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Research Article

Guidelines for Nurses on Guiding Young Individuals on Self-Management Following the Death of a Family Member to HIV/AIDS

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ABSTRACT

The fatalities caused by HIV/AIDS frequently lead to mental distress among young individuals and impose additional obligations on their parents, such as assuming the care of younger siblings. Youths may respond in many forms, such as increasing alcohol usage and relationships with their siblings may be positively or negatively affected. Individuals experiencing distress often exhibit a heightened prevalence of depression, which subsequently diminishes their inclination to partake in proactive self-management techniques, such as physical activity. Adolescents seek medical care in public hospitals for a range of reasons, such as experiencing panic attacks and anxiety, which frequently occur following the death of a relative. The researcher has found an upsurge in youths visiting a comprehensive primary healthcare clinic in Cape Town after being traumatised due to the demise 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. The Khayelitsha Site B comprehensive primary healthcare study in the Western Cape province of South Africa utilised a descriptive phenomenological design. The sample was chosen using purposive sampling until data saturation was reached. Individual semi-structured interviews with 11 participants achieved data saturation. During the interviews, a structured questionnaire and written observations were employed. The interviews took place in a secluded area where young individuals aged 18 to 25 who had experienced the loss of a family member due to HIV/AIDS visited a comprehensive primary healthcare clinic in Cape Town.

The study employed interpretative phenomenological analysis, revealing that time-related conditions shape behaviour concerning death. Individuals who experience the sudden loss of a family member undergo distinct phases of mourning, encompassing a spectrum of emotions, including denial and eventual acceptance. This bereaved individual also must confront challenging alterations in their daily routines and as a result, requires supportive measures. While assuming responsibility for assisting individuals whom the departed individual previously helped, they may sacrifice their aspirations. Unpleasant encounters overshadowed recollections of positive moments with the departed and individuals primarily prioritised acquiring support systems to progress.

The study's results have the potential to be advantageous for the wider nursing community and offer self-management recommendations for young individuals seeking care at a comprehensive primary healthcare clinic in Cape Town following the loss of a family member due to HIV/AIDS.

Keywords: HIV/AIDS; Family; Outpatient; Youths; Comprehensive primary healthcare

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INTRODUCTION

A family typically serves as a crucial supply of emotional assistance, affection, stability and safeguarding and may offer a distinct sense of inclusion and principles that are not readily available in other connections. The advantages of having a family are extensive and inclusive. Consequently, in the aftermath of a family member's demise, the surviving family members encounter challenges and health issues, such as insomnia, particularly within the initial year following the calamity. The demise of a family member entails the deprivation of the support that the remaining family members formerly enjoyed. Parenting becomes significantly more challenging for the surviving spouse. Self-management may be necessary, involving the deliberate practice of self-care to enhance the well-being of family members, bolster their inner strength, regain a sense of tranquillity and instil optimism for the future.

According to Lenzen, Daniels, Bokhoven, van der Weijden and Beursken [1], self-management refers to the extent to which individuals possess the capacity or desire to regulate their everyday activities and effectively adapt to changes independently. The main goal of effective self-management is to enhance individual autonomy and health status. It is often more advantageous for young individuals to acquire self-management abilities rather than relocate from their residences [2].

Engaging in self-management practices can alleviate the sadness accompanying a significant life event, such as losing a family member. Empirical research validates that individuals actively participate in self-management get improved health outcomes. Self-management is a procedure in which individuals utilise their knowledge, beliefs related to their illness and self-regulation skills.

Experiencing periods of stress is an inherent aspect of life, which can lead to feelings of distraction, inundation and a sense of powerlessness. It is advisable to derive significance from one's present hardship or circumstance, provide ample relaxation, engage in regular physical activity and maintain a nutritious diet [3].

The initial clinical manifestations of HIV/AIDS, including diarrhoea, TB, various infections, white spots on the tongue (hairy leukoplakia, oral candidiasis), weight loss, fever, dermatological issues and dyspnea, can be distressing. After the death of a family member, such as a parent, the remaining young family members may exhibit signs of dread and perplexity. They may experience behavioural changes or emotional withdrawal. Adolescents who have experienced the death of their parents may exhibit an escalation in their alcohol consumption and their interactions with their siblings may be influenced either positively or negatively. Youths fall within the age range of 18 to 25 years. Additionally, the term encompasses the condition or characteristic of being young, vibrant and lacking maturity. Adolescents must possess the capacity to effectively handle their emotions and behaviour in response to the death of a relative [4].

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 by HIV/AIDS [5].

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

According to UNAIDS, 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, there are 1.7 million children in South Africa who have lost parents due to AIDS. UNAIDS 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.

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 [6].

MATERIALS AND METHODS

According to Lenzen, self-management refers to the extent to which individuals possess the capacity or desire to exert control over their everyday lives by effectively dealing with symptoms such as pain and making necessary changes to their lifestyle. Self-management refers to the act of managing one's health and wellness without the involvement of professionals. This may encompass a variety of actions, including adhering to medication regimens, adopting positive health behaviours, maintaining physical fitness and engaging in activities that promote psychological well-being, such as relaxing.

Self-management can be attained through both active and passive methods. Adopting a passive strategy enhances knowledge but may not necessarily lead to a corresponding rise in self-efficacy and behaviour modification. For this particular technique to yield the desired results, it is essential to furnish customised information [7].

An active approach, which incorporates cognitive and behavioural methods, fosters the development of self-management skills through self-reflection, problem-solving and proactive goal planning. The positive health effects of active self-management techniques are primarily dictated by the quality outcomes. Individuals need to continue practising self-management skills, even when experiencing emotional pain. This continual healing process is necessary for developing the ability to detach oneself from pain and cultivate self-efficacy [8].

Problem statement

To enhance the process of planning and implementing self-management therapies, it is crucial to comprehend the individual experiences that lead to pain thoroughly. Following the demise of a familial breadwinner who struggled with HIV/AIDS, adolescents may experience a spectrum of feelings encompassing worry and depression. As a result of HIV/AIDS, certain families are compelled to undergo a transition when a younger member of the family has the responsibility of becoming the provider for the family. Assuming a considerable responsibility at a young age might result in bodily discomfort, as well as a substantially heightened susceptibility to mental depression. The outcome of such experience leads to a decreased likelihood of kids engaging in active self-management methods [9].

Most youths attend public clinics because of panic attacks and anxiety following a family member's death.

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 enhance self-efficacy and help them change their behaviour.

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 [10].

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 [11].

Population and sampling

According to Boswell and Cannon, the study of a population involves examining certain elements that satisfy specific criteria, such as individuals, family members, communities, medical records or events. Population research encompasses the complete group of individuals or items that interest the researcher. However, the researcher must ensure that the needs or criteria they are interested in investigating are fulfilled. The study focused on a specific population: Young individuals who had experienced the loss of a family member due to HIV/AIDS and who regularly visited a comprehensive primary healthcare clinic in Cape Town.

Typically, researchers often need access to the complete population. However, when they do have access and can study a community, it is referred to as an "accessible population" or the "study population".

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 they lost a family member to HIV/AIDS.

Sampling

The qualitative research employed non-probability sampling due to the researcher's inability to access the complete population. Non-probability sampling is based on the researcher's subjective opinion and the researcher determines the sampling approach as the investigation unfolds [12].

The study's participants were selected through purposive sampling, which involved the researcher's discernment in choosing individuals who were representative or had significant expertise in the subject matter being investigated. The selection of participants was based on specific qualities or characteristics that would facilitate the investigation of the research issues. Patino and Ferreira employed suitability/eligibility criteria in the form of inclusion and exclusion criteria to define the specific traits participants needed [13].

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 they lost a family member to HIV/AIDS.

Design

Dudovskiy defines a research design as a comprehensive framework that addresses research inquiries about data gathering and analysis, encompassing research techniques and methodologies.

A qualitative research design signifies the necessity of conducting a study within a particular community to get insight into the requirements, intended outcomes or perspectives on suitable solutions held by the group members. Qualitative research enables the articulation of a phenomenon and facilitates the identification of research questions with a specific focus. It possesses descriptive and inductive characteristics. This research uses qualitative methods, relying on verbal descriptions rather than numerical data, to elucidate a phenomenon. The qualitative study was conducted in a naturalistic environment, investigating the firsthand experiences of young individuals who

have suffered the loss of a family member due to HIV/AIDS [14].

This study employed a descriptive phenomenological design. A descriptive phenomenological approach is used to create a concise representation of the subject or occurrence of interes, specifically focusing on young individuals coping with the aftermath of losing a family member to HIV/AIDS. The utilisation of descriptive phenomenology enabled the researcher to get a comprehensive comprehension of the distinctive attributes exhibited by a specific demographic (youth) inside a particular circumstance, namely, the experience of losing a family member to HIV/AIDS. The study design was characterised by its exploratory, descriptive and contextual nature [15].

The exploratory research design aimed to investigate the phenomena by primarily concentrating on the lived experiences of participants, specifically regarding the loss of a family member to HIV/AIDS. A descriptive design entails the detailed depiction of certain occurrences, such as the self-management of young individuals in the context of experiencing the loss of a family member.

According to Malpass, contextual design involves researching in a natural setting by observing or interviewing study participants to gain a deeper understanding of their self-leadership. Holtzblatt and Beyer define contextual design as a systematic and clearly defined design process that focuses on the needs and experiences of users. It offers several techniques for gathering data from participants within the field. The data on the participants' life experiences was collected within a specialised outpatient unit, which served as the study's backdrop [16].

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 [17].

Study setting

South Africa's population exceeds 56.5 million individuals, distributed among nine provinces and 52 health districts. The research was conducted in the Khayelitsha township. Khayelitsha is a socioeconomically disadvantaged residential district located in the Cape Flats region of Cape Town. The township, founded in 1983, was intended to offer accommodation (mostly tiny two-bedroom dwellings) to around 120,000 African residents in Cape Town. "Khayelitsha" originates from the Xhosa language and translates to "Our new home". The establishment of this township resulted from the surge in the African populace from the Eastern Cape who migrated in pursuit of job opportunities [18].

Lusinga and de Groot state that the township has two primary dwelling categories. Approximately 45% of the housing units are classified as formal residences and the remaining 55% consists of huts located in informal settlements or the rear portions of traditional dwellings. The formal dwellings in Khayelitsha are typically compact, composed of two to four rooms. The majority of residents in this township are comprised of black South Africans and African migrants, accounting for 98.6% of the total population [19].

The neighbourhood is characterised by a high concentration of young individuals in terms of demographic composition. The country's population is distributed as follows: 28.1% are under the age of 14, 70.2% are between the ages of 15 and 64 and just 1.6% are 65 or older. Khayelitsha is an impoverished township where 74% of the households earn R3 200 or less monthly. Khayelitsha is situated at a considerable distance from the city as a result of the racial segregation enforced during apartheid. Consequently, the township is isolated from the most prosperous economic centre and needs more job prospects. The current unemployment rates stand at over 40%. There exists a significant prevalence of poverty and criminal behaviour. A considerable portion of the population is engaged in low-paying occupations such as domestic work, informal sector entrepreneurship and garbage collecting [20].

Data gathering

Data gathering is a systematic procedure for collecting observations or measurements. Data collecting is essential for gaining firsthand knowledge and novel insights in research, regardless of whether it is conducted for business, governmental or academic goals. Although there may be variations in methods and objectives across different sectors, the fundamental data-gathering process stays pretty the same. The subsequent part will elucidate the process of field preparation, data collection and analysis [21].

Interviews

The researcher was the primary tool for gathering data in the semi-structured interviews, as they formulated the questions and actively sought detailed responses from the participants through probing techniques.

The data-gathering process employed phenomenological interviews, which are utilised to investigate the lived experiences of persons to comprehend both the experiences themselves and the underlying phenomenon.

Individual semi-structured interviews were conducted to gather data, enabling an in-depth examination of the participants' lived experiences and the ability to address the intricacies of the research topic.

The primary aim of this study was to investigate the personal experiences of young individuals in coping with the aftermath of losing a family member to HIV/AIDS. The study employed phenomenological interviews with semi-structured questions to investigate the lived experiences of the participants selected for this research.

The interviews were recorded digitally and the gadget was tested to ensure its proper functioning before the interviews. The

predetermined interview timetable presented the research inquiries on the interview agenda.

Throughout the interviews, the researcher asked the participants incisive questions to scrutinise and uncover further information, aiming to gain a comprehensive comprehension of the phenomenon. For instance, the researcher said, "Could you provide further elaboration on this?"

The data gathered was influenced by the verbal and non-verbal exchanges between the researcher and participant. The duration of the interviews ranged from 30 to 45 minutes. As stated by Daniel, qualitative interviews typically last approximately one hour. However, they may extend beyond that due to their comprehensive nature. As the researcher conducted more interviews, his efficiency increased and the duration of the interviews decreased. Data saturation occurred when the participants no longer provided new information.

The indigenous language spoken in the specific region is Xhosa. The local language was employed to accommodate people who lacked comprehension of the English language. It facilitated their ability to express themselves without constraint. The researcher transcribed their dialogue from the transcripts to English, using the native language, Xhosa.

Field notes were utilised as a method of recording essential contextual information. As data sharing and analysis become more prevalent, field notes play a crucial role in preserving the comprehensive context of the original research project. Although field note collection is commonly considered necessary, there needs to be more literature guiding this topic. Consequently, the researcher took notes on their observations and made additional notes during the interviews.

The researchers employed triangulation of methods to get comprehensive data on shared experiences. Data gathering methods can encompass observation, interviews and recording field notes. The researcher diligently recorded field notes as essential to generating documentation and analysing qualitative research. The notes served as a valuable data source for studying the significance of participants' statements and actions within their specific setting.

RESULTS AND DISCUSSION

Data analysis

The researcher was bilingual in English and isiXhosa and specific transcripts were translated from isiXhosa to English.

The data transcription process commences by determining the specific unit of analysis to be examined and selecting the individual responsible for conducting the study, typically the researcher themselves. The section discusses the process of determining whether information should be included in a transcription and the various forms of transcription that can take place. Churcher provides an overview of how data transcription fits into the qualitative research process and explains the expectations and steps involved in the transcription process.

The interview data and field notes were promptly coded upon the completion of the interviews. The researcher translated the interviews into the local language into English, and an editor proficient in both languages performed a back translation to ensure reliability.

Qualitative data analysis entails the consolidation and amalgamation of non-numeric narrative material, which is then condensed into themes and categories by the utilisation of a coding process. The ATLAS.ti tool, Version 8, was utilised to arrange the data to investigate categories and themes. ATLAS.ti is a computer software mainly used for qualitative research and analysis of qualitative data. However, it is not limited to this purpose. ATLAS.ti is not an acronym but a designated name for this scientific software.

A freelance programmer was hired to verify the accurate implementation of codes and guarantee that his code version matched the researcher's. While coders are typically used to demonstrate consistency in measurements, coding assistance was chosen for enhanced reliability in this case. Independent coder reliability refers to the agreement between two or more coders with the same judgement on coding relevant content using the same coding scheme. The researcher and the researcher had an ongoing meeting.

Ethics

The investigation was conducted with strict adherence to ethical considerations. Approval was granted by the research and ethics committee of the faculty of health and wellness at a university (Ethics clearance number: CPUT/HW-REC 2019/H2), as well as the Department of Health of the Western Cape Province after applying to The National Health Research Database (Ethics clearance number: WC_201911_032) and the comprehensive primary healthcare clinic in Cape Town.

Demographic profile of participants

Eleven participants were selected to participate in semi-structured interviews conducted in February 2020. Each individual provided their signature on a written consent form.

The majority of the participants had already attended the clinic. They were recognised in the waiting area for a nurse or doctor. They were provided information about the study and asked if they would be interviewed after completing their purpose for visiting the clinic. Thus, the study managed to prevent any interference with clinical services.

The sample consisted only of female individuals between the ages of 18 and 25, which also included the participants of the pilot interview. Table 1 displays the demographic data of the eleven participants and their association with the individual who died from HIV/AIDS-related reasons.

Table 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 years old	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.

Findings

During data analysis, certain content was discovered to fit into many categories. However, quotes were assigned to the subject and category that best represented the expressed theme.

Individuals experiencing the loss of a family member undergo a range of grief stages that may not always be comprehensively grasped. These stages are typically time-dependent and each stage is important for progressing to the subsequent level. During the process of transformation, individuals who are mourning typically require the assistance of others. Change is the underlying connection among all individuals who are experiencing grief. Not only do individuals undergo internal changes, but alterations in their daily lives and routines also occur instantaneously, resulting in a need for adaptation and causing potential difficulties in coping. This method also requires assistance. Due to the richness of the data quotes were places under and category most appropriate (Table 2).

Table 2: Themes that emerged during semi-structured interviews.

Themes	Categories
Theme 1: Time-related circumstances define behaviour to manage death of a family member	Consequences of death while siblings still at school
	Suddenness of death triggers feeling anxiousness due to the rapid shift in role
	Unexpected reality that family member withheld information
	Developing unusual behaviour due to detachment from reality
Theme 2: Youths go through different stages after the un-expected loss of the family member	Denial and grief
	Guilt at being unable to do more before the family member passed away

	Struggle of those left behind to realise there is a future
	Hardship of losing someone dear about whom one has fond memories
	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	Rapid shift from family member to household authority and breadwinner
	Financial needs
	Family fights and not dealing with reality
	Stigma in the community
Theme 4: Support measures for the next of kin	Communicating and speaking out as part of emotional support
	Financial assistance
	Social worker availability
	Realisation of stumbling blocks and new possibilities
	Own role in providing hope for the future
	Counselling

Theme 1: Time related circumstances define behaviour to manage death of a family member

When a significant and unforeseen event occurs, individuals who encounter it undergo substantial upheaval and a considerable number may struggle to adapt to it in a constructive manner. The occurrence of an unforeseen demise of a relative is abrupt and unsettling. Contemporary youth endure a significant number of distressing incidents, such as the regularity with which they encounter unexpected fatalities.

Theme 2: Youths go through different stages after the unexpected loss of the family member

People react to adversity in various manners. Individuals who are grieving may experience emotions such as sympathy, longing, guilt, outrage or loneliness. In some cases, there may even be a sense of freedom, particularly if the relationship with the deceased was difficult or troubled. Individuals who must confront the bereavement of a close friend or family member frequently encounter difficulties. The loss of a spouse, sibling or parent can elicit an especially profound sense of sadness. The demise of an individual is acknowledged as an inherent aspect of existence, yet those who remain can still be overwhelmed with astonishment and bewilderment, resulting in protracted periods of sorrow or despondency. Nevertheless, each of these stages constitutes an integral component of the grieving process, a crucial undertaking for surmounting adverse emotions and commencing the acceptance of cherished memories shared with a beloved individual.

Theme 3: Managing difficult changes in daily lives of the next of kin

The loss of a primary earner in a household and the presence of single parents have led to changes in family dynamics, necessitating that young individuals assume the role of caretakers for their families.

Shah states that the death of a parent necessitates the presence of an extra set of hands to contribute to earning income. Older siblings in the household typically assume unforeseen duties, which may necessitate their withdrawal from school.

Theme 4: Support measures for the next of kin

The cycle of life encompasses the processes of birth and mortality that occur in all individuals. Discussing death is linked to reduced mourning issues and mental health disturbances compared to situations when individuals refrain from discussing it.

Nevertheless, several societies continue to uphold the stigmatisation of death and dying, which poses challenges in communication and gives rise to various adverse consequences. Discussing mortality facilitates individuals in effectively addressing their anxieties.

A family that engages in effective communication provides an additional layer of safeguarding and promoting psychological well-being among its members. This corroborates the hypothesis that manipulating perceptions can be achieved by diverting attention from unpleasant elements.

Theme 1 revealed that the timing of the death was unforeseen, leading participants to adapt their behaviour in response to the event. The majority of the participants in the study were still attending school at the time of their family member's demise. They expressed their lack of agency in the altered circumstances and had to withdraw from school to assume the duties left by the deceased and become the primary earner. The majority of the participants were still in mourning and unable to cope with the reality and their feelings due to the deceased's profound impact on them.

Their relatives' unexpected demise provoked apprehension over the unfamiliar. These young individuals were compelled to assume responsibility for the care of children and siblings, so forfeiting the pursuit of their own aspirations.

Participants were confronted with the unforeseen fact that the dead had concealed information regarding their health status. Prior to their demise, they were unaware of the HIV status of their beloved individuals. The majority of the deceased individuals choose to keep it confidential, thereby preventing their family members from providing adequate support. Several people had to ascertain the HIV status of their deceased loved ones at the clinic. The young individuals experienced a sense of remorse for their inability to provide support to their loved ones, attributing the death of their loved one to their own actions. The young individuals struggled to handle the intricacies resulting from the demise of their beloved ones and the subsequent effects it had on their life.

The adolescents exhibited inappropriate conduct as a result of their disconnection from the harsh reality of mortality. They experienced a sense of apocalyptic despair and harboured pessimistic notions. The overwhelming tension they endured proved insufferable, resulting in depression and panic attacks for numerous individuals.

Theme 2 explored the various phases involved in coping with the unforeseen death of a relative. Participants had feelings of sorrow and refusal as a result of the unforeseen bereavement that occurred within their family. People exhibited varied responses to grief, and participants encountered difficulties in accepting the circumstance. Their sorrow was abrupt and startling to them.

Participants felt regretful for their inability to provide greater support to the deceased in their HIV treatment regimen. The young individuals were incapable of understanding the implications of the future that lay ahead of them. Consequently, following the demise, certain individuals experienced a sense of being unloved by the remaining family members. The adolescents succumbed to alcohol and drug use as a result of the strain caused by coping with loss.

The young individuals grappled with the implications of what the future held for those who were not present. The passing of a family member gives rise to complexities for that remain. The young individuals witnessed their aspirations being halted.

The young individuals found it challenging to cope with the loss of a beloved person whom they held cherished recollections of. They endured anguish and sorrow as they reminisced about the recollections of the moments they had shared with the deceased. Occasionally, young individuals relied on these deceased providers for support. They were compelled to assume self-reliance and carry out responsibilities that were previously undertaken by their dear ones.

The young individuals longed for the presence of a family member who made a beneficial impact on their life. They experienced challenging periods of solitude and mourned the absence of the deceased's beneficial impact on their life. The adversities they encountered were occasionally insufferable. The young individuals exhibited a deficiency in their ability to motivate themselves and maintain a positive mindset, which was instilled in them by their deceased loved ones.

Theme 3 highlighted the challenging alterations in the everyday routines of the close relatives of the deceased. As a result, young individuals were compelled to assume the role of primary earners and abandon their education at an early stage. The demise of their family members had a profound impact on the younger generation, causing significant challenges in their life. Their deficiency in self-management stemmed from a dearth of assistance from family members, who allocated all their care towards their siblings.

The family had financial requirements and a necessity for sustenance. The majority of individuals who died in this study were the primary earners for their families and as a result, their deaths led to a loss of revenue for the family. Certain individuals had to rely on social welfare benefits.

The death of an older person or parent frequently leads to family disarray. Interfamilial conflicts arose among the relatives of the study subjects. These conflicts inflict physical and emotional distress onto young individuals. Furthermore, they lacked the knowledge of how to effectively address the challenges they encountered, as well as the demeaning and derogatory behaviour that ensued from conflicts. Hence, it is imperative to design a strategy to assist young individuals in managing their emotions, mitigating familial conflicts, and fostering harmony within the household. It is important for the younger members of the family to establish a nurturing environment. Young individuals should actively support their siblings by recognising their requirements and urging them to seek assistance from a counsellor if they wish to express their sorrow and confront their difficulties.

The stigmatisation associated with HIV/AIDS persists in communities. The offspring of those who have succumbed to HIV/AIDS continue to endure the repercussions of being stigmatised by their own peers within the community. In this study, children experienced discrimination both on the playgrounds and at school. Adolescents were confronted with the challenge of dealing with the social disgrace associated with HIV/AIDS, as well as the act of community members engaging in malicious gossip about them.

Assistance measures for the immediate family members were necessary. Verbalising and expressing oneself were identified as a means of acquiring emotional assistance. The experience of grieving had a profound impact on the emotional state of an individual who carried the weight of not having somebody to

confide in regarding their emotions. The lack of therapeutic sessions resulted in a deficiency in the youths' ability to self-manage, as they were deprived of emotional support and assistance in their healing journey.

Assuming the responsibility of being resilient and providing sole support for your siblings can lead to significant levels of stress. The local clinic required the assistance of a social worker to provide counselling and support for the individual in coping with the emotional and societal consequences following the death of their loved one.

The young individuals appeared to lack awareness of obstacles and emerging opportunities. They faced significant difficulty in discontinuing their education at both the school and university levels in order to assume responsibility for their families. They fiercely struggled to handle the problem and to assert themselves by taking action that their friends were neglecting. During that period, their peers were still pursuing education and attending university, while they were compelled to seek employment in order to provide for their siblings and family. While their peers enjoyed the freedom of socialising with friends at their leisure, they were deprived of such privileges due to assuming the responsibility of being the primary financial provider for their household.

The young individuals were required to offer optimism for the future to their siblings, relatives and themselves. They acquired resilience and fortitude from life's lessons in order to support and protect their siblings. They were unable to concentrate on their own needs. Several individuals had to return to school in order to acquire formal education and enhance their prospects for a more promising future.

The demise of a parent possesses the capacity to exert a lasting influence on an individual's psychological well-being, perhaps leading to self-reproach, substance misuse, excessive eating driven by emotions and withdrawal from social activities. The adolescents in this study lacked the skills to effectively regulate their emotions, mostly due to the emotional weight they were carrying and the lack of group support sessions to address their grief.

Guidelines

Four guidelines were developed from the themes that were generated by the data analysis. They are outlined in the Table 3, 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 3: 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 refers to an individual's capacity to regulate their emotions and behaviours. Having strong self-management skills enables individuals to autonomously establish objectives in unforeseen circumstances and proactively work towards accomplishing them. As per Acharyya, self-management refers to the ability to supervise unforeseen duties. It also implies possessing the aptitude, competence and self-assurance to assume control over oneself and one's everyday obligations and duties.

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: Matthews argues that there are no predictable sequences, standard responses or prescribed guidelines for grieving the loss of a loved one. The phenomenon of death has a profound impact on families, manifesting in a multitude of emotional and physical consequences. Additionally, it alters the dynamics of family systems and influences spirituality. Lekalakala-Makgele asserts that every individual's experience of sorrow is distinct and does not adhere to any specific pattern or trajectory. The various manifestations of sadness, such as tears, apprehension and rage, are widespread and universally observed.

Nevertheless, it is imperative to take cultural factors into account while assessing persons experiencing intricate grief. The majority of individuals who have lost a loved one are able to overcome their sorrow, yet, in certain instances, grieving might persist or become more complex.

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

Assuming ownership is asserting oneself and assuming accountability for carrying out a certain activity or project. Moreover, assuming ownership entails being responsible and making a proactive and fervent dedication. A breadwinner is a someone who financially supports their family. In previous years, the term "breadwinner" typically denoted a situation where one spouse earned the sole income while the other stayed at home. However, in contemporary times, the term can encompass both men and women individually or both partners collectively.

This guideline empowers nurses to cultivate a positive mindset and provide guidance and support to economically disadvantaged young individuals who seek healthcare services. This guideline also underscores the significance of community campaigns in raising awareness about HIV/AIDS and addressing the social stigma associated with HIV/AIDS within the community.

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

Emotional support entails the sincere provision of encouragement, comfort and sympathy from one individual to another. This act encompasses verbal manifestations of compassion or physical demonstrations of tenderness. Emotional support can be derived from various sources, including religious or spiritual sources, community activities and others. Providing emotional support is a strategy that can enhance an individual's mindset and overall well-being. Emotional support is regarded as a significant social construct and a proficiency that individuals cultivate from a young age. Emotional assistance may not be universally applicable across various circumstances. Professionals such as counsellors and psychotherapists are regarded as more adept at providing suitable emotional support compared to others due to their qualifications in offering this service. Emotionally supportive acts refer to behaviours that aim to enhance positive emotional states in individuals, hence helping them overcome negative emotional states.

This guideline was created to aid nurses in offering supportive interventions to young individuals visiting the healthcare facility, facilitating their access to eligible financial help, such as social grants. This guideline also aims to ensure the provision of assistance, such as social work services and/or counselling, to these young individuals. Individuals employ several strategies to manage or deal with challenging situations. The utilisation of spiritual coping mechanisms can facilitate a profound metamorphosis in individuals experiencing grief, while also fostering a sense of optimism amidst intense suffering. Empirical evidence has substantiated the efficacy of spiritual coping in alleviating chronic illness. An empathetic therapist can assist individuals who have experienced the loss of a family member in managing their present circumstances.

Recommendations for nursing education and nursing research

This study presented facts and insights on the firsthand experiences of young individuals who have suffered the loss of a family member due to HIV/AIDS in the Western Cape, namely in Cape Town. The youths' overall experiences following the demise of their loved one were decidedly negative. Consequently, utilising the research results, recommendations have been established to assist nurses in providing advice to young individuals coping with the aftermath of losing a family member to HIV/AIDS. The subsequent sections include guidelines about nursing education and nursing research.

Recommendations for nursing education

It is imperative to incorporate education on trauma-affected youth within the curriculum of the Bachelor of Nursing. Students should be mandated to receive short courses on counselling as a compulsory component of their curriculum, in accordance with the regulations set by the South African Nursing Council. Nurses are accountable for their own professional growth and should enhance their knowledge by engaging with literature on topics such as self-management of adolescents, counselling, social work services and the advantages they offer to individuals requiring assistance.

Nurses should be offered learning opportunities in counselling and delivering therapeutic sessions to individuals and families experiencing grief. This will enhance their understanding of how to manage loss and provide optimal care for individuals experiencing bereavement.

Nurses should offer in-service training to the clinic's general public on the sequential stages of the grief process. The majority of individuals who were mourning the death of their relative lacked knowledge regarding the appropriate sources of assistance to seek during this period of bereavement, anguish and disorientation.

Several nursing universities and colleges have already incorporated brief courses on HIV/AIDS counselling into their curricula. It is advisable to offer nursing students, who will become future nurses, a brief training programme focused on grief counselling and facilitating therapy sessions for those experiencing grief, suffering and disorientation as a result of the loss of a loved one.

CONCLUSION

The results unveiled that the departure of a family member has a profound impact on the entire family. Subsequently, a more experienced family member must assume a position of leadership and exhibit resilience in order to provide support to their siblings and maintain their focus on the future. These role models may be required to assume responsibilities at a young age and they themselves require assistance to exhibit strength and emulate their parents, for example. Research has revealed that the loss of a family member can lead to conflict, necessitating specific measures to restore harmony among family members. The death of a family member might lead to a situation where various necessary adjustments must be made in order to stabilise the circumstances.

RECOMMENDATIONS

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.

LIMITATIONS OF THE STUDY

The study was done only in a single comprehensive primary healthcare facility located in the urban area of Cape Town, specifically in Khayelitsha. This study is of a qualitative character and as such, the findings cannot be extrapolated to the wider community of young people in Khayelitsha. The study exclusively examined individuals between the ages of 18 and 25 who sought care at a comprehensive primary healthcare clinic in Cape Town following the death of a family member due to HIV/AIDS during the past year and who expressed a willingness to take part in the study. All individuals who met the requirements were of the feminine gender. To ensure the legitimacy of the participants' responses in Xhosa, the researcher might provide an interpretation of the findings in English.

An further potential constraint of this study is the exclusive inclusion of female participants, despite the fact that the criteria for participation encompassed both males and females who experienced the loss of a family member due to HIV/AIDS. (The rationales behind this were elucidated in the preceding section.)

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COMPETING INTERESTS

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

AUTHORS' CONTRIBUTIONS

S.D.H designed the proposal with input from K.J., S.D.H conducted the interviews and K.J. analysed the data within a structural framework. S.D.H. wrote the manuscript with input from all authors. S.D.H. was in charge of overall direction and planning.

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DATA AVAILABILITY

The data supporting this study's findings are available from the corresponding author, S.D.H., upon reasonable request.

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