejia-Pailles, G., Berrington, A., Seeley, J., McGrath, N., & Hosegood, V. (2017). Children and adolescents living with disability in a high HIV prevalence area in rural South Africa. *IUSSP*, 1–7.

Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation* (4th ed.). San Francisco: Jossey-Bass.

Mgwaba, T., & Maharaj, P. (2018). Unpacking the practice of ukujola in contemporary South Africa: understanding informal/casual sexual relations of young African adults in the context of HIV and AIDS. *African Journal of AIDS Research*, *17*(4), 341–351. https://doi.org/10.2989/16085906.2018.1544573

Mkhwanazi, N., Makusha, T., Blackie, D., Manderson, L., Hall, K., & Huijbregts, M. (2018). *Negotiating the care of children and support for caregivers. In South African Child Gauge*.

Monserud, M. A. (2008). Intergenerational relationships and affectual solidarity between grandparents and young adults. *Journal of Marriage and Family*, *70*(1), 182–195. https://doi.org/10.1111/j.1741-3737.2007.00470.x

Morris, S. M. (2001). Joint and individual interviewing in the context of cancer. *Qualitative Health Research*, *11*(4), 553–567.

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, *25*(9), 1212–1222. https://doi.org/10.1177/1049732315588501

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, *1*(2), 13–22. https://doi.org/10.1177/160940690200100202

Mottiar, S., & Lodge, T. (2018). The role of community health workers in supporting South Africa’s HIV/ AIDS treatment programme. *African Journal of AIDS Research*, *17*(1), 54–61. https://doi.org/10.2989/16085906.2017.1402793

Muchiri, E., Odimegwu, C., & De Wet, N. (2017). South Africa: a cumulative risk analysis. *Southern African Journal of Infectious Diseases*, *32*(3), 105–110. https://doi.org/10.1080/23120053.2017.1332800

Mudege, N. N., & Ezeh, A. C. (2009). Gender, aging, poverty and health: Survival strategies of older men and women in Nairobi slums. *Journal of Aging Studies*, *23*, 245–257. https://doi.org/10.1016/j.jaging.2007.12.021

Mugisha, J., Schatz, E. J., Randell, M., Kuteesa, M., Kowal, P., Negin, J., & Seeley, J. (2016). Chronic disease, risk factors and disability in adults aged 50 and above living with and without HIV: findings from the Wellbeing of Older People Study in Uganda. *Global Health Action*, *9*(1), 31098. https://doi.org/10.3402/gha.v9.31098

Mugisha, J., Schatz, E., Seeley, J., & Kowal, P. (2015). Gender perspectives in care provision and care receipt among older people infected and affected by HIV in Uganda. *African Journal of AIDS Research*, *14*(2), 159–167. https://doi.org/10.2989/16085906.2015.1040805

Mugisha, J., Scholten, F., Owilla, S., Naidoo, N., Seeley, J., Chatterji, S., … Boerma, T. (2013). Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda. *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*. https://doi.org/10.1080/09540121.2013.765936

Muhanguzi, F. K. (2011). Gender and sexual vulnerability of young women in Africa: Experiences of young girls in secondary schools in Uganda. *Culture, Health and Sexuality*, *13*(6), 713–725. https://doi.org/10.1080/13691058.2011.571290

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. https://doi.org/10.1177/0164027510361829

Murphy, D. A., Roberts, K. J., & Hoffman, D. (2002). Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus. *Journal of Child and Family Studies*, *11*(2), 191–202. https://doi.org/10.1023/A:1015177609382

Murray, S. A., Kendall, M., Carduff, E., Worth, A., Harris, F., Lloyd, A., … Sheikh, A. (2009). Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ*, *339*, 1–7. https://doi.org/doi.org/10.1136/bmj.b3702

Nalugya, R., Russell, S., Zalwango, F., & Seeley, J. (2018). The role of children in their HIV-positive parents' management of antiretroviral therapy in Uganda. *African Journal of AIDS Research*, *17*(1), 37–46. https://doi.org/10.2989/16085906.2017.1394332

Neale, B., & Flowerdew, J. (2003). Time, texture and childhood: The contours of longitudinal qualitative research. *International Journal of Social Research Methodology: Theory and Practice*, *6*(3), 189–199. https://doi.org/10.1080/1364557032000091798

Newman, W. L. (1997). *Social research methods: quantitative and qualitative approaches*. Boston: Allyn & Bacon.

Newman, W. L. (2014). *Social Research Methods: Qualitative and Quantitative Approaches* (7th ed.). Essex: Pearson.

Ngabaza, S., Shefer, T., & Macleod, C. I. (2016). "Girls need to behave like girls you know": the complexities of applying a gender justice goal within sexuality education in South African schools. *Reproductive Health Matters*, *24*(48), 71–78. https://doi.org/10.1016/j.rhm.2016.11.007

Ngwenya, N., Gumede, D., Shahmanesh, M., McGrath, N., Grant, A., & Seeley, J. (2018). Community perceptions of the socio-economic structural context influencing HIV and TB risk, prevention and treatment in a high prevalence area in the era of antiretroviral therapy. *African Journal of AIDS Research*, *17*(1), 72–81. https://doi.org/10.2989/16085906.2017.1415214

Ngwenya, N., Nkosi, B., Mchunu, L. S., Ferguson, J., Seeley, J., & Doyle, A. M. (2020). Behavioural and socio-ecological factors that influence access and utilisation of health services by young people living in rural KwaZulu-Natal, South Africa: Implications for intervention. *PLoS ONE*, *15*(4), 1–15.

https://doi.org/10.1371/journal.pone.0231080

Ninsiima, A. B., Leye, E., Michielsen, K., Kemigisha, E., Nyakato, V. N., & Coene, G. (2018). “Girls have more challenges; they need to be locked up”: A qualitative study of gender norms and the sexuality of young adolescents in Uganda. *International Journal of Environmental Research and Public Health*, *15*(193), 1–16. https://doi.org/10.3390/ijerph15020193

Nkosi, B., Seeley, J., Ngwenya, N., Mchunu, S. L., Gumede, D., Ferguson, J., & Doyle, A. M. (2019). Exploring adolescents and young people ’ s candidacy for utilising health services in a rural district , South Africa. *BMC Health Services Research*, *19*(195), 1–12. https://doi.org//doi.org/10.1186/s12913-019-3960-1 (2019)

Nyanzi, S., Pool, R., & Kinsman, J. (2001). The negotiation of sexual relationships among school pupils in south-western Uganda. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *13*(1), 83–98. https://doi.org/10.1080/09540120020018206

Nyirenda, M., Newell, M. L., Mugisha, J., Mutevedzi, P. C., Seeley, J., Scholten, F., & Kowal, P. (2013). Health, wellbeing, and disability among older people infected or affected by HIV in Uganda and South Africa. *Global Health Action*, *6*(1), 19201. https://doi.org/10.3402/gha.v6i0.19201

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. https://doi.org/10.1007/s10823-010-9129-3

Okawa, S., Mwanza-Kabaghe, S., Mwiya, M., Kikuchi, K., Jimba, M., Kankasa, C., & Ishikawa, N. (2018). Sexual and reproductive health behavior and unmet needs among a sample of adolescents living with HIV in Zambia: A cross-sectional study. *Reproductive Health*, *15*(55), 1–10. https://doi.org/10.1186/s12978-018-0493-8

Pamungkas, R. A., Chamroonsawasdi, K., & Vatanasomboon, P. (2017). A systematic review: Family support integrated with diabetes self-management among uncontrolled type II diabetes mellitus patients. *Behavioral Sciences*, *7*(62), 1–17.

https://doi.org/10.3390/bs7030062

Pantelic, M., Casale, M., Cluver, L., Toska, E., & Moshabela, M. (2020). Multiple forms of discrimination and internalized stigma compromise retention in HIV care among adolescents: findings from a South African cohort. *Journal of the International AIDS Society*, *23*(e25488), 1–8. https://doi.org/10.1002/jia2.25488

Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Los Angeles: SAGE.

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., … Mellins, C. (2010). Sources of stress among police officials : a Qualitative Investigation. *AIDS Care*, *22*(8), 970–978. https://doi.org/10.1080/09540121003623693

Petroni, S., Steinhaus, M., Fenn, N. S., Stoebenau, K., & Gregowski, A. (2017). New Findings on Child Marriage in Sub-Saharan Africa. *Annals of Global Health*, *83*(5–6), 781–790. https://doi.org/10.1016/j.aogh.2017.09.001

Phillips, E. A., Comeau, D. L., Pisa, P. T., Stein, A. D., & Norris, S. A. (2016). Perceptions of diet, physical activity, and obesity-related health among black daughter-mother pairs in Soweto, South Africa: A qualitative study. *BMC Public Health*, *16*(750), 1–10. https://doi.org/10.1186/s12889-016-3436-8

Polak, L., & Green, J. (2016). Using joint interviews to add analytic value. *Qualitative Health Research*, *26*(12), 1638–1648. https://doi.org/10.1177/1049732315580103

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, *52*(2), 126–136. https://doi.org/10.1037/0022-0167.52.2.126

Ponterotto, J. G. (2006). Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The Qualitative Report*, *11*(3), 538–549.

Reeves, S., Kuper, A., & Hodges, B. D. (2008). Qualitative research methodologies: ethnography. *British Medical Journal*, *337*(7668), 512–514.

https://doi.org/10.1136/bmj.alO20

Reyland, S. A., Higgins-D’Alessandro, A., & McMahon, T. J. (2002). Tell them you love them because you never know when things could change: Voices of adolescents living with HIV-positive mothers. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *14*(2), 285–294. https://doi.org/10.1080/09540120120076977

Reynolds, Z., Gottert, A., Luben, E., Mamba, B., Shabangu, P., Dlamini, N., … Pulerwitz, J. (2018). Who are the male partners of adolescent girls and young women in Swaziland? Analysis of survey data from community venues across 19 DREAMS districts. *PLoS ONE*, *13*(9), 1–13. https://doi.org/10.1371/journal.pone.0203208

Richter, L. M., Sherr, L., Adato, M., Belsey, M., Chandan, U., Desmond, C., … Wakhweya, A. (2009). Strengthening families to support children affected by HIV and AIDS. *AIDS Care*, *21*(S1), 3–12. https://doi.org/10.1080/09540120902923121

Ritchwood, T. D., Penn, D., Peasant, C., & Albritton, T. (2017). Condom Use Self-Efficacy Among Younger Rural Adolescents: The Influence of Parent-Teen Communication, and Knowledge of and Attitudes Toward Condoms. *Journal of Early Adolescence*, *37*(2), 267–283. https://doi.org/10.1177/0272431615599065

Rochat, T. J., Bland, R., Coovadia, H., Stein, A., & Newell, M.-L. (2011). Towards a family-centered approach to HIV treatment and care for HIV-exposed children, their mothers and their families in poorly resourced settings. *Future Virol*, *6*(6), 687–696.

Rochat, T. J., Mitchell, J., Stein, A., Mkwanazi, N. B., & Bland, R. M. (2016). The Amagugu Intervention: A Conceptual Framework for Increasing HIV Disclosure and Parent-Led Communication about Health among HIV-Infected Parents with HIV-Uninfected Primary School-Aged Children. *Frontiers in Public Health*, *4*(183), 1–12. https://doi.org/10.3389/fpubh.2016.00183

Rochat, T. J., Mkwanazi, N., & Bland, R. (2013). Maternal HIV disclosure to HIV-uninfected children in rural South Africa: A pilot study of a family-based intervention. *BMC Public Health*, *13*(147), 1–16. https://doi.org/10.1186/1471-2458-13-147

Rogers, A. A., Ha, T., Stormshak, E. A., & Dishion, T. J. (2015). Quality of Parent-Adolescent Conversations about Sex and Adolescent Sexual Behavior: An Observational Study. *J Adolesc Health*, *57*(2), 174–178. https://doi.org/10.1016/j.jadohealth.2015.04.010

Roos, V., Silvestre, S., & De Jager, T. (2017). Intergenerational Care Perceptions of Older Women and Middle Adolescents in a Resource-Constrained Community in South Africa. *Journal of Gerontological Social Work*, *60*(2), 104–119. https://doi.org/10.1080/01634372.2016.1268231

Rosland, A.-M., Heisler, M., Choi, H., Silveira, M. J., & Piette, J. D. (2010). Family influences on self-management among functionally independent adults with diabetes or heart Failure: Do family members hinder as much as they help? *Chronic Illn*, *6*(1), 22–33. https://doi.org/10.1177/1742395309354608.

Rubin, A., & Babbie, E. . (1993). *Research methods for social work* (2nd ed.). Carlifonia: Brooks.

Russell, Steve, Martin, F., Zalwango, F., Namukwaya, S., Nalugya, R., Muhumuza, R., … Seeley, J. (2016). Finding meaning: HIV self-management and wellbeing among people taking antiretroviral therapy in Uganda. *PLoS ONE*, *11*(1), 1–16. https://doi.org/10.1371/journal.pone.0147896

Russell, Steven, & Seeley, J. (2010). The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. *Social Science & Medicine*, *70*, 375–382. https://doi.org/10.1016/j.socscimed.2009.10.039

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*, 2120–2134. https://doi.org/10.3390/ijerph120202120

Ruzibiza, Y. (2020). ‘They are a shame to the community … ’ stigma, school attendance, solitude and resilience among pregnant teenagers and teenage mothers in Mahama refugee camp, Rwanda. *Global Public Health*, 1–13. https://doi.org/10.1080/17441692.2020.1751230

Saldana, J. (2003). *Longitudinal qualitative research: Analyzing change through time*. New York: AltaMira.

Saul, J., Bachman, G., Allen, S., Toiv, N. F., Cooney, C., & Beamon, T. (2018). The DREAMS core package of interventions: A comprehensive approach to preventing HIV among adolescent girls and young women. *Plos One*, *13*(12), e0208167. https://doi.org/10.1371/journal.pone.0208167

Scaglioni, S., De Cosmi, V., Ciappolino, V., Parazzini, F., Brambilla, P., & Agostoni, C. (2018). Factors influencing children’s eating behaviours. *Nutrients*, *10*(706), 1–17. https://doi.org/10.3390/nu10060706

Schatz, E. J. (2007). “Taking care of my own blood ”: Older women’s relationships to their households in rural South Africa1. *Scand J Public Health Suppl*, *69*, 147–154. https://doi.org/10.1080/14034950701355676.

Schatz, E. J., & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health: An International Journal for Research, Policy and Practice*, 1–18. https://doi.org/10.1080/17441692.2015.1035664

Schatz, E., Madhavan, S., Collinson, M., Gomez-Olive, F., & Ralston, M. (2015). Dependent or Productive? A New Approach to Understanding the Social Positioning of Older South Africans Through Living Arrangements. *Research on Aging*, *37*(6), 581–605. https://doi.org/10.1177/0164027514545976

Scholten, F., Mugisha, J., Seeley, J., Kinyanda, E., Nakubukwa, S., Kowal, P., … Grosskurth, H. (2011). Health and functional status among older people with HIV / AIDS in Uganda. *BMC Public Health*, *11*(886), 1–10.

Schoon, I., & Heckhausen, J. (2019). Conceptualizing Individual Agency in the

Transition from School to Work: A Social-Ecological Developmental Perspective. *Adolescent Research Review*, *4*(2), 135–148. https://doi.org/10.1007/s40894-019-00111-3

Schriver, B., Meagley, K., Norris, S., Geary, R., & Stein, A. D. (2014). Young people's perceptions of youth-oriented health services in urban Soweto, South Africa: A qualitative investigation. *BMC Health Services Research*, *14*(625), 1–7. https://doi.org/10.1186/s12913-014-0625-y

Schulman-Green, D., Feder, S. L., Dionne-Odom, J. N., Batten, J., En Long, V. J., Harris, Y., … Whittemore, R. (2020). Family Caregiver Support of Patient Self-Management During Chronic, Life-Limiting Illness: A Qualitative Metasynthesis. *Journal of Family Nursing*, 1–18. https://doi.org/10.1177/1074840720977180

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., … Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, *44*(2), 136–144. https://doi.org/10.1111/j.1547-5069.2012.01444.x.Processes

Seale, C., Charteris-Black, J., Dumelow, C., Locock, L., & Ziebland, S. (2008). The effect of joint interviewing on the performance of gender. *Field Methods*, *20*(2), 107–128. https://doi.org/10.1177/1525822X07313837

Seif, S. A., Kohi, T. W., & Moshiro, C. S. (2019). Sexual and reproductive health communication intervention for caretakers of adolescents: A quasi-experimental study in Unguja-Zanzibar. *Reproductive Health*, *16*(92). https://doi.org/10.1186/s12978-019-0756-z

Seif, S. A., Thecla, W., & Moshiro, C. S. (2018). Caretaker-adolescent communication on sexual and reproductive health : a cross- sectional study in Unguja-Tanzania Zanzibar. *BMC Public Health*, *18*(31), 1–13. https://doi.org/10.1186/s12889-017-4591-2

Selikow, T.-A., Ahmed, N., Flisher, A. J., Mathews, C., & Mukoma, W. (2009). I am not "umqwayito": A qualitative study of peer pressure and sexual risk behaviour among young adolescents in Cape Town, South Africa. *Scandinavian Journal of*

Public Health, *37*(Suppl 2), 107–112. https://doi.org/10.1177/1403494809103903

Silva, D., Vilela, A., Nery, A., Duarte, A., Alves, M., & Meira, S. (2015). Dynamics of intergenerational family relationships from the viewpoint of elderly residents in the city of Jequié (Bahia), Brazil. *Ciência & Saúde Coletiva*, *20*(7), 2183–2191. https://doi.org/10.1590/1413-81232015207.17972014

Skovdal, M. (2010). Children caring for their caregivers: Exploring the caring arrangements in households affected by AIDS in Western Kenya. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *22*(1), 96–103. https://doi.org/10.1080/09540120903016537

Skovdal, M., & Cornish, F. (2015). *Qualitative Research for Development: A guide for practitioners*. UK: Practical Action Publishing. https://doi.org/10.3362/9781780448534

Skovdal, M., Ogutu, V. O., Aoro, C., & Campbell, C. (2009a). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya. *Social Science and Medicine*, *69*(4), 587–595. https://doi.org/10.1016/j.socscimed.2009.06.016

Skovdal, M., Ogutu, V. O. V. ., Aoro, C., & Campbell, C. (2009b). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya. *Social Science and Medicine*, *69*(4), 587–595. https://doi.org/10.1016/j.socscimed.2009.06.016

Solanki, G., Kelly, G., Cornell, J., Daviaud, E., & Geffen, L. (2019). Population ageing in South Africa: trends, impact, and challenge for the health sector. In T. Moeti & A. Padarath (Eds.), *South African Health Review 2019* (pp. 173–182). Durban: Health Systems Trust.

Soon, C. N., Kaida, A., Nkala, B., Dietrich, J., Cescon, A., Gray, G., … Miller, C. L. (2013). Adolescent experiences of HIV and sexual health communication with parents and caregivers in Soweto, South Africa. *Journal of Social Aspects of HIV/AIDS*, *10*(3–4), 163–169. https://doi.org/10.1080/17290376.2014.902769

South African National Department of Health. (2017). *South Africa's National Strategic Plan for HIV, TB and STIs 2017-2022*. Retrieved from http://sanac.org.za/2017/05/11/download-the-full-version-of-the-national-strategic-plan-for-hiv-tb-and-stis-2017-2022/

Ssewanyana, D., Mwangala, P. N., Marsh, V., Jao, I., van Baar, A., Newton, C. R., & Abubakar, A. (2018). Young people's and stakeholders' perspectives of adolescent sexual risk behavior in Kilifi County, Kenya: A qualitative study. *Journal of Health Psychology*, *23*(2), 188–205. https://doi.org/10.1177/1359105317736783

Statistics South Africa. (2018). *Grandparenthood in the context of ageing in South Africa*. Pretoria.

Statistics South Africa. (2019). *Statistical Release: General Household Survey 2018*. Pretoria. Retrieved from www.statssa.gov.zainfo@statssa.gov.za

Stats SA. (2015). *Patterns of morbidity and mortality among older persons in South Africa, 2013*. Retrieved from www.statssa.gov.za

Stephenson, R., Winter, A., & Elfstrom, M. (2013). Community environments shaping transectional sex among sexually active men inMalawi, Nigeria, and Tanzania. *AIDS Care*, *25*(6), 784–792. https://doi.org/10.1080/09540121.2012.748161

Suleiman, A. B., Galván, A., Harden, K. P., & Dahl, R. E. (2017). Becoming a sexual being: The 'elephant in the room' of adolescent brain development. *Developmental Cognitive Neuroscience*, *25*, 209–220. https://doi.org/10.1016/j.dcn.2016.09.004

Sun, F., Norman, I. J., & While, A. E. (2013). Physical activity in older people: a systematic review. *BMC Public Health*, *13*(449), 1–17.

Surmiak, A. (2018). Confidentiality in Qualitative Research Involving Vulnerable Participants: Researchers' Perspectives. *Forum: Qualitative Social Research*, *3*(12), 1–27. Retrieved from http://www.qualitative-research.net/

Sylvester, O. A. (2014). Influence of Self-Esteem, Parenting Style and Parental

Monitoring on Sexual Risk Behaviour of Adolescents in Ibadan. *Gender & Behaviour*, *12*(2), 6341–6353.

Tafere, Y. (2015). Intergenerational Relationships and the Life Course: Children-Caregivers’ Relations in Ethiopia. *Journal of Intergenerational Relationships*, *13*(4), 320–333. https://doi.org/10.1080/15350770.2015.1110511

Tan, J. P. (2018). Do grandparents matter? Intergenerational relationships between the closest grandparents and Malaysian adolescents. *Contemporary Social Science*, *13*(2), 246–260. https://doi.org/10.1080/21582041.2018.1424931

Tanser, F., Hosegood, V., Bärnighausen, T., Herbst, K., Nyirenda, M., Muhwava, W., … Newell, M. L. (2008). Cohort profile: Africa centre demographic information system (ACDIS) and population-based HIV survey. *International Journal of Epidemiology*, *37*(5), 956–962. https://doi.org/10.1093/ije/dym211

Taylor, B., & de Vocht, H. (2011). Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research*, *21*(11), 1576–1587. https://doi.org/10.1177/1049732311415288

The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1979). *The Belmont Report*. https://doi.org/10.1021/bi00780a005

Thomas, D. R. (2006). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, *27*(2), 237–246. https://doi.org/10.1177/1098214005283748

Thurman, T. R., Nice, J., Visser, M., & Luckett, B. G. (2020). Pathways to sexual health communication between adolescent girls and their female caregivers participating in a structured HIV prevention intervention in South Africa. *Social Science and Medicine*, *260*, 1–7. https://doi.org/10.1016/j.socscimed.2020.113168

Tolman, D. L. (2012). Female Adolescents, Sexual Empowerment and Desire: A Missing Discourse of Gender Inequity. *Sex Roles*, *66*(11–12), 746–757. https://doi.org/10.1007/s11199-012-0122-x

Triado, C., Feliciano, V., Sole, C., Osuna, M.-J., & Pinazo, S. (2005). The meaning of grandparenthood: Do adolescent grandchildren perceive the relationship and role in the same way as their grandparents do? *Journal of Intergenerational Relationships*, *3*(2), 101–121. https://doi.org/10.1300/J194v03n02_07

Tsala Dimbuene, Z., & Kuate Defo, B. (2011). Fostering accurate HIV/AIDS knowledge among unmarried youths in Cameroon: Do family environment and peers matter? *BMC Public Health*, *11*. https://doi.org/10.1186/1471-2458-11-348

Udlis, K. A. (2011). Self-management in chronic illness: concept and dimensional analysis. *Journal of Nursing and Healthcare of Chronic Illness*, *3*, 130–139. https://doi.org/10.1111/j.1752-9824.2011.01085.x

Umberson, D., Pudrovska, T., & Reczek, C. (2010). Parenthood, Childlessness, and Well-Being: A Life Course Perspective. *J Marriage Fam.*, *72*(3), 612–629. https://doi.org/10.1111/j.1741-3737.2010.00721.x.

Ummel, D., & Achille, M. (2016). How not to let secrets out when conducting qualitative research with dyads. *Qualitative Health Research*, *26*(6), 807–815. https://doi.org/10.1177/1049732315627427

UNAIDS. (2010). *Combination HIV Prevention: Tailoring and Coordinating Biomedical, Behavioural and Structural Strategies to Reduce New HIV Infections*. Geneva. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/JC2007_Combination_Prevention_paper_en.pdf.%5Cnhttp://www.unaids.org/sites/default/files/media_asset/JC2007_Combination_Prevention_paper_en_0.pdf

UNAIDS. (2016a). *Global AIDS Update 2016*. Geneva. https://doi.org/10.1097/00002030-199001001-00040

UNAIDS. (2016b). *Prevention Gap Report: UNAIDS*. Geneva.

UNAIDS. (2017). *Disability and HIV*. Geneva.

UNAIDS. (2018). *Global Factsheet: 2018*. *AIDSinfo*. Retrieved from https://aidsinfo.unaids.org/%0D

UNAIDS. (2020a). *Fact sheet: Global HIV Statistics*.

UNAIDS. (2020b). *Global AIDS Update 2020: Tackling entrenched inequalities to end epidemics*.

UNICEF. (2012). *Promoting community-based strategies for and with children and adolescents with disabilities*.

UNICEF. (2016). *For Every Child, End AIDS: Seventh Stocktaking Report*. New York. Retrieved from www.childrenandaids.org

UNICEF. (2020). *A New Era for Girls Contents: Taking stock of 25 years of progress*. New York. Retrieved from www.unicef.org/gender

United Nations. (2020). *Policy Brief: The Impact of COVID-19 on older persons*. Retrieved from https://apps.who.int/iris/handle/10665/186463

Valentine, G. (1999). Doing household research: interviewing couples together and apart. *Area*, *31*(1), 67–74.

van de Bongardt, D., Reitz, E., Sandfort, T., & Deković, M. (2015). A Meta-Analysis of the Relations Between Three Types of Peer Norms and Adolescent Sexual Behavior. *Personality and Social Psychology Review*, *19*(3), 203–234. https://doi.org/10.1177/1088868314544223

Van Houtum, L., Rijken, M., & Groenewegen, P. (2015). Do everyday problems of people with chronic illness interfere with their disease management? Chronic Disease epidemiology. *BMC Public Health*, *15*(1000), 1–9. https://doi.org/10.1186/s12889-015-2303-3

van Rooyen, H., Essack, Z., Rochat, T., Wight, D., Knight, L., Bland, R., & Celum, C. (2016). Taking HIV Testing to Families: Designing a Family-Based Intervention to Facilitate HIV Testing, Disclosure, and Intergenerational Communication. *Frontiers in Public Health*, *4*(154), 1–14. https://doi.org/10.3389/fpubh.2016.00154

Vilanculos, E., & Nduna, M. (2017). “The child can remember your voice”: parent–child communication about sexuality in the South African context. *African Journal of AIDS Research*, *16*(1), 81–89. https://doi.org/10.2989/16085906.2017.1302486

Vincent, K. A. (2013). The advantages of repeat interviews in a study with pregnant schoolgirls and schoolgirl mothers: piecing together the jigsaw. *International Journal of Research and Method in Education*, *36*(4), 341–354. https://doi.org/10.1080/1743727X.2012.705276

Voltelen, B., Konradsen, H., & Ostergaard, B. (2017). Ethical considerations when conducting joint interviews with close relatives or family: an integrative review. *Scand J Caring Sci*, 1–12. https://doi.org/10.1111/scs.12535

Vorster, C., Roos, V., & Beukes, M. (2013). A Psycho-Diagnostic Tool for Psychotherapy: Interactional Pattern Analysis (IPA). *Journal of Psychology in Africa*, *23*(3), 525–530. https://doi.org/10.1080/14330237.2013.10820663

Wagner, C., Kawulich, B. B., & Garner, M. (2012). *Doing social research: A global context*. Maidenhead: McGraw Hill.

Walker, J.-A. (2012). Early marriage in Africa -Trends, harmful effects and interventions. *African Journal of Reproductive Health*, *16*(2), 231–240.

Wamoyi, J., Fenwick, A., Urassa, M., Zaba, B., & Stones, W. (2010). Parent-child communication about sexual and reproductive health in rural Tanzania: Implications for young people’s sexual health interventions. *Reproductive Health*, *7*(1), 6. https://doi.org/10.1186/1742-4755-7-6

Wamoyi, J., Fenwick, A., Urassa, M., Zaba, B., & Stones, W. (2011). Parental control and monitoring of young people’s sexual behaviour in rural North-Western Tanzania: Implications for sexual and reproductive health interventions. *BMC Public Health*, *11*(1), 106. https://doi.org/10.1186/1471-2458-11-106

Wamoyi, J., Stobeanau, K., Bobrova, N., Abramsky, T., & Watts, C. (2016). Transactional sex and risk for HIV infection in sub-Saharan Africa: a systematic review and meta-analysis. *Journal of the International AIDS Society*, *19*(1), 20992. https://doi.org/10.7448/ias.19.1.20992

Wamoyi, J., Wight, D., Plummer, M., Mshana, G. H., & Ross, D. (2010). Transactional sex amongst young people in rural northern Tanzania: an ethnography of young women's motivations and negotiation. *Reproductive Health*, *7*(1), 2. https://doi.org/10.1186/1742-4755-7-2

Wamoyi, J., Wight, D., & Remes, P. (2015). The structural influence of family and parenting on young people's sexual and reproductive health in rural northern Tanzania. *Culture, Health & Sexuality*. Taylor & Francis. https://doi.org/10.1080/13691058.2014.992044

Weaver, K., & Olson, J. (2006). Understanding paradigms for nursing research. *Journal of Advanced Nursing*, *53*(4), 459–469. https://doi.org/10.1111/j.1365-2648.2006.03740.x

Weir, S. S., Pailman, C., Mahlalela, X., Coetzee, N., Meidany, F., & Boerma, J. T. (2003). From people to places: Focusing AIDS prevention efforts where it matters most. *Aids*, *17*(6), 895–903. https://doi.org/10.1097/00002030-200304110-00015

Werfalli, M., Kassanjee, R., Kalula, S., Kowal, P., Phaswana-Mafuya, N., & Levitt, N. S. (2018). Diabetes in South African older adults: prevalence and impact on quality of life and functional disability–as assessed using SAGE Wave 1 data. *Global Health Action*, *11*. https://doi.org/10.1080/16549716.2018.1449924

Westaway, M. S. (2009). The impact of chronic diseases on the health and well-being of South Africans in early and later old age. *Archives of Gerontology and Geriatrics*. https://doi.org/10.1016/j.archger.2009.03.012

WHO. (2002). *Innovative care for chronic conditions: building blocks for action: global report*.

WHO. (2007). *Helping parents in developing countries improve adolescents' health*.

WHO. (2011). *World report on disability.* https://doi.org/10.3109/09638288.2011.590392

WHO. (2013). *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV*. Geneva. Retrieved from www.who.int

WHO. (2017). *Global Accelerated Action for the Health of Adolescents (AA-HA!): Guidance to Support Country Implementation*. Geneva. Retrieved from http://www.who.int/maternal_child_adolescent/topics/adolescence/framework-accelerated-action/en. Accessed 17 May 2018

Widman, L., Bradley-Choukas, S., Noar, S. M., Nesi, J., & Garrett, K. (2017). Parent-Adolescent Sexual Communication and Adolescent Safer Sex Behavior: A Meta-Analysis. *JAMA Pediatr.*, *170*(1), 52–61. https://doi.org/10.1001/jamapediatrics.2015.2731

Wilson, E. K., & Koo, H. P. (2010). Mothers, fathers, sons, and daughters: Gender differences in factors associated with parent-child communication about sexual topics. *Reproductive Health*, *7*(31), 1–9. https://doi.org/10.1186/1742-4755-7-31

Wittenborn, A. K., Dolbin-MacNab, M. L., & Keiley, M. K. (2013). Dyadic research in marriage and family therapy: Methodological considerations. *Journal of Marital & Family Therapy*, *39*(1), 5–16. https://doi.org/10.1111/j.1752-0606.2012.00306.x

Yadav, S., & Srivastava, S. . (2019). A study of marital satisfaction and happiness among love married couples and arrange married couples. *International Review of Social Sciences and Humanities*, *9*(8), 1–9.

Zarhin, D. (2018). Conducting joint interviews with couples: Ethical and methodological challenges. *Qualitative Health Research*, *28*(5), 844–854. https://doi.org/10.1177/1049732317749196

Zhao, C., Wang, F., Zhou, X., Jiang, M., & Hesketh, T. (2018). Impact of parental migration on psychosocial well-being of children left behind: A qualitative study in rural China. *International Journal for Equity in Health*, *17*(80), 1–10. https://doi.org/10.1186/s12939-018-0795-z

Zuma, K., Mzolo, T., & Makonko, E. (2011). Determinants of age at sexual debut and associated risks among South African youths. *African Journal of AIDS Research*, *10*(3), 189–194. https://doi.org/10.2989/16085906.2011.626283

Zuma, T., Seeley, J., Mdluli, S., Chimbindi, N., McGrath, N., Floyd, S., … Shahmanesh, M. (2020). Young people’s experiences of sexual and reproductive health interventions in rural KwaZulu-Natal, South Africa. *International Journal of Adolescence and Youth*, *25*(1), 1058–1075. https://doi.org/10.1080/02673843.2020.1831558

Zuma, T., Seeley, J., Sibiya, L. O., & Chimbindi, N. (2019). The Changing Landscape of Diverse HIV Treatment and Prevention Interventions : Experiences and Perceptions of Adolescents and Young Adults in Rural. *Frontiers in Public Health*, *7*, 1–12. https://doi.org/10.3389/fpubh.2019.00336

APPENDICES

Appendix 1: Ethical Clearance Certificate

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

21 September 2017

Mrs Dumile Olivia Gumede (941355344)
School of Applied Human Sciences - Psychology
Howard College Campus

Dear Mrs Gumede,

Protocol reference number : HSS/1109/017D
Project title: Caring of adolescents by older carers in the context of DREAMS interventions. An ethnographic study in rural KwaZulu-Natal, SA

Approval Notification – Full Committee Reviewed Protocol

With regards to your response received on 19 September 2017 to our letter of 03 September 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

[redacted]

Dr Shenuka Singh (Chair)

/ms

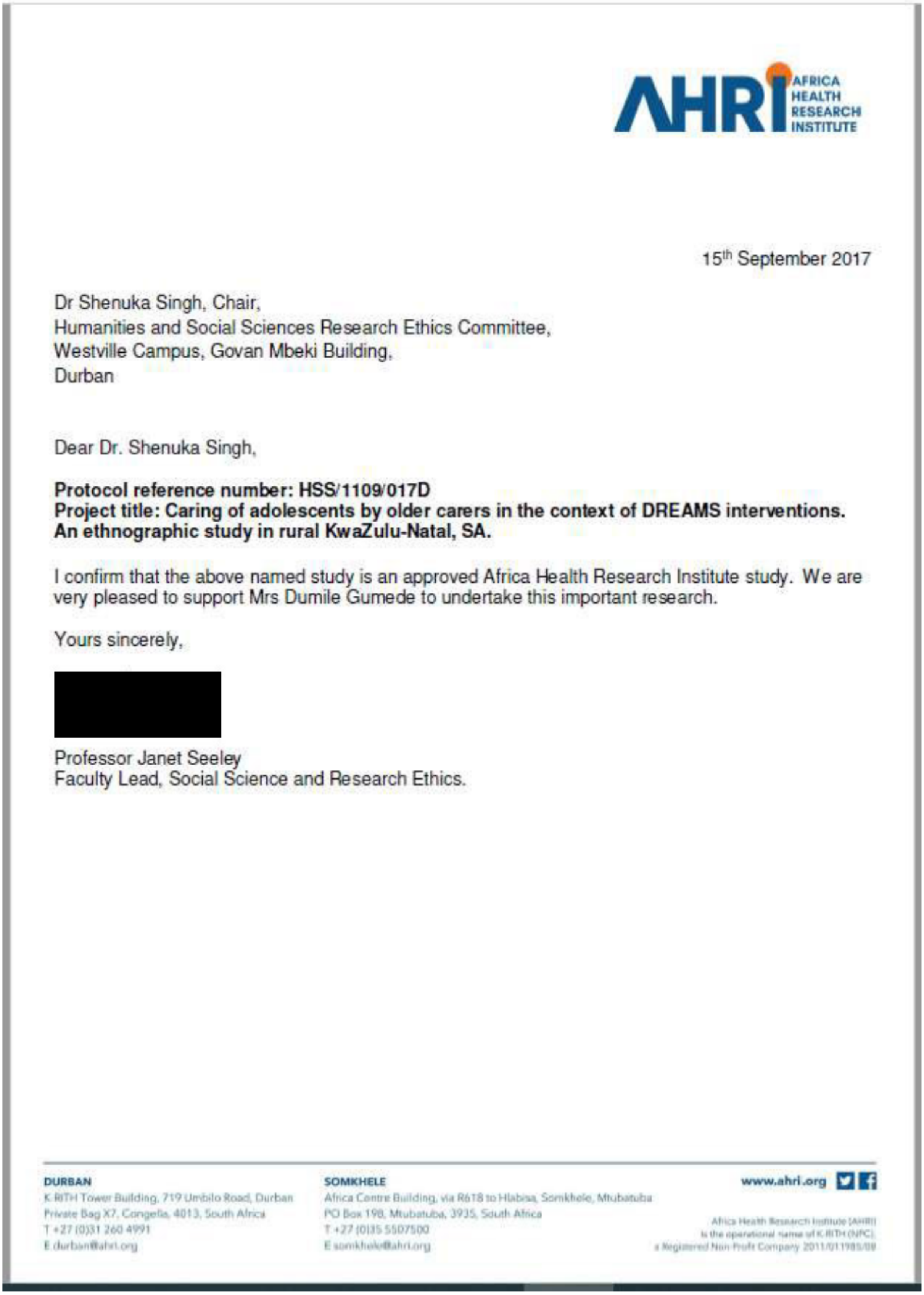
cc Supervisor: Professor Anna Meyer-Weitz
cc Academic Leader Research: Dr Jean Steyn
cc School Administrator: Ms Ayanda Ntuli

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za / mohunp@ukzn.ac.za
Website: www.ukzn.ac.za

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses 🟥 Edgewood 🟧 Howard College 🟨 Medical School 🟩 Pietermaritzburg 🟦 Westville

Appendix 2: AHRI Permission Letter



AHRI
AFRICA
HEALTH
RESEARCH
INSTITUTE

15th September 2017

Dr Shenuka Singh, Chair,
Humanities and Social Sciences Research Ethics Committee,
Westville Campus, Govan Mbeki Building,
Durban

Dear Dr. Shenuka Singh,

Protocol reference number: HSS/1109/017D
Project title: Caring of adolescents by older carers in the context of DREAMS interventions. An ethnographic study in rural KwaZulu-Natal, SA.

I confirm that the above named study is an approved Africa Health Research Institute study. We are very pleased to support Mrs Dumile Gumede to undertake this important research.

Yours sincerely,

[redacted]

Professor Janet Seeley
Faculty Lead, Social Science and Research Ethics.

DURBAN
K-RITH Tower Building, 719 Umbilo Road, Durban
Private Bag X7, Congella, 4013, South Africa
T +27 (0)31 260 4991
E durban@ahri.org

SOMKHELE
Africa Centre Building, via R618 to Hlabisa, Somkhele, Mtubatuba
PO Box 198, Mtubatuba, 3935, South Africa
T +27 (0)35 5507500
E somkhele@ahri.org

www.ahri.org

Africa Health Research Institute (AHRI)
is the operational name of K-RITH (NPC),
a Registered Non-Profit Company 2011/011985/08

Appendix 3: DREAMS Permission Letter

AHRI
AFRICA
HEALTH
RESEARCH
INSTITUTE

17 September 2017

Mrs. Dumile Olivia Gumede
56 Forsdick Rd
Glenmore
4001

Dear Mrs. Gumede,

RE: PERMISSION TO CONDUCT RESEARCH

This serves to notify you that the DREAMS Research Group has granted permission for you to conduct a sub-study, titled: *Caring of adolescents by older carers in the context of DREAMS interventions: An ethnographic study in rural KwaZulu-Natal, South Africa*, within DREAMS Impact Evaluation Study. This project is well aligned with one of our objectives i.e. to describe the experiences with implementation of DREAMS.

Yours sincerely,

[redacted]

Maryam Shahmanesh MA (Cantab) MRCP PhD
Principal Investigator: DREAMS Impact Evaluation Study
Senior Clinical Lecturer/(Hon) Consultant in Sexual Health and HIV
UCL Institute of Global Health
Faculty (HIV Prevention) Africa Health Research Institute, South Africa
Programme director UCL MSc Population Health
m.shahmanesh@ucl.ac.uk
+44 7776185572

DURBAN
K-RITH Tower Building, 719 Umbilo Road, Durban
Private Bag X7, Congella, 4013, South Africa
T +27 (0)31 260 4991
E durban@ahri.org

SOMKHELE
Africa Centre Building, via R618 to Hlabisa, Somkhele, Mtubatuba
PO Box 198, Mtubatuba, 3935, South Africa
T +27 (0)35 5507500
E somkhele@ahri.org

www.ahri.org

Africa Health Research Institute (AHRI)
is the operational name of K-RITH (NPC),
a Registered Non-Profit Company 2011/011955/08

Appendix 4: Community Advisory Board Permission Letter

COMMUNITY ADVISORY BOARD

AHRI AFRICA HEALTH RESEARCH INSTITUTE

29 June 2017

Biomedical Research Ethics Committee
University Of KwaZulu-Natal
Private Bag x7
Congella
4013

Dear Sir/Madam

Project title: Caring of adolescents by older carers in the context of DREAMS interventions: An ethnographic study in rural KwaZulu-Natal, South Africa

This serves to advise that the above-mentioned study was presented in detail to the Africa Health Research Institute (AHRI), formerly known as Africa Centre Community Advisory Board (CAB), during a monthly meeting held on 29th June 2017.

We, as AHRI CAB members, asked questions about a wide range of aspects relating to the study. The questions and comments were adequately addressed by the study presenter, Dumile Gumede (PhD student at the University of KwaZulu-Natal). She outlined the study design and methodology, answered questions from the CAB about the study.

We carefully considered the benefits of the study to individual participants and the community as whole. We supported the study and gave permission that the study is very good for the community researched by AHRI.

After considering benefits that the study will provide, we then granted the study its unconditional approval.

Yours sincerely,

[redacted] [redacted]

CAB Chairperson **CAB Secretary**

Mr SK Zulu MISS ~~Mr~~ S Mamba

Community Advisory Board Management Committee SK Zulu, S Mamba, S Mvuyane, S Mbuyazi, M Buthelezi

Postal: PO Box 198, Mtubatuba 3935, South Africa **Physical:** Africa Centre, R618 en route to Hlabisa, Somkhele
Tel: +27 (0)35 550 7500 Fax +27 (0)35 550 7565 E-mail: info@africacentre.ac.za
Website: www.africacentre.ac.za

Appendix 5: Participant Information Sheet – HIV Programme Facilitators

PARTICIPANT INFORMATION SHEET – HIV PROGRAMME FACILITATORS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

Introduction

Good day, my name is Dumile Gumede from the Africa Health Research Institute (AHRI) but also a registered PhD student in the School of Applied Human Sciences in the Discipline of Psychology. I am doing my PhD Research Project on the topic titled **'caring for adolescents by older carers'**, which you are being asked to take part in. This study is nested within an ongoing larger study called *DREAMS Impact Evaluation* at AHRI.

What is the goal of this study?

The aim of this study is to understand caring of adolescents by older carers in the context of DREAMS interventions, from the perspective of older carers, adolescents and DREAMS implementers. Consideration will be given to these interventions' impact on the psychosocial, cultural and risk behavioural dimensions of adolescents' sexual behaviours. In addition, the study will also explore the influence of DREAMS interventions on caring attitudes and behaviours of older carers and risk taking behaviours of adolescents. This study will help us offer lessons for scale-up to those implementing DREAMS and to inform future investments in adolescents' health and well-being.

Who will take part in this study?

We are selecting a small number of adolescent girls and boys aged 13 to 19 years who live with and cared for by older carers within Hlabisa sub-district; and (2) participating in a DREAMS intervention delivering parenting/caregiver programme in the community. You are selected because you are involved in the delivery of the parenting/caregiver programme within the sub-district. We will interview up to 4 individuals responsible for implementation of DREAMS parenting/caregiver activities.

What will happen if you agree to take part in the study?

The researcher will arrange a suitable time to meet and talk with you about your experiences of delivering your intervention. The researcher will explore with you (1) coverage and reach of your DREAMS intervention; (2) motivators and barriers to participation in the intervention by adolescents and older carers; (3) challenges and benefits of working with adolescents and older carers; and (4) influence of intervention on caring behaviours of older carers and risk taking behaviours of adolescents? Following this initial in-depth interview exploring your experiences, the researcher will be visiting your organization to spend time with you and beneficiaries to observe the environment in which the intervention is delivered and to do follow up interviews. The initial in-depth interview is expected to be about 45 - 60 minutes long. Thereafter, the researcher will ask to follow you up through brief informal in-depth interviews (up to 4) over the 9-month study period.

What if you do not want to take part in any part of the study?

Taking part in the study is voluntary. You are free to refuse to answer some, or all, questions.

What if you cannot decide now or you change your mind later?

Your decision to participate is completely voluntary. If you decide later that you would like to participate, or withdraw, please contact our Community Engagement Office on 0800 203 695 (free of charge).

Is there any risk being in the study?

We do not anticipate any physical risk by participating. However, we will never force you to answer any question and you can choose not to answer any question that makes you feel uncomfortable.

What are the benefits to being in the study?

By participating in this study, you are helping contribute to research knowledge and providing a better understanding of caring of adolescents by older carers and whether the DREAMS interventions are shaping adolescents' behaviours and the care they receive from older carers and why. This is important for future planning and scale-up of interventions targeted at adolescents' health and well-being which will benefit you and your community.

Will you receive any compensation?

Although we will not be providing money, we will be providing a drink and a snack for your time and participation.

Audio recording of interviews

During discussions with you, we would like to make an audio recording of the conversation. Recording the discussion means that the researcher does not need to take detailed notes of what is said, and can help us make the best use of the information that you share with us. We will not ask for your name during audio recordings or anything that identifies you. We will ask for your permission to audio record the discussion via a consent form.

Who will see the information that is collected?

All the information collected is kept private and confidential. There will be no name only a number. All the data will be kept on a secure computer using only this number not your name. Your identifiable information (such as your name, the place where you live or your contact number) will be kept separately. One person (Dr Maryam Shahmanesh, Principal Investigator) has custody of this information. In this way the data is locked so that scientists cannot relate results to a single name or homestead. Scientists can be given permission to analyze the findings from this study and may also write about the findings in scientific journals to share the information that we learn with scientists, doctors and others in South Africa and the world. Scientific writing is never about named individuals. We take all possible steps to reduce the risk of people being identified.

The recording will be transcribed and the recording will then be destroyed. Only authorized study staff will have access to this information. The information that is recorded will be typed into a password protected computer at the Africa Health Research Institute in Somkhele and stored on a secure computer server for at least five years. Only authorized study staff will have access to this information. The hard copies of all forms we have used to write down information that you give us will be destroyed after entry on the computer. We will store data in a secure location while the information is waiting for data entry onto the computer.

The ethics committee

This study has been approved by the Humanities and Social Science Research Ethics (HSSRE) at the University of KwaZulu-Natal, South Africa (REFERENCE NUMBER: HSS/1109/017D). The Ethics Committee may look at the information from the study to check that procedures are being correctly and safely followed but they will not see your name.

Communication of research findings

At the end of the study, we will inform the Community Advisory Board, DREAMS organizations, and the local community about the findings of the study but not the results of any individual.

Who to contact if you want to know more, or if you have a problem or complaint at any time?

If you ever have questions about this study, or in case you are injured as a result of participation in the study, you should contact Dr Maryam Shahmanesh (Principal Investigator) or Dumile Gumede (PhD student) at the Africa Health Research Institute (035 550 7500) or Ms Ncengani Mthethwa of our Community Engagement Office (0800 203 695).

If you require any further clarification regarding this study, feel free to contact my study supervisor. You can also contact the administrator at the Humanities and Social Science Ethics Committee of UKZN. All contact details are below:

Supervisor

Prof Anna Meyer-Weitz Telephone: 031-2607618 Email: meyerweitza@ukzn.ac.za

Humanities and Social Science Ethics Committee of the University of KwaZulu-Natal:

Mr. Pemlal Mohun Telephone: 031-260 4557/2384 Email: MOHUNP@ukzn.ac.za

Appendix 6: Participant Information Sheet – Older Carers

PARTICIPANT INFORMATION SHEET - OLDER CARERS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

Introduction

Good day, my name is Dumile Gumede from the Africa Health Research Institute (AHRI) but also a registered PhD student in the School of Applied Human Sciences in the Discipline of Psychology. I am doing my PhD Research Project on the topic titled ‘**caring for adolescents by older carers’**, which you are being asked to take part in. This study is nested within an ongoing larger study called *DREAMS Impact Evaluation* at AHRI.

Since you are caring for a child younger than 18 years of age, you as the carer are requested to provide consent for your child to participate in this study. This does not mean that your child has to agree to be in the study.

- If you as the carer agree to your child’s participation in the study, we will still require your child to agree to participate in this study.
- Consent is the permission given by you as the carer for your child to participate in the study.
- Assent is a term used to describe your child’s agreement to participate in this study because your child is under 18 years of age.
- We would like to receive both consent from you and assent from your child to participate in this study since your child is under 18 years of age.
- The information sheet will describe to you the purpose of the study, study procedures, the type of information that we will be collecting, the risks, benefits and your child’s rights as a study participant.

This document gives you information about the study that will be discussed with you. Once you understand the study, and if you agree to provide consent for your child to take part, you will be asked to sign this consent form or make your mark in front of a witness. You will be given a copy of this consent to keep.

Please note that

- **Your child's participation in this research is entirely voluntary.**
- **You may decide not to provide consent or to withdraw consent from the study at any time.**
- **If you decide not to provide consent, your child cannot participate in this study.**

What is the goal of this study?

The aim of this study is to understand caring of adolescents by older carers in the context of DREAMS interventions, from the perspective of older carers, adolescents and DREAMS implementers. Consideration will be given to these interventions' impact on the psychosocial, cultural and risk behavioural dimensions of adolescents' sexual behaviours. In addition, the study will also explore the influence of DREAMS interventions on caring attitudes and behaviours of older carers and risk taking behaviours of adolescents. This study will help us offer lessons for scale-up to those implementing DREAMS and to inform future investments in adolescents' health and well-being.

Who will take part in this study?

We are selecting a small number of adolescent girls and boys aged 13 to 19 years and their older carers who live within uMkhanyakude district; and, participating in a DREAMS intervention. You are selected because you are caring for an adolescent child within the age-group of young people we are interested in. For 13 to 17 year olds we will seek their assent, as well as the consent of their older carers.

What will happen if you and your child agree to take part in the study?

Once you have agreed, we will ask you to consent for your participation in the study and to consent for your child to participate. We will then ask your child to assent to take part in the study. The researcher will arrange a suitable time to meet and talk with you about your experiences of being an older carer and experiences you may have of participating in DREAMS organisation in the delivery of parenting/caregiver programmes. The researcher will explore with you the nature of your relationship with the young person; nature of communication between you and the young person about sexual and reproductive health issues; parenting styles that you employ; behaviours that you model; and your experiences and perceptions of DREAMS intervention and its influence in your life and the young person. Following this initial in-depth interview exploring your experiences, the researcher will be visiting your home to spend time with you to observe the environment in which you live in and to do follow up interviews. The initial in-depth interview is expected to be about 45 - 60 minutes long. Thereafter, the researcher will ask to follow you up through brief informal in-depth interviews (up to 4) over the 9-month study period.

What if you do not want to take part in any part of the study?

Taking part in the study is voluntary. You and the young person are free to refuse to answer some, or all, questions.

What if you cannot decide now or you change your mind later?

Your decision to participate is completely voluntary. If you decide later that you would like to participate, or withdraw, please contact our Community Engagement Office on 0800 203 695 (free of charge).

Is there any risk being in the study?

We do not anticipate any physical risk by participating. We will ask you questions about your health and behaviour, some of which you may feel is personal or is information that you don't usually share. However, we will never force you to answer any question and you can choose not to answer any question that makes you feel uncomfortable.

What are the benefits to being in the study?

By participating in this study, you are helping contribute to research knowledge and providing a better understanding of caring of adolescents by older carers and whether the DREAMS interventions are shaping adolescents' behaviours and the care they receive from older carers and why. This is important for future planning and scale-up of interventions targeted at adolescents' health and well-being which will benefit you and your community.

Will you receive any compensation?

Although we will not be providing money, we will be providing a drink and a snack for your time and participation.

Audio recording of interviews

During discussions with you, we would like to make an audio recording of the conversation. Recording the discussion means that the researcher does not need to take detailed notes of what is said, and can help us make the best use of the information that you share with us. We will not ask for your name during audio recordings or anything that identifies you. We will ask for your permission to audio record the discussion via a consent form.

Who will see the information that is collected?

All the information collected is kept private and confidential. There will be no name only a number. All the data will be kept on a secure computer using only this number not your name. Your identifiable information (such as your name, the place where you live or your contact number) will be kept separately. One person (Dr Maryam Shahmanesh, Principal Investigator) has custody of this information. In this way the data is locked so that scientists cannot relate results to a single name or homestead. Scientists can be given permission to analyze the findings from this study and may also write about the findings in scientific journals to share the information that we learn with scientists, doctors and others in South Africa and the world. Scientific writing is never about named individuals. We take all possible steps to reduce the risk of people being identified.

The recording will be transcribed and the recording will then be destroyed. Only authorized study staff will have access to this information. The information that is recorded will be typed into a password protected computer at the Africa Health Research Institute in Somkhele and stored on a secure computer server for at least five years. Only authorized study staff will have access to this information. The hard copies of all forms we have used to write down information that you give us will be destroyed after entry on the computer. We will store data in a secure location while the information is waiting for data entry onto the computer.

The ethics committee

This study has been approved by the Humanities and Social Science Research Ethics (HSSRE) at the University of KwaZulu-Natal, South Africa (REFERENCE NUMBER: HSS/1109/017D). The Ethics Committee may look at the information from the study to check that procedures are being correctly and safely followed but they will not see your name.

Communication of research findings

At the end of the study, we will inform the Community Advisory Board, DREAMS organizations, and the local community about the findings of the study but not the results of any individual.

Who to contact if you want to know more, or if you have a problem or complaint at any time?

If you ever have questions about this study, or in case you are injured as a result of participation in the study, you should contact Dr Maryam Shahmanesh (Principal Investigator) or Dumile Gumede (PhD student) at the Africa Health Research Institute (035 550 7500) or Ms Ncengani Mthethwa of our Community Engagement Office (0800 203 695).

If you require any further clarification regarding this study, feel free to contact my study supervisor. You can also contact the administrator at the Humanities and Social Science Ethics Committee of UKZN. All contact details are below:

Supervisor

Prof Anna Meyer-Weitz Telephone: 031-2607618 Email: meyerweitza@ukzn.ac.za

Humanities and Social Science Ethics Committee of the University of KwaZulu-Natal:

Mr. Pemlal Mohun Telephone: 031-260 4557/2384 Email: MOHUNP@ukzn.ac.za

Appendix 7: Participant Information Sheet - Adolescents

PARTICIPANT INFORMATION SHEET - ADOLESCENTS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

Introduction

Good day, my name is Dumile Gumede from the Africa Health Research Institute (AHRI) but also a registered PhD student in the School of Applied Human Sciences in the Discipline of Psychology. I am doing my PhD Research Project on the topic titled '**caring for adolescents by older carers'**, which you are being asked to take part in. This study is nested within an ongoing larger study called *DREAMS Impact Evaluation* at AHRI.

What is the goal of this study?

The aim of this study is to understand caring of adolescents by older carers in the context of DREAMS interventions, from the perspective of older carers, adolescents and DREAMS implementers. Consideration will be given to these interventions' impact on the psychosocial, cultural and risk behavioural dimensions of adolescents' sexual behaviours. In addition, the study will also explore the influence of DREAMS interventions on caring attitudes and behaviours of older carers and risk taking behaviours of adolescents. This study will help us offer lessons for scale-up to those implementing DREAMS and to inform future investments in adolescents' health and well-being.

Who will take part in this study?

We are selecting a small number of adolescent girls and boys aged 13 to 19 years who (1) live with older carers within uMkhanyakude district; and (2) participating in a DREAMS intervention. You are selected because you are within the age-group of young people we are interested in, and you are being cared for by an older person. For 13 to 17 year olds we will seek their assent, as well as the consent of their older carers.

What will happen if you agree to take part in the study?

The researcher will arrange a suitable time to meet and talk with you about your experiences of being cared for by an older carer and experiences you may have of participating in DREAMS organisation in the delivery of parenting/caregiver programmes. The researcher will explore with you the nature of your relationship with your older carer; nature of communication between you and your older carer about sexual and reproductive health issues; parenting styles that your older carer employ; behaviours that your older carer models; and your experiences and perceptions of DREAMS intervention and its influence in your life. Following this initial in-depth interview exploring your experiences, the researcher will be visiting your home to spend time with you to observe the environment in which you live in and to do follow up interviews. The initial in-depth interview is expected to be about 45 - 60 minutes long. Thereafter, the researcher will ask to follow you up through brief informal in-depth interviews (up to 4) over the 9-month study period.

What if you do not want to take part in any part of the study?

Taking part in the study is voluntary. You are free to refuse to answer some, or all, questions.

What if you cannot decide now or you change your mind later?

Your decision to participate is completely voluntary. If you decide later that you would like to participate, or withdraw, please contact our Community Engagement Office on 0800 203 695 (free of charge).

Is there any risk being in the study?

We do not anticipate any physical risk by participating. We will ask you questions about your health and behaviour, some of which you may feel is personal or is information that you don’t usually share. However, we will never force you to answer any question and you can choose not to answer any question that makes you feel uncomfortable.

What are the benefits to being in the study?

By participating in this study, you are helping contribute to research knowledge and providing a better understanding of caring of adolescents by older carers and whether the DREAMS interventions are shaping adolescents’ behaviours and the care they receive from older carers and why. This is important for future planning and scale-up of interventions targeted at adolescents’ health and well-being which will benefit you and your community.

Will you receive any compensation?

Although we will not be providing money, we will be providing a drink and a snack for your time and participation.

Audio recording of interviews

During discussions with you, we would like to make an audio recording of the conversation. Recording the discussion means that the researcher does not need to take detailed notes of what is said, and can help us make the best use of the information that you share with us. We will not ask for your name during audio recordings or anything that identifies you. We will ask for your permission to audio record the discussion via a consent form.

Who will see the information that is collected?

All the information collected is kept private and confidential. There will be no name only a number. All the data will be kept on a secure computer using only this number not your name. Your identifiable information (such as your name, the place where you live or your contact number) will be kept separately. One person (Dr Maryam Shahmanesh, Principal Investigator) has custody of this information. In this way the data is locked so that scientists cannot relate results to a single name or homestead. Scientists can be given permission to analyze the findings from this study and may also write about the findings in scientific journals to share the information that we learn with scientists, doctors and others in South Africa and the world. Scientific writing is never about named individuals. We take all possible steps to reduce the risk of people being identified.

The recording will be transcribed and the recording will then be destroyed. Only authorized study staff will have access to this information. The information that is recorded will be typed into a password protected computer at the Africa Health Research Institute in Somkhele and stored on a secure computer server for at least five years. Only authorized study staff will have access to this information. The hard copies of all forms we have used to write down information that you give us will be destroyed after entry on the computer. We will store data in a secure location while the information is waiting for data entry onto the computer.

The ethics committee

This study has been approved by the Humanities and Social Science Research Ethics (HSSRE) at the University of KwaZulu-Natal, South Africa (REFERENCE NUMBER: HSS/1109/017D). The Ethics Committee may look at the information from the study to check that procedures are being correctly and safely followed but they will not see your name.

Communication of research findings

At the end of the study, we will inform the Community Advisory Board, DREAMS organizations, and the local community about the findings of the study but not the results of any individual.

Who to contact if you want to know more, or if you have a problem or complaint at any time?

If you ever have questions about this study, or in case you are injured as a result of participation in the study, you should contact Dr Maryam Shahmanesh (Principal Investigator) or Dumile Gumede (PhD student) at the Africa Health Research Institute (035 550 7500) or Ms Ncengani Mthethwa of our Community Engagement Office (0800 203 695).

If you require any further clarification regarding this study, feel free to contact my study supervisor. You can also contact the administrator at the Humanities and Social Science Ethics Committee of UKZN. All contact details are below:

Supervisor

Prof Anna Meyer-Weitz Telephone: 031-2607618 Email: meyerweitza@ukzn.ac.za

Humanities and Social Science Ethics Committee of the University of KwaZulu-Natal:

Mr. Pemlal Mohun Telephone: 031-260 4557/2384 Email: MOHUNP@ukzn.ac.za

Appendix 8: Informed Consent Form – HIV Programme Facilitators

STATEMENT OF INFORMED CONSENT – HIV PROGRAMME FACILITATORS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

If you agree to take part, you will be asked to sign this consent form or make your mark in front of a witness. You will be given a copy of this consent to keep.

Please circle the correct answer:

1	Have you received enough information about the study in a language that you understand?	YES	NO
2	Have you received copy of the information sheet with all the study and contact information?	YES	NO
3	Have you been given an opportunity to ask questions about the study and been given answers to your satisfaction?	YES	NO
4	Do you agree to take part in this study?	YES	NO
5	Do you agree for the interview to be audio taped?	YES	NO

If 'NO' to any of the above the individual is ineligible for the study.

Do you agree to be contacted by phone in order to make appointments for follow up interviews or discussion of our preliminary findings? Phone number ____________________________ An alternative phone number is ______________________. This belongs to ___________________ (my ___________).	YES	NO

Signature/Thumb-print of individual

Signature or thumb-print		Date of signature	
Print name and surname			

Signature of witness (if individual illiterate) to state: "*I witnessed the information and consent process and confirm that the above named participant consented of free will*".

Signature		Date of signature	
Print name and surname			

Tick box if participant is not literate and refuses to have witness present: ☐

Signature of researcher taking consent

Signature		Date of signature	
Print name and surname			

Appendix 9: Informed Consent Form – Older Carers

STATEMENT OF INFORMED CONSENT - OLDER CARERS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

If you agree to take part, you will be asked to sign this consent form or make your mark in front of a witness. You will be given a copy of this consent to keep.

Please circle the correct answer:

1	Have you received enough information about the study in a language that you understand?	YES	NO
2	Have you received copy of the information sheet with all the study and contact information?	YES	NO
3	Have you been given an opportunity to ask questions about the study and been given answers to your satisfaction?	YES	NO
4	Do you agree to take part in this study?	YES	NO
5	Do you agree for the adolescent child aged 13 to 17 in your care to take part in this study? (if applicable)	YES	NO
6	Do you agree for the interview to be audio taped?	YES	NO

If 'NO' to 1 - 5 of the above the individual is ineligible for the study.

FOR OLDER CARER CONSENTING FOR ADOLESCENT CHILD AGED 13 – 17 YEARS

Child's name	____ **Surname, First names**
Child's Date of Birth	[_|_] * [_|_|_] * [_|_|_|_] **Day Month Year**

Do you agree to be contacted by phone in order to make appointments for follow up interviews or discussion of our preliminary findings?	YES	NO

Phone number ____________________________ An alternative phone number is _______________________. This belongs to ___________________ (my ____________).		

Signature/Thumb-print of individual

Signature or thumb-print		Date of signature	
Print name and surname			

Signature of witness (if individual illiterate) to state: “*I witnessed the information and consent process and confirm that the above named participant consented of free will*”.

Signature		Date of signature	
Print name and surname			

Tick box if participant is not literate and refuses to have witness present: ☐

Signature of researcher taking consent

Signature		Date of signature	
Print name and surname			

Appendix 10: Informed Consent Form – Adolescents (aged 18 – 19)

STATEMENT OF INFORMED CONSENT - ADOLESCENTS (AGED 18 – 19 YEARS)

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

If you agree to take part, you will be asked to sign this consent form or make your mark in front of a witness. You will be given a copy of this consent to keep.

Please circle the correct answer:

1	Have you received enough information about the study in a language that you understand?	YES	NO
2	Have you received copy of the information sheet with all the study and contact information?	YES	NO
3	Have you been given an opportunity to ask questions about the study and been given answers to your satisfaction?	YES	NO
4	Do you agree to take part in this study?	YES	NO
5	Do you agree for the interview to be audio taped?	YES	NO

If 'NO' to any of the above the individual is ineligible for the study.

Do you agree to be contacted by phone in order to make appointments for follow up interviews or discussion of our preliminary findings? Phone number ____________________________ An alternative phone number is _______________________. This belongs to ___________________ (my ____________).	YES	NO

Signature/Thumb-print of individual

Signature or thumb-print		Date of signature	
Print name and surname			

Signature of witness (if individual illiterate) to state: "*I witnessed the information and consent process and confirm that the above named participant consented of free will*".

Signature		Date of signature	
Print name and surname			

Tick box if participant is not literate and refuses to have witness present: ☐

Signature of researcher taking consent

Signature		Date of signature	
Print name and surname			

Appendix 11: Assent Form – Adolescents (aged 13-17)

STATEMENT OF ASSENT - ADOLESCENTS (AGED 13 – 17 YEARS)

CARING OF ADOLESCENTS BY OLDER CARERS STUDY

If you agree to take part, you will be asked to sign this assent form or make your mark in front of a witness. You will be given a copy of this consent to keep.

Please circle the correct answer:

1	Have you received enough information about the study in a language that you understand?	YES	NO
2	Have you received copy of the information sheet with all the study and contact information?	YES	NO
3	Have you been given an opportunity to ask questions about the study and been given answers to your satisfaction?	YES	NO
4	Do you agree to take part in this study?	YES	NO
5	Do you agree for the interview to be audio taped?	YES	NO

If 'NO' to any of the above the individual is ineligible for the study.

Do you agree to be contacted by phone in order to make appointments for follow up interviews or discussion of our preliminary findings? Phone number ____________________________ An alternative phone number is _______________________. This belongs to ___________________ (my ____________).	YES	NO

Signature/Thumb-print of individual

Signature or thumb-print		Date of signature	
Print name and surname			

Signature of witness (if individual illiterate) to state: “*I witnessed the information and consent process and confirm that the above named participant consented of free will*”.

Signature		Date of signature	
Print name and surname			

Tick box if participant is not literate and refuses to have witness present: ☐

Signature of researcher taking consent

Signature		Date of signature	
Print name and surname			

Appendix 12: Observation Guide

OBSERVATION GUIDE

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

1. Record date, time started and ended, and place.

2. Draw the physical appearance of the setting.

3. Describe the setting and the context. Indicate roughly what the setting is like, size, facilities, number of people (gender, age), and so on.

4. Indicate what is happening, who is involved in the action, interactions between people.

5. Conduct informal chats with people around.

6. Record questions to follow up in future interviews.

Appendix 13: Interview Guide – HIV Programme Facilitators

INTERVIEW GUIDE – HIV PROGRAMME FACILITATORS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

INTRODUCTION

Please tell me about yourself. [*As a way to establish rapport and get to know the participant] Let the participant tell you anything about themselves – probe for age, educational level, employment history, position in organization, start date, nature of duties, and any other general information***.**

Please tell me about what your organization.

*Let the participant tell you anything about their organization – probe about date of establishment, organogram, goals, programmes, sources of funding, focus prior to DREAMS, and any other general information***.** *Draw an organizational organogram.*

Please tell me about your programme.

*Let the participant tell you anything about their programme – probe about programme goals, programme activities, beneficiaries, selection criteria, coverage and reach, and any other general information***.**

Theme 1: Perceptions of caring of adolescents by older carers

1. What trends are you seeing regarding children in the care of older carers in this community? Has there been an increase/decrease?
2. What are the reasons for children to be cared for by older carers in this community?
3. What do you think are the risks and protective factors for adolescents to be cared for by older carers?

Theme 2: Experiences and perceptions of DREAMS programme delivery

1. What motivates and hinders participation of adolescents and older cares to this programme?
2. What are the challenges and benefits of working with adolescents and older carers?
3. What are the achievements in providing the programme?
4. What are the challenges in providing the programme?
5. Are there any services your organization is not able to provide?
6. Do you have a sense of whether things have changed in this community since you started this programme? If so, why and how?
7. How do you think your programme has/is influencing caring behaviours of older carers and risk taking behaviours of adolescents?
8. What could be improved in this programme?

Appendix 14: Interview Guide – Older Carers

INTERVIEW GUIDE – OLDER CARERS

CARING OF ADOLESCENTS BY OLDER CARERS STUDY

INTRODUCTION

Please tell me about yourself. [*As a way to establish rapport and get to know the participant] Let the participant tell you anything about themselves – probe for age, marital status, place of birth, religion, educational level, whether they are working, source of income, motherhood/fatherhood, and any other general information***.**

Please tell me about your family.

Let the participant tell you anything about their family – probe about spouse and children, family members, source of family income, number and ages of children in their care, reasons, and any other general information. Draw a family tree.

Theme 1: Nature of relationship with adolescent

1. How are you related to [adolescent]?
2. How would you describe [adolescent]?
3. When did you start living with [adolescent]?
4. How did it happened that you are caring for [adolescent]?
5. What kind of relationship do you have with [adolescent]?
6. What are your responsibilities towards [adolescent]?
7. What type of activities do you do together and how often?
8. What type of support do you receive from [adolescent]?
9. What type of support do you provide to [adolescent]?
10. What does [adolescent] mean to you? What does it mean to be an older carer?
11. What are the challenges and benefits of caring for [adolescent]?

Theme 2: Parenting styles

1. What are the main rules in your family?
2. What happens when [adolescent] break the rules?
3. How do you discipline [adolescent]?
4. What happens when [adolescent] is successful at something (or did something that pleased you)?
5. What happens when [adolescent] failed at something (or disappointed you)?
6. How do you know about what [adolescent] is up to and his/her whereabouts?
7. To whom do you turn to for comfort, advice or support? Why?

Theme 3: Nature of communication about sexual and reproductive health (SRH) issues

1 What kind of topics do you discuss with [adolescent] in general?
2 What sex-related topics do you talk about with [adolescent]? Initiator? Triggers? Timing? Frequency?

Probe:
- Physical/biological development (e.g. puberty, menstruation, reproduction)
- Gender roles
- Sex (e.g. sexual feelings, age to start sexual intercourse, choosing sexual partner, handling sexual pressure, safer sex, marriage, homosexuality)
- STIs, HIV, contraceptives, condoms, pregnancy, circumcision,
- Substance use

3. What are the challenges and benefits to discuss SRH issues with [adolescent]? (Probe: age difference, capacity of older carer to provide practical information and advice around SRH issues, application)
4. Where do you get SRH information?
5. How communication about SRH with [adolescent] has/is influencing [adolescent's] sexual and reproductive behaviour?

Theme 4: Knowledge and exposure to community-based interventions (including DREAMS and non-DREAMS interventions)

1. What kinds of interventions are already ongoing in your community focusing on adolescents? (Please probe for the organisations and the type of interventions being mentioned).

2. Ask about new interventions they know about [probe for approximate time when they started, if they are still ongoing and who is running them].

3. Now ask the participants about DREAMS - we want to focus on the DREAMS intervention from now on.

   a. Which DREAMS interventions do you know/ aware of? [Interviewer should have a list of interventions activities and probe using this only when the participants are not forthcoming].

   b. What are the differences and similarities between DREAMS and non-DREAMS?

Theme 5: Experience and perceptions with DREAMS interventions/activities

1. Do you have a DREAMS identifier? It could be a reference number, ID or code. Would you like to share it with me?
2. Which intervention(s) have you ever used (participated in/ been invited to participate in) or supported? Probe: where, which organization and location.

3. Please describe your experience with the activities. Probe if they think it's good or bad?

Theme 6: Experience with DREAMS programme

1. Which organization are you participating in for a DREAMS programme?
2. How and why you became involved? Who approached you? How did they know about you? Why were you chosen and what steps did they take?
3. How did you arrive to a decision for you and/ [adolescent] to participate in the programme?
4. What kind of activities are you doing as part of the intervention? How often?

5. What do you think about the programme? Positive and negative experiences?
6. What do you like/dislike about the programme?
7. What could be done better or differently?
8. What support are you getting from [adolescent] and any other person to participate in the intervention?
9. When you think about the things you learnt from the programme, how do you use that in your life? How did the programme change your life and the relationship with [adolescent]?
    - Think about your relationship with [adolescent] before the programme and think about it during/after the programme. How has it changed/is it changing? Probe around caring attitudes and behaviours of older carer.
    - Think about your life before the programme and think about it during/after the programme. How has it changed/is it changing? Probe around risk taking behaviours of [adolescent].

Appendix 15: Interview Guide – Adolescents (aged 13-19)

INTERVIEW GUIDE – ADOLESCENTS AGED 13 – 19 YEARS

CARING FOR ADOLESCENTS BY OLDER CARERS STUDY

INTRODUCTION

Please tell me about yourself. *[As a way to establish rapport and get to know the participant] Let the participant tell you anything about themselves – probe for age, place of birth, religion, educational status whether in/out of school, whether they are working, motherhood/fatherhood, and any other general information.*

Please tell me about your family.

Let the participant tell you anything about their family – probe about parents and siblings, family members, source of family income, home safety, and any other general information. Draw a family tree.

Theme 1: Nature of relationship with older carer

12. How are you related to your older carer?
13. How would you describe your older carer?
14. When did you start living with your older carer?
15. How did it happened that your older carer is your primary carer?
16. How many other children in the family and their ages are cared for by the same older carer?
17. What kind of relationship do you have with your older carer?
18. What are the responsibilities of your older carer towards you?
19. What type of activities do you do together and how often?
20. What type of support do you receive from your older carer?
21. What type of support do you provide to your older carer?
22. What does your older carer mean to you? What does it mean to be cared for by an older carer?
23. What have you learnt from your older carer?
24. What are the challenges and benefits of being cared for by an older carer?

Theme 2: Parenting styles

8. What are the main rules in your family?
9. What happens when you break the rules?
10. How does your older carer discipline you?
11. What happens when you are successful at something (or did something that pleased your older carer)?
12. What happens when you failed at something (or disappointed your older carer)?
13. How does your older carer know about what you are up to and your whereabouts?

14. To whom do you turn to for comfort, advice or support? Why?

Theme 3: Nature of communication about sexual and reproductive health (SRH) issues

3 What kind of topics do you discuss with your older carer in general?

4 What sex-related topics do you talk about with your older carer? Initiator? Triggers? Timing? Frequency?

Probe:

- Physical/biological development (e.g. puberty, menstruation, reproduction)
- Gender roles
- Sex (e.g. sexual feelings, age to start sexual intercourse, choosing sexual partner, handling sexual pressure, safer sex, marriage, homosexuality)
- STIs, HIV, contraceptives, condoms, pregnancy, circumcision,
- Substance use

6. What are the challenges and benefits to discuss SRH issues with older carer? (Probe: age difference, capacity of older carer to provide practical information and advice around SRH issues, application)
7. What are the similarities and differences between SRH information offered by older carers and other sources?
8. How communication about SRH with your older carer has/is influencing your sexual and reproductive behaviour?

Theme 4: Knowledge and exposure to community-based interventions (including DREAMS and non-DREAMS interventions)

4. What kinds of interventions are already ongoing in your community focusing on adolescents? (Please probe for the organisations and the type of interventions being mentioned).

5. Ask about new interventions they know about [probe for approximate time when they started, if they are still ongoing and who is running them].

6. Now ask the participants about DREAMS - we want to focus on the DREAMS intervention from now on.

   a. Which DREAMS interventions do you know/ aware of? [Interviewer should have a list of interventions activities and probe using this only when the participants are not forthcoming].

Theme 5: Experience and perceptions with DREAMS interventions/activities (excluding parenting/caregiver programme)

4. Do you have a DREAMS identifier? It could be a reference number, ID or code. Would you like to share it with me?
5. Which intervention(s) have you ever used (participated in/ been invited to participate in) or supported? Probe: where, which organization and location.

6. Please describe your experience with the activities. Probe if they think it’s good or bad?

Theme 6: Experience with DREAMS programme

10. Which organization are you participating in for DREAMS programme?
11. How and why they became involved? Who approached you? How did they know about you? Why were you chosen and what steps did they take?
12. How did you arrive to a decision for you and/or your older to participate in the DREAMS programme?
13. What kind of activities are you doing as part of the intervention? How often?
14. What do you think about the programme? Positive and negative experiences?
15. What do you like/dislike about the programme?
16. What could be done better or differently?
17. What support are you getting from your older carer and any other person to participate in the intervention?
18. When you think about the things you learnt from the programme, how do you use that in your life? How did the programme change your life and the relationship with your older carer?
    - Think about your relationship with your older carer before the programme and think about it during/after the programme. How has it changed/is it changing? Probe around caring attitudes and behaviours of older carer.
    - Think about your life before the programme and think about it during/after the programme. How has it changed/is it changing? Probe around risk taking behaviours.