2020

Experiences of a Loss of a Parent to AIDS During Adolescence on Young Adults

Angela Thorpe-Moss
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Angela Thorpe-Moss

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Rolande Murray, Committee Chairperson, Psychology Faculty
Dr. Robert Meyer, Committee Member, Psychology Faculty
Dr. John Astin, University Reviewer, Psychology Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2020

Abstract

Experiences of a Loss of a Parent to AIDS During Adolescence on Young Adults

by

Angela Thorpe-Moss

MS, University of Phoenix, 2012

BS, University of Phoenix, 2010

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Health Psychology

Walden University

November 2020

Abstract

Acquired immunodeficiency syndrome (AIDS) continues to be a major healthcare issue for many countries, including the United States. Millions of adolescent children under the age of 18 have lost 1 or both parents to AIDS-related complications. The death of a parent to AIDS-related complications is severe; however, limited data describes how this type of death affects adolescents after they have become young adults. It is important to determine how these adolescents are affected by exploring their lived experiences of losing a parent to AIDS-related complications. The purpose of this qualitative phenomenological study was to understand the lived experiences associated with losing a parent to AIDS-related complications during adolescence and how it may or may not have a significant impact on individuals as young adults. The conceptual framework for this study was based on the transactional stress and coping model that emphasizes appraisal of the threat of harm and the challenges to coping with stressful events. After conducting interviews with 8 participants, I coded, grouped, and analyzed the interview data into themes. The results yielded themes such as anger, sadness, substance abuse, negative judgement, self-isolation, loneliness, grief, stigma/discrimination, and availability of resources. The 3 most prominent themes shared among all participants were sadness, stigma/discrimination, and negative beliefs. The results of this study will help communities understand how to address individuals who have experienced such a loss and how to assist them in addressing their current needs resulting in positive social change.

Experiences of a Loss of a Parent to AIDS During Adolescence on Young Adults

by

Angela Thorpe-Moss

MS, University of Phoenix, 2012

BS, University of Phoenix, 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Psychology

Walden University

September 2020

Dedication

My first dedication is to my Lord and Savior Jesus Christ. Without you in my life none of my accomplishments would have been possible. My second dedication is to Rosa M. Ferrell, my biological sister. Thank you for believing and supporting me in all my endeavors. I would also like to share this dedication with my wonderful husband Wayne D. Moss, Jr. In 2007, God placed Wayne in my life when I could not see my way through. Wayne, you inspired me to complete my bachelor and master's degrees and to further my education in the doctorate program at Walden University as a Health Psychologist. Without your physical, emotional, spiritual, and financial support, I would not have had the courage to complete my undergraduate and graduate programs.

To an amazing and strong mother, Rose Lee Harris, without God using your birth canal, I would not have been here to impact others. Without your Godly teachings in my life, none of this would have been possible. Thank you for your guidance. I thank God for allowing you and my biological father, John Henry Thorpe (Jake) for birthing a child such as me, a child that is determined to impact and change the lives of God's people with great conviction from God. To my stepfather Marshall Ray Harris, thank you for assisting my mother in molding me to become an inspiration to others and for having patience with me as I grew and took a walk on the path that God had predestined for me. I especially dedicate this study to my brother the late Henry Thomas Thorpe. When I started working on this study, Henry was alive and living with HIV/AIDS. On April 9, 2020, Henry was brutally murdered in Raleigh, North Carolina. During one of his speeches he stated to me that "I can't wait to see what you do next." Henry, you are not here to see what I physically do next, but I am finished. Thank you for being an angel watching over me. I love you and you will never be forgotten. To my late cousin Emma Jean Johnson who transitioned on August 7, 2020. I am going to miss you. Thanks for believing in me. RIP.

Acknowledgments

This educational journey has been challenging. My husband, Wayne Moss, Jr. has been a champ. Thank you, Wayne, for putting up with me and empowering me to continue this walk even when I was on the verge of quitting. I could not have done this without your love, moral and financial support.

I am grateful to my committee and chair for empowering and assisting me through this process. I could not have done it without your mentorship and support. You are the greatest. Dr. Rolande Murray, Dr. Robert Meyer, and Dr. John Astin, my hat goes off to each of you. Job well done! Dr. Murray, I was happy to receive you as my new chair. You came on board at the point where I was really frustrated and wanted to throw in the towel. Your expertise and soft voice made me feel comfortable with trusting you with this process. I felt as if I can finally get beyond this veil that had been over my life for the past six years. I am also thankful to all the participants who saw the importance of my study and wanted to be a part of making positive social changes along side of me. I thank Dr. Angela Jiles-Charles, Dr. Tonya Chavis-Thomas and Dr. Erroll Royal for taking the time out of their busy schedules to assist with editing my work. Last but certainly not least, to the almighty God, I thank you for leading me in this direction. I thank you for empowering and equipping me with the motivation and knowledge to get this literary work completed. As always, you have a way that is mighty sweet.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Acquired immunodeficiency syndrome (AIDS) is a significant healthcare issue for many countries including the United States. A 2017 report by the Center for Disease Control and Prevention indicated that approximately 473,000 people in the United States were diagnosed with AIDS, not HIV, which is the virus that causes AIDS (National Institutes of Health, 2017). The AIDS epidemic has impacted men and women in the United States for the past 35 years. Over time, AIDS has become a chronic disease that has claimed the lives of many. The leading age group associated with HIV/AIDS stems from individuals 25 to 34 years of age. One of the third leading cause of death from AIDS impacted age groups between 35 to 44 years of age. (Gielen, Ghandour, & Burke, 2007). In a report titled *The Current Trends Mortality Attributable to HIV/AIDS Infection*, the Centers for Disease Control and Prevention (2020) reported that by the year of 1988, AIDS had become the third leading cause of death for individuals among the ages 25-44.

Since the onset of AIDS in the early 1980s, many individuals have lost their lives to AIDS-related opportunistic infections that include pneumonia, salmonella, candidiasis, toxoplasmosis, tuberculosis, invasive cervical cancer, coccidioidomycosis, cryptococcosis, encephalopathy, histoplasmosis, kaposis sarcoma, lymphoma, and wasting syndrome. Parents with young children are among those who have fallen victim to this disease. These young children are often left behind to be raised by siblings and extended family or placed in foster care programs (Carten & Fennoy, 1997). This qualitative study was intended to determine how young children, now adults, were affected by the loss of a parent to AIDS-related complications. This research of lived experiences entailed identifying gaps, strategies, and new ideas that may assist in applying an action to promote self-worth and dignity among children who lose a parent to AIDS-related complications. This study is based on the transactional stress and coping model conceptual framework that emphasizes appraisal of threat of harm and challenges to coping with stressful events. I drew participants from community-based organizations, local nonprofit organizations, AIDS services agencies, and internet advertisements. I invited eight participants to participate in a semistructured interview to provide information about their lived experiences during adolescence. There is insufficient research that addressed the problems adolescents face following the loss of a parent to AIDS-related complications.

Background of the Study

AIDS has a profound impact on the health and economy of many countries (Dixon, McDonald, & Roberts, 2002). Since the onset of AIDS in the early 1980s, 1,216, 917 Americans have been diagnosed with the disease (Centers for Disease Control and Preventions, 2017). In 2012, 12,960 individuals died from AIDS-related complications (Avert, 2017). Young adults who lose a parent to AIDS-related complications during adolescence may be psychologically affected (Bauman, Silver, Draimin & Hudis, 2007). The psychological impact of losing a parent to AIDS continues to be viewed differently from losing a parent to other chronic diseases. This difference is due in part to stigma and early perceptions of the disease. At the outset, people who were diagnosed with AIDS-related complications died in the hallways of hospitals; some nurses would not place their hands on them. Individuals were made to leave their homes, insurance policies were cancelled, and some lost their jobs (Burr, 1997). While a lot has changed over the course of the past 20 years, the stigma associated with the prevalence of AIDS is still active and sometimes shows up in the form of negative beliefs and feelings towards people (Dealing with Stigma and Discrimination, 2020).

Typically, adolescents who live in homes where they lost a parent to AIDS-related complications are likely to suffer from depression, anxiety, social withdrawal, and learning disabilities, including attention-deficit disorder (Bauman et al., 2007). These adolescents experience more psychosocial difficulties in academic and social functioning than their peers (Lichtenstein, Sturdivant, & Mujumdar, 2010). Adolescents who have experienced a dying parent due to AIDS-related complications sometimes engaged in harmful behaviors that include risky sexualized behaviors and criminal misconduct (Rotheram-Borus, Weiss, Alber, & Lester, 2005). They sometimes have lower psychological functioning than their peers (Rotheram-Borus et al, 2005). They also experienced greater psychosocial difficulties in academic and social functioning. Psychosocial problems of adolescents affected by HIV/AIDS need to be identified and more effectively managed to eliminate other negative behaviors that may arise (Lichtenstien et al., 2010). The gap in research showed insufficient research to address the problems adolescents face following the loss of a parent to AIDS. This empirical research provides insights needed to determine how the experience of losing a parent to AIDS-related complications during adolescence impacts a child of that parent during young adulthood.

Problem Statement

By the end of 2010, 17.1 million adolescent children under the age of 18 had lost one or both parents to AIDS-related complications, and millions continued to face the potential loss of their parents to this deadly disease (Chi & Xiaoming, 2013). Adolescent children of parents who have died are growing up to become adults who have experienced the trauma of losing a parent to AIDS-related complications. The loss of a parent to AIDS-related complications during adolescence may significantly impact an individual’s young adulthood. Some adolescents are afraid of the stigmatization, discrimination, embarrassment, prejudice, and negative attitudes. Sometimes individuals’ living family members are physically abused due to being connected with someone known to have AIDS (Global Information and Education on HIV/AIDS, 2019).

Purpose of the Study

The purpose of this qualitative study was to determine the lived experiences of losing a parent to AIDS-related complications during adolescence has on young adults. The literature lacks sufficient data on the effects of losing a parent due to AIDS-related complications during adolescence.

Research Questions

The overarching research questions guiding this study were:

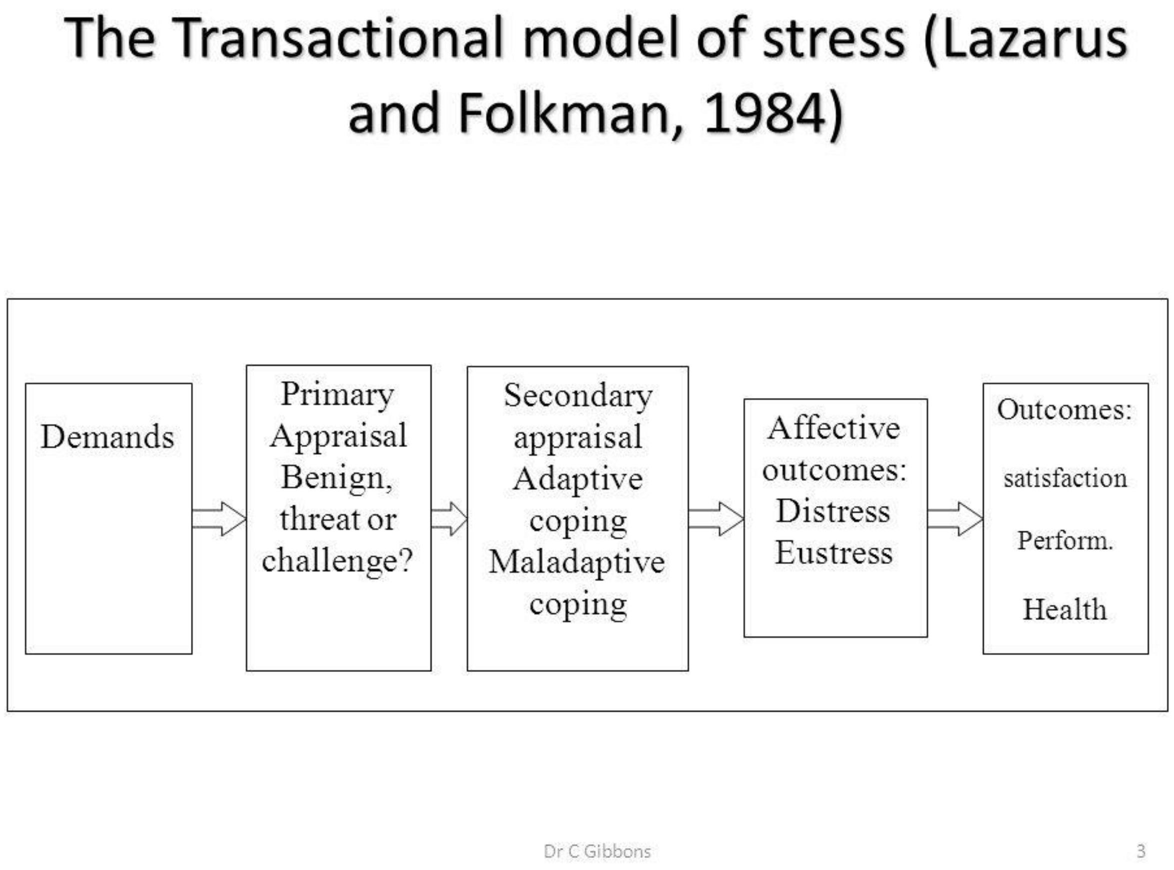
Research Question 1 (RQ1): What are the lived experiences of young adults who lost a parent to AIDS- related complications during adolescence?

Research Question 2 (RQ2): How does an adolescent understand the stigma associated with losing a parent to complications from AIDS?

Conceptual Framework

The conceptual framework of this phenomenological study lens is Lazarus and Folkman's (1987) transactional model of stress and coping. The framework of the transactional model emphasizes appraisal of threat of harm and challenges as key to the determination of how effectively individuals can cope with stressful events (Lazarus & Folkman, 1987). Stress usually occurs when an individual's body feels it is being attacked and the body decides to switch to fight or flight mode. This response releases hormones and chemicals to help the body prepare for the physical action that is taking place. Stress can cause internal and external pressure that results in psychological, physiological, and behavioral changes (Cranwell-Ward, & Abbey, 2005).

The concepts of focus were appraisal and coping measures, and daily stress. Appraisal is the evaluation of harm, threat, and challenges that occur as a result of coping with events that present as stress people's lives. People can evaluate stress in the form of thoughts, feelings, emotions, and behaviors (Lazarus & Folkman, 1987). In this descriptive phenomenological study, I used this transactional model to guide the research and subquestions of this study. According to Mohammad, Mazloomy, and Barkhordari, (2013), the transactional model of stress is one of the most comprehensive models to use when investigating stress.



The Transactional model of stress (Lazarus and Folkman, 1984)

Demands

Primary Appraisal Benign, threat or challenge?

Secondary appraisal Adaptive coping Maladaptive coping

Affective outcomes: Distress Eustress

Outcomes: satisfaction Perform. Health

Dr C Gibbons 3

Figure 1. The transactional stress and coping model. Reprinted from *Stress, Appraisal, and Coping* (p. 234) by R. S. Lazarus & S. Folkman, 1984, Springer. Copyright 1994 by Springer Publishing Company.

Nature of the Study

The phenomenon of interest was understanding the lived experiences of young adults who have lost a parent to AIDS-related complications. I invited people from community-based organizations, local nonprofit organizations, AIDS services agencies, and individuals who responded based to an internet advertisement to participate in a semistructured interview. I asked participants to provide information about their lived experiences of having lost a parent to AIDS-related complications when they were between the ages of 10 and 19. I used a phenomenological qualitive research approach. I conducted one face to face interview, and seven telephone interviews with participants between the ages of 18 and 35 who lost a parent to AIDS-related complications during adolescence. I compiled the data for this qualitative research study using Dedoose software version 7 data-analysis software. This software assists researchers in coding and identifying themes. In coding theme information, I assigned a word, phrase, or number to each category.

Definitions

Adolescence: The period following the onset of puberty during which a young person develops from a child into an adult is between the ages of 10 and 19 (Rotheram-Borus et al., 2001).

Adolescent: A young person in the process of developing from a child to an adult (Rotheram-Borus et al., 2001).

AIDS Related Complications: Disease or infections related to AIDS (Chu &Selwyn, 2011).

Childhood Parental Loss: Losing a parent during childhood age (Lis-Turlejska et al., 2008).

Coping Behavior: A trait and frequently default behavior or group of behaviors that ensue whenever coping with taxing or hazardous scenarios. Such actions can be either negative or positive in nature (Psychology Dictionary, 2019).

Coping Efforts: Strategies used to mediate primary and secondary appraisals evaluating whether any given option will achieve the desired outcome in the context of the individual and the encounter (Graham, 2014).

Psychological Effect: Pertains to the mind or to mental phenomena as the subject matter of psychology. Psychological effect focuses on function of awareness, feeling, or motivation (Bauman et al., 2007).

Psychological Functioning: The ability to achieve goals. It includes an individual's behavior, emotion, social skills, and overall mental health (Bauman et al., 2007).

Stress: *“T*o subject (a material thing, a bodily organ, a mental faculty) to stress or strain; to overwork, fatigue” (Butler, 2018, p.1).

Well-Being: The state of being comfortable, healthy, or happy (Bauman et al., 2007).

Assumptions

A first assumption associated with the research is that adults can accurately and vividly recall their lived experiences during adolescence and can appropriately convey their experiences during the interview. Therefore, I assumed that their reported experiences were truthful and accurate. Second, I assumed that the study participants were close enough to their parents that they would have experienced psychological effects resulting from the loss of that parent. Third, I assumed the young adults’ parent's death was one of the traumatic events experienced during adolescence, and the loss of the parent could explain any negative psychological effects experienced in adulthood.

Scope and Delimitations

The delimitations of this this study are important. Delimitations are features that come to light from limitations in the scope of the study that can define the boundaries of the study. Delimitations are under the control of the researcher (Simon, 2013). The delimitations of this study include the criteria that (a) participants must have been adults between the ages of 18 and 35 who lost a parent to AIDS-related complications during adolescence, (b) I posted flyers and used social media to recruit participants, (c) I used conventional and snowballing sampling strategies until reaching data saturation, and (d) I followed-up with participants by using member checking.

The research problem determined the scope of this study, which was the effects of losing a parent to AIDS-related complications and the lived experiences of those who suffered such a loss during adolescence. According to the Centers for Disease Control and Prevention (2015), as of 2015, 1,194,039 people in the United States were living with AIDS. These statistics mean many families in the United States are at risk for experiencing losing a parent to AIDS-related complications.

According to the World Health Organization, neuropsychiatric disorders, cardiovascular, and circulatory diseases are the top two disorders and diseases in the United States (U.S. Leading Categories of Diseases/Disorders, 2019). Reports indicate that 610,000 people die of heart disease yearly in the United States, equaling one in every four deaths per year (Heart Disease in The United States, 2019). This tragic disease continues to claim the lives of many. In the United States, 13,000 people die yearly due to AIDS-related complications (The Scope and Impact of HIV in the United States, 2019). Although more people die of neuropsychiatric disorder, cardiovascular, and circulatory diseases each year in the United States, they do not face the stigma aligned with dying from AIDS-related complications. AIDS is more stigmatizing than neuropsychiatric disorder, cardiovascular, cancer, and other chronic diseases (The Scope and Impact of HIV in the United States, 2019). The severe stigmatization stems in part from the misconception that individuals diagnosed with HIV/AIDS are at fault for getting the disease.

The literature indicated that adolescents who lived in homes where the experience of a lost parent to AIDS-related complications are likely to suffer from depression, anxiety, social withdrawal, and learning disabilities, including attention deficit disorder (Bauman et al., 2007). Some adolescents are negatively affected by the loss of a parent. Meanwhile, previous studies have provided insights indicating that there is limited research written on the long-term effects on adolescents who have experienced such a loss (Bauman et al., 2007).

Limitations

According to Center for Innovation in Research and Technology (2019), researchers experience influences or disadvantages that they are not able to control. Research quality depends on the researcher’s individual skills and is influenced by the researcher’s personal biases (Lipsitch et al., 2015). This study had three limitations that will be addressed: (a) eliminating personal biases, (b) extensive phone interviews, and (c) a small sampling population. Personal bias in this study can impact the reliability and validity of study findings and can consequently affect decisions in a negative way. I may have personal biases due to the life experiences in the workforce with a population of individuals living with AIDS. To avoid any personal biases in this study, I used numbers to identify participants and added their information to a checklist. Additionally, I asked participants to review how I interpreted their responses for consistency.

Although I had to reframe from conducting face-to-face interviews due to the Coronavirus pandemic, I had an opportunity to conduct one face-to-face interview before the university asked research students to practice social distancing. The interview process was time consuming due to having to conduct the interviews, transcribe the interviews, and analyze the data. I worked diligently to make the interview process user-friendly to get the desired outcome from participants. I used semistructured open-ended questions and effective ways of conducting face-to-face interviews. The final limitation concern was having a small sample because the small sample size can possibly increase the likelihood of errors that can skew the results which in terms make the study less generalizable. However, based on the population of this study, if saturation had not met the standards, there could have been other factors impeding on the outcome (Mason, 2010).

Significance of the Study

The finding from this research could increase awareness of the unique issues young adults encounter during adolescence after losing a parent to AIDS-related complications. Community organizations, nonprofit agencies, AIDS organizations, and human services providers who work with survivors of parental AIDS need to be aware of the unique issues these young adults encounter during adolescence. Providers may gain the additional tools needed to be sensitive to the psychological well-being, emotional experiences, and limited support given to these adolescents during the loss of their parent. In addition, this research study corresponds to the mission and social change goals of Walden University, as the vision and mission of the University promotes dignity and develops robust, and healthy communities. It is important that communities know how to address this issue to empower others to live self-directed lives with dignity and hope, and to promote healthy communities across the globe.

Summary and Transition

As AIDS-related complications illnesses continues to claim lives in the United States, it is important to think about the children who have been affected by such a loss. It is reported that 3.1 million adults and 570,000 children have died of AIDS related complications this year (Zarocostas, 2005); in the United States approximately thirteen thousand individuals die of AIDS related complication each year (Today's HIV/AIDS Epidemic, 2016). Children who have experienced such a loss are sometimes affected by the stigma and stress that aligns with losing a parent to AIDS- related-complications. Adolescents who have a dying parent due to AIDS-related complications sometimes engage in harmful behaviors that include sexually risky behaviors and criminal misconduct (Rotheram-Borus et al., 2005) and may evidence lower psychological functioning and experience more psychosocial difficulties in academic and social functioning. Psychosocial problems of adolescents affected by a family member diagnosed and living with HIV/AIDS need to be identified and quickly managed to better address other negative behaviors that may arise (Lichtenstien et al., 2010). In this study I found that lived experiences of such a loss experienced as an adolescent does have a long-term effect when the adolescent became an adult. In Chapter 2, I provide a synopsis of the current literature used to describe the relevant problem and the conceptual framework that guided the research questions in this study.

Chapter 2: Literature Review

AIDS has affected many families in and outside the United States. Adolescents who lived in homes where they lost a parent to AIDS-related complications are more likely to suffer from depression, anxiety, social withdrawal, and learning disabilities, including attention-deficit disorder (Bauman et al., 2007). Globally, AIDS-related parental death caused 13 million children to lose a parent in 2002 (Rotheram-Borus et al., 2005). In the United States, 36,000 to 65,000 adolescents have experienced a parent dying from AIDS-related complications since the emergence of HIV/AIDS. By 2010, more than 40 million adolescents in over 34 countries are likely to have experienced the trauma of losing a parent in an AIDS-related death (Bauman et al., 2006).

Literature Search Strategy

Inquiries of library databases and search engines were conducted based on peer-reviewed journals and data from the Centers for Disease Control and Prevention. The databases included were ProQuest, Sage, PsycInfo, Thoreau, PsycTest, PsycExtra, PsycBooks, PsycArticles, and Google Scholar with Full Text. These databases were used to locate current existing literature and to cross reference articles. Recent relevant studies, articles from online printed journals, and trade publications related to parental death due to AIDS-related complications were utilized. Keywords and phrases used as search terms included *HIV/AIDS, adolescents, adolescence, parent, parents, child, children, young adults, adults, transmit, transmission mode, infect, infection, psychological functioning, economic deprivation, psychological effect, psychological well-being, significant impact, well-being, coping efforts, coping behavioral and cognitive, and transactional model of* *coping* and *stress theory*. In some cases, current research was found. According to the literature on this topic, a limited body of knowledge addressed the psychological effects of losing a parent to HIV/AIDS. Because new insight will be contributed to this area, I sought to locate studies that were similar to the current research study. However, prior research is limited and does not sufficiently address how adolescents are affected by losing a parent to AIDS-related complications. I was unable to locate literature that focused on how adolescents have been impacted by the loss of a parent from AIDS-related complications and whether it was any different from losing a parent to any other chronic disease.

Conceptual Framework

The framework of this study rests on the transactional stress and coping model. Lazarus and Folkman created the transactional model of stress and coping in 1966 as a framework that emphasizes appraisal of threat of harm and challenges to coping with stressful events (Lazarus & Folkman, 1987). Researchers do not commonly study stress and coping from a transactional viewpoint. The two concepts of focus for the present study will be appraisal and coping. Appraisal refers to the evaluation of harm, threat, and challenge that can occur as a result of encountering events that present as stressful in people’s lives (Lazarus & Folkman, 1987). Coping is when one face and deal with responsibilities that may arise. Researchers have applied the transactional stress and coping model to other studies (e.g., sickle cell and school bullying); however, limited literature addresses whether this theory is applicable to the experience of losing a parent to AIDS-related complications.

One study emerged that used the transactional stress and coping model as a tool to understand retention in HIV care across the life span and found that behavioral theories are not always accurate in guiding retention in care research (Lazarus & Folkman, 1987). However, Lazarus and Folkman's 1987 transactional stress and coping model has proven effective in guiding research that focused on people living with AIDS unrelated to retention care. The positive steps individuals take were frequently reported to assist them in addressing the loss of a parent, including the identification of frequent resources used during the time of their loss. The participants in this study will have faced marked stress during their adolescence; therefore, this theory can be applied to describe their coping mechanisms in adulthood.

A study called *The Spiritual Framework of Coping Through the Voices of Cancer Survivor* (2011) used Lazarus and Folkman's 1987 transactional stress and coping model to determine the meaning of an event or circumstance. The study simplified the model to offer grounds for discussing the spirituality framework. The transactional stress and coping model include both primary and secondary appraisals. The primary appraisal determines how significant an event or circumstance is, or whether it is stressful, unrelated, positive, controlling, or challenging. The secondary appraisal system identifies available resources and offers options to allow participants to cope with the stressful situation (Stewart, 2011).

Another study examined the effect of spiritual striving, acceptance coping, and depressive symptoms among adults living with HIV or AIDS. Researchers used the transactional stress and coping model to provide a framework to understand the relationship of spirituality and coping (Perez, Vosvick, George-Felton, Spiegel, Chartier, & Koopman, 2009). The model proposes that positive affect and distress can occur together during stressful lived experiences. This study used the model to guide assessment of the relationship between spiritual striving and depressive symptoms of people living with HIV and AIDS. The study results showed that people living with HIV or AIDS who struggle with spiritual growth in their illness experience a less negative affect (Perez et al., 2009).

Literature Review

HIV/AIDS impact in the United States and other Countries

HIV/AIDS is a major health problem in most countries, including the United States. In the United States, 1.2 million people are living with HIV (Avert, 2017). Since the explosion of the HIV epidemic, 675,000 people have died of AIDS related-complications. In 1986, African Americans comprised 25% of new HIV/AIDS cases in the United States. By 2004, African Americans were responsible for 51% of the newly diagnosed infections. The continent of Africa also has a large incidence of HIV/AIDS cases. In sub-Saharan Africa, 15% of infected women living with HIV are between the ages of 15 and 24 (Avert, 2017).

At an international AIDS meeting in Canada in 1989, the former head of the National Cancer Society declared that AIDS should be considered a chronic disease and follow the same treatment model as cancer. At that time, the identification of AIDS shifted from an acute to a chronic illness. Chronic illnesses are uncertain, unlimited, and have periods of severe crisis and remission (Scandlyn, 2000). When AIDS was considered an acute illness, people viewed the disease as a death sentence. As a chronic disease today, people are expected to manage the disease like any other chronic illness (Scandlyn, 2000).

Although HIV/AIDS remains pandemic, particularly in certain parts of the world, the knowledge, attitudes, practices, and misconceptions among physicians persist (Quach, Mayer, McGarvey, Lurie, & Do, 2005). Quach et al. (2005) found misconceptions regarding (a) transmission modes, (b) the amount of knowledge of HIV/AIDS, (c) attitudes regarding people infected with HIV/AIDS, and (d) knowledge about the action and use of antiretroviral medications. In 2003, a cross-sectional survey with 151 physicians who served those living with HIV/AIDS as patients found that physicians had some misconceptions about the transmission modes of HIV/AIDS, and, 39.9% of respondents believed eating healthy with proper nutrition could keep one from becoming infected; 12.1% thought sharing a toilet with someone who was infected could infect an individual; and 41.6 % of physicians were aware that more than one type of HIV existed (Quach et al., 2005). Acquiring knowledge about HIV/AIDS and its misconceptions forms self-empowerment that could influence an individual’s perception of risk and create awareness for sexual-behavior changes (Tenkorang, 2013). Reportedly, AIDS knowledge and awareness is high in most parts of sub-Saharan Africa (Tenkorang, 2013).

Physicians’ Perceptions and Attitudes About HIV/AIDS

Younger physicians had a more positive attitude than older physicians, and younger physicians were more informed about HIV/AIDS. A third of participants reported positive attitudes regarding their interaction with HIV/AIDS patients and were unlikely to support mandatory testing to exclude HIV/AIDS patients from their practices. Of physicians, 73% worried about becoming infected when treating this population; 47% felt differently about treating patients with HIV/AIDS than any other disease; 40% reported feeling uncomfortable about touching infected patients; 67% felt patients with HIV/AIDS should be treated in specialized hospital or clinics; and 93% thought health professionals could provide an HIV test without informed consent (Quach, Mayer, & McGarvey, Lurie, & Do, 2005). Vietnamese physicians who provided healthcare for HIV/AIDS patients level of knowledge, attitudes, and practices regarding HIV/AIDS treatment suggested training is needed to improve physicians' ability to deliver appropriate treatment to HIV/AIDS patients (Quach et al., 2005).

Researchers asked some physicians in a large city to read a patient scenario and complete some objective attitude-measuring questionnaires about their reactions to patients in the scenario. The patients' scenarios were identical except of patients who were diagnosed with either Acquired Immuno-Deficiency Syndrome (AIDS) or cancer. Sexual preferences were heterosexual or homosexual. Patients who had AIDS were judged harshly and physicians were not willing to interact in conversations after discovering the patients had AIDS. Many individuals who have AIDS are seeking healthcare. Medical providers must develop programs to dispel unreasonable stigma and prejudice attitudes toward people living with HIV/AIDS (Kelly, St. Lawrence, Smith, Hood & Cook, 1998). Due to the lack of current data it is difficult to determine if this data is still current.

Adolescents Caring for HIV/AIDS Parents

Sometimes adolescents are left to care for their ill parent(s) and younger siblings. Adolescents who have lost a parent to AIDS-related complications experience stressful difficulties that align with caring for and the loss of an ill parent (Bauman, Foster, Silver, Berman, Gamble & Muchaneta, 2006).

The worst trauma a child could face in life is the death of a parent (Bauman et al., 2006). Adolescents who lost a parent to AIDS-related illnesses reported problems with peers, depression, worry, stress, and fear (Bauman et al., 2006). Although depression rates were high among adolescents. Adolescents from Zimbabwe scored higher in the clinically depressed range than children in the United States (Bauman et al., 2006). Evans and Becker (2009) stated the dynamics of a family changes when a parent is ill due to HIV/AIDS-related complications or has a physical illness for which they must depend on other family members, charitable organizations, local welfare system, churches, and other sector organizations for assistant.

Children are tasked with providing formal and informal care to the ill parent. Children’s and young people’s involvement in caring for parents is challenging and is not the daily norm in childhood involvement (Evans & Becker, 2009). Often, family members do not want the responsibility of being the lead caregiver and try to pass those responsibilities to community agencies that care for ill patients.

Emotionally Disturbed Adolescents Affected by HIV/AIDS

Sinha and Kumar (2010) evaluated the usefulness of mindfulness-based cognitive behavior therapy (MCBT) to treat behavioral problems, internalizing problems, depression, anxiety, hopelessness, and perceived stress in a sample of adolescents affected by HIV/AIDS. Recent studies of cognitive-based therapy on mindfulness have demonstrated the effectiveness of this psychologically based approach for a wide range of clinical problems including anxiety, depression, stress management, obsessive-compulsive disorder, social anxiety, and personality disorders (Sinha & Kumar, 2010). Participants were 12 children, ranging in age from 13 to 16, living with a parent with HIV/AIDS and receiving a 12-week intervention. Results indicated that MCBT was useful in reducing symptoms of emotional disturbance on self- and teacher-reported surveys to clinical levels with reliable changes. High attendance and retention rates, adequate compliance, and positive feedback supported treatment feasibility and acceptability. Study findings also showed that MCBT was a potential treatment for emotional disturbances in HIV/AIDS-affected adolescents with adequate feasibility and acceptability. Further research is needed to test the efficacy of the intervention with a larger sample of adolescents and with those who meet diagnostic criteria for clinical disorders (Sinha & Kumar, 2010).

Another study described how adolescents who lost a parent to AIDS-related complications experienced economic loss, emotions that included sadness, fear, anger, loneliness, anxiety, and isolation. Adolescents who reported having to find a new home were poorly treated by their relatives, and they felt they did not have anyone in whom to confide (Zhao, Li, Kaljee, Zhang, Fang, Zhao, Lin, Lin, & Staton, 2009).

Adolescents Responses to the Death of a Parent

It is difficult to imagine experiencing death due to any type of illness when it concerns parents, let alone when associated with an illness that is associated with a stigma attached to death. Society is reluctant when it comes to embracing HIV/AIDS in communities. Needless to say, adolescents live in a relational world (Tyson-Rawson, 1996). Most adolescents who experience the loss of a parent due to AIDS-related complications have separation and connection issues, in that an adolescent's source of stability, self-contrast, and continuity has been broken (Tyson-Rawson, 1996). Sometimes experiencing the death of a parent during one's adolescent years is difficult to conceptualize. After having experienced the loss of a parent, adolescents may feel they need to reorganize their existence and create new aspects of their internal working model that does not include that significant parent (Tyson-Rawson, 1996).

Some complications from the loss of a parent can include adverse outcomes following the parent's death. Adversity can emerge in the form of depression and conduct disorders. Therefore, if adolescents do not address the issues of losing a parent to AIDS-related complications, over time, they may experience significant psychological problems (Tyson-Raswon, 1996). Some disorders and other psychological aberrations can result from having such a loss (Tyson-Raswon, 1996). Dane and Levine (1994) considered these adolescents as *damage survivors* after having experienced the death of either parent to AIDS-related complications. Damage survivors are those adolescents who address parents using drugs. They had to go from one crisis to another with their parents. Their lifestyle and socioeconomic status are disrupted. These adolescents may have been burdened by parents being heavily involved with substance abuse and other negative health behaviors that led them from one crisis to another crisis with their parent(s) (Dane & Levine, 1994). Adolescent development is extremely broad and complex and not every aspect of their lives can and need to be covered in a discussion of the impact of parental death due to AIDS-related complications (Dane & Levine, 1994).

Adolescent Response and Adjustment After HIV/AIDS- Related Parental Death

Some children grow up to become adolescents who have experienced losing a parent to AIDS-related complications. According to the literature, most knowledge concerning parental death due to AIDS-related complications comes from the clinical literature (Rotheram-Borus, Stein, & Lin, 2001). In more than 500 articles in the past 10 years, several clinicians stated that parental death has a substantial negative impact on adolescents (Rotheram-Borus, et al., 2001). Children who had a deceased parent showed signs of emotional distress and behavior problems. However, the literature does not elaborate on the extent to which these adolescents are impacted and the length of time of the impact.

An adolescent may experience a substantial and prolonged developmental impact while the parent is living and after parental death (Rothram-Borus, et al.,2001). These children experience stigma that may cause them to feel alienated, isolated, and extremely sensitive to peer support. Previous studies may be inadequate to understand the impact on families with many preexisting social stressors (Rotheram-Borus, et al., 2001).

Bereaved adolescents have significantly more emotional distress, adverse life events, and criminal issues than peer adolescents who were not bereaved (Rotheram-

Borus, Weiss, Alber, & Lester, 2005). However, behavioral symptoms and passive problem solving increased soon after parental death compared with adolescents who were not bereaved. A year following parental death, depression and passive problem solving were similar to levels of peers who were not bereaved (Rotheram-Borus, et al., 2005). Rotheram-Borus et al.'s (2005) study postulated that interventions are beneficial, but no intervention benefits accrued to those who were bereaved compared with young people who were not bereaved. Researchers used an intervention based on the Teens and Adults Learning to Communicate model, which included three modules and 31 sessions that addressed coping with illness, planning legacy, and a new beginning. Future interventions are needed to improve adolescents' coping skills and address HIV/AIDS-related challenges. Such interventions may help decrease problem behaviors and contact with the criminal justice system among adolescents in the period before parental death (Rotheram-Borus et al., 2005).

Adjusting to the death of a parent due to HIV/AIDS-related complications is not easy for adolescents. This type of death brings stress to the entire family (Rotherman-Borus at el., 2005). These children can experience stigma that causes them to isolate and alienate themselves from their peers and sometimes from the outside world. Parental death during a child's childhood has been linked to increased mortality and mental health problems after adolescents' transition into adulthood (Berg, 2014). The child may also experience lower grades and school failure compared to children who have not experienced maternal or paternal death during childhood. These adolescents had psychosocial and socioeconomic problems that caused them to display poor performance in school. Most often, decreased school performance in children who are bereaved relates to family background characteristics rather than the actual loss. Schools should give an adequate amount of attention to bereaved children to prevent a decline in school performance. Interventions from health services are needed to support bereaved children. The interventions should be designed to adequately address not only psychological needs but adversity and psychosocial problems in the family environment (Berg, 2014).

In a study conducted by Menna and Worku (2014) the focus was on the association of AIDS-related parental death and the sexual behavior of secondary school adolescents in Ethiopia. Results indicated that adolescents who lost at least one parent to AIDS-related complications seemed to be more exposed to HIV. Sometimes these adolescents put themselves at risk by displaying the same sexual behaviors as their parent. Various researchers provided an assessment of the different types of behaviors that can arise after the loss of a parent from an AIDS-related death; however, studies do not address the long-term impact of these behaviors Rothernam et al., (2005) and Menna et al., (2014).

The Potential Psychological Disorders of Adolescents with Parents with HIV/AIDS

HIV/AIDS has affected almost every household in the United States in one way or another (Dixon, McDonald, & Roberts, 2002). AIDS has caused a profound impact on health and on the economy of many countries (Dixon, McDonald, & Roberts, 2002). In 2012, in the United States 12,960 individuals died from AIDS-related complications (Avert, 2017) and some of these individuals had adolescent children (Bauman, Silver, Draimin, & Hudis, 2007).

Bauman (2007) measured the mental health of adolescents between the ages of 10 and 19 who lost a parent. The researcher asserted that most children whose parents were infected with AIDS should engage in some type of psychological screening, which includes monitoring. The researcher indicated that children of infected mothers were at high risk of developing psychological disturbances. They recommended that providers should focus on depression, anxiety, and externalizing conduct problems (Bauman et al., 2007). Other researchers have examined attentional, cognitive, and social competence in adolescents between the ages of 10 and 19 and found these adolescents to have problems in other areas (Bauaman et al., 2007). Children's behavior problems were associated to their mother's psychological distress of having HIV/AIDS illness-related activity restrictions (Bauman, Camacho, Silver, Hudis, & Draimin, 2002). The children displayed multiple risk factors for being psychologically disturbed. Researchers believed that most risk factors were related to their mother's AIDS diagnosis (Bauman, 2002).

The researchers recommended community organizers and individuals working with this population plan programs to assist these children in coping successfully with their mother's illness (Bauman et al., 2002). Parentification has become common among adolescents who have an ill parent with AIDS. These children prematurely assume the roles of an adult before they are developmentally or emotionally ready. They are not ready to successfully manage parenting roles and experience stress as a result. Life-threatening illnesses such as AIDS usually have a profound impact on children's psychological and physical well-being (Stein, Riedel, & Rotheram-Borus, 2004). Children sometimes model their parents' dysfunctional behaviors, develop conduct disorders, or become sexually promiscuous, which can increase the risk of contracting HIV/AIDS (Stein et al., 2004).

Parents’ Hardship When Informing Children of Their Status

A multivariate analysis showed that parents with higher income in a heterosexual HIV-risk group with higher CD4 counts, with greater social isolation, and with younger children were less likely than their counterparts to report to their children that they have HIV (Corona, 2006). Parents struggle to share their HIV/AIDS status with their children. These parents usually do not know what to share, when it is appropriate to share, and how to share such information. Parents reported that 11% of children are worried about catching HIV from their parent; 67% of parents are worried children might tell someone, and 36% did not know how to tell their children. Corona (2006) completed interviews with 274 parents from a nationally representative sample of adults receiving healthcare for HIV. Results indicated that 44% of children aged 5 to 17 knew about a parent’s HIV/AIDS status and parents had conversations about their status with 90% of their children, indicating that they may die from AIDS-related complications (Corona, 2006).

Corona (2006) conducted a few studies in Africa about parents disclosing their HIV/AIDS status to their children to discern if the children understood the incidence rates of HIV/AIDS transmission among sexual partners in numerous countries. The World Health Organization (WHO) developed guidelines on HIV/AIDS counseling to assist children 12 years of age and older. The WHO organization focused on teaching and encouraging parent(s) to disclose their HIV/AIDS status to their children. The WHO organization is teaching infected parent(s) that they can disclose their status at various stages of the disease. One way is to share their health information directly or indirectly or they can partially disclose their status by having a general discussion about specific terms related to HIV or AIDS. The discussion would allow the child(ren) to become aware of their parent's status (Osingada et al., 2017). Regardless of the disclosure, HIV/AIDS is still difficult, and it still affects communities and family members. The disease touches many lives, and the children of HIV/AIDS- infected parents face so many challenges (Osingada et al., 2007).

Support Systems for Children Who Lost a Parent to HIV/AIDS

Carten and Fennoy (1997) conducted a study to examine African American children who had experienced losing a parent to AIDS-related complications. The researchers presented that 32,000 had died of AIDS-related cases, and of those, 23,000 were between the ages of 25 and 44 with dependent children. On average, the women had two children; 42,000 children were estimated to be at risk of losing their mother to AIDS-related complications (Carten & Fennoy, 1997). Children who suffered from the premature loss of a parent to AIDS complications have different needs than other children served by the child welfare system (Carten & Fennoy, 1997). These children can suffer from behavior and emotional problems; however, the literature does not express if those psychological issues can affect the children in adulthood (How Parental HIV Affects Children, 2018).

Children who experience the loss of a parent to AIDS-related complications can benefit from being connected to peer support, families, and other support groups to reduce loneliness and isolation (How Parental HIV Affects Children, 2018). This connection can help children learn how to express their feelings of loss of a parent and can learn important information concerning the transmission of HIV and AIDS and how it affects communities at large.

Children who face the inevitable death of a parent need a comprehensive array of services (Carten & Fennoy, 1997). Some type of support should be offered during the experience and in the aftermath of the death of the parent(s). Much is unknown about how this group of children are faring over time and to what extent existing services accommodate their past and future needs. More future clinical research is needed to reveal more about children affected by these dramatic and cumulative losses. Researchers should examine the effects of the massive downsizing of services and a new managed-care environment on the ability of health and human services personnel to provide the highest quality of care for children over time (Carten & Fennoy, 1997). Coping with the disease can become challenging for parents who have become too ill to continue caring for their children. These parents try to cope with taking care for their children as long as they can. These parents realize that children who are taken out of their custody while they are ill can be subject to behavior problems that may affect them in their young adulthood (How Parental HIV Affects Children, 2018).

Parental Loss Due to HIV/AIDS

The literature indicated that the number of AIDS cases and death increased in the 1980s, however, the number of AIDS deaths decline in the late 1990s (*HIV and AIDS--United States,* 2001). Approximately 125,000 children will have lost a parent to HIV/AIDS by the year 2000 (Taylor-Brown et al., 1998). In 1996, 500 children in

Rochester, New York, experienced the loss of a parent from AIDS-related complications; such a loss has much stigma in the community (Taylor-Brown et al., 1998). The study by Taylor-Brown et al (1998) postulated that children need child-centered permanency services. Services related to permanency placement are few, and most are fragmented and reactive. Future permanency services need to be available at whatever point the child enters the service-delivery system. Services need to be expanded from parent-centered to family-centered activities to work with the children of a parent who is dying in order to be substantially effective. Family centered services for children affected by HIV/AIDS has been recognized for a long time. some time. The changing of social realities and the needs of children in families affected by HIV/AIDS is important. Rendering services to children through families, in both high-prevalence and concentrated epidemic settings, has been slow to materialize. Despite the creation of various model approaches, interventions, medical and psychological providers still tend to focus on individuals and not families. The literature clearly states that individual approaches to children affected by HIV/AIDS can lead to confusion and misdirection of the global, national, and local response (Richter, 2010).

Children who experience poverty and disruption of family structure and other social relationships sometimes become orphaned by HIV/AIDS parents' death. The personal challenges these children face is sometimes similar across various care arrangements e.g., AIDS foster children and family-based care; (Zhao, Kaljee, & Zhang, 2009). According to Zhao et al. (2009), "it may be more salient to consider not the type of arrangement as much as the stability and quality of the institutions or households in which these children live and grow to adulthood" (p.- 774). After interviewing children in the study, researchers were able to better understand the emotional and psychological stressors resulting from the experiences of HIV/AIDS-related parental illness and death but were unable to determine the length of impact of those stressors (Zhao et al., 2009).

When these children become young adults, they report having symptoms of not being able to sleep, issues with difficulty getting along with others, getting upset when they think about their parents, and having difficulties trying to remember significant memories or events that had taken place with their parents (Mark, Jun & Song, 2007). The loss is difficult during adolescence and young adulthood and could potentially affect their lives as adults (Mark et al., 2007).

Gender Comparison in the Loss of a Parent to AIDS

In a 2001 study, female adolescents showed more emotional distress at baseline and at 2 years than their male counterparts (Rotheram-Borus, Stein, & Lin, 2001). Boys showed more conduct problems and girls showed more emotional distress. Clinicians have argued that parental death has a pervasive negative effect on adolescents' emotional distress and behavioral problems, but researchers do not indicate if this negative impact affects the individual in young adulthood (Rotheram-Borus et al., 2001). In fact, some girls who lose a parent to AIDS-related complications before the age of 15 are likely to experience sex by the age of 15. Some boys under the age of 12 when their parent died are more likely to be ones to initiate sex than those who had a parent die later. Generally, mothers play a notable role in the HIV/AIDS risks of their female children, however, fathers play a role in both the male and female lives (Nyirenda, McGrath, & Newell, 2010).

The death of a parent during adolescence has been associated with increased depression, anxiety, conduct problems, academic difficulties, somatic complaints, and some suicidal ideation in adolescents; however, the literature does not clearly describe how participants were affected during young adulthood (Rotheram-Borus, Weiss, Alber, & Lester, 2005). (Rotheram-Borus et al., 2001). Furthermore, research is needed to identify specific mechanisms associated with emotional distress and to determine whether findings hold among samples of adolescents who experience the loss of a parent due to AIDS-related illness (Rotheram-Borus et al., 2001).

Effects of Parental Loss and Age at Exposure of Well-being

Researchers expect the traumatic loss of a parent during childhood to result in emotional distress, increased anxiety and depression, and diminishing physical health and emotional attachment that results in social estrangement (Lis-Turlesjsa et al., 2008). The attachment theory’s dual-process model assumes that the death of a loved one may result in long-term negative effects but does not give a length of time for this long-term effect. The loss of a parent was the strongest predictor for developing depression or PTSD within 2–5 months of such a devasting loss. Early loss of a parent has a traumatic impact on adolescents and the well-being of adults as well (Lis-Turlesjsa et al., 2008). Additional research is needed to confirm the impact of parental death (Lis-Turlesjsa et al., 2008). This traumatic experience can affect adolescents economically, changes the dynamics of the family, impact their education, housing status, psychosocial skills (Richter, 2019).

Further research is needed to confirm the impact of parental death over time (Lis-Turlesjsa et al., 2008).

Summary and Conclusions

In summary, in Chapter 2 I described research studies that investigated effects on adolescents who had lost a parent to AIDS-related complications. The literature is sparse and limited. Researchers found that there is extraordinarily little information that captures how these affected adolescents’ loss experiences affect them as young adults. Although some studies discuss needed resources after they have experienced such loss, and how there are very little services available to them, none of the findings provide information on how losing a parent to AIDS-related complications during adolescents affects individuals when they become young adults.

Thus, I this literature shows that this study is needed to understand better how these children are affected as adolescents and later in life. Additional research would aid in better understanding the norms of children who have lost a parent to AIDS-related serious illness (Bauman et al., 2006). Providers should focus on depression, anxiety, and externalizing conduct problems. Past studies examined attentional, cognitive, and social competence in adolescents between the ages of 10 to 19 and found these adolescents have problems in other areas as well (Bauman et al., 2006). The reviewed research did not show an association between parental deaths with HIV/AIDS and how adolescents’ problems impacted their young adulthood. The extant literature on the mental health of adolescents whose parents died from AIDS-related illnesses is limited in several ways. Future research is needed to identify disorders among a general population of adolescents in high-risk groups and how they are impacted by the loss of a parent to AIDS-related illnesses, even in young adulthood (Bauman et al., 2007).

Chapter 3: Research Method

This phenomenological qualitative research study aimed to explore how the experience of losing a parent to AIDS-related complications during adolescence significantly impacts an individual’s psychological well-being as a young adult. The literature does not provide sufficient information regarding the effects of losing a parent to AIDS-related complications. This chapter covers the research design and rationale, the role of the researcher, the methodology, instruments, recruitment, participation, data collection, data analysis plan, ethical procedures, and a summary. I used semistructured questions in a face-to-face interview with one participant, eliciting their perceptions of what they experienced.

The goal of the study was to identify issues participants faced. I described the reported experiences of young adult participants facing the death of a parent due to complications from AIDS during their adolescence. In this study, I also worked to determine how losing a parent to AIDS-related complications during adolescence affects an individual as a young adult.

Research Design and Rationale

Researchers can choose among several qualitative research designs: narratives, phenomenological, ethnographic, case studies, and grounded theory (Creswell, 2014). The narrative research design allows one or more participants to provide stories. Phenomenological research allows the researcher to identify human experiences described by participants. An ethnographic design allows the researcher to study culture and nature over a period of time with group interactions. Case studies allow the researcher to explore a phenomenon in-depth. Grounded theory allows the researcher to develop a general theory of a process that has been grounded in the views of participants. I chose phenomenological approach to give participants an opportunity to tell about their lived experiences. Using this paradigm allowed me to explore how adolescents were affected by losing a parent to AIDS-related complications during adolescence, and how it may have affected participants during young adulthood. The study goal was to explore the meaning of this phenomenon comprehensively because the extant literature does not provide enough information regarding the psychological effects of losing a parent due to AIDS-related complications.

For this study I used qualitative research design. The overarching research questions that guided the study were:

RQ1: What are the lived experiences of young adults who lost a parent to AIDS related complication during adolescence?

RQ2: How does an adolescent understand the stigma associated with losing a parent to complications from AIDS?

Role of the Researcher

I was not acquainted with participants in this study. After the study, I will no longer have contact with the participants. I recruited participants, developed semistructured interview questions to guide the research, analyzed data, and reporting the findings. Researchers are unable to avoid biases in research. Qualitative researchers' biases can affect the validity and reliability of research findings. The assumption in research is that biases can diminish the data which can skew the research findings. I took the time to recognize biases in my research, worked to reduce them, or at least to remain aware of them. One of the biases I encountered was interviewer bias, which is a methodical alteration among how the researcher gathers, records, and interprets information. (Pannucci & Wilkins, 2010).

Methodology

Participant Selection Logic

Study participants were young adults who experienced losing a parent to AIDS-related complications when they were between 10 to 19 years of age. The interviews were supposed to be conducted face to face. Prior to the onset of the Corona virus pandemic, I was able to complete one face to face interview before the university sanctioned research students from conducting in person interviews. Thus, the rest of the interviews were done by phone. I used a homogeneous purposeful-sampling strategy in this qualitative research study. Homogenous sampling "looks at whole units (e.g., people, cases, etc.) that share the same (or very similar) characteristics or traits (e.g., a group of people that are similar in terms of age, gender, background, occupation, etc." (Center for Innovation in Research and Teaching, 2018, p. 14). I chose a small-sampling process because my goal as the researcher was to report specific findings to a specific group of interest. Study participants were young adults between the ages of 18 and 35 who lost a parent to AIDS-related complications.

Each participant completed a demographic information fact sheet prior to participating in the interview sessions. I used passive and active approaches to recruit participants for this study. Each participant was allowed to ask as many questions as they wished.

As an active approach, I contacted identified individuals in person, by e-mail, or by phone. As a passive approach of recruitment, I contacted communities through in-person meetings, public notices, public service announcements, volunteering at community agencies to engage participants, and using an Institutional Review Board (IRB) approved flyer to announce the invitation to participate in interviews. The flyer contained information about the study, monetary compensation, interview dates and locations, and my contact information. I posted flyers at AIDS services organizations, nonprofit organizations, civic groups, community centers, churches, apartment complexes, hair/barber salons, coffee shops, student-union areas at several colleges, and particularly at historically Black colleges.

Those recruited by active or passive methods completed the same demographic fact sheet. Typically, qualitative research studies tend to focus on small, nonrandom samples. I interviewed participants until data was saturated. Saturation is a tool used to assure that satisfactory and quality data is accrue that supports the goals of the study (Walker, 2012).

Qualitative research is not like quantitative research, which quantifies or counts numbers. Qualitative studies aim to explore opinions eliciting a richness of views. The number of participants depends upon the type of research being conducted and how many participants are needed to answer the research questions. Researchers should not focus on sample size to determine the quality of the research (Van Rijnsoever, 2017). Rather, the focus should be on data saturation. As Van Rijnsoever (2007) notes, "The collection of data and analysis should continue until no new codes or concepts emerge, or no new codes that signify new properties of uncovered patterns emerge. At this point, theoretical saturation is reached; all the relevant information that is needed to gain complete insights into a topic has been found" (p. 2).

Instrumentation

The primary instruments of the particular design for use in this study consisted of the interview protocol document (see Appendix A), interview protocol (see Appendix B), interview questionnaire (see Appendix C), participant fact sheet (see Appendix D), participant screener document (see Appendix E), protocol for managing distress (see Appendix F), themes identified non prominent (see Appendix G), permission to use thematic analysis table from author. All participants signed an informed consent form as part of the study. The demographic fact sheet asked for participants' (a) age, (b) marital status, (c) if they had a parent pass from AIDS-related complications, (d) if they know what HIV or AIDS means? (e) how old they were when their parent(s) passed, and (f) how long it has been since their parent(s) passed. The demographic data allowed me to understand information about participants' lives. The interview protocol included (a) an interviewee identification number, (b) the interviewee's name, (c) the location of the interview, (d) the date, (e) the time the interview began and ended, and (f) open-ended questions used to probe participants. I based the interview questions on a review of literature for the study. The letter of cooperation from research sites gave me permission to conduct interviews on their premises, as was necessary.

I used a consent form to permit me to administer the interview with participants. The research brochure informs the community and agencies about the study. The brochure included (a) the purpose of the study, (b) the aim of the study, (c) monetary compensation, (d) proposed age of participants, (e) dates conducted, and (f) information about me including the name of the institution that approved the research. A sample of the questions that guided this study follows:

1. Which of the following psychological issues did you experience most after losing a parent to AIDS-related complications?
   a. Depression
   b. Anxiety
   c. Social withdrawals
2. Which psychological issues did you experience most after losing a parent to AIDS complications, if, any?
3. What emotions do you currently experience that may directly be related to the loss of your parent from AIDS-related complications?

Procedures for Recruitment, Participation, and Data Collection

Participants in this study were required to participate in a face -to- face interview and have had a parent die from AIDS-related complications between the ages of 10 and 19. If requested, I would have conducted audio-conferencing interviews. After determining eligible participants who met all study criteria, I informed participants of the date and time of their interviews. The face- to -face interviews were supposed to be held at a location in the city where participants reside (e.g., at a community-agency interview room, faith-based conference room, or library conference room). However, due to the Coronavirus pandemic, one face-to- face interviews were held before the university halted all face to face contacts. I gave participants a reminder by phone call, e-mail, or text the day before the scheduled interview to confirm their availability prior to the scheduled time of their phone interviews.

Once participants met the study criteria and scheduled a phone interview, they completed a demographic summary prior to the interview. I took interview notes by hand and informed participants that the interview was being recorded to ensure important information was not omitted. The entire interview process took approximately 60 minutes, and data accrued in one sitting. After completing the interviews, participants had an opportunity to ask questions, make additional comments, or reflect on the questions they were asked. I did not use any historical or legal documentation as a source of data. This study did not include any follow-up interviews.

Data Analysis Plan

Qualitative research involves a sequence of questions and the relationships among the questions must be clear (Braun & Clarke, 2006). The research questions guided this phenomenological qualitative study. Some questions guided the coding and data analysis process. Thematic Analysis requires a researcher to be able to search across the data to locate repeated patterns and meanings. Upon completion of participant interviews, interviewees participated in member checking. I returned the transcript of the interviews to participants to ensure the data captured reflected the participants' voice. I entered all collected data in the Dedoose application software system. I used Dedoose version 7 to help me code and analyze participants' data. The coding process of analyzing qualitative data entailed identifying groups of textual data to analyze together and separately among cases. I used Dedoose software to code keywords, ideas, or categories. This software is an application researchers use to analyze qualitative and mixed methods research. Dedoose software analyzes text, photographs, audio, videos, spreadsheets, and other data. The software helped me identify similarities and emergent themes to code and analyze my data. I reproduced the checklist and phase of Thematic Analysis (Braun & Clarke, 2006) to create the steps in completing a Thematic Analysis (See Tables 1 and 2).

Table 1

A 15-Point Checklist of Criteria for Good Thematic Analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for accuracy.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive, and comprehensive.
	4	All relevant extracts for each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analyzed, interpreted, and made sense of rather than just paraphrased or described.
	8	Analysis and data match each other, and the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once over lightly.
Written report	12	The assumptions about and specific approach to thematic analysis is clearly explicated.
	13	There is a good fit between what you claim you do and what you show you have done – i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as active in the research process; themes do not just emerge.

Note. From "Using Thematic Analysis in Psychology, by V. Braun & V. Clarke, 2006, Qualitative Research in Psychology, 3(2), p. 77. https:/doi.org/10.1191/1478088706qp063oa. Reprinted with permission (see Appendix M).

Table 2

Phases of Thematic Analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic map of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Note. From "Using Thematic Analysis in Psychology, by V. Braun & V. Clarke, 2006, *Qualitative* Research *in Psychology, 3*(2), p. 78. https:/doi.org/10.1191/1478088706qp063oa. Reprinted with permission (See Appendix N).

Issues of Trustworthiness

Credibility

Researchers seek a junction of evidence that is credible and that allows the researcher to feel confident about observations, interpretations, and conclusions. A researcher tries to identify recurring behaviors or actions and consider disconfirming evidence and contrary interpretations. Credibility in qualitative research is extremely important. Qualitative research must be credible and consistent with the findings (Metler, 2015). I clearly reviewed the purpose of this study with each participant who has met the study criteria and informed them that they could ask questions at any time. I followed the same methods of data collection with each participant, asking the same interview questions throughout the face-to-face interviews. I consulted with my committee chair expert to review the findings of my study to assure credibility.

Transferability

To strengthen transferability in this study, I provided thorough descriptions of the data collection and data analysis processes. Readers can follow a user-friendly description of how I conducted the research. The research text details site information, date and time of interviews, assumptions, and limitations that were significant to this study.

Dependability

To strengthen dependability in this study, I described any difficult conditions that occurred during the interview process. I explained how these conditions may have influenced how I conducted the study. My committee members had an opportunity to review my study to ensure the data analysis was accurate and that I did not intentionally eliminate or modify my findings.

Confirmability

Confirmability refers to the degree to which others can confirm or corroborate the results of the study (Qualitative Validity, 2018). I developed a procedure to check and recheck the data during the study. I identified a doctorate- level colleague to play “devil’s advocate” as it relates to the results of the study. This individual documented the findings. I asked community leaders who work with the HIV and AIDS population to conduct a peer assessment of my study. Other strategies included actively searching for and describing negative instances that contradict prior observations. A data audit examines the data collection and analysis procedures and makes judgments about any potential bias or distortion (Qualitative Validity, 2018).

Reliability

The instrument should provide consistent data throughout the study (Allison, 2016). The reader can determine the transferability of the study (Quick & Hall, 2015). Various strategies for reliability include methodical triangulation, member checking, and continuous input and feedback from participants throughout the research process.

Ethical Procedures

Ethical issues can be broad (Creswell, 2009) and include collecting and analyzing the data as well as writing and disseminating final research. Some ethical issues that occur when writing a dissertation can involve documenting false information and creating lost findings to meet the audience of the researcher. Although this happens in research, it is not accepted or allowed in professional research communities. Ethical issues can occur in the implementation and planning stages of research. It is important for researchers to consider the consequences of falsifying and manipulating information for an audience; researchers must not misuse the results to take advantage of one group or another. Creswell (2009) emphasized the importance of releasing all the characteristics of the study, including the study design for the audience and readers to determine the credibility of the study.

The relationship between the researcher and participants can be perplexing (Sanjari et al., 2014). I had no personal relationships with participants. I managed biases using the procedure to check response bias through a respondent/non-respondent analysis. Specific guidelines were in place to ensure participants were respected and treated fairly, were not subjected to any physical harm, and had anonymity, confidentiality, and the right to give informed consent (Sanjari et al., 2014). The data acquired in this study included human participants. I gained an IRB approval number (02-20-038520) from Walden University before I engaged and recruited participants or participated in any interview activities. I addressed all ethical concerns throughout the study and upheld the integrity of the study to the highest standard.

I initially contacted agencies to identify participants through a written letter and a flyer to post in their organizations. The letter outlined the purpose of the study and provided contact information. I was available for organizations and potential participants to contact me and ask questions concerning the study. I informed participants they could leave the study at any time without consequences and did not need to share their reasons for withdrawing. Should any participants have withdrawn, I would have provided contact information should they have any questions after withdrawing from the study. If the participants would have liked a letter of withdrawal from the study, I would have provided a withdrawal letter for the participants. I provided resources to all participants regardless if they expressed the need for mental health counseling or therapy after reliving the experiences of losing a parent to AIDS-related complications.

As the researcher, I am the only person who has access to the information accumulated for this study. I have stored the information in a locked fireproof file box in my office at home. All hard copies on the computer excel spreadsheet are password protected. I assigned each participant a number and a pseudonym. I used participant numbers throughout the research process. All signed documents, consents, texts, e-mails, and voicemail messages are kept confidential and password protected. All documents will be shredded, and records expunged five years following the conclusion of the study.

Summary

In summary, what are the effects on young adults after they lose parents to AIDS? One big hindrance to the study was the limited literature on the effects of losing parents to AIDS-related complications. Using qualitative methods, I examined the following research questions What are the lived experiences of young adults who loses a parent to AIDS-related complications during adolescence? What stigmas did young adults experience who lost a parent to AIDS or AIDS-related complications during adolescence? How did adolescents understand the stigma associated to losing a parent to complications from AIDS?

As I transition to chapter 4, I recruited participants, developed interview questions to guide the research, analyzed the findings, and created the report. I have no personal relationships with participants. Participants were young adults who experienced losing a parent to AIDS-related complications during adolescence. The adolescent would have been in the age range of 10 to 19 during their loss. To qualify for the study, participants were young adults between the ages of 18 to 35 who lost a parent to AIDS-related complications.

The instruments designed for the study consist of the interview protocol document, interview questionnaire, demographic fact sheet recruitment brochure, and a letter of cooperation from agencies allowing me to post flyers and flyers in the agency common areas. Originally the interviews were supposed to be at a location in the city where the participants reside. After the onset of the Corona Virus pandemic the university informed research students not to conduct face to face interviews. I contacted the reminding seven participants to inform them of the new policy and asked if they were still interested in participating in the study. Each participant received a reminder phone call, e-mail, or text one day before the scheduled interview. I used Dedoose software version 7 to code and analyze participant data. The coding process of analyzing qualitative data identified groups of textual data to be analyzed together and separately among cases. Dedoose software coded keywords, ideas, or categories. The software helped me understand and make sense of the information.

Chapter 4: Results

Introductions

The purpose of this phenomenological qualitative research study was to determine the lived experiences of losing a parent to AIDS-related complications during adolescence. The literature lacks data regarding the effects of losing a parent due to AIDS-related complications during adolescence. The individuals in this study provided information regarding their lived experiences and how they understood the stigma relating to losing a parent to AIDS-related complications during adolescence. In this chapter, I will provide the outcome of the data collection, identify the number of agencies that displayed the study flyers, discuss the research instrument used, discuss the settings where interviews took place, discuss recruiting methods, and the data analysis process.

The overarching research questions that guided this study are:

RQ1: What are the lived experiences of young adults who lost a parent to AIDS-related complications during adolescence?

RQ2: How does an adolescent understand the stigma associated with losing a parent to complications from AIDS?

During the weeks of March 5, 2020, and March 23, 2020, I was able to interview eight participants. The first and only face-to-face interview was digitally recorded and held at an agreed upon location. The other seven interviews were conducted via phone and digitally recorded. The data collected were attained by using the 13 semistructured open-ended interview questions. The in-depth audio interviews were conducted from my home office. The individuals were in a quiet place of their choice where they felt safe and confident that their information would remain confidential.

By using the homogeneous purposeful-sampling strategy in this qualitative research study, it allowed me to look at whole units (e.g., people, cases, etc.) that share the same (or very similar) characteristics or traits (e.g. a group of people that are similar in terms of age, gender, background, occupation; Center for Innovation in Research and Teaching, 2018). The gap in the literature to explore was the meaning of this phenomenon comprehensively because the existing literature does not provide enough information regarding the effects of losing a parent due to AIDS-related complications.

Research Setting

The interview locations were strategically determined with the researcher keeping in mind that a quiet place with no interruptions, privacy, and distractions was needed. Originally, I'd planned to reserve rooms through the room request tab on the local library website. I would then give participants the option of selecting the library where they desired to meet. However, due to the onset of the Covid19 pandemic, the university recommended that all interviews be conducted virtually. One interview was conducted face to face before it was recommended that research students refrain from conducting face-to-face interviews. All interviews except one were conducted by phone. The study participants chose a place of their choice where they felt safe, and that their information would be confidential. The participants were asked the interview questions, allowed to stop the interview if they felt unsafe, or if they could not move further in the interview process due to opening old wounds and creating new emotions. Participants were aware of these elements prior to starting the interview process.

Demographics

Demographic data were collected on the participants that participated in the study. A total of eight African Americans participated in the study. There were three males and five females. The ages ranged from 26 to 53 years of age. Four participants were single, one separated, and three divorced. The demographic data of each participant are presented in table 1.

Table 3

Participants' Demographics

Participant	Gender	Marital status	Age when parent died	Current age
100001	Female	Single	13	37
100002	Female	Divorce	16	41
100003	Male	Single	16	39
100004	Female	Divorce	14	35
100005	Female	Single	10	35
100006	Female	Divorce	19	53
100007	Male	Separated	13	34
100008	Male	Single	14	26

Data Collection

Before the data collection process, agencies were contacted and given information about the study and were asked to display study recruitment flyers on their premises where clients congregated. Sixteen agencies agreed to display the study flyers. I was also able to virtually display my flyers on Instagram, Facebook, and Positivity Dee website.

The entire interview process was scheduled for up to 60 minutes in order to review documents with participants and answer any questions. However, each interview took an average of 20 to 25 minutes. Generally, qualitative interviews can take up to 30 minutes to 1 hour. This population is sensitive. The interviews for this study were not cut short. However, given the population, after probing, the participants still did not feel a need to add more to their responses.

Table 4

Participants interviews Duration and Date

Participants	Duration	Date
100001	15:00 minutes	March 5, 2020
100002	20:00 minutes	March 3, 2020
100003	25:00 minutes	March 8, 2020
100004	25:00 minutes	March 25, 2020
100005	15:00 minutes	March 12, 2020
100006	15:00 minutes	March 13, 2020
100007	20:00 minutes	March 15, 2020
100008	20:00 minutes	March 23, 2020

The data were recorded on my smartphone by using the voice recorder app and uploaded to a password protected folder on my password protected laptop. The participants were forthcoming with sharing their lived experiences with no foreseen occurrences that hindered the interview process. The interview process began by calling participants a few minutes ahead to confirm the interview was still scheduled to take place. The one face-to-face interview was scheduled and confirmed as well. The participants were reminded the phone interviews are recorded to transcribe the data accurately.

The purpose of the study, research questions, and interview was reviewed and clarified with each participant. The following documents were sent electronically to participants recruited for the study. They received these in advance: participant invitation letter, interview protocol, supportive resource list, protocol for managing distress guidelines, and approved informed consent which was reviewed with each participant. Each participant was emailed a copy of the informed consent after agreeing to be a part of the study. Before the interviews, the informed consent was reviewed with participants prior to starting the phone interviews. The face-to-face participant was able to review the consent in person with me and it was emailed in advance. The initial screener and demographic documents were completed with each participant before the interviews. The initial screener document asked (a) are you between the age of 18-35, (b) did you have a parent die from AIDS-related complications, (c) were you between the ages of 10-18 when you parent(s) died?, How old were you?, (d) how long has it been since your parent (s) died? The demographic document included questions on (a) gender, (b) current age, (c) current marital status, and (d) age when a parent died. An interview questionnaire with 13 semistructured open-ended questions was created to address questions the research. After completing the recorded interviews, I asked questions to clarify responses that seemed a little vague or unclear for member checking. I made handwritten notes when necessary. I also summarized each participant's response to check for accuracy and clarity when needed as a part of member checking. There were no unusual circumstances encountered during my data collection process. Before the interviews, I provided each participant with a clear description of the research questions that my study would be addressing. I began to build a rapport by thanking each participant in advance for participating in the study.

Data Analysis

Each digitally recorded interview was transcribed verbatim to ensure the information was accurate. I listened to the audio recorded data many times to familiarized myself with the data. The interview transcripts were thoroughly analyzed by using the checklist criteria for good thematic analysis. The process involved reading each transcript countless times for accuracy and to understand what the participants were describing. The data were manually hand-coded to determine similar themes and codes; I also uploaded all data into the Dedoose software to remove any possible human error. In this process, I highlighted and made handwritten notes of the statements made by participants who experienced losing a parent to AIDS-related complications. When interview responses were given that did not address the two research questions guiding my study, the responses were not used and deemed as not pertinent. All eight participants' demographic information such as age, gender, marital status, and the age of each participant when his or her parent died from AIDS-related complications was added to the descriptors tab.

Next, the transcripts were individually imported under the media tab, and I was able to add excerpts and code my data. If themes or codes were not populated in this process, I was able to add themes and codes which I manually identified. The codes and themes identified were grief, loneliness, negative judgmental beliefs, promiscuity, anger, sadness, self-isolation, stigma, and discrimination, substance abuse, resources available or not, and suicidal attempts. The codes stemmed from the participants interviewed allowed the connection to the conceptual framework of the study. The conceptual framework: transactional stress and coping model provided the bases for the ninety codes). Due to the transactional stress theory, the most prevalent codes facilitated in developing the themes are negative judgement beliefs, sadness, and stigma/discrimination. The themes identified from the code's deduction took place by purposefully viewing the conceptual framework only through the lens of the participants.

The most prominent themes that were used among participants were (a) negative judgmental beliefs, (b) sadness, and (c) stigma and discrimination. At the end of the analysis, this process allowed me to identify frequent categories, trends, themes, and codes.

The software also allowed me to isolate pertinent data and themes in each transcript, which I used to support the analysis and understand my results. The eight participants' responses were coded and documented for frequency. In this study all responses were taken seriously and were used to contribute to possibly developing a theme. Some themes identified did not emerge from responses that were shared by each participant; however, each theme that was not deemed as pertinent was highlighted in Appendix G. The lived experiences of the participants were not shared among all eight participants. Negative judgmental beliefs, sadness stigma/discrimination were pertinent themes because they were shared among all eight participants. Other themes that included grief, loneliness, promiscuity, anger, self-isolation, substance abuse, suicidal attempts, having resource, and not having available was not themes that was shared among all eight participants.

Evidence of Trustworthiness

Credibility

I aimed for a junction of evidence that was credible and would allow me to feel confident about the observations, interpretations, and conclusions. I tried to identify recurring behaviors or actions and consider disconfirming evidence and contrary interpretations. Credibility in qualitative research is extremely important. Qualitative research must be credible and consistent with its findings (Metler, 2015). I reviewed the purpose of this study with each participant who had met the study criteria and informed them that they could ask questions at any time. I followed the same methods of data collection with each participant by asking the same semi-structured open-ended interview questions throughout the study. The data collection method consisted of seven phone interviews and one face to face interview. I consulted with my committee chair expert to review the findings of my study to assure credibility.

Transferability

To strengthen transferability, I provided a thorough description of the data collection and data-analysis processes. I felt my audience would be able to follow a user-friendly description of how I conducted the research. The research flyers detailed the criteria of the study, the purpose, contact information, and participation incentive.

Dependability

To strengthen the dependability of this qualitative study, I described difficult conditions that could occur during the interview process. I explained how those conditions might influence the way I conducted this qualitative study. I also created a distress managing protocol to assist participants that were having a difficult time reliving those emotional events. Each participant was given a follow-up call within 5 minutes after the interview to determine if they were emotionally satisfied or, if they needed any type of crisis assistance services. Fortunately, none of the participants stated that they needed crisis assistance services. Each participant was given a copy of the resource list to future use.

Confirmability

I used the reflexivity approach to improve the objectivity of my qualitative research to ensure that I was being truly independent from perceptions, emotions, or imaginations. I identified a doctorate level colleague to review the data, ensure accurate accountability, and to eliminate human error and discuss the findings before entering the data in the Dedoose software system. A confidentiality form was signed, and no identifying information was shared about the participants.

Study Results

I designed a phenomenological qualitative research study to determine the lived experiences of young adults who lost a parent to AIDS-related complications during adolescence and how does an adolescent understand the stigma associated with losing a parent to complications from AIDS? The Dedoose software showed that I analyzed 90 codes from the data collection process and identified 12 prominent themes as seen in this section in Figure 1 as a word cloud image. This word cloud was used to commonly highlight trending terms and patterns that were prominent. Word clouds are increasingly being employed as a simple tool to identify the focus of written material. For example, they have been used in politics, business, and education, to visualize the content of political speeches. Word clouds should be interpreted with certain caveats (Atenstaedt, 2012 p. 148).

Figure 2. Word cloud. Dedoose (2020). Retrieved from Dedoose.com

RQ1: What are the lived experiences of young adults who lost a parent to AIDS-related complications during adolescence? The interview question that was asked to address this research question asked participants to describe their lived experiences associated with the death of losing a parent (s) to AIDS-related complications. Each participant was asked the same questions. The most common prominent themes reported as having been experienced were negative judgmental beliefs, sadness, stigma/discrimination. Other themes identified were grief, loneliness, anger, self-isolation, substance abuse, suicidal attempts, having resources available or not, and promiscuity. However, these themes were not shared as lives experiences among 100 % of the participants that participated in this study.

Prominent Theme 1: Negative Judgmental Beliefs

The first them identified was negative judgmental beliefs. Negative judgmental beliefs mean that a participant believes that they have experienced someone judging them negatively due to being associated with a parent to die from AIDS-related complications. Seven of eight participants reported experiencing negative judgement beliefs. Participant # 3 believes “They're black sheep. People shun away from them. "You got AIDS, get away from me. You're not a part of this society." People with AIDS, they're put in a box. People without AIDS put in a box. People with syphilis, put in a box. Gonorrhea put in a box. So, on and so on. All the categories of different diseases, they all go around. It's like a cycle. The end results. Iron boxes, funeral homes.”

Prominent Theme 2: Sadness

Sadness was the second theme that materialized from conducting the study. All the participants reported having experienced sadness throughout their lived experiences of the death of a parent. Participant # 1 stated “Oh my God, Very, very hurt, sad, confused, angry, lost.” Participant # 2 also remembered dealing with sadness. She quoted “My dad was gone almost twenty years. I miss my mom more than I miss him. It is like I mourn sadness more over my mom than my dad, if that make sense, you know what I mean.”

Prominent Theme 3: Stigma/Discrimination

Stigma/discrimination. The final prominent theme identified is stigma/discrimination. Six participants were able to identify with experiencing stigma/discrimination. Stigma is disgrace that can be associated with a circumstance, quality, or person (Webster, 2020) Discrimination is associated with an unjust prejudiced treatment. The individuals in this study provided information regarding their lived experiences and how they understood the stigma relating to losing a parent. Participant # 2 stated that people thought she would be like her mother. She went on to add that “I would say when we went to my mother's side, they were like, "No, he can't sleep here because he got that AIDS." I felt like that was negative. I do. Even though like I said, I feel life is just a whole bunch of hypocritical stuff, that they loved us in one breath but then in another breath, they made the person that if my dad and my mom didn't get together, it would be no me.” Participant # 3 added “I was stigmatized due to my mother having AIDS. I had to go live with my fiancé. Most of the time I isolated myself. I did not have many friends." More information on the prominent themes can be found in Table 5 and Table 6.

Table 5

Prominent Themes Table

Questions	Themes
RQ1 What are the lived experiences of young adults who lost a parent to AIDS related complication during adolescence?	Sadness Stigma/discrimination Negative beliefs
RQ 2 How did you as an adolescent understand the stigma associated with losing a parent to complications from AIDS?	Stigma/discrimination

Table 6

Prominent Themes and Participants Quotes

Participants	Major themes	Quotations
100001	Sadness	"Oh my God, Very, very hurt, sad, confused, angry, lost."
	Negative Judgmental Beliefs	"The community then was very judgmental towards someone who had AIDS or HIV. Basically, it was like things were kept secretive."
	Stigma/ Discrimination	"It took me many years to figure that out. I was an adult. It was just learning how to cope and understand and how to deal with it."
100002	Sadness	"My dad was gone almost twenty years. I miss my mom more than I miss him. It is like I mourn sadness more over my mom than my dad, if that make sense, you know what I mean."
	Negative Judgmental Beliefs	"They had it like if you touch somebody you can get it. If they cough on you, you're dead. They'd sit on a seat, those type of things, being uneducated but I get it because it wasn't released back then, allegedly."
	Stigma/ Discrimination	"I would say when we went to my mother's side, they were like, "No, he can't sleep here because he got that AIDS." I felt like that was negative. I do. Even though like I said, I feel life is just a whole bunch of hypocritical stuff, that they loved us in one breath but then in another breath, they made the person that if my dad and my mom didn't get together, it would be no me."

Participants	Major themes	Quotations
100003	Negative Judgmental Beliefs	“They're black sheep. People shun away from them. "You got AIDS, get away from me. You're not a part of this society." People with AIDS, they're put in a box. People without AIDS put in a box. People with syphilis, put in a box. Gonorrhea put in a box. So, on and so on. All the categories of different diseases, they all go around. It's like a cycle. The end results. Iron boxes, funeral homes.”
	Stigma/ Discrimination	“I was stigmatized due to my mother having AIDS. I had to go live with my fiancé” Most of the time I isolated myself. I did not have many friends.”
100004	Sadness	“Well, my mom actually told us that she was going to die. It was a month prior to her death, and she got us ready, told us what things were. We were sad and we cried when she told us, but when she did past away, I was sad still but we went to the role because she told us what role we should play with each other, and that she wanted to make sure we stayed together, that she wanted us to know that just in case somebody told us differently. That's why we were growing with my grandmother because all of us had different fathers, each of us.”
	Negative Judgmental Beliefs	“I believe that because she had AIDS, things were done and allowed to happen maybe because she didn’t know herself worth, I don’t know, or had issues dealing with it, that’s AIDS. That’s why it's hard to answer some questions.”
	Stigma/ Discrimination	“I’ve had somebody that seems to have no stigma and then we disconnect. Now, I see how stigmatizing that can be just to be malicious or just to be hurtful. Just because it’s something to say, you can get hurt. They just say stuff. People know that it can be negative, but people deal with the hurt or the pain.”

Nonprominent Themes

Other themes were identified but was not determined to be prominent. Themes were determined as prominent if 100% of the participants did not report shared lived experiences among all eight participants. Those non prominent themes included anger, substance abuse, suicidal ideations, grief, promiscuity, loneliness, having available resources, and not having available resources. Of the reported lived experiences among participants 62.5% experienced anger, 37.5% reported substance abuse, suicidal ideations, grief, loneliness, and having resources available to them. Twenty-five percent of participants also reported experiencing promiscuity while 20% indicated that they did not have resources available to them. Some quoted examples of non-prominent themes shared participants were:

100001

Anger “Oh my god. Very, very hurt, sad, confused, angry, lost.”

Substance Abuse “I started drinking, me not listening to my mom. I ended up having a baby.”

Suicidal Ideations “No suicidal attempts for thought”

Resources Available “felt like if I had the resources, I would have went through a rough stage in my teenage years being disobedient and rebellious and feel remorse.”

100002

Anger, if I'm saying it right. I think the biggest one was anger.”

Grief “Well, grief is one. Questioning, like how, why.”

No Resources available” None. No resources available to me.”

100004

Anger “We were going to stay with my grandmother, and I guess for me, I didn't really grieve her at that time. It explains as I grew, because I was very angry, and felt closed off an shut off.”

Grief “We were sad and we cried when she told us, but when she did past away, I was sad, I grieved her everyday but we still went to the role because she told us what role we should play with each other, and that she wanted to make sure we stayed together.”

Suicidal Ideations" Suicide ideations and attempts happened, but it had nothing to do with your mom having AIDS or dying from complications of AIDS."

Self-Isolation" I was very angry and felt closed off an shut off."

Resources Available "Well, I was extremely lucky because I went to a one-stop shop. One-stop shop just means all the services are just under one umbrella, one agency."

100006

Anger "I was very angry and beating up people caused me to go to prison. I missed being with my dad."

Suicidal Ideations "I became suicidal. When my dad died of HIV."

100007

Substance Abuse "I had a child. I didn't want him to grow up in that environment he was living." His dad, we all lived in the same area again and his dad was-- he was the one supplying the people with the stuff that caused them to get that situation. Heroin."

No Resources Available "I think he had a nurse. He had a nurse that gave him a lot of Ensures."

RQ 2 How did you as an adolescent understand the stigma associated with losing a parent to complications from AIDS? The only theme that emerged was stigma/discrimination. Some participants responses were not similar and relevant due to participants understanding of how to articulate what stigma looked like to them.

Stigma

The participants discussed their understanding of stigma and shared horrifying events rather than giving a clear statement explaining how they understood stigma. Based on these participants their shared experiences derived from events that took place in their lives. When asked how you as an adolescent understood the stigma associated with losing a parent to complications from AIDS; participant number 100001-DH responded by stating, “it took years. I was an adult. I was just learning how to cope and understand how to deal with it.” This participant was just learning how to cope with the death of a parent to AIDS-related complication and how stigma is associated with this type of death. The participants had minor differences in the verbiage which was essential in the development of the word cloud. The word cloud for this study shows similar visualizations amongst participants which include popularity, trends, and frequency. When addressing RQ1, the eight participants’ responses were similar in content; however, when addressing RQ2, there was a lack of similarities. Some participant's responses were not relevant to the research questions.

Summary

The purpose of this phenomenological qualitative research study was to determine the experience of losing a parent to AIDS-related complications during adolescence has on young adults. An overview was provided to explain the process of how data was collected, and managed. A thematic analysis was used to analyze data. The overview also described how the participants were recruited, identified, and interviewed. All participants were selected based on the purposeful sampling methods. After participants met the study criteria and consent to participate, informed consent was sent to them for review. The participants were able to interview in a space where they deemed as safe, and confidential wherever they reside (e.g., home, shelter, etc.). All interviews were digitally recorded and then uploaded to a password-protected folder. The issues of credibility, transferability, trustworthiness, and dependability issues were addressed. As a part of the interview process, the informed consent was reviewed again and clarified by the researcher. The interview and review of document process took up to 60 minutes.

The most prominent themes that were indicated from the lived experiences of the participants were negative judgmental beliefs, sadness, and stigma/discrimination. Other themes that were not prominent but addressed and documented were anger, grief, loneliness, promiscuity, self-isolation, substance abuse, suicidal attempts, resources, and no resources available to them during their lived experience. These themes were identified but was not shared as lives experiences among all eight participants. My experience conducting this study, the interpretation of findings, study limitations, recommendations for future studies, and social change implications are provided in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This chapter captures the discussion of the findings from interviews with participants who have lost a parent to AIDS-related complications during adolescence. The purpose of this phenomenological qualitative study was to determine lived experiences of losing a parent to AIDS-related complications during adolescence has on individuals during young adulthood. This disease continues to claim lives and greatly impacts families in many ways. Many communities need adequate resources to assist adolescents who have been impacted by such a loss. Therefore, healthcare providers, psychologists, social workers, and those that serve in the human services capacity can better focus on these adolescents struggling with adverse childhood experiences, depression, anxiety, and externalizing conduct issues.

The current data from the literature does not show how these adolescent children may be impacted, how their lived experiences are affected, and how their well-being is compromised when they become young adults. Past studies have examined attentional, cognitive, and social competence in adolescents between the ages of eight and 12 and found these adolescents have problems in other areas as well, but the literature is sparse in identifying these issues (Bauman et al., 2006). Thus, with this study, I aimed to fill this gap.

Key Findings

The following themes were identified for this study: (a) all participants from the study experienced sadness, (b) over half of the participants experienced negative judgmental beliefs, (c) half of the participants discussed experiencing various types of stigma, (d) one participant was able to articulate and report understanding the stigma that was associated with the death of a parent to AIDS during adolescence, (e) participants believed they had resources at the time of experiencing the loss of a parent to AIDS complications, (f) participants experienced some substance abuse, (g) participants experienced grief and loneliness, (h) very few participants reported having no resources available, (i) there was a low consensus of promiscuity, (j) participants discussed being angry and sad, (k) self-isolation was experienced by some and (l) some thought about attempting suicide after the loss of a parent to AIDS complications.

Interpretation of Findings

The findings of this study were consistent with literature used to determine the experience of a loss of a parent to AIDS during adolescence on young adults. The literature indicated participants reported experiencing stigma/discrimination, sadness, anger, and judgmental beliefs, among other disparities. The three prominent themes that were relevant to the participants' experiences were: negative judgmental beliefs, sadness, and stigma/discrimination.

Overarching Research Questions

My first overarching research question is to determine what are the lived experiences of young adults who lost a parent to AIDS-related complications during adolescence? All three prominent themes addressed this question.

Prominent Theme 1: Negative judgmental beliefs. After reviewing the participants' interviews, I found that all except one participant had experienced negative judgmental beliefs. Participants discussed how they were judged based on something that happened to their parents. They experienced people assuming that they had AIDS. Their community was very judgmental towards someone who had AIDS. Due to some knowing that they had a parent to die from AIDS complications, they experienced people not knowing the transmission mode and thinking if they touched them, they would contract AIDS. This theme aligns with the work of Tenkorang (2013) who stated that people need to acquire knowledge of HIV/AIDS and its misconceptions are a form of self-empowerment that can influence an individual's perception of risk and create awareness for sexual-behavior changes.

Prominent Theme 2: Sadness. All the participants in this study talked about experiencing sadness. Their grief process brought upon sadness. Participant 100002, "stated she mourned sadness more over her mom's death to AIDS complications than her father's, who also died from AIDS complications." Another participant talked about being sad and cried, but still had to play the role in which their mom instructed them to do before her death. Although sadness was one of the most prominent themes, these participants still experienced grief, loneliness, promiscuity, anger, self-isolation, substance abuse, and suicide attempts. Those factors support the work by Bauman et al., (2006) and Zhao et al., (2009). Bauman et al. stated the worst trauma for a child is to lose a parent to death. Adolescents who lost a parent to AIDS complications reported problems with peers, depression, worry, stress, and fear. Zhao et al.'s (2009) study also supports the finding that adolescents who lost a parent to AIDS complications reported sadness, fear, anger, loneliness, anxiety, stigma, and isolation.

Prominent Theme 3: Stigma/discrimination. Over half of the participants reported experiencing stigma. Participants reported not being able to attend school in their home. Another participant shared when visiting family members, they were able to stay in their home but the father who had AIDS was not allowed to stay. They were not allowed to eat and drink from the same dishes that other family members were able to use. Others were called names in public and by family, which caused them to self-stigmatize and self-isolate. This theme supports the work of Quach et al. (2005) which stated that more programs dispel unreasonable stigma, prejudices, and attitudes towards people who are affected and infected with HIV/AIDS. Kelly et al (1998) also suggested that medical providers should develop programs to dispel unreasonable stigma and prejudice attitudes toward people living with HIV/AIDS.

Secondly, I wanted to determine how adolescent understand stigma associated with losing a parent to complications from AIDS? The prominent theme of stigma most closely addressed this second research question.

Prominent Theme 1: Stigma. When participants were asked how they understood stigma that was associated with losing a parent to AIDS complications, one participant answered by stating it took a long time to understand what those behaviors were in that moment. She reported she did not have a clear understanding of stigma until she became an adult. The other participants answered by recapturing an event that showed how they were stigmatized at that time. That participant response was not relevant in terms of addressing the research question as it related to stigma.

Limitations of the Study

Several limitations to the research were identified. I used the purposeful sample method to identify participants who had experienced losing a parent to AIDS-related complications while they were adolescents. This small sample limited the extension of research findings and conclusions to my population. The study had eight qualifying participants who lost a parent to AIDS-related complications during adolescence, resulting in limitation for this study. I cannot give any assurance that adolescents in other regions have the same perceptions of lived experiences and understanding the stigma associated with losing a parent to AIDS complications.

The researcher bias is the final limitation of this study. According to research, there is going to be some type of biases in research (Groenwold, 2013). No researcher is immune from experiencing biases. After being a provider in the field of HIV/AIDS services work for many years, I was careful not to invalidate my work by imposing research bias into my study. This type of bias can occur when researchers influence their work to get the outcome they would like to obtain. I worked hard to ensure that my biases would not unknowingly reflect my research. The biases that I bring are that these individuals must have experienced some type of long-term psychological effect from their lived experiences. I addressed this limitation by allowing a doctorate level colleague to sign the confidentiality document to observe and assist me with hand-coding my data to obtain the codes and themes for this study. The colleague facilitated in gathering information based on themes in which I might have missed by utilizing probing questions. She questioned my process for each step theme based on the research questions. The participants were identified by assigned identification numbers. The researcher did not disclose names of participants in any form. While working together, I then entered additional hand coded themes and code into Dedoose 7 software to reduce any further human error.

Recommendations

In this study, I investigated how the loss of a parent to AIDS-related complication was reflected in the lived experience of young adolescence. Seven of the participants were from North Carolina and one participant reported being from Ghana. I recommend that additional qualitative studies be conducted to address how adolescents were affected to see if there were any psychological affects that were carried over into adulthood. This is important because some adverse child behaviors can linger into adulthood if untreated. This is a part of childhood adverse effects that most public-school systems are learning about in our communities.

According to the literature, Bauman (2006) found that future research is needed to get a better understanding of how these children are affected as adolescents and later in life. Additional research would aid in better understanding the norms of children who have lost a parent to AIDS-related serious illness. Providers should focus on depression, anxiety, and externalizing conduct problems. Past studies examined attentional, cognitive, and social competence in adolescents between the ages of 10 to 19 and found these adolescents have problems in other areas as well. Rotheram-Borus et al., (2001) reported that clinicians have argued that parental death had a pervasive negative effect on adolescents' emotional distress and behavioral problems, but researchers do not indicate if the negative impact affects the individuals in young adulthood. Mark, Jun, and Song (2007) added that the loss of a parent to AIDS-related complications is difficult during adolescence compared to during young adulthood. This could potentially affect their lives as adults. Lastly, Zhao (2009) reported where researchers were able to better understand the emotional and psychological stressors resulting from the experiences of HIV/AIDS-related parental illness and death but were unable to determine the length of the impact of those stressors.

Implications

The positive social change implications for this study include understanding the lived experiences of adolescents who lost a parent to AIDS-related complications and how they understood the stigma they may have experienced during that time of loss. The information gained can help healthcare providers, psychologists, social workers, mental health professionals, and those that serve in the human services field understand adolescents struggling with social and psychological issues.

The results of this study can create social change by adding to the existing research regarding the lived experiences of a loss of a parent to AIDS during adolescence. In addition, the results can enhance how providers serve adolescents who seem to have psychological and social problems due to adverse childhood experiences that had not been identified. We as providers can identify those adverse childhood experiences by gathering history from the families and caretakers early on. It is my belief that early prevention and intervention strategies can prevent a lot of the behavioral issues that our adolescents experience. For example, if those issues are addressed early enough, some adolescents do not have to let it carry over into their young adulthood. Adolescents are resilient when trauma-informed services are offered. They have an opportunity to engage in treatment and become more successful.

It is my intention to disseminate the results of this study by participating in community and human services AIDS agencies presentation, HIV/AIDS conferences, and other professional conferences.

Conclusions

In conclusion, this disease continues to claim lives and destroy families around the country. Our communities need adequate resources to assist adolescents who have been impacted by such a loss. Studies have shown that adverse childhood experiences are common in adolescence and it is generally not recognized (Felitti, 2009). If we as providers identify those adverse childhood experiences by gathering history from the families and caretakers, it is my belief that we can prevent a lot of the issues that our adolescents experience. The adverse childhood experience needs assessment reflects neglect, substance use, psychological issues, physical and sexual abuse. The assessment should also reflect losing a parent to HIV/AIDS and other grief trauma. These adolescents are resilient. If early interventions are implemented, we would be able to better identify trauma and reduce the chances of any long-term psychological effects. Not only that, but this will also assist healthcare providers, psychologists, social workers, and those that serve in the human services capacity with this information they can focus on these adolescents struggling with depression, anxiety, and externalizing conduct issues to determine the root of their problems. Currently, the data were insufficient and does not currently show how these adolescents are impacted and how their well-being is compromised when they become young adults.

References

Atenstaedt R. (2012). Word cloud analysis of the BJGP. *The British journal of general practice: the journal of the Royal College of General Practitioners, 62*(596), 148. https://doi.org/10.3399/bjgp12X630142

Avert. (2017). HIV and AIDS in the United States. Retrieved from http://www.avert.org/professionals/hiv-around-world/western-central-europe-north-america/usa

Bauman, L. J., Camacho, S., Silver, E. J., Hudis, J., & Draimin, B. (2002). Behavioral problems in school-aged children of mothers with AIDS. *Clinical Child Psychology and Psychiatry, 7,* 39–54. https://doi.org/10.1177/1359104502007001004

Bauman, L. J., Foster, G., Silver, E. J., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies, 1,* 56–70. https://doi.org/10.1080/17450120600659077

Bauman, L. J., Silver, E. J., Draimin, B. H., & Hudis, J. (2007). Children of mothers with HIV/AIDS: Unmet needs for mental health services. *Pediatrics, 120,* e1141–e1147.https://doi.org/10.1542/peds.2005-2680

Berg, L., Rostila, M., Saarela, J., & Hjern, A. (2014). Parental death during childhood and subsequent school performance. *Journal of the American Academy of Pediatrics, 133,* 682–689. https://doi.org/10.1542/peds.2013-2771

Bezuidenhoudt, C., Elago, H., Kalenga, E., Klazen, S., Nghipondoka, K., & Ashton, D. (2004). *The psychological impact of HIV/AIDS: People are more than statistics.* Retrieved from http://org.elon.edu/Summit/Essays/Essay4.Pdf

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77–101. https://doi.org/10.1191/1478088706qp063oa

Burr, C. (1997, June). The AIDS exception: Privacy vs. public health. *The Atlantic.* Retrieved from https://www.theatlantic.com/magazine/archive/1997/06/the-aids-exception-privacy -vs-public-health/308779/

Butler, G. (2018). Definitions of stress. *Occasional Paper Series.* Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2560943/pdf/occpaper00115-0007.pdf

Carten, A. J., & Fennoy, I. (1997). African American Families and HIV/AIDS: Caring for surviving children. *Child Welfare, 76,* 107–125. Retrieved from https://www.cwla.org/child-welfare-journal/

Center for Innovation in Research and Teaching. (2018). *Qualitative sampling methods.* Retrieved from https://cirt.gcu.edu/research/developmentresources/research_ready /qualitative/sampling

Center for Innovation in Research and Teaching. (2019). *Benefits and limitations of experimental research.* Retrieved from cirt.gcu.edu/research/development resources/research ready/experimental/benefits limits

Centers for Disease Control and Prevention. (2016). *HIV among women: The numbers, HIV diagnosis.* Retrieved from http://www.cdc.gov/hiv/group/gender/women/index.html

Centers for Disease Control and Prevention. (2017). *HIV in the United States and dependent areas.* Retrieved from https://www.cdc.gov/hiv/statistics/overview/ataglance.html

Centers for Disease Control and Prevention. (2019a). *Heart disease facts.* Retrieved from https://www.cdc.gov/heartdisease/facts.htm

Centers for Disease Control and Prevention. (2019b). The scope and impact of HIV in the United States. (2019). Retrieved from https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf

Centers for Disease Control and Prevention. (2019c). *Violence prevention.* Retrieved from https://www.cdc.gov/violenceprevention/acestudy/index.html

Centers for Disease Control and Prevention. (2020). Current Trends Mortality to HIV infection/AIDS. Retrieved from https://www.cdc.gov/mmwr/preview/mmwrhtml/00001880.htm

Cerniglia, L., Cimino, S., Ballarotto, G., & Monniello, G. (2014). Parental loss during childhood and outcomes on adolescent's psychological profiles: A longitudinal study. *Current Psychology, 33,* 546–556. https://doi.org/10.1007/s12144-014-9228-3

Chi, P. L., & Li, X. M. (2013). Impact of parental HIV/AIDS on children's psychological well-being: A systematic review of global literature. *AIDS and Behavior, 17,* 2554–2574. https://doi.org/10.1007/s10461-012-0290-2

Chu, C., & Selwyn, P. (2011, February). Complications of HIV infection: A systems-based approach. *American Family Physician, 83,* 395–406. Retrieved from https://www.aafp.org/journals/afp.html

Coping behavior. (2019). *Psychology dictionary.* Retrieved from https://psychologydictionary.org/coping-behavior.

Corona, R., Beckett, C. R., Cowgill, B. O., Elliott, M. N., Murphy, D. A., Zhou, A. J., & Schuster, M. A. (2006). Do children know their parent's HIV status? Parental reports of child awareness in a nationally representative sample. *Ambulatory Pediatrics, 6,* 138–144. https://doi.org/10.1016/j.ambp.2006.02.005

Cranwell-Ward J., & Abbey A. (2005) What is stress? In *Organizational stress.* London, England: Palgrave Macmillan.

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage.

Dane, B. O., & Levine, C. (1994). AIDS *and the new orphans: Coping with death*. Westport, CT: Greenwood.

Dealing with Stigma and Discrimination. (2020, July 31). Center for Disease Control and Prevention. https://www.cdc.gov/hiv/basics/livingwithhiv/stigma-discrimination.html

Dedoose(2020). Retrieved from https://ecampus.phoenix.edu/secure/aapd/cwe/citation_generator/index.html

Dixon, S., McDonald, S., & Roberts, J. (2002). The impact of HIV and AIDS on Africa's economic development. *British Medical Journal, 324,* 232–234. https://doi.org/10.1136/bmj.324.7331.232

Earnshaw V. A., & Kalichman S. C. (2013). Stigma experienced by people living with HIV/AIDS. In P. Liamputtong P. (Ed.), *Stigma, discrimination and living with HIV/AIDS.* Dordrecht, The Netherlands: Springer. https://doi.org/10.1007/978-94-007-6324-1_2

Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology, 43,* 13–35. https://doi.org/10.1163/156916212X632943

Evans, R., & Becker, S. (2009). *Children caring for parents with HIV and AIDS: Global issues and policy responses*. Portland, OR: Bristol University Press. https://doi.org/10.2307/j.ctt9qgvzh

Felitti, Vincent J. (2009). Adverse Childhood Experiences and Adult Health. Retrieved from http://event.capconcorp.com/wp/hpog-2016/wp-content/uploads/sites/7/2016/09/Schilling_AdverseChildhoodExperiencesandAdultHealth-508.pdf

Foundation for AIDS Research. (2019). *Thirty years of HIV/AIDS: Snapshots of an epidemic*. Retrieved from https://www.amfar.org/thirty-years-of-hiv/aids-snapshots-of-an-epidemic/

Frankfort-Nachmias, C., & Frankfort-Nachmias, D. (2008). *Research methods in social sciences* (7th Ed.). New York, NY: Worth.

Gielen, A., Ghandour, R., Burke, J., Mahoney, P., McDonnell, K. A., & O'Campo, P. (2007). HIV/AIDS and intimate partner violence: Intersecting women's health issues in the United States. *Trauma, Violence and Abuse, 8*(2), 178–198. https://doi.org/10.1177/1524838007301476

Global Information and Education on HIV/AIDS. (2019). *HIV stigma and discrimination.* Retrieved from https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination

Graham, L. J. (2014). Integration of the interaction model of client behavior and transactional model of stress and coping as a tool for understanding retention in HIV care across the life span. *Journal of the Association of Nurses in AIDS Care, 26,* 100–109. https://doi.org/j.jana.2014.11.009

Groenwold RH. Three types of bias: distortion of research results and how that can be prevented. Nederlands Tijdschrift Voor Geneeskunde. 2013 ;157(40): A6497

HIV and AIDS--United States, 1981-2000. (2001, November 30). National Library of Medicine. https://pubmed.ncbi.nlm.nih.gov/11475378/

Ji, G., Li, L., Ding, Y., Xiao, Y., & Tian, J. (2012). Parents living with HIV and children's stress and delinquent behaviors in China. *Vulnerable Children and Youth Studies, 7,* 249–259. https://doi.org/10.1080/17450128.2012.672777

Kelly, J. A., St. Lawrence, J. S., Smith, S., Jr., Hood, H. V., & Cook, D. J. (1987). Stigmatization of AIDS patients by physicians. *American Journal of Public Health, 77,* 789–791. https://doi.org/10.2105.ajph.77.7.789

Kharsany, A. B., & Karim, Q. A. (2016). HIV infection and AIDS in Sub-Saharan Africa: Current status, challenges and opportunities. *Open AIDS Journal, 12*(15), 34–38. https://doi.org/10.2174/1874613601610010034

Laurencin, C. T., Christensen, D. M., & Taylor, E. D. (2008). HIV/AIDS and the African American community: A state of emergency. *Journal of the National Medical Association, 100*(1), 34–43. https://doi.org/10.1016/s0027-9684(15)31172-x

Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality, 1,* 141-169. https://doi.org/10.1002/per .2410010304

Lichtenstein, B., Sturdivant, M. S., & Mujumdar, A. A. (2010). Psychosocial stressors of families affected by HIV/AIDS: Implications for social work practice. *Journal of HIV/AIDS & Social Services, 9,* 130–152. https://doi.org/10.1080/15381501003795717

Lipsitch, M., Donnelly, C. A., Fraser, C., Blake, I. M., Cori, A., Dorigatti, I., Hernán, M. A. (2015). Potential biases in estimating absolute and relative case-fatality risks during outbreaks. *PLOS Neglected Tropical Diseases, 9*(7), Art. e0003846. https://doi.org/10.1371/journal.pntd.0003846

Lis-Turlejska, M., Luszczynska, A., Plichta, A., & Benight, C. C. (2008). Jewish and non-Jewish World War II child and adolescent survivors at 60 years after war: Effects of parental loss and age at exposure on well-being. *American Journal of Orthopsychiatry, 78,* 369–377. https://doi.org/10.1037/a0014166

Maltured, K., Siersma, V. D., & Guassora, A. D. (2015). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26,* 1753–1760. https://doi.org/10.1177/1049732315617444

Marks, F., Jun, H., & Song, J. (2007). Death of parents and adult psychological and physical wellbeing: A prospective U.S. national study. *Journal of Family Issues, 28,* 1611–1638. https://doi.org/10.1177/0192513X07302728

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative social research, 11*(3) Art, 8. Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027.

Menna, T., Ali, A., & Worku, A. (2014). Prevalence of “HIV/AIDS related” parental death and its association with sexual behavior of secondary school youth in Addis Ababa, Ethiopia: A cross sectional study. *BMC Public Health, 14,* Art. 1120. https://doi.org/10.1186/1471-2458-14-1120

Mertler, C. A. (2015). *Introduction to educational research.* Thousand Oaks, CA: Sage.

Mohammad, M., Mahmoodabad, S. S. M., Zadehe, D. S., Barkhordari, A., Hosaini, F., Kaveh, M. H., Maleh, A. S., & Rahiminegad, M. (2013). The study of the effects of stress management program on transactional model constructs in Yazd teachers of primary schools. *European Journal of Experimental Biology, 3*(4), 188–193. Retrieved from http://www.imedpub.com

National Institute of Mental Health. (2019). *U.S. leading categories of diseases/disorders.* Retrieved from https://www.nimh.nih.gov/health/statistics/disability/us-leading-categories-of-diseases-disorders.shtml

National Institute on Drug Abuse. (2017). *What is HIV/AIDS?* Retrieved from https://www.drugabuse.gov/publications/research-reports/hivaids/what-hivaids

Nyirenda, M., MCGrath, N., & Newell, M.-L. (2010). Gender differentials in the impact of parental death: Adolescent's sexual behaviour and risk of HIV infection in rural South Africa. *Vulnerable Children and Youth Studies, 5,* 284–296. https://doi.org/10.1080/17450128.2010.507804

Osingada, C. R., Okuga, M., Nabirye, R. C., Sewankamboo, N. K., & Nakanjako, N. (2017). Disclosure of parental HIV status to children: Experiences of adults receiving antiretroviral treatment at an urban clinic in Kampala, Uganda. *AIDS Research and Treatment, 2017,* Art. 3458684. https://doi.org/10.1155/2017/3458684

Pannucci, C. J., & Wilkins, E. G. (2010). Identifying and avoiding bias in research. *Plastic and Reconstructive Surgery, 126,* 619–625. https://doi.org/10.1097/PRS.0b013e3181de24bc

Perez, J. E., Chartier, M., Koopman, C., Vosvick, M., Gore-Felton, C., & Spiegel, D. (2009). Spiritual striving, acceptance coping and depressive symptoms among adults living with HIV/AIDS. *Journal of Health Psychology, 14,* 88–97. https://doi.org/10.1177/1359105308097949

Quach, L., Mayer, K., McGarvey, S. T., Lurie, M. N., & Do, P. (2005). Knowledge, attitudes, and practices among physicians on HIV/AIDS in Quang Ninh, Vietnam. *AIDS Patient Care and STDs, 19,* 335–345. https://doi.org/10.1089/apc.2005.19.335

Quick, J., & Hall, S. (2015). Part two: Qualitative research. *Journal of Perioperative Practice, 25,* 129–133. https://doi.org/10.1177/1750458915025007-803

Rand Corporation. (2018). *How parental HIV affects children.* Retrieved from https://www.rand.org/pubs/research_briefs/RB9372/index1.html

Richter L. (2010). An introduction to family-centered services for children affected by HIV and AIDS. *Journal of the International AIDS Society, 13 Suppl 2*(Suppl 2), S1. https://doi.org/10.1186/1758-2652-13-S2-S1

Richter, L. (2019). The impact of HIV/AIDS on the development of children. In R. Pharoah, L. Richter, & B. Killian (Eds.), *A generation at risk? HIV/AIDS, vulnerable children and security in Southern Africa* (pp. 9–31). Retrieved from http://www.hsrc.ac.za/uploads/pageContent/1641/TheimpactofHIVAIDSonthedevelopmentofchildren.pdf

Roller, M. R., & Lavrakas, P. J. (2015). *Applied qualitative research design: A total quality framework approach.* New York, NY. Guilford.

Rotheram-Borus, M. J., Stein, J. A., & Lin, Y. Y. (2001). Impact of parent death and an intervention on the adjustment of adolescents whose parents have HIV/AIDS. *Journal of Consulting and Clinical Psychology, 69,* 763–733. https://doi.org/10.1037/0022-006X.69 .5.763

Rotheram-Borus, M. J., Weiss, R., Alber, S., & Lester, P. (2005). Adolescent adjustment before and after HIV-related parental death. *Journal of Consulting and Clinical Psychology, 73*, 221–228. https://doi.org/10.1037/0022-006X.73.2.221

Salkind, N. J. (2012). Methods. *Encyclopedia of research design.* https://doi.org/10.4135 /9781412961288.n157

Sanjari, M., Bahramnezhad, F., Fomani, F. K., Shoghi, M., & Cheraghi, M. A. (2014). Ethical challenges of researchers in qualitative studies: The necessity to develop a specific guideline. *Journal of Medical Ethics and History of Medicine, 7,* Art. 14. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4263394/

Scandlyn, J. (2000). When AIDS became a chronic disease. *Western Journal of Medicine, 172,* 130–133. https://doi.org/10.1136.ewjm.172.2.130

Simon, M. K., & Goes, J. (2013). *Assumptions, limitations, delimitations, and scope of the study*. Retrieved from http://www.dissertationrecipes.com/wp-content/uploads/2011/04/Assumptions-Limitations-Delimitations-and-Scope-of-the-Study.pdf

Sinha, U. K., & Kumar, D. (2010). Mindfulness-based cognitive behaviour therapy with emotionally disturbed adolescents affected by HIV/AIDS. *Journal of Indian Association for Child and Adolescent Mental Health*, *6*(1), 19–30. Available from ERIC database. (EJ942534)

Stein, J. A., Riedel, M., & Rotheram-Borus, M. (2004). Parentification and its impact on adolescent children of parents with AIDS. *Family Process, 38,* 193–208. https://doi.org/10.1111/j.1545-5300.1999.00193.x

Stewart, K. A. (2011). The spiritual framework of coping through the voices of cancer narratives. *Omega, 63,* 45–77. https://doi.org/10.2190/OM.63.1.c

Taylor-Brown, S., Teeter, J. A., Blackburn, E., Oinen, L., & Wedderburn, L. (1998). Parental loss due to HIV: Caring for children as a community issue—The Rochester, New York experience. *Child Welfare, 77,* 137–160. https://doi.org/10.4324/9781351321006-4

Tenkorang, E. Y. (2013). Myths and misconceptions about HIV transmission in Ghana: What are the drivers? *Culture, Health & Sexuality, 15,* 296–310. https://doi.org/10.1080/13691058.2012.752107

Today’s HIV/AIDS Epidemic. (2016, August). CDC Fact Sheet. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf

Transactional stress and coping model. (2019). Retrieved from https://www.google.com/search?q=image+of+lazarus+and+folkman+stress+and+coping+model&tbm=isch&source=hp&sa=X&ved=2ahUKEwinmrXbqrjjA

Tyson-Rawson, K. (1996). Relationship and heritage: Manifestations of ongoing attachment following father death. In D. Klass, P. R. Silverman, & S. L. Nickman (Eds.), *Series in death education, aging, and health care. Continuing bonds: New understandings of grief* (pp. 125–145). Philadelphia, PA, US: Taylor & Francis.

U.S. Department of Health & Human Services. (2012). *Minority women's health: African Americans.* Retrieved from http://womenshealth.gov/minority-health/african-americans

U.S. Department of Health and Human Services. (2018a). *Global statistics.* Retrieved from https://www.hiv.gov/hiv-basics/overview/data-and-trends/global-statistics

U.S. Department of Health and Human Services. (2018b). *HIV and opportunistic infections, coinfections, and conditions.* Retrieved from https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/26/86/what-is-an-opportunistic-infection

Van Rijnsoever, F. J. (2017). (I Can't Get No) Saturation: A simulation and guidelines for sample sizes in qualitative research. *PLoS ONE, 12,* Art. e0181689. https://doi.org/10.1371/journal.pone.0181689

Walden University. (2011). Walden University handbook. Retrieved from https://catalog.waldenu.edu/content.php?catoid=158&navoid=52518

Zarocostas, J. (2005). Number of people infected with HIV worldwide reaches 40m. *BMJ*, *331*(7527), 1224.2. https://doi.org/10.1136/bmj.331.7527.1224-a

Appendix A: Interview Protocol

Interview: Exploring the Effects of a Loss Parent to AIDS during Adolescence on Young Adults

Interview ID number: ____________________

Interviewer_________________________

Location: ______________________________

Date: ___________________________ Begin Time: ___________

End Time: ____________

Part I.

The purpose of this qualitative study is to determine if losing a parent (s) to AIDS- related complications during adolescence has any effect on individuals once they have grown into a young adult and is this loss different from losing a parent to any other chronic disease.

Part II.

1. The interview session will begin with relationship building, salutations, and introducing myself to the research participant. After introductions, the research topic will be introduced.

2. I will take the time to thank each participant for taking the time to respond to my invitation to participate in the study.

3. I will explain the informed consent. The participant will read the consent form and ask any necessary questions before proceeding to sign the informed consent.

4. The participant will be given a copy of the informed consent for their records.

5. The audio recorder (or electronic storage device) will be turned on. The date, time and county the interview is taking place will be recorded. The participant will be informed that the session is being recorded.

6. The coded sequential interpretation of the participants' name and/or church name (e.g. respondent Q1…) will be indicated on the audio recorder and documented on the consent form and the interview will begin.

7. The interview will take approximately 45 – 60 minutes for responses to the 3 research questions.

8. Participants will be reminded of the purpose of the study.

9. The participant will be informed regarding the review of the interview report that will be made available after transcription.

Appendix B: Interview Questionnaire for Participants

1. How were you treated as the results of your parent death from AIDS-related complications?
2. Describe your lived experiences associated with the death of your parent(s) to AIDS-related complications.
3. What emotions (e.g. sadness, guilt, denial, anger) did you experience after the death of your parent?
4. What do you feel is the perception of the community (e.g. family, friends, faith) due to the loss of an individual to AIDS-related complications?
5. What behaviors did you display after losing a parent?
6. What emotions do you currently experience that may be directly related to the loss of your parent?
7. Describe any suicidal ideations that you may have had as it relates to the death of your parent.
8. Describe a time where you felt you were treated negatively as a result of your parent (s) dying from AIDS-related complications.
9. How did you understand the stigma associated to losing a parent to complications from AIDS?
10. Do you think you experienced some type of stigma that was associated to your parent dying of AIDS-related complications? If so, why, or why not.
11. Do you think stigma still exist in society today regarding dying from AIDS-related complication? If so, why, or why not?

12. What beliefs do you feel exist about individuals who have AIDS? Why do you think those beliefs exist?
13. What resources were available to you during adolescence to help you cope with the loss of a parent?

Appendix C: Participant Demographic Fact Sheet

1. Are you between the ages of 18-35? What is your age?
   (a) Yes ______
   (b) No ______

2. What is your current marital status?
   (a) Married _______
   (b) Single _______
   (c) Divorced _______
   (d) Widow _______
   (e) Separated _______

3. Did you have a parent to pass due to AIDS-related complications?
   (a) Yes _______
   (b) No _______

4. Do you know what HIV or AIDS mean?
   (a) Yes _______
   (b) No _______

5. Were you between the ages of 10-18 when you parent (s) died? What age were you?
   (a) Yes ______
   (b) No ______

6. How long has it been since your parent(s) died?
   (a) Within the past 12 months _______
   (b) More than 12 months _______
   (c) 3-5 years _______
   (d) 10-20 years _______
   (e) More than 20 years _______

Appendix D: Participant Screener Document

1. Are you between the ages of 18-35? What is your age?
   (c) Yes ______
   (d) No ______

1. Did you have a parent to pass due to AIDS-related complications?
   (c) Yes _______
   (d) No _______

2. Were you between the ages of 10-18 when you parent (s) died? What age were you?
   (c) Yes ______
   (d) No ______

3. How long has it been since your parent(s) died?
   (f) Within the past 12 months _______
   (g) More than 12 months _______
   (h) 3-5 years _______
   (i) 10-20 years _______
   (j) More than 20 years _______

Appendix E: Protocol for Managing Distress

The Protocol for Managing Distress in the Context of a Research Interview

DISTRESS

- A participant indicates they are experiencing a high level of stress or emotional distress

OR

- Exhibit behaviors suggestive that the discussion/interview is to stress such as controlling crying, shaking, etc.

STAGE I

- Stop the discussion and offer immediate support
- Assess mental status:

a. Tell me what thoughts you are having.
b. Tell me what you are feeling right now,
c. Do you feel you are able to go on about your day?
d. Do you feel safe?

REVIEW

- If participants feel able to carry on resume the interview/discussion
- If participants are unable to carry on; go to stage 2

STAGE 2 RESPONSE

- Remove participation from discussion and accompany to quite areas or discontinue interview
- Encourage the participation to contract their general provider or mental health provider

OR

- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team that is treating them for further advices/support

FOLLOW-UP

- Follow participant up with courtesy call (if participants consent) OR
- Encourage the participants to call either if he/she experiences increased distress in the hours/days following the focus group

The Protocol for Managing Distress in the Context of a Research focus Group/Interview

PRE-DATA COLLECTION

- The researcher should consider the potential physical and psychological impact on the researcher of the participants description of life experiences
- The researcher should consider how interview could be undertaken in a week
- The researcher should be aware of the potential for emotional exhaustion

DATA COLLECTION STAGE

- If the topic is potentially sensitive/distressing data collection to be undertaken by two members of the research team
- Regular scheduled debriefing sessions with a named member of the research team
- May be encouraged to journal their thoughts and feelings which may then become part of field work notes in some research approaches

ANALYSIS

- Is alerted prior to transcription review of potentially "challenging" or difficult" interviews
- Has regular scheduled debriefing sessions with a named member of the research team

FOLLOW-UP

- Encourage the researcher to access to research mentor if he/she experiences increased distress in the hours/days following transcription

The Protocol for Managing Distress in the Context of a Research focus Group/Interview

PRE-DATA COLLECTION

- The transcriber should be considered in any research proposal, with a clear indication of how this person will be provided with a safe "safe working environment while also maintaining the "quality' of the research

ETHICAL REVEW STAGE

- Be included in the ethical clearance process
- Is informed of the nature of the research and the type of date

PRE-TRANSCRIPTION

- Is alerted prior to the transcription of potentially "challenging" or difficult" interviews as
- Has regular schedule debriefing sessions with a named member of the research team

DURING TRANSCRIPTION

- Has prompt access to an appropriate person for crisis counseling

- Has a clearly documented termination from the transcription process that includes resolution of personal issues which arose as a consequence of the work
- May be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches

FOLLOW-UP

- Follow transcriber up with courtesy call (if transcriber consents)

OR

- Encourage the transcriber to call if he/she experiences increased distress in the hours/days following transcription

Appendix F: Themes Identified (Not Prominent) Table

Table F1

Themes Identified (Not Prominent)

Participants	Themes
100001	Anger Substance abuse Suicidal attempts Resources available
100002	Anger Grief Promiscuity No resources available
100003	Anger Self-isolation Promiscuity Loneliness Resources available
100004	Anger Resources available Grief Suicidal attempts Self-isolation
100005	No resources available Suicidal attempts Substance abuse Self-isolation loneliness
100006	Anger Substance abuse

Participants	Themes
100007	Substance abuse No resources available
100008	Suicidal attempts Self-isolation Loneliness Grief No resources available

Appendix G: Permission to Use the Thematic Analysis Tables

Thank you for your query about TA

VB

Virginia Braun <v.braun@auckland.ac.nz>
Sat 6/13/2020 7:05 PM

Dear Colleague

Thank you for your email. We get lots of queries about TA (and qualitative research more broadly). Please note: Victoria has recently been diagnosed with a progressive form of multiple sclerosis and for the foreseeable future, will not be able to respond to any TA-related requests. Ginny also has challenging chronic health issues which impact her work capacity, and so all we can offer by way of response to your query is this generic email. Thanks for your understanding.

We have put together this email to point you to many of the resources we have developed related to TA. We have attached all of our papers on TA that we have PDFs of - many of our contributions are book chapters, so we don't have PDFs of most of these.

If you have asked a question about the use or underlying philosophy of our approach to TA, many of the questions we receive via email are addressed in our wider body of work, and particularly in our more recent publications and public lectures. Our thinking around TA has developed since our original 2006 paper, so we do recommend reading some of our more recent publications, alongside our original and earlier writing.

For permissions, please contact the relevant publisher. For our 2006 article, you can submit a permissions request online here (click on Reprints & Permissions). *If* you have provided full details of what you wish to reproduce, where you wish to reproduce it and for what purpose, please treat this email as confirmation of our permission - but generally you will need to seek permission from the publisher.

You can find a full list of our, and other, publications on TA, FAQs about TA (including the differences between our reflexive TA approach and other TA approaches, and between TA and other approaches like qualitative content analysis and IPA), and other resources on our thematic analysis website.

Here are links to two public lectures we have given on TA. In this lecture, we provide an introduction to our approach to TA. In this lecture, Victoria maps out the different types of TA and different conceptualisations of 'themes' in TA research.

If you are searching for examples of particular applications of TA - find our 2006 paper on Google Scholar and click on the citations (Cited by...), this takes you into a different window, click the 'Search within cited articles' box, and then you can search within the citations and find examples of particular uses and applications of TA. The last time we checked this paper had over 69,000 Google Scholar citations, so there are usually at least a few examples of whatever it is people want to find. Given that our approach is very widely used, we're simply not able to track all the different disciplines, fields and research areas in which it is used.

Our 2013 textbook Successful qualitative research includes a lengthy discussion of TA, with worked examples and a detailed overview of our recommended transcription notation for TA, and the companion website includes materials that can be used in teaching TA (including data-sets).

If you have asked about teaching, we have run TA workshops in the past, but due to current circumstances we have no plans to run TA workshops in the foreseeable future. We are not currently able to offer teaching at other institutions either.

If you have asked about external supervision/mentoring/collaboration/meetings to discuss your research – we are fully committed and have no capacity for supervision/mentoring/collaboration/meetings for the foreseeable future.

Thank you for your interest in our approach to TA, and good luck with your research!
Kind regards,

Ginny & Victoria

Professor, School of Psychology/Te Kura Mātai Hinengaro, The University of Auckland/Te Whare Wānanga o Tāmaki Makaurau
| Dr Virginia Braun | twitter | thematic analysis | Successful Qualitative Research: A Practical Guide for Beginners | story completion | Collecting Qualitative Data | sexual politics now |