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Title:

Exploring Depression in Grandparents Caring for Orphans as a Result of HIV/AIDS

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Supervisor: Inge Petersen

Declaration:

I, **Jessica Parker** declare that this research thesis titled: Exploring Depression in Grandparents Caring for Orphans as a Result of HIV/AIDS is my original work except where otherwise stated. I declare that this thesis has not previously been submitted for any qualification at any other university. I have acknowledged all sources in the reference list.

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Jessica Parker

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It would not have been possible to write this Thesis without the help and support of a number of people.

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And finally, to the Gogo's who participated in the study, I thank you for sharing your stories with me and for making this thesis possible.

Dedication

To my mom, who I know is with me every step of the way. And to my Gran, without her none of this would have been possible.

Abstract

Background: In 2011 South Africa was home to 5,300,000 to 5,900,000 people living with HIV. An estimated 240,000 to 300,000 deaths due to AIDS occurred during this year, resulting in 2,000,000 to 2,300,000 orphans aged 0-17 years (UNAIDS, 2011). Grandmothers are increasingly recognised as African Heroes, as the ones looking after orphans and the sick, as primary care givers (Lewis, 2007). If depression is left untreated it can affect the grandparent's health, as well as their ability to care for orphans.

Aim: The aim of the study seeks to understand depression in grandparents as primary care givers to orphaned children and to explore factors that may contribute to depression.

Method: This study used a qualitative, interpretive phenomenological research approach. Data was obtained through semi-structured focus group discussions using three focus groups with 4-5 participants. Thematic analysis was used to analyse the data.

Results: Findings from the study suggest that a number of factors played a part in either precipitating or perpetuating depression in elderly caregivers of orphans. Socio economic status, namely a lack of food and income played a large role in the experience of depression. The results also point to social isolation and lack of support, as well as poor parenting skills as exacerbating factors.

Conclusion: The literature review, along with the results of this study provides insights on how depression is experienced in elderly caregivers of orphans as well as contributing factors.. It is hoped that the results of this study will be useful in implementing effective interventions for grandparents of orphans in the future.

Keyword: HIV/AIDS, depression, grandparents, orphans.

Contents

Chapter 1

Introduction:

Background and Rationale of the Study

Statistics from 2011 show that between 5,300,000 to 5,900,000 people in South Africa are living with HIV, there were between 240,000 to 300,000 deaths due to AIDS, in that year, and as a result 2,000,000 to 2,300,000 children aged 0-17 years were orphaned due to AIDS, (UNAIDS, 2011). With the demise of the parents the majority of this burden has fallen on the grandparents. As a result, a time that should be filled with nostalgia and retirement, has instead been replaced by new concerns and stressors. Help Age International (2006) estimates that 40% to 60% of orphans in Sub-Saharan countries live in grandmother headed households. Grandmothers are increasingly recognised as African Heroes, as the ones looking after orphans and the sick (Lewis, 2005).

A review of the available literature indicates a number of common factors that could be explored further when investigating depression in care givers of orphans. The primary stressor that was reported in the literature reviewed is related to finance and socio-economic factors leading to overcrowding in small houses, scarce resources for an entire family and other related issues such as orphaned children not attending school due to lack of transport fees etc.(Kuo, Operario, & Cluver, 2011)

Grief is also an important aspect that needs to be explored further as this deeply affects both the carer who needs to be strong for the orphan and the orphan who has to deal with losing either one or both parents.(Chazan, 2008). Grief work may be an important aspect of an intervention for depression.

Another issue involves the carer's ability to parent and their concerns regarding difficulty talking about sensitive matters. This extends to the difficulty of caring for orphans who have emotional issues due to their circumstances (Chazan, 2008). This also needs to be explored further as this could be included in an intervention for depression by giving carers the tools they need to address these issues with the children they are caring for.

Health concerns were another stressor as many carers have been found to have hypertension, arthritis and other chronic illnesses. Often these illnesses are left untreated as all resources are used for the orphans in their care (Chazan, 2008).

All of these factors could be possible triggers of depression that can impact negatively on the care provided for orphaned children. Little is being done to meet the material, emotional and social needs of the elderly care givers and foster caregivers (Marais, 2005).

The purpose of the study was to understand depression in grandparents as primary care givers to orphaned children by HIV\AIDS and to further explore factors, such as those already stated above, that may contribute to depression. This was done with the view to informing the development of culturally and contextually appropriate psychosocial interventions for treating depression in elderly caregivers.

Chapter 2

Literature Review

Socio Economic Factors

The phenomenon of grandmothers looking after grandchildren in South Africa is not a new one. Adults in the past have often had to migrate for work, leaving their children in the care of grandparents. However, income and support from these parents was mostly available as they would send money home to support their families. This is no longer the case as grandparents of orphaned children have the sole responsibility of grandchildren (Ice, Zidron, & Juma, 2008).

In today's economic climate supporting a household can be a very stressful task in South Africa, compounded by the fact that most households comprise of several members and most households have only 5 rooms for everyone, which includes all rooms in the dwelling (StatsSA, 2013). Most grandmothers depend on their monthly pension or government grant to support an entire family. This is often the only source of income. Pensions once aimed at reducing poverty among older people have been transformed into a lifeline for the supported younger household members (Marais, 2005; Legido-Quiley, 2003).

Sometimes this pension is not even available. It was found by Chazan (2008) that the median age for becoming a grandmother in South Africa is 40 years of age. These younger grandmothers are not eligible for an old age pension. The South African Government tried to relieve some of this burden by creating a Foster Care Social Grant that would ensure financial security for orphans. However it has been found that grandparents often have difficulty accessing foster grants due to the fact that after the

primary care giver passes away, the surviving parent who often has not been around since the birth of the child needs to be traced to sign the relevant documents which often is very difficult to do.

Caregivers of orphans have reported having to sell their assets or borrow money in order to keep up with the financial challenges in raising children where additional costs are created by food, health care, school fees and uniforms (Kuo & Operario, 2011). What meagre resources they do have are often spent on treatment for sick family members as well as funerals for loved ones.

Another unfortunate outcome due to this burden is that many orphaned and vulnerable children are, as a result of their grandparents financial constraints unable to attend school. Often, although elderly carers may find the funds for school fees they are then unable to meet costs for transport to school as well as uniforms, stationary and other necessary requirements.

A study investigating depression in carers of orphaned children suggested that increasing access to salaried employment, addressing food insecurity, access to piped water and improving access to social welfare grants might reduce depression (Kuo, Operario, & Cluver, 2011). This shows that socio-economic factors are indeed very real factors affecting depression. Economic hardship has previously been found to be a major risk factor for depression (Ross and Huber 1985). Thus it can be seen that economic difficulties could play a role in depression of elderly care givers of orphans.

Grief

Although bereaved persons often have depressive symptoms, grief typically runs its course within 2 to 6 months requiring no treatment. However, it seems that the course of

bereavement in care givers of orphans seems to be disrupted and these unresolved issues could indeed lead to depression. It is a common complaint that grandmothers often cannot go through the process of bereavement for losing a child as they have to be emotionally and physically strong to support the children left behind (Reddy, 2005).

Whether the child is an infant or an adult, parental grief is especially severe, complicated and long lasting. It has been found that when a child's death is caused by AIDS, the likelihood that the mourning process will be hindered is increased (Winston, 2003). In a study by Chazan (2008), on grandmothers in KwaZulu Natal it was found that the high levels of emotional stress were mostly related to the grief of losing a child.

Parenting Abilities

The current generation of grandparents come from an era where certain topics were considered taboo and issues such as sex were not discussed until marriage. Because of this, grandparents have difficulty broaching these sensitive issues with their grandchildren.

Chazan (2008) found that a trigger of emotional stress in grandmothers in South Africa was talking to their grandchildren about sensitive issues. Another study indicated that the more liberal lifestyles and behaviour of the younger generation in comparison with those of the elderly impacts on their dignity and respect from others in the community. As one of the study participants said: "We never used to smoke and drink the way our children and grandchildren do ... Children have the freedom to do what they want" (Chigali et al.2002:24; Bohman et al. 2007).

Another stressor relating to parenting is the behavioural problems and emotional distress of the children. It has been found that HIV- affected children have substantial

emotional issues (Linsk & Mason, 2004), which grandparents may not have the skills to deal with. In addition, elderly grandparents may find it difficult to give young children the attention and stimulation they need owing to their own health concerns. Due to financial constraints they may also are unable to put these children in a crèche where they may receive better psychosocial stimulation which is important for cognitive development.

Health Concerns

With age comes a new set of health concerns which are aggravated by the stress incurred by grandparents of orphans. The elderly are known to be at increased risk of impaired nutritional status with increasing age (Oldewage-Theron, 2008). This is even more likely for those with a low income.

Chazan (2008) found that grandmothers suffered from conditions such as hypertension, diabetes and arthritis which they left largely untreated due to financial hardship; using what money they had to ensure that the needs of their grandchildren were met first. Orphan-carers are faced with even greater levels of health and psychological problems than non- orphan carers (Kuo & Operarion, 2011), attributed to the high levels of stress associated with this.

Late Life Depression

Depression is a common mental disorder, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness and poor concentration.

Depression is one of the most common causes of emotional distress in elderly globally, according to the World Health Organization (M.T. Yasamy, 2013). The

prevalence of major depressive disorders at any given time in community samples of adults in South Africa aged 65 and above ranges from 1 to 12.3%, and clinically significant depressive symptoms are present in 9.8-39% of community-dwelling older adults (Peltzer & Phaswana-Mafuya, 2013).

A recent study reports, the overall prevalence of symptom-based depression in the past 12 months was 4.0% in a national sample of older adults in South Africa. (Peltzer & Phaswana-Mafuya, 2013). There is a high degree of under-diagnosis and under-treatment of late life depression internationally with the most serious consequence being premature death (Gottfries, 2001).

Depression in later life may result from several factors (Bruce, 2002). Among those commonly reported are low socio-demographic status (Bruce & Hoff, 1994), negative life events, poor physical health (Geerlings *et al.* 2000), disability (Bruce & Hoff, 1994) and poor social network and support (Areán & Reynolds, 2005). With the elderly already being at a higher risk for depression, the added stressors that exist in caring for orphaned grandchildren may increase the risk for late life depression.

Coping Skills

Despite the burden, grandparents often report that care giving is rewarding and express relief that they are able to raise their grandchildren, as heritage is extremely important culturally and express happiness at being able to provide a good home for children (Burton; Minkler et al., 1992).

This positive outlook felt by some grandparents, despite the burden of caring for orphaned children, may be due to their affiliation with support groups, religious beliefs,

interacting with friends as well as involving themselves in community activities, which seem to be factors that may be related to an improved psychological state.

Theoretical Framework

Kleinman's explanatory model of illness was used as a theoretical framework informing the study. An explanatory model of illness is a conceptual tool to understand how different cultural and social contexts affect the ways that people understand their illness (Kleinman 1980). Explanatory models are created and recreated by individuals living within a cultural matrix of social values, expectations, beliefs, and relationships. These comprise what Kleinman defines as social or cultural reality, which is distinguished from the physical reality of the environment and the biological reality of the body. For any particular episode of sickness, a person attaches meaning to the experience of illness by creating narratives describing its causes (etiology), how it is manifested (symptoms), how it affects the body or person (pathophysiology), how it is expected to proceed (course), and what should be done about it (treatment/helpful interventions) (Kleinman 1980).

Conclusion

From research that has been done on this topic, a number of factors have been identified as potentially leading to depression. Although there has been work done in South Africa on carers of orphaned children generally, there has been no research which has focused on the causes of depression in grandparent care givers specifically.

The lived experience of depressed grandmothers who are primary care givers of orphaned children needs to be better understood so that culturally and contextually appropriate interventions can be designed and implemented in the future. It is important to better understand this phenomenon and to design appropriate interventions as

depression can have a direct effect on how they care for their grandchildren and have negative outcomes for these children's socio-emotional and cognitive development (Geerlings *et al.* 2000).

The literature indicates that factors such as socio economic factors, parenting skills, physical well-being and coping skills may contribute to depression in elderly care givers of orphaned children. This research aims to further explore these and others factors that may contribute to depression.

Chapter 3

Methodology

Introduction

This chapter provides an overview of the aim and the research methodology used in this study. Rationale for the qualitative methods used is provided. It also outlines the research design, data collection techniques, method of analysis and ethical considerations for the study.

Aim

The aim of the study seeks to understand depression in grandparents as primary care givers to orphaned children.

Research Questions

1. How do elderly caregivers understand the causes of their depressive symptoms?
2. What are the symptoms of depression experienced by the elderly caregivers?
3. How do elderly caregivers perceive that the symptoms they have will progress?
4. What do elderly caregivers consider appropriate ways to address their symptoms of depression?

Research Design

In order to address the aims and research questions involved in this study, a qualitative approach was used. Participants were screened for depression and then three semi structured focus groups were conducted to capture the essence of the social situation under study.

The semi structured focus groups used an interpretive phenomenological research approach as this was best suited to understand the experiences as they are lived by the respondents. For phenomenology, human meaning is the key to the study of lived experience (J. A. Smith, 2007). The original Greek meaning of the word phenomenology is ‘bring to light’ which sums up the goal of phenomenological research in which a person’s lived experience is better understood (Moustakas, 1994).

To study a particular phenomenon, individuals having first-hand experience describe the experience. This then translates into gathering ‘deep’ information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participants (Lester, 1999).

Interpretive Phenomenological research has overlaps with other essentially qualitative approaches including ethnography which seeks to describe values and practices of cultures and communities (Mertens, 1998).

In multiple participant research, the strength of inference which can be made increases rapidly once factors start to recur with more than one participant (Lester, 1999).

As with other qualitative approaches, there is no methodological orthodoxy within phenomenology (Whiteford and Wilcock, 2000). Instead, the data should guide the nature and form of the study (Wilding & Whiteford, 2005). Interpretive Phenomenological research thus emphasises a holistic approach to studying human experience.

Study Site

The research was conducted at 1000 Hills Community Helpers in Inchanga, KwaZulu Natal. The site's vision is to improve the lives of HIV/Aids infected and affected children and adults through treatment, clinics, feeding schemes, counselling, home-based care, crèches and support groups. The primary healthcare clinic runs five days a week as well as a feeding scheme that also runs 5 days a week. HIV/AIDS infected patients are counselled by Care Givers as are bedridden patients.

The children's development facility with its extensive bathrooms and educational amenities provides food, clothing, respite and coaching to children who are currently living with extended family, foster parents or Grannies. Community care workers also make home visits and assist community members with home based care and social issues.

Research Participants

Participants were identified by the community workers at 1000 Hills Community Helpers as being grandparents who are caring for orphans. After initial screening for depressive symptoms using the PHQ-9, 17 participants were selected to take part in the focus group interviews.

All of the participants were African females, living in a rural community of Fredville, situated in the Valley of 1000 Hills, KwaZulu Natal. Their ages ranged from 50 years to 90 years. None of the participants were employed, although some were able to do temporary work when available. Most of the participants do receive a pension, which is their main source of income. Many of the participants were responsible for large families, comprising on average of 7 members, other than the orphans in their care. The participants had between 2 and 13 orphans in their care.

Sampling Method

Purposive sampling (Neuman, 2007) was used to obtain a sample of depressed grandparents of orphans. To obtain this sample, community workers at the 1000 Hills Community Centre identified grandparents caring for orphans; a depression screening was then administered. Specifically, grandparents at the Thousand Hills Community Helpers completed the PHQ-9 psychometric assessment which is used to screen for depression and which has proven effective in a geriatric populations (Löewe B ,et al, 2004 Medical Care). The PHQ-9 incorporates DSM-IV depression diagnostic criteria into a brief self-report tool. The PHQ-9 is thus a dual-purpose instrument that, with the same nine items, can establish provisional depressive disorder diagnoses as well as grade depressive symptom severity. Respondents who screened 5 or more on the PHQ9 were invited to participate in the focus group discussions, as a score of 5 and above would indicate varying degrees of depression, i.e. mild to severe depression. Participants were then randomly allocated to one of three semi-structured focus groups. In total 18 grandmothers were screen and 17 screened positive and were thus eligible to participate in the focus group discussions.

Data Collection

In order to gain an understanding of the participants experience of depression, semi-structured focus group discussions were utilised as a qualitative data collection tool. A total of three focus groups were conducted with the elderly grandmothers who had been identified using the PHQ-9 instrument. The discussions were held the Zulu speaking research assistant, while the researcher was in attendance. The open-ended discussions

with participants provided an atmosphere in which participants were able to speak freely, which gave the researcher a greater in-depth understanding of their experience of depression. It also allowed the researcher to facilitate the use of observation of participants in the group discussion, which was informative during the analysis of the data.

Data Analysis

Interviews conducted in isiZulu were translated into English with back-translation checks applied.

Due to the exploratory nature of this research, thematic analysis was used. Themes are patterns across data sets that emerge and are often associated with a specific research question. These themes then become the categories for coding the raw data (Braun & Clarke, 2006).

Thematic analysis consisted of the following steps:

1. Familiarisation with the data

This stage involves achieving a better understanding of the data (Terre Blanche, Durrheim, Painer, 2006). Repeated reading of the data as well as note taking allowed the researcher to become familiar with the data and to start making basic interpretation.

2. Searching for Themes

In this stage one becomes aware of overarching themes and sub-themes (Blanche, Durrheim, Painer, 2006). The researcher started to think about possible relationships between themes.

3. Generating Initial Codes

In this phase initial codes for themes were produced in a meaningful way.

4. Reviewing Themes

This phase allowed for further expansion on and revision of themes as they developed. Some existing themes were collapsed into each other, while other themes needed to be condensed into one.

5. Defining and naming themes

This phase involves further refining of themes. The researcher then identified each theme's essence and how each specific theme affects the entire picture of the data.

6. Producing the report

In the final step the researcher began the process of writing the final report. The goal of this phase was to convey the story the data tells across themes.

Ethical Considerations

- Ethical clearance for the study was obtained from the University of KwaZulu-Natal's Ethics Committee (Ethical Clearance No: HSS/0737/013M).
- Informed consent was obtained from each participant. Each participant was made aware of their right to withdraw from the study at any stage.
- Measures to avoid harm to participants were taken, for example to provide psychological assistance when deemed to be necessary.

- Confidentiality and anonymity was assured. Thus, all participants received a letter explaining the research aims and process and ethical considerations and asked to complete an informed consent form (see Appendix1).

Conclusion

In this study, a qualitative method approach was used, with data collection involving semi-structured focus group interviews. In this chapter, the research design, data collection, ethical considerations and data analysis was outlined.

Chapter 4

Results

This chapter presents the findings which arose out of the interview process and subsequent data analysis. Through the process of analysis which has been explicated in Chapter Three (Methodology) and using the conceptual framework discussed in the same chapter, the following themes emerged which help elucidate depression in elderly care givers of orphans.

The major themes included:

- Causes of Depression
- Exacerbating Factors
- Symptoms of Depression experienced by the participants
- Interventions perceived as Helpful by the participants

These themes, as well as the subthemes identified, will be examined below and substantiated by quotations taken from the interview transcripts. Firstly, results from the Patient Health Questionnaire 9, will be presented.

Patient Health Questionnaire 9

PHQ-9 psychometric assessment tool was used to screen participants for depression. The PHQ-9 has proven effective in geriatric populations (Löewe B, et al, 2004 Medical Care). The PHQ-9 incorporates DSM-IV depression diagnostic criteria into a brief self-report tool.

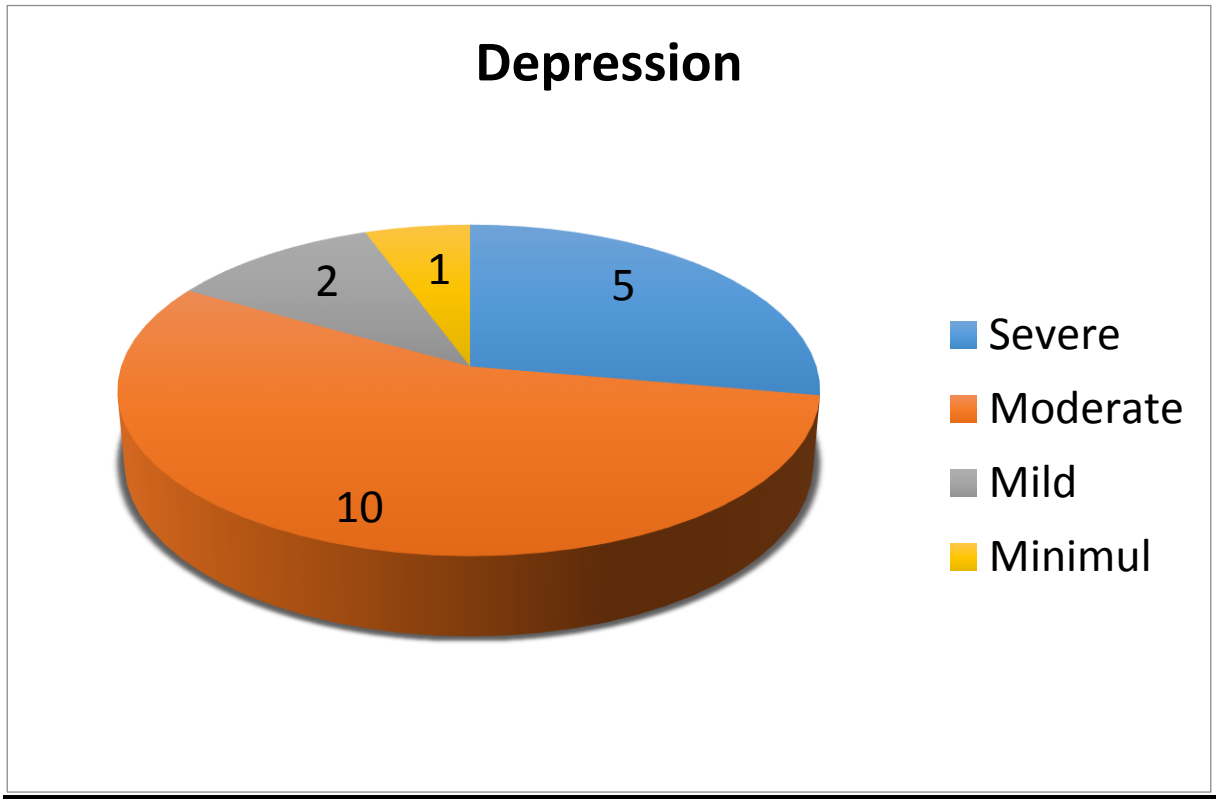
18 participants were screened for depression, of which the following results were found after scoring the Patient Health Questionnaires (see figure 1.1):

- 10 participants indicated a provisional diagnosis of moderate depression, this would indicate that psychotherapy is recommended and pharmacotherapy should be considered if deemed necessary.
- 5 participants indicated a provisional diagnosis of severe depression, indicating that immediate pharmacotherapy and psychotherapy is needed.
- 2 participants indicated a provisional diagnosis of minimal depressive symptoms, indicating that they may need some support and psycho-education.
- 1 of the participants indicated a provisional diagnosis of mild depression, indicating that a repeat PHQ-9 should be done, as well as a follow up.

Treatment as Indicated by the PHQ-9

PHQ-9 Score	Provisional Diagnosis ..	Treatment Recommendation *Patient Preferences should be considered*
5-9	Minimal Symptoms	Support, educate to call if worse, return in one month
10-14	Minor depression Dysthymia Major Depression, mild	Support, watchful waiting Antidepressant or psychotherapy Antidepressant or psychotherapy
15-19	Major depression, moderately severe	Antidepressant or psychotherapy
>20	Major Depression, severe	Antidepressant and psychotherapy (especially if not improved on monotherapy)

Figure 1.1: Showing the Severity of Depression in Screened Participants



Cause of Depression

Lack of Resources

Analysis of the transcripts revealed that the overarching concern of all participants was directly related to a lack of resources; expressed as a lack of food and/or income. Many of the participants reported that their pension was often the only source of income, with some participants having up to 13 children to feed.

Worrying where the next meal will come from is a preoccupation of the participants:

'I worry; when the food is finished I don't know what I am going to do.'

One participant described how she often has to sacrifice her own needs for the needs of her family:

'There are too many in my house. At meals I will only eat two spoonfuls then I give the children the food.'

Basic needs appear to be the major concern of all participants:

'The biggest problem is the money.'

There appears to be a direct relation between depression and a lack of resources:

'When all the food starts running out, I start thinking too much… This worries me a lot, where am I going to get food?'

Some participants had to rely primarily on the foster care grant as they are too young to receive a pension, but too old to find steady employment:

'I am too old to work; I only get a (foster care) grant. This is too small. It finishes earlier and then the food also finishes earlier (before the end of the month) and I don't know what I am going to do now'

One participant described how she uses her foster care grant on basic household needs and anything else is considered a luxury:

'Water costs R600. Electricity, then it's (the grant) finished'

Again, another participant describes having to use her pension on the needs of the orphan and having to stretch that money as far as she can:

'The thing that stresses me is that I am looking after this orphan but she didn't get a foster grant. I have to use my pension to help her because she is in school and when the food is finished I don't know what to do.'

As previously noted, many of the participants reported having to care for large families, over and above the orphans in their care. One participant described how her daughter's lack of responsibility was now affecting her:

'My older daughter has six children who are getting grants but she doesn't buy the children any food. So I have to help them with my pension.'

Social Isolation

Analysis of the transcripts also revealed a sense of isolation among the grandmothers. Some of the participants reported either not having or not knowing anyone that they could go to for support. Participants reported having worries regarding stigmatisation. They feared that others would judge them, if they were to talk about the problems they are facing.

One participant described how she no longer has any support:

'My son used to help me but he passed away. Now there is no one supporting me or the children.'

One participant expressed her irritation at having looked after an orphan into adulthood, but now that he is finished school, he is still not contributing to the family:

'He is older now but still eating my money. I am not working. Because he is older he is supposed to be working because the grant stopped'

A common sense amongst the participants was making sure that all appeared okay to people outside of their families:

' But you can't talk to your neighbours because they will laugh at you'

Although support can be obtained at the 1000 Hills community Centre, these resources too are limited. Members of the community are given the opportunity to volunteer at the centre in return for a monthly food parcel, which works on a rotational basis:

'I was working for Aunty Maduma (founder of the NGO) and she would help me, but now nothing.'

Oftentimes food and other goods that have been donated to the 1000 Hills Community Centre are distributed to members of the community. This is often the only lifeline to many of those in the community:

'I try hard until maybe I get something here (1000 Hills Community Helpers) that I can use for support'

Home Based Care workers from the Department of Social Development, as well as 1000 Hills Community helpers, visit community homes daily in order to assist those who cannot make it to the relevant resource centres, as well as to assess the need for food distribution. One participant reported feeling that this support too, is flawed:

'Sometimes the home base care workers come to our house but don't go inside so they can't see we need help.'

Exacerbating Factors

Analysis of the transcripts revealed that the participants had stress factors that cause/exacerbate their depressive symptoms.

Orphan's Behaviour

When asked about the challenges of caring for orphans, most of the participants reported having difficulty with the disrespectful, undisciplined behaviour and attitude of entitlement of the orphans in their care. A predominant sub-theme was the orphans having a sense of entitlement to their foster grant money.

Many of the participants reported that the orphans in their care would want money for school on a daily basis:

(Participant)'We worry because they want money every day and maybe we don't have. And if I do have money, how much I must give?'

(Interviewer)'Why do you have to give them every day?'

(Participant)'They will cry if we don't give it to them'

Participants generally found the orphans to be disrespectful:

'Children these days are too lazy.'

'They don't listen'

One participant explained how the orphans want certain things that they cannot afford:

'They want expensive clothes'

Participants appeared to be resentful of the fact that they are left with the burden of raising their grandchildren:

One participant expressed the fact that her child should still be alive and to take parental responsibility:

'They don't respect us and they don't respect the teachers. Their parents are supposed to teach them how to respect other people.'

One participant even reported experiencing difficulties with one child's rebellious behaviour:

'These children give me lots of stress, especially the one. He never listens to me. When I talk he puts on the radio. This boy smokes dagga.'

There also seemed to be a sense of attributing the orphan's difficult behaviour to the loss of their parents:

'He (orphan) lost his mother and father but he does a lot of things that make me stressed.'

One participant appeared to feel like there was no appreciation for the sacrifices she has made to care for these orphans:

'I started looking after this boy in 2002. Now he is older he doesn't want to stay with me. He sleeps all over. He comes home to eat the food. I have no grant, nothing.'

Again, another participant felt that she had no control over the orphans in her care:

'I ask them to go wash the dishes after school but all they want to do is play with the ball.'

One participant was concerned that the orphan in her care would also eventually become disrespectful:

'My child is good now and loves school, but I don't know if when she gets older if she will get an attitude'

Many of the participants reported that the orphans had expectations that they were owed things because of their parents passing away:

'Looking after these children is too hard. They complaining they want money. When their parents passed away they expect lots of things'

Grief

When speaking about their children who have passed away, many of the participants became emotional and struggled to speak about their loss. A sense of some of the participants still grieving the loss of their loved ones could be felt:

'*Sometimes the children do things that remind you of your child*.'(nodding and crying)

Symptoms of Depression

Analysis of the transcripts revealed that participants were experiencing a variety of depressive symptoms. These are listed below:

Rumination

The most common symptom, experienced by a large number of participants was depressive rumination. This was commonly expressed as the feeling that they are thinking too much. When asked how the stress of caring for an orphan/s was affecting their daily life, some of the participants expressed the following:

'I am thinking all the time.'

'It's, thinking all the time, thinking.'

Depressive Automatic Thoughts

Many of the participants appeared to have negative thought patterns, which seem to be related to the experience of chronic stress in their lives, as well as depression which has been left untreated for a significant period of time.

When asked how looking after an orphan was affecting her, one participant replied:

'This is destroying my life'

When asked what they could do to relieve some of their stress, some participants replied:

'nothing'

'There is nothing much you can do'

Physical Symptoms

A number of the participants reported having physical manifestations of depression, including appetite disturbance, sleep difficulties, lack of concentration and fatigue.

One participant acknowledged that her health deteriorated as a result of the stress related in caring for orphans:

'I had a stroke and can't work'

Another participant mentioned that looking after orphans affected her both physically, as well as emotionally:

'This stress destroys my life and I'm losing the weight because I am thinking too much. I don't know how to get help.'

Anhedonia

One symptom that appeared to be present in almost all participants was a loss of interest in activities or events that were once found to be enjoyable. Participants also reported hardly ever being able to do anything pleasurable for themselves. This could also be related to the fact that a lot of their time and resources were used on the orphan/s in their care.

When asked whether they ever did anything nice for themselves, one group began laughing in a manner that indicated even the idea itself was ludicrous. Another group, when asked the same question, responded only by making sounds of surprise.

Feelings of helplessness and hopelessness

Many of the participants felt that their situation was hopeless and that there was not much that could be done to improve things. Many participants also reported feeling quite helpless regarding their situation. Some did not know who they could turn to for help, while others reported experiencing frustration and dead-ends when they had sought help. This in turn contributed to feelings of hopelessness in the groups.

One participant related her challenges that she experienced; it was clear by the tone in her voice that she felt defeated:

'I have two children who were getting grants;, the problem is the one has lost her ID so I lost the grant. The grant stopped. Last month I never got the grant, even this month I didn't get the grant'

Many of the participants experienced frustration when pursuing assistance, which led to many of them feeling helpless about what to do next. Unfortunately due to a multitude of problems, social workers in the area often report having extremely high caseloads which then affects their ability to attend to 'less serious' cases in a timely manner. One participant related her experience of such issues:

'The grant has stopped since 2010. I am supporting that child with my pension. I have been to SASSA to reapply but they tell me to wait; it will come. Now I don't want to go back there. I have to pay school fees and buy food; I don't know how long I will wait.'

Some of the participant's sense of hopelessness was compounded by the feeling of guilt, for not being able to provide adequately for the orphans in their care:

'We want to give our children the best we can but it's not always possible'

When asked if anyone had ever done anything to help them that was useful, one group replied by collective sighing. This seems to speak to the overall sense of hopelessness that was felt in the room. It gave the sense that the participants felt that there was not much that could be done to improve their situations.

Possible Interventions

Perhaps due to the overall sense of hopelessness and negative thinking, the majority of the participants externalised the problem and felt an intervention would be best suited for the orphans themselves to help them have better manners and learn to respect their elders:

'It would help if someone could teach the children and help them to understand that today there is no money, if there is money another day I can give her. Then make them understand.'

However, they did agree that having a support group where they could share their stories and help each other would be a good idea and where they could learn how to handle the children under their care better.

'*Learning to deal with difficult children'*

(Participant)*'Something like now where we can see that we all have problems*.'

(Interviewer)*'Like a support group*?'

(Participant)'*Yes*'

A small number of participants did report having support systems that they felt brought them a sense of comfort. A main support system did seem to be their church community.

'I go to church and also talk to people at church.'

The 1000 Hills Community Centre is also a big support to members of the community, including the elderly:

'Someone brought me here that helped'

Chapter 5

Discussion

Introduction

The aim of the study was to explore the experience of depression amongst the elderly caregivers of orphans. This chapter provides an interpretation of the findings obtained. In this chapter the discussion of research results with reference to previous literature will be presented. It also looks at the strengths and limitations of the study findings. Finally it will give recommendations and conclusion of the study.

PHQ-9

As indicated by the number of grandmothers screening positive on the PHQ9, in which 17 out of the 18 elderly screened matched the criteria for depression, depression is a reality that appears to be affecting a large number of elderly caregivers of orphans. Most alarming is the number of participants, 5 out of 18, who fit the diagnosis of severe depression. This finding is especially significant as internationally there is a high degree of under diagnosis and under treatment of late life depression (Gottfries (2001).

The evidence from the focus groups suggests that caring for orphans has adverse effects on the elderly with subsequent consequences for their mental and physical health. A previous study found that the prevalence of depression in older South African Adults is at 4% (Peltzer & Phaswana-Mafuya, 2013), however in contrast to this the findings from the PHQ-9 administered to the participants in the study who are care givers of orphans, found that the prevalence of depression was much higher, with 75 percent of the

participants experiencing at least moderate depression. This shows that intervention for depression is needed in such groups.

Symptoms of Depression

In addition to feelings of helplessness and hopelessness, loss of interest in daily activities, appetite or weight changes, sleep changes, anger or irritability, loss of energy, concentration problems and unexplained aches and pains, all the caregivers described their depression as the experience of intrusive thoughts. This was described as ‘thinking too much’. Most participants reported experiencing intrusive thoughts, constantly worrying about their circumstances which cause them sleep and concentration difficulties.

This repeated dwelling or brooding is called depressive rumination (Edward Watkins, 2012). Rumination includes dwelling on a problem over and over again without getting anywhere, getting stuck thinking over why you feel depressed, repeatedly reviewing your failings and mistakes, and constantly judging and evaluating yourself (Edward Watkins, 2012).

Depression is associated with an increased tendency to focus attention on the self (Ingram, 1990). In particular, ruminative self-focus exacerbates dysphoria (Nolen-Hoeksema, 1991), and increases the likelihood, severity and duration of syndromal depression.

In an extensive programme of research, Professor Susan Nolen-Hoeksema, now at Yale University, has shown that this response style is characteristic of—and often perpetuates—depression. For example, a large-scale community study found that individuals who reported ruminating more frequently—e.g., almost always thinking "Why do I have problems other people don't have?"—when feeling down, sad or

depressed were more likely to have elevated symptoms of depression a year later than people who reported thinking these statements less often (Nolen-Hoeksema, 2000).

Many of the participants also displayed maladaptive cognitive structures, which could contribute to their experience of depression. In the 1960's Dr Aaron Beck discovered that depressed patients displayed a characteristic negative bias in their thinking. They continually had spontaneously occurring negative cognitions ("automatic thoughts" that were verbal or imaginal in nature) about themselves, their worlds, and their future (Beck, 2010). People generate negative thoughts so automatically they are unaware that it is happening, that it is actually a choice they are making (Marano, 2001). This would account for the negativistic thinking that the participants experienced.

With their negative cognitions only perpetuating the depressive cycle, the participants felt that caring for the orphans had negatively impacted their lives. The elderly spend every waking moment in this constant state of stress and worry. A loss of enjoyment in pleasurable activities was reported and the caregivers reported spending little time on concerns about their own health and wellbeing, often sacrificing what few resources they have for the orphans in their care.

Finally in a period of their lives where they should be enjoying retirement, many participants reported feeling hopeless about the future. Research on the cognitive theory of depression has shown that people who are depressed struggle with feelings of hopelessness and helplessness more so than people who are not depressed (Sacco & Beck, 1995).

Causes of Depression

Lack of resources

Economic hardship has previously been found to be a major risk factor for depression (Ross and Huber 1985). Income and support for these participants is scarce. Most have to rely on their pension, which if they are lucky enough, is supplemented by the small foster grant provided to them by the Department of Social Development. Problems with tracking down the ID documents of orphans which are needed to apply for this grant, once the parent has passed away, was experienced by some of the participants. Having been through the process of trying to apply for foster grants and having no further clarity regarding the outcome of such applications seems to reinforce a sense of hopelessness in some participants. Some participants reported having as many as 10-15 orphans in their care which is in line with the General Household Survey, done by Statistics South Africa (StatsSA, 2013), which found that that most South African Households comprise of seven members. Feeding this many people with one pension is very difficult.

Social Isolation

Grandparents are left with the guilt that they cannot provide for the orphans future (Kuo & Operario, 2011). During the focus groups, all of the participants spoke about the stress and worry of not providing enough for their families, as well as a sense of guilt that they were not able to provide adequately enough. Most participants in the focus groups felt that they could not turn to anyone for help for fear of judgement. This in turn perpetuates the cycle of depression and social isolation with the elderly withdrawing themselves from others.

A study on the causes of depression has shown that poor social network and support is a commonly reported cause of depression (Areán & Reynolds, 2005). Self-stigmatisation makes patients shameful and secretive and can prevent proper treatment(Wolpert, 2001).

Stigmatising beliefs about depression, whether actual or perceived, can have a substantial impact on people with depression. Perceptions that others may respond negatively may lead to help-seeking avoidance(Barney, Griffiths, Christensen, & Jorm, 2009)

Grief

Grief typically runs its course within 6 months, however during the focus groups, one could tell that the grief these participants were experiencing was still painful to them. This could be understood in a number of ways. Firstly it was reported that many of their children who have passed away were previously working and contributing financially. The loss of their child now brings with it a financial loss and therefore more worries.

At the same time they expressed the fact that burying a child is not the natural order of things and at any age parental grief is often severe and long lasting. Reddy(2005) also found that grandmothers often cannot go through the process of bereavement for losing a child as they have to be emotionally and physically strong to support the children left behind. A child's death caused by AIDS also increases the likelihood that the mourning process will be hindered (Winston, 2003).

Mixed with resentment toward their late children and the shame they feel for not taking adequate care of the orphans left behind, it is reasonable to see why the grief process can become complicated. Research on complicated grief shows that if left untreated, it can become a serious health threat to the individual (Sidney Zisook, 2009).

Exacerbating Factors

Orphan's Behaviour

These elderly caregivers have been robbed of the opportunity to be grandparents and to enjoy their grandchildren in this role. Instead they have been forced back into the role of parent. Research has found that children affected by HIV have substantial emotional issues, which could explain reports of them acting out (Linsk & Mason, 2004). In traditional African culture it is expected that a child will respect an elder and not to talk back to them. However, the participants associated this 'acting out' behaviour as being disrespectful. Nearly all the participants found their orphans to be rude and disrespectful. The participants also felt that the orphans displayed a sense of entitlement.

As mentioned in a study conducted by Kuo and Operario(2011), many of the participants felt that they were not providing adequately for the orphan under their care leading to many of them feeling pressure to provide money when they could actually not afford to. Smith and Segal (2014) suggest that grandparents as parents, may feel anger or resentment toward the grandchild's parents for leaving them with the responsibility of caring for their child. This study found a similar finding with some participants expressing resentment toward their late children who they felt should be around to teach and to discipline their own children.

Possible Interventions

Support

On a positive note, some participants did report finding some comfort in their church groups. This confirmed the idea that support groups for elderly caregivers of orphans could be useful. And although many of the participants felt that it was the orphans themselves who needed the intervention, they all did agree that having a support group, where they could find strength in each other would be a good intervention.

Limitations, Conclusion and Recommendations

Limitations

While undertaking this study, the researcher encountered some limitations. Most notably, the small number of participant's meant that one has to be cautious in generalising from the findings. This was particularly a challenge due to a number of participants not arriving for the focus groups as agreed upon.

When conducting any type of research it is valuable to carry out the research on a larger and more in-depth scale in order to allow a more thorough analysis of the study. However, the use of semi-structured focus groups provided very useful and meaningful data from the participants. These focus groups allowed the researcher to gain an invaluable insight into the participants' personal experiences of depression and its effect on their overall well-being.

In terms of the validity of focus groups, Kreuger (1994) suggests that they have high face validity, which is due in large part to the believability of comments from

participants. The advantage of having a high face validity allows for data to be easily understood since the results can be presented **in** lay terminology embellished with quotations from group participants (Kreuger, 1996). Reliability of Focus groups is also hard to establish, as it is difficult to standardize focus group interviews and respondents may be asked different questions they are encouraged to talk freely and in depth.

The second most notable limitation was the facilitation of the focus groups which had to be conducted in IsiZulu. One IsiZulu speaking fieldworker conducted the focus group, discussions as well as assisting in the translation. Due to the researcher's lack of understanding in IsiZulu, it also proved difficult to provide cues to the participants, and discussion was lead primarily by the facilitator who has a limited understanding of depression. Transcripts were translated into English and back-translation checks were applied in an attempt to ensure validity of the data gathered. It is important to note that misinterpretations and the loss of subtle distinction of meaning could have occurred, despite the presence of the researcher during the focus groups.

Another limitation relates to researcher bias which is always a risk in any type of research study. Albeit the researcher tried to be aware of and to be vigilant to researcher bias. Furthermore it could be argued that the type of data collected could leave room for interpretation due to its nature.

It is important to note that the emergent data can be interpreted in many different ways and therefore, qualitative research "…requires reflexivity on the part of researchers as to their role in the research process" (Petersen, 2000).

Finally measures to avoid harm to participants were taken. Psychological assistance was provided when deemed to be necessary. Informed consent was obtained from all

participants. Each participant was made aware of their right to withdraw from the study at any stage. Confidentiality and anonymity was assured and all transcripts and audio recordings were secured by the researcher.

Recommendations

Based on the results of the research, it can be seen that an intervention directed at depression in elderly caregivers of orphans as a result of HIV/AIDS is necessary. Firstly, further research would be necessary to identify whether this is a problem that is specific to one community or if this is a shared experience of elderly care givers of orphans in general.

A similar study could also be conducted with a larger group of participants. Further research is also needed in order to see how depression is affecting the elderly caregiver's ability to care effectively for orphans.

Secondly, low mental health literacy with respect to depression requires interventions to improve mental health literacy and promote help seeking and a more positive attitude towards those who are depressed. The government provides support to individual's caring for orphans through financial support mechanisms. While this alone is helpful to the individual, it could be of assistance if psychological support mechanisms were put in place for those who are battling emotionally to cope with their situation.

As many of the participants found the support that they received from the 1000 Hills Community Helpers centre to be of the greatest assistance to them, this could be an indicator of what kinds of interventions would be useful in similar communities. Mondays and Wednesdays is clinic day for the elderly, which deals specifically with the

needs of the elderly in the community. The kitchen runs a feeding scheme five days a week, Monday's to Friday's providing two meals a day, breakfast and lunch, which brings some relief for the grandparents to at least provide the orphans in their care with a hot meal. The children's development facility with its extensive bathrooms and educational amenities provides food, clothing, respite and coaching to these children who are currently living with caregivers or Grannies, where it is evident that the care giver is not managing.

Although these resources do exist there are still challenges in terms of mental health care for the elderly caregivers. Access to mental health care professionals is limited. A psychologist has been volunteering on a Thursday, however the case load for one person is very high. A psychiatrist is also available once fortnightly at a local clinic, however this clinic albeit local is some distance away and although referrals are made by the primary health care workers, members of the community report they do not attend due to cost of transport.

Given that access to mental health providers is limited, psychological support could be provided using a task sharing approach by primary and community health care workers who are already available in communities. These health care workers would need to be trained to provide psycho education on depression, grief support, empowerment of parents through training in parenting skills, as well as assisting in the support of elderly care givers of orphans through the formation of support groups.

These support groups could, in time, be run entirely by the elderly themselves, empowering them as well as forming a network of support. These support groups could also encourage participants to engage in income generating activities; making crafts or

growing vegetables or any other activity that would help grandmothers to become active as well as supplement their grant income and help to alleviate financial stress.

Conclusion

With a growing number of orphans in South Africa, grandparents often have to take on the role of caregiver. The information gained from this study focuses specifically on understanding the experience of a particular group of grandparents, of the Fredville Community, in relation to depression and the factors that they feel contribute to this. Results indicate that a number of factors played a part in either precipitating or perpetuating their depressive symptoms. Socio economic status, namely a lack of food and income played a large role in the causing and maintaining depression in the participants and was found to be largely the cause of depressive rumination.

The results also point to a sense of isolation and lack of support. Participants felt that they could not turn to anyone for help for fear that they may be judged for not being able to adequately care for the orphans in their care.

Many of the participants also found that the orphans' in their care displayed acting out behaviour and had difficulty in managing them, highlighting the need for parenting skills to be disseminated to the elderly and not only to young mothers.

References

The 2002 Uganda population and housing census, population composition. (2006). (Vol. null).

2008 report on the global AIDS epidemic. (2008). (Vol. null).

Barney, L., Griffiths, K., Christensen, H., & Jorm, A. (2009). Exploring the nature of stigmatising beliefs about depression and help-seeking: Implications for reducing stigma. *BMC Public Health, 9*(1), 61.

Beck, J. S. (2010). Cognitive Therapy *The Corsini Encyclopedia of Psychology*: John Wiley & Sons, Inc.

Blazer, D. G. (2003). Depression in late life: Review and commentary. *The Journals of Gerontology, 58A*(3), 249-265.

Bohne, A., Musil, C., Burant, C., & Warner, C. (2004). PREDICTORS OF DEPRESSIVE SYMPTOMS AMONG GRANDMOTHERS CARING FOR THEIR GRANDCHILDREN. *Gerontologist, 44*(1), 278-278.

Boon, H., Ruiter, R. A., James, S., Van Den Borne, B., Williams, E., & Reddy, P. (2009). The Impact of a Community-based Pilot Health Education Intervention for Older People as Caregivers of Orphaned and Sick Children as a Result of HIV and AIDS in South Africa. *J Cross Cult Gerontol, 24*(4), 373-389.

Chazan, M. A. Y. (2008). Seven 'deadly' assumptions: unravelling the implications of HIV/AIDS among grandmothers in South Africa and beyond. [10.1017/S0144686X08007265]. *Ageing & Society, 28*(07), 935-958.

A conceptual framework and basis for action: HIV/AIDS stigma and discrimination (World AIDS Campaign 2002–2003). (2002). (Vol. null).

Conway, F. (2004). THE RELATION BETWEEN COGNITIVE REAPPRAISAL TO PSYCHOLOGICAL AND PHYSICAL HEALTH AMONG AFRICAN AMERICAN AND LATINO GRANDMOTHERS CARING FOR THEIR GRANDCHILDREN. *Gerontologist, 44*(1), 652-652.

The cost of love. Older people in the fight against AIDS in Tanzania. (2004). (Vol. null).

Edward Watkins, P. D. (2012). Thinking Too Much in Depression

Can you analyze your problems and feelings too much? *Psychology Today*.

Gottfries, C.-g. (2001). Late life depression. *European Archives of Psychiatry and Clinical Neuroscience, 251*, II57-61.

Gould, P. R. (1993). *The slow plague: A geography of the AIDS pandemic* (Vol. null).

Gureje, O., Oladeji, B., & Abiona, T. (2011). Incidence and risk factors for late-life depression in the Ibadan Study of Ageing. *Psychological Medicine, 41*(9), 1897-1906.

Hansell, P., Hughes, C., Caliandro, G., Russo, P., Budin, W., Hartman, B., . . . Joslin, D. (2002). *Invisible caregivers: Older adults raising children in the wake of HIV/AIDS* (Vol. null).

Hayslip, B., & Kaminski, P. L. (2005). Grandparents Raising Their Grandchildren: A Review of the Literature and Suggestions for Practice. *Gerontologist, 45*(2), 262-269.

HIV-related stigma, discrimination and human rights violation. Case studies of successful programmes. (2005). (Vol. null).

HIV/AIDS and ageing: A briefing paper. (2003). (Vol. null).

Hosegood, V., Timaeus, I., Cohen, B., & Menken, J. (2006). *Aging in sub-Saharan Africa: Recommendations for furthering research* (Vol. null).

House, J., Lepkowski, J., Kinney, A., Mero, R., Kessler, R., & Herzog, A. (1994). *Journal of Health and Social Behavior, 35*(null), 213.

Hughes, M. E., Waite, L. J., LaPierre, T. A., & Luo, Y. (2007). All in the Family: The Impact of Caring for Grandchildren on Grandparents' Health. *The Journals of Gerontology, 62B*(2), S108-119.

Ice, G. H., Zidron, A., & Juma, E. (2008). Health and Health Perceptions Among Kenyan Grandparents. *J Cross Cult Gerontol, 23*(2), 111-129.

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. doi: 10.1080/09540121.2011.554527

Kuo, C., Operario, D., & Cluver, L. (2011). Depression among carers of AIDS-orphaned and other-orphaned children in Umlazi Township, South Africa. *Global Public Health, 7*(3), 253-269. doi: 10.1080/17441692.2011.626436

Lester, S. (1999). An introduction to phenomenological research *Taunton UK, Stan Lester Developments*.

Levecque, K., Van Rossem, R., De Boyser, K., Van de Velde, S., & Bracke, P. (2011). Economic Hardship and Depression across the Life Course: The Impact of Welfare State Regimes. *Journal of Health and Social Behavior, 52*(2), 262-276.

Lewis, S. (2005). *Race Against Time*. Toronto, Ontario, Canada: House of Anansi Press.

Linsk, N. L., & Mason, S. (2004). Stresses On Grandparents And Other Relatives Caring For Children Affected By Hiv/aids. *Health Soc Work, 29*(2), 127-136. doi: 10.1037/0022-006x.66.3.513.1998-02631-00810.1037/0022-006x.66.3.513

Long, J., Lichtenberg, P., Artinian, N., & Washington, O. (2004). Hypertensive African American Grandparents And Parental Stress. *Gerontologist, 44*(1), 477-477.

M.T. Yasamy, T. D., M. Harper, S. Saxena. (2013). Mental Health of Older Adults, Addressing a Growing Concern. Retrieved from

Marais, H. (2005). Buckling : The Impact of AIDS in South Africa. *University of Pretoria Press*.

Marano, H. E. (2001). Depression Doing the Thinking. *Psychology Today*.

Minkler, M., & Fuller-Thomson, E. (1999). The health of grandparents raising grandchildren: Results of a national study. *Am J Public Health, 89*(9), 1384-1389.

Ntozi, J. P. M., Nakayiwa, S., Orubuloye, I. O., & Caldwell, J. C. (1999). *The Continuing African AIDS Epidemic: Responses and Coping Strategies* (Vol. null).

Oldewage-Theron, W. H. S., T.J.C. (2008). Impact of food and nutrition interventions on poverty in an informal settlement in the Vaal Region of South Africa. *Proceedings of the Nutrition Society*.

Oosthuizen, P. N., D. Stein,D. and Seedat, S. (2005). ANXIETY DISORDERS. *Handbook for Psychiatry*.

Peltzer, K., & Phaswana-Mafuya, N. (2013). Depression and associated factors in older adults in South Africa. [Research Support, N.I.H., Extramural

Research Support, Non-U.S. Gov't]. *Glob Health Action, 6*(0), 1-9. doi: 10.3402/gha.v6i0.18871

Pruchno, R. A., & McKenney, D. (2002). Psychological Well-Being of Black and White Grandmothers Raising Grandchildren: Examination of a Two-Factor Model. *The Journals of Gerontology, 57B*(5), P444-452.

Reddy, P. (2005). Inkala ixinge etyeni: Trapped in a difficult situation"

The burden of care on the elderly in the Eastern Cape, South Africa. 6.

Ruiz, D. S. (2008). The Changing Roles of African American Grandmothers Raising Grandchildren: An Exploratory Study in the Piedmont Region of North Carolina. *Western Journal of Black Studies, 32*(1), 62-71.

Settles, B. H., Zhao, J., Mancini, K. D., Rich, A., Pierre, S., & Oduor, A. (2009). Grandparents Caring for their Grandchildren: Emerging Roles and Exchanges in Global Perspectives. *Journal of Comparative Family Studies, 40*(5), 827-XII.

Shishana, O., Rehle, T., Simbayi, L., Parker, W., Zuma, K., Bhana, A., & Pillay, V. (2005). *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey* (Vol. null).

Sidney Zisook, K. S. (2009). Grief and bereavement: what psychiatrists need to know. *World Psychiatry*.

Smith, G. (2008). THE IMPACT OF CARING FOR MULTIPLE GRANDCHILDREN ON CUSTODIAL GRANDMOTHERS' APPRAISALS OF CAREGIVING. *Gerontologist, 48*, 555-555.

Smith, J. (2008). *KwaZulu Natal province: District and province profiles* (Vol. null).

Smith, J. A. (2007). *Qualitative Psychology: A Practical Guide to Research Methods*: SAGE Publications.

Smith, M. M. A., and Segal,J. Ph.D. (2014). Grandparents as Parents

The Rewards & Challenges of Raising Grandchildren. *Havard Health Publications*

Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care, 21*(3), 309-314. doi: 10.1080/09540120802183461

StatsSA. (2013). *General household survey*.

Stein, D., Seedat, S., Herman, A., Heeringa, S., Moomal, H., Myer, L., & Williams, D. (2007). *Findings from the first South African Stress and Health Study* (Vol. null).

Uganda demographic and health survey 2000–2001. (2001). (Vol. null).

Wang, Y., & Marcotte, D. E. (2007). Golden Years? The Labor Market Effects of Caring for Grandchildren. *Journal of Marriage and Family, 69*(5), 1283-1296.

Ware, J. (2004). *The SF-36 Health Survey: An update* (Vol. null).

Wilding, C., & Whiteford, G. (2005). Phenomenological Research: An Exploration of Conceptual, Theoretical, and Practical Issues. *OTJR, 25*(3), 98-104.

Williams, A., Tumwekwase, G., Thomas, P., & Bissell, S. (1999). *Education for sustainable development* (Vol. null).

Winston, C. A. (2003). African American grandmothers parenting AIDS orphans: concomitant grief and loss. *Am J Orthopsychiatry, 73*(1), 91-100.

Wolpert, L. (2001). Stigma of depression – a personal view. *British Medical Bulletin, 57*(1), 221-224. doi: 10.1093/bmb/57.1.221

World population data sheet. (2002). (Vol. null).

APPENDIX 1

STUDY INFORMATION AND INFORMED CONSENT

Faculty of Humanities, Development and Social Sciences

Department of Psychology

Understanding depression in elderly caregiver's of orphans

Study Information Sheet

The Research Study

My name is Jessica Parker and I am a Counselling Psychology Masters student at the University of KwaZulu-Natal. As part of my Masters course, I am conducting a study for my final research dissertation. I am asking you to participate in a research study aimed at

understanding the lived experience of elderly grandparents who are caring for orphans and, their experience of depression.

What are we trying to learn?

In this research I am trying to understand how grandparents caring for orphans experience depression, and what has caused the depression.

Why is it important?

This study is important because insights gained from this study can help to develop more culturally and contextually appropriate psychosocial interventions for elderly caregivers of orphans. Thus depression could be prevented and treated more effectively.

Who will be involved and how long will it last?

Grandparents of orphans who have been found to be depressed from the 1000 hills community. Participants will be involved in one focus group.

What will it mean if you participate in the study?

If you agree to participate in this study you will be asked to answer a number of questions about your thoughts on caring for orphans and whether you believe this to contribute to your depression. How you are experiencing depression, the helpfulness of the treatment that you received, and what kind of treatment you think would have been most helpful. You will also be asked questions about any symptoms you may be experiencing as a result of your experience. The focus group will last approximately an hour and will be

recorded on an audio recorder. The interview will be conducted in the language that you are comfortable with (either English or an African language.

Is there any disadvantage from participating in this study?

Since the focus of the study is your thoughts about the depression that you are experiencing, there is a possibility that you may feel upset or distressed as a result of taking part in this study. If this is the case, you will be referred to a counselling centre where you can get psychological help.

What if I change my mind later?

Participation is completely voluntary so you are free to withdraw at any stage from participating in the study and your decision will not disadvantage you in any way.

Who will see the information that we collected?

All information will be kept completely confidential and your identity will be anonymous. In my final dissertation no research material will be used in which you may be identifiable. After the data has been analysed, it will be kept for five years in a safe and secure place in order to abide by the regulations of the University. Thereafter the tapes will be destroyed and the transcripts will be shredded. The data will only be seen by the researchers and supervisor.

Who to contact if you want to know more, or if you have a problem at any time?

Your participation will be highly appreciated, so if you want more information on the study before deciding whether or not to participate, or if you participate and later need help or have questions, please contact me or my supervisor:

Researcher:

Jessica Parker

E-mail: psych.jparker@gmail.com

Cell: 084 431 2505

Supervisor:

Prof. Inge Petersen

E-mail: PETERSENI@ukzn.ac.za

If you wish to obtain information on your rights as a participant, please contact Ms Phumelele Ximba, Research Office, UKZN, on 031 260 3587.

Consent to Enrol

I, _____ agree to participate in the research study on understanding the lived experience of elderly grandparents who are caring for orphans and, their experience of depression. I have received and understood the study information sheet. I have discussed the advantages and disadvantages of participating in the study and I agree to participate in the interviews as stated in the information sheet. I agree to have the stated interviews audio recorded with the understanding that my identity will be protected.

I know I can leave the research study at any time without prejudice and be referred for psychological help if need be.

Signature: _____

Name: _____

Date: _____

You may keep the information sheet. The signed consent form will remain in our study files.

APPENDIX 2

PATIENT HEALTH QUESTIONNAIRE - 9

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: _____ **DATE:** _____

Over the *last 2 weeks,* how often have you been bothered by any of the following problems? *(use "✓" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3
	add columns:		+	+
	TOTAL:			

10. If you checked off *any* problems, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?	**Not difficult at all** _____ **Somewhat difficult** _____ **Very difficult** _____ **Extremely difficult** _____

APPENDIX 3

INTERVIEW SCHEDULE

Interview Schedule:

1. Depression is a medical illness that causes a constant feeling of sadness in a person and lack of interest. Is that something you can identify with?
2. What do you think caused you to feel this way?
3. What other factors contribute to your feeling this way?
4. How do you think these symptoms affect you and your life?
5. What are your concerns about caring for orphans?
6. How do you think these symptoms should be treated?
7. Who would you turn to for help when you feel very sad and down?
8. Have you had any treatment that you found helpful?
9. Is there any other comments or questions that you have?