Cape Peninsula
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Guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member with HIV/AIDS

by

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DECLARATION

I, Siphesihle Delani Hlophe declare that the contents of *Self-management of youths who have lost a family member to HIV/AIDS in a Comprehensive Primary Healthcare clinic in Cape Town* represents my own unaided work, and that the thesis has not previously been submitted for academic examination towards any qualification and that all the sources have been indicated and acknowledged by complete references. Furthermore, it represents my own opinions and not necessarily those of the Cape Peninsula University of Technology.

December 2020

Signed   Date

ACKNOWLEDGEMENTS

This work is the result of both direct and indirect contributions of different people in my life. I would love to use this time to at least acknowledge the generosity of numerous people who have contributed to this success.

I wish to thank:

DEDICATION

I dedicate this thesis to my late mother, Busisiwe Pearl Madondo. Mama, I am sure that you are pleased with this achievement. You were not only the architect of my successes but also a reliable source of encouragement and strength in difficult times. Everything I do, I do it with pride and to make you happy as your one and only child.

To my aunt, Nonkululeko Madondo and my granny, Christina Nono Madondo: this degree is the fruit of your sacrifices, encouragement and unconditional love.

ABSTRACT

HIV/AIDS-related deaths often result in emotional turmoil in youths and added responsibilities by their parents, such as taking care of siblings. Youths may respond in various manners, such as increased alcohol use, and relationships with their siblings may be positively or negatively affected. There is also a high incidence of depression in people who are distressed, making them less likely to engage in active self-management strategies such as exercise. Youths visit public hospitals for various reasons, including panic attacks and anxiety, which are often experienced after the passing of a family member. The researcher has observed an increase in youths visiting a Comprehensive Primary Healthcare clinic in Cape Town after being traumatized due to the passing of a family member.

The purpose of this study was to develop guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member with HIV/AIDS.

A descriptive phenomenological design was followed for a study at Khayelitsha Site B Comprehensive Primary Healthcare in the Western Cape Province of South Africa. The sample was selected through purposive sampling until data saturation was achieved. Individual semi-structured interviews with 11 participants were conducted, after which data saturation was established. An interview schedule and field notes were used during the interviews, which were conducted in a private room with youth aged between 18 and 25 years who visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

Interpretative phenomenological analysis was conducted and findings indicated that time related circumstances define behaviour with which to manage death. Someone who unexpectedly loses a family member goes through specific stages of grief, ranging from emotions such as denial to acceptance. This grieving person also has to deal with difficult changes in daily lives and therefore need support measures. In the process of taking ownership of their new role of supporting others (who were previously supported by the departed person), they sometimes give up their own dreams. Sad experiences blocked out memories of good times with the deceased and participants focused mainly on obtaining support systems to move forward.

The findings of the study could benefit the broader community of nurses and provide self-management guidelines for youths visiting a Comprehensive Primary Healthcare clinic in Cape Town after losing a family member to HIV/AIDS.

KEY WORDS:

HIV/AIDS, family, outpatient, youths, Comprehensive Primary Healthcare (CHC)

ABBREVIATIONS

HIV/AIDS: Human Immunodeficiency Virus and acquired immunodeficiency syndrome

CHC: Comprehensive Primary Healthcare

OPERATIONAL DEFINITIONS

Self-management

Practising intentional self-care that can help family members to feel stronger, restore their sense of peace, and fill her/him with hope for what lies ahead (Wolf, 2019). In this study, it referred to the planning, organising, directing and control of the youths deal with after the loss of a family member, themselves.

Youth

Youths are defined as persons between the ages of 18 and 25 years and also involves the state or quality of being young, energetic and immature (UNESCO, 2017). In this study, youths were individuals of the above age that lost a family member to HIV/AIDS.

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1.1   INTRODUCTION

A family is often a source of emotional support, love, security and protection and may provide a unique sense of belonging and values that cannot be found in other relationships. The benefits of having a family are far-reaching and all-encompassing (Revilla, 2019). Therefore, after the death of a family member, the remaining family faces difficulties and health-related problems such as sleeplessness, especially in the first year following the tragedy (Glatt, 2018:103). The loss of a family member means that the surviving family members lose support they once had. For the remaining spouse, parenting becomes much more difficult (Glatt, 2018:103). This could require self-management, the simple act of practising intentional self-care that can help family members to feel stronger, restore their sense of peace and fill her/him with hope for what lies ahead (Wolf, 2019).

Self-management is defined by Lenzen, Daniels, Bokhoven, Van der Weijden and Beurskens (2017:1) as the degree to which persons have the ability to or want to control their own daily lives and cope effectively with adjustment. The primary objective of successful self-management is to increase one's own autonomy and improve one's health status (Crowley, Van der Merwe, Kidd & Skinner, 2019). It is usually better for the young person to learn self-management skills rather than to move out of home (Lo, 2018).

The management of oneself could decrease distress associated with a life event such as losing a family member. Empirical evidence confirms that health outcomes are enhanced in individuals who engage in self-management. Self-management is thus a process in which individuals use condition-specific knowledge and beliefs and self-regulation skills (Crowley et al., 2019).

Going through stressful times is part of life, but they may make you feel unfocused, overwhelmed and helpless. One should therefore find meaning in one's current struggle or situation, get plenty of rest, exercise regularly and eat healthily (Griffin, 2019).

Early clinical signs of HIV/AIDS, such as diarrhoea, tuberculosis, different infections, white patches on the tongue (hairy leucoplakia, oral candidiasis), losing weight, fever, skin problems, and shortness of breath, could be traumatic (Tharu, 2017). When a family member, e.g. a parent(s), later dies, the young family members who are left behind may start showing fear and confusion and may begin to have behavioural changes or withdraw from their emotions (Glatt, 2018:114). Youths who have lost their parents may also increase their alcohol use and their relationship with siblings may be positively or negatively affected (Glatt, 2018:115). Youths are defined as persons between the ages of 18 and 25 years and also involves the state or quality of being young, energetic and immature (UNESCO, 2017). The youth must be able to manage themselves when faced with the loss of a family member.

1.2 BACKGROUND

1.2.1 INCREASE IN HIV/AIDS

According to the United Nations Programme for HIV and AIDS (UNAIDS, 2020), at the end of 2019, there were around 38 million people of all ages living with HIV/AIDS globally. UNICEF (2020) also estimates that, globally in 2019, 38 million people lived with HIV. Of these, 2.8 million were children and adolescents below 19 years of age. UNAIDS (2020) states that in 2019, an approximate number of 1.7 million people were newly infected with HIV, and about 690 000 people died from AIDS-related causes, mostly because of inadequate access to HIV prevention, care and treatment services.

The UNAIDS (2020) states that since the start of the epidemic, more than 75.7 million people have been infected with HIV and a total estimated number of 32.7 million have died of HIV. A population of just above half a million, 690 000 people, has also died due to AIDS-related illnesses. According to Avert (2019), East and Southern Africa still have the most severely affected population. These parts of Africa are home to around 6.2% of the world's population but make out over 54% of the total number of people living with HIV in the world (20.6 million people are affected).

Of the 38 million people with HIV globally in 2019, South African had 7.5 million people with HIV/AIDS. In 2019, an estimated number of AIDS-related deaths in South Africa was 72 000 [58 000 – 89 000], with new HIV infections of all ages accounting for 200 000 people (UNAIDS, 2020: 80).

HIV is prevalent in African countries, as stated above. Eastern and Southern Africa remain the regions most affected by the HIV epidemic in Africa, accounting for 20.7 million people living with HIV in 2019 (UNAIDS, 2020: 6). An estimated 730 000 people living with HIV in Eastern and Southern Africa acquired the virus in 2019, and an estimated 300 000 people died of AIDS-related illnesses (Avert, 2019).

The number of AIDS orphans in South Africa is 1 200 000 (950 000 – 1 500 000). The global figure is 14 900 000 (11 300 000 – 19 100 000), with 7 500 000 (5 900 000 – 9 300 000) in Eastern and Southern Africa; 3 400 000 (2 400 000 – 4 600 000) in Western and Central Africa; and 110 000 (82 000 – 150 000) in Middle and North Africa (UNAIDS, 2018).

Western and Central Africa had 4.9 people living with HIV in 2019, of whom 420 00 are children. They experienced 140 000 AIDS-related deaths. Less than a third of children living with HIV/AIDS in the region were on treatment, the lowest coverage rate for this age group in the world (Avert, 2019). In Middle and North Africa, there were 240 00 people living with HIV, and amongst them were 20 000 new HIV infections and 8 000 AIDS-related deaths (AVERT, 2019).

1.2.2   HIV AND RELATED FACTORS

Approximately 62% of new global HIV infections in 2019 were among populations such as men who have sex with other men, sex workers, people who inject drugs and transgender people. In 2019, 1.8 million children aged 15 and below were living with HIV (AmfAR, 2019). HIV remains one of the top ten causes of death among adolescents aged 10–19 years. AIDS-related illnesses remain the leading cause of death among women of reproductive age (15–49 years) globally. The studies revealed that an estimated number of 1.7 million people became newly infected with HIV in 2019 (AmfAR, 2019). Statistics for 2020 are not yet available.

Table 1.1: South African HIV/AIDS statistics 2019

HIV/AIDS-related deaths 2019	
AGE GROUPS	STATISTICS – 72 000 [58 000 – 89 000]
Deaths due to AIDS among adults aged 15 and over	68 000 [54 000 – 85 000]
Deaths due to AIDS among women aged 15 and over	33 000 [25 000 – 42 000]
Deaths due to AIDS among men aged 15 and over	35 000 [29 000 – 45 000]
Deaths due to AIDS among children aged up to 14	4 100 [3 000 – 6 100]

1.2.3   EFFECTS OF HIV ON THE YOUTH AND FAMILY ENVIRONMENT

An estimated 13.4 million children and adolescents worldwide had lost one or both parents as of 2015. More than 80% of these children (10.9 million) live in Sub-Saharan Africa. In some countries which are badly affected by the epidemic, a large percentage of all orphaned children – for example 74% in Zimbabwe, and 63% in South Africa – are orphaned to HIV/AIDS (AVERT, 2017).

The United States President's Emergency Plan for AIDS Relief (2017) confirms that over 13.4 million children worldwide are living without one or both parents due to AIDS. UNAIDS (2018) states that 16.5 million orphans globally have lost one or both parents to AIDS.

According to UNAIDS (2018), the number of orphans in South Africa due to AIDS aged 0–17 years is 1 200 000 (950 000 – 1 500 000). Globally, there are 14 900 000 (11 300 000 – 19 100 000) such orphans; 7 500 000 (5 900 000 – 9 300 000) in Eastern and Southern Africa; 3 400 000 (2 400 000 – 4 600 000) in Western and Central Africa and 110 000 (82 000 – 150 000) in Middle and North Africa.

According to SOS Children's Villages (2017), there are 1.7 million children in South Africa who have lost parents due to AIDS. UNAIDS (2018) also confirms the same number of 1.71 million children through the death of one or both parents from AIDS.

In Africa, Mozambique has the leading rate, after South Africa, of children who have lost one or both parents to AIDS with 1.21 million, followed by Tanzania with 1.05 million, the Democratic Republic of Congo with 515 163, Zambia with 452 944, Botswana with 68 089, and lastly Namibia with 63 597 (UNAIDS, 2018).

Western and Central Africa have 280 000 AIDS-related deaths, which is higher among children aged 0–14 years). It is estimated that 5 million children (0–17 years) in Western and Central Africa have been orphaned by AIDS since the epidemic began (AVERT, 2017).

1.3 LITERATURE

Self-management is defined by Lenzen et al. (2017:1) as the degree to which individuals have the ability to or want to control their daily lives through coping effectively with symptoms of e.g. hurt and making lifestyle adjustments. Self-management is viewed as the management of the self, of one's own health and wellbeing, without any professional input. This could involve a range of activities such as taking medication, implementing positive health-behaviour, being health-conscious and fit, and performing activities that encourage psychological wellbeing, for e.g. relaxation (Crowley et al., 2019).

Self-management can be achieved through active and passive approaches. A passive approach helps to improve knowledge which does not necessarily translate to increased self-efficacy and behaviour change. For this type of approach to be effective, personalised information needs to be provided (Devan, Hale, Hempel, Saipe & Perry, 2018:382).

An active approach (including cognitive and behavioural strategies) develops self-management skills via self-reflection, solving problems and active goal setting. Positive health consequences for active self-management approaches are mainly determined by the quality outcomes (Dineen-Griffin, Garcia-Cardenas, Williams & Benrimoj, 2019: 11). Individuals must not discontinue practising self-management strategies, regardless of their emotional pain, as it is an ongoing healing process that is crucial for the development of the ability to separate the "self" from pain and to develop self-efficacy (Devan et al., 2018:393).

1.3.1   THEORETICAL DEPARTURE OF THE STUDY

Three strategies are associated with the self, namely behaviour-focused, natural reward and constructive thought strategies (Pavlovic, 2019). In this study it is assumed that the three strategies are part of self-management.

Cognitive (constructive thought) behavioural therapy in the context of self-management may be needed as an intervention to train attention and working memory to improve the ability to exploit episodic memories and solve problems. It was assumed that self-management in the cognitive behavioural domain:

- aims to encourage people to become their own therapist and to feel confident in managing their own situation (Martz, 2017); and
- involves self-monitoring, positive self-talk and the promotion of physical activity.

Behaviour-focused approaches were assumed to include:

- self-management support for individuals that may help to improve the wellbeing of individuals who are suffering due to the loss of a family member; and
- obtaining self-efficacy during self-management as support will help with behaviour change and enable the individual to manage their trauma better (Devan et al.,2018:382).

Natural reward strategies were assumed to create situations in which a person is motivated or rewarded by inherently enjoying aspects of activities. There are two natural reward strategies, namely:

- building more pleasant and enjoyable features into a given activity so that the task itself becomes naturally rewarding; and
- involving the shaping perceptions by focusing attention away from unpleasant aspects of a task and refocusing it on the task's inherently rewarding aspects.

Both strategies are most likely to create feelings of self-determination and competence, as well as acting as mechanisms of motivation (Pavlovic, 2019).

1.4 PROBLEM STATEMENT

It is essential to understand the experiences causing pain to individuals in order to optimise the design and delivery of self-management interventions (Devan et al., 2018:382). Youths could experience emotions such as fear and depression after the loss of a family member with HIV/AIDS. In some families, a young person must then act as a parent when the actual parent passes away to HIV/AIDS (Glatt, 2018:107). People who are experiencing pain are very likely to be depressed and consequently less likely to engage in active self-management strategies (Devan et al., 2018:394).

The youth visit public clinics for various reasons, but most of the visits are the result of panic attacks and anxiety experienced after the passing of a family member.

The research questions that came to the fore were;

- What are the lived experiences of youths managing themselves who lost a family member to HIV/AIDS?
- How should youth manage themselves after losing a family member to HIV/AIDS?

The health status of individuals may improve if they set goals and plan self-management, since this will improve self-efficacy and help them to change their behaviour (Lenzen et al., 2017: 2).

1.5 PURPOSE OF THE STUDY

The purpose of this study was to develop guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member with HIV/AIDS.

1.6 OBJECTIVES

The objectives of this study were to:

- Explore the lived experiences of youths on managing themselves after losing a family member to HIV/AIDS; and
- Develop guidelines for nurses to advise youths on self-management following the loss of a family member to HIV/AIDS.

1.7   POPULATION AND SAMPLING

Boswell and Cannon (2017: 278) define the study of a population as a study of the elements that meet specified criteria such as a person, a family member, a community, a medical record or an event. The research of a population covers the entire group of persons or objects that are of interest to the researcher, but the requirements or criteria that the researcher are interested in studying, must be met (Brink, Van der Walt & Van Rensburg, 2018: 116). In this study, the population was thus: Youths who had lost a family member to HIV/AIDS who visit a Comprehensive Primary Healthcare clinic in Cape Town.

Most of the time, a researcher hardly has access to the entire population, but when they do have access to and are able to study a population, it is called an "accessible population" or the "study population" (Gray, Grove & Sutherland, 2016).

In this study, the target population was youth participants aged 18–25 who had lost a family member to HIV/AIDS and visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

1.8   SAMPLING

Non-probability sampling was followed in this qualitative research as the researcher was unable to locate the entire population (Brink et al., 2018: 124). Non-probability sampling is constructed from an objective judgement as a starting point, and the direction the sampling takes will be a decision made by the researcher as the study progresses (Gray et al., 2016).

Purposive sampling was based on the researcher's judgement regarding participants who are typical of or especially knowledgeable about the study phenomenon. Participants were selected based on the features or characteristics which will help to explore the research questions (Brink et al., 2018:159). Suitability/eligibility criteria (in the form of inclusion and exclusion criteria) were used for the description of characteristics that the participants had to possess (Patino & Ferreira, 2018).

1.8.1   INCLUSION CRITERIA

The participants were:

- Males and females;
- Aged 18–25 years;
- Youths who lost a family member in the last 12 months to HIV/AIDS; and
- Youth who visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

1.8.2   EXCLUSION CRITERIA

The study excluded youths with a mental illness.

Data saturation determined the sample size. The researcher continued to collect data and asked probing questions until no new gaps, categories or themes emerged (Daniel, 2016). Eleven participants were individually interviewed in this study after which data saturation was reached.

1.9   DESIGN

Dudovskiy (2019) explains a research design as a general plan with which to answer research questions about data collection and analysis, which include research strategies and methods.

A *qualitative research* design indicates that a study is needed within a specific population to understand the needs of, desired outcomes of, or views on appropriate interventions held by the members of the group (Gray et al., 2016). Qualitative research makes the verbalisation of a phenomenon possible and helps to discover orientated research questions. It is descriptive and inductive in nature. Instead of using numbers, as in quantitative research, this research uses words to explain a phenomenon. The qualitative study took place in a naturalistic setting (LoBiondo-Wood & Haber, 2018: 88), exploring lived experiences of youth who lost a family member to HIV/AIDS.

A *descriptive phenomenological* design was followed in this study. A descriptive phenomenological design is used to develop a snapshot of the topic or phenomenon

of interest (Willis, Sullivan-Bolyai, Knafl & Cohen, 2016), youths managing themselves after losing a family member to HIV/AIDS. Descriptive phenomenology allowed the researcher to gain an understanding of the characteristics of a group of people (youth) in a given situation (Sekaran & Bougie, 2016: 43-44), where they lost a family member to HIV/AIDS. The study design was exploratory, descriptive and contextual in nature.

The *exploratory research design* sought to explore answers about the phenomenon, mainly focusing on "what", i.e. the lived experiences of participants, e.g. on losing a family member to HIV/AIDS (Holloway & Galvin, 2017:93). A *descriptive design* involved describing specific phenomena such as self-management of youth in the research area of losing a family member (Dudovskiy, 2019).

Malpass (2018) describes *contextual design* as conducting research by going out to a natural environment and observing or conducting interviews to find out more about your preferred study participants and their self-leadership. Holtzblatt and Beyer (2019) describe contextual design as a structured and well-defined user-centred design process that provides methods to collect data about participants in the field of study. In this study, a specific outpatient unit was the context in which the data, on the lived experiences of the participants, was collected.

1.10   METHOD

A qualitative research approach was used in this study, where individuals were interviewed using an individual semi-structured inquiry method with the youth visiting the Khayelitsha Site B, Comprehensive Primary Healthcare clinic.

The method of data gathering was through *phenomenological interviews* to gain an understanding of the lived experiences of individuals, which in turn helped to understand the phenomenon of managing oneself to losing a family member to HIV/AIDS being studied (Neubauer, Witkop & Varpio, 2019).

1.10.1 DATA GATHERING

Data gathering is a systematic process of gathering observations or measurements. Whether you are performing research for business, governmental or academic purposes, data collection allows you to gain first-hand knowledge and original insights

into your research. While methods and aims may differ between fields, the overall process of data collection remains largely the same (Bhandari, 2020). In the following section it will be explained how the field was prepared and data was collected and analysed.

1.10.1.1 PREPARATION OF THE FIELD

Permission was obtained from the Research and Ethics Committee of a Faculty of Health and Wellness at a university (Ethics clearance number: CPUT/HW-REC 2019/H2), and the Department of Health of the Western Cape Province, after applying on The National Health Research Database (Ethics clearance number: WC_201911_032). The unit manager of the Comprehensive Primary Healthcare clinic in Cape Town was contacted to obtain permission to place posters in the clinic, asking clients to partake voluntary after their examination/appointment at the clinic. The purpose and information on the study were provided on the poster. The use of a private room on the premises was asked. The unit manager was informed about the purpose of the study and advantages for giving advice to youth managing themselves due to losing a family member to HIV/AIDS. The researcher explained the purpose of the study. He then asked if staff working in the clinic, after their consultations with patients, could refer their patients, to a private room in which they could be interviewed. The research, purpose and their right to withdraw (Annexure A - information sheet) were explained to the participants. The interviews were conducted without disturbances in a private room and all participants also preferred the private room as the interview setting. They were asked to give written consent (Annexure B).

1.10.1.2 PILOT INTERVIEW

In a quantitative study, pre-testing of an instruments for possible faults in the instrument and determine whether the variables defined by operational definitions are observable and measurable (Brink et al., 2018: 161). In this study, the researcher followed a qualitative approach and started with a pilot interview with one participant to ensure that the semi-structured interviews answered the research questions that would address the purpose of the study.

1.10.1.3 INTERVIEWS

The researcher was the primary instrument for data collection in the semi-structured interviews as he posed the questions and pursued the participants' descriptions through probing (Denny, 2018).

The method of data gathering was through *phenomenological interviews* that are used to study the lived experiences of individuals in order to understand those experiences and the phenomenon (Neubauer et al., 2019).

Data was collected using individual semi-structured interviews, which allowed an exploration of the lived experiences of the participants and offered the potential to attend to the complexities of a research theme (Denny, 2018).

The first objective of this study explored the lived experiences of youths on managing themselves after losing a family member to HIV/AIDS. Phenomenological interviews with semi-structured questions were used to study the lived experiences of participants, which were sampled for this research.

All interviews were digitally recorded, and the device was tested to be in good working order before the interviews. The research questions on the interview schedule (Annexure B) were posed according to an interview schedule.

During the interviews, the researcher posed probing questions to the participants to examine or to discover more detail and to obtain an in-depth understanding of the phenomenon, e.g. "Can you tell me more about it?"

Verbal and non-verbal interactions between the researcher and participant shaped the data collected (Hong, Taylor-Lange, D'Oca, Yan & Corgnati, 2016). Interviews lasted 30–45 minutes. According to Daniel (2016), qualitative interviews usually last about an hour, although they could be much longer because of their in-depth nature. The more the researcher interviewed participants, the more efficient he became and less time the interviews took.

Data saturation was reached when no new information was obtained from the participants (Daniel, 2016).

The local language of the targeted area is Xhosa. The local language was also used for the sake of the participants who did not understand English. It helped them to express themselves freely. Their dialogue was then translated from the transcripts to English by the researcher (original language Xhosa0 was used.

Taking field notes was used as a means of documenting necessary contextual information. With the growing use of data sharing and data analysis field notes ensured that rich context can persists beyond the original research study. However, while widely regarded as essential, there is no guide to field note collection within the literature (Phillippi & Lauderdale, 2017), the researcher thus wrote notes he observed and made notes during the interviews.

Triangulation of methods was used to obtain rich data of shared experiences (Brink et al., 2018:84). Methods of data collection can also include observation, interviews and taking field notes (Moser & Korstjens, 2017). The researcher took field notes as an integral part of creating documentation and analysis in qualitative research. These notes provided a rich source of data which was used to examine the meaning of participants' words and actions in their context (Maharaj, 2016: 115).

1.10.1.4   DATA ANALYSIS

The researcher can speak a few languages and was able to translate transcripts from Xhosa to English. Transcribing appeared to be a straightforward technical task, but, in fact, involved judgements about what level of details to choose, data interpretation and data presentation. The transcription of data involves the close observation of data through repeated careful listening and watching; this is the first important step in data analysis (Daniel, 2016).

All interview data and field notes were coded together as soon as the interviews were concluded. The interviews in the local language were translated into English by the researcher and back translated by an editor who also speaks both languages.

Qualitative analysis of data involves the integration and synthesis of narrative non-numeric data which is reduced to themes and categories with the help of a coding procedure (Brink et al., 2018:46). Therefore, data was organised by the ATLAS programme, Version 8, to explore categories and themes. Open coding was followed

and an independent coder confirmed the analyses. The data analysis is discussed in Chapter 2. ATLAS.ti Version 9 Windows is a computer program used mostly, but not exclusively, in qualitative research or qualitative data analysis. The name ATLAS.ti is not an abbreviation but a name given to this scientific software.

From the data analysis, guidelines were developed according to Muller and Bester (2016: 108) by using the four themes discussed in Chapter 2.

1.11   TRUSTWORTHINESS

Polit and Beck (2017: 295) suggest four criteria for developing the trustworthiness of qualitative study.

Credibility was ensured through triangulation as it involved the use of different data collection methods in order to ensure consistency of the findings. For example, the researcher familiarise himself with the details of the individuals/accessible population under investigation, collecting data that was required by conducting one-on-one interviews to get in-depth information.

Dependability was ensured by using an independent coder who analysed the data and results of the study and had a consensus meeting with the researcher

In order to ensure *confirmability*, that the data reflected the voices of the participants, techniques of inquiry audit, reflexivity (fairness in inclusion criteria) and triangulation of data (interviews and fieldnotes).

Transferability in the study was established by providing a thick description of the methodology and findings as evidence that the research study's findings could be applicable to other contexts, situations, times and populations (Brink et al., 2018:159).

1.12   ETHICS

Ethical considerations were adhered to in the course of this study. Permission was obtained from the Research and Ethics Committee of a Faculty of Health and Wellness at a university (Ethics clearance number: CPUT/HW-REC 2019/H2), and the Department of Health of the Western Cape Province after applying on The National

Health Research Database (Ethics clearance number: WC_201911_032), and the Comprehensive Primary Healthcare clinic in Cape Town.

Participants were asked to participate voluntarily and were advised of their rights and that they could withdraw from the study at any point, should they feel uncomfortable to participate (Annexure A). The participants were made aware that a counsellor who was working at the clinic was available during and after the interviews if participants had the need to be debriefed and have a consultation. After explaining the process of the interviews and the benefits, all participants signed a written informed consent form (Annexure B).

The principles of withdrawal, informed consent, beneficence, privacy, autonomy, justice and confidentiality will be discussed in Chapter 2.

1.13   OUTLINE OF THE STUDY

The report is organised as follows:

CHAPTER 1

Introduction and background to the study: This chapter provided an introduction to all the chapters in the study. A detailed description of the participants and the study setting was given. The purpose of this study was to develop guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member to HIV/AIDS.

CHAPTER 2

In this chapter, the research methodology is discussed. The reason for using a qualitative approach is described and the limitations of using this approach are highlighted. The descriptive phenomenological research design was used to explore the lived experiences of youths after losing a family member to HIV/AIDS and to develop guidelines for nurses with which to advise youths on self-management after losing a family member to HIV/AIDS. Details of the study design, sampling method, data collection and data analysis are presented and the measures to ensure trustworthiness of the research described.

CHAPTER 3

This chapter outlines and discusses the research findings. The participants' demographic data as well as the summary of themes that emerged from the research were presented. The four main themes are discussed in detail and quotes from the transcripts are included to give a direct voice to the participants. Findings of the study are substantiated by literature.

CHAPTER 4

This chapter discusses the implications of this study on further research and the limitations of the study are outlined.

1.14   SUMMARY

The research study provided an in-depth understanding of the lived experience of youths who have lost a family member to HIV/AIDS. It can assist the broader community of nurses in providing guidelines on the self-management of youths after losing a family member to HIV/AIDS.

CHAPTER 2:   METHODOLOGY

2.1   INTRODUCTION

A qualitative research approach was followed in this study, where individual semi-structured interviews were conducted with the youth who visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

A *phenomenological research approach* was used, as it allowed the research to develop an in-depth understanding of self-leadership following the loss of a family member. Probing questions could be used to gain insight into the lived experienced of the individuals (Ellis, 2019: 48).

This chapter outlines the process in which the researcher obtained the purpose of the study.

2.1.1   RESEARCH DESIGN

According to Akhtar (2019: 68) the research design is considered a structure that binds research elements and the research project together. It is basically a proposed plan for the research work.

Qualitative research is the type of research that obtain its results from interviewing people and analysing the data. Qualitative research is a form of community inquiry that puts attention on the way people make sense of their own experiences and the world in which they live. Qualitative research has the objective – to understand, be able to describe and interpret social phenomena as supposed by individuals, groups and cultures (Holloway & Galvin, 2017: 3).

When using a qualitative research design to study a phenomenon, multiple data collection methods, ranging from interviews to observation, might be needed to understand the problem (Rutberg & Bouikidis, 2018: 209-211). This type of research is flexible and adaptable, allowing the researcher to develop a understanding of the phenomenon they are studying (Rutberg & Bouikidis, 2018: 209-211).

The word "qualitative" originates from a word quality. This means one is investigating the quality of something rather than the quantity, amount or strength of regularity (Boswell & Cannon, 2017: 136) of the phenomena under investigation.

A *descriptive phenomenological design* was followed. Descriptive phenomenological design is a research method used when doing a study that explore and give a description of the lived experiences of an appropriate, accessible population, such as youth which the researcher was interested in studying (Christensen, Welch & Barr, 2018; Lomotey, Bam, Diji, Asante, Asante & Osei, 2020: 151).

The study design was exploratory descriptive and contextual in nature. A comprehensive description of the studied population was produced, which was possible as the study is transparent and voices were heard (Reiter, 2017:129).

When investigating a research topic that is not well understood, descriptive research is the most appropriate and used design. Exploratory research is characterised by an absence of a formal structure and a high degree of flexibility (Essays, 2018).

In this type of research, the researcher tries to uncover the similarities in experiences of the current existing phenomenon and obtain new information about or insight into the problem. It all starts with the researcher's general ideas, and research outcomes are then used to find issues that relate to the topic of interest (Pratap, 2019).

Descriptive research was used to obtain information of current concern (Essays, 2018). The commonly used designs in nursing and healthcare research are qualitative descriptive designs due to their flexibility, simplicity and utility in diverse healthcare contexts. It can be difficult to clearly differentiate between a descriptive research design and the range of other methodologies at the disposal of qualitative researchers (Doyle, McCabe, Keogh, Brady & McCann, 2019).

As the name implies, it involves a description of a specific phenomenon in the research area (Dudovskiy, 2019) such as losing a family member.

Malpass (2018) describes *contextual design* as conducting research by going out to a natural environment and observing, or conducting interviews to find out more about your preferred study participants and their motivations. Holtzblatt and Beyer (2019)

describe contextual design as a structured and well-defined user-centred design process that provides methods with which to collect data about participants in the field. In this study, a specific outpatient unit will be the context for data collection.

The core philosophy of contextual design is that the researcher can become familiar with the participants' fundamental intents, desires and drivers. The only way to gather this information is to go out in the field and talk to them (Holtzblatt & Beyer, 2019).

2.2 PHENOMENOLOGICAL APPROACH

Phenomenology is a qualitative approach to research that aims to develop a new understanding of the lived experiences of individuals or a population, obtained through participant interviews. It depends on first-person accounts, through which insights are developed and meanings generated (Gentles, Charles, Ploeg & McKibbon, 2015:1773). Phenomenology derives perspectives defined by experience and circumstance, and the benefit of this research is that a deeper and/or boarder understanding of these perspectives can be obtained. To ensure that perspectives are revealed, rather than prescribed, phenomenology avoids abstract concepts. The researchers do not ask participants to justify their opinions or defend their behaviours. Rather, they investigate the participants' own terms in an organic way, since people do not share the same interpretation of words or labels (Matt, 2017).

Phenomenology is used to explore unstructured and conversational interviews (Matt, 2017). According to Guerrero-Castañeda, Menezes and Ojeda-Vargas (2017: 3), however, a phenomenological approach uses interviews with other frameworks for data collection. Some of the most common methods are structured and semi-structured interviews, in-depth interviews and interviews in focus groups with open questionnaires.

When the research asks a "why" question, it can cause participants to respond in ways that they think the researcher wants to hear, which may not be what is in their thoughts or heart. Instead, phenomenology researchers obtain stories from research participants by asking questions like: "Can you tell me an example of when you …?" or: "What was it like …?" In this way, the researcher seeks and values context as much as the action or the experience (Matt, 2017).

The phenomenological questions are in the form of an interview that is structured or semi-structured. "Inside-out" questions are asked, such as: "What does this mean to you?" or "Can you please describe in as much detail as possible a situation in which you experienced …?" (Alirezaei & Latifnejad-Roudsari, 2020: 1986). These types of questions allowed the researcher to ask probing questions as a means of follow-up (Alirezaei & Latifnejad-Roudsari, 2020: 1987).

2.3   STUDY SETTING

South Africa has a population of over 56.5 million people living within nine different provinces and 52 health districts (Bresick, Von Pressentin & Mash, 2019: 110). This study took place in Khayelitsha township. Khayelitsha is a low-income residential area in the Cape Flats, Cape Town. The township, established in 1983, was meant to provide housing (small two bed-roomed houses) to about 120 000 African people in Cape Town. The name Khayelitsha is Xhosa and means "Our new home". The creation of this township was a result of the influx of the African population from the Eastern Cape in search of employment (Lusinga & De Groot, 2019: 202).

According to Lusinga and De Groot (2019: 202), the township is made up of two main housing types. Around 45% are formal houses, while the other 55% is made up of shacks in informal areas or the backyards of formal houses. Khayelitsha's formal houses are generally small and generally have between two and four rooms. This township is mostly populated by black South Africans and African migrants, who make up 98.6% of the total.

Demographically, the area has many young people. 28.1% of its population is under the age of 14 years, 70.2% is between 15 and 64 years old and only 1.6% is aged 65 years or above. Khayelitsha is a very poor township, with 74% of the households earning R3 200 or less a month. Due to the separation of races during apartheid, Khayelitsha is located far from the City. As a result, the township is cut off from the most financial middle and lacks employment opportunities. Unemployment rates are around 40%. There are high levels of poverty and criminal activities. Many of its populations work in low-wage employment including domestic work, entrepreneurs in the informal sector and refuse collection (Lusinga & De Groot, 2019: 202, & Smit, de Lannoy, Dover, Lambert, Levitt, & Watson, 2016: 198).

Figure 2.1: Map of South Africa

2.4 POPULATION AND SAMPLING

Polit and Beck (2018:162) define population as the entire group of people that the researcher is interested in. A population can be a family member, a community, a medical record or an event. A population is the entire collection of elements. The population that the research intends to research about is called the target populations. This population meets the criteria and requirements that the researcher is interested in studying (LoBiondo-Wood & Haber, 2018: 213). The population was thus: youths who lost a family member to HIV/AIDS who visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

When the researcher has access to and can study the population, it is called an "accessible population" or the "study population" (LoBiondo-Wood & Haber, 2018:213). In this study, the target population was young participants aged from 18–25 years who have lost a family member to HIV/AIDS and visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

2.4.1 SAMPLING

The non-probability sampling technique is a technique that does not allow the probability that elements in the population all have a chance to be included in the study sample (Etikan & Bala, 2017: 215). In this type of sampling, the access to the elements or population is limited and the researcher cannot be certain that all participants have an equal chance to participate (Brink et al., 2018: 124).

Purposive sampling of qualitative research is guided by the principles of ethics and the opportunity of gaining access to the population who could provide the researcher with rich data through observation or in-depth interviews (Holloway & Galvin, 2017: 143). Participants are selected based on the features or characteristics of the phenomenon to help explore the research question (Holloway & Galvin, 2017: 143), also in this study.

Suitability/eligibility criteria is where the researcher specifies the population of the study in order to determine whether the person qualifies through what is called inclusion and exclusion criteria (Polit & Beck, 2018: 162).

2.4.2 INCLUSION CRITERIA

To be included, participants had to be:

- Males and females;
- Aged 18–25 years;
- Youths who lost a family member in the last 12 months to HIV/AIDS; and
- Youth who visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS.

2.4.3 EXCLUSION CRITERIA

The study excluded youths with a mental illness.

Data saturation determined the sample size. During data collection, probing questions were asked until no new gaps, categories or themes emerged, and thereafter no new interviews were conducted. Eleven participants took part in the study.

2.5   METHOD

A qualitative research approach was employed in this study, with semi-structured individual interviews conducted with a sample of 11 youth who visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS. Individual interviews were held based on the inquiry method and a semi-structured interview guide.

The approach to data gathering was phenomenological. A phenomenological approach to interviews allows the researcher to gain an in-depth understanding about a phenomenon, through the use of probing questions that yield insight into the lived experienced of the individual (Ellis, 2019: 48).

2.5.1   PREPARATION OF THE FIELD

Permission was obtained from the Research and Ethics Committee of the Faculty of Health and Wellness at a university, and the Department of Health of the Western Cape Province (see Annexure E). The unit manager of the Comprehensive Primary healthcare clinic in Cape Town was contacted to obtain permission to place posters in the clinic, asking clients to partake voluntary after their examination/appointment at the clinic. The purpose and information on the study were provided on the poster. The use of a private room on the premises was asked. The unit manager was informed about the purpose of the study and advantages for giving advice to youth managing themselves due to losing a family member to HIV/AIDS. This all happened after the researcher has first received approval from the Department of Health of the Western Cape Province to conduct the study at this clinic. The researcher explained the purpose of the study. The researcher also indicated that he would present health talk with patients around the topic of HIV/AIDS and related problems. He asked staff, after consultations with patients, to refer them to a private room for the interviews. The purpose of the research was explained to the participants, along with the voluntary nature of their participation and their right to withdraw at any time. Participants were given a choice of whether to be interviewed in their natural setting (at home) but all chose to be interviewed at the private clinic room where there were no disturbances. The research setting was a natural setting and all were comfortable with being

interviewed in a private room allocated. Finally, they were all asked to give informed their written consent to participate.

2.5.2   PILOT INTERVIEW

A pilot study allows the researcher to give the questions a 'trial run' in order to evaluate the data collection instrument and ascertain if participants understand all questions (Polit & Beck, 2018: 35). It was a small-scale study conducted before the major study, and helps assess the feasibility of the questions and the method. In this study, the researcher started with a pilot interview with a participant to ensure that the research questions yielded answers that would address the purpose of the study.

The pilot interview data was included in the final analysis as the pilot study resulted in answering the research questions.

2.6   DATA COLLECTION

The researcher was the primary instrument for data collection in semi-structured interviews, as he posed the questions and pursued the participants' descriptions through probing (Denny, 2018).

Neubauer et al. (2019) concur that phenomenological interviews are ideal for studying the lived experiences of individuals, in order to understand those experiences and the phenomenon. The benefits of phenomenological interviews are that they yield (1) unique perspectives – enabling the researcher to gather direct information regarding how people perceive an event or phenomenon; (2) understanding – they provide a profound, detailed source of understanding of a single phenomenon, and (3) rich data. This is the form of research that allows qualitative data to emerge that is rich and varied and enables a researcher to truly understand a topic. (Ayres, 2017).

Phenomenological research is meant to explore the lived experiences of participants. Through it, the researcher and the participant work together to enhance understanding of the phenomenon being studied (Alirezaei & Latifnejad-Roudsari, 2020: 1986).

One of the primary objectives of this study was to explore the lived experiences of youths on managing themselves after losing a family member to HIV/AIDS. Phenomenological, semi-structured interviews were deemed the best way to probe

the lived experiences of individuals whose responses would help answering the research questions.

A semi-structured interview has a few structured questions that are combined with unstructured, unplanned, probing questions. Probing questions arose during the interview based on what the participant told the researcher and were free flowing in nature. They enabled the researcher to understand more about what was being said by the participant (Bhasin, 2019), and offered the potential to address the complexities of a research theme (Denny, 2018).

All interviews were digitally recorded, and the device was tested and ascertained to be in good working order before the interviews were conducted. The research questions were posed to participants, with the interview schedule (Annexure C) acting as a guide.

During the interviews, probing questions were asked in order to uncover more details where necessary, to obtain an in-depth understanding of the phenomenon. An example of a probing question was, "Can you tell me more about it?"

Verbal and non-verbal interactions between the researcher and participant shaped the data collected (Hong et al., 2016). Interviews took 30 - 45 minutes to complete. According to Daniel (2016), qualitative interviews usually last about an hour, sometimes much longer because of the in-depth nature of some interview. In this case, the more the researcher interviewed participants, the more skilled he became at posing questions, and interviews took less time.

Data saturation was reached when no new information was added. This point was reached when the participants started to sound the same and the researcher was confident that he had sufficiently answered the research questions. At this point the researcher may decide to stop collecting data and analyse what has been collected *(*Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, Burroughs & Jinks, 2018: 1893).

The local language of the targeted area was isiXhosa, which was used by the researcher when needed. The local language was used for the sake of the participants

who did not have understood English, enabling them to express themselves freely. Data responses were translated into English during data analysis.

Triangulation is known as the method that is used to increase credibility and validity in the research findings. "Triangulation, by combining theories, methods or observers in a research study, can help ensure that fundamental biases arising from the use of a single method or a single observer are overcome" (Noble & Heale, 2019: 67). Taking field notes was an integral part of documentation and analysis in this study. These notes provided a rich source of data for examining the meaning of participants' words and actions in their context (Flick, 2018: 2).

2.7   DATA ANALYSIS

The researcher spoke both English and isiXhosa and some transcripts were translated from isiXhosa to English.

Data transcription begins with establishing the unit of analysis to be studied, as well as choosing the individual to conduct the analysis, in most cases it is the research him/herself. The entry addresses the process by which information is or is not included in a transcription, as well as the types of transcription that may occur. Finally, it situates data transcription within the qualitative research process and details what someone may anticipate from a transcription and the transcription process (Churcher, 2017: 1).

All interview data and field notes were coded as soon as the interviews were concluded. The interviews in the local language were translated into English by the researcher and back translated by an editor who also spoke both languages, for dependability.

Qualitative analysis of data involves the integration and synthesis of narrative non-numeric data which is reduced to themes and categories with the help of a coding procedure (Brink, Van der Walt & Van Rensburg, 2018: 46). Data was organised by the ATLAS.ti programme, Version 8, to explore categories and themes. ATLAS.ti is a computer programme used mostly, but not exclusively, in qualitative research or qualitative data analysis. The name ATLAS.ti is not an abbreviation but a name given to this scientific software.

Re-contextualisation is when the meaning of units has been acknowledged; the researcher need to check whether all aspects have been covered from the context in relation to the purpose of the study by re-reading the original text alongside a list of meaning units (Bengtsson, 2016: 12). The third step is categorisation. Before categorising the extended meanings, units must be reduced without losing their content (Bengtsson, 2016: 12). Fourthly, compilation occurs, when the categories are established, and the analysis and writing up process begins (Bengtsson, 2016: 12).

An independent coder was enlisted to ensure that correct codes were applied and that his version of the codes aligned with the researcher's. Although the generic use of a coder is to ensure measurement consistency, a coding assistant was appropriate here for reliability. When two or more independent coders share the same opinion on the coding of relevant content with the implementation of the same coding scheme, this is known as independent coder reliability (Palazzo, 2019). The researcher and the researcher had a continuous meeting.

2.7.1   DEVELOPMENT OF GUIDELINES

Objective two was to develop guidelines for nurses to advise youths on self-management following the loss of a family member to HIV/AIDS, with which to advise youths on self-management following the loss of a family member with HIV/AIDS.

The method used by Muller and Bester (2016: 204) to develop guidelines was applied during this research study. The steps followed were:

This process of data analysis involved identifying guidelines from the themes, which in this case were collaborative approach, decision-making, resources management, quality assurance to procure agency nurses, time related-circumstances define behaviour to manage death, stages of going through the unexpected loss of a family member, difficult changes in daily lives of the next of kin, and support measures for next of kin. The theme headings served as a departure point to formulate the overall broad guidelines to procure agency nurses. The themes that emerged are, time related circumstances defined behaviour to manage death of a family member, youth go through different stages after the unexpected loss of a family member, managing

difficult changes after the unexpected loss of the family member, and support measures for the next of kin.

A guideline has a rational and activities. A rationale was written based on supporting literature for each guideline. This was written in relation to the context of the study. Based on the findings of the themes, specific actions were described to meet the proposed guidelines.

Each action was described with reference to the appropriate literature to support the recommended actions where needed.

Guidelines are addressed in Chapter 4. After refinement of the guidelines, the guidelines were concluded.

2.8   TRUSTWORTHINESS

Brink et al. (2018:159) suggest four criteria for ensuring the trustworthiness of a qualitative study.

Trustworthiness in qualitative research is one way that can persuade researchers and readers that the findings of the study are worthy of attention. The concept of trustworthiness is by introducing the criteria of credibility, transferability, dependability, and confirmability to parallel the conventional quantitative assessment criteria of validity and reliability (Nowell, Norris, White & Moules, 2017: 3). "Transferability is communicated through description of sampling factors such as: geographical location of the study, number and characteristics of participants, and the timeframe of data collection and analysis" (Johnson, Adkins & Chauvin, 2020: 145).

The process of demonstrating the credibility of research is rooted in honest and transparent reporting of how biases and other possible confounders were identified and addressed throughout study processes (Johnson et al., 2020: 145).When researchers or readers are encountered with the experience, they can recognize Credibility. Credibility seeks to addresses the "fit" between respondents' views and the researcher's representation of them. The techniques that are used to address credibility involved activities such as prolonged engagement, persistent observation, data collection triangulation, and researcher triangulation (Nowell at al., 2017: 3).

Dependability – for researchers to achieve it they need to ensure that the research process is logical, traceable, and clearly documented. When readers are able to examine the research process, they are better able to judge the dependability of the research. One way that a research study may demonstrate dependability is for its process to be audited at the end (Nowell at al., 2017: 3). The research method was reported in detail to ensure dependability so that the reader could determine proper research practices that were followed and that future researchers can repeat the study (Johnson et al., 2020: 145).

Confirmability is concerned with establishing that the researcher's interpretations and findings are clearly derived from the data, requiring the researcher to demonstrate how conclusions and interpretations have been reached. Confirmability is established when credibility, transferability, and dependability are all achieved (Nowell at al., 2017: 3). The confirmability of the results was through letting the voice of the partcipants heard, the triangulation of the field notes and data notes analysis, and going back to the participants to clarify their answers on the notes (member checking).

Transferability refers to the generalizability of inquiry. In qualitative research, this concerns only to case-to-case transfers. The researcher provided thick descriptions, so that those who seek to transfer the findings to their own site, can evaluate transferability (Nowell at al., 2017: 3).

2.8.1   ETHICS

Research ethics is concerned with treating research participants with respect throughout the research study, and with adhering to ethical practices with regard to the handling and storing of their data. It also refers to the trustworthiness of the study and the truth of the findings as reported. Ethical standards are designed to protect all parties; participants, researchers and their institutions, and the reputation of research (Alderson & Morrow, 2020: 3). According to the World Health Organisation (2020) research ethics govern the standards of conduct for scientific researchers. It is important to follow ethical principles in order to protect the dignity, rights and welfare of research participants.

In this study, participants were asked to participate voluntary and were advised of their right to withdraw from the study at any point should they feel uncomfortable with

participating (see Annexure A). To prevent harm, they were also made aware that a counsellor working at the clinic was available during and after the interviews if participants felt the need to be debriefed and have a consultation (Annexure A: Information sheet). The researcher explained the process of the interviews and the benefits of the study, and all participants signed a written informed consent form (see Annexure B).

All research involving human beings should be reviewed by a recognised ethics committee to ensure that the appropriate ethical standards are upheld as stipulated. A discussion of the ethical principles of beneficence, justice and autonomy are central to ethical review (WHO, 2020). The research ethics committee reviewed the research design, recruitment strategy, informed consent process and protection afforded to the research subjects, and the manner in which their rights are respected (Hickey, 2018:15). The committee did review the application in light of their established criteria and may decline to consider the application pending the receipt of additional information (Hickey, 2018:15).

2.8.1.1 PRINCIPLE OF RESPECT FOR THE PERSON

Individuals' names were kept anonymous, they had the right to decide whether they wanted to participate in the study or not and they could withdraw at any stage of the study. The researcher endeavoured to treat each person with respect and sensitivity in view of the sensitive subject being probed.

2.8.1.2 PRINCIPLE OF BENEFICENCE

The researcher also endeavoured to uphold the principle of beneficence, which means to have an attitude of good intent toward the participants and to protect them from all harm. Participants who decided to participate in the study were not showing extraordinary emotional feelings about the topic under discussion, which was the loss of a family member. The researcher was sensitive to this fact and took the trouble to ensure that a counsellor was available at the clinic should the participants feel the need for one. In the event of any unforeseen circumstance, the interview would have been stopped, and the necessary assistance would have been given by the counsellor. In the end, there was no need for the help of the counsellor. The data was presented

to the participants after the study, when requested by them. An article will be published in an accredited journal after conclusion of the study.

2.8.1.3 PRINCIPLE OF JUSTICE

All participants had the right to fair selection and treatment. Fair selection was ensured in this study based on whether a particular participant met the inclusion criteria of the study. The Research and Ethics Committee of the Faculty of Health and Wellness of the university, considered every aspect of the research process, including the ethical aspects.

2.8.1.4 PRINCIPLE OF ANONYMITY

No name appeared on the interview schedule and the recordings were all numbered with no name mentioned on them. No names were mentioned in the findings and a numbering method used.

2.8.1.5 PERMISSION TO CONDUCT THE STUDY

When conducting this research, all the gatekeepers were respected by obtaining ethical clearance from the Research and Ethics Committee of the Faculty of Health and Wellness of the university (CPUT/HW-REC 2019/H2), as well as the ethics committee of the Department of Health (DOH) in the Western Cape (WC_201911_032). Permission was requested to conduct research in the Comprehensive Primary Healthcare clinic in Cape Town (Annexure D), and the researcher informed the management of the clinic about the research before it was conducted.

2.8.1.6 CONFIDENTIALITY

All information provided by the participants was kept securely and seen by no one other than the researcher and the assistant coder. Analysed data was available only to the researcher, supervisor, and data adviser, and was kept in a file on Google drive. It will be stored there for five years after the research report has been submitted, and then deleted.

2.9   SUMMARY

The researcher used a qualitative, descriptive study design. Semi-structured interviews were conducted to obtain data from a purposively selected sample of eleven (including pilot) participants. The researcher used open-ended questions in interviews, allowing participants to volunteer more detailed descriptions and narratives. Inclusion criteria were that participants had to be youth males and females aged 18 to 25 years who had lost a family member in the last 12 months to HIV/AIDS and who were visiting the Comprehensive Primary Healthcare clinic in Cape Town where the interviews were conducted.

When conducting this research, all the gatekeepers were respected. A presentation was done to the management of the clinic before permission was sought to conduct interviews there. Consent was obtained from the participants themselves. Anonymity, privacy and confidentiality were ensured during the interviews and report writing.

This chapter has described the research methodology, including the population, sample, data collection instruments and the strategies used to ensure the maintenance of ethical standards and the reliability and validity of the study. Consensus was reached by the primary researcher and an independent coder before the final themes were generated, to promote the study's trustworthiness.

CHAPTER 3:   FINDINGS

3.1   INTRODUCTION

Data analysis and presentation go hand in hand and form the core of an empirical research paper. These aspects are particularly valuable in the health sciences and in medical research. The accurate presentation and communication of data in the scientific community is crucial to ensure that data is reliable (Nieminen, 2020: 1). Data shows whether the data analysis is correct and answers the research questions. Researchers also present data to show a measure of uncertainty, as a richer discussion may be made possible when dealing with the uncertainties. According to In and Lee, Jeong and Choi (2019: 268), the presentation of data through text is a powerful communication tool. The data presented in this chapter addresses the first objective, which was to explore the lived experiences of youths on managing themselves after losing a family member to HIV/AIDS.

3.2   DEMOGRAPHIC PROFILE OF PARTICIPANTS

Eleven clients were considered for participation in semi-structured interviews, held during February 2020. Each signed a written consent form.

Most of the participants had visited the clinic before. They were identified in the waiting area as they waited to be attended to by a nurse or doctor, given information about the study and asked if they were prepared to be interviewed after they had done what they came to clinic to do. In this way, the study avoided any disruption of clinical services.

All participants were females aged 18 to 25, including the participant in the pilot interview. Table 3.1 shows the demographic information of all eleven participants, and their relationship with the person who had passed away from HIV/AIDS-related causes.

Table 3.1: Demographic information and participants' losses

	RACE	YEARS	GENDER	JOB	CHILDREN	LOST
P1 (pilot)	BLACK	24	FEMALE	PHARMACIST ASSISTANCE	1	MOTHER
P2	BLACK	25	FEMALE	NOT WORKING. COLLEGE FOR OFFICE ADMINISTRATION	1	AUNT
P3	BLACK	25	FEMALE	ADMINISTRATION	1	SISTER
P4	BLACK	24	FEMALE	STUDYING GRADE 11	0	SISTER
P5	BLACK	19	FEMALE	MATRIC	0	GRANDMOTHER
P6	BLACK	23	FEMALE	HEALTH PROMOTION	0	SISTER
P7	BLACK	22	FEMALE	MATRIC	0	AUNT
P8	BLACK	22	FEMALE	MUNICIPALITY	2	MOTHER
P9	BLACK	21	FEMALE	STUDY COLLEGE	0	SISTER
P10	BLACK	25	FEMALE	PRIVATE COLLEGE	1	BROTHER
P11	BLACK	25	FEMALE	VOLUNTARY WORK	1	AUNT

The mean age of the participants was 23 years, with ages ranging from 19 to 25. All participants had lost a family member to HIV/AIDS. Six participants had children, while the remaining five had to take care of the children left behind by the deceased family member. Six of the participants were attending school or a college and five were

working. Two of the participants had lost their mothers while nine participants had lost other family members.

3.3 FINDINGS

In analysing the data, some of the content could be placed under two categories, however, quotes were placed under the theme and category where it was found to express the theme the best.

Individuals who lose a family member go through various stages of grief which they may not always fully understand. These stages are often time related, and each stage is necessary to reach the following stage. In this process of change, grieving people almost always need the support of others. The common thread for all grieving people is change. Not only do they change inwardly, but changes in daily life and routines change immediately, leading to a measure of adjustment and disruption which can be hard to deal with. This process, too, needs support.

Data analysis from the eleven interviews resulted in the emergence of six major themes (see Table 3.2). Theme 1 was time related circumstances which defined their behaviour. This involves dealing with the consequences of the death while young children are still at school, the suddenness of the death that triggers feeling of anxiety about one's new role, dealing with the realisation that the deceased kept their condition hidden, and the unusual behaviour some family members developed as a result of their growing detachment from reality following the death.

The second theme was the stages of going through an unexpected loss. Participants spoke of both experiencing denial and grief in succession. They also spoke of a sense of guilt in not being able to do more for the family member before they passed away, the struggle of those left behind to realise that there is a future, the experience of having fond memories of someone one loved, and the sense of missing someone who contributed positively to the lives of others.

Theme 3 was difficult changes in the daily lives of the next to kin. These changes included having to rapidly shift from family member to household authority and family breadwinner, coping with the financial needs of the family, family fights and not dealing with reality, and dealing with stigma in the community.

Theme 4 was support measures for the next of kin – in this case, for the participants and their families. This involved the need to communicate and speak out about the death, the need for financial assistance, the process of seeking and obtaining social grants, the availability of social workers, understanding one's own stumbling blocks as well as new possibilities, and one's own role in providing hope for the future, often realised after counselling.

Due to the richness of the data quotes were places under and category most appropriate to.

Table 3.2: Themes that emerged during semi-structured interviews

Themes	Categories
Theme 1: Time-related circumstances define behaviour to manage death of a family member	1.1 Consequences of death while siblings still at school
	1.2 Suddenness of death triggers feeling anxiousness due to the rapid shift in role
	1.3 Unexpected reality that family member withheld information
	1.4 Developing unusual behaviour due to detachment from reality

Theme 2: Youths go through different stages after the un-expected loss of the family member	2.1 Denial and grief
	2.2 Guilt at being unable to do more before the family member passed away
	2.3 Struggle of those left behind to realise there is a future
	2.4 Hardship of losing someone dear about whom one has fond memories
	2.5 Participants missed the deceased who had a positive effect in their lives
Theme 3: Managing difficult changes in daily lives of the next of kin	3.1 Rapid shift from family member to household authority and breadwinner
	3.2 Financial needs
	3.3 Family fights and not dealing with reality
	3.4 Stigma in the community
Theme 4: Support measures for the next of kin	4.1 Communicating and speaking out as part of emotional support
	4.2 Financial assistance
	4.3 Social worker availability
	4.4 Realisation of stumbling blocks and new possibilities
	4.5 Own role in providing hope for the future
	4.6 Counselling

3.4 THEME 1: TIME RELATED CIRCUMSTANCES DEFINE BEHAVIOUR TO MANAGE DEATH OF A FAMILY MEMBER

When a serious, unexpected event happens, those who go through it experience major disruption, and many may fail adjust to it in a positive way (Oosterhoff, Kaplow & Layne, 2018: 2). The experience of an unexpected death of a family member is sudden and disruptive. Today's young people suffer a high level of traumatic events, including the frequency with which they experience sudden death (Oosterhoff et al., 2018: 4).

3.4.1 CATEGORY: CONSEQUENCES OF DEATH WHILE SIBLINGS STILL AT SCHOOL

The loss of a family member can bring about changes in the interests and attitudes of children towards their schoolwork. The death of a family member may result in siblings crying every day and refusing to go to school; in other cases, siblings attend school but cannot focus during the bereavement phase (Apelian & Nesteruk, 2017: 5). As a result, poorer school performance is almost inevitable for such children. Participants spoke of teachers reporting that children were not coping with their grief and had no interest in schoolwork (Akard, Skeens, Fortney, Dietrich, Gilmer, Vannatta, Barrera, Davies, Wray & Gerhardt, 2019: 5). A study conducted by Ngesa, Tuikong and Ongaro (2020: 462) speaks of the psychological impact that grief has on children, including the inability to focus at school or remain at school. These authors point out that decreased academic performance is a very real possibility.

One of the participants mentioned that all educational opportunities ceased for the older brother in the family, who had to drop out of school at a difficult time to support his siblings. This participant clearly felt a sense of pity for her brother:

> *"My brother had to leave school, drop out, so that he can look for work so that he can then take care of us." (P7)*

Ngesa et al. (2020: 462) state that the psychological impact on siblings includes the possibility that some will drop out of school before they complete school. In the above case, the move was necessitated by financial need.

"A participant spoke of her own struggles to continue with schooling after the death of her mother, as her home environment and guardian that previously looked after her, changed to new circumstances: "And I end up drop off the school then my cousin sister takes me, and I stay with her. She did everything for me. Like, she always talks to me that I can go to school so I can be like other children. But it was so hard." (Sad face reaction.) (P8).

The negative impact of the passing away of a family member and breadwinner led to siblings having to make sudden radical changes, including leaving home and school:

"Since we were living with her, she was the only old person we are living with. We were living with her in Eastern Cape, my mom was here in Cape Town. And, my siblings, my cousin and so on we were just children living with her. She was the old one. We were schooling". (P5)

A consequence of the death had a personal impact at the time of school activities.

A participant spoke of losing focus and of experiencing herself as inferior to others, seeming to have experienced the loss as a personal failure:

"At school I couldn't focus. I couldn't go out with other children. I had a low self-esteem. And, (mmm) I look myself down on others. Ja". (Body shaking, avoiding eye contact.) (P5)

The loss of a parent has a great effect on the psychological and emotional health of the youth (Levey, Oppenheim, Lange, Plasky, Harris, Lekpeh, Kekulah, Henderson & Borba, 2017: 16). Orphans attending school may often feel inferior to their peers and may even receive inferior treatment at school (Levey et al., 2017: 1).

Mental health related disorders such as PTSD and symptoms of depression are associated with a deficiency in school performance after the death of a loved one (Malizia, 2017: 13). Malizia (2017: 16) found that those in grief go through various changes. These changes may include substance abuse, shame and guilt, self-destructive behaviour, interpersonal difficulties, and stress and depression.

From the above it was clear that constructive thoughts were needs to manage the situation.

It was mentioned that a participant had negative behaviour-focused changes at school, with a feeling of carelessness of consequences:

> *"I didn't cope at school (takes a deep breath). And one of my teachers noticed that I'm not the same. I am not concentrating at school. I'm careless. And, I ended up to be a disturber, by disturbing other children in the class. I am not listening. I am not doing my homework. I don't care anymore".* (Sad face with tears in the eyes.) (P10)

According to Skovdal (2016: 42), a child or youth affected by a HIV/AIDS related experience is likely to have poor educational outcomes. Such children lack concentration at school, and there is a lowering in performance, failing to attend school regularly or dropping out of school entirely. The loss of a sibling can result in negative life challenges, particularly in education and in the relationships of those left behind.

Akard et al. (2019: 81) concur that the immediate effect on children following the death of a parent is changes in attitude towards school and loss of respect for others, resulting in arguments and disruption in the family.

3.4.2 CATEGORY: SUDDENNESS OF DEATH TRIGGERS FEELING ANXIOUSNESS DUE TO THE RAPID SHIFT IN ROLE

When a family member passes away, it affects all family members, with many experiencing anxiety and fear with regard to the unknown (Krychiw, James & Ward-Ciesielski, 2018: 92).

Behaviour-focuses constructive thoughts were needed in managing the situation. It is uncommon to move from being a dependent family member to being the sole breadwinner overnight, and having to raise children that are not one's own. One participant spoke of having to assume new responsibilities on her own:

> *"Yes, so my worry was that what are we going to do with these two children. Because we are all staying in one house. So, ja. I was very worried about her children mostly".* (Sad face.) (P6)

It was mentioned that family routines and practices ended abruptly and triggered emotional feelings, and that the deceased person had fulfilled many background responsibilities that would now have to be taken on by someone else:

> "It was tough. It was tough. Because we benefit to her. She was the one who buys food for us. She was the one who always play a role of being a parent because we don't have mom and we stay with our father. So, she was having four kids. She was the one who always grocer, pay for TV licence, always do everything when things are going down and up. She always did it well but now we can't do anything". (Praises the sister and looks sad). (P4)

The loss of the significant family member is an emotionally charged event and often results in the family members losing hope and fearing that they will not survive. They experience a 'shattered sense of self' and wonder if they have the ability to do things for themselves in a life without the deceased (Kentish-Barnes & Prigerson, 2016: 1279). It was assured in Chapter 1, that the focus of persons on negative aspects should be refocused towards positive outcomes (reward).

The feeling of fear was quite overwhelming for some.

> "Okay … aaaah … to be honest, mostly I had fear". (P1)

One young person spoke of uncertainty and distress regarding her ability to support her siblings financially and emotionally:

> "I feared that … uh … because my mom is no longer around I may not be able to give the kind of support that she would have given to my siblings. That is supporting them financially, emotionally". (P1)

A study by van der Mark, Conradie, Dedding and Broerse (2019: 104) reveal that women who are breadwinners and live in poor communities, struggle to pay for school and groceries and to support the needs of their siblings.

Another participant spoke of the feeling shocked about sudden loss:

> "So, we were very shocked". (Facial expression of disbelief.) (P6)

Dealing with loss is particularly difficult for those attending school. Students often feel fear, confusion, and pressure along with the shock of newfound independence (Zakeri, 2019). In addition, there is depression. Haravuori, Suomalainen and Marttunen (2016: 46) state that depression resulting from traumatic events affects quality of life even more than post-traumatic stress disorder in youth.

3.4.3 CATEGORY: UNEXPECTED REALITY THAT FAMILY MEMBER WITHHELD INFORMATION

An aspect of the unexpected death of a family member is the realisation amongst family members that the deceased kept their condition hidden, and therefore their death came as a complete shock. Disclosure of information on one's health status is a decision many are unwilling to make. It involves difficult decisions such as who to disclose to, and where and when (Serovich, Laschober, Brown, Kimberly & Lescano, 2020).

A participant was disillusioned and sorrowful about the unexpected death of her brother, especially after the medical staff informed her about his health status:

> *"So, by the time he was sick I didn't realise that he was HIV positive. He didn't tell any family member that he is HIV positive. Not unless my sister went to the clinic by the day he passed away to search how was he sick, to search about his health history. So, they tell my sister that my brother had HIV/AIDS. So, he defaults to the treatment".* (Sad face). (P10)

Another participant felt disbelief about the irresponsible behaviour of the deceased in concealing her condition and her negligence in not taking the prescribed medicine:

> *"She hides it from us because she didn't tell us that she was HIV positive. She was not doing anything. She was just coming when she feels like to come to the clinic. So, she wasn't taking her medication correct".* (Shakes head). (P6)

The disclosure of an illness such as tuberculosis or HIV/AIDS is a key strategy for the sufferer to ensure that they adhere to their treatment (Nyangoma, Bajunirwe & Atwine, 2020: 15). By not disclosing, the family members who had died prevented any

accountability to others with regard to taking their medicine regularly; as a result they failed to take it correctly and died.

The fact that the deceased concealed her condition and ignored her treatment caused a participant to feel shock and anger:

> *"The reason why we were shocked is that she hide it from us that she was HIV positive. We only found out when saw the pills and asked the doctors, and they told us, "No, this person was HIV positive. And she was defaulting, that's why she passed away".* (Angry face). (P6)

> *"She could have told us that she was HIV positive".* (Calm voice). (P6)

The failure to disclose one's HIV status remains a great problem in communities. People who are HIV positive often experience a dilemma concerning their privacy and fears of stigmatisation. Research shows that the disclosure of HIV status by the individual to their loved ones is important (Bird, Everman & Voisin, 2017). Although people have the right to choose not to disclose, disclosure of their health status increases their compliance with treatment protocols (Bird et al., 2017: 829).

The Centre for Disease Control for HIV Basics (2017) states that the disclosure of HIV/AIDS status to family and friends has many benefits. One of the greatest benefits is increased compliance with HIV/AIDS treatment. This study also assumed that constructive thoughts improve positive memories.

3.4.4 CATEGORY: DEVELOPING UNUSUAL BEHAVIOUR DUE TO DETACHMENT FROM REALITY

Exposure to traumatic life events can cause a detachment from reality and various mental health problems such as post-traumatic stress disorder (PTSD), which involves depression and anxiety (Haravuori, Suomalainen & Marttunen, 2016: 32).

The findings indicated changes in behaviour in participants related to stress and anxiety, panicking and negative thinking.

A participant mentioned her irrational thoughts and stress concerning the challenges that lay ahead:

"When you stress, you think stupid things because of, you know that the person that died is a breadwinner at home. You think now where are you going to get the things she used to buy for me. It's about that. You are going to suffer more, because she was a breadwinner". (Strokes the chin). (P7)

Many participants spoke of the inability to stop dwelling on the event, and their anxiety when they thought about the consequences:

"Eish, I was panicking then, I was panicking, and I was depressed. I was thinking all the time that … oohh … I was thinking all the time". (Bites nails). (P8)

The findings concur with the assumption in Chapter 1 that constructive thoughts could assist during difficult situations though self-monitoring, positive self-talk and physical activities.

3.5   THEME 2: YOUTHS GO THROUGH DIFFERENT STAGES AFTER THE UNEXPECTED LOSS OF THE FAMILY MEMBER

Individuals respond to misfortune in all sorts of ways. Grieving people may feel pity, longing, blame, outrage or loneliness, while a few may even feel a certain sense of liberation, especially where they had a problematic relationship with the deceased (Meyers, 2016). Individuals that have to cope with the loss of a close friend or family member are often faced with challenges. When a spouse, sibling or parent is lost the grief can be particularly intense. The loss of an individual is understood as a natural part of life, but those left behind can still be overcome by shock and confusion, leading to prolonged periods of sadness or depression. However, all these stages are part of the grieving process, which is an important process to go through in order to overcome the negative feelings and begin to embrace the good times one had with a loved one (Nordal, 2020).

3.5.1   CATEGORY: DENIAL AND GRIEF

People experience a variety of emotions related to death, depending on one's relationship with the deceased, the time and manner of death, and other contributing factors. The pattern of grief is unique to each person and does not necessarily follow

any pattern or route. Common reactions to grief include crying, anger and fear (Lekalakala-Mokgele, 2018: 151).

Grief after the loss of a family member can cause great difficulties, challenges and complications (Zakeri, 2019). In some cases, the loss of a family is similar to the experience of family estrangement, where a person experiences the loss of affection previously received (Ro, 2019). According to Griefic (2020), there are several signs and symptoms of early acute grief, with loss of focus and concentration the most common indicator. The experience causes frustration in many individuals. The common emotions related to grief are shock, fear, confusion and loneliness (Glatt, 2018: 109).

It was mentioned that in many cases, family members had passed away without disclosing their HIV/AIDS status. This led to anger in some.

> *"I was failing to accept the situation … because my sister didn't eat her treatment well and she was hide that she is positive. I also find out that she died because of HIV when she passed away".* (Angry face). (P9)

Some of the participants experienced pain and hurt at the loss of their family member. To some it came unexpectedly and resulted in a failure to accept the situation. A participant said:

> *"It was very painful. Because it's something that comes unexpectedly".* (Tearful). (P6)

The pain of losing someone close can be experienced as unbearable. Unlike other pain, death can cause a heartache that is sometimes carried to the grave (Drake, 2019). Death is certain to happen, but this does not make it any easier for those left behind. A participant spoke of her denial of the death:

> *"I was not accepting it at all. I was not accepting it and … yho..."* (P8)

Testoni, Franco, Palazzo, Lacona, Zamperini and Wieser (2020: 1) concur that grief is an inescapable part of life since death is inevitable. They state that for human beings, grief is a natural reaction to loss, and can be expressed in different forms, depending on the individual.

Elisabeth Kübler-Ross' grief model involves the steps of denial (Ackerman, 2020a). Denial is the failure to accept the situation one currently faces, i.e., the reality of the loss. Grief may present with clinical symptoms such as psychological distress, depression, anxiety and PTSD (Testoni et al., 2020: 1).

The findings indicated that it concurred with the assumption in this study, that cognitive behaviour therapy is needed to manage their specific situation.

3.5.2 CATEGORY: GUILT AT BEING UNABLE TO DO MORE BEFORE THE FAMILY MEMBER PASSED AWAY

According to Slepian, Kirby and Kalokerinos (2020: 323), guilt is associated with negative evaluations of the one's behaviour and feelings of remorse or regret, while shame is associated with negative evaluations of the self and feeling helpless or small. Guilt manifests in a negative evaluation of one's own behaviour and a sense of remorse at not having done more, a failure to adapt and an inability to cope with stress after the loss of a loved one (Slepian et al., 2020: 323)

A study conducted in China by Wang, Lu, Peng, Wang, Liu, Chen, Jiang, Li and Zhang (2016: 93) reveal that when individuals disclose their HIV/AIDS status to family, they generally receive support. Families might express shock and cry, but after grief about the condition they offer support and help to the affected person. In the same study participants revealed that after they had disclosed their status to their families, they received great love and expressions of fear about losing them, and in many cases were treated better than they had been treated before.

In the following participant, the failure of the deceased, a sister, to reveal her HIV status led to a participant feeling guilty that she had not done more to support her sister and possibly prevent the loss. She felt she would have encouraged more clinic visits to collect chronic medication, had she known:

> *"Because if she would tell us, there was nothing wrong to be HIV positive. We understand, we could have managed to tell her to go to the clinic all the time, but she was not going to the clinic".* (P6)

Living with a sense of guilt is difficult and can make it hard to get through each day. Those with a sense guilt may struggle to connect with their family, fail to maintain relationships, and experience an inability to focus on work or school (Clark, 2012: 140). A person with a sense of guilt can be supported by seeing a therapist. A nurse cannot fix the problems that may have caused real guilt, but can help reduce the sense of guilt and help the sufferer overcome the crippling nature of the problem and begin to see a better future. Talking to someone they trust can help individuals get through their emotions and change. Counselling is an effective form of support for those experiencing a sense of guilt. Counselling for a sense of guilt typically involves the concepts of acceptance and forgiveness. Clark (2012: 140) speaks of the ability to "reframe negative self-talk" as a way of getting over a sense of guilt.

On the other hand, some participants felt anger and blamed the deceased for their sudden death. These feelings were coupled with a sense of guilt in the following participant who had lost of her brother. It bothered her that various ways of appropriate support could have been provided to the brother had the family known.

> *"You know that I always blame my brother, neh, for not telling me. Maybe I was going to do something better if he told me his status. But he didn't. Why? I don't know. Maybe I'll find information and places where he can get help. Maybe he didn't die – maybe he shouldn't die by that time".* (P10)

A participant mentioned that she had guilt feelings about her mother, such as not appreciating her enough, as when peers spoke about their mothers, she could not participate in the conversation:

> *"I was having stress because other children at school were talking about their mothers. Maybe they say my mother buy me this and that, while I was feeling guilty but ekuhambeni kwexesha nda right".* (as time went by I became alright.) (Sad face). (P8)

After the death of a loved one those that are left behind often face the challenge of dealing with a sense of guilt and self-blame. 'Responsibility guilt' is a feeling that one could have done something to prevent the death of the loved one (Li, Tendeiro & Stroebe, 2019: 457).

The findings confirmed, as assumed in Chapter 1, that youth could use self-reward strategies to focus on more pleasant memories.

3.5.3 CATEGORY: STRUGGLE OF THOSE LEFT BEHIND TO REALISE THERE IS A FUTURE

Adolescents who are still at school after losing a family member often experience a sharp decline in thire academic performance, emotional health and social functioning. The struggle to move forward affects a number of daily activities, including sleep, interpersonal relationships, and attending to daily activities such as school, all of which can lead to drug and alcohol abuse (Adams, 2018: 1-4).

A participant mentioned that she had lost a sense of the future due to her fearfulness following the death of her mother:

> *"… so I felt like also my dreams have come to an end. I will not be able to pursue my dreams since I have to take over as a breadwinner at home. Those were my fears".* (Points to her chest). (P1)

The loss of a loved one who played the role of breadwinner in the family can result in fear about future responsibilities that are now passed to the older children. The eldest child may fear being unable to cope with financial duress. Older children have to make major changes in their life, such as paying bills, taking care of younger siblings and possibly getting a job that pays better than an existing job (Schulz & Eden, 2016: 1).

In the case of the following participant, the loss of her brother led to a loss of a sense of purpose in life and thoughts that she had lost everything. Because of the sense of devastation and loss of purpose, she resorted to self-destructive behaviour:

> *"So, after he passed away I lost everything. By trying to forget him I just wanted to drink alcohol and smoke cigarettes".* (Looks down, avoids eye contact). (P10)

Another participant was fixated on her feeling that her world was falling apart:

> *"I felt like my whole world has come to an end".* (P1)

Adult children encounter many of the same difficulties that younger ones do, often with a far greater sense of responsibility and anxiety about the future. They may lose

interest in life or abandon hopes and plans they previously held for the future. Many people who go through loss that they experience as devastating end up increasing their use of alcohol (Glatt, 2018: 105).

Losing a brother that loved one deeply can feel like the loss of everything:

> *"When I'm talking about losing everything I'm talking about love. I didn't find love the way he (the brother) did, the way he used to love me".* (Becomes emotional). (P10)

Individuals from poor backgrounds and communities use various resources to improve their chances of survival, and dependence on a family member for almost everything is very common (Myroniuk, 2016: 231). When that person is removed from one's life, the loss may be experienced as more devastating than if one has many resources and many strong relationships.

Studies have shown that sisters are more affected by the loss of a sibling than brothers are; they frequently lose a sense of themselves, lacking a sense of self-existence (Glatt, 2018: 109). They may also experience difficulty or inability to realise their self-worth or feel confidence about the future (Glatt, 2018: 109).

The assumption that self-leadership could sharpen ones perceptions towards rewarding aspects, was confirmed in the findings.

3.5.4 CATEGORY: HARDSHIP OF LOSING SOMEONE DEAR ABOUT WHOM ONE HAS FOND MEMORIES

The death experience, especially of a parent or a close family member, is one of the most negative events in a person's life (Greene, & McGovern, 2017: 2). When a close family member dies, the world can seem 'turned upside down', regardless of the cause of death. Some people experience a sense that the death was not right, that it should not have been possible (Andriessen, Mowll, Lobb, Draper, Dudley & Mitchell, 2018: 607). The hardship of parental loss is reported to have higher chances of causing mental health problems to the bereaved individuals than the loss of other family members (Rosenbaum-Feldbrügge, 2019 :1828).

Participants mentioned that losing someone they loved and had shared memories with was hard. They spoke of thinking a lot about the person's good qualities and the good things the person used to do for them.

"You know, it's not nice when a person you depend on passes away". (P2)

Another participant mentioned that it was hard for her as her sister left two children behind:

"It's not easy to lose somebody that you love, it's not very easy. So, the pain is that she had only two children". (Rubs hands on thighs). (P6)

Common emotions triggered by loss include emotional pain, a feeling of being astounded by the loss, difficulty in accepting the loss, and intense longing for the deceased (Krychiw et al., 2018: 92).

One participant stated that the brother used to do all the chores at home, including her homework. She said:

"He used to do everything for me, my homework, wash my clothes and preparing school things for me". (P10)

Individuals seem to be trying to fill a gap by engaging in negative behaviour instead of looking forward and seeing that their life still has a purpose.

A participant mentioned that her brother had been her anchor in life and she was having difficulty in forgetting him:

"Just to try and forget about him because he was there, he was everything to me". (P10)

An anchor in one's life is someone who provides stability when uncertain situations arise (Stok, 2019). It appears that people can weather almost any storm as long as they have an anchor, whether that person is a friend or a family member. Rosalia (2016) states that the death of a loved has an ongoing effect on the entire family. Family members may sense an emptiness where that person once was, as they provided emotional support and played a significant role in the daily routines of the family members (Rosalia: 2016).

The findings concurred that constructive thoughts could encourage youth to assist themselves.

3.5.5 CATEGORY: PARTICIPANTS MISSED THE DECEASED WHO HAD A POSITIVE EFFECT IN THEIR LIVES.

Family connections are significant for one's wellbeing over the course of life. These connections become more critical to the wellbeing of people as they age, when the need for caregiving may increase, and social ties in other spaces such as the work environment become less central to one's life (Thomas, Liu & Umberson, 2017: 1).

Some participants mentioned the good and positive things that the lost family member had inculcated in them. These family members had made them feel comfortable, positive and self-confident. The loss resulted in a devastating change in self-perception. One participant said she sometimes did not want to go home because her brother was not there:

> *"Sometimes I didn't wanna go home just because I know, he used to cook for me. And, we used to sing for each other and pray together. So, there was no one who did that with me after he passed away. I ended up to live with friends at the street".* (Voice shakes.) (P10)

The loss of her sister made a participant longing for her no other option but to look for a job in order to take care of herself. Her father seemed unable to provide for her, either financially or emotionally. She said:

> *"I miss her a lot (emotional face and tears in the eyes). I always think about her now. When my life is going down and up, I end up find myself to go and look for job, but there's no one to comfort me anymore besides my dad".* (Emotional face). (P4)

Depression sets in when a person's social connections do not meet their interpersonal needs or wants (Haley, 2016).

A participant mentioned that she missed her sister who used to make her feel comfortable and with whom she shared life challenges and experiences. She felt that she had lost a part of herself with the loss of her sister.

"She was a grocer. She was the one who carries me when I'm in a bad mood, and I talk. She was the one who makes me comfortable when I want to talk. And she was the one who ask me about school, my things in life. I was feeling comfortable but now I don't have anyone to talk to. I am scared to talk to my father how I feel. I lost very much, and I still miss her until now". (Sits all the way back on the seat.) (P4)

Haley (2016) states that loneliness is dependent on what an individual "needs and desires". Loneliness is individual and changes from one person to the next.

According to Thomas et al. (2017: 3) the quality of family connections, determined by positive factors such as love, advice and care (known as 'social backing') and negative affect wellbeing through psychosocial, behavioural, and physiological pathways.

A participant mentioned that her sister had been an extrovert person:

"So, I was very sad because she was a very talkative person". (P6)

A participant who was HIV/AIDS positive herself missed her grandmother who used to make her feel positive and confident regardless of her condition:

"For me it was really hard. … Hmm .. first of all I am also infected with HIV/AIDS and then my grandmother was the one who gave me support. Eh! She was the one who made me feel positive. The one who gave me like the spirit to have confidence in myself. Not to compare myself with other children". (P5)

Receiving a medical diagnosis like HIV can result in a loss of certainty, at least at first. Loss of certainty affects many aspects of life (McClain, 2019). Ackerman's (2020c) research found that self-confidence gives people a sense of positivity about a wide range of life experiences. In the case of the above participant, the potentially negative experience of being found to be HIV positive was ameliorated by the positive impact of the now deceased grandmother on her life.

A participant went on that to say that words of encouragement from her grandmother had motivated her to the point that she still felt she was no different to others, despite her HIV status. In other words, her grandmother's positive influence remained with her, to some extent.

"Like (takes a deep breath) she would convince me to, show me ways and come up with examples, like I'm like other children. I'm not different. I can do whatever I want to. Since I have this disease, I am not different to others. Like she tried by all means, showing me that I'm not differ to others". (P5)

Her grandmother had given her motivation, and there was now a need to keep that motivation and make it self-motivation. Self-motivation is the drive to work toward one's objectives, to put exertion into self-development, and to realise individual fulfilment (Ackerman, 2020b). These refer to cognitive behavioural therapy.

A participant also participant mentioned that her grandmother convinced her to be in a relationship and gave her advice with family planning methods:

"Firstly, since my grandmother was positive, and I was also positive. Like I was comparing myself. I didn't want to go out, but my grandmother would convince me to. I was scared dating, but she is the one who gave me ideas, if I want to date I must go and prevent, I must not be ashamed of what I have. And, even at school I must be a kid. Ja, for now …" (no eye contact, looking down and biting nails.) (P5)

The participant seemingly still needed assurance about her self-worth. According to the American Heritage Dictionary (2016), self-assurance refers to having or showing confidence in the validity and value of one's own ideas and opinions, and composure. The family is the primary means of building the self-esteem of a child. It has a crucial part to play in the improvement of a child's capacities. As a concept, self-esteem alludes to someone's evaluation of themselves. Self-esteem depends on a few perspectives, among which are self-evaluation and the criticism we get from others (Cabral, 2018).

3.6 THEME 3: MANAGING DIFFICULT CHANGES IN DAILY LIVES OF THE NEXT OF KIN

3.6.1 CATEGORY: RAPID SHIFT FROM FAMILY MEMBER TO HOUSEHOLD AUTHORITY AND BREADWINNER

The changes in family structure due to the loss of a breadwinner in the household and single parenthood have resulted in youth having to take on the responsibility of caring for their families (Adeojo, 2017: 45).

According to Shah (2018: 8), when a parent dies, an additional pair of earning hands is needed. Older children in the family end up taking on responsibilities they may not be prepared for, often having to leave school (Shah, 2018: 8).

A participant mentioned that when she lost her grandmother who was a breadwinner, she also lost emotional support. Many things changed at home and she found herself with no one to communicate with:

> *"And she was the one who were like a breadwinner. Because we were depending on her (stutters), on – on her grant. Like it was really hard because ever since she died, I never got the support, the support that I used to get before. A lot of things changed at home because there was no longer that person who used to support us and discuss about life, about HIV and so on".* (Shakes while speaking, rubs nose). (P5)

In many cases in South Africa, parents die before their children are grown, and as a result the children complete their growing up in exceptionally challenging circumstances, exacerbated by poverty. Daily lives and lifestyles change following a parent's death (Apelian & Nesteruk, 2017: 80). A family member may feel abandoned by the parent, whether or not that abandonment was deliberate. Mkhize (2016) states that abandonment is defined as intentionally leaving an identified person, with the purpose not to return. However, as this study shows, death can also feel like abandonment.

It was assumed in this study that behavioural focused approaches should include self-management support to improve their wellbeing.

Due to the loss of the breadwinner in the family, many participants had to let go of everything and look for a job.

"It was so difficult for me because I was the older person in the house, so I had to struggle to go and look for a job". (P2)

"Like I said … uh … after my mom passed on, I had to take over as a breadwinner. So I'm currently, I am not full time working. I am working part time". (P1)

The loss of her mother has resulted in her following in the footsteps of her late mother and becoming the breadwinner for this participant:

"And also, being the eldest for my siblings, now my whole life had to change because now I have to become the breadwinner, and also giver support to my younger siblings". (P1)

Parental death affects children of all ages but particularly the adolescent or older siblings. Studies reveal that their death is a disruption to the steadiness of their lives and changes things financially, socially and emotionally. Changes include increased household expenses (more common in the death of the mother) and a possible need for employment to support younger siblings (Apelian & Nesteruk, 2017: 81). They need to act as role models, to fill the gaps left by the parent who has passed away. Being a role model requires one to play a role one may not be ready for, modelling qualities such as determination, hope, integrity, optimism and compassion. Role modelling plays a very important role in positive child development (Prince-Mitchell, 2017).

A participant mentioned that when the breadwinner of the family died, remaining family members were left with many difficulties:

"She was the only one taking care for us, me and my siblings and my son. That is why we faced difficulties". (Voice shakes, eyes fill with tears, tight body posture.) (P2)

The responsibilities of the sister had to become the following participant's responsibilities after her sister passed away. She and her siblings depended on her father's grant.

"But now, and I just benefit to my dad's grant now. And that why I don't like it. She was always care for me and about the things and cared about her children but now it's my responsibility to take care of her children. It's my responsibility now". (P4)

Adolescent and young adult breadwinners are a result mostly of poverty and a necessary response to social and economic hardship.

A study by Apelian and Nesteruk (2017: 81) found that the death of a mother has a particularly negative impact on girls, as they have to become the caregiver, which may be a burdensome responsibility at an early stage in life.

3.6.2   CATEGORY: FINANCIAL NEEDS

People from middle- and low-income homes may be subjected to food insecurity on a daily basis, which further affects their wellbeing after a death. Food insecurity means having food shortages which may include having no choice about what to eat or inability to eat at all, which may be accompanied by feelings of shame at being labelled poor (Morrow, Tafere, Chuta & Zharkevich, 2017: 2).

A participant mentioned that when the breadwinner passed away they had nothing to eat and resolved to access the government grant. The participant also runs a small business now to support her siblings.

"We was having nothing to eat, neh. Now since we do have that grant and I do sell the small chips and sweets and stuff so that we can be able to buy bread or something that is short at home … she was the only one that was working at home, she was the only one that was putting food on the table". (Strokes chin.) (P2)

A study by Stack and Meredith (2018: 233) states that poverty results in lack of food and that sacrifices have to be made by adults to ensure that children's needs are taken care of. In this study participants reported not having food and struggling to pay bills.

A participant described how her small business helped her support her siblings and child:

> *"And I did find the money to start a small business for me so that I can put something on the table for my aunt's kids and my baby as well".* (Looks very sad). (P2)

In this study it was also assumed that more pleasant activities becomes naturally rewarding.

The loss of her aunt has resulted in great financial strain for P2.

> *"There was no one working at home unless it was only my aunt that was working, right? Now for that fact that she had died to HIV. Now the things were getting hard at home, now we have nothing to eat and … uh … there was no one to look after us".* (P2)

Adams (2020) concurs that many people find themselves pulled into financial debt due to the loss of a family member.

Financial difficulties resulting from a death prolong the grief of an individual. The financial hardship associated with death of a loved one results in a low level of satisfaction in life (Morris, Fletcher & Goldstein, 2019: 332).

3.6.3   CATEGORY: FAMILY FIGHTS AND NOT DEALING WITH REALITY

A study by Feigelman, Rosen, Joiner, Silva, and Mueller (2017: 138) found that young adults who are bereaved are often exposed to violence and fighting amongst the remaining family members. The loss of a parent or a family member can also result in delinquency, depression, suicidal thoughts and the use of drugs in order to avoid dealing with reality (Feigelman et al., 2017: 136). All of these behaviours exacerbate family fights.

Rice and Tan (2017: 82) studied people experiencing psychiatric hospitalisation after the loss of a family member. The causes of their psychological problems were found to be no communication with parents(s), physical and verbal fights with parents or siblings, parental conflicts and a lack of parental involvement.

Before her sister passed away, a participant experienced family fights, with her sister bottling things up inside her as she was not an emotionally open person. She said:

"Fights. Family fights. She (her sister) doesn't want to talk. She's always quiet. She keeps things inside of her. And when she hurts, she doesn't want to talk about that thing she hurted about". (Looks exhausted and throws hands in the air). (P4)

Family members had to contend with the death of the loved in an unsupportive atmosphere (Haley, 2020).

The above participant mentioned she missed her sister and how she used to address her feelings and pain through private conversations with her.

"When she (her sister) wants to talk, she calls me and talk to me and says, "This, I'm hurt and I don't like to talk too much, but I know it's painful for me." Now she's gone and we can't do anything. Ja, she's gone, and I miss her so much". (P4)

This confirms the assumption in the study that positive self-talk is a constructive thought.

A participant mentioned that the children at home were the cause of her stress as they did not listen when she told them what to do. As a result she kept quiet to avoid saying thing she might regret later.

"Yho, stress is a lot. Yho … I have lots of stress. (Holds head and pulls hair.) I'm stressing because of her children is annoying me. (Makes angry face.) When I'm saying someone must do that, they should just do that. I always want to encourage children to listen because they make someone to be stressful all the time, to feel like …hmm, I feel like I should keep quiet sometimes so that that thing inside will make me regret what I am going to say". (P4)

Death and pain can make individuals act almost insanely and can shake a family's sense of centre, or stability. When the passing happens inside the nuclear family, family miscommunication and misunderstandings may easily arise, partly because people grieve in different ways (Haley 2015). Some family members may begin to bargain around their new roles in the family, as new patterns of authority and behaviour become necessary. People also have differing mourning styles, and may experience

complicated feelings in response to other family members' changed behaviour (Haley, 2015).

A participant experienced her aunt calling her bad names after she had moved in to live with her after her sister passed away:

> *"She (the aunt) was calling me stupid girl because while my sister was alive she said I take her for granted. And now that my sister is passed away I want her to look after me, and she don't have that money to look after me because she also have children (Body shakes while sharing). Where must I stay now and who do you stay with?"* (P9)

Krull (2020) points out that grief and greedy family members are a dangerous combination. This writer states that grieving family members may have no choice but to bargain with "narrow-minded relatives" after the passing of a cherished one. Krull (2020) also observes that people do not always grieve in positive ways, and can be damaging to themselves and to others.

This indicates that youths need to focus their attention away from unpleasant situations.

A participant, experienced difficulties after her sister passed away when her sister's husband chased her and her children out of the house and she had to move in with her grandmother:

> *"It was very difficult, because I was staying with her and her husband and her three children. So, after she passed away, the husband chased us away. And we had to move back and stay with my grandmother".* (Sad face and shaking.) (P11)

A study conducted by Levey et al. (2017: 10) found that those children living with caregivers after a parent's death are vulnerable and may experience neglect, exploitation and inferior treatment.

3.6.4 CATEGORY: STIGMA IN THE COMMUNITY

Community stigma related to HIV/AIDS affects the psychological wellbeing of children. Such children experience devaluation, victimisation and rejection by their peers (Yassin, Erasmus & Frantz, 2019). Stigma affect not only children but also youth and adults, who may may experience bullying, discrimination, social isolation and denial of access to formal education. Young adults, teenagers and children living with extended family members due to the loss of parent(s) often report being abused and treated unfairly (Yassin et al., 2019). It is this thus important to address it through the assumption that feeling confident should be built in managing one's own situation.

A participant mentioned that she experienced stigmatisation in the community after the loss of her mother:

> *"And also, the stigma from my community is one of the things that I experienced after the loss of my mom".* (Emotional and sad facial expression). (P1)

Children whose parents have or had HIV/AIDS are vulnerable to stigma in the community and are more likely to experience low self-esteem and symptoms of depression than unaffected peers (Domlyn, Jiang, Harrison, Qiao & Li, 2020: 500). A participant mentioned that the stigma caused people in the community to talk behind her back:

> *"So basically, what happened after my mom passed most of the community members within my community were talking behind our backs because my mom died of HIV/AIDS".* (P1)

This participant went on that the children in her community began rejecting her younger siblings, seemingly afraid that they might be carrying HIV/AIDS:

> *"Also, the kids that were mostly friends with my siblings, now it's like, my siblings were discriminated against because of the HIV/AIDS that my mom had. I also feel like maybe they think even us, we were infected by HIV/AIDS". (Looks worried).* (P1)

According to Meini and Tognetti-Bordogna (2018: 541), "the vast majority of children orphaned by AIDS or made vulnerable by HIV are ostracized, discriminated against, an isolated due to the shame associated with the disease".

3.7 THEME 4: SUPPORT MEASURES FOR THE NEXT OF KIN

3.7.1 CATEGORY: COMMUNICATING AND SPEAKING OUT AS PART OF EMOTIONAL SUPPORT

The cycle of life involves birth and death in all humans. When death occurs, the ability to talk about it is associated with fewer grief difficulties and mental health disturbances that in cases where the affected person does not talk about it (Levi-Belz & Lev-Ari, 2019: 2).

However, the stigmatisation of death and dying in some cultures still exists, making it difficult to communicate and having several negative implications. Talking about death helps individuals to work through their fears better (Lambert-South & Elton, 2017: 1).

A communicating family has an added element of protection and healing for the psychological health of its members (Weber, Alvariza, Kreicbergs & Sveen, 2019: 1). This supports the assumption that shaping perceptions can be done though focusing away from unpleasant aspects.

One participant was negative in that she had not been part of the process of her mother's dying, since her mother had not shared her condition and the reasons for her deterioration with her:

"Yho … Okay. Since I couldn't share things with my mom, I end up thinking a lot. Thinking negatively. I even ended up not going to school that time, I think for weeks and I didn't have a reason. I was not myself. I was hurt. That's all I can say". (P5)

Advice from one of the participants was to communicate to a family member or friends, or to seek professional help for emotional support:

> *"Okay especially from me, I would advise them to speak out. Speak to someone, its either your friends, family member, or if you don't have anyone that you trust then seek for professional assistance. Talk to a social worker,*

psychologist that they provide at your local clinic. And also – ja, that, mostly". (Demonstrates 'speaking out' with hands). (P1).

Close relationships with peers also provides support for children, adolescents and young adults, and is effective in helping grieving persons to come to terms with their loss (Apelian, & Nesteruk, 2017: 83). It is important to seek supportive assistance after the loss of a loved one to help prevent prolonged suffering (Oates & Maani-Fogelman, 2019).

A participant revealed that self-confidence in speaking out is therapeutic as it helps decrease the burden of keeping things to oneself:

> *"I feel like when you speak out you don't bottle things in, it's like the more you speak about it the more you feel better about it. Especially if you talk to someone who understands like the professional assistance. I feel like it's good for one when you are in that moment when you recently lost a family member".* (P1)

According to Peterson (2020), self-confidence is the strength to know oneself, accept oneself, and act on one's convictions. Self-confidence can be seen as a positive feeling about oneself and the world that leads to courageous actions born out of a sense of self-respect (Peterson, 2020). This is a natural rewarding strategy.

In a study conducted by Aoun, Breen, Rumbold, Christian, Same and Abel (2019: 8), participants report that professional assistance helped when they experienced grief. Being able to talk freely helped, although some complained of a lack of feedback from professionals.

Participant recognised the value of communication in support groups and the advice of professional counsellors:

> *"Hmm … I'd say also, the youth. Seek for kind of support that would help in terms of speaking out, being around people with the same experiences would help. For example, support groups where I can sit around and talk with the youth that is also affected".* (P1)

"Like having to talk to someone about what you are going through. And then them giving back advices". (P11)

A study by Aoun et al. (2019: 7) reveal that taking the bold step of joining a support group during the grief stage after a loss can give one emotional strength and support as well as needed information on overcome grief.

Having no one to communicate with can lead to suffering, participants revealed.

"Then we were suffering with almost everything in the house because we had no one to talk to". (P9)

"I think it's to communicate, but since I've lost my grandmother, I have no one to communicate". (P5)

There are numerous families whose normal way of functioning is not to talk about many issues, feelings and suppositions. Schwartz (2015) says that in such families, when any sign of conflict arises, everybody "closes down" or "stuffs it". Schwartz (2015) defines 'stuffing it' as keeping one's thoughts and feelings to oneself so as not to affect the emotions of other individuals in the family. In such families, strife is labelled as perilous and harmful (Schwartz, 2015).

When parents refuse to take time to listen to their child, giving them no safe outlet for their emotions, the child can resort to destructive behaviour.

"Now I'm living with my mom since my grandmother have died. Since ever I lived with my mom, I have never communicated like serious issues with her because my mom is strict, and she is not that kind of a person who ... She is not like my grandmother. She cannot talk stuff with us because she thinks we are young. And, at home we are scared sharing things with her. So, we rather keep it in ourselves. That leads to stress. I even end up smoking, I thought it's a better way of living". (Pulls fingers). (P5).

It has been shown that girls of unloving and emotionally 'unattuned' mothers share common characteristics. The unmet need for maternal warmth and approval negatively affects their sense of self, making them gravitate to undesirable

relationships, and can shape them in ways that are both seen and unseen (Streep, 2015).

Amongst some participants, there was a sense of great faith in God and a strongly felt need to attend church.

> *"The parent of my friend invited me to church, one day took me to church. I feel free there and I make new friends and so, I joined activities there. I ended up enjoying to go to church even alone. Of my friend is not going to church I go alone because I know I have friends there. I have people to talk to".* (P10)

One's belief system plays a role in one's recovery from the loss of a loved one (Zed, 2017). In some cases, beliefs help people during suffering or hardship, bringing a sense of control or power, although Zed (2017) points out that sometimes beliefs can be a preventative to personal growth and development. This is assumed to be promoted by constructive thoughts.

A study by McDeffie (2019: 45) suggests that social support is particularly valuable in African American communities, where it is often coupled with the spiritual or religious component of life. T

3.7.2   CATEGORY: FINANCIAL ASSISTANCE

The government of South Africa has invested time and resources in social development, prioritising basic human needs by providing social grants for financial assistance, healthcare and basic education (Koswana, 2019: 1).

A participant spoke of the need for financial assistance, whether through finding a permanent job, from a social worker, or in the form of food support.

> *"So, financially assistance would be good, even if I can get a permanent job so that I will be able to take care of my younger siblings. If it's not a job, then financially assistance from the social workers. Food support also, stuff like that".* (P1)

A study conducted by Apelian and Nesteruk (2017: 88) reveals that those who have lost a family member who took care of the family's needs are often faced with financial

distress after their passing way. As a result, older siblings have to seek employment to support their younger siblings.

One participant mentioned receiving support from church members:

> *"Some supporting financially where they can. Like buying shoes for the children or buying some sort of groceries. That kind of support".* (P11)

Access to food is precarious for many, in view of the high unemployment rate. In desperation, many individuals and families look for jobs in urban areas, but their searches are not always successful and all members of families become dependent on social grants (Koswana, 2019: 15).

A participant who had not yet accessed the foster care grant from the government mentioned how helpful it would be:

> *"I think the, I think the foster care … at least we manage to go to school, we manage to buy clothes, buy uniform".* (Uses figure tips to count). (P3)

Research studies have shown the important role and value that the social support grant plays in poor households for the improvement of food security and nutrition, and its positive educational effects (Haney, 2018: 1231).

In the Republic of South Africa, the Social Assistance Act of 2004 makes provision for seven social support grants; the old age grant, the child support grant, the disability grant, the foster care grant, the war veteran's grant, the care dependency grant and the grant in aid (Koswana, 2019: 32).

The establishment of the child support grant in 1998 was intended to support the children of South Africa. The person responsible for receiving grant for the child should live in South Africa, and earn R4000 or less to qualify (Republic of South Africa, 2019., Koswana, 2019: 33).

This confirms the assumption that better situations become naturally rewarding.

A participant's current job was low paying, and she struggled to support both herself and her siblings. She ended up having to register for the foster care grant from the government.

"I am old, mos, so we get that money for foster care, they call it foster care when you don't have any parents that is working and you not working, even if you are working but your money is less than R3500 you are able to get that money". (Shakes). (P2)

A participant believed that the social grant would help her to pursue studies at university:

"Support, I think also social grant. (Scratches head.) So that I could go study further in varsity. And, even at home I am the older one and we are living with my mom, there are four of us. At home we are depending on her, she is working. It's a one-year contract so after that contract we will be depending on the grant of the two children who are coming after me". (P2)

The access to a social grant described in research conducted by Bonilla, Zarzur, Handa, Nowlin, Peterman, Ring and Seidenfeld (2017: 55), indicated positive effects on the financial empowerment of women, giving them a measure of control over their lives and future plans.

A participant reported that she and her siblings depended on the grant of their grandmother, as their own grant was received by their mother who kept it for herself:

"We were depending on her grant. We had a social grant, but our mother was not sending our grants every day, like every month. Sometimes they will not send it and we will depend on our grandmother's social grant". (Head tilts to the side). (P5)

Studies have shown that the child social grant meant to support children's growth, development and food requirements is often misused by the recipient or the caregivers of the children, which exacerbates poverty in the home where the children reside (Khosa & Kaseke, 2017: 356).

3.7.3   CATEGORY: SOCIAL WORKER AVAILABILITY

The services of social workers are indispensable for families under great stress, as they facilitate communication and act as a social support structure. A relationship with a caring social worker can have tremendously positive effect on individuals, helping to

ease grief and enabling people to move on. Social workers may engage in one-on-one sessions with children and other family members (Winter, Cree, Hallett, Hadfield, Ruch, Morrison & Holland, 2017:1427).

A participant mentioned that she would appreciate the support of a social worker.

> *Social worker… someone who can look after us. Someone who can come and check us every day that we are okay and give us support so that we won't stress ourselves and thinking about her. To give us strength to be strong and to have faith that one day they will be someone who will do the same like this. (Looks very worried.) (P4)*

Messam and Hart (2019: 267) state that strong bonds with a loved one who has passed away may result in a level of grief that requires professional assistance such as counselling by a professional. Although social workers are not trained psychologists, they can fulfil this kind of role in the lives of people left behind, particularly in the case of households headed by very young people.

A participant had to access a social grant provided by the government to support her siblings and son.

> *"It was very hard unless we go to the social service to get foster care … social grant … we did get the foster care there because we don't have parents, its only me, the siblings and my son".* (Palms open, facing upward.) (P2)

South Africa has perhaps the most all-encompassing social protection system on the continent (Hahmann, 2017), since it involves seven grants and access to social workers.

The ability to recognise one's need of counselling is valuable in itself. Some people may not recognise this need in themselves, and try to push on without help. It seems that young women, in particular, are aware of their emotional needs, and that this is often key to receiving much-needed assistance. A participant mentioned the value of counselling and indicated plans to visit a social worker for support in dealing with stress and accepting the loss of her sister:

"I think I can go to counselling to support myself because even now I still can't accept that my sister is no more. Go to visit social workers". (Eyes fill with tears.) (P9)

The primary responsibility of social workers for clients in grief is to provide individual support and counselling. Grief support provided by the social worker may also include the suggestion of group support and other resources in the community (Kornusky, Cooper & Gates, 2018: 1).

The findings support the assumption that supports help with behavioural change and enable the individual to manage trauma better.

3.7.4   CATEGORY: REALISATION OF STUMBLING BLOCKS AND NEW POSSIBILITIES

According to Winter et al. (2017: 1428), studies in social worker processes have shown that even after a single contact session with a skilled social worker, children and families show changes in their behaviour, stemming from changes in their thinking. Counselling enables people to come to a new understanding of themselves and to see possibilities for the future rather than being overwhelmed by grief. This ability to begin to see the future through new eyes is particularly pronounced in youth and young adults.

A participant showed insight into the kinds of behaviour and thinking that would enable her to move on from her current unhappiness:

"Not to over think about it … hmm … be humble, man, with it, so that I can know how life is, I've been too much disappointed". (P2)

This participant showed that she was eager to let go of the grief and to continue living with hope and strength:

"Strength is when someone always giving always power to have that thing that makes you feel "I am okay now," and let me move on, and just accept it in my heart that she is no more and she won't come back. If there is no someone that is going to give me that strength or tell us, "You are going to be okay, and this is not just happening to you only, it's happening on everyone". You are not here

in the world to stay forever; we are here to visit. So here in the world we must be strong and move on with life and live just like everyone lives". (P2)

Factors that promote positive outcomes lie mostly within the individual. These factors include a strong self-concept, bonding with a caregiver and the capacity to think about the experience in a positive manner (Greene & McGovern, 2017: 1).

A participant seemed to use the positive self-talk spoken of by Clark (2012: 140) when she spoke of what she needed to do.

"Just want to say if you lose someone that you love, it's not the end of the world. You must pull up your socks, go out there and look for a job. So that you can manage to build the others, so that they can see that everything happens for a reason". (P2)

When individuals permit themselves to be open to new possibilities, they tend to become more positive, and can in the end accomplish what others might think is incomprehensible. Social relationships and a focus on others helps, too. Meier (2016) states that when people motivate others, they, in turn, become more motivated.

After the passing of her sister, a participant realised the importance of education in order to get a job:

"After passing away of my sister I told myself that I won't go to school anymore. I realise that if I don't go to school, I won't get jobs easily. So, I rather go to study, go further with my study and not focus on the past and all the things, but going up". (P9)

Life presents challenges to all. However, with the necessary guidance and support, people are able to overcome great obstacles and achieve victory over all sorts of circumstance, including grief, anxiety and financial hardship. For financial hardship, especially, education is key. Education helps people live with understanding and purpose, opening the mind so that they can conceive of new concepts and ways of doing things. Education also helps people to make wiser life choices (Sharma, 2016). Cook (2017) points out that without motivation and inspiration, one cannot accomplish anything.

A participant mentioned that at first, living with HIV/AIDS seemed to take away her freedom to live like her peers did, but that as time went by, she developed the ability to focus on things that helped her family:

"I couldn't live the life that the other children … people at my age. I couldn't do the things that people at my age did. Like going out with friends, for instance, but its better now. Like studying, I had to work to focus myself on the kids and what they will be eating". (P11)

This participant was pleased with the support she had received from her church, simply talking to someone you care for:

"I spoke to people and also church members. I also receive support from church members as well". (Smiling). (P11)

According to Smith and Segal (2019), by simply talking to somebody else, one cares about, can assist people to deal with grief. Some people feel embarrassed at their own need of help, but those who overcome this embarrassment are more likely to find healing than those who bottle up their feelings. It appears that some received valuable social and practical support from her fellow church members.

The findings confirm the assumption that moving towards individual's involvement in activities assist in self-management to well-being.

3.7.5   CATEGORY: OWN ROLE IN PROVIDING HOPE FOR THE FUTURE

Jack (2016) states that at times people become their own 'stumbling block'. It takes work to look inward and see where one's own attitudes may be hampering progress, and to change one's perspective.

Attending a self-help group can help individuals pursue changes in life. Nordenmark, Landstad and Hedlund (2020: 618) state that self-help is based on people sharing experiences with peers who have experienced similar circumstances. The goal is to achieve new outcomes and regain lost hope for the future through making sound decisions. Self-evaluation, self-development and self-intervention form part of this process. Self-help groups can involve spiritual guidance, the enhancement of self-confidence, encouragement, and reflection on personal values.

The difficulties that participants had been through seemed to have had the effect of making them stronger. A contributor to this strengthening process was the fact that they had others to take care of – family members who depended on them. Becoming the breadwinner caused participants to make sacrifices for those who needed them. One said:

> "So that they can know that I will never leave them alone, I will always be there for them. Even no matter how hard, but I'm there. Do you understand?" (P2)

Sonnenberg (2017) states every relationship requires a certain level of sacrifice to remain healthy. P2 showed great awareness that others looked to her to remain strong, and seemed to be doing her best to forget the past and move forward in a way that included the needs of others around her.

> "I like not to think about my aunt, because the more I think about her is the more that… (Takes deep breath.) Like I did see that the world is too much for me, I am the only person that is older than them. They are looking up to me. When they see me, they must have hope that everything is going to be alright because we do have the big sister now, I am the only one that is old. The other one is 18, and the other one is 10 and then my son is 7". (Bites nails). (P2)

Sonnenberg (2017) explains that giving birth to children is not the same as being a parent. A parent can be a guardian or caregiver entrusted with the role of raising children, who in many cases must sacrifice a great deal to raise strong, secure and positive young people who have the confidence to face the world and overcome its many obstacles.

The experience of parental death leaves siblings having to lean more on one another for support. The relationship among the siblings can become stronger due to the experience of shared pain. Older siblings can take the role of becoming the head and support for the younger ones (Apelian & Nesteruk, 2017: 90).

At the same time, the burden on the oldest sibling can be great. A participant spoke of her dreams of academic achievement vanishing due to the fact that she had to become the head of the family:

"The only thing that I want to say is that it has been a struggle because I couldn't focus on myself. I had to do everything for the children. Even like having … I had dreams of going to varsity but none of that happened because I had to do something that will bring food at the table. So, life isn't about me anymore, it's about them. I wanted to be something in my life. But none of that has happened". (Voice shakes, about to cry). (P11)

The death of a close family member had necessitated a huge shift in priorities for most participants. All seemed to be struggling, but many revealed glimpses of the strength that they were seeking. A participant seemed to know the right attitude to take.

"There's something I need. I as me, I always want to give myself as this person as I am and I want to make myself strong, strong and strong. I just want to encourage other people so that when there is someone pass away with this, so that she could be strong and not blame him or herself about this. Because it's not about someone's fault, it's just an illness that we could accept in oneself that one day we can't fight this illness for long time. Always make sure you eat healthy, exercise every day. Always talk and encourage other people about this illness, go to the clinic and check that you are okay". (Sad face while sharing.) (P4)

It was concluded that focusing away of unpleasant memories, refocus one on more rewarding aspects.

3.7.6   CATEGORY: COUNSELLING

The death of a family member is a painful experience and has the potential of long-term impact on the psychological health of the remaining family members. Some turn to self-blame, substance abuse, emotional eating and behavioural disengagement. Death also increases depression, stress, and anxiety (Høeg, Appel, Von Heymann-Horan, Frederiksen, Johansen, Bøge, Dencker, Dyregrov, Mathiesen & Bidstrup, 2017: 1). However, when grief counselling is received by individuals in the bereavement process, they are greatly helped to adapt to the loss and resolve their grief (Høeg et al., 2017: 2).

The kind of support that the youth in this study seemed most in need of, and which they themselves valued most, was emotional support.

> *"Oh … just counselling. I think counselling is very good. Because at counselling we get to talk about lots of things, how are you feeling, and how does it affect you".* (P6)

A participant felt that she needed counselling. She said that the counselling sessions would help her cope and relieve her stress her related to grief after the loss of a family member.

> *"I can be supported with … uh … maybe going to counselling so that I can help relieve my stress".* (P2)

A participant spoke of in informal group of her peers who helped by counselling her:

> *"I was hurt. My mother talk to me and take me to other people so that ndizoyeka uku stresser ('I'll stop stressing'). Those people who you go to when you want to talk about that. There is a group in my stress that when you are stressed, and you want to talk about what you are stressing about. There is a group of people that is doing that project. So, I was going there to talk about what I was stressing about. Then they counselled me. They counselled me, after two to three weeks ndaye nda right* (I became alright)." (Sad face). (P7)

Group counselling sessions have a positive role in the stress reduction process (Ehsan, Yazdkhasti, Rahimzadeh, Ataee & Esmaelzadeh-Saeieh, 2019: 169). The experience of joining a professional counselling group is reported to be important after the loss of a family member, helping a lot with stress relief and also with practical methods of coping to avoid mental health problems (Kassymova, Tokar, Tashcheva, Slepukhina, Gridneva, Bazhenova, Shpakovskaya & Arpentieva, 2019: 26).

A participant showed awareness of her own need of guidance. She was concerned at the lack of support she was receiving after her grandmother passed away, and expressed a need of someone to help with both the practical aspects of life, such as applying for university, and with the emotional side of her life.

"Like, I'm a girl. I've got my needs. I am dating. I need someone to be my guide. Like someone to tell me what to do, what not. And, someone who will push me to do the right things. Like now I'm supposed to be in varsity, but I had no one who could help me with that stuff of going to varsity". (Uses fingers to count). (P5)

This quote confirms the assumption that obtaining self-efficacy during self-management can improve ones well-being.

Parents who neglect their own children for support may be narcissistic. Määttä and Uusiautti (2020: 4) explain narcissism, as adapted from Sigmund Freud; a narcissistic parent is cold, rejecting and indifferent to the needs of others, including their own children. They have no emotional reserves with which to help others and care only about themselves. A narcissistic mother can result in dysfunctional interactions between mother and children (Määttä & Uusiautti, 2020: 6).

Individuals who attend counselling during stressful times have reported a positive experience that has helped them improve their resilience (Lee et al., 2019: 1). A study conducted by Esfandiari, Faramarzi, Amiri, Parsian, Chehrazi, Pasha, Omidvar and Gholinia (2020: 7) show that counselling also has the ability to increase knowledge and compliance with health-promoting activities.

3.8   CONCLUSION

A death in the family causes many challenges to those left behind, exacerbated if the deceased was a breadwinner. Evidence from the participants showed that participants had to cope not only with the emotional pain of loss, but the practical effects of being left without a source of income. The evidence also shows that many resorted to unhealthy behaviours such as drinking and smoking in their effort to reduce stress.

Most young women interviewed expressed feelings of shock and denial when first they heard that their loved one had passed away from a cause they had kept hidden. This gave rise to mixed feelings, including anger, remorse and a sense of guilt. The loss of a family member leaves relatives struggling to remain stable and to realise that there is still a future for them, despite their many financial needs and the added stress of conflicts in the family. A few of the participants in the study reported that their lived

experience they had attended community self-help sessions, seen a social worker at the local clinic, or spoken to someone at church in order to deal with the situations they were facing. It is clear from the participants' comments that many were aware of their need for counselling, and felt that professional counselling would help them.

CHAPTER 4: CONCLUSIONS, GUIDELINES, LIMITATIONS AND RECOMMENDATIONS OF THE STUDY

4.1 INTRODUCTION

This section describes conclusions drawn from the findings, followed by specific actions to be taken with respect to policy, practice, theory or subsequent research. The second objective of this study was to develop guidelines for nurses to advise youths on self-management following the loss of a family member to HIV/AIDS.

Written guidelines for nurses are needed to enable them to support the youths in the clinical facility who have lost a family member to HIV/AIDS. These guidelines will help the youths to deal with grief and anxiety and guide them on steps that should be followed to access government grant for basic needs. Recommendations for nursing educators, future research and nursing practice as well as limitations of the study are also discussed.

4.2 CONCLUSIONS

In Theme 1 it was found that the time at which the death occurred was unexpected (time-related circumstances) and defined the behaviour of participants to manage themselves due to the death. Most of the participants in the study were still in school when the death of their family had occurred. They indicated they had no control over the changed situation and had to drop out of school and take over the responsibilities left behind by the deceased and become a breadwinner. Most of the participants were still grieving and could not deal with the reality and could not deal with their emotions because the deceased left them with a heavy burden.

Their loved ones' sudden death triggered anxiety about the unknown. These young people had to take care of children and siblings instead of realising their own dreams.

Participants were faced with an unexpected reality that the deceased withheld information about her/his health condition. They did not know about the HIV status of their loved ones before they passed away. Most of the deceased kept it a secret therefore could not be better supported by their family members. Some of the participants had to find out the HIV status of their loved ones at the clinic after they

had passed away. The youths went through feeling guilty about not being able to be there for their loved ones, blaming themselves for the death of their loved one. The youth did not cope with the complications caused by the death of their loved ones and the impact of it on their lives.

The youths developed inappropriate behaviour due to their detachment from the reality of the death. They felt like it's the end of the world and had negative thoughts. The stress that they were experiencing was unbearable and lead to depression and panic attacks in many.

Theme 2 addressed the different stages of going through the unexpected loss of a family member. Participants experienced grief and denial due to the unexpected loss that happened in the family. Individuals responded to grief in different ways, and participants struggled to accept the situation. Their grief was sudden and shocking to them.

Participants experienced remorse about not being able to be more supportive to the deceased with their HIV treatment therapy. The youths were unable to comprehend what the future ahead of them would entail and, as result of the death, some experienced feeling unloved by the relatives who were left behind. The youths became involved with alcohol and drugs due to the stress of dealing with the grief.

The youths struggled with what the future of those left behind entailed. A death in the family brings about complications for those who are left behind. The youths saw their dreams coming to a standstill.

It was difficult for the youths to deal with the loss of someone dear to them of who they had fond memories. They experienced pain and sadness and remembered the memories of the moments shared with the deceased. Youths were also sometimes dependent on these deceased breadwinners. They had to start doing things for themselves and execute tasks that were once done by their loved ones.

The youths missed a family member who contributed positively to their lives. They faced difficult times of loneliness and missed the positive contribution of the deceased to their lives. The hardship they faced were sometimes unbearable. The youth lacked

self-motivation and positivity in which was brought by their loved ones that had passed away.

Theme 3 indicated the difficult changes in the daily lives of the next of kin of the deceased. Changes took place as youths had to become the breadwinners and drop out of school at a very young age. Youths were badly affected by the death of their family members and brought about difficulties in their lives. Their lack in self-management resulted from a minimum support from relatives who directed all their own support to siblings.

The family had financial needs and needed to eat. Most deceased in this study were breadwinners and their passing resulted in no income for the family. Some had to depend on social grants.

When an elderly person or parent dies, it often results in family disorganization. Family members of the participants in this study were fighting amongst themselves. These fights cause pain and hurt in the youths. They also did not know how to respond to the difficulties they faced and degrading and belittling treatment that resulted from fights. Therefore, a plan needs to be developed to help the youths to control their emotions, prevent family fights and bring peace into the family. Within the family the youths should create a supportive atmosphere. Youths should be an advocate of their siblings by identifying their needs and encouraging them to speak to a counsellor if they need to speak out about their grief and challenges.

The stigmatization that is attached to HIV/AIDS still exists within communities. Children of those who passed away to HIV/AIDS still suffer the consequences of being stigmatized by their own peers in the community. In this study, children were discriminated against on the playgrounds and at school. Youths were faced with coping with the stigma attached to HIV/AIDS and community members gossiping behind their backs about them.

Support measures for the next of kin were needed. Communicating and speaking out were mentioned as a method of gaining emotional support. Grieving had an effect on the emotions of an individual who experienced the burden of not having someone to speak to about their feelings. Youths did not know how to manage themselves as a

result of a lack of therapeutic sessions, which could provide emotional support and help them with their healing process.

Having to be strong and support your siblings alone can cause much stress. A social worker in their local clinic was needed to help them with counselling and social effects after their loved one passed away.

The youths did not seem to be aware of stumbling blocks and new possibilities. It was hard for them to drop out of school and university in order to take care of their families. They battled to manage the situation and to stand up and do what their peers were not doing. At that time their peers were still attending school and going to university while they had to go and work in order to support their siblings and family, most youth as their peers was enjoying life by going out with friends anytime they want, but they didn't have that privilege because they had taken the role of becoming breadwinner at home.

The youths had to provide hope for the future for their siblings, family and themselves. Life taught them to grow and be strong for their siblings. They could not focus on themselves. Some of the participants had to go back to school in order to have formal education and a brighter future.

The death of a parent has the potential of having a long-term impact on one's psychological health and could result in self-blame, substance abuse, emotional eating and behavioural disengagement. The youths in this study did not know how to manage themselves due to the emotional burden they were carrying around and the absence of group support sessions for dealing with their grief.

4.3   GUIDELINES

Four guidelines were developed from the themes that were generated by the data analysis. They are outlined in the Table 4, followed by a description of each guideline. The guidelines also assumed theoretical departure indicating the cognitive behavioural therapy, behavioural focused approach and natural rewarding approach.

Table 4.1: Themes and guidelines

Themes generated	Guidelines for youth
Theme 1: Time-related circumstances define behaviour to manage death of a family member	Guideline 1: The youths need to practice self-management during unexpected situations to enable them to cope with the death of family members with HIV/AIDS.
Theme 2: Youths go through different stages after the unexpected loss of the family member.	Guideline 2: Youths going through the unexpected death of a family member should be assisted in dealing with grief and in establishing a positive mind set about realizing a great future.
Theme 3: Managing difficult changes in daily lives of the youths and next to kin.	Guideline 3: Youths should lead and take on the responsibility of being the breadwinner, mentor and motivator of the siblings and young ones.
Theme 4: Support measures for the youth and next of kin.	Guideline 4: Youths should be provided with emotional support both in the community and healthcare facilities in order to in the end help others who are going through the same crisis.

GUIDELINE 1: THE YOUTHS NEED TO PRACTICE SELF-MANAGEMENT DURING UNEXPECTED SITUATIONS TO ENABLE THEM TO COPE WITH THE DEATH OF FAMILY MEMBERS WITH HIV/AIDS

Self-management is the ability of an individual to control their feelings and actions. When one has solid self-management abilities, you are able to set goals independently in unexpected situations and take the initiative to achieve them. According to Acharyya (2017), self-management means being able to oversee unexpected tasks. It also

means having the skills, ability and confidence to take charge of yourself and your daily roles and responsibilities.

Rationale

Nurses should understand the grief of youths who lost a family member to HIV/AIDS in order for them to provide appropriate guidance to these youths who are experiencing anxiety and fear of the unknown. HIV-related deaths or illnesses affecting the family have a huge impact on the individuals and may lead to experiences of post-traumatic stress symptoms (PTSS) or post-traumatic stress disorder (PTSD). Additional mental health problems of depression and anxiety could occur (Gorman, Engel-Rebitzer, Ledoux, Bovin & Marx, 2016: 2). When parents die, children become the head of the household in some families. They take over responsivities of their parents and have to leave their childhood stage of development. This is a huge trauma and stress to them, often leading to mental health problems such as depression, anxiety and post-traumatic stress disorder (Lamothe, 2017).

The following actions address Guideline 1:

The role of the nurse

Behavioural-focused approach

- The nurse should first acknowledge the youth's sadness about the situation and show empathy and care by using good interrelationship skills. Empathy is commonly known as a need during times of loss (Goldade, 2019).
- The nurse should be there and assist the youth by listening and helping the youth to understand their own value in life even after the loss of the loved ones. Youths need to regain their strength after the difficulties and challenges they have faced in their mourning over the deceased. Purposeful self-management can assist a youth to coordinate the direction of their career and guarantee that they seek opportunities to reach their goals (Say, 2020).

Individual sessions of the nurse with the youth

Natural reward approach

- Although the youth will be traumatised due to the passing of their loved one, they should be advised to focus on their future and own life. The youth needs to realise the importance of continuing their professional development of for e.g. their career so that they contribute to the community and support their family.

Cognitive behavioural therapy

- The youths need to talk to the nurse in a private room about their feelings so that they can realise that they are not responsible for the behaviour of the family member who did not take all the necessary steps to manage HIV/AIDS before passing away.
- The youth should be given a booklet to read and become mindful of the specific steps to take to forgive the deceased.

Peer mentoring

Behavioural-focused approach

- A peer or peer group who have had similar experiences can act as mentors for the youth (mentees). Sessions with the purpose of assisting and role play can be arranged with the youth to help them with the grievance process and to accept what has happened to their loved ones.
- Numerous treatment options can be used to deal with complicated grief. Some of the interventions include grief education, support groups, group therapy, spiritual and religious sessions and individual counselling (Strachan-Proudfit (2019: 1).
- The youth needs to take the step in joining the peer group introduced to him and to see the value. Group therapy focuses on changing a person's thoughts and behaviours, while support groups help a person to cope with life challenges by providing helpful coping skills in a supportive environment (Strachan-Proudfit, 2019: 36).

Natural reward approach

- The youth should understand how to be an anchor for their siblings after the loss of a family member in order to provide stability in the family.

Own decision-making about healing after loss

Cognitive behavioural approach

- The nurse must acknowledge that the youth has been traumatized and give the youth the time and opportunity to talk about the loss. The nurse should also monitor the youth for the possible development of for e.g. posttraumatic stress disorder (PTSD).

- The nurse should identify a need for referral and explain the purpose of such a referral to the youth. The youth must be helped to be aware of the signs of experiencing shock and anger as a result of the loss and take the decision to follow up the referral to a clinical psychologist or pastoral psychologist.

- The youth needs to understand and acknowledge that the death of their loved ones has placed them in a different situation now and that they have to accept the responsibilities they have to take over. Many individuals suffer from self-blame and feelings of being stuck in their grief (Giacomucci, 2020: 5).

- It is important for the youth to be aware that you act on what you know and that people have different responsibilities in life. They should also know that they have to respect and accept the decision of the individual who has died to kept their HIV/AIDS status confidential and that it was not anyone's fault.

Behavioural-focused approach

- Youths at the healthcare facility should be provided with or be able to access anger management sessions to release anger they are facing due to the sudden death of a loved one. Grievers who are stuck in grief appear to have on-going difficulty in managing their anger and even physical health (Strachan-Proudfit, 2019: 1).

- The nurse should provide information to youth on the availability of different therapeutic sessions in the community or clinic. The youth must identify which sessions are important for reinforcing a positive outlook of their world.

- A therapeutic session can involve the encouragement of the youth to share ways of dealing with stress and negative thinking. In this way, youths are given solutions to their own situations. The facilitator can direct the discussion towards a positive outcome, while the youth can experience being the problem-solver.

Natural reward approach

- Following the death of the family member, the youth should plan their daily activities in order to keep their pace and attention. This will help them to realise and understand their own importance in the family and environment instead of dwelling on things they can't change. The study conducted by Carlsson, Bremer, Alvariza, Årestedt, and Axelsson (2020: 3) revealed that, after the death of a loved one, an individual who was close to them would suddenly experience that activities in everyday life become pointless when one is alone, and therefore needs to be planned ahead.

- Youths should monitor their health and show that they accept the responsibility to learn the techniques for dealing or handling their anxiety and panic attacks.

- Youths should organise their time and allocate enough time for the responsibilities they have inherited from the deceased. They should also share their time-management progress, which will help them to keep busy during their handling of their grief.

GUIDELINE 2: YOUTHS GOING THROUGH THE UNEXPECTED DEATH OF A FAMILY MEMBER SHOULD BE ASSISTED WITH HANDLING GRIEF AND ESTABLISHING A POSITIVE MIND SET ABOUT REALIZING THEIR FUTURE.

Rationale

According to Matthews (2017), when it comes to grieving the death of a loved one, there are no linear patterns, no 'normal' reactions, no formulas to follow. The reality of death affects families in a myriad of emotional/physical ways while also shifting family systems and impacting spirituality. Lekalakala-Makgele (2018:151) explains that each person's grief is unique and does not follow any pattern or path. The different ways of showing grief such as crying, fear and anger are common and universal; however, cultural should also be considered when evaluating individuals with complicated grief.

Most bereaved people can overcome their grief, but in some cases, grief becomes prolonged or complicated.

The following actions address Guideline 2:

Youths' handling of grief

Cognitive behavioural approach

- The nurse can include the youth in closed group sessions for dealing with denial and grief. This can take place in the healthcare facility or the nurse can arrange a home visit. Group sessions provide the opportunity for instilling hope, generating altruism, understanding the universality of the psychological experience, imparting information, socialization, promoting interpersonal learning and creating group cohesiveness (Strachan-Proudfit, 2019: 30).

- The nurse should allow the youths to talk about their fears and cry if necessary, as this is part of the grieving process. Allowing the individual to grief appropriately and letting them express their feelings are very important (Purandare & Sathiyaseelan, 2018: 138). Strength in coping can be drawn from various resources such as "one's belief in God, religious activities and rituals" (Strachan-Proudfit, 2019: 34).

- The youth should understand that it is normal to go through the different stages of the grieving process and that there's no time frame attached to each stage of grief – it varies from person to person, depending on how close you were with the person who passed away. Grieving is an important component of dealing with the trauma of parental death (Purandare & Sathiyaseelan, 2018: 137).

- The youths should be encouraged to talk about their pain and hurt they are experiencing due to the loss of their loved one as it comes as a shock to many. This will help them transform their pain into purpose, tragedy into treasure, and mourning into mission (Abi-Hashem, 2017: 251).

Behavioural-focused approach

- If the youth is unable to handle grief, he/she should return to the clinic to make an appointment with the nurse in order to be referred to a clinical psychologist or pastoral psychologist. Those who experience complicated grief are observed

to become stuck and unable to move through the grieving process independently (Strachan-Proudfit, 2019: 1).

Realising there is a future

Natural reward approach

- The youths should be able to demonstrate that they have changed their guilt and negative feeling, are moving in a positive direction (e.g. finding a job) and acknowledge their value to support the family. According to Purandare and Sathiyaseelan (2018: 138), when dealing with traumatic events in life in which nature plays a major role the individuals should learn to follow some coping mechanisms for promoting positive health.

- As part of self-management of stress, the youths should set up a weekly calendar to ensure that they get enough sleep, excise, eat healthy, keep themselves busy by engaging with positive people, go to church and find a job. This will help in their healing and restoration process and will facilitate personal growth, thus promoting not only mere coping and survival but also remarkable strength, growth and resiliency (Abi-Hashem, 2017: 251).

- Youths should not isolate themselves when facing the loss of the family member but should be encouraged to continue with their daily activities. In doing so, they will keep themselves busy and fill the gap left by the death of their loved one.

- Youths should be monitored if they make time to attend positive social events and helped to realize the positivity in their lives, control their negative thoughts and increase their self-esteem.

Developing a positive mind set

Cognitive behavioural approach

- The youth should share the ways in which he/she can channel his/her energy towards e.g. engaging in community activities. They can also help or assist with volunteer work at old age homes. Abi-Hashem (2017: 251) states that helping the bereaved to re-invest and re-channel their psychological energy, which has been consumed in the loss, is an important step towards the resolution of grief.

- Through talking about HIV/AIDS, it is important that youths realise that HIV/AIDS is part of our lives, and that HIV/AIDS is not linked to age, social economic status, religion, race or intelligent.

Natural reward approach

- The youths should be informed on how to encourage the family to celebrate the life of their loved one who died and share positive memories by holding a memorial service. The youths should be provided with study material in order for them to learn techniques of adapting to things that have changed and to do things differently without the person whom they shared responsibilities with. According to study of Carlsson et al. (2020: 3), one should get together with others to talk about and remember good times after the death of a loved one, thereby keeping the loved lost one close and a part of the family.

- Youths should demonstrate that they use the techniques of building their self-confidence on their own and get role models to assist in building self-confidence after the loss of the loved one.

- Youths should read self-encouragement books and blogs and share their stories about positive influences on their lives.

- The youths should keep an open mind and look for ways in which the family can function. They should stay calm and in control of the family situation. After the death of a family member, an individual needs to seek consolation and start a grieving process, but at the same time needs to push away feelings in order to keep functioning in everyday life (Carlsson et al., 2020: 3).

GUIDELINE 3: YOUTHS SHOULD TAKE OWNERSHIP TO LEAD AND TAKE UP THE RESPONSIBILITIES LEFT BEHIND BY THE DECEASED BREADWINNER TO BE THE MENTOR AND MOTIVATOR OF THE SIBLINGS AND YOUNG ONES

Taking ownership means standing up and taking responsibility for executing a particular task or project. Furthermore, taking ownership will mean being accountable and making an active and enthusiastic commitment (Golod, 2018). "A breadwinner is referred to as a person who is the provider of the family financially. Over the past years a breadwinner would be referred to a single income of one spouse while the other is at home, nowadays it can refer to either the women or men, or both together (Kagan, 2020).

This guideline enables the nurses to have a positive attitude and give direction and guidance to those youths who visit the healthcare institution and lack financial resources. This guideline also emphasises the importance of the community campaigns in promoting awareness of HIV/AIDS and combating the stigma attached to HIV/AIDS in the community.

The following actions address Guideline 3:

Changing daily routines of the youths

Natural reward approach

- The youths should be guided to change their daily routine while accepting change in their lives and having to live without their loved one. The death of a family member is accompanied by changes in emotions, roles and responsibilities (Frivold, Slettebø & Dale, 2016:400).

Youths as role-models

Natural reward approach

- The nurse should describe the meaning of a role-model to the youths. The youths should be the role model in the family by showing a determination to move forward and being optimistic about the future ahead. A study conducted by Johnson, Buckingham, Morris and Suzuki (2016: 126) has revealed that the young individual in the family look up to someone they know personally.

- The youths should learn how to have compassion with the grief of the family members. By doing so, they continue with their personal development as individuals.

- The youths must share their understanding of how it is to follow in the footsteps of the breadwinner who deceased.

- Youths should identify their specific hobbies or talents that they can use and discuss how they will be able to generate money out of it.

- Youth should be encouraged to find new hobbies and share their life experiences and challenges, with the purpose of encouraging those who are in the same situation due to the loss of loved ones.

The role of the youths and financial management

Behavioural-focused approach

- Those who are left behind with siblings should access the government grant or open a small business in order to support the family and themselves financially.

- Youths should try to cut the cost of their monthly expenses to save and also read more about a health budget that is cost effective.

- The youths must encourage siblings to assist, if possible, by doing small tasks at events or jobs over the weekends to generate financial income for the family.

Being in emotional control

Cognitive behavioural approach

- The youths should learn techniques with which to control their emotions, prevent family fights and bring peace into the family. Youths who have lost a family member suffer from anxiety and depression due to failure to handle life without the support of their loved ones. Depression resulting from traumatic events is more negative to quality of life than PTSD in youths (Haravuori, Suomalainen & Marttunen, 2016: 46).

- Youths should create a supportive atmosphere within the family and create space for everyone.

- Youths should be an advocate of the siblings by identifying their needs and advising them to speak to a counsellor if they need to speak about their grief and challenges.

- Youths should make time to attend campaigns that are conducted by the Department of Health in the community to fight against the stigmatization attached to HIV/AIDS.

- The youths should have goals for the future and should continue to dream of a brighter future, regardless of the consequences of death. Losing a close person inevitably means being apart and suddenly losing the future as it was once intended, therefore they need to reorganize and restructure a future without the deceased family member (Carlsson et al, 2020: 3).

GUIDELINE 4: YOUTHS SHOULD BE PROVIDED WITH EMOTIONAL SUPPORT BOTH IN THE COMMUNITY AND HEALTHCARE FACILITIES IN ORDER TO BECOME A REPRESENTATIVE VOICE FOR OTHERS GOING THROUGH THE SAME CRISIS

Rationale

Emotional support is given when one person offers genuine encouragement, reassurance and compassion to another. This act includes verbal expressions of sympathy or physical gestures of affection. There are different sources that emotional support can come from, namely religious or spiritual sources, community activities, etc. Emotional support is one of the measures that can improve anyone's attitude and general wellness (Legg & Raypole, 2020). Emotional support is considered as an important social concept and a skill that people develop from an early age. The same emotional support may not be equally suitable in different situations. Some people, such as counsellors and psychotherapies, are considered as being better at providing appropriate emotional support than others since they are qualified to offer this service. Emotionally supportive actions are those with the purpose of increasing positive emotional states of a person in order to overcome negative emotional states (Kindness, Masthoff & Mellish, 2017: 2).

This guideline was developed to assist nurses to provide supportive measures for the youths who visit the healthcare institution to enable them to access financial assistance, such as social grants, that they qualify for. This guideline is also aimed at ensuring the delivery of services such as social work services and/or counselling to these youths. People cope in different ways. Spiritual coping can lead to a griever's transformation and instil hope during deep pain. It has even been proven that spiritual coping has helped with chronic illness. A compassionate counsellor can help those who have lost family member to cope with their current situation (Ackerman, 2020a).

The following actions will address Guideline 4:

Peer development sessions in the community

Behavioural-focused approach

- The youths should share their experience about what they went or are going through. By doing so, they can be enabled to create their own youth group to support other youth. Research studies have emphasized the importance of establishing safety, trust and security through being with others who have experienced similar trauma (Strachan-Proudfit, 2019: 30).

- Youths should join church or community youth groups in order to talk about death, since talking about death help individuals to work through their fears. According to Strachan-Proudfit (2019: 35), pastors can be intentional about incorporating stories of grief into their sermons since many of the stories in the Bible are espoused with real life losses and stories of hope. Other steps of grief resolutions according to Abi-Hashem (2017: 251) are to encourage the bereaved individuals to become involved in their community, develop new interests and engage in productive activities or public service.

- Youths should be encouraged to talk to someone they trust. This can help them to cope with their emotions. Although pastors are not trained grief counsellors, "they can support individuals through listening to their grief and give appropriate advice (Strachan-Proudfit, 2019: 35).

- The youths should partake in community projects that deal with HIV/AIDS to help them to understand the situation of those living with the disease by talking to them in person. A study conducted by Carlsson et al. (2020: 6) reveal that family and friends played a significant role in the grief process, and family members emphasized the importance of narrating and being listened to.

The need for family support

Behavioural-focused approach

- Youths should create an environment in the family that supports communication about their challenges, thereby assisting with emotional support. A

communicating family is known to be a protective factor for the psychological health of individuals in grief (Weber et al., 2019: 1).

Taking the lead in self-help

Cognitive behavioural approach

- Youths should seek supportive assistance provided by healthcare facilities to help them to deal with emotions they face during the death of the family member.

- The youths must seek a safe outlet, which could be for example be the pastor to talk to in order to assist with dealing with emotions. The results of a study conducted by Carlsson et al. (2020: 6) reveal that family members emphasised the importance of being able to talk about and share the story of their loss, even to unacquainted persons.

- Youths should be supported to deal with their emotions in order for them to be become aware of their own strength. Most people accept some facts about the loss merely on an intellectual but not emotional level – that is why they should receive as much support as they can be provided with (Abi-Hashem, 2017: 250).

- Youths should attend stress reduction counselling *group sessions*. Grief counselling support groups are a very effective method of handling loss. It provides individuals with comradery, a safe space to share their story, and the ability to not feel alone and isolated in their complicated grief (Strachan-Proudfit, 2019: 38).

- Youths should make time to see an occupational therapist to do therapeutic constructive tasks with them.

- The youths should seek the help of the social worker in the healthcare facility to help them to realize new possibilities.

- The youths must share a few self-motivational techniques they have been implementing after being taught and write it down in a dairy, showing the frequency of and increase in self-motivation.

- The youths should share their dreams and their focus on their goals and link them with the importance of looking after their family, going to work and going

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to school. Steps of grief resolution include focusing on new dreams and goals (Abi-Hashem, 2017: 251).

- Youths should identify churches in the community that support those who don't have parents, and also locate feeding schemes in the community. Studies reveal that most people touched by grief are on the fence or stuck, not knowing where to locate support (Strachan-Proudfit, 2019: 38).

4.4   RECOMMENDATIONS FOR NURSING EDUCATION AND NURSING RESEARCH

This study provided findings and information on the lived experience of youths who lost a family member to HIV/AIDS in the Western Cape, Cape Town. The overall experiences of the youths after the death of their loved one was not a positive one. Accordingly, based on the findings, the research has developed guidelines which nurses can use to advise youths managing themselves after losing a family member to HIV/AIDS. Recommendations around nursing education and nursing research are outlined in the following sections.

4.4.1   RECOMMENDATIONS FOR NURSING EDUCATION

Traumatised youth should be included in the curriculum of the Bachelor of Nursing. Short courses on counselling should be provided to students as part of their curriculum (as required by the South African Nursing Council). It remains the responsibility of nurses to work on their development and equip themselves with new knowledge by reading articles on the self-management of youths, counselling and social work services and their benefits to those in need.

Learning opportunities with regards to counselling and the provision of therapeutic sessions to grieving individuals and families should be provided to nurses. This will increase their knowledge of how to handle grief and deliver the care best suitable for those who are grieving.

Nurses should provide in-service training on the steps involved in grieving to the general public who accesses the clinic. Most of the participants who were grieving the loss of their family member didn't have an idea of where to look for help during this time of grief, pain and confusion.

Some of the nursing universities and colleges have already implemented short courses on HIV/AIDS counselling as part of their curriculum. It is recommended that nursing students, who are future nurses, should be provided with a short course related to grief counselling and conducting therapeutic sessions for those in grief, pain and confusion due to death of their loved one.

4.4.2   RECOMMENDATIONS FOR NURSING RESEARCH

The researcher recommends that further qualitative research is conducted on the social impact on the youth who are affected by death that is related to HIV/AIDS.

The researcher further recommends that a similar study is conducted with male participants. There was an absence of males at the clinic, which indicates that males who may feel the same pain, grief, and confusion are not seeking the help they need.

4.5   LIMITATIONS OF THE STUDY

The study was conducted at only one of the Comprehensive Primary Healthcare facilities in the urban area in Cape Town, Khayelitsha. The study is qualitative in nature and the findings cannot be generalised to the broader population of the youth in Khayelitsha. The study only focused on youths aged 18–25 years who have visited a Comprehensive Primary Healthcare clinic in Cape Town after the lost a family member to HIV/AIDS, who lost a family member in the last 12 months and were willing to participate in the study. Everyone that qualified were female. The researcher could interpret the findings in English to ensure credibility of what the participants in Xhosa.

Another possible limitation of this study is that all the participants were females, even though the inclusion criteria included both males and females who had lost a family member to HIV/AIDS. (The reasons for this were explained in the previous section.)

4.6   CONCLUSION

The findings revealed that a family is greatly affected by the loss of a family member. One of the more senior family members then has to step into a position of authority and remain strong to support her/his siblings to focus on the future. These role models sometimes have to take on responsibilities at an early stage, and they themselves need support to act strong and to follow in the footsteps of e.g. parents. It was found

that conflict can arise after the loss of a family member, and that certain supportive steps must be taken to unite the family members again. The loss of a family member can create an environment of many forced changes that requires adapted behaviours to stabilise circumstances.

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PARTICIPANT'S INFORMATION SHEET

Project Title: Guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member with HIV/AIDS

Dear participant

Introduction

My name is Siphesihle Delani Hlophe and I am a registered Master's student in Nursing Science at the Cape Peninsula University of Technology. I would like to ask you to offer me an opportunity to explain the research that I wish to undertake and to ask you to kindly participate in an individual interview. Please note that you are allowed to ask any question you may have at any time.

Purpose of the research study

Youths have emotions, fears and may feel depressed after the loss of a family member with HIV. In some families, a young member must act as a parent when the actual parent passed away due to AIDS. There is also a high incidence of depression in people feeling pain, they are less likely to engage in active self-management strategies

such as exercise. Youths visit a public clinic for various reasons, one is when they experience panic attacks and anxiety due to the passing of a family member.

The outcome of the study will benefit the broader community of nurses to evaluate the value of using the self-management guidelines to youths after losing a family member with AIDS. It will also develop guidelines for nurses to advise youths visiting a Comprehensive Primary Healthcare clinic in Cape Town, to manage themselves after losing a family member with AIDS. Further research can be identified to explore healthcare needs of the youth more specifically.

Description of study procedures

Individual semi-structured interviews will be conducted in a private room at the outpatient unit, as agreed with the participant. The interview will take not more than 30 - 45 minutes of your time. The interview will be recorded with your permission. The reason for recording is to allow the researcher to analyse the interviewee's experiences to gain insight, to listen to the interview more than once, and to share the data obtained with only the supervisor. The researcher will also take notes, so that at the end of the interview he/she can reflect on it to identify gaps that might need to be explored in a follow-up interview.

Risks or discomfort

Should you decide to participate in the study, you may feel emotional about the loss of your family member, however, there will be no physical risk. In the event of any unforeseen circumstance, the interview will be stopped and the necessary assistance will be offered by a counsellor that will be arranged to be available at the clinic.

Benefits to the participant or others

The outcome of the study will benefit the broader community of nurses and provide self-management guidelines for nurses to advise youths visiting a Comprehensive Primary Healthcare clinic in Cape Town after losing a family member with HIV/AIDS.

Privacy and confidentiality

Participants' information will remain strictly confidential. No names will be recorded anywhere during this research, only numbers on the consent form, and the audio recording will not be linked to your name. Only the researcher and supervisors will have access to the information. All your information will be kept under lock and key (electronic data password-protected on the computer) for five years after the report has been published, then it will be destroyed/deleted.

Conditions of participation

Please understand that taking part in this study is voluntary and you are not being forced to participate. The decision to participate is entirely up to you. However, I would appreciate it if you share your views with me. If you decide not to participate in the study, this will not affect any care at this outpatient unit. You will get the treatment as needed. If you agree to participate and later decide to withdraw at any stage of the interview or study, you can do so. There will be no interruption of services during the research project as a private room will be used to conduct the interviews, thus no negative impact on the clinic's service delivery and patients' management will occur.

Expenses

You will not pay anything, and you will not be paid for participating in this study.

Contact details

This research is being conducted by Siphesihle Delani Hlophe, a professional nurse working at Tygerberg Hospital in Emergency Department C1DWest.

If you have any questions about the research study itself, please contact:

Researcher: Siphesihle Hlophe

Telephone: 0781070687 / 0662025953

Email address: 219401578@mycput.ac.za

Should you have any questions regarding this study and your rights as a research participant, or if you wish to report any problems you have experienced related to the study, please contact:

Research Supervisor/ Head of the Department of Nursing

Prof. K. Jooste

Cape Peninsula University of Technology

P O Box 1906, Bellville, 7535

Telephone: (021) 959 2271

Email: kjooste1@gmail.com

 joosteka@cput.ac.za

ANNEXURE B: CONSENT FORM

**Cape Peninsula
University of Technology**

PO Box 1906, Bellville, 7535

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WRITTEN INFORMED CONSENT

Letter of request to participate in the study

Project title:

Guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member with HIV/AIDS

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered after reading the information sheet. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's signature……………………………….

I further agree that the interview is digitally recorded.

Participant's signature……………………………….

I further agree that the researcher takes field notes.

Participant's signature……………………………….

Witness ……………………………….

Date……………………..

ANNEXURE C: INTERVIEW SCHEDULE

Cape Peninsula
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Introductory questions

Welcome and explain the purpose of the study.

What are your age and demographics?

Main questions

- What is self-management for you?
- What was your lived experience of self-management after the loss of your family member who had HIV/AIDS?
- How can you be supported to manage yourself after the loss of your family member?

Examples of probing questions

- How is it for you after the loss of a family member with HIV/AIDS?

- Tell me more …………………….

- What advice would you give a youth who's going through the loss of a family member with HIV/AIDS?

ANNEXURE D: LETTER OF REQUEST TO CLINIC

Cape Peninsula
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PO Box 1906, Bellville, 7535

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Email: 219401578@mycput.ac.za

September 2019

Request for permission to conduct research study

I am Siphesihle Delani Hlophe, a student registered for a Master's degree at the Cape Peninsula University of Technology. I hereby request to conduct a research study at your Comprehensive Primary Healthcare clinic in Cape Town. The study is entitled: Guidelines for nurses at a Comprehensive Primary Healthcare clinic in Cape Town, with which to advise youths on self-management following the loss of a family member with HIV/AIDS

The study will be done under the supervision and guidance of Professor K. Jooste of the Cape Peninsula University of Technology.

Data collection will be obtained by:

- Individual semi-structured interviews which will be held at the Khayelitsha Site B Comprehensive Primary Healthcare. Participants invited to partake will be

youths (18-25 years), both male and female, who have lost a family member within 12 months. Interviews will be held in a private room and will take not more than 30 – 45 minutes for individual interviews.

- The researcher will adhere to participants' rights to privacy and confidentiality. In this study, no names will be attached to the data obtained and the interview transcripts will be numbered. The participants' names will not be linked to the research findings. The research will not harm the participants in any way. Participants will be informed that they can withdraw from the study at any time they wish to. In this study, the researcher will make use of semi-structured individual interviews and field notes to develop a comprehensive understanding of the phenomenon. The interviews will not take more than 30-45 minutes and will be conducted in a private room at the clinic in the research setting. While conducting the interviews, the researcher will record the views and experiences shared by the participants with their permission. The transcribed data of the interviews, together with the field notes, will be triangulated for analysis after translation and back-translation. Open coding will be used to organise data collected and an independent coder (experienced researcher and supervisor) will assist in this regard.

I am also requesting a private room at the clinic to be available, where there is a private space. I am attaching the proposal, information sheet as well as the informed consent sheets for your information.

Researcher: Siphesihle Hlophe, Clinical Mentor

1 Bester Road

Bellville South

Cape Town

Cell: 0662025953: Email address: 219401578@mycput.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Research supervisor

Prof. K. Jooste

Cape Peninsula University of Technology

P O Box 1906, Bellville, 7535

Telephone :(021) 959 2271

Email: kjooste1@gmail.com

joosteka@cput.ac.za

This research has been approved by the Research and Ethics Committee of the Faculty of Health and Wellness of CPUT.

ANNEXURE E: LETTER TO THE DEPARTMENT OF HEALTH, WESTERN CAPE PROVINCE

Cape Peninsula
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The Head,

Department of Health

Western Cape Government

PO Box 2060,

Cape Town,

8000.

The Head

Request to conduct a study at the Khayelitsha Site B Comprehensive Primary Healthcare.

I write to seek permission from your office to conduct a study at the Khayelitsha Site B Comprehensive Primary Healthcare.

I'm a nursing student registered for a Master's of Nursing at the Cape Peninsula University of Technology. In fulfilment of this course, I am required to conduct a research project. The topic of the study is: Self-management of youths who have lost a family member with HIV/AIDS in a Comprehensive Primary Healthcare clinic in Cape Town. The purpose of the study is to develop guidelines for youths to manage themselves after losing a family member with AIDS.

The study population will be youths aged between 18 and 25 years, both male and female, youths who have visited a Comprehensive Primary Healthcare clinic in Khayelitsha after the lost a family member to HIV/AIDS, and youths who have lost a family member in the last 12 months.

The participants will be interviewed by the researcher himself, using a prepared question guide. The researcher will adhere to participants' rights to privacy and confidentiality. In this study, no names will be attached, only numbers on the interview transcripts. The participants' names will not be linked to the research findings. The research will not harm the participants in any way. Participants will be informed that they can withdraw from the study at any time they wish to. In this study, the researcher will make use of semi-structured individual interviews and field notes to develop a comprehensive understanding of the phenomenon. The interviews will take about 30 – 45 minutes in a private room at the clinic. The researcher will record the views and experiences shared by the participants with their permission. The transcribed data of the interviews, together with the field notes, will be triangulated for analysis. Open coding will be used and an independent coder (experienced researcher) will assist in this regard.

I am attaching the proposal, information sheet to participants and informed consent sheets for your information.

Looking forward to your favourable consideration.

Yours faithfully

Siphesihle Hlophe……………………………………………. Date………….

Supervisor's signature…………………………………………. Date…………

Researcher: Siphesihle Hlophe

Clinical Metor

1 Bester Road

Bellville South

Cape Town

Cell: 0662025953

Email address: 219401578@mycput.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Research Supervisor/ Head of Department Nursing Science, Health and wellness science:

Prof. K. Jooste

Cape Peninsula University of Technology

P O Box 1906, Bellville, 7535

Telephone: (021) 959 2271

Email: kjooste1@gmail.com

This research has been approved by the Research and Ethics Committee of the Faculty of Health and Wellness of a university of the Cape Peninsula University of Technology and the ethics committee of the WC Department of Health.

ANNEXURE F: ETHICAL CLEARANCE CERTIFICATES

Cape Peninsula
University of Technology

HEALTH AND WELLNESS SCIENCES RESEARCH ETHICS COMMITTEE (HW-REC)
Registration Number NHREC: REC- 230408-014

P.O. Box 1906 • Bellville 7535 South Africa
Symphony Road Bellville 7535
Tel: +27 21 959 6917
Email: simonsy@cput.ac.za

4 November 2019
REC Approval Reference No:
CPUT/HW-REC 2019/H2

Dear Ms Siphesihle Delani Hlophe

Re: APPLICATION TO THE HW-REC FOR ETHICS CLEARANCE

Approval was granted by the Health and Wellness Sciences-REC to Ms Siphesihle Delani Hlophe for ethical clearance on 4 November 2019. This approval is for research activities related to student research in the Department of Nursing of this Institution.

TITLE: Self-management of youths who have lost a family member to HIV/AIDS in a comprehensive primary healthcare centre in Cape Town

Supervisor: Prof K Jooste

Comment:

Approval will not extend beyond 5 November 2020. An extension should be applied for 6 weeks before this expiry date should data collection and use/analysis of data, information and/or samples for this study continue beyond this date.

The investigator(s) should understand the ethical conditions under which they are authorized to carry out this study and they should be compliant to these conditions. It is required that the investigator(s) complete an **annual progress report** that should be submitted to the HWS-REC in December of that particular year, for the HWS-REC to be kept informed of the progress and of any problems you may have encountered.

Kind Regards

Dr. Navindhra Naidoo
Chairperson – Research Ethics Committee
Faculty of Health and Wellness Sciences

Western Cape Government
Health

REFERENCE: WC_201911_032
ENQUIRIES: Dr Sabela Petros

P.O. Box 1906
Symphony Road
Bellville
7535
South Africa

For attention: MR Siphesihle Delani Hlope

Re: Self-management of youths who have lost a family member to HIV/AIDS in a comprehensive primary healthcare centre in Cape Town

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

| Khayelitsha (Site B) CHC | Leigh Wagner | 021 360 5228/ 5238 |

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.

2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (annexure 9) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR G DENICKER
ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 18/12/2019
CC