THE DEVELOPMENT OF A MODEL THAT EXAMINES PARENTAL HIV-RELATED STIGMA AND THE PSYCHOSOCIAL WELL-BEING OF CHILDREN ORPHANED BY AIDS

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ABSTRACT

The growing interest in the well-being of children who have been orphaned due to HIV/AIDS is widely reflected in the emerging body of research. Children orphaned by AIDS-related causes are identified as a vulnerable population of youth who display lower levels of psychosocial well-being and experience increased psychosocial distress. While HIV-related stigma remains a salient risk factor hindering the psychosocial well-being of children orphaned by AIDS, the concept remains elusive and poorly understood. Hence, the call for a comprehensive understanding to support an effective response to stigma reduction, and for the systematic identification and response to the psychosocial needs and challenges of children in the context of HIV/AIDS. The overall aim of this study was therefore to develop a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS. A mixed method, exploratory, sequential design situated within a theory generative research approach was implemented in four sequential phases geared towards model development. The specific objectives of this study were to: (1) review existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS (systematic review); (2) explore children orphaned by AIDS perceptions and experiences of HIV-related stigma (qualitative exploratory design); (3) develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS (a theory generative design); and (4) determine the functionality of the developed model through the use of the Delphi technique (a modified Delphi technique).

The systematic review conducted in Phase I indicated the presence of HIV-related stigma, which inhibited the psychosocial well-being of children orphaned by AIDS. The findings further highlighted the mediating role of maladaptive coping strategies and social support likely to reduce healthy psychosocial well-being and cause psychosocial distress among children orphaned by AIDS. Similarly, the findings arising from the qualitative exploration in Phase II indicated that children orphaned by AIDS were highly perceptive and experienced HIV-related stigma as a result of parental illness and death. These experiences negatively affected the psychological, emotional, and social well-being, self-concept and self-esteem, and future orientation of children orphaned by AIDS. The theory generative design in Phase III identified, classified, and defined six focal concepts upon which the model is based, namely, (1) enacted stigma, (2) perceived stigma, (3) internalized stigma, (4) coping strategies, (5) psychosocial well-being, and (6) interpersonal relations. The developed relationship statements of the model indicated: (1) the bidirectional relationship between enacted, perceived, and internalized stigma; (2) the mediating role of coping strategies; (3) the direct and indirect influences of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS; and (4) the contextual role of interpersonal relationships in which the process of stigmatization may unfold. The modified Delphi technique conducted in Phase IV indicated that the developed model was simplistic, clear, generalizable, accessible, and important for use in research and practice.

The developed model will aid future studies by providing a theoretical lens through which HIV-related stigma and its influence on the psychosocial well-being of children orphaned by AIDS may be viewed. HIV-related stigma should be considered strongly when addressing the well-being of orphaned children, so that tailored programs, interventions, and services may be set in place to effectively bring about the reduction of stigma and ensure the psychosocial well-being of children. The recommendations set out serves to further inform practice and programs and form a baseline for future empirical research focusing on HIV-related stigma and the psychosocial well-being of children orphaned by AIDS.

KEYWORDS

HIV/AIDS

HIV-related stigma

Children orphaned by AIDS

Psychosocial well-being

Theory generative approach

Mixed methods design

Model development

DECLARATION

I, *Zeenat Yassin*, hereby declare that “***The development of a model that examines parental HIV-related stigma and the psychosocial well-being of children orphaned by AIDS***’ is my own work. I also declare that the thesis has not been submitted for any degree or examination to any other university and all sources I have used or quoted have been indicated and acknowledged by complete references.

Name: Zeenat Yassin

Date: April 2020

Signature:

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DEDICATION

I dedicate this work to all children who have found themselves orphaned and vulnerable due to the HIV/AIDS pandemic. I sincerely hope that this research study will shed light on your plight, and that my contribution will bring about positive change that will result in the betterment of your circumstances, lives, and well-being. With you being our future, may you always shine bright and reach for the stars.

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AIDS:	Acquired Immunodeficiency Syndrome
ART:	Antiretroviral therapy
CASP:	The Critical Appraisal Skill Program
CDI:	Child Depression Inventory
CES-DC:	Centre for Epidemiological Studies Depression Scale for Children
CFI:	Comparative Fit Index
CLS:	Children’s Loneliness Scale
COA:	Children orphaned by AIDS
COO:	Children orphaned by other causes
CRS:	Children’s Rating Scale
DSM-IV:	Diagnostic and Statistical Manual of Mental Disorders (5th Edition)
HIV:	Human Immunodeficiency Virus
HOPE:	Hopefulness about Future Scale
HSC:	The Hopelessness Scale for Children
LSD:	Least significant difference
MOS:	Medical Outcome Study
NGO:	Non-Governmental Organization
PANAS:	Positive and Negative Affect Schedule
PEO:	Participant, Exposure Outcome
PLWHA:	People living with HIV/AIDS
PRISMA:	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PTG:	Post-traumatic growth
PTSD:	Post-traumatic Stress Disorder

PTGI-CR: Post-Traumatic Growth Scale for Children

R-CMAS: Children’s Manifest Anxiety Scale-Revised

RMSEA: Root Mean Square Error of Approximation

SACAA: The Stigma against Children Affected by AIDS Scale

SAHARA: Social Aspects of HIV/AIDS Research Alliance

SDQ: Strength and Difficulties Questionnaire

SES: Socioeconomic status

SSA: Sub-Saharan Africa

STDs: Sexually transmitted diseases

SPSS: Statistical Package for the Social Sciences

UCLA: The University of California at Los Angeles

UNCRC: United Nations Convention on the Rights of the Child

UNAIDS: The Joint United Nations Programme on HIV/AIDS

UNICEF: The United Nations Children’s Fund

UNISA: University of South Africa

USAID: United States Agency for International Development

WHO: World Health Organisation

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Chapter 1

Overview

1.1 Introduction

In this introductory chapter the background, context, rationale, and problem statement are presented, along with the main and subsidiary research questions, together with the aim and objectives of the study. The significance of the study, definitions of key terms, and outline of chapters are also described.

1.2 Background

1.2.1 The HIV/AIDS pandemic

The human immunodeficiency virus (HIV) and the acquired immunodeficiency syndrome (AIDS) is viewed as one of the world's most infectious diseases and remains one of the greatest public health challenges today (Tran & Mwanri, 2013; Sharp, Jardin, Marais, & Bolvin, 2015; WHO, 2011). To date, an average of 36.7 million (30.8 million–42.9 million) individuals, including women and children, are living with HIV worldwide, with an estimated 5,000 new infections daily (UNAIDS, 2017). While global efforts to strengthen programs focusing on the prevention and treatment of HIV/AIDS has resulted in a reduction of HIV transmission, incidence rates of new infections remained high in the year 2016 at an average of 1.8 million new infections (UNAIDS, 2017). Pronounced decreases in new infections were seen in regions with the highest prevalence rates of HIV/AIDS, namely, Southern Africa, Asia and the Pacific, Western and Central Europe, and Northern America. However, these decreasing trends in incidence rates are not true for all regions of the world as Eastern Europe and Central Asia saw an alarming 60% increase in 2016 (UNAIDS, 2017).

Despite the recent decline in incidence and prevalence rates reported in 2016, the HIV/AIDS pandemic is accompanied by AIDS-related mortality and has resulted in more than 39 million AIDS-related deaths worldwide (Tran & Mwanri, 2013; UNAIDS, 2014a; WHO, 2011). A decline in AIDS-related deaths has been achieved in several regions owing to the rapid upscaling of antiretroviral therapy (ART), which has converted HIV from a fatal disease to a chronic manageable condition prolonging the average lifespan of an individual living with HIV. Despite these advances, AIDS-related illnesses continue to remain the leading cause of mortality, especially among women (Kharsany & Karim, 2016; UNAIDS, 2017; WHO, 2016). However, it is significant that global regions experience varying amounts of the HIV/AIDS burden and AIDS-related mortality. Granich et al., (2015) infer that there remains a salient variation in the regional burden of AIDS-related mortality, with sub-Saharan Africa, Asia, and the Pacific housing more than 90% of the AIDS-related mortality burden.

1.2.2 The HIV/AIDS epidemic in sub-Saharan Africa

Sub-Saharan Africa (SSA), geographically located on the African continent south of the Sahara (UNAIDS, 2010), has been severely affected by the HIV/AIDS pandemic. SSA is the epicenter of the HIV/AIDS pandemic. While the region only consists of 12% of the global population, it carries a disproportionate burden of the HIV/AIDS pandemic, as it houses three quarters of the population living with HIV/AIDS (Kharsany & Karim, 2016; Poku & Whiteside, 2004/2017; Vollmer et al., 2017). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2014a), 10 countries in SSA account for 80% of global HIV-infections, namely: South Africa (25%), Nigeria (13%), Uganda (6%), Tanzania (6%), Kenya (6%), Mozambique (6%), Zimbabwe (6%), Zambia (4%), Malawi (4%), and Ethiopia (3%).

The existing social, economic, and human deprivation conditions influenced by various medical, social, economic, and cultural factors in SSA creates a fertile environment for the easy transmission of HIV. In turn, HIV/AIDS continues to worsen the deprivation experienced by individuals in the region (Poku & Whiteside, 2004/2017). Poku and Whiteside (2004/2017) indicated that there are biological, sociocultural and economic factors at play, rapidly fueling the HIV/AIDS epidemic in SSA. Biologically, there are three key factors responsible for the high prevalence rates of HIV in SSA, viz. undiagnosed and untreated sexually transmitted diseases, the low rate of medical male circumcision, and the physiological vulnerability of women. Africa has the highest incidence of treatable sexually transmitted diseases (STDs) in individuals between the ages of 15 and 49 years. As heterosexual sexual intercourse remains the primary mode of HIV transmission in SSA, untreated STDs can enhance the acquisition and transmission of HIV among individuals during sexual contact (Kharsany & Karim, 2016; Poku & Whiteside, 2004/2017; UNAIDS, 2017).

Medical male circumcision is likely to reduce female–male transmission of HIV by as much as 60%, as circumcised men are half as likely to contract HIV in comparison to uncircumcised males (Mbonye et al., 2016). The low rate of medical male circumcision in the region is therefore likely to influence the transmission of HIV in SSA (Poku & Whiteman, 2004/2017). While medical male circumcision may potentially reduce the transmission and spread of HIV, Mbonye et al., (2016) caution against cultural beliefs and practices that may hinder the anticipated beneficial outcomes and effectiveness of medical male circumcision. These include the belief that contact with vaginal fluids promote healing, and sexual intercourse with non-regular partners rids an individual of spirits. Moreover, females are disproportionately affected by HIV, as 58% of the population of people living with HIV are women (Kharsany & Karim, 2016; UNAIDS, 2017). For women, the likeliness of HIV-infection is due to their physiological vulnerability, as they have a bigger surface area of mucosa exposed to the male’s sexual secretion during intercourse. Moreover, HIV infected semen contains a higher concentration of the virus than female sexual secretions (Poku & Whiteside, 2004/2017).

Additionally, socio-cultural factors deriving from traditions and practices has had a significant impact on the HIV/AIDS epidemic in Africa. Polygamous and multi-partner sexual networking, based on the belief that a single sexual partner cannot satisfy a male, places both males and females at risk of contracting HIV. Polygamous practices—a view espoused by many African societies—asserts that males may generally and legitimately engage in multiple sexual relationships despite their marital status, while woman may not. These socio-cultural practices place women at further risk of contracting HIV and fuels the vertical transmission of HIV (mother-to-child transmission), as SSA accounted for 90% of global new pediatric HIV infections in the year 2012 (Gumede-Moyo, Filteau, Munthali, Todd, & Musonda, 2017; Poku & Whiteside, 2004/2017). In addition to biological and socio-cultural factors, poverty is believed to be a driver of the epidemic in the SSA region. Poverty and human deprivation forces individuals residing in low socioeconomic communities characterized by poverty to engage in risky activities, such as transactional sex, prostitution, drug abuse, migration, and unsafe health activities to produce sustainable livelihoods for themselves and their families. Engagement in such risky activities increases an individual's likelihood of being exposed—contracting or transmitting HIV (Ahmad, Berma, & Bakar, 2012; Poku & Whiteside, 2004/2017).

While SSA continues to boast the highest prevalence rates of HIV/AIDS, incidents of new infections and AIDS-related mortality steadily declined by 39% in the year 2013. This was particularly due to the increased availability of and access to ART within the region (UNAIDS, 2014; Weil, 2017). Effective ART treatment has significantly contributed to the steady decline in AIDS-related mortality, increasing the life expectancy of individuals living with HIV (Simbayi et al., 2019). Individuals living with HIV—accessing and adhering to ART treatment—are now able to live the normal expected lifespan of a human being. Notwithstanding the benefits of ART, SSA accounted for 74% of all AIDS-related deaths (Kharsany & Karim, 2016). The high prevalence rate of morbidity accompanying HIV in SSA is associated with a steep increase in AIDS-mortality and is reflected by the 800,000 AIDS-related deaths reported in the year 2015 (UNAIDS, 2014a). Increased AIDS-related mortality places children at risk of losing one or both of their parents to HIV/AIDS, subsequently increasing the orphaned population (Raymond & Zolnikov, 2018).

1.2.3 HIV/AIDS and AIDS orphanhood

The rapid increase in mortality rates due to HIV/AIDS has resulted in an international increase in AIDS orphanhood and the categorization of children orphaned by AIDS. "Orphanhood" is defined by the UNICEF, UNAIDS and USAID (2004) as a child(ren) under the age of 18 who has/have lost one (single orphan) or both (double orphan) of their parents to an AIDS-related illness. While the introduction and implementation of ART had resulted in a decline mortality and consequentially orphanhood, the population of orphaned children remains alarmingly high (Kharsany & Karim, 2016; WHO 2016). In 2012, 17.8 million children lost one or both of their parents to AIDS-related causes, 90% of whom are located in SSA while millions more face being orphaned (Chi & Li, 2013; Sharp et al., 2015). A total of 40 million children will be orphaned by HIV/AIDS by 2020 (Boyes & Cluver, 2013). Due to the long incubation period of HIV/AIDS, the proportion of children orphaned by AIDS (COA) is expected to rise and remain patently high through to the year 2030 (Tran & Mwanri, 2013). Therefore, AIDS remains the leading cause of orphanhood, both globally and within SSA, creating a new generation of orphaned children without adequate support, resources, parental affection, and guidance (Phetlhu & Watson, 2014; Rukundo & Daniel, 2016).

1.2.4 The plight of children orphaned by AIDS

Limited budgets and the lack of financial resources underscores the governmental response to the orphaning crisis, marking their inability to provide adequately for children who have been orphaned and/or made vulnerable by HIV/AIDS (Rukundo & Daniel, 2016). Consequently, AIDS affected communities are confronted with the major challenge of caring for orphaned children (Yarney, Mba, & Asampong, 2015). A significant burden has been placed on traditional support systems offered by extended family, mainly grandparents, who assume the role of raising COA (Wagstaff & Therivel, 2017). The UNAIDS (2008) report indicated that half of the global orphaned population are cared for by their aging grandparents who are not financially, physically, or emotionally able to assume the responsibility of this new role as a caregiver. As a result, caring for COA poses detrimental effects on the health of the elderly, increasing their vulnerability to psychical alignments such as chronic diseases and backaches (Phetlhu & Watson, 2014).

While grandparents often assume the role of caring for COA, the responsibility too falls on immediate extended family members and relatives who may not be able to afford to provide for the child(ren) of a deceased relative (Wagstaff & Therivel, 2017). As the living conditions of families are often characterized by poverty and deprivation, especially families located in developing countries, they are unable to adequately care for and satisfy the unique and essential needs presented by COA (Rukundo & Daniel, 2016; Wagstaff & Therivel, 2017). While these socioeconomic conditions threaten the well-being and development of COA, research (Amde & Tadele, 2013; Wagstaff & Therivel, 2017; Yarney et al., 2015) suggests that they are exposed to differential treatment compared to other children within the homestead, such as exclusion, ill-treatment, inadequate food, clothing and shelter, and lack of formal educational opportunities. In turn, children leave the homestead, increasing their vulnerability to other forms of abuse and exploitation, such as child labor, recruitment to organized crime, sexual and physical abuse, substance use, sex trade, and sexual transmitted diseases, including HIV/AIDS (Wagstaff & Therivel, 2017; Yi, Chhoun, Brant, Kita, & Tuot, 2015).

Institutional care able to help and care for COA is often discouraged; however, the inability of extended family members to care for orphaned children has resulted in alternative living arrangements for COA, placing them in orphanages, community and faith-based organizations, non-governmental organizations, and child-headed households. These institutional care facilities, however, compromise the quality of care extended to children placed within the facility in that, due to the lack of adequate funding, physical facilities, and management, they are equipped to meet just the basic and essential needs of these children (Wagstaff & Therivel, 2017; Miller, 2007; Mann, Long, Delap, & Connell, 2012). This view characterizes institutional care facilities as incapable of providing supportive and consistent caregiving necessary to assist optimal development and the formation of healthy attachment relationships (Wagstaff & Therivel, 2017). Scholars have indicated that the living conditions of COA placed in institutional care facilities are characterized by great difficulty, placing them at risk for poor development, abuse, exploitation, neglect, psychological distress, and externalizing behaviors (Mann et al., 2012; Miller, 2007; Morantz & Heymann, 2010; Rukundo & Daniel, 2016). Contrastingly, several community-based institutional care facilities hold the potential to adequately address the developmental needs of the child(ren) as they mirror a familial setting or environment, resulting in positive outcomes for COA (Wagstaff & Therivel, 2017).

1.2.5 The psychosocial well-being of children orphaned by AIDS

Evidently, the well-being and development of COA remains a concern as COA are regarded as a vulnerable population of youth whose lives are characterized by significant difficulties, unforeseen life changes, psychosocial distress, discrimination, and loss (Chi & Li, 2013;

Deacon & Stephney, 2007; Goldberg & Short, 2016; Sharp et al., 2015). COA are left vulnerable and exposed to innumerable stressors, as they are not excluded from the negative consequences of parental illness and death. Conversely, they are likely to experience the adversity and stressors affecting their HIV-positive parent/s, such as increased poverty, family disruption, and social isolation (Chi & Li, 2013; Cluver, Orkin, Boyes, Beban, & Madisha, 2018; Cluver et al., 2013; Ishikawa, Pridmore, Carr-Hill, & Chaimuangdee, 2010; Lata & Verma, 2013; Lichtenstein, 2008). Besides these stressors, parental HIV/AIDS infection and death has been identified as having a negative impact on the psychosocial well-being, adjustment, and functioning of COA (Skeen et al., 2017). There is an apparent need to address the psychosocial well-being of COA as it remains a much-neglected area of study (Skeen et al., 2017).

Psychosocial well-being, defined as the amalgamation of mental and social well-being which has been used to widely reflect an individual's thoughts, feelings, behavior, and reactions to the social environment (Fujishima-Hachiya & Inoue, 2012), is regarded as essential to the healthy growth and development of children, and plays a pivotal role in their ability to achieve their full potential. The notion of psychosocial well-being addresses the holistic well-being of COA, encompassing psychological well-being, resilience, and social inclusion (Snider & Dawes, 2006). Despite the paucity of literature, numerous risk factors have been identified in contributing to the poor levels of psychosocial well-being displayed by COA, namely, parental loss and bereavement, financial deprivation, the lack of educational opportunities, social isolation, abuse, and exploitation (Ishakawa et al., 2010; Mwoma & Pillay, 2015; Saraswat & Unisa, 2017; Snider & Dawes, 2006; Stein, 2003).

AIDS orphanhood commences with parental illness rather than death, as children bear witness to the physical suffering and deterioration of their parents (Cluver et al., 2018; Deacon & Stephney, 2007; Stein, 2003). The death of a parent has a profound impact on the psychosocial well-being of COA, as they are susceptible to complicated or unresolved bereavement as a result of their developmental vulnerability (intellectual immaturity and emotional dependency) (Li et al., 2008; Snider & Dawes, 2006; Thupayagale-Tshweneagae, 2011). Additionally, the death of a parent brings about immediate changes in the lives, roles, and responsibilities of COA, as they encounter multiple social and psychological challenges, such as poverty, depression, sadness, and the lack of social support (de Witt & Lessing, 2010; Lalthapersad-Pillay, 2008; Li et al., 2008; Snider & Dawes, 2006).

AIDS orphanhood is often characterized by an overwhelming sense of poverty and greater economic strain, as most resources are allocated to the treatment of sick parent/s (Cluver et al., 2018; de Witt & Lessing, 2010; Li et al., 2008; Nickerson, Bryant, Aderka, Hinton, & Hofmann, 2013; Zhao et al., 2009). Such economic hardship results in COA living with unmet basic needs—such as food, shelter, and health—which are imperative for healthy psychosocial adjustment and well-being (Lin et al., 2010). Despite the socioeconomic needs presented by COA, many governments are unable to provide the financial support needed for their psychosocial well-being and development (Li et al., 2008). Additionally, COA risk being exploited by extended family members as welfare provision and grants are seen as an economic asset in households already under financial strain; although these contributions may not necessarily reach the orphans for whom they were intended (Thupayagale-Tshweneagae, 2011).

Poverty, too, has been identified as the leading cause of educational challenges among COA. Consequentially, economic hardship results in an increase in school non-attendance, involvement in economic activities, and exploitation, as COA work for measly salaries or unpaid labor in the hopes of supporting themselves and their families. School nonattendance is likely to hinder the attainment of scholastic knowledge and necessary life skills needed for sustainable employment and future prospects (Delva et al., 2009; Li et al., 2008). The lack of educational opportunities acts to perpetuate the poor psychosocial well-being of COA, as they are subjected to economic, psychological, social, and health problems, thereby perpetuating the cycle of poverty (Adejuwon & Oki, 2011; Case, Paxson, & Ableidinger, 2004). Furthermore, school attendance awards them the opportunity to socialize and overcome negative emotions associated with grieving.

The abandonment and victimization of COA by family and peers may perpetuate the culture of school nonattendance. Educational expenses may act as the deciding factor for caring for orphaned youth, instigating the abandonment of COA. Moreover, they may be victimized, teased, or gossiped about by their peers, which results in the withdrawal of COA, perpetuating the culture of school nonattendance. Such abandonment and victimization of COA leads to limiting their support structures causing social isolation and withdrawal. Subsequently, such social support is necessary to foster healthy adjustment and the psychosocial well-being of COA (Adejuwon & Oki, 2011; Delva et al., 2009).

It may be argued that poor psychosocial well-being is the outcome of AIDS orphanhood. However, COA displayed poorer levels of psychosocial well-being than non-orphans and other orphaned youth (Nyamukapa et al., 2008). Attention is therefore turned towards HIV-related stigma which distinguishes COA from other groups of orphans, vulnerable children, and non-orphans regardless of their HIV status. HIV-related stigma has been identified as a core risk factor contributing to the poor psychosocial well-being displayed by COA, independent of orphanhood status and other key demographic factors (Lin et al., 2010; Lata & Verma, 2013). Likewise, Sharp and her colleagues (2015) have found HIV-related stigma to mediate the effects of AIDS orphanhood, negatively influencing the well-being and adjustment of COA.

1.2.6 The epidemic of HIV-related stigma

HIV/AIDS is regarded as a highly stigmatized disease resulting in an epidemic of HIV-related stigma which may be defined as the prejudice, discrediting, and discounting directed at people living with HIV/AIDS (PLWHA) and individuals, groups, and communities with whom they are associated (Parker & Aggleton, 2003). The current body of evidence on the negative impact of HIV-related stigma has focused on the adult population, as the stigmatization of PLWHA impacts their treatment and care, social support, preventative behaviors, and psychosocial well-being (Lin et al., 2010; Varas-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005; Zhao et al., 2009). While few empirical studies have been conducted on HIV-related stigma and COA, it has gained much interest as stigmatization resulting from parental illness and death remains a key challenge faced by this population of orphaned youth (Adejuwon & Oki, 2011; Cluver, Gardner, & Operario, 2008; Kheswa & Duncan, 2011; Sharp et al., 2015). Although less evidence is available on COA, they are found to be particularly susceptible to HIV-related stigma and discrimination as they are not in control of their circumstances and less likely to assert their rights (Cree, Kay, Tisdall, & Wallace, 2004; Tran & Mwanri, 2013).

Four measures of HIV-related stigma extended to COA have been identified, namely, enacted, vicarious, felt, and internalized stigma. Enacted stigma refers to overt acts of discrimination, hostility, and traumatizing behaviors received from others. Vicarious stigma is the exposure or witnessing of HIV-related stigma experienced by others, while felt stigma is an individual’s perceptions regarding the prevalence of stigmatizing norms within society. Internalized stigma refers to the extent to which beliefs about the norms and prevalence of HIV-related stigma are regarded as valid and truthful by an individual (Mo, Lau, Yu, & Gu, 2015; Steward et al., 2008). Such stigmatization is expected to result in isolation, educational challenges, limited health care and support services, being ridiculed and attacked by peers, abuse, low self-esteem, bleak aspirations for the future, and exploitation of COA (Lin et al., 2010; Ostrom, Serovich, Lim, & Mason, 2006; Tran & Mwanri, 2013). COA similarly, experience measures of HIV-related stigma as a result of their association with parental infection and death regardless of their own HIV status. These experiences reported by HIV negative COA are often referred to as associated stigma (McAteer et al., 2016). Evidently, measures of HIV-related stigma endanger the overall well-being and psychosocial adjustment of COA (Li et al., 2008; Lin et al., 2010).

1.3 Problem statement

Considering the complex nature of HIV-related stigma, an understanding of the manner in which it affects the psychosocial well-being of COA is of tremendous import when addressing their psychosocial needs and holistic well-being (Earnshaw & Chaudoir, 2009; Surkan et al., 2010). Such an understanding is particularly valuable as it relates to HIV negative children who have been orphaned by AIDS as they continue to experience measures of HIV-related stigma as a result of parental illness and death. However, such an understanding is rather elusive as to date, as there is no model that provides an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA (Chi & Li, 2013; Deacon, 2006; Li et al., 2008; Holzemer et al., 2007; Sharp et al., 2015). The lack of a suitable model is a barrier in addressing the psychosocial well-being of COA and fuels our inability to understand how HIV-related stigma has affected their well-being, reduce their experience of HIV-related stigma, and improve their psychosocial well-being (Earnshaw & Chaudoir, 2009). Since researchers have found it difficult to reach a theoretical consensus regarding HIV-related stigma and its associated effects, the need for a sustainable model has become evident. The development of a sustainable model offers an understanding of the manner in which HIV-related stigma has affected the psychosocial well-being of COA, while bridging the gap between research and the development of appropriate services and interventions aimed at addressing COAs experiences of HIV-related stigma and their psychosocial needs (Chi & Li, 2013; Deacon, 2006; Earnshaw & Chaudoir, 2009; Sharp et al., 2015).

Finally, there is an existing relationship between HIV-related stigma and the poor psychosocial well-being of COA (Lin et al., 2010; Snider & Dawes, 2006). However, little is understood about the nature and severity of the relationship. Without a sustainable model examining HIV-related stigma and the psychosocial well-being of COA, measures directed at ensuring the well-being of COA shall be poorly informed while perpetuating the epidemic of HIV-related stigma and the poor psychosocial well-being of COA.

1.4 Rationale of the study

The rationale for this study is twofold. Firstly, there is a need to explore the impact of HIV-related stigma on the psychosocial well-being of COA. Secondly, there is a need to gain an understanding of HIV-related stigma as experienced by COA and its impact on their psychosocial well-being.

A systematic review conducted by Yassin and Erasmus (2016) focused on the impact of HIV-related stigma on the psychological well-being of COA. While the findings of the review outlined COAs experiences of stigma and its associated outcomes for psychological well-being, it also highlighted the paucity of published research through its limited findings (Yassin & Erasmus, 2016). While the body of literature focusing on the psychological health of COA has grown (for example, see Gamarel, Kuo, Boyes & Cluver, 2017; Mason & Sultzman, 2019; Mo et al., 2015), the psychosocial well-being of COA remains largely ignored. Ssewamala, Nabunya, Ilic, Mukasa, and Ddamulira (2015) argue for the promotion of child psychosocial well-being to ensure the attainment of better outcomes among children. Studies (for example, by Lin et al., 2010; Tran & Mwanri, 2013; Sharp et al., 2015) have demonstrated that HIV-related stigma has not exclusively influenced the psychological well-being of COA but operates to negatively affect the psychosocial well-being of COA, placing their healthy development and survival at risk. The shift to psychosocial well-being is imperative as great strides are taken to ensure the holistic well-being of children, rather than placing an emphasis on a singular domain of well-being. Therefore, this study, through the development of a model, sought to explore the psychosocial well-being of COA within the context of HIV-related stigma to provide an understanding of the manner in which the psychosocial well-being of COA have been influenced and compromised.

Secondly, HIV-related stigma has been identified as a major risk factor exerting a substantial impact on the psychosocial well-being of COA (Caserta, Pirttilä-Backman, & Punamäki, 2015). Despite its importance, HIV-related stigma is still poorly understood and marked by a lack of conceptual consensus (Link & Phelan, 2001). A review conducted by Sharp and colleagues (2015) and Chi and Li (2013) have indicated that few empirical studies have provided a theoretical underpinning or lens through which their findings may be understood. The lack of the use of a theoretical underpinning is coupled with the adoption of frameworks developed for understanding health-related stigma within an adult population. The seminal work of Goffman (1963) on epilepsy is frequently used to underpin and guide current research and intervention with regards to HIV-related stigma and orphaned children. While the work of Goffman (1963) provides an understanding of stigma, it fails to address the individualistic experiences and psychosocial outcomes for children. Chi and Li (2013) have called for a sound theoretical or conceptual framework that may guide future research and intervention, therefore highlighting the increased need for theoretical integration and development.

Deacon (2006) suggests that the development of a sustainable theory of stigma is crucial to understanding the origins and associated effects of stigma. This would provide a means to bridge the divide between current theoretical models, emerging evidence, and interventions.

The development of a model which fosters an understanding of HIV-related stigma as experienced by COA and its associated impact on their psychosocial well-being is therefore imperative if we are to systematically identify and meaningfully address the specific needs of children in the context of HIV/AIDS (Chi & Li, 2013).

1.5 Research questions

This study addressed the following main research question: "How can a model of HIV-related stigma be developed for the purpose of fostering an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS?"

To answer the main research question, four sub-research questions were formulated in accordance with the objectives of the current study:

1) What is the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS?
2) How do children who have been orphaned by AIDS perceive and experience HIV-related stigma?
3) What factors should be considered for the development of a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS?
4) What is the functionality of the developed model according to various stakeholders?

1.6 Aim

The overall aim of the study was to develop a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS.

1.7 Objectives

The objectives of this study were to:

1. Systematically review existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS.
2. Explore children orphaned by AIDS perceptions and experiences of HIV-related stigma.
3. Develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS.
4. Determine the functionality of the developed model through the use of the Delphi technique.

1.8 Significance of the study

This is the first known study that endeavors to develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. Considering the lack of consensus and varying conceptualizations and understandings of HIV-related stigma with regards to orphaned and vulnerable children, this study makes several important contributions to current knowledge, practice, and policies.

1.8.1 HIV-related stigma theories

Theories and conceptualizations of HIV-related stigma will be enhanced as the model developed in this study provides a framework for understanding HIV-related stigma and its associated outcomes, specifically with regards to child psychosocial well-being. This model is to provide scholars, practitioners, policy makers, and programme developers with a deeper understanding of HIV-related stigma as experienced and perceived by children, moving away from the development and understandings of theory that focuses on the adult population and their timely treatment, testing, and care. Additionally, the conceptual framework underpinning the study will provide further insight into the origin, manifestations, and impact of HIV-related stigma on the psychosocial well-being of COA.

1.8.2 Health-related research

This study makes several noteworthy contributions towards health-related research. Firstly, it is envisioned that the developed model would guide future research focusing on children in the context of HIV/AIDS. Secondly, the developed model may underpin future studies offering a standpoint from which HIV-related stigma with regards to children may be understood. Due to the unique understanding of HIV-related stigma, specifically with regards to children, the model is to assist in the dissemination of future research studies focusing on the impact of stigma or the context of HIV/AIDS on orphaned children. Thirdly, the study expands the current body of knowledge focusing on orphaned children and HIV-related stigma as evidence on HIV-related stigma and its impact on psychosocial well-being was systematically reviewed, followed by an in-depth exploration of the experiences and perceptions of orphaned children with regards to stigma and their psychosocial well-being.

A large proportion of evidence on HIV-related stigma and children has inferred conclusions from data collected from adult populations, such as the caregivers of orphaned children; this study, therefore, provides evidence from the experiences and perspectives of children themselves, thereby significantly contributing towards current evidence. Additionally, as most evidence has continued to focus on the psychological impact of stigma for children, the findings of this study encompass the domain of psychological well-being to consider all domains of well-being. The inclusion of various domains of psychosocial well-being would allow for the further exploration and understanding of the holistic well-being of COA, and how the various domains are interconnected and dependent upon each other. Lastly, while there remains little consensus among scholars on understanding HIV-related stigma, this study contributes to the body of knowledge and highlights gaps in evidence that may be further explored.

1.8.3 Child well-being and HIV-related stigma interventions

This model attempts to bridge the gap in the current literature and provide an understanding of the manner in which HIV-related stigma has affected the psychosocial well-being of COA, thus increasing our ability to effectively identify and address both experiences of HIV-related stigma and the psychosocial needs of COA. The findings disseminated in this study, together with the developed model, emphasizes the experiences, needs, and struggles of COA with regards to HIV-related stigma, their coping strategies, and psychosocial well-being. A clear focus, identification, and understanding of HIV-related stigma and its influence on the psychosocial well-being of COA, allows for appropriate interventions and policies to be developed or adapted to suit the needs of this vulnerable population. The study would allow for child specific strategies geared towards HIV-related stigma reduction to be appropriately developed and implemented. The study facilitates an understanding of COAs response to their perceptions and experiences of HIV-related stigma, therefore guiding the development of appropriate interventions geared towards equipping COA with healthy coping strategies to lessen the impact of HIV-related stigma on their psychosocial well-being. Lastly, the study and the developed model provides an understanding of the manner in which specific components and measures of HIV-related stigma influences various domains of psychosocial well-being of children. This knowledge allows for the development or adaption of existing programmes and interventions focusing on improving the psychosocial well-being of COA.

1.8.4 Policy and practice

As a multidisciplinary approach was used to develop the model, it is accessible and understandable to all disciplines interested in understanding the impact of HIV-related stigma on the psychosocial well-being of COA. The study would enable both policy makers and practitioners to understand COAs experiences of HIV-related stigma. It is important to note that HIV-related stigma is not consistent, but rather manifests in varying ways to influence the psychosocial well-being of COA. This unique understanding makes a noteworthy contribution towards current policy and practice. A clearer understanding, as presented in this study, would allow for practitioners to effectively address COAs experiences and assist in maintaining their well-being and survival. Lastly, the study would guide policy makers in the establishment of policies and legislation that addresses the unique needs of COA, affording them sufficient protection against adverse effects and adequate policies addressing their psychosocial needs and challenges.

1.9 Definitions of terms

1.9.1 Human immunodeficiency virus

Human immunodeficiency virus (HIV) is a retrovirus which causes acquired immunodeficiency syndrome (AIDS)—the most progressive stage of the HIV virus. There are two strands of the HIV virus, namely: HIV-1 and HIV-2; the latter being more progressive than the former. HIV acts to attack and destroy CD4 lymphocytes, weakening the immune system, leaving the individual vulnerable to life-threatening infections, diseases, and cancers. HIV transmission can occur either (1) horizontally through direct exposure to HIV-infected bodily fluids, such as genital secretions, blood, and semen; and/or (2) vertically, from an HIV-positive mother to child during the process of pregnancy, birth, and breastfeeding (AIDSinfo, 2011).

1.9.2 Acquired immunodeficiency syndrome

The acquired immunodeficiency syndrome (AIDS) refers to the most advanced stage of HIV infection resulting in the formation of a disease of the immune system due to advanced progression to the final stage of HIV (AIDSinfo, 2011).

1.9.3 People living with HIV/AIDS

People living with HIV/AIDS (PLWHA) are individuals who are infected with the HIV virus or those whose HIV infection has progressed to the final stage of infection, resulting in the development of AIDS (Deacon & Stephney, 2007).

1.9.4 Children orphaned by AIDS

Children orphaned by AIDS (COA) is defined as a child(ren) under the age of 18 who has/have lost one (single orphan) or both (double orphan) of their parents to an AIDS-related illness (UNICEF, UNAIDS & USAID, 2004).

1.9.5 Discrimination

Discrimination refers to the unjust and unfair treatment of an individual as a result of their real or perceived HIV status. HIV-related discrimination is often based upon stigmatizing attitudes and beliefs about populations, practices, behaviors, sex, illness, and death (UNAIDS, 2014b).

1.9.6 HIV-related stigma

HIV-related stigma is regarded as the prejudice, discounting, and discrediting of people living with HIV/AIDS, and may be extended to individuals, groups, and communities with whom they are associated (Steward et al., 2008). HIV-related stigma is often conceptualized in two complementary forms—interpersonal stigma and intrapersonal stigma. Each form of HIV-related stigma includes varying types of stigma that are related but remain conceptually distinct.

1.9.7 Interpersonal stigma

Interpersonal stigma refers to social interactions between stigmatized and non-stigmatized individuals in which discrimination, rejection, and hostility occurs (Hatzenbuehler, 2016). Two components of interpersonal stigma are considered in relation to HIV-related stigma, namely, enacted and perceived stigma (Steward et al., 2008).

1.9.7.1 Enacted stigma

Enacted stigma includes real actions and experiences of overt discrimination, hostility, rejection, and humiliation by the stigmatized individual as a result of stigmatizing beliefs, behaviors, and attitudes (Steward et al., 2008).

1.9.7.2 Vicarious stigma

The concept "vicarious stigma" is aligned with the assumptions of the social learning theory and refers to channels through which HIV-related stigma may be conveyed. Vicarious stigma refers to witnessing or hearing about experiences of enacted stigma and is likely to increase perceived stigma (Steward et al., 2008).

1.9.8 Intrapersonal stigma

Intrapersonal stigma refers to the psychological or rather internal processes in which stigmatized individuals engage and respond to stigma (Hatzenbuehler, 2016). Two components of intrapersonal stigma are recognized in relation to HIV-related stigma, namely, perceived stigma and internalized stigma (Steward et al., 2008).

1.9.8.1 Perceived stigma

Perceived stigma, also referred to as "felt stigma," refers to the subjective awareness of social stigma (Chi & Li, 2013). An all-inclusive definition of perceived stigma, which refers the subjective awareness of stigma, represents the belief about the prevalence of stigmatizing attitudes among people in the local community or the degree to which stigma is perceived as normative, either by the infected individual, or by individuals or groups with whom they are associated (Steward et al., 2008).

1.9.8.2 Internalized stigma

Internalized stigma, also known as self-stigma, refers to “the extent to which an individual accepts stigma as valid” or truthful (Steward et al., 2003, p. 3). Internalized stigma “involves the thoughts and behaviours stemming from the person’s own negative perceptions about themselves because of their HIV status” (Zhao et al., 2010, p. 1303).

1.9.9 Psychosocial well-being

Psychosocial well-being is defined as the combination of the psychological and social well-being of an individual; it widely reflects an individual’s thoughts, feelings, behavior, and reactions towards their social environment (Fujishima-Hachiya & Inoue, 2012) Psychosocial well-being is regarded as essential to the healthy growth and development of children and plays a pivotal role in their ability to achieve their full potential. The notion of psychosocial well-being addresses the holistic well-being of COA, encompassing psychological well-being, resilience, and social inclusion (Snider & Dawes, 2006). Psychosocial well-being in this study includes five domains, namely: psychological well-being, emotional well-being, self-concept and self-esteem, social well-being, and perceived future orientation.

1.9.10 Model

A model is regarded as a mental or diagrammatic presentation of a phenomenon that is systematically constructed and enables practitioners to organize their thinking about practice, patients, and their profession. Additionally, a model may be regarded as the symbolic representation of empirical evidence that may be visually expressed in words, pictures, and/or diagrams (Chinn & Kramer, 2008).

1.10 Dissertation Layout

Chapter One elucidates the background and context of the current study which focuses on the manner in which HIV-related stigma impacts the psychosocial well-being of COA. The chapter also comprises of the problem statement, rationale, research questions, aim, objectives, significance of the study, definitions of key terms, and layout of the forthcoming chapters.

Chapter Two provides an overview of the conceptual framework that guides and underpins the research study. The conceptual framework fuses together relevant literature and the theoretical and conceptual understanding of HIV-related stigma and child psychosocial well-being to provide a comprehensive understanding of the phenomena under investigation. The conceptual framework is discussed along the origins and causes of stigma, manifestations of HIV-related stigma, and impact on psychosocial well-being of children who have been orphaned by AIDS-related causes. The conceptual framework provides a point from which the findings may be understood and is diffused into the discussion sections of the various chapters and manuscripts. Additionally, the conceptual framework is infused with the model description (discussed in Chapter 7) underpinning the theoretical assumptions of the developed model.

Chapter 3 outlines the methodology undertaken in this study. The methodological worldview is discussed, followed by the designs, methods, sampling techniques, data collection procedures, and data analysis techniques used throughout the four interconnected phases of this study. Lastly, trustworthiness and ethical considerations are explained and discussed.

Chapter 4 introduces Phase I of the study, a systematic review, which reviews recent literature reporting on the effects of HIV-related stigma on the psychosocial well-being of COA. The chapter is presented as a manuscript which was accepted and published in the *Journal of Vulnerable Children and Youth Studies.* Yassin, Z., Erasmus, C., & Frantz, J. (2018). HIV-related stigma and the psychosocial well being of children orphaned by AIDS: a systematic review. *Vulnerable Children and Youth Studies, 13*(3), 247–258. doi.org/10.1080/17450128.2018.1457193

Chapter 5 presents Phase II of the study which explores COAs experiences and perceptions of HIV-related stigma and how it has impacted their psychosocial well-being. The study is presented as a manuscript which was published in the *Journal of Global Social Welfare.* Yassin, Z., Erasmus, C. J., & Frantz, J. (2019). Qualitative exploration of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS. *Global Social Welfare,* 1–12. doi.org/10.1007/s40609-019-00147-2

Chapter 6 introduces the commencement of Phase III, Stage 1 and 2, which is geared towards concept and statement development, vital aspects of model development. Concept development was conducted using a concept synthesis strategy and is presented as concept identification, concept classification, and the defining of concepts in this chapter. Statement development was conducted using a statement synthesis strategy within concept classification.

Chapter 7 contains Stage 3 of Phase III, which is geared towards model description. It includes an overview, purpose, context, assumptions, theoretical definitions of concepts, relational statements, and process structure of the developed model.

Chapter 8, the fourth and final stage of Phase III, presents the model evaluation in the form of a modified Delphi study aimed at assessing the functionality of the developed model through the achieved consensus among a panel of experts. Chapters 6, 7 and 8 are combined to form a publication submitted to the *Sub-Saharan Journal of the Social Aspects of HIV/AIDS*.

Chapter 9 presents a summary of Phases III and IV in the form of a manuscript that has been submitted to the *Journal of Social Aspects of HIV/AIDS* (SAHARA-J). The manuscript contains a full structural narrative and graphical presentation of the social transactional model of HIV-related stigma and the psychosocial well-being of COA. Yassin, Z., Erasmus, C., & Frantz, J. (2020). *A model to understand HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A theory generative approach*. Manuscript submitted for publication.

Chapter 10, the final concluding chapter, presents a summary of each phase, highlighting the particular objective and research question addressed in that phase, as well as the methodology that was utilized, and the key findigns of that phase. The summary is followed by the limitations and recommendations of the study.

1.11 Conclusion

This chapter highlighted the plight of COA in the context of HIV/AIDS. Evidently, the survival, well-being, and functioning of COA are negatively impacted by parental illness and death. Surpassing these struggles are COAs experiences of HIV-related stigma resulting from familial HIV-related stigma which is uniquely associated with negative outcomes for child well-being. Despite the negative impact of HIV-related stigma, it remains poorly understood, while the psychosocial well-being of COA has been limitedly explored. There is a call for an in-depth understanding of HIV-related stigma and the manner in which it may impact the psychosocial well-being of COA. Therefore, the aim of this study was to develop a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of COA. The developed model is envisioned to contribute to theoretical knowledge, research, interventions, policies, and practices. Furthermore, this chapter provided the research questions, objectives, definitions of key terms, and the dissertation layout. The following chapter presents the conceptual framework, which provides the theoretical underpinning for the study through the integration of theory and recent literature.

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Chapter 2

Conceptual Framework

2.1 Introduction

The previous chapter introduced the current study by providing an overview which included the background, research questions, aim, objectives, rationale, purpose, significance, definition of key concepts, and dissertation layout. This chapter presents a conceptual framework to underpin this study and provides a reference point from which to understand the manifestation of HIV-related stigma as experienced by COA and its associated outcomes for the psychosocial well-being of children orphaned by AIDS. This chapter explores the (1) social epidemic of HIV-related stigma, (2) characteristics of HIV-related stigma, (3) tribal stigma and COA, (4) othering and layered stigma, (5) a multi-component framework of HIV-related stigma, (6) manifestations of stigma, and (7) HIV-related stigma and the psychosocial well-being of COA.

2.2 The social epidemic of HIV-related stigma

HIV/AIDS is no longer recognized as a mere medical problem affecting the health and survival of PLWHA. Rather, HIV/AIDS has been identified as a social problem that has aroused a deep human response (Alonzo & Reynolds, 1995; Mawar, Sahay, Pandit, & Mahajan, 2005; Rushing, 2018). Rushing (2018) asserts that the social meaning of HIV/AIDS has resulted in a negative and extreme social response. This response refers to the social reaction to HIV/AIDS, which is characterized by high levels of stigmatization, discrimination, and ostracism, and has widely come to be known as HIV-related stigma (Kalichman, Katner, Banas, & Kalichman, 2017; Steward et al., 2008; Rushing, 2018). Herek, Capitanio, and Widaman (2002) suggest that PLWHA and the social groups to which they belong have been stigmatized worldwide since the epidemic began. These individuals may in turn suffer discrimination, leading to the loss of employment, housing, estrangement from their families and societies, and at increased risk for physical violence and abuse (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Gilbert & Walker, 2010). Beyond such disadvantage, studies have recently identified HIV-related stigma as a major risk factor that inhibits the healthy functioning and well-being of PLWHA (Dahlui et al., 2015; Rao et al., 2012; Tsai et al., 2013). Recently, there has been a shift in focus surpassing the infected individual to understand the experiences and impact of HIV-related stigma on individuals with whom they are associated, specifically children affected by familial HIV/AIDS illness and death (Campbell, Skovdal, Mupambireyi, & Gregson, 2010; Gamarel et al., 2017; McAteer et al., 2016; Messer et al., 2010; Zhao et al., 2010).

HIV-related stigma impedes the timely testing, treatment, and prevention of HIV/AIDS, diminishing the well-being of PLWHA and their families. These implications have resulted in a global call to adequately respond to and reduce HIV-related stigma (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Such a response may, however, only be realized through an in-depth understanding of the origin, functionality, and impact of HIV-related stigma, which is yet to be fully realized. However, there remains a lack of consensus when understanding HIV-related stigma. According to various studies, HIV-related stigma as a phenomenon is not easily understood and is constantly in flux according to geographical location, the severity of the epidemic within a region, cultural beliefs, and societal norms. These varying understandings of HIV-related stigma and the lack of an appropriate framework outlining the manner in which individuals are affected by their experiences of HIV-related stigma, forms a significant barrier to understanding and adequately addressing HIV-related stigma to produce better outcomes for orphaned children (Genberg et al., 2009; Campbell & Gibbs, 2016). Multiple conceptualizations and understandings of HIV-related stigma have emerged over the past four decades and are reflected in the varying definitions of HIV-related stigma (Link & Phelan, 2001).

The work of Goffman (1963) has largely informed contemporary perspectives and understandings of stigma and has been recognized as the benchmark social theory for the association between stigma and disease (Castro & Farmer, 2005). Goffman (1963) referred to stigma as an "attribute that is deeply discrediting" resulting in the reduction of an individual "from a whole and usual person to a tainted and discounted one" (Goffman, 1963, p. 3). Steward and colleagues (2008) built on Goffman's (1963) conceptualization of stigma and suggested that stigma is socially constructed and refers to a devaluated status of an individual with an attribute or characteristic viewed as undesirable or threatening. Therefore, stigma is largely socially constructed meanings associated with particular characteristics and attributes that are used to convey the devalued status of an individual. Upon this understanding, HIV-related stigma may refer to "socially shared knowledge about the devalued status of people living with HIV. It is manifested in prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV and the individuals, groups and communities with which they are associated" (Steward et al., 2008, p. 1226). Similarly, Herek (1999) highlighted the following indicators of stigma: prejudice, discounting, discrediting, and discrimination directed towards people living with or perceived to have HIV/AIDS and their close associations. An integrative review conducted by Florom-Smith and De Santis (2012, p. 9) extended the definition offered by Herek (1999) and claims that HIV-related stigma is "the collection of adverse attitudes, beliefs and actions of others against people living or affected by HIV, which may result in deleterious internalized beliefs or actions taken by persons living with or affected by HIV infection that may result in negative health outcomes." Florom-Smith and De Santis (2012), unlike previous definitions, account for both the attitudes and beliefs of the stigmatized and non-stigmatized alike. These definitions share the assumption that stigmatized individuals are perceived to have an attribute or characteristic that marks them as different or tainted, leading to their devaluation by others within society (Major & O'Brien, 2005). Secondly, despite its universality, a multidisciplinary approach was adopted to evaluate the concept, arriving at a varied conceptualization viewed from the perspective of both the stigmatized and non-stigmatized.

2.3 Characteristics of HIV-related stigma

While the definitions of HIV-related stigma are continually evolving, reflecting the varying conceptualizations of HIV-related stigma, Herek et al., (2002) acknowledge that HIV-related stigma is both universal and deeply embedded within the social response to HIV/AIDS. Herek (1999) asserts that while other illnesses may be differentially stigmatized, stigmatization associated with HIV/AIDS is rather universal in its negative evaluation. Herek (1999) argues that characteristics of HIV/AIDS as an illness makes associated stigmatization inevitable. Four characteristics of HIV/AIDS have been identified as likely to evoke stigma, namely: (1) illness associated with deviant or socially undesirable behaviors, (2) illnesses regarded as degenerative or unalterable, (3) a condition perceived to be contagious, and (4) conditions apparent or visible to others (Herek, 1999). The characteristics of stigma identified above draw strong similarities to the three forms of stigma coined by Goffman (1963), as presented below.

Firstly, methods of transmission of HIV/AIDS are often associated with deviant or socially undesirable behaviors. This increases the tendency for HIV-related illness to be associated with moral impropriety, which promotes the assumption that illness is a direct result of bad behavior, and therefore, a product of personal choice (Ogden & Nyblade, 2005). Similarly, Parker and Aggleton (2003) argue that as HIV is mainly sexually transmitted, HIV-related stigma acts to appropriate and reinforce pre-existing sexual stigma attached to sexually transmitted diseases, homosexuality, promiscuity, prostitution, and sexual deviance. These conceptualizations of the causes of stigma relates to the work of Goffman (1963), who identified blemishes of the individual character as one form of stigma. Goffman (1963) holds that stigmatization is a result of an individual’s character, identity, or way of being, such as prisoners, sex workers, drug users, and alcoholics. Blemishes of the individual character closely represent behaviors that are conceived to be socially undesirable and associated with moral impropriety.

Secondly, stigma is often associated with conditions considered to be degenerative and unalterable (Herek, 1999). At inception, HIV was deemed a fatal condition, life-threatening, incurable, and often associated with death (Blake & Arkin, 1998). These descriptions communicate the lethality of the illness, bringing fear and apprehension to the general population (Herek, 1999; Parker & Aggleton, 2003). Although the development of effective treatment and care has transformed HIV to a chronic illness, the perception of HIV as a life-threatening illness associated with death remains prevalent within society.

Thirdly, HIV is considered contagious and threatening to the community. As HIV is incurable and considered a life-threatening illness associated with an undesirable and unaesthetic form of death, it has led to increased fear regarding the contagion of HIV.

Lastly, Goffman (1963) stated that abominations of the body, which refers to outward bodily appearances or deficits representing difference or illness, are a primary source of stigma. Herek (1999) confirmed that illnesses are stigmatized when it is apparent to others in the form of outward bodily defects perceived as ugly or disturbing. The progression of HIV to AIDS, particularly when untreated, results in a variety of symptoms, such as rapid weight loss, fatigue, swollen lymph glands, and apparent bodily deformations visible to others (UNAIDS, 2000). Considering the dimensions and causes of stigma, as presented by Herek (1999) and Goffman (1963), and the characteristics of HIV/AIDS, it is patent why HIV/AIDS has evoked such a deep stigmatic response. Herek (1999), who delineated the causes and dimensions of stigma as proposed by Goffman (1963), Katz (1979), and Jones and colleagues (1984), has suggested that HIV/AIDS is stigmatized because it is: (1) associated with deviant behavior, (2) viewed as the responsibility of the individual, (3) a signifier of immorality, (4) perceived as contagious or threatening to the community, (5) associated with an undesirable and unaesthetic form of death, and (6) not understood by the lay community and negatively regarded by health professionals. These ideas consistently reflect the socially constructed meanings assigned to the characteristics of HIV/AIDS, forming shared assumptions about a devalued characteristic or trait carried by the stigmatized individual. Formed assumptions conveying the devalued status of an individual produces' undesirable and negative consequences for stigmatized individuals, including PLWHA, their families, and the communities with which they are associated (Herek, 1999; Florom-Smith & De Santis, 2012; Steward et al., 2008).

Goffman (1963) further illustrates the social nature and construction of stigma, focusing much on the conceptualization of stigma within dyadic social interactions. Goffman (1963) posits that the process of stigmatization is grounded in social interactions between the stigmatized and the non-stigmatized, known as "mixed contacts." It is through such interactions that the process of stigmatization unfolds (Chaudoir, Earnshaw, & Andel, 2013; Goffman, 1963). Interaction between the stigmatized and non-stigmatized is often characterized by uncertainty and strain that may undermine health. Furthermore, it is also believed that the cultural and socially accepted understandings of stigmatized attributes are communicated through social processes, which refers to Goffman's (1963) moral careers. Four moral careers are outlined and related to the manner in which information is conveyed about a stigmatizing attribute. Firstly, individuals born with stigmatized attributes are reared in an environment that warns them of their perceived difference. This allows individuals to learn about the social beliefs and attitudes towards their perceived deviance and consciously anticipate stigmatizing attitudes and behaviors from others (Goffman, 1963). Alternatively, as a measure of protection, individuals may be actively socialized by their families or societies regarding the perceived deviance or devalued attribute (Goffman, 1963). This serves to protect the stigmatized individual by offering support and acceptance while providing warnings of caution. Thirdly, an individual who acquires a stigmatizing attribute later in life must learn to accept their deviance. Lastly, individuals of age are expected to leave their protective environments and adjust to the new requirements set upon them within their new environment (Goffman, 1963). These moral careers allow for an understanding in which stigma is grounded within social processes and interpersonal interaction between the stigmatized and their social environment (Chaudoir et al., 2013; Goffman, 1963).

While much emphasis is placed on the social construction, characteristics and definitions of HIV-related stigma and applications of stigma to well-being have been largely misdirected. Much focus on health-related stigma pertaining to HIV/AIDS has been placed on the adult population living with HIV/AIDS, as stigma operates to produce undesirable and negative consequences for those affected (Herek, 1999; Florom-Smith & De Santis, 2012; Steward et al., 2008). Research, interventions, and theoretical understandings have largely focused on addressing the experiences and outcomes for PLWHA, as HIV-related stigma acts to inhibit progress made to halt the pandemic by negatively impacting timely testing, treatment, and adherence to treatment (Treves-Kagan et al., 2015). The strong emphasis and focus on the adult population overlook the needs of children who may be either directly or indirectly affected by parental illness and HIV-related stigma.

2.4 Tribal stigma and children orphaned by AIDS

Experiences of HIV-related stigma for children associated with parental illness may be explained by Goffman's (1963) concept of tribal stigma, commonly known as courtesy stigma or stigma by association. Tribal stigma derives from an individual's association with heritages—groups or individuals who possess a stigmatized trait or characteristic. Goffman (1963) recognizes the social risks carried by affiliates of stigmatized individuals, as they are awarded admission into the stigmatized group and share the tainted stigma or identity (Pryor, Reeder, & Monroe, 2012). Similarly, Major and O'Brien (2005, p. 395) identified tribal stigma within their study stating that, "…they are a poor partner for social exchange, carry a parasitic infection or they belong to an out-group which may be exploited for in-group gain." Therefore, it is suggested that tribal stigma may be shared by individuals connected to the stigmatized through social structure associations or by virtue of choice (Pryor et al., 2012).

Goffman (1963) denotes that family ties, ethnic identification, and chosen affiliation are strong predictors of tribal stigma in comparison to simple associations. The notion of tribal stigma is therefore based on the concept of entitativity—the degree to which two or more individuals are tied together to form a meaningful social unit (Campbell, 1958; Pryor et al., 2012), with intimacy groups, such as families, being the highest amongst all forms of social groups. Therefore, COA, because they are the child/ren of the stigmatized, they are considered part of the intimacy groups, placing them at risk for experiencing HIV-related stigma and its related outcomes. Goffman (1963, p. 30) contended that individuals associated with the stigmatized are likely to "share some of the discredit of the stigmatized person to whom they are related." COA, irrespective of their own HIV status, become stigmatized by association, and may thus experience HIV-related stigma as acutely as their deceased parents to whom they are closely connected (Cree et al., 2004; Goffman, 1963; Mason & Sultzman, 2019). Tribal stigma holds strong implications for COA and their well-being, regardless of their own HIV status. These children are shaped through the prism of problems as once faced by their parents (Ornacka, 2014). To understand the experience of HIV-related stigma and its outcomes for COA, two following aspects—the process of othering and layered stigma—ought to be considered.

2.5 The process of othering and layered stigma

Tribal stigma, like the other forms of stigma described by Goffman (1963), leads to the process of othering. Link and Phelan (2001), whose ideas are rooted in psychodynamic theory, implied that stigma is the co-occurrence of labelling, stereotyping, the categorization of in-group and out-group separation, status loss, and discrimination, which is governed by the exercise of power. This definition provided by Link and Phelan (2001) sheds light on the process of "othering" through the categorization of in-and out-groups. Due to the universal human fear of danger or uncertainty, the non-stigmatized project undesirable characteristics onto out-groups, differentiating and distancing themselves from "others" and the perceived threat which is maintained by a negative response towards the out-group (Campbell & Deacon, 2006). Similarly, Deacon and Stephney (2007, p. 6) maintain that stigma allows people to "distance themselves from the risk of infection by blaming contraction of the disease on characteristics normally associated with out-groups." While COA may not be HIV positive, they bear the "mark" of HIV, an illness that is associated with impropriety and considered degenerative, untreatable, contagious, and likely to be visible to others with its progression to AIDS (Earnshaw & Kalichman, 2013; Herek et al., 2002). Therefore, COA are classified as the "other" by placing them in an out-group which separates the stigmatized from the non-stigmatized as a result of perceived risk (Goffman, 1963).

Othering, too, is important for understanding how the process of stigmatization unfolds. Goffman (1963) states that stigma, which constitutes difference, does not manifest in isolation, but is rather situated within social relationships. Deviance and difference are through interaction between the stigmatized and non-stigmatized. In addition, Deacon and Stephney (2006) suggest that this process of othering draws on existing patterns of social differentiation. This idea gives precedence to intersecting stigmas, commonly known as "layered stigma." Turan et al., (2019) opine that the stigmatized identities of individuals are often examined in isolation; however, they do not exist in a vacuum. Although intersecting forms of stigma are often experienced by the stigmatized, the concept of layered stigma remains poorly understood (Elafros et al., 2018; Turan et al., 2019). Layered stigma refers to the convergence of multiple stigmatized identities within a person or group (Turan et al., 2019). For health and well-being, the joint effects of such stigmatized identities are to be addressed (Turan et al., 2019). Ogden and Nyblade (2005) stated that layered stigma borrows from the notion of "double" or "triple" oppression and follows the fault lines of society. As stigma disproportionately affects disempowered individuals, layered stigma deepens the existing social divisions of the already marginalized. Globally, heath-related stigma has been strongly associated with other vulnerabilities, such as gender, sexuality, ethnic minorities, poor socio-economic status, intravenous drug use, and promiscuity (Elafros et al., 2018). Therefore, individuals considered as "others" are already likely to be oppressed and marginalized, with COA being no different.

Orphanhood poses a social risk for marginalization as it results in the disintegration of the family system and social ties, lack of support and care, and increased poverty for the affected child (Pouw & Hodgkinson, 2016). Regions of SSA—home to the largest population of COA—have witnessed the disintegration of the family system both as a result of an ever-changing social, economic, and cultural climate, and the rapidly increasing orphan population (Ntozi, Ahimbisibwe, Odwee, Ayiga, & Okurut, 1999). In traditional African societies, orphaned children were absorbed into the extended family. However, the magnitude of the orphan population due to the HIV/AIDS epidemic has rendered traditional and contemporary structures ineffective for providing and caring for the needs of these children (Kimane, 2005). Extended family members can no longer afford to fulfill the basic and necessary needs for the well-being of children. The disintegration of the family system increases the prevalence of child-headed households as COA assume care for their younger siblings and are burdened with greater responsibility. Tanga (2013) argued that the family system is rupturing rather than disintegrating. Extended families are likely to care for COA by being incentivized with financial and material assistance received from governments and non-profit organizations (Tanga, 2013). This draws on the ideology presented by Dahl (2009) that caregiving within Africa is rooted in the expectation of exchange and material resources, rather than affection. This speaks towards the exploitative practices against COA who are rendered vulnerable by their orphaned status. Secondly, institutional caregiving facilities are often over-capacitated and under-resourced. These children are likely to experience increased poverty, stunting due to malnourishment, denial of a formal education, and/or receive inadequate health care.

As a result of marginalization, COA are regarded as vulnerable and lack the necessary opportunities and resources to fully participate in economic, socio-cultural, and political life considered normal within the society and vital for healthy well-being (Subbarao & Coury, 2004)). COA suffer economically, socially, and psychologically, and are at an increased risk for experiencing HIV-related stigma due to their association with parental illness and death. It is thus apparent that COA are vulnerable to experiencing HIV-related stigma both as a result of being perceived as the “other” and through marginalization—both are resultant of parental illness and death. Consistent with these ideas, research has indicated that COA and other vulnerable groups of children are likely to experience several manifestations of HIV-related stigma which is likely to impact the health and well-being of children associated with or orphaned by AIDS related causes. As Goffman (1963) provides an ideological understanding of the origin and the root causes of stigma, the work of Steward and colleagues (2008) may be applied to understand the various manifestations of HIV-related stigma as experienced by COA.

2.6 The multi-component framework of HIV-related stigma

Steward et al., (2008) devised a multi-component framework through the adaptation of Scambler's (1989) hidden distress model. This framework focuses on the manifestations of HIV-related stigma, capturing both interpersonal and intrapersonal aspects of stigmatization and its contribution towards the production of psychological distress for infected individuals (Steward et al., 2008). While the framework was developed for the adult population, it offers a valuable understanding of the manner in which COA may experience both interpersonal and intrapersonal forms of stigma and its associated psychological effects. Additionally, the framework offers an understanding of the "insiders" perspective, which allows for the conceptual understanding of how manifestations of HIV-related stigma are perceived by COA themselves. The framework is divided into two components— interpersonal and intrapersonal stigma—which emphasizes four main ways in which stigma is experienced and considered important for stigma management in the presence of social interaction, namely, enacted stigma, vicarious stigma, perceived stigma, and internalized stigma.

2.6.1 Interpersonal vs intrapersonal stigma

Steward et al., (2008) distinguish between interpersonal and intrapersonal forms of stigmatization, claiming that each form constitutes varying experiences of stigma for the stigmatized individual. The former captures interpersonal actions such as discrimination or hostility occurring within the process of social interaction between stigmatized and non-stigmatized individuals (Steward et al., 2008). Hatzenbuehler (2016) recognized interpersonal stigma as social interaction characterized by discrimination, rejection, and hostility between stigmatized and non-stigmatized individuals. Two manifestations of interpersonal stigma are outlined by Steward et al., (2008), namely, enacted and vicarious stigma. Conversely, intrapersonal stigma captures stigmatized individuals' intrapersonal experience of HIV-related stigma (Steward et al., 2008). Unlike experiencing real enactments of discrimination, intrapersonal stigma draws on the intrinsic and psychological experience of stigma. Hatzenbuehler (2016) refers to intrapersonal stigma as a psychological or internal process in which stigmatized individuals engage and respond to stigmatization. Steward et al., (2008) recognized perceived and internalized stigma as intrapersonal forms of HIV-related stigma. A review conducted by Florom-Smith and De Santis (2012, p. 155) recognized this perceivable difference, claiming that stigma may be experienced "by individuals either externally and internally, simultaneously, or stigma may be experienced externally or internally separately."

The perceived difference between interpersonal and intrapersonal forms of stigmatization draws on the distinction between the concepts of discrimination and stigmatization. Deacon (2006) claims that defining stigma in terms of discrimination is problematic, as the two concepts are distinct and conceptually different, and should not be used interchangeably. Deacon and Stephney (2007) note that stigma is often defined as resulting in discrimination, which suggests that discrimination is the goal or end point of stigmatization. This conceptualization limits our understanding of how HIV-related stigma impacts affected individuals and reduces analytical clarity regarding stigma and its associated effects (Deacon, 2006). While separating the two concepts allows for a broader understanding of the impact of HIV-related stigma, this distinction allows for a better understanding of interpersonal stigma, which often results in acts of discrimination and disadvantage. However, interpersonal stigma in the absence of discrimination continues to occur, as it is internally experienced, and is often associated with adverse outcomes for the well-being and behaviors of stigmatized individuals (Deacon, 2006). Stigma, therefore, should be considered an ideology, and discrimination a practice resulting from such an ideology (Deacon & Stephney, 2007).

2.6.2 Enacted stigma

The first component captures an interpersonal aspect of stigma known as enacted stigma. Enacted stigma refers to “overt acts of discrimination and hostility directed at a person because of his/her perceived stigmatized status” (Steward et al., 2008, p. 3). Some scholars, for example, Gabe, Bury, and Elston (2004), Gilbert and Walker (2010), and Scambler (1989), to name a few, consider enacted stigma as the real actions of stigmatization and discrimination as experienced by the stigmatized individual. COAs experiences of enacted stigma are congruent with the definition provided by Steward et al., (2008, p. 3) which states that enacted stigma is “overt acts of discrimination and hostility directed at a person because of his or her perceived stigmatized status.” Overt acts of discrimination and hostility from others are often experienced by COA and these manifestations of enacted stigma include, but are not limited to, alienation, isolation, rejection, exclusion, bullying, victimization, ill-treatment, neglect, and abuse (Adejuwon & Oki, 2011; Asikhia & Mohangi, 2016; Bogart et al., 2008; Chama & Ramirez, 2015; Cheney, 2015; Chi et al., 2015; de Witt & Lessing, 2010; Ishikawa, Pridmore, Carr-Hill, & Chaimuangdee, 2011; Louw, Mokhosi, & van den Berg, 2012; Mason & Sultzman, 2019; Mason, Sultzman & Berger, 2014). However, as stigma is socially constructed, manifestations of enacted stigma may vary according to geographical location and time (Scambler & Paoli, 2008).

Steward et al., (2008) indicated that experiences of enacted stigma are likely to result in psychological distress for the stigmatized. A growing production of knowledge focusing on the relationship between health-related stigma and the psychological well-being of COA has confirmed the expected association (Cluver et al., 2008; Doku & Minnis, 2016; Li, Chi, Sherr, Cluver, & Stanton, 2015; Mo et al., 2015). Enacted stigma has resulted in the presentation of increased psychological distress among COA, such as depression, anxiety, loneliness, post-traumatic stress disorder (PTSD), and externalizing disorders (Boyes & Cluver, 2013, 2015;

Bogart et al., 2008; Chama & Ramirez, 2015; Gamarel et al., 2017; Mason & Sultzman, 2019; Mason et al., 2014; Williams & Aber, 2019). The outcome of increased psychological distress is also presented in the findings of a study conducted by Ogina (2012, p. 435) who indicated that COA were left feeling alienated, angry, frustrated, and helpless. However, Steward et al., (2008) argued that enacted stigma does not contribute to perceived stigma in isolation. Furthermore, Steward et al., (2008) coined the term "vicarious stigma," adding an additional form of interpersonal stigma that may widely contribute towards an increase in intrapersonal forms of stigma.

2.6.3 Vicarious stigma

Vicarious stigma—an interpersonal form of stigma—is used to explain the psychological distress experienced by stigmatized individuals in the absence of enacted stigma (Steward et al., 2008). Vicarious stigma refers to the communication or other channels used to convey HIV-related information, usually driven by hearing stories entailing or witnessing actual acts of overt hostility and discrimination towards stigmatized individuals (Sengupta et al., 2010; Steward et al., 2008). Vicarious stigma therefore conveys information about the reality and perceived associated consequences of HIV-related stigma through the lived experiences or information relayed by others. This allows the experience to be real for individuals who then come to fear its consequences (Sengupta et al., 2010; Steward et al., 2008). Consistent with the social learning theory by Bandura (1979), witnessing or hearing about the experiences of others leads to the future anticipation of experiencing discrimination and stigmatization. These ideas denote that enacted stigma does not need to be present for HIV-related stigma to be experienced and perceived as real by those considered to carry a stigmatized trait or characteristic (Steward et al., 2008). Enacted and vicarious stigma alike have been identified as contributing towards the development of perceived stigma.

While interpersonal stigma leads to the formation of perceived stigma, Steward et al., (2008) reported low prevalence rates of enacted stigma within their study. These results may be understood by Goffman's (1963) suggestion that the concealability or visual conspicuousness of a stigmatized attribute would largely influence an individual's experience of stigma (Chaudoir et al., 2013). This distinction is discussed through the introduction of discredited and discreditable identities (Goffman, 1963). The former refers to stigmatizing attributes that are predominately visible, such as a physical disability, race, or gender, while the latter refers to an attribute that is concealable, such as a mental illness (Chaudoir et al., 2013; Goffman, 1963). In this sense, COA may be considered as the "discreditable" as they are "marked" because of their association with familial HIV/AIDS rather than contracting or displaying symptoms of the virus itself. While the discredited are likely to experience greater enacted stigma (Stutterheim et al., 2012), perceived stigma is likely to be experienced by both the discredited and discreditable (Chaudoir et al., 2013).

6.2.4 Perceived stigma

The hidden distress framework holds that the anticipation of discrimination and stigmatization introduces faulty beliefs regarding the prevalence and normativity of HIV-related stigma within an individual's social environment (Steward et al., 2008). Therefore, perceived stigma, also known as "felt stigma," is defined as one's perception regarding the prevalence and normativity of stigmatizing attitudes and behaviors within their environment.

It could be argued that the notion of perceived stigma substantiates Goffman's (1963) understanding of stigma as a social construct, which underscores the existence of a shared understanding among out-group members regarding their devalued status based on dominant cultural and social stereotypes. Goffman (1963) is of the opinion that individuals are knowledgeable about the manner in which they are negatively perceived and devalued within society. Similarly, Crocker, Major, and Steele (1998) declared that the stigmatized hold shared understandings of the manner in which their devalued status is understood and perceived at large. Therefore, COA, being regarded as the discreditable, are likely to anticipate and guard against experiencing overt hostility and rejection from others, based upon their perceptions and shared understanding of their devalued status.

It has previously been noted that COA are rather perceptive of HIV-related stigma in the anticipation of experiencing overt discrimination and hostility (Boyes & Cluver, 2013; Chi et al., 2015; Mason & Sultzman, 2019). Levels of perceived stigma were commonly manifested as fear of overt discrimination, such as being rejected, ill-treated, ostracized, or teased by others (Chama & Ramirez, 2015; Chi et al., 2016; Lin et al., 2010; Mason & Sultzman, 2019; McHenry et al., 2017). Although Steward et al., (2008) maintain that perceived stigma is fueled by interpersonal forms of stigma, a study conducted by Mo et al., (2015) suggests that there is a bidirectional relationship between enacted and perceived stigma. These ideas are consistent with those of Major and O'Brien (2005) who suggest that psychopathological symptoms, such as depression and anxiety caused by enacted stigma, may predict perceptions of discrimination or hostility. Steward et al., (2008), who insist that internalized stigma should remain distinct from perceived and enacted stigma despite their association as it is only partially driven by perceived stigma, introduced a fourth component called internalized stigma.

2.6.5 Internalized stigma

Internalized stigma, also known as "self-stigma," is an intrapersonal measure of stigma constituting the fourth component of the hidden distress model. Internalized stigma is regarded as the extent to which an individual accepts stigma as valid and truthful (Herek, 2008; Steward et al., 2008). This definition offered by Steward et al., (2008) is consistent with the descriptions of internalized stigma utilized by other scholars (Audet, McGowan, Wallston, & Kipp, 2013;

Bennett, Traub, Mace, Juarascio, & O’Hayer, 2016; Bos, Pryor, Reeder & Stutterheim, 2013; Earnshaw et al., 2014; Gamarel et al., 2017). Stigmatized individuals come to accept the negative view and discredited status afforded to them by society as both truthful and valid (Herek, 2008; Steward et al., 2008). As a result, the self-concept and shame held by the stigmatized are congruent with such internalized beliefs and attitudes and reflects their devalued status (Bennett et al., 2016; Major & O’Brien, 2005; Sengupta et al., 2010; Steward et al., 2008). Prior studies have outlined COAs experience of internalized stigma as a result of parental illness and death (Adejuwon & Oki, 2011; Asikhia & Mohangi, 2016; Bogart et al., 2008; Kheswa & Duncan, 2011; Mo et al., 2015; Ogden & Nyblade, 2005; Stuenkel & Wong, 2013). The internalization of the negative beliefs and attitudes held by society is reflected in the manifestations of internalized stigma described by several studies as chronic feelings of shame, inferiority, embarrassment, self-hatred, and the belief that they are a burden upon society (Adejuwon & Oki, 2011; Asikhia & Mohangi, 2016; Bogart et al., 2008; Florom-Smith & De Santis, 2015; Kheswa & Duncan, 2011; Louw et al., 2008; Mo et al., 2015; Ogden & Nyblade, 2005).

The framework developed by Steward et al., (2008) suggests that these four components of stigma uniquely contribute towards poor psychological well-being. However, the impact on psychological well-being may also be mediated by the responses of COA to their experiences and perceptions of HIV-related stigma.

2.7 Response to HIV-related stigma

The impact of HIV-related stigma on the psychosocial well-being of COA may be mediated by their response to HIV-related stigma. Kittikorn, Street, and Blackford (2006), and Goffman (1963) acknowledge the adoption of various coping strategies to deal with and avoid discrimination by stigmatized individuals. Healthy responses or coping strategies adopted to combat stigma may successfully mitigate the impact on the well-being of stigmatized individuals (Lyimo et al., 2014). However, unhealthy behaviors and maladaptive responses or strategies to being stigmatized may result in negative health outcomes (Chi et al., 2015; Fuller-Rowell, Doan, & Eccles, 2012; Klonoff, 2014).

Firstly, COA may disassociate themselves from biographical others, which may be the leading cause of stigmatization (Goffman, 1963). Disassociation is consistent with the process of disidentification proposed by Major and O’Brien (2005). By creating such distance, COA may escape the stigmatizing attribute, leaving behind the devalued status to construct a new social identity. However, this may not be possible for COA, as they remain dependent on their parents, who are their primary caregivers, and therefore bare the mark of difference within society.

Secondly, Major and O’Brien (2005, p. 405) suggest that disengagement, the process of “withdrawing their efforts and/or disengaging their self-esteem from domains in which they are negatively stereotyped or fear being the target of discrimination,” is another coping strategy that may be adopted. The adoption of disengagement strategies by COA is strongly reflected in behaviors of self-isolation and withdrawal as reported by several studies (Lata & Verma, 2013; Li et al., 2008; Makoae et al., 2008; Tran & Mwanri, 2013; Zhao et al., 2007). Disengagement may be considered as an avoidant-coping strategy in which individuals use both cognitive and behavioral efforts to avoid or minimize dealing with stressors and negative situations. However, it actively undermines the development of the healthy formation of meaningful social relationships and networks, fueling a sense of loneliness (Schibalski et al., 2017).

Lastly, covering a form of information management is a strategy to hide a discrediting attribute of oneself to avoid stigma (Goffman, 1963; Stuenkel& Wong, 2009). These ideas share similarities with problem-focused coping strategies, which seeks to alter the relationship between the stigmatized and social environment. This may be achieved through secrecy, selective disclosure, and non-disclosure practices (Stutterheim et al., 2012). Selective and non-disclosure practices are widely discussed in literature pertaining to COA and HIV-related stigma (Bogart et al., 2008; Cheney, 2015; de Witt & Lessing, 2010; Florom-Smith & De Santis, 2012; Kheswa & Duncan, 2011). These coping strategies, too, may inhibit the formation of healthy relationships, which limits the opportunity of COA to healthily express their feelings and discuss traumatic and stressful life events. Therefore, components of HIV-related stigma may either negatively affect the psychosocial well-being of COA directly or through the adoption of negative coping strategies.

2.8 Stigma and the psychosocial well-being of COA

HIV-related stigma has been recognized as compromising the psychosocial well-being of COA (Campbell et al., 2016; Caserta et al., 2016; Chi et al., 2015; Cluver et al., 2008; Deacon & Stephney, 2008; Nyamukapa et al., 2008; Li et al., 2008; Li et al., 2017; Thupayagale-Tshweneagae & Benedict, 2011; Zhao et al., 2010). It is believed that each component of HIV-related stigma uniquely affects the well-being of stigmatized individuals. It is therefore also important to note that psychosocial well-being is a multifaceted component made up of various dimensions that form the psychosocial well-being of an individual, namely, psychological and social well-being (Louw et al., 2012; Thornton, 2001; Zhao et al., 2010), self-esteem and self-concept (Major & O’Brien), and future orientation (Li et al., 2017). Therefore, each measure of HIV-related stigma may uniquely interact with coping strategies or directly act to negatively affect the dimensions of psychosocial well-being. To gain an understanding of the impact of HIV-related stigma on the psychological well-being of COA, it is necessary to engage with the works of both Steward et al., (2008) and Major and O’Brien (2005). While Steward et al., (2008) only account for poor psychological well-being, the work of Major and O’Brien (2005) is used to account for other dimensions of psychosocial well-being, including social well-being, self-concept and self-esteem, and future orientation.

2.8.1 Psychological well-being

HIV-related stigma is expected to directly influence the psychosocial well-being of COA. In terms of psychological well-being, Steward et al., (2008) suggest that enacted and internalized stigma directly produces psychological distress for COA. Likewise, Major and O'Brien (2005) propose that members of a stigmatized group are likely to experience psychological distress because of their appraisals and subjective experiences of stigmatization. However, perceived stigma is exclusively mediated by avoidance of disclosure strategies, such as non-disclosure and/or selected disclosure, which may result in negative psychological outcomes for the stigmatized individual (Steward et al., 2008). Psychological distress resulting from stigma may manifest as depression, anxiety, PTSD, and externalizing disorders.

2.8.2 Social well-being

The social well-being of stigmatized individuals may be irrationally influenced through maladaptive coping strategies, such as non-disclosure, self-isolation, and withdrawal. These maladaptive strategies act to inhibit the perceived social support available to stigmatized individuals, leading to the impairment of social attachments and the healthy formation of trusting relationships with others, perpetuating social isolation (Steward et al., 2008). Social support is regarded as the extent to which individuals are willing and available to provide resources for the successful coping and resolution of traumatic life events (Galvan, Davis, Banks, & Bing, 2008; Prati & Pietrantoni, 2009; Xanthopoulos & Daniel, 2013). Poor social well-being serves to negatively affect the self-concept and self-esteem of stigmatized individuals.

2.8.3 Self-concept and self-esteem

Self-esteem is regarded as an imperative component of well-being and psychological health (DeNeve & Harris, 1998). Major and O’Brien (2005) are of the opinion that the internalization of stigma negatively affects the self-concept and self-esteem of stigmatized individuals. It is believed that the self-image of a stigmatized individual is rendered parallel to the degree to which they are negatively devalued and viewed within society. As a result of internalized stigma, COA are likely to hold a negative evaluation of themselves which mirrors the devalued and tainted view afforded by society, resulting in self-depreciation (Major & O’Brien, 2005; Mo et al., 2015). The self-concept develops through one’s interactions with others and is a reflection of an individual’s self-appraisal of him/herself. Through dyadic mixed contacts, COA may adopt coping strategies, such as self-withdrawal and isolation, which hinders the formation of healthy relationships or interaction with others necessary for a healthy self-concept and self-esteem (Major & O’Brien, 2005; Mo et al., 2015).

2.8.4 Future orientation

Optimism and perceived control of the future may be negatively influenced by experiences of stigma and discrimination. Major and O’Brien (2005) theorized that environments characterized by discrimination may hamper academic performance of stigmatized individuals through the adoption of maladaptive coping strategies, such as withdrawal and isolation. Educational environments characterized by discrimination have previously been identified as fueling school non-attendance, as COA attempt to minimize experiences of enacted stigma (Asikhia & Mohangi, 2016; Deacon & Stephney, 2007; de Witt & Lessing, 2010; Lalthapersad-Pillay, 2008). School attendance is strongly related to the acquisition of scholastic knowledge and skills needed for securing gainful employment later in life (Asikhia & Mohangi, 2016).

This is met with a sense of hopelessness and diminished sense of perceived control over their future.

2.9 Conclusion

In the absence of a suitable theoretical framework, this chapter provided a conceptual integrated understanding of HIV-related stigma for application to orphaned children and their psychosocial well-being. It further dealt with the origin of stigma, experiences of HIV-related stigma, and the outcomes of HIV-related stigma. This framework was used to underpin the current research study; it was also integrated into the discussion of each phase and formed the assumptions of the model developed in Chapter 7. The next chapter provides an overview of the methodological aspects of the study.

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Chapter 3

Methodology

3.1 Introduction

The previous chapter provided a conceptual framework for the current study by exploring the origin, experience, responses, and outcomes of HIV-related stigma among children who have been orphaned by AIDS-related causes. The current chapter provides an overview of the methodological aspects undertaken in this study for the development of a model which provides an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. Included in this chapter is a (1) theory generative framework, (2) methodological framework and mixed methods, (3) mixed method typologies, (4) Phase I: systematic review, (5) Phase II: qualitative explorative descriptive study, (6) Phase III: model development, (7) Phase IV: Delphi study, (8) trustworthiness, (9) ethical considerations, and (10) a concluding statement.

3.2 Theory generation as a framework

The core methodological aspects of this study are geared towards theory generation, which is regarded as knowledge development. According to Chinn and Kramer (2008, p. 2), knowledge refers to “knowing that is expressed in a form that can be shared or communicated with others.” Knowledge may also be understood as a collective representation, a reasonable and accurate understanding of the world within a specific discipline (Chinn & Kramer, 2008). Knowledge generation is based upon five patterns of knowing, namely: emancipatory knowing, ethics, personal knowing, aesthetics, and empirics. This study draws on the empiric pattern of knowing, which is grounded in traditional ideas of science, and is based upon the assumption that that which is known is accessible through the physical senses, such as seeing, touching, and hearing (Chinn & Kramer, 2008). Therefore, empiric knowing may be expressed as scientific competence in the form of “theories, statements of facts, or formalized descriptions and interpretations of empiric events or objects” (Chinn & Kramer, 2008, p. 9). Chinn and Kramer (2008) highlight the role of conceptualizing and structuring ideas into knowledge expressions in the form of theories or formal descriptions, consequentially providing formal descriptions which become shared empiric knowledge. Theory is defined as “a creative and rigorous structuring of ideas that projects a tentative, purposeful and systematic view of phenomena” (Chinn & Kramer, 2008, p. 182).

There is a continuing argument that theory is largely purposive and created for a particular reason. In relation to the overall aim of this study, the developed model seeks to illuminate a given phenomenon—HIV-related stigma and the psychosocial well-being of COA—through the grouping of knowledge ideas and experiences that are symbolically presented (Watson, 1985). Additionally, in the absence of an appropriate theoretical framework or understanding of HIV-related stigma in relation to orphaned children and their psychosocial well-being, the developed model would serve to guide future research and practice. Similarly, Walker and Avant (2005) stated that theory development is needed to enrich research and practice within a discipline, as there is often an absence of theory or the theory being utilized fails to incorporate the relevant perspective needed to understand phenomena.

While theory development is often a creative process, the methods or explicit approaches utilized and their application to theory construction may be fully described by the theorist/s (Chinn & Kramer, 2008; Walker & Avant, 2005). Methodology refers to the framework of assumptions, philosophies, and approaches used in the process of developing knowledge (Chinn & Kramer, 2008). In accordance with these views, this chapter provides a full overview of the methodological approaches and assumptions utilized to develop the core aspects of the developed model displayed in Chapter 7.

3.3 Methodological framework

The methodological framework, as discussed here, includes the introduction of mixed methods as a methodological approach, the rationale of mixed methods, and mixed methods typologies followed by the four sequential stages (Phase I – IV) geared towards model development.

3.3.1 Mixed methods

Given the lack of consensus surrounding HIV-related stigma and the psychosocial well-being of COA, this study adopts a mixed methods approach for model development. There are several motivations for using mixed methods within this study. Firstly, grounded within a theory generative approach, Walker and Avant (2005) hold that varying strategies may be adopted for theory generation, including qualitative, quantitative, and literary methods. Similarly, Chinn and Kramer (2008) allude to the use of varying methods of inquiry for the formation of conceptual meaning upon which a theory is generally based.

Secondly, HIV research has been recognized as a key field in which mixed methods research frameworks have been adopted as it allows for the exploration of complex issues such as social stigma (Grace, 2014; Haile, 2009). Gilbert, Cattell, Edwards, and Bowen (2017) concur that the mixed methods framework is an effective approach for the investigation of complex issues.

Lastly, Jones and Summer (2009) argue that research on well-being places little emphasis on the uniqueness of children’s experiences of deprivation or ill-being and the complex linkages between the evolving physical, neurological, and psychosocial capacities of children and the diverse social conditions of childhood. For better exploration that captures the multi-dimensionality of child well-being and the social and cultural systems upon which it is dependent, Jones and Summer (2009) call for child well-being researchers to adopt a mixed methods approach. Based on these arguments, the adoption of a mixed methods approach was deemed suitable for this study upon its ability to provide a comprehensive base of empiric evidence which allows for a broader and deeper understanding of human phenomenon (Doyle, Brady, & Byrne, 2009; Creswell & Plano Clark, 2006). The definition of mixed methods used in this study has been advanced by Johnson, Onwuegbuzie, and Turner (2007, p. 123), who suggest that:

> Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.

Evidently, mixed methods involve the collection, analysis, and mix of qualitative and quantitative data in a single study or multiphase programme of inquiry (Creswell & Plano Clark, 2006). While mixed methods research allows for a deeper understanding of phenomenon, the assumption that it is superior to a mono-method design is often challenged (Sandelowski, 2014). This lends to the argument that sufficient justification is to be provided for the adoption of mixed method studies. The justification for mixing methods within this study follows the commonly identified rationales presented by Doyle et al., (2009), which draws on the reasoning provided by Greene, Caracelli, and Graham (1989), and Bryman (2006). Its application within this study is provided in Table 3.1 below.

Table 3.1: Justification for Mixed Methods (Doyle et al., 2009)

Justification	Description	Application within study
Triangulation	Seeks convergence, corroboration, and correspondence of results from different methods.	• The results generated from Phases I, II and IV are triangulated to inform the developed model.
Expansion	Seeks to extend the breath and range of inquiry by using different methods for different inquiry components.	• The concepts identified within the findings from Phase I are qualitatively explored in Phase II. • This exploration allowed for the development of relationship statements integrated in Phase III, which seeks to explain and clarify the relationship between two concepts, and uncover other concepts and uses of such concepts.
Development	Seeks to use the results from one method to develop or inform the other, where development is broadly construed to include sampling and implementation, as well as measurement decisions.	• Phase I is used to identify concepts to be explored in Phase 2. • The results from Phase I informs the development of the interview guide used in Phase II. • The results from Phase I and II are used for theory development in Phase III. • The theory generative methodology utilized in Phase III is used to develop the evaluative questionnaire implemented in Phase IV. • The quantitative data collected in Phase IV is used to determine the functionality of the model developed in Phase III.
Illustration	Qualitative data is used to illuminate quantitative findings.	• As most of the studies included in Phase I utilized quantitative study designs, Phase II served to fully explore these concepts through the perceptions and experiences of the target population.

3.3.2 Mixed methods typologies

Numerous mixed methods designs have emerged, creating confusion for both novice and experienced researchers. Morse (2010) points out that there is little consensus regarding what mixed methods actually are. Mixed methods may refer to either the combination of qualitative and quantitative methods or the application of two methods within one paradigm (Leech, 2010). There has been a call for a return to more simplistic research designs resulting in the categorization of six overreaching typologies that are either concurrent or sequential (Creswell, Plano Clark, Gutmann, & Hanson, 2003), as presented in Table 3.2 below. In assessing different mixed methods design, the exploratory sequential design was deemed suitable for this study. This design typically involves an initial phase of qualitative data collection and analysis, followed by a second phase of quantitative data collection and analysis, which are to be analyzed and integrated during interpretation (Kroll & Neri, 2009). The results generated by the first phase of collection and analysis are used to inform and design later phases in the study (Creswell & Plano Clark, 2011).

Table 3.2: Mixed Methods Typologies

Design	Description
Sequential explanatory	• The collection and analysis of quantitative data is followed by the collection and analysis of qualitative data. • The use of qualitative data assists in explaining the findings of quantitative data. • Priority is given to quantitative data. • Not necessarily guided by a theoretical perspective.
Sequential exploratory	• The collection and analysis of qualitative data is followed by the collection and analysis of quantitative data. • Used to explore a phenomenon and explain and interpret relationships within a selected population. • Priority is given to qualitative data. • Not necessarily guided by a theoretical perspective.
Sequential transformative	• Two distinct data collection phases, with one following the other. Either method may be used first. • Priority may be given to quantitative and/or qualitative data. • A theoretical perspective is present to guide the study. • This design serves to employ methods best suited to the theoretical perspective of the researcher.
Concurrent triangulation	• Simultaneous collection and analysis of quantitative and qualitative data. • The design allows for the confirmation, cross-validation, or corroboration of qualitative and quantitative data within a study. • Often used to account for the strengths and weakness of each method, • Equal priority is given to both qualitative and quantitative data, depending on application.

Concurrent nested	• Simultaneous collection of qualitative and quantitative data nested within the predominant method guiding the study. • Priority is given to the predominant method of the study. • Used to gain broader perspectives afforded by varying methods as opposed to the singular use of the predominant method. • May be guided by a theoretical perspective.
Concurrent transformative	• Simultaneous collection of qualitative and quantitative data in a singular data collection process in one phase. • May take on the design features of either triangulation or nested designs. • Priority may either be equal or unequal. • Often used by researchers positioned within a transformative framework. • Guided by a theoretical perspective.

This design is recommended as the procedure of choice for theory development and for testing elements of an emergent theory (Creswell, 2007; Morgan, 1998; Morse, 1991). It facilitates the exploration of a phenomenon in a selected population and of relationships among variables that are unknown (Hanson, Creswell, Plano Clark, Petska & Creswell, 2005). These functions are enabled by the priory given to qualitative data which withholds its salient focus on the contexts and meaning of human lives and experiences for the purpose of theory-development driven research (Creswell et al., 2003). This design allows for the identification and development of concepts and relational statements for theory generation as discussed by Walker and Avant (2005).

The current study embodies a mixed methods, exploratory, sequential design within a theory generative research approach, which unfolds in four sequential stages that are geared towards the facilitation of model development. Chinn and Kramer (2008), Walker and Avant (2005), and Dickoff, James, and Wiedenbach (1968) suggest four stages for successful model development, namely: (1) concept identification, (2) model development, (3) model description, and (4) model evaluation. Through the implementation of this design, four stages of model development are realized. Additionally, during the planning of this mixed methods study, the four core aspects influencing the design, as proposed by Creswell (2009), were considered, namely, (1) timing, (2) weighting, (3) mixing, and (4) theorizing.

Phase I (Article 1), a systematic review, was qualitatively analyzed through the use of a meta-synthesis analysis. This phase was to identify concepts upon which the model was built. The narrative findings from this phase guided the development of an interview guide used in Phase II. Phase II (Article 2), a qualitative exploratory descriptive study, further explored these concepts and identified the relationship statements between the identified concepts. Phase III, which was grounded in a theory generative design, integrated the findings from Phases I and II to develop a model which provides an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. In Phase IV, a Delphi study was conducted by using the quantitative descriptive results to evaluate the model through the consensus of key stakeholders within the field. Phases III and IV spans across Chapters 6, 7 and 8 of this dissertation and is presented in Article 3. The four sequential phases of the study and their contribution towards model development is provided in Figure 3.1 below.

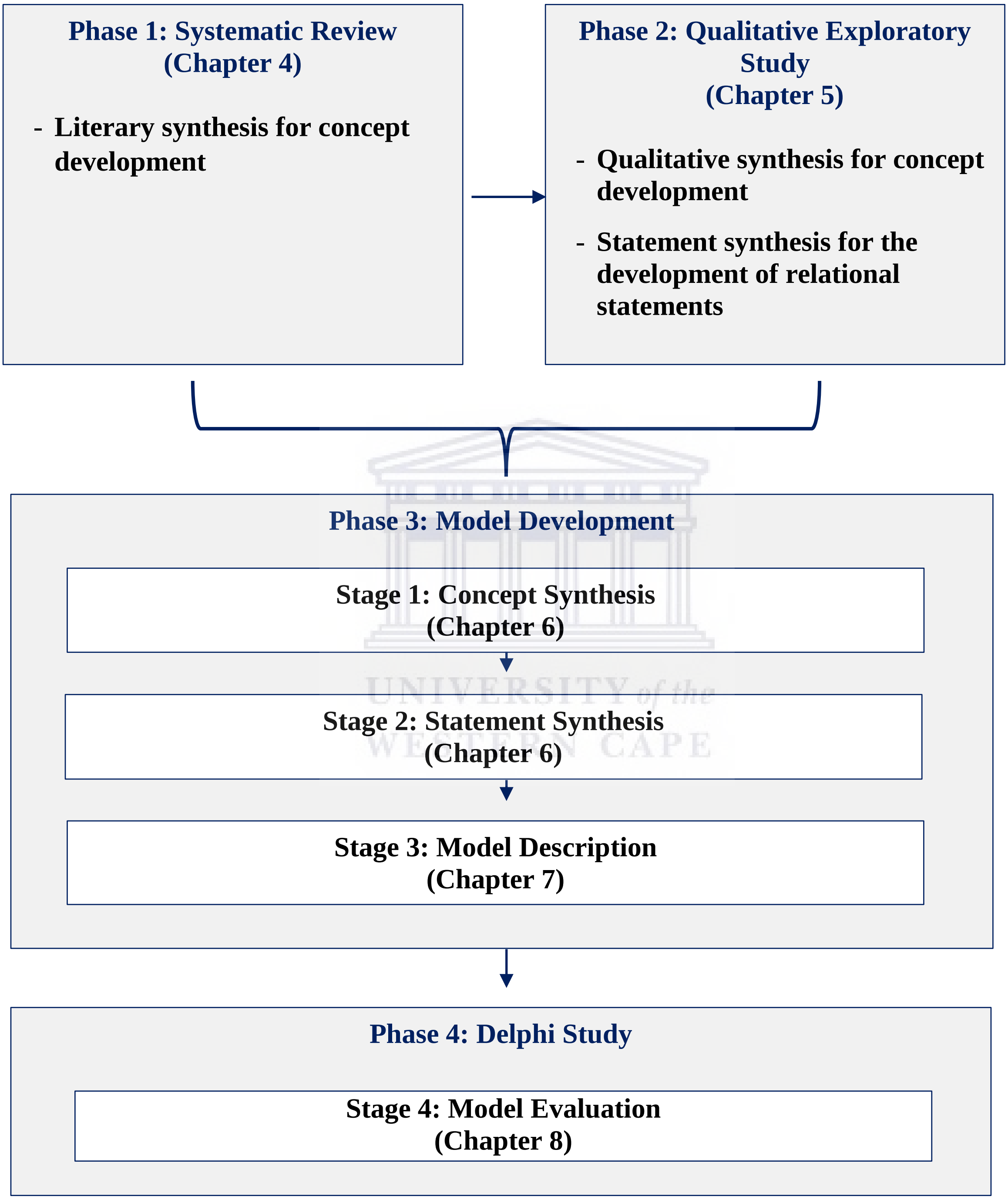

Figure 3.1: Sequential Phases of the Study

3.4 Phase 1: A systematic review

The purpose of Phase I was to conduct a systematic review to examine the impact of HIV-related stigma on the psychosocial well-being of COA. A systematic review is regarded as the explicit and systematic method employed to amalgamate evidence reported by a group of interrelated studies on a particular phenomenon (Higgens & Green (Ed.), 2011; Mulrow, 1994). Phase I serves to address the overall aim of the study as well as objective 1: ***To systematically review existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS.*** Furthermore, Phase I serves several interrelated purposes:

- The systematic review serves as a literary concept synthesis allowing for the acquisition of new insights about the phenomenon and identifies previously unidentified concepts contributing to model development in Phase III (Walker & Avant, 2005). Here, the systematic review serves to identify concepts, the basic building blocks of a theory upon which the model is based (Chinn & Kramer, 2008). Phase 1 is therefore an integral step towards concept development carried out in Phase III.
- The findings of Phase I are needed to inform (1) the qualitative exploration carried out in Phase II, and (2) the development of the interview guide, which facilitates further exploration of the identified concepts and the rational statements between these concepts.

Phase I of the study is presented and fully described in Chapter 4 (Article 1) of this dissertation.

3.4.1 Research question

The review was guided by the research question, “What are the effects of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS?” This research question was formulated using the population (COA), exposure (HIV-related stigma), and outcome (psychosocial well-being of COA) method (PEO), as advocated by Pollock and Berge (2018) for the conduction of systematic review studies. This clear research question assists in clarifying the eligibility criteria for the inclusion and exclusion of studies for the review.

3.4.2 Inclusion and exclusion criteria

Inclusion criteria required that the studies (1) be published between 2007 and 2017; (2) exemplify a qualitative, quantitative, and/or mixed methodology study design; (3) be in the English medium, full-text, and peer reviewed; (4) include children who are under 18 years of age, who have been orphaned (lost either one or both parents to HIV/AIDS), and (5) examine and report the effects of HIV-related stigma on the psychosocial well-being of COA. Owing to the recent focus placed on the well-being of orphaned and vulnerable children, the time frame was limited to the past 10 years, to include the most recent developments in the literature (Meline, 2006). Studies of qualitative, quantitative, and mixed methods designs were considered for inclusion, as this review set out to identify concepts pertaining to HIV-related stigma and child psychosocial well-being rather than categorize findings within their methodological approaches.

Studies were excluded if they failed to meet the specified predetermined inclusion criteria. Additionally, intervention studies and reviews were excluded as the current study examines how HIV-related stigma has impacted the psychosocial well-being of COA rather than evaluate the effectiveness of interventions directed at reducing stigma or improving the psychosocial well-being of COA.

3.4.3 Search strategy

The search strategy followed the four levels of review outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA), namely: (1) identification, (2) screening, (3) eligibility, and (4) inclusion (Liberati et al., 2009) (see Figure 3.2).

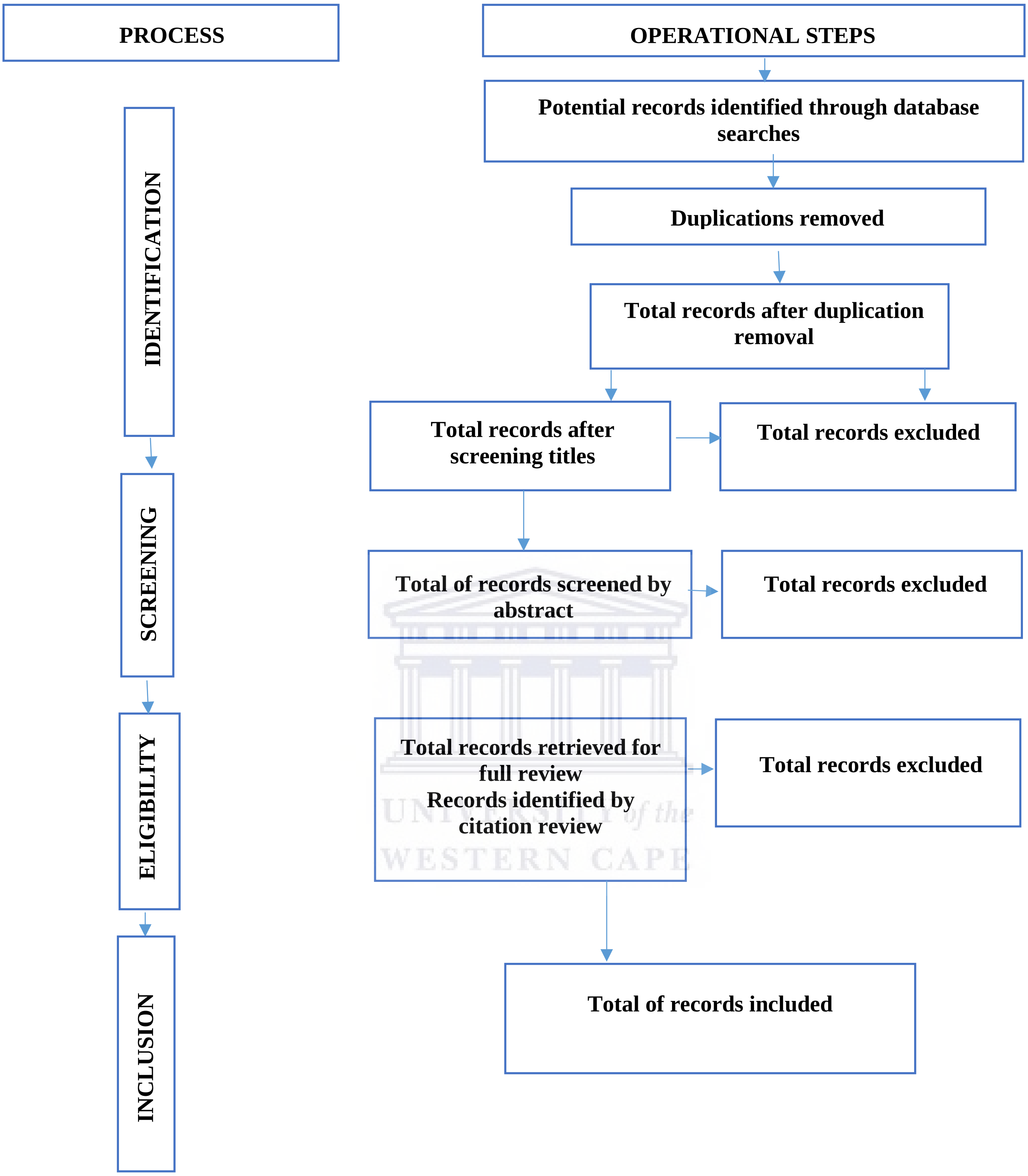

Figure 3.2: PRISMA Levels of Review

The following databases were comprehensively searched using Boolean strings of suitable keywords and search terms: Academic Search Complete, PubMed, PsychArticles, and SA ePublications.

However, the journal *AIDS Care* was identified as housing relevant articles within the specified focus area and subsequently added to the list of databases to be searched for the identification of relevant studies. Databases were selected according to their discipline and relevance to the subject matter of the study. Keywords and search terms forming Boolean strings using appropriate operators were identified, expanded, and refined in a preliminary search preceding the searching of the databases. These keywords and search terms were subjected to a pilot test assessing their strength to illicit relevant studies for inclusion. The following Boolean strings were entered into the respective databases after testing their accuracy and reliability within EBSCOhost:

(1) ‘AIDS orphans’

(2) ‘HIV/AIDS’ AND ‘stigma’ AND ‘children’

(3) ‘HIV/AIDS’ AND ‘stigma’ AND ‘children’ AND ‘well-being’ OR ‘well being’ OR ‘wellbeing’

(4) ‘HIV stigma’ AND ‘orphans’ AND ‘psychosocial well-being’

(5) ‘HIV stigma’ AND ‘AIDS orphans’ AND ‘psychosocial well-being’

(6) ‘AIDS related stigma’ AND ‘orphans’ AND ‘well-being’

3.4.4 Method of review

Two reviewers (ZY and CJE) conducted the databases searches across the four levels of review. During identification, relevant titles pertaining to the study were identified. The results were recorded in an Excel spreadsheet indicating the hits, extracted titles, duplicates, and relevant titles. The abstracts of relevant studies were retrieved and screened according to pre-defined inclusion criteria for inclusion. For eligibility, the full text of pertinent abstracts were rigorously and critically appraised for methodological quality before being included in the review. All disagreements regarding the methodological quality and inclusion were discussed until consensus was reached.

3.4.5 Quality assessment

Inherent to systematic reviews is the appraisal of the methodological quality of included studies. Critical appraisal tools were independently adapted to assess the different study designs—qualitative, quantitative, and mixed methods. The Critical Appraisal Skill Program (CASP, 2014) and the Evaluative Tool for Mixed Method Studies (Long, 2005) was adapted for the appraisal of qualitative, quantitative, and mixed methods research along the guidelines proposed by Law at al., (1998) (Appendices 1–3).

These adapted appraisal tools aimed to evaluate holistically potential studies according to several domains: (1) study purpose, (2) study design, (3) sampling techniques, (4) data collection methods, (5) methods of analysis, and (6) ethical considerations. Such evaluation ensures both the overall quality and the methodological quality of each sub-section (Siering, Eikerman, Hausner, Hoffman-Eber, & Neugebauer, 2013). Rating scales of appraisal tools were adjusted to produce a composite score indicating the quality of studies from weak (0–30), moderate (31–65), strong (66–80) and excellent (81–100) (Tierney & Simon, 2004; Law et al., 1998). The predetermined threshold score set for this study was studies within the categories of strong and above. Appraisal tools were piloted to ascertain the validity and reliability of individual items, resulting in the addition of missing items and the deletion of extraneous items for an improved reviewing process (Kitchenham, 2004; Siering et al., 2013).

3.4.6 Data extraction

All included studies were subjected to a process of data extraction prior to analysis using a self-constructed data extraction sheet (Appendix 4). The data extraction sheet was developed along the guidelines provided in the Cochrane Data Extraction and Assessment Form (Higgins & Green (Eds.), 2011) and separated into three sections, namely: general description, methodology, and findings. These sections included the author/s, publication year, aim, problem statement, target population, geographical location, study design, theoretical underpinnings, sampling method, sample size, data collection methods and instruments, methods of data analysis, findings, and authors' conclusions. The self-constructed data extraction sheet was piloted to reduce bias (Kitchenham, 2004).

3.4.7 Data analysis

A meta-synthesis analysis, regarded as the joining or uniting of interrelated group of studies, was undertaken (Schreiber, Crooks, & Stern, 1997). A meta-synthesis analysis allowed for a deep and holistic understanding of HIV-related stigma and the psychosocial well-being of COA (Walsh & Downe, 2005) through the critical discussion of the emerging themes from the findings of included studies. The analysis was divided into a descriptive meta-synthesis and theory explication following the procedural guidelines proposed by Noblit and Hare (1988). The descriptive meta-synthesis produces a descriptive amalgamation of results extracted from findings and is represented as the process of results and data extraction (Schreiber et al., 1997; Finfgeld, 2003). Theory explication consists of reciprocal translations, refutational synthesis, and lines-of-argument synthesis (Noblit & Hare, 1988).

A meta-synthesis analysis was deemed appropriate for the current review as its overall goal is to produce a new and integrative explanation of findings through the deconstruction, reconstruction and synthesis of the findings, which illuminates concepts and relationships between these concepts (Finfgeld, 2003). Additionally, it allows for the emergence and alteration of operational models and theories (Finfgeld, 2003; Schreiber et al., 1997). Therefore, the analysis allows for the identification of concepts and the conceptualization of relationship statements needed for model development (Chinn & Kramer, 2008; Walker & Avant, 2005).

3.5 Phase II: Qualitative exploration

In Phase II, a qualitative exploratory descriptive study was implemented to answer the research question: "How do children who have been orphaned by AIDS perceive and experience HIV-related stigma and the manner in which it has affected their psychosocial well-being?" Phase II serves to address the overall aim of the study and satisfy objective 2: ***To explore children orphaned by AIDS perceptions and experiences of HIV-related stigma.*** The in-depth exploration undertaken during this phase serves to:

- Deeply engage with and understand COA experiences of HIV-related stigma with regards to their psychosocial well-being, thus expanding the understanding of the findings obtained in Phase I.
- Further expand, refine, and validate concepts identified during Phase I, as Walker and Avant (2005) suggest that qualitative and literary approaches may be combined for concept synthesis.
- Contribute towards statement synthesis in Phase III by identifying and exploring relationship statements among identified concepts (Walker & Avant, 2005).

Phase II of this study is presented and fully described in Chapter 5 of this dissertation.

3.5.1 Research design

A qualitative explorative descriptive study design allowed for a rich, in-depth, and holistic understanding of both HIV-related stigma and its relation to the psychosocial well-being as experienced by COA themselves (Polit & Beck, 2004; Lewis & Ritchie, 2003). This design was considered appropriate due its ability to (1) identify the nature of features of a phenomenon, and (2) map the range of dimensions of a social phenomenon, such as the varying dimensions and manifestations of HIV-related stigma and psychosocial well-being. An exploratory descriptive design is often used to investigate complex social phenomenon poorly understood. Considering the lack of consensus surrounding HIV-related stigma, which hinders a comprehensive understanding of stigma and its impact, this design was identified as suitable for this study (Deacon, 2006). Lastly, the flexible and modifiable approach offered by exploratory designs allows the theorist to select observations which contribute towards the emerging picture of a phenomenon and its relations, thus facilitating statement synthesis carried out in Phase III (Walker & Avant, 2005).

3.5.2 Study setting

The study was conducted within the Western Cape, South Africa. South Africa, located within sub-Saharan Africa, houses the highest population of PLWHA within the region (UNAIDS, 2014). In 2018, an estimated 7.25 million individuals were HIV positive totaling 13.1% of the general South African population (Statistics South Africa, 2018). HIV-infection resulted in an increase in mortality claiming 3,242,979 lives since the year 2002, with 11,567 AIDS relation deaths in 2018, accounting for 22.06% of total mortalities. High mortality rates have increased the orphan population to an estimated 2.3 million youth (UNAIDS 2014). However, a demographic study by Hall and Sambu (2018) concluded that 2.8 million children where orphaned in South Africa, which constituted 16 percent of the total population of children. Thirty percent of the population located within the Western Cape Province consisted of children, 6.7% of whom have been orphaned either maternally and/or paternally (Statistics South Africa, 2011). The study was conducted in an urban suburb and a township situated within Cape Town, namely, Athlone and Gugulethu, respectively. These geographical locations were considered to be socio-economically diverse.

Gugulethu is located on the Cape Flats, approximately 18km south-east of the city centre between the following neighboring areas: Manenberg, Heideveld, Bonteheuwel, and Bishop Lavis. The township has a population of 98,469, which are predominantly Black African (99%) inhabitants. According to the South African Census (Statistics South Africa, 2012), youth under 24 years of age totaled 45.3% of the township’s population. The township boasted a 39.66% unemployment rate, with 71% earning a monthly income of R3,200 or less. While the majority of the population resided in a formal dwelling, a large percentage of the population (40.7%) continues to live in informal dwellings such as a shack (Statistics South Africa, 2012).

Athlone is an urban suburb located east of the city center on the Cape Flats. While the suburb is mainly residential, it includes both commercial and industrial zones. The suburb of Athlone consists of sub-suburbs, including Gatesville, Rylands, Belgravia Estate, Bridgetown, and Hazendal. The suburb houses a population of 237,414 individuals, which are predominantly Coloured (87%) inhabitants. According to the South African Census (Statistics South Africa, 2012), youth under the age of 14 years constituted 26% of the suburb's population, with 65% of the population regarded as working age, ranging from 15–64 years of age. The suburb attained an 11.5% unemployment rate, while 18.6% of the population earned a monthly salary of between R19,601 and R38,200. The majority of the population (91.4%) resides in formal dwellings, such as a house which has access to sanitation (94%), clean running water (92.6%), electricity (98.4%), and refuse removal (99%) (Statistics South Africa, 2012).

3.5.3 Sampling

A non-probability purposive sampling technique was used to identify participants. The purposive sampling technique allows for the identification and selection of information-rich cases of interest (Patton, 2002), which is consistent with the objective to explore the experiences and perceptions of COA to gather a more in-depth understanding. As the technique allows for the identification and selection of individuals/groups of individuals that are knowledgeable and/or have experienced the phenomenon of interest, a criterion was developed to guide the selection process of participants. Participants were required to be children, and they were eligible to participate in the study if they (1) were between the age of 7–17 years, (2) had lost one or both parents to AIDS-related causes, (3) were HIV-negative, and (4) have been orphaned for a period longer than six months. The children were required to be HIV-negative in order to ascertain whether their experiences and perceptions of HIV-related stigma were resultant of familial HIV/AIDS illness and death, rather than their own HIV status. As suggested by Boyes and Cluver (2013), children orphaned in the last six months were excluded from participating in the study to prevent reactions of acute bereavement and minimize stress.

While it was envisioned that a sample size of 15–20 participants shall be recruited for participation in the study, non-disclosure strategies adopted by families and children alike deferred their willingness to participate, fearful that others may discover their relation to HIV/AIDS, a stigmatized illness in South Africa. Additionally, the study sought to include children within the developmental period of adolescence due to their cognitive ability to comprehend matters and experiences more abstractly. However, due to the vulnerability of COA and non-disclosure surrounding parental illness and death, children parentally bereaved in the last six months were excluded from the study. A total of thirteen children participated in the study and was deemed sufficient for the exploration of complex phenomenon such as HIV-related stigma (Polit, Beck, & Hungler, 2001). These participants were recruited through non-profit organizations, social workers, counselors, and community workers.

To gain access to the sample population, the primary researcher contacted several (n=46) non-profit organizations, social workers, and community workers assisting orphaned children, to explain the purpose and significance of the current study. Additionally, the researcher contacted the HIV/AIDS unit at the University of the Western Cape, to identify any unidentified organizations. An informed consent form was provided to all respective parties outlining the purpose and aim of the study, confidentiality, voluntary participation, perceived risks, and the benefits of the research; it included the contact details of the primary investigator and her supervisors for any further queries. These informed consent forms were distributed by the relevant parties to eligible families and organizations to ascertain whether the child would like to participate in the study. Furthermore, the primary researcher attended organizational meetings to personally explain the purpose of the study and gain access to the sample population. Once consent was obtained from the guardian, parent, or caregiver, the primary researcher met with the participants at a place and time of their choosing to begin the process of informed consent and reiterate the purpose, perceived benefits, and risks, and explain the conditions of confidentiality and voluntary participation. These aspects, together with the informed consent sheet, were explained to the participants in a language they could understand, and any questions regarding the study and the research process were fully addressed. Consent and assent forms were attained from the parent, legal guardian, or caregivers before the commencement of the interview process.

3.5.4 Data collection

Data collection was achieved through the use of individual open-ended face-to-face interviews to descriptively explore COAs experiences and perceptions of HIV-related stigma and its associated consequences for psychosocial well-being (Barbour & Schostak, 2005). This technique is favored as it seeks deep and rich information usually concerning personal matters, such as lived experiences, cultural knowledge, or an informant's perspective, and is therefore deemed suitable for the current study (Johnson, 2001). Interviews were conducted by a trained investigator in either English or Afrikaans at a private setting and time chosen by the participant. Interview duration ranged between 20–50 minutes, but did not exceed an hour, as suggested by Marshall (1996). Participants were reminded of their rights and limitations to confidentiality and voluntary participation, affording them the right to withdraw their participation from the study (National Health Research Ethics Council, 2015; Tsheko, 2007).

Pseudonym names were assigned to each participant to protect their identity and no identifying information was used throughout the interviewing process. Permission was obtained from the participants beforehand to audio-record the interviews. To minimize the issues of "being on record," as identified by Warren (2001), the investigator kept field notes of the interview to account for any data conveyed by the participant once the recording stopped. As suggested by Irwin and Johnson (2005), forms of play, such as drawings, were used as a means of building rapport with younger participants to reduce their anxiety and increase their comfortability prior to the interview process. Acknowledging the sensitivity of HIV/AIDS and issues around non-disclosure, terminology and questions pertaining specifically to HIV/AIDS were avoided by the investigator unless discussed by the participant themselves. Field notes and observational cues were recorded at the end of each interview and included the documentation of the context of the interview, key themes, and any adverse events. The data collection procedure ended once saturation was reached. Data saturation, although a universal approach, remains difficult to define and implement. This study therefore followed the guidelines proposed by Ness and Fusch (2015) for reaching data saturation when conducting individual interviews with participants. Aligned with these guidelines, the study interview guide facilitated the process of asking multiple participants the same open-ended questions, and the primary researcher remained sensitive when approaching gatekeepers who held the ability to restrict access to participants. Data saturation, in this study, was determined when (1) no new data emerged, (2) no new themes were presented, (3) further coding was not feasible, and (4) the process allowed the replication of the current study (Guest, Bunce, & Johnson, 2006). Additionally, the use of non-probability purposive sampling ensured the selection of participants according to common criteria. The similarity of the participants' experiences facilitated data saturation, as proposed by Guest, Bunce, and Johnson (2006).

3.5.5 Data collection tool

Individual open-ended face-to-face interviews were guided by an interview guide consisting of a series of open-ended questions and prompts (Appendix 5). The interview guide was developed along the guidelines proposed by Shaw, Brady, and Davey (2011) and the findings extracted from the systematic review conducted in Phase I. The open-ended questions centered around the concepts identified in Phase I to facilitate further exploration of identified concepts and elicit the associations between these concepts. Inherent to open-ended interviews, the interview guide was suggestive and flexible, allowing for the improvising of fruitful questions and the pursuit of unanticipated lines of inquiry (Millward, 1995). The developed guide was suitable for the study as it served to facilitate the descriptive exploration of COA experiences and perceptions of HIV-related stigma and how it has affected their well-being (Barbour & Schostak, 2005). Importantly, HIV/AIDS and parental bereavement was not explicitly mentioned to avoid distress in participants, remaining cognizant of the sensitive nature of the study. However, items remained sensitive enough to detect experiences of HIV-related stigma and poor psychosocial well-being.

Additionally, observation and field notes were used as a means of data collection. Simple observations were used by the researcher, as suggested by Babbie and Mouton (2001), and allowed for the collection of additional visual information that fosters a deeper understanding of the perceptions and experiences of HIV-related stigma as reported by COA. Simple observations allowed for the documentation of unusual aspects portrayed during interviews and the language and behavior of COA, contributing towards the richness of the data (Babbie & Mouton, 2001). Similarly, Creswell (2003) advocated for the use of observations as a data collection tool during the exploration of sensitive and complex issues.

Field notes were deduced from observations during the interview and was considered a critical aspect to understanding a phenomenon (Allen, 2017). Therefore, field notes are the documentation of simple observations outlining adverse events, along with behavioral cues, responses, and language used by participants (Creswell, 2003). Consistent with the guidelines provided by Strydom and Delport (2002), the researcher documented a comprehensive account of the participant, researcher-participant interaction, interview discussion, adverse events, usual and/or adverse behavioral cues and responses of participants, and the researcher’s thoughts, feelings, and attitudes experienced throughout the interview process.

3.5.6 Pilot test

Considering issues surrounding the sensitive nature of the explored phenomenon and non-disclosure techniques, a pilot study was conducted to test the developed interview guide. Therefore, the pilot study set out to (1) test the quality of the instrument, (2) identify and reduce any bias, (3) identify ambiguities, (4) clarify the wording of open-ended questions for its suitability for the South African population, and (5) identify unnecessary or difficult questions (Chenail, 2011; Noor, 2008). A single pilot interview was carried out and analyzed prior to the commencement of the data collection procedure. The pilot interview was conducted at a place and time of the participant's choosing. During the interview the researcher attained a sense of whether the questions were truly exploring the participants' perceptions and in-depth experiences of HIV-related stigma and their psychosocial well-being using the developed interview guide. The data collected during the pilot test was analyzed along the steps proposed by Braun and Clarke (2006). As rich information was elicited during the pilot testing, it was included in the actual data set.

3.5.7 Data analysis

A thematic analysis was conducted along the six suggestive guidelines proposed by Braun and Clarke (2006), namely: (1) familiarizing yourself with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. A thematic analysis is regarded as a method for identifying, analyzing, and reporting patterns within a set of data allowing for the data to be described in rich detail (Braun & Clarke, 2006). Given the mixed methods approach of this study, a thematic analysis was deemed appropriate as it is independent from theory and epistemology, meaning that it may be applied across a range of approaches (Braun & Clarke, 2006). Secondly, considering the explorative nature of this study, the method is flexible and proves to be a useful tool in providing a rich, detailed, and complex account of the data—being the experiences and perceptions of COA as they emerge (Braun & Clarke, 2006). Such exploration is needed for the development of relational statements to tie the identified concepts together as proposed by Walker and Avant (2005).

Atlas.ti (version 8) was used to facilitate the process of data analysis. The analysis adopted an iterative approach, requiring the researcher to move back and forth between the data set and the suggestive steps outlined above (Braun & Clarke, 2006). The analysis process began with the verbatim transcription of interviews. Each transcription was double-checked by the primary researcher for quality, accuracy, and errors against the audio-recordings captured during the interviews. Thereafter, transcripts were actively read and notes regarding the significance and importance as well as similarities and differences of the raw data were made in the margins, facilitating familiarization of the data. Transcripts were actively read twice before generating initial codes. Post familiarization, initial codes were formed, which refers to the “most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Braun & Clarke, 2006, p. 18). The researcher worked systematically through each transcript forming the entire data set, giving her full attention to each data item in order to identify aspects in the data items that formed repeated patterns across the data set. Extracts deemed interesting were coded, generating a list of initial codes, thus collating all extracts relevant to each initial code. During this stage, the researcher inclusively coded as many extracts as possible, ensuring that the context in which the data is presented is retained.

The next stage involved refocusing the analysis at the broader level and searching for themes. The list of codes was analyzed; codes relating to one another were clustered, resulting in the collation of all relevant coded extracts, giving rise to themes. The developed themes and sub-themes were revised by re-examining the codes forming each theme and their associated extracts to determine whether the codes forming each theme truly reflected the nature and meaning of COAs perceptions and experiences. This process of refinement resulted in the combination or further breaking down of possible themes into sub-themes. Once the researcher was satisfied with the themes and sub-themes that had emerged from the data, each theme was defined and named to reflect their essence. The final report was narratively presented in the form of the findings section in Chapter 5 of the dissertation. The findings outlined and discussed each theme and its associated sub-themes which emerged from the data to reflect COAs experiences and perceptions of HIV-related stigma and the manner in which it has impacted their psychosocial well-being.

3.6 Phase III: Development of a social transactional model

In Phase III, a theory generative design was employed to answer the research question, "What factors should be considered for the development of a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS?" Phase III addressed the overall aim of the study and satisfied objective 3: ***To develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS.*** The theory generative research approach adopted in this phase served to:

- Represent factors that precede or influence a specific phenomenon and event. HIV-related stigma was explored, thus signifying its origin and manifestations.
- Indicating the impact resulting from a specific phenomenon. The domains of psychosocial well-being of COA as influenced by HIV-related stigma were identified and highlighted.
- Categorize discrete and related scientific information into a theoretically organized form. Therefore, the results emerging from Phases I and II informed the theory generative approach undertaken in this phase. The findings collected in the previous phases were categorized into concepts and statements which formed a theoretical network or a whole, resulting in the developed model (Walker & Avant, 2005).

3.6.1 A theory generative design

Theory generative design is often conceived as an inductive approach and refers to research undertaken to clarify and describe relationships without imposing preconceived ideas about what these relationships mean prior to its development (Chinn & Kramer, 2004). Watson's (1985) definition of theory is consistent with the overall aim of this study and was therefore applied here. Watson (1985) states that a theory is an imaginative grouping of knowledge, ideas and experiences that are represented symbolically and seeks to illuminate a phenomenon. Aligned to this study, Watson (1985) holds that the purpose of theory is to understand what a phenomenon is rather than its direct application to practice. The grouping of knowledge, ideas and experiences that reflect human experience refers to the process of creating conceptual meaning (Chinn & Kramer, 2008). Conceptual meaning is created through the examination of thoughts and ideas arising from word symbols (Chinn & Kramer, 2008). Therefore, conceptual meaning is created through the examination of the experiences and perceptions of COA which are expressed in words (Phase II) and word symbols presented in published works (Phase I). A theory generative design was deemed appropriate for the current study as conceptual meaning portrays a mental image of what phenomenon is like and the manner it is perceived in human experience (Chinn & Kramer, 2008). The developed model in this study sought to provide a mental image of HIV-related stigma and its consequences for psychosocial well-being as it is perceived by COA.

3.6.2 Elements of theory building

Three elements of theory building are identified in theory generative research, namely: (1) concepts, (2) statements, and (3) theories (Walker & Avant, 2005), as discussed below:

1. **Concepts**

   Concepts form the basic building blocks of a theory, which is reliant on the identification and explication of concepts (Hardy, 1974; Walker & Avant, 2005). Concepts allow for the classification of experiences that may be expressed in a meaningful way and comes to present a "mental image of a phenomenon, idea or construct in the mind about a thing or action" (Walker & Avant, 2005, p. 59). Alternatively, concepts may be regarded as a complex mental formulation of experience (Chinn & Kramer, 2008). Experience is considered empiric when it may be symbolically shared and verified by others. Chinn and Kramer (2008) state that three sources of experiences inform the meaning of a concept, namely: (1) the word or symbolic label, (2) the thing itself, and (3) feelings, attitudes, and values associated with the word or its perception. According to Reynolds (1971), concepts vary in degree of abstractness, and may be labeled as primitive, concrete, and abstract. Concepts formed the foundation for developing a model for understanding HIV-related stigma and how it has affected the psychosocial well-being of COA.

2. Statements

Statements express the relationship between two or more concepts and provides an interrelational structure for the developed model (Chinn & Kramer, 2008; Walker & Avant, 2005). Statements are divided into relational and non-relational statements. The former declares a relationship or association between or two or more concepts, while the latter expresses the existence of a concept or definition that is either theoretical or operational. Relational statements presented in this study embody an associational nature which demonstrates whether concepts occur together. These statements may indicate a positive or negative association between concepts. A positive association implies that the occurrence or change of one concept results in the occurrence or change of another in the same direction (Walker & Avant, 2005). Contrastingly, a negative association indicates that the occurrence and change of a concept results in an occurrence or change of the associated concept in the opposite direction (Walker & Avant, 2005). The relational statements of this model began to form through the emergence and identification of concepts. Specific attention was directed towards the substance, direction, strength, and quality of interaction between concepts during Phase II.

3. Theories

Theories are formulated by systematically organizing concepts and relational statements to provide an integrative understanding of phenomenon. Theories are useful to describe, explain, predict, direct, and control a phenomenon (Walker & Avant, 2005). This study systematically organized concepts and relational statements to provide an understanding of HIV-related stigma and the manner in which it impacts the psychosocial well-being of COA. As suggested by Walker and Avant (2005), the theory developed is graphically presented as a model.

These elements are interrelated, as theory development often begins with the process of concept and statement development, giving rise to a graphical presentation of the developed theory, which is regarded as a model.

3.6.3 Approaches to theory building

For the development of these elements comprising a theory, three basic approaches of theory building are suggested, namely: derivation, synthesis, and analysis. These approaches for the development of concepts, statements, and theories—amounting to nine strategies—are presented in Table 3.3 below.

Table 3.3: Strategies for Theory Building

Element of theory	**Derivation**	**Synthesis**	**Analysis**
Concept	Concept Derivation	Concept synthesis	Concept analysis
Statement	Statement Derivation	Statement synthesis	Statement analysis
Theory	Theory Derivation	Theory synthesis	Theory analysis

Walker and Avant (2005) propose that the theorist needs to determine a suitable theory-building strategy, by selecting (1) an element that best suits their needs, and (2) an approach dependent on the extent and type of literature and data available on the current topic. The twelve-item list created by Walker and Avant (2005) guided the selection of approaches and strategies for theory development undertaken in this study and is presented in Table 3.4 below:

Table 3.4: Strategy Selection

Item	Selection questions for consideration
Selecting elements for theory building	
1	What is the existing extent of the theory development on the topic of interest?
2	How adequate is the existing theory development?
3	In which element is the available theory the weakest: concepts, statements, or the overall theory?
4	What do the review articles suggest about the kind of theory development needed next on this topic?
5	What is my personal judgment about the element of theory development that would be the most productive for me to peruse on my own topic of interest?
Selecting approaches for theory building	
6	Is there any existing literature on the topic?
7	If literature exists, is it research based or purely speculative?
8	Is the literature tied together by any common conceptual or theoretical frameworks?
9	What do the “state of the art” articles suggest about the adequacy of the existing theoretical work on the topic?
10	What types of information or data do I have direct access to?
11	What unique resources do I, as the theory builder, have access to that would facilitate theory-building efforts?
12	What is my personal judgment about the approach to theory building that would be most productive for the pursuit of my topic of interest?

This study adopted a synthesis approach to theory development for the development of concepts, statements, and the overall model. The synthesis approach was deemed appropriate for the study as it is often implemented for the construction of a new concept, statement, or theory in the absence of an explicit theoretical framework. This strategy allows for the shifting of important information from large sources of descriptive data (qualitative data) and has been identified as a key strategy for making sense of data which has been mined from large databases (systematic review) (Walker & Avant, 2005). This synthesis approach is grounded in the steps of Phase III towards theory development.

The process of model development unfolds in four stages resulting in the developed model. Phase III included three of these proposed stages, namely, concept development (Chapter 6), statement development (Chapter 6), and model description (Chapter 7). While model evaluation is often coupled with model description, this study presented the evaluation in the form of a Delphi study presented in Phase IV. Additionally, Phase III marked the integration of the findings presented in Phase I and II, which is presented as the developed model.

- Stage 1: Concept development serves to draw on the findings of Phases I and II to develop focal and related concepts forming the foundation upon which the model is based.
- Stage 2: Statement development draws on the findings of Phase II to identify and specify relationships between the developed focal and related concepts within the model. These statements allow for the formation of networks between concepts in order to form a whole.
- Stage 3: Model description integrates the developed concepts and relationship statements to accurately describe and visually represent the social transactional model of HIV-related stigma and the psychosocial well-being of COA, as proposed by Chinn and Kramer (2008).

3.6.4 Stage 1: Concept development

Concept development is considered a critical task in theory development as concepts constitute the basic blocks of a theory, forming the foundation upon which a theory is built (Walker & Avant, 2005). The stage of concept development included (1) concept identification, (2) concept classification, and (3) definitions of concepts, as proposed by Chinn and Kramer (2008), Walker and Avant (2005), and Dickoff et al., (1968), and is presented in Chapter six of this dissertation.

3.6.4.1 Concept identification

Concepts enable the categorization and classification of similar experiences or constructs in a meaningful way that may be conveyed to others (Walker & Avant, 2005). According to Chinn and Kramer (2008), concepts may be derived from several sources, including life experiences, clinical practice, and research or existing evidence. Concept synthesis begins with raw data; therefore, a mixed methods approach consisting of a literary (Phase I) and qualitative synthesis (Phase II) were analyzed for concept identification as suggested by Walker and Avant (2005). These approaches were deemed suitable for the current study as they allow for the identification of similarities and differences between two data sets. According to Chinn and Kramer (2008), the identification of concepts is guided by the purpose and expressed values related to the study (Chinn & Kramer, 2008). The identification of concepts in this study was therefore guided by the pursuit to understand HIV-related stigma and its impact on the psychosocial well-being of COA. Concept identification is further influenced by the values of the researcher, which includes their beliefs about the following constructs: HIV-related stigma, the psychosocial well-being of COA, and the social environment in which the phenomenon would occur.

The identification of concepts adopted an iterative approach to searching and clustering words or groups of words representing a phenomenon, until theoretical saturation was reached (Chinn & Kramer, 2008; Glaser & Strauss, 1967; Walker & Avant, 2005). The first round of concept identification was ingrained in the meta-synthesis analysis carried out in Phase I. Words that appeared repeatedly and conveyed thoughts, feelings, ideas, or knowledge about HIV-related stigma and the psychosocial well-being of COA were coded. On completion of the analysis, a code report was generated, and each code was reviewed. These codes were clustered to form initial concepts upon which to base the model. The results from the meta-synthesis analysis and the initial list of concepts was used to inform the development of an interview guide to facilitate the exploration of experiences and perceptions of COA regarding HIV-related stigma and their psychosocial well-being. The thematic analysis conducted in Phase II allowed for the further identification and expansion of concepts. Again, word items were coded producing a list of codes representing concepts as expressed by COA. The two concept lists from Phases I and II were combined to produce an extensive list of concepts and related concepts. The review of each concept and their associated codes and extracts resulted in assimilation. Concepts were further refined through the process of clustering. Overlapping concepts were clustered together to form focal or overarching concepts, until theoretical saturation was reached. Focal concepts containing many sub-categories were awarded related concepts to provide clarity for each focal and related concept.

3.6.4.2 Concept classification

The survey list developed by Dickoff et al., (1968) was used to classify the focal concepts of the model. The survey list (Dickoff et al., 1968) highlights six significant activity aspects, namely: (1) agency, (2) recipiency, (3) framework, (4) dynamics, (5) procedure, and (6) terminus, as presented in Table 3.5 below. Each activity is guided by individual questions. These aspects are to be considered and applied for the full exploration of HIV-related stigma and its impact on the psychosocial well-being of COA (Dickoff et al., 1968).

Table 3.5: Aspects of Concept Classification (Dickoff et al., 1968)

Aspect	Activity
Agency	Who or what performs the activity?
Recipiency	Who or what is the receipt of the activity?
Framework	In what context is the activity performed?
Terminus	What is the end point of the activity?
Procedure	What is the guiding procedure, technique, or protocol of the activity?
Dynamics	What is the energy source for the activity?

3.6.4.3 Defining concepts

According to Walker and Avant (2005), once a new concept has been developed and considered adequate, it should be defined using a theoretical or subject-specific definition. Similarly, Chinn and Kramer (2008) suggest that definitions of concepts convey conceptual meaning and thereby help clarify ideas and usages associated with a concept; they also propose the use of dictionary definitions. These definitions represent core elements associated with a concept or word, including perceptions, feelings, and objects. This study, therefore, utilized (1) a dictionary definition, (2) a subject-specific definition, and (3) a summary to define focal concepts of the model. The integration of dictionary and subject-specific definitions provides a synopsis of definitions contextually specific to the current study. These synthesized definitions create conceptual meaning of the focal concepts, forming the model to understand HIV-related stigma and its impact on the psychosocial well-being of COA, as argued by Chinn and Kramer (2008).

3.6.5 Stage 2: Statement development

Statement synthesis was employed to specify relationships between two or more concepts at the concept development stages, based on the collected evidence as suggested by Walker and Avant (2005). Similarly, Chinn and Kramer (2008) suggest that relationship statements structurally interrelate concepts of a proposed theory ranging from simple statements to complex statements which account for interaction among multiple concepts. Drawing on the qualitative findings that were extracted in Phase II, statements were developed from observations of the phenomenon being studied and outlining the relationship between developed focal and related concepts (Walker & Avant, 2005). While qualitative studies are diverse and vary in their purpose and method, their flexible and modifiable approach permits the theorist to select observations related to the emerging picture of the studied phenomenon (Walker & Avant, 2005). The qualitative exploration undertaken in Phase II, therefore, adopts an iterative approach, allowing for the validation and refinement of concepts and statement relationships. The qualitative exploration assisted the primary researcher to make inferences from the data, moving from specific to abstract inferences. These inferences were facilitated by the literary synthesis undertaken in Phase I. Relationship statements were further categorized by the survey list provided by Dickoff et al., (1967) and are presented in the survey list and model description in Chapters 6 and 7 of this dissertation. Developed relationship statements projecting the interrelation between and among concepts provides the substance and form of the developed model (Chinn & Kramer, 2008). All relationship statements were derived from or supported by the evidence collected during Phases I and II and are displayed in the description of the developed model outlined in Chapter 7 of this dissertation.

3.6.6 Stage 3: Model description

Once a theory has been developed, it is necessary to fully describe the theory to facilitate a clear understanding of the nature and flow of the developed theory for use in research or practice (Chinn & Kramer, 2008). Description centers on the descriptive components of a theory which forms the basis for understanding what a theory is and how it works. Theory description allows for the process of critical reflection, examining the value of the developed theory for various purposes (Chinn & Kramer, 2008). This study followed the guide for theory description proposed by Chinn and Kramer (2008), which focuses on six core descriptive components, namely, the (1) purpose, (2) concepts, (3) definitions, (4) relationships, (5) structure, and (6) assumptions of the social transactional model of HIV-related stigma and child psychosocial well-being (Appendix 6). In addition to the theory guide, the theory description undertaken in this study is further guided by the six questions identified by Chinn and Kramer (2008) for adequately describing the developed model, and is presented below:

1. What is the purpose of the theory?

   This question serves to address why a theory was developed and reflects the contexts and situations in which the developed model may be applied.

2. What are the concepts of the theory?

This question serves to explicitly identify the concepts and the structure and relations of concepts in a model. Explicit identification of concepts is significant as they contribute towards the understanding of the form of the developed model.

3. How are concepts defined?

   This question allows for the clarification of the meaning of concepts within the theory and questions the empiric evidence represented by these concepts.

4. What is the nature of relationships?

   This question addresses the interrelations and links between concepts. It places focus on the various forms of relationship statements and the structure they provide within the model.

5. What is the structure of the theory?

   This question explores the overall form of the model—including its conceptual interrelationships. This question discerns whether the developed model has a partial structure or a singular basic form. The structure of the model includes a geographical representation of the developed model along with an in-depth description of its structure and form.

6. On what assumptions does the theory build?

   This question highlights the basic truths which underlie the developed model, representing its theoretic reasoning. These assumptions may reflect philosophic values or factual assertions. The assumptions underlying the model developed in the study were drawn from the conceptual framework presented in Chapter 2 and is considered the theoretical lens underpinning the developed model.

3.7 Phase IV: The Delphi technique

In Phase IV, a Delphi technique was implemented to answer the research question, “What is the functionality of the developed model according to various stakeholders?” Phase IV was implemented to address the overall aim of the study and objective 4: ***To determine the functionality of the***

developed model through the use of the Delphi technique. The Delphi technique adopted during this phase served to:

- Reach a consensus among key stakeholders regarding the functionality of the developed model that fosters an understanding of HIV-related stigma and how it affects the psychosocial well-being of COA (Hasson, Keeney & McKenna, 2000; Hsu & Sandford, 2007).
- Move beyond gathering consensus and act as the critical reflection necessary for understanding the nature and value of the developed model (Chinn & Kramer, 2008).
- Contribute towards the assessment of the functionality and structure of the developed model.

Phase IV of this study is presented and fully described in Chapter 8 of this dissertation. The Delphi study sought to provide a critical evaluation of the developed model, representing the fourth and final stage of model development. This evaluation was aligned with Chinn and Kramer's (2008) suggestion that the theorist conduct a critical reflection as an evaluation technique as a stage for model development. Phase IV, therefore, sought to gain key stakeholder's opinions and consensus regarding the functionality of the developed model using the critical reflection guidelines proposed by Chinn and Kramer (2008) (Appendix 7). While Chinn and Kramer (2008) refer to model description and evaluation as a unified stage, they are presented in this study as two separate stages, as the reflective evaluation is embodied as a Delphi technique rather than a self-evaluation completed by the theorist herself.

3.7.1 Study design

A modified Delphi technique was utilized to determine the functionality of the developed model in this study. Generally, the Delphi technique is regarded as a systematic approach which seeks to obtain consensus on the opinions of key stakeholders or experts through a series of structured questionnaires for the undertaking of a critical evaluation (Hasson et al., 2000; Young & Jamieson, 2001). However, a modified Delphi technique differs from traditional consensus seeking methods, as it fails to seek answers from panel experts during the first round (Avella, 2016). Rather, the modified design allows for the researcher to present previously elicited answers to an expert panel, initiating the consensus seeking process (Avella, 2016). Correspondingly, the methodological design used to develop the presented model previously gathered answers from (1) a relevant systematic review, and (2) a qualitative exploration. Additionally, the theory generative approach to model development was accompanied by an evaluative questionnaire that held the potential to illicit consensus regarding the aspects, description, and formulation of the developed model (Chinn & Kramer, 2008). As the execution of the Delphi technique design may take many different forms despite the perceived purpose, the technique was deemed suitable for gathering consensus among experts on the developed model (Avella, 2016).

Aligned with the theory generative approach, the modified Delphi technique centered around the points of critical reflection outlined by Chinn and Kramer (2008), including (1) simplicity, (2) clarity, (3) generalizability, (4) accessibility, and (5) importance. These points seek to contribute to an understanding of how well a developed model relates to practice, research, and/or educational activities (Chinn & Kramer, 2008). In turn, this phase seeks to gather group consensus regarding the understanding of the developed model as it relates to practice, research, and educational purposes.

The modified Delphi technique was deemed suitable as (1) it is a verified method of consensus building which ensures the functionality and validity of the preliminary findings upon which the social transactional model of stigma for child psychosocial well-being was built; (2) it is applicable in an area of interest where there is limited evidence, such as HIV-related stigma and its impact on the psychosocial well-being of COA; and (3) it is applicable to large complex problems or situations plagued with much uncertainty, such as the conceptualization of stigma; and (4) it has the ability to gather the collective subjective judgements of experts, which are beneficial to understanding a phenomenon in the light of limited research (Avella, 2016; Hasson et al., 2000; Hejblum et al., 2008; Young & Jamieson, 2001. The Delhi technique process, as displayed in this study, combined expert opinions, formulating group consensus of HIV-related stigma and the manner in which it has impacted the psychosocial well-being of COA. The modified Delphi technique, as carried out in this study, followed the suggestive guidelines of Boulkedid, Abdoul, Loustau, Sibony, and Albert (2011) that specifies four quality indicators for optimal use and reporting of a Delphi method.

3.7.2 Participant selection

As Delphi subjects are required to be “highly trained and competent within the specialised area of knowledge related to the target issue,” a purposive non-probability sampling technique was utilized for the selection of participants (Hsu & Sandford, 2007, p. 3). Experts were selected according to predetermined criteria as the strategic selection of experts is deemed vital if group consensus is to be reached (Duffield, 1993). Similarly, Boulkedid et al., (2011) regarded the careful selection of experts as a quality indicator. Consequentially, participants were required to be experts who are skilled, trained, and knowledgeable about HIV-related stigma and the psychosocial well-being of children who have been orphaned by AIDS. Experts could be of either local or international backgrounds. As the inclusion criteria places a large focus on expertise and knowledge regarding the target issue, careful consideration was awarded to the occupation, specialization, and education and training of selected experts (Hsu & Sandford, 2007). Therefore, experts to be included were required to be (1) healthcare professionals; (2) organizational members; (3) scholars focusing on stigma, discrimination, and child well-being; (5) renowned experts in the field; and (6) informal caregivers (Hsu & Sandford, 2007). The selection criteria were aligned with the notion that expert selection is dependent upon the disciplinary areas required by the specific issue, which in this study was HIV-related stigma and the psychosocial well-being of COA (Hsu & Sandford, 2007). Participants were therefore selected according to their contribution to the field of HIV-related stigma and child well-being. As the psychosocial well-being of children orphaned by AIDS remains largely unexplored, the criterion for inclusion regarding ‘child well-being,’ included experts focusing on particular domains of well-being, such as child psychological health.

The initial respondents selected via purposive sampling facilitated the further selection of participants through snowball sampling. Experts suggested by participants were examined for eligibility against the predetermined inclusion criteria. Experts deemed eligible for inclusion in the study were invited to partake in the current study.

The sample size, which was deemed sufficient for the current study, was guided by the suggestions highlighted by Hsu and Sandford (2007) who proposed that the appropriate sample size for reaching consensus should range from 10–15 experts. Simultaneously, Hsu and Sandford (2007) maintained that the sample size of Delphi technique studies vary. This study therefore strove to obtain a sample size ranging from 10–15 expert participants. While the desired sample size envisioned for the study was 15 experts, a total of 14 experts participated in the current study due to lower response rates to the invitation to participate, a well anticipated drawback of implementing the Delphi technique (Hsu & Sandford, 2007).

3.7.3 Data collection tool

A self-administered questionnaire based upon the critical reflective evaluation proposed by Chinn and Kramer (2008) was developed for consensus building among participating experts, as suggested by Avella (2016). The self-administered questionnaire consisted of 3 parts, namely: (A) a full narrative description of the social transactional model of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS; (B) biographical information; and (C) a 30-item questionnaire focusing on the simplicity, clarity, generalizability, accessibility, and importance of the presented model (Appendix 8).

Section A presented a full narrative description of the developed model, as provided under Phase III of the study which outlines the structural process, concepts, relational statements, and opalization of the model. This description built upon the empirical findings of the systematic review and qualitative explorative descriptive study undertaken in Phases I and II, respectively.

Section B captured the biographical information to be elicited from panel experts, namely, demographic details, gender, institution, occupation, and area of interest.

Section C presented 30-items pertaining to the (1) clarity, (2) simplicity, (3) generalizability, (4) accessibility, and (5) importance of the social transactional model of HIV-related stigma and the psychosocial well-being of COA, as suggested by Chinn and Kramer (2004; 2008). These items were important for evaluating the functionality of the model and acts as a critical reflection of the model, as developed within this study. However, the evaluative questionnaire was adapted removing items pertaining to semantic clarity, structural clarity, and structural consistency. These adaptations were deemed appropriate as the graphical structure of the model was not presented to expert panels. A further 3 items were removed, as they pertained to the nursing discipline for which the theory generative methodology was developed. The questions posed by Chinn and Kramer to encourage reflective evaluation among theorists were adapted into statements, with items to be rated by panel experts. Items were rated using a 4-point Likert scale ranging from (1) Strongly Disagree, (2) Disagree, (3) Agree, and (4) Strongly Agree to determine the consensus among participating panel experts.

3.7.4 Data collection procedure

The recruitment process continued over an eight-month period from the 5th of January 2019 until the 28th of August 2019. Invitations to participate in the current study were sent to prospective participants at the beginning of January 2019. Several methods were used to purposefully select potential participants, namely, the assessment of biographies, both local and international conferences, workshops, and organizational discussions. The biographies of potential experts were scrutinized according to the pre-defined inclusion criteria for eligibility for participation. The primary researcher engaged in networking initiatives at conferences, workshops, and organizational discussions were undertaken to identify additional eligible participants interested in participating in the Delphi study. Consistent with the inclusion criteria, potential participants were identified and selected upon their expertise and contribution in the field of HIV/AIDS, stigma, and child well-being. This process of identification resulted in a compiled list of eligible participants with their contact details in December 2018 (Boulkedid et al., 2011). Thirty-five experts were identified and invited to participate in the Delphi study at the beginning of January 2019. Invited participants were of both national and international geographical locations. Additionally, invited participants varied in their expertise in the field of interest, allowing for recruitment of a heterogeneous sample. Aligned with the indicators of quality, invited participants were heterogeneous in nature, speaking to the creditability and acceptance of quality indicators, as the expert panel is to reflect a diverse and full range of key stakeholders who are interested in the developed model and the empirical evidence upon which it is based. The varying views of a heterogeneous sample allows for the enrichment of the result produced by the Delphi technique (Boulkedid et al., 2011).

As suggested by Hsu and Sandford (2007), the use of electronic technologies facilitated the participant recruitment process. Potential participants were electronically invited via email, which included a brief description of the invitation, an information sheet, informed consent, and the self-administered questionnaire designed as an editable document. The consent of participating, indicating their willingness and agreement to participate, was received via email. Electronic technology allowed for an easy application of the Delphi technique and offered the advantage of the maintenance of participant anonymity, the potential for responsive feedback, and the efficiency of storing, processing, and the dissemination of findings (Hsu & Sandford, 2007; Witkin & Altschuld, 1995). The benefit of the anonymity of participants is regarded as vital for consensus building as it acts to minimize the impact of dominant participants likely to influence the opinions of others (Hsu & Sandford, 2007). The viewpoint of dominant participants is minimized, along with other downsides associated with group dynamics, such as manipulation, conformity, and coercion (Adams, 2001; Hsu & Sandford, 2007).

Once the consent of participants was received, participants were instructed to carefully read the full-description of the social transactional model of HIV-related stigma and the psychosocial well-being of COA. Thereafter, participants were instructed to rate their agreeableness with each item on a Likert scale ranging from (1) Strongly Disagree to (4) Strongly Agree. Once completed, participants were to return the completed questionnaire to the primary researcher electronically, where the responses were extracted and populated into an Excel spreadsheet. Data was collected until consensus was reached. While it was envisioned that multiple iterations or rounds would be completed for the attainment of group consensus, preliminary findings indicated that group consensus had been achieved. As a result, only one round was necessary and completed (Hsu & Sandford, 2007).

3.7.5 Data analysis

Collected data was subject to a process of extraction and analysis. The collected data was extracted, coded and cleaned. A descriptive statistical analysis was carried out using the Statistical Package for the Social Sciences (SPSS) version 26. The raw data was checked for completeness and correctness by the researcher before carrying out the statistical analysis. In line with the quality indicators, descriptive statistics and levels of dispersion is most commonly used to present the collective judgments of responding experts (Hasson et al., 2000). The use of the median is strongly favored and inherently appears to be the best suited method to reflect the convergence of opinion (Hill & Fowles, 1975; Hsu & Sandford, 2007). Additionally, consensus was determined by the mode. Prior to the determination of the mode for each item, the Likert scale was dichotomized. Therefore, this study determined consensus by using the mode and median, which are regarded as the most favorable methods. As suggested by Boulkedid et al., (2011), and Hsu and Sandford (2007), 70% of respondents are to rate 3 or higher on a 4-point Likert scale and attain a median of 3,25 or higher, indicating consensus. For levels of dispersion, the interquartile range was identified as best practice and was calculated to reflect consensus among the respondents.

3.8 Trustworthiness

In the pursuit of trustworthiness, the four main aspects suggested by Shenton (2004) were considered in this study, namely: (1) credibility, (2) transferability, (3) dependability, and (4) confirmability, and are discussed below.

- ***Credibility***

  Appropriate and recognized research methods were adopted from empirical bodies of work which proved to be both successful and reliable. Triangulation was implemented through the use of multiple methods of data collection spanning across Phases I, II, and IV. Triangulation was further facilitated by the use of multiple data collection tools, such as in-depth face-to-face interviews, field notes, and observations (Shenton, 2004).

  The systematic review conducted in Phase I allowed for the examination of previous findings which acts to frame the findings of the current study, promoting credibility. Similarly, the participation in varying research studies employed in this study provides confirmation of emerging findings while increasing the breadth of the phenomenon of interest. The amalgamation of findings from different studies across the phases allowed for the attainment of multiple perspectives and the validation of findings (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). In Phase II, credibility was ensured by first conducting a pilot study. This enabled familiarization with the culture of the participants and organizations prior to the study, which served to foster an understanding of the phenomenon and to establish trust between the primary researcher and participants (Shenton, 2004). The honesty of participants throughout all phases was ensured through honest data collection methods where participants were completely aware that their participation was voluntary, anonymous, and confidential. Supervision sessions were held between the researcher and her supervisors. The purpose of these sessions were to broaden the researcher’s vision, develop ideas and interpretations, and discuss alternative approaches. Lastly, credibility was ensured through the use of qualified and experienced investigators for data collection and analysis for all phases throughout this study.

- **Transferability**

A mixed methods methodology was implemented, as a wide range of participants are able to provide a holistic contextual depiction of the phenomenon under study. This promotes transferability as it increases the extent to which the findings of this study may be applied to other situations (Shenton, 2004). In addition, the in-depth account of the study's methodological aspects, as discussed in this chapter, and a full account of the study's background and description of the phenomenon, increased the transferability of the current study.

- **Dependability**

To ensure dependability, the research process should be described in detail enabling the replication of the study (Shenton, 2004). Dependability in the current study was therefore ensured through explicitly accounting for the study site, criteria for participant inclusion, sample size, data collection methods, data collection procedures, and the time period in which the study was conducted, so that the study can be replicated.

- **Conformability**

Lastly, conformability was ensured by the reduction of researcher bias through the use of bracketing, provision of in-depth methodological procedures, and the acknowledgement of the limitations of the study. The in-depth methodological description allows for the integrity of the research results of the study to be scrutinized (Shenton, 2004). The limitations of the current study and its potential effects were explicitly identified and discussed. The primary researcher engaged in a reflective process of bracketing where she recognized and set aside any presuppositions, biases, and past experiences to ensure that the study's findings report the experiences and thoughts of the participants (Tufford & Newman, 2010).

3.9 Reflexivity

Introspective reflexivity is regarded as an explicit self-aware meta-analysis (Finlay, 2002). It was utilized to address interviewer bias and enhance the trustworthiness, transparency, and accountability of the research study. With the use of a self-reflective journal, the researcher engaged in reflection on personal meanings, insights, and experiences drawn from the research process. Moreover, engagement with key stakeholders also served to limit bias, misconceptions, and misunderstandings that may be held by the researcher, thus ensuring the accuracy and trustworthiness of the findings.

3.10 Ethic considerations

The ethical considerations in this study included: Permission to conduct the study was granted by the University of the Western Cape's Senate Research Ethics Committee under grant no. HS17/1/17 (Appendix 9). Upon receiving ethical approval, the systematic review in Phase I was undertaken following the ethical guidelines for systematic reviews as proposed by Vergnes, Marchal-Sixou, Nabet, Maret, and Hamel (2010) and Wager and Wiffen (2011). All studies included in the review were peer-reviewed published articles available in the public domain to ensure transparency. As suggested, the primary researcher was sufficiently trained and efficient in the research methodology and, as a registered student of the University of the Western Cape, had full access to all the respective databases. All the necessary steps were followed by the primary researcher to maintain the integrity of the study and avoid any misconduct and plagiarism (Wager & Wiffen, 2011). The study remains sensitive to the ethical shortfalls of systematic reviews as identified by Vergnes et al., (2010), increasing the trustworthiness and reliability of the study's analysis and findings.

Upon completion of Phase I, contact was established with registered non-profit organizations working with COA and other vulnerable children for permission to conduct the study in accordance with the Non-Profit Organizations Act (Act 71 of 1997). The resident practitioner at the respective organizations approached the parents, legal guardians and participants, informing them about the study and providing them with an information sheet (Appendix 10). The information sheet consisted of the purpose of the study, expectations of participants, their rights to confidentiality, risks and benefits of the research, voluntary participation, and contact details for further queries. Informed consent (Appendix 11) from the legal guardian/s and assent (Appendix 12) from the participants who were willing to partake in the study were obtained using informed consent and assent forms and is regarded as good practice (Delva et al., 2009; Strode, Slack, & Essack, 2010; Tsheko, 2007).

Considering the sensitive nature of the topic, interviews were conducted separately with each participant on days best suited to their availability in a non-threating environment. Due to the sensitive nature of the phenomenon being explored and the knowledge and insights that were sought from the participants, it was critical to ensure that their participation would not expose them to any risk, unfair treatment, emotional distress, or stigmatization (Tsheko, 2007). Participants were protected through confidentiality, anonymity, and their rights, which were upheld and protected by the entire research team (primary researcher, supervisor, and any research assistant present where applicable) (National Health Research Ethics Council, 2015). Confidentiality and anonymity were observed by allocating pseudonyms to each participant being interviewed for identification purposes. All information gathered remained confidential as stipulated in the consent forms (Zhao et al., 2009). Information that was shared with the supervisor was for supervisory purposes only, and excluded all other individuals, including family members and personnel from the non-profit organizations (Thupayagale-Tshweneagae & Benedict, 2011). Confidentiality was maintained except where participants were at risk of significant harm or requested assistance. The limitation of confidentiality was fully explained to participants prior to their participation in the current study.

A participant's disclosure of abuse or risk of harm was to be reported to the necessary protection services or personnel, such as the parent or legal guardian and social services (Children's Act 38 of 2005; Mahery, Proudlock, & Jamieson, 2010). Information was not published in a form that would reveal the identities of the participants, thus safeguarding their identity (UNISA, 2013). Data was stored in a locked cabinet in the researcher's locked office. Electronic data files were encrypted, with access limited to the researcher; the computer used by the researcher was also password protected. In terms of disposal, data will be by shredding or incineration. Participation was voluntary and participants could withdraw their participation at any given time, without consequence. The purpose of the study, perceived benefits, and the possibility of any risk or harm was reiterated before the commencement of the study, affording participants the opportunity to withdraw their participation (National Health Research Ethics Council, 2015; Tsheko, 2007). To decrease the arousal of distress, participants orphaned in the last six months were excluded from the study (Boyes & Cluver, 2013). The researcher respected the sensitive nature of the phenomenon being studied and displayed her sensitivity to the issues and experience of participants through the sensitive and respectful treatment of participants. The respect, dignity, safety and well-being of participants were upheld as the researcher did not undermine any participant—all were treated with honesty and integrity (National Health Research Ethics Council, 2015).

The researcher acknowledged that participants regarded as children or vulnerable implied an unequal relationship between the researcher and participants. Trust was therefore maintained by (1) communicating any changes or amendments to the research project; (2) promoting the best interest of the participant and protecting their well-being; (3) continually reiterating the conditions of participation; (4) refraining from any action that constitutes improper pressure on the participant to participate; and (5) creating a space for the participant to freely discuss their concerns (Human-Vogel, 2007). No deception was used in this study. Information was at no stage withheld and correct information was disseminated to the participants, legal guardians, and non-profit organizations. Despite the following precautions, safety monitoring was implemented, and the primary researcher was equipped and appropriately trained to deal with any issues that may arise during the data collection procedure. Observation was used to identify any sign of distress displayed by the participant. In such an event, a short break was awarded to the distressed participant (5–10 minutes). If the participant remained distressed or upset after the break, the interview/session was terminated. All adverse events were documented and adequate provisions—a resource list—was provided to trained staff members and participants if debriefing was needed (National Health Research Ethics Council, 2015; UNISA, 2013). A psychologist and clinical social worker were appointed by the respective organization to offer support or provide assistance to participants if the need arose. They were fully trained to deal with signs of distress presented by the participant and were therefore qualified to offer the appropriate services needed.

3.11 Conclusion

This chapter introduced and fully described the methodological aspects of the current study as presented across Phases I, II, III, and IV. Trustworthiness and reflexivity was also addressed, and further consideration was given to ethical issues relevant to this study. The following chapter introduces a manuscript presenting Phase I of the current study.

3.12 References

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Chapter 4

Phase I: A systematic review focusing on HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

4.1 Introduction

The previous chapter provided an overview of the research methodology employed in this study. The current chapter introduces Phase I of the study, which embodies a systematic review methodology (see Figure 4.1). HIV-related stigma has been identified as a salient stressor in the lives of COA, separating them from other groups of orphaned and vulnerable children. HIV-related stigma has been recognized as a mediating factor with the potential to affect the psychosocial well-being of COA. Consequently, this chapter presents the findings of a systematic review that examined the impact of HIV-related stigma on the psychosocial well-being of COA in the form of a published manuscript, denoting the first article of this dissertation (Article 1).

4.2 Publication details

Article 1 has been published in the *Journal of Vulnerable Children and Youth Studies*, the details of which are provided in Table 4.1 below.

Table 4.6: Article 1: Publication Details

Title	**HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A systematic review**
Author	Yassin, Z., Erasmus, C. J., & Frantz, J. M.
Year	2018
Journal	Vulnerable Children & Youth Studies
Volume	13
Issue	3
Page no.	247–258
Status	Published (30 March 2018)
Full citation	Yassin, Z., Erasmus, C., & Frantz, J. (2018). HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: a systematic review. *Vulnerable Children and Youth Studies*, *13*(3), 247–258. doi.org/10.1080/17450128.2018.1457193

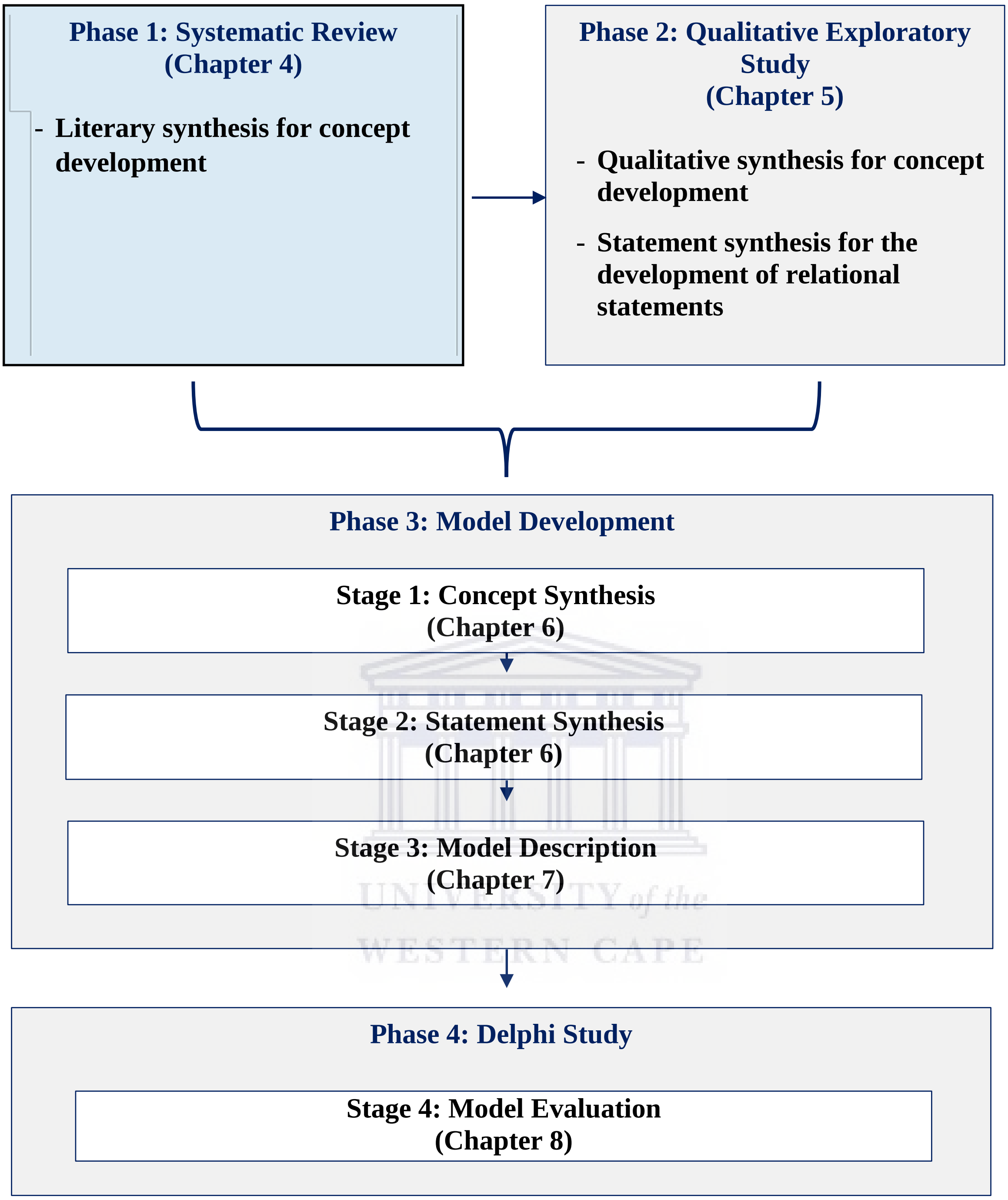

Figure 4.3: Systematic Review

4.3 Journal overview

The manuscript was published in the journal titled, *Vulnerable Children and Youth Studies: An International Interdisciplinary Journal for Research, Policy and Care*. The international, peer-reviewed journal stored under Taylor and Francis publishing house, focuses on vulnerability in childhood from both scholarly and experiential perspectives to facilitate the dissemination of learning and good practice for improving the lives of children. The focus on childhood vulnerability includes psychological, sociological, health, gender, cultural, economic, and education aspects of childhood and adolescence within developed and developing countries. More specifically, the journal adopts an interdisciplinary approach to focusing on vulnerable children and youth at risk in relation to their health and welfare issues. These issues include mental health, illness, HIV/AIDS, disability, abuse, neglect, poverty, orphanhood, exploitation, war, violence, and disaster.

4.4 Phase I: Published article

HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A systematic review

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Article was submitted to Vulnerable Children and Youth Studies (Accepted on 13 March 2018).[1]

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[1] Unlike the dissertation, wich is written in US English (as per APA) the 3 published/submitted articles (in Chapters 4, 5 and 9) utilize UK spelling (as per the requirements of each particular journal).

Abstract

The study aimed to systematically review existing literature reporting on the effects of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS. A systematic review methodology was used to search electronic databases and journals including Academic Search Complete, AIDS Care, PsychArticles, PubMed and SA ePublications from January 2006 to December 2016. Included studies were required to be peer reviewed, full text, in the English-medium, embody a quantitative, qualitative, or mixed methodology, and focus on HIV-related stigma and its impact on the psychosocial well-being of children orphaned by AIDS. Findings were extracted in four steps: (1) identification, (2) screening, (3) eligibility, and (4) inclusion. A meta-synthesis was used for the extraction and amalgamation of findings. Thirteen studies were included in the final review and consistently indicated that HIV-related stigma inhibited the psychosocial functioning and well-being of children orphaned by AIDS. This study sheds light on the impact of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS but has been limited by a culture of non-disclosure of parental HIV infection or death or failing to report on parental cause of death.

Keywords: HIV/AIDS, children, orphans, psychosocial well-being, HIV-related stigma

Background

The human immunodeficiency virus and the acquired immunodeficiency syndrome (HIV/AIDS) has resulted in a rapid increase in mortality, ensuing a substantial rise in orphanhood worldwide (Chi & Li, 2013; Tran & Mwanri, 2013). Roughly 16 million children were orphaned by HIV/AIDS, with an expected increase of 40 million orphaned children by the year 2020 (Chi & Li, 2013; Cluver, Orkin, Boyes, Sherr, Makasi, & Nikelo, 2013). Children orphaned by AIDS (COA) are critically affected by parental illness and death, and experience adversities and stressors likely to affect their psychosocial well-being (Goldberg & Short, 2016). Psychosocial well-being is the amalgamation of psychological and social well-being—encompassing psychological well-being, resilience and social inclusion—and widely reflects an individual's thoughts, feelings, behaviours, and reactions to the social environment

(Fujishima-Hachiya & Inoue, 2012; Snider, 2006). Risk factors associated with orphanhood contributes to the poor levels of psychosocial well-being displayed by COA, as the death of a parent during childhood is traumatic and exhibits a profound and long lasting impact on a child’s development and psychosocial well-being (Fang, et al., 2009). COA continue to display lower levels of psychosocial well-being than children orphaned by other causes (Fang, et al., 2009; Nyamukapa, Lopman, Saito, & Roeland, 2008; Orkin, Boyes, Cluver, & Zhang, 2014). Therefore, attention is drawn to HIV-related stigma, a risk factor separating COA from their counterparts (Boyes & Cluver, 2013). Lata and Verma (2013) identified HIV-related stigma as a core risk factor contributing to poor psychosocial well-being displayed by COA, independent of orphanhood status and other key demographic variables. Sharp, Jardin, Marias, and Bolvin, (2015) and Cheney (2015) have found HIV-related stigma to mediate the effects of AIDS orphanhood, negatively impacting the well-being and adjustment of COA. Despite the paucity in current literature, a few studies (Cheney, 2015; Fang, et al., 2009; Lata & Verma, 2015; Nyamukapa et al., 2008; Orkin et al., 2014) have set out to evaluate the impact of HIV-related stigma on the psychosocial-well-being of COA. This study aims to systematically review existing literature reporting on the effects of HIV-related stigma and the psychosocial well-being of COA to provide a critical understanding of the manner in which the psychosocial well-being of COA is influenced by HIV-related stigma. Such an understanding remains essential for ensuring child well-being and the development of effective interventions (Cluver et al., 2013; Li et al., 2008).

Conceptual Framework

This study utilizes the work of Goffman (1963) and Major and O’Brien (2005) to conceptually underpin the concept of HIV-related stigma and its impact on the psychosocial well-being of COA. Goffman (1963, p.3) defined stigma “as an attribute that is deeply discrediting, a mark of one’s self that is social devalued.” Goffman (1963) argued the importance of social interaction where these attributes are constructed as a reflection of an individuals tarnished character. Therefore, the concept of stigma is a complex and powerful phenomenon cultivated by society. While Goffman (1963) postulated three causes of stigma, the notion of tribal stigma focuses on the study's population, as stigma is extended to COA simply because of their affiliation with parental HIV/AIDS rather than their own HIV status (Goffman, 1963; Attell, 2013). As social meanings are created and assigned to those infected or affected by HIV/AIDS, COA may be viewed as "invasive agents within a healthy society," resulting in social exclusion, isolation, and rejection (Varas-Díaz, Serrano-García, & Toro-Alfonso, 2005, p. 170).

Stigmatization jeopardizes the physical well-being of stigmatised individuals through limited access to vital recourses, such as health care, education, and adequate housing. These resources, just being a few, are fundamental for the development and survival of COA. However, the effects of stigmatisation reach far beyond one's physical well-being to include psychological and social consequences, which exerts a negative impact on the emotions, thoughts, and behaviours of stigmatised individuals (Heatherton, 2003; Major & O'Brien, 2005). Evidently, the stigmatization of COA may negatively contribute to poorer levels of psychosocial well-being as displayed by COA.

The works of Major and O'Brien (2005) focuses on the impact of stigmatisation on the well-being of stigmatised individuals. Major and O'Brien (2005) argue that the possession of a stigmatized identity increases one's exposure to stressful and threatening situations and that coping with stigma may result in a positive self-concept and higher levels of self-esteem. However, these outcomes are largely dependent on a volitional reaction to stressful situations and the method of coping strategies employed. Contrastingly, non-volitional reactions to stigmatisation and emotion-focused coping, such as non-disclosure, silence, secrecy, and withdrawal, is associated with negative implications for the psychosocial well-being of stigmatised individuals including poor self-concept and lower self-esteem, internalizing disorders, as well as, anxiety and depression, poor academic performance, and underachievement (Major & O'Brien, 2005; Isaksson et al., 2017). Therefore, COA employment of non-volitional responses to stigma may negatively impact all domains of psychosocial well-being, including poor physical, psychological, and social well-being, lower levels of self-esteem and a poor self-concept, poor academic performance, and a negative future orientation.

Methods

Study design

A systematic review methodology was used to determine the effects of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS.

Research question

The research question, “What are the effects of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS?” was formulated using the PEO method, which represented the population of interest (COA), exposure (HIV-related stigma), and the outcome of interest (psychosocial well-being of COA).

Inclusion and exclusion criteria

Studies included in the current review were required to: (1) be published between 2006 and 2016; (2) embody a quantitative, qualitative, or mixed methods methodology; (3) be in the English-medium; (4) be full text and peer reviewed; (5) include children under the age of 18 who have lost one/both parents to HIV/AIDS; and (6) examine and report on the effects of HIV-related stigma on the psychosocial well-being of COA. Due to the paucity of current literature, studies including children residing with parents infected with HIV/AIDS along with orphaned children were included in the current review. The selected time period was limited to include the most recent developments in the literature (Meline, 2006). Studies were excluded from the current review if they were not published within the designated time period, were not in the English-medium or peer-reviewed, if an inappropriate population was sampled, and if they failed to report on HIV-related stigma and the psychosocial well-being of COA. Intervention studies and reviews were excluded as the current study aimed to examine HIV-related stigma and the manner in which it impacted the psychosocial well-being of COA rather than evaluate effective ways to reduce HIV-related stigma or improve the psychosocial well-being of COA.

Search strategy

The search strategy was adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA), which depicts four levels of review: (1) identification, (2) screening, (3) eligibility, and (4) inclusion (Moher et al., 2009). Comprehensive searches using Boolean strings of suitable keywords and search terms of the following electronic databases and journals, namely, Academic Search Complete, PubMed, PsychArticles, AIDS Care, and SA ePublications from 2006 to 2016 were conducted. Databases were selected according to discipline and relevance to the subject matter, while Boolean strings were piloted prior to the commencement of the review. Currency (2006–2016), language (English-medium), peer-reviewed and full text limiters were applied across searches.

Search terms

The following strings of search terms and keywords were entered into the respective databases:

(1) 'AIDS orphans'

(2) 'HIV/AIDS' AND 'stigma' AND 'children'

(3) 'HIV/AIDS' AND 'stigma' AND 'children' AND 'well-being' OR 'well being' OR 'wellbeing'

(4) 'HIV stigma' AND 'orphans' AND 'psychosocial well-being'

(5) 'HIV stigma' AND 'AIDS orphans' AND 'psychosocial well-being'

(6) ‘AIDS related stigma’ AND ‘orphans’ AND ‘well-being’

Method of review

The titles of prospective studies were screened by the primary researcher. Abstracts of pertinent titles were extracted and reviewed. The full text of abstracts pertinent to the study were retrieved for rigorous and critical appraisal for eligibility and inclusion by two independent researchers. All disagreements regarding the methodological quality and inclusion of studies were discussed until consensus was reached. Studies meeting the predetermined threshold for inclusion proceeded to the level of inclusion and were subjected to the process of data extraction.

Study methodological quality

Critical appraisal tools were adapted for the independent appraisal of qualitative, quantitative, and mixed methods studies. The Critical Appraisal Skill Program (CASP, 2014) was adapted along the guidelines proposed by Law and colleagues (1998) for the evaluation of qualitative and quantitative studies. The Evaluative Tool for Mixed Method Studies (Long, 2005) was similarly adapted for the evaluation of mixed methods studies. The critical appraisal tools evaluated the study’s purpose, design, data collection methods, methods of analysis, and ethical considerations of prospective studies guaranteeing the methodological quality of each subsection (Siering, Eikerman, Hausner, Hoffman-Eber, & Neugebauer, 2013). Rating scale rubrics of appraisal tools were adjusted to produce a composite score for an overall percentage of quality. Appraisal tools were piloted by the primary researcher. Final items were divided across subsections for an improved reviewing process (Siering et al., 2013).

Data extraction and analysis

Data was extracted using a self-constructed data extraction sheet constructed along the guidelines provided in the Cochrane Data Extraction and Assessment Form (Higgens & Green, 2011). The following information was extracted from each study, namely, author/s, publication year, aim, problem statement, target population, geographical location, study design, theoretical underpinnings, sampling method, sample size, data collection methods and instruments, methods of analysis, findings and conclusions. To reduce bias, the primary researcher piloted a data extraction sheet. The study uses a meta-synthesis analysis consisting of a descriptive meta-synthesis and theory explication to critically analyse and discuss emerging themes from the findings of the included studies (Schreiber, Crooks, & Stern, 1997).

Ethical considerations

Ethical permission was obtained from the University of the Western Cape's Senate Research Ethics Committee. All studies included are published, peer-reviewed articles available in the public domain, ensuring transparency. The primary researcher is a registered student at the University of the Western Cape and is efficiently trained with full access to the respective databases. Steps were employed by the primary researcher to maintain the integrity of the study through the avoidance of misconduct and plagiarism (Wager & Wiffen, 2011). The study remains sensitive to the ethical shortfalls of systematic reviews (Vergnes, Marchal-Sixou, Nabet, Maret, & Hamel, 2010).

Process of Results

The initial search yielded a total of 1462 potential titles across databases. After the removal of duplications, 1281 prospective titles were screened for their relevance to the current study, resulting in the exclusion of 1225 titles. The remaining 56 titles were reviewed by abstract for relevance and suitability to the current study, excluding 27 studies. Due to the paucity of literature, the citation lists of the remaining 29 studies were reviewed for further identification of prospective studies, of which 2 potential studies were relevant to the study’s purpose and underwent full review for eligibility. A total of 31 potential studies were methodologically appraised and 18 studies were excluded. The main reasons for exclusion included their failure to meet the predetermined threshold score for inclusion (n=8), failure to report on the psychosocial outcomes of HIV-related stigma for COA (n=5), inappropriate sample populations (n=4), and an inappropriate methodology (n=1). A total of 13 studies were included in the current review, each obtaining excellent composite scores (81% – 100%) based on their methodological assessment and underwent data extraction. A visual representation of the screening process at each level of review is presented in Figure 4.2 below.

General description of included studies

Included studies consisted of quantitative (n=9), qualitative (n=3), and mixed (n=1) methodologies. Sample populations consisted of single orphans, double orphans, or vulnerable children affected by HIV/AIDS. Three (n=3) included studies that sampled caregivers, social care professionals and local community members along with COA and vulnerable children (Cluver & Gardner, 2007; Nyamukapa et al., 2010; Xu et al., 2009). The geographical locations of study settings varied across China (n=7), South Africa (n=2), Uganda (n=1), Tanzania (n=1), India (n=1), and Zimbabwe (n=1). All studies (n=13) aimed to explore, examine, and understand the various risk factors associated with poor psychosocial well-being of COA. Of these risk factors, HIV-related stigma was either identified as the main variable associated with poor psychosocial well-being of COA or a variable extensively discussed with regards to the psychosocial well-being of COA. A general description of and the methodological aspects and findings of the included studies are outlined in Tables 4.2, 4.3 and 4.4, respectively.

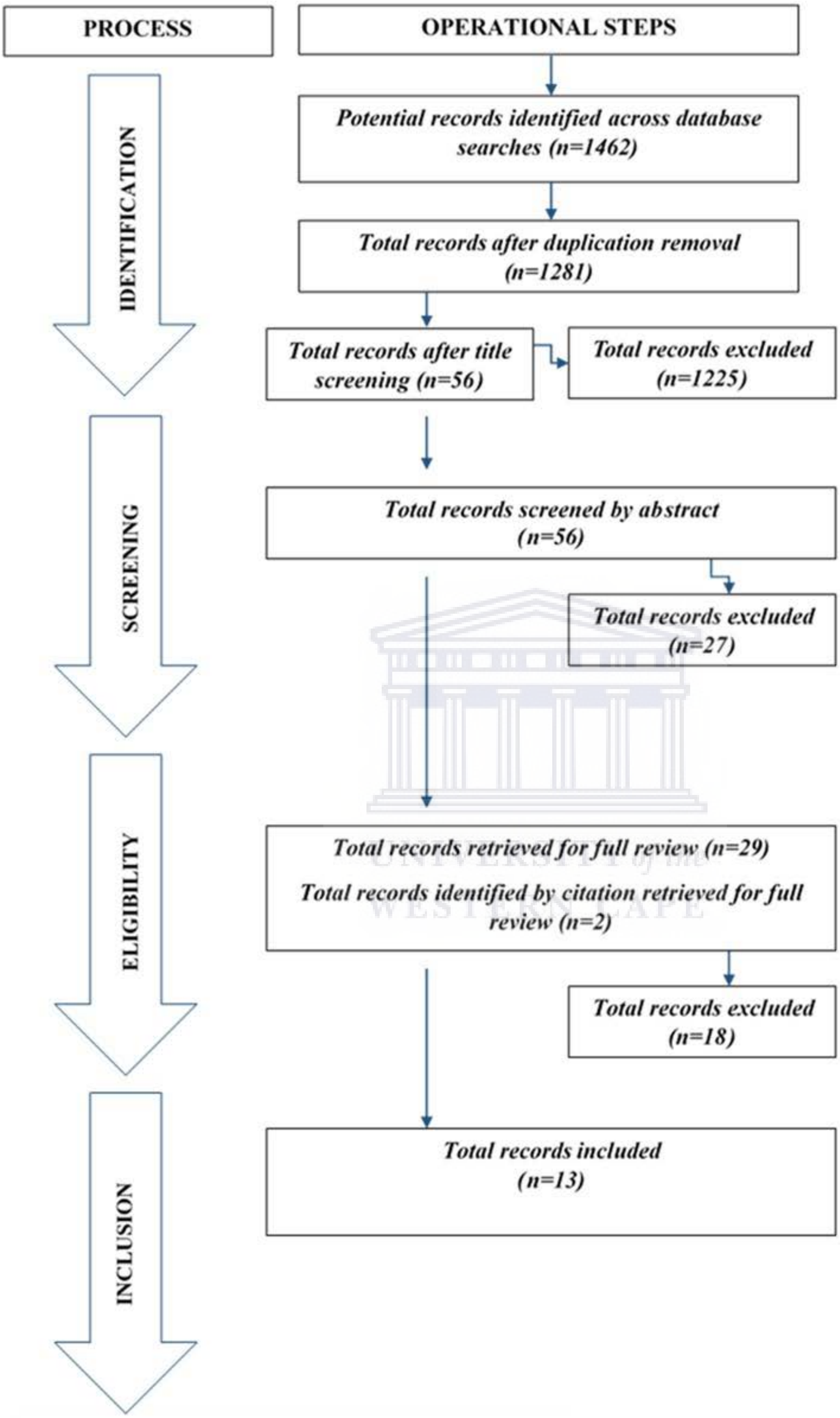

Figure 4.4: Levels of Review and Results

Table 4.7: General Description of Results

General Description				
Author	**Sample Population**	**Geographical location**	**Aim**	**Problem Statement**
Chi, Li, Zhao, & Zhao (2014)	Single orphans, double orphans, and vulnerable children	Rural China	To explore the longitudinal reciprocal effects of depressive symptoms and stigma, specifically enacted stigma and perceived stigma among children affected by HIV/AIDS.	Various components of stigma may contribute uniquely to different mental health problems and increases the risk of psychological distress among people living with HIV and AIDS and their families. Although cross-sectional studies have found the destructive effect of HIV-related stigma on the mental health of children affected by parental HIV/AIDS, limited data were available regarding the impact of different forms of stigma on children's mental health in a longitudinal perspective in a resource-limited setting.
Cluver & Gardner (2007)	Single orphans, double orphans, caregivers and social care professionals	South Africa, Cape Town	To explore the perceptions of orphaned children, their caregivers, and care professionals about factors contributing to well-being in orphaned children.	The psychological well-being of children orphaned by HIV/AIDS is under-researched; therefore, the reliance on available evidence is insufficient. Even less is known about factors present in the lives of these children, which may affect their psychological health.
Cluver & Orkin (2009)	Single orphans, double orphans, children orphaned by other causes, and non-orphans	South Africa, Cape Town	To comprehensively established the relationship between poverty, bullying and HIV-related stigma and identify the interactions between risk factors affecting child mental health.	For the development of appropriate services and interventions directed at children orphaned by AIDS, reliable evidence regarding factors mediating the risk for clinical range disorder is needed. To date, few studies have examined the interactions between AIDS orphanhood, particular risk factors and child psychological well-being. The present study is the first known study to examine interactive effects in relation to child mental health in the developing world.
Harms, Jack, Ssebunnya, & Kizza (2010)	Single orphans and double orphans	Uganda, Kampala	To conduct an in-depth exploration of youths narratives regarding the orphaning experience.	The individual experience of orphanhood as expressed through the personal perspectives of orphaned youth has been comparatively neglected, resulting in a current body of literature that is somewhat unbalanced. The experiences of youth who have lost parents to the HIV/AIDS epidemic provides an important insight into this complex, evolving, multi-dimensional phenomenon.
Hermenau, Eggert, Landolt, & Hecker (2015)	Single orphans, double orphans & non-orphans	Southern Tanzania	To systematically investigate orphans' experiences of maltreatment and stigmatization to identify factors that relate to their psychological distress.	Very few studies have assessed perceived stigmatisation of an orphan. Further research is required to understand the impact of stigmatization on psychological health, specifically depression and its interaction with other adverse experiences, particularly neglect.

Kumar, Dandona, Kumar, Ramgopal, & Dandona (2014)	Single orphans, double orphans and children orphaned by reasons other than HIV/AIDS	Southern India, Hyderabad City	To explore depression and its associated risk factors among orphaned children in Hyderabad city in South India	Given the lag time between HIV infection and death from AIDS, the estimation is that the number of children orphaned by AIDS is on the rise. India is signatory to the political declaration on HIV/AIDS wherein the government is committed to addressing the issues of children orphaned by AIDS. Despite the attempts of non-governmental and faith-based organisations to support and care for the growing population of orphans, systematic data on mental health issues among orphaned children are not readily available in India.
Lin, Zhao, Li, Stanton, Zhang, Hong, Zhao, & Fang (2010)	Single orphans, double orphans, vulnerable children, and comparative children (not associated with HIV/AIDS illness and death)	Central China	To examine the unique contribution of HIV-related stigma to children's poor psychosocial adjustment above and beyond the impact of parental HIV/AIDS.	To date, the body of evidence regarding the negative impact of HIV-related stigma has focused on the adult population, while only few studies have examined HIV-related stigma among children who are affected by HIV/AIDS. HIV in China is a highly stigmatised disease and is considered to be a significant barrier in combating the HIV epidemic. However, the extent to which HIV-related stigma has impacted children's psychosocial development in local communities in China remains unclear.
Nyamukapa, Gregson, Wambe, Mushore, Lopman, Mupambireyi, Nhongo, …& Jukes (2010)	Single orphans, double orphans, non-orphans, caregivers, local community members, adults orphaned during childhood and survey interviewers	Eastern Zimbabwe, Manicaland Province	To determine the effects of orphanhood on psychological distress and test mechanisms for greater distress amongst orphans as suggested in a recently published theoretical framework.	Substantial resources are invested in the psychological support for children orphaned or made vulnerable by HIV/AIDS. However, there is limited evidence for greater psychological distress amongst orphans and even less evidence is available regarding the effectiveness of current support strategies.
Qiao, Li, Zhao, Zhao, & Stanton (2012)	Single orphans, double orphans, vulnerable children	Central China	To explore children's perceptions of secondary disclosure and their association with children's demographic and psychosocial factors.	Although, disclosing parental HIV status to others is a significant challenge to many children, few studies have examined the experiences and perceptions of children regarding secondary disclosure and the relationship of such experiences and perceptions with children's psychosocial well-being.

Wei, Li, Harrison, Zhao, & Zhao (2016)	Single orphans and double orphans	Rural Central China	To examine the association between HIV-related stigma, including enacted and perceived stigma, and the emotional status among HIV-affected children as well as to evaluate the mediating effects of emotional regulation on the relationship between HIV-related stigma and emotional status.	The psychosocial needs of children affected by HIV/AIDS often go unaddressed in traditional treatment approaches. Children affected by HIV/AIDS are more likely to encounter stigma, overt discriminatory behaviours, and stereotyped attitudes. Additionally, they are at risk for experiencing negative affects, including sadness and depression. Although previous studies have identified a link between HIV-related stigma and the subsequent emotional status of children affected by HIV/AIDS, limited data regarding the protective psychological factors that can mitigate the effects of HIV-related stigma and promote resiliency among affected children are available.
Wei, Li, Tu, Zhao, & Zhao (2016)	Single orphans and double orphans	Central China	To examine the mediating effects of perceived social support, hopefulness, and emotional regulation on the relationship between enacted stigma and PTG among HIV-affected children.	Previous studies have revealed a negative impact of enacted stigma on post-traumatic growth (PTG) of children affected by HIV/AIDS, but little is known about protective psychological factors that can mitigate the effect of enacted stigma on children's PTG.
Xu, Yan, Duan, Wang, Rou, & Wu (2009)	Single orphans, double orphans, vulnerable children, caregivers, community informants	China, Longchuan county Yunnan Province	To explore the psychosocial experiences of children affected by HIV/AIDS, including emotional problems, interpersonal relationships, and stigma and discrimination.	More research is required to profoundly understand the psychosocial impact of HIV/AIDS on children and appropriately indicate the need for intervention.
Zhao, Li, Zhao, Zhang, & Stanton (2012)	Single orphans, double orphans, vulnerable children, and non-orphans	Central China	To assess the relative importance of four measures of HIV-related stigma in predicting psychological problems among children affected by HIV.	Limited studies have examined the relative importance of various measures of HIV-related stigma in predicting psychological outcomes. Additionally, few studies have focused on secondary stigma upon children affected by HIV, and limited data are available in regions where HIV-related stigma continues to act as a barrier to HIV prevention, treatment, and care efforts.

Table 4.3: Methodology

Methodology					
Author	**Study Design**	**Theoretical Underpinnings**	**Sampling Method**	**Sample Size**	**Data collection methods/ Instruments**
Chi, Li, Zhao, & Zhao (2014)	Quantitative longitudinal cohort design	Not Specified	Probability cluster sampling	272 participants (consisting of double orphans, paternal orphans, and maternal orphans; however, percentages are not specifically identified) 249 vulnerable children	Each participant completed an assessment inventory consisting of: • A sheet recording demographic characteristics. • Centre for Epidemiological Studies Depression Scale for Children (CES-DC). • Stigma Against Children Affected by AIDS. • Enacted stigma was measured with the use of a 12-item scale, in which children were asked to report whether they have experienced some stigmatized actions after parental illness.
Cluver & Gardner (2007)	Qualitative study design, grounded theory approach	Not specified	Non-probability convenience sampling	60 participants consisting of double orphans (20%), maternal orphans (23%), paternal orphans (27%); the unknown whereabouts of parents amounted to 30% 42 caregivers of orphaned children 20 care professionals	For qualitative data collection the following data collection tools and methods were employed: • Worksheet-based semi-structured interviews featuring popular cartoon characters. The interview guide consisted of open-ended questions and did not prompt responses. These guides explored various factors perceived as affecting their happiness, sadness, anger and coping. • Interviews were conducted in Xhosa (52%); the English-medium (15%), or dual language (33%). • Children were given the option to respond in first person (themselves) or third person (the cartoon character). • Children could choose to respond either in writing, drawings, or verbally; independently or with interviewer assistance to accommodate a vast range of literacy levels. • Caregivers participated in focus groups conducted in the English-medium or Xhosa. The interview guide used to facilitate focus group discussions was a verbal adaption of the children’s interview guide. • Social care professionals participated in open-ended discussions focusing on risk and protective factors. Data collected included worksheets and interview notes.

Cluver & Orkin (2009)	Quantitative study design (not further specified)	Not Specified	Non-probability, purposive sampling	1025 participants consisting of 425 children orphaned by AIDS (the percentage of double, paternal and maternal orphans were not specified), 241 children orphaned by other causes, and 278 non-orphaned children. 81 participants were excluded as the cause of orphanhood could not be confirmed	Each participant completed an anonymous self-report questionnaire consisting of: • Child Depression Inventory (CDI). • Children's Manifest Anxiety Scale-Revised (R-CMAS). • Child PTSD Checklist. • Social and Health Assessment Peer Victimisation Scale (Adapted from the Multidimensional Peer Victimisation Scale). • A brief 4-item stigma by association scale was devised from the Berger Stigma Scale for HIV Youth Revised. • Food insecurity was assessed using self-reports of 0-7 days without food over the past week.
Harms, Jack, Ssebunnya, & Kizza (2010)	Fundamental qualitative descriptive research design	Not Specified	Non-probability convenience sampling	13 participants consisting of 7 double orphans, 5 paternal orphans, and 1 maternal orphan	For qualitative data collection the following data collection tools and methods were employed: • Short written questionnaire for recording demographic data. • Individual in-depth semi-structured interviews. • An interview guide was developed and adapted as data collection progressed. • Predetermined open-ended questions were used to explore phenomenon being studied. • Interviews were conducted in Luganda. • Field notes were completed for each interview Interviews were recorded. Permission to do so was obtained from participants.

Hermenau, Eggert, Landolt, & Hecker (2015)	Quantitative study design (not further specified)	Not specified	Non-probability sampling (not further specified)	89 participants consisting of double orphans (18%) and single orphans (82%). The percentage of maternal and paternal orphans was not specified 89 non-orphans	Each participant completed an assessment inventory consisting of: • A sheet recording socio-demographic information. • Maltreatment and Abuse Chronology of Exposure-Paediatric Version (been validated for use with children in Tanzania). • Parental loss was assessed using one question: Has your mother and/or your father passed away? If both parents were deceased, the child's age at both times were identified and recorded. • Reactive-Protective Questionnaire. One item was removed, and two items were rephrased to suit the living conditions of Tanzanian children. • Children's Depression Inventory (CDI). • Strength and Difficulties Questionnaire (SDQ). • UCLA PTSD Reaction Index for DSM-IV. • Perceived stigmatization was measured with the use of 10 purpose-built questions referring to orphans' perceptions of being devalued by peers and teachers because of their orphan status. The validity of the developed scale was tested by correlating the sum score with stigma-related items of the SDQ and CDI.
Kumar, Dandona, Kuma, Ramgopal, & Dandona (2014)	Quantitative comparative study design	Not specified	Probability simple random sampling and stratified random sampling	397 participants consisting of children orphaned by AIDS (COA) and children orphaned by other causes (COO). The percentage of COA and COO were matched. The sample consisted of double orphans (30.7%), paternal orphans (51.8%), and maternal orphans (15.1%)	Each participant completed an assessment inventory consisting of: • A sheet recording demographic information of children. • Cause of parental death was established from the individual details maintained for each child at the orphanage. • The Centre of Epidemiologic Studies-Depression Scale (CES-DC). The scale was translated into the local language languages for use by researchers, back translated and field tested to ensure proper readability. As cultural was a major concern in translating the (CES-DC) researchers closely collaborated with mental health experts, child counsellors and the NGO/orphanage staff to achieve accuracy of cultural understanding and translation. • History of abuse and violence by friends and relatives including the type of abuse, experience of abuse in orphanage, and witnessing fights between parents were documented. History of experience with discrimination from friends, relatives, and the community were documented.

					• The study instrument was piloted by study investigators in consultation with a psychologist who worked with children. Additional inputs from mental health experts, child counsellors and the NGO/orphanage staff were obtained to refine and validate the study instrument for the study population. • Definitions were simplified, revisions in local language translation for Hindi and Telugu were made, and interview techniques approved.
Lin, Zhao, Li, Stanton, Zhang, Hong, Zhao, & Fang (2010)	Quantitative cross-sectional study design	Developmental psychopathology framework of psychosocial needs of children affected by HIV/AIDS	Not specified	755 orphans (consisting of double orphans, paternal orphans, and maternal orphans; however, percentages are not specified) 466 vulnerable children 404 non-orphans	Each participant completed an assessment inventory consisting of: • A sheet recording demographic characteristics of participants and their family. • Two HIV-related stigma measures (perceived public stigma and personal stigma) were developed based on existing measures of HIV-related stigma in the literature. • Centre of Epidemiological Studies-Depression Scale for Children. • The Children's Loneliness Scale. • The Self-Esteem Scale. • A modified version of the Children Future Expectation Scale. • The Hopefulness about Future and the Perceived Control over Future Scales.

Nyamukapa, Gregson, Wambe, Mushore, Lopman, Mupambireyi, Nhongo, …& Jukes (2010)	Mixed methods study design (Quantitative and qualitative methods used; study designs not further specified)	Theoretical framework on the causes and consequences of psychosocial distress amongst orphans in the context of a larger-scale HIV/AIDS epidemic	Probability stratified random sampling	Quantitative sample size: 444 orphans consisting of double orphans (41.6%), paternal orphans (33.8%), and maternal orphans (24.6%) 83 non-orphans Qualitative sample size: 4 children affected by HIV/AIDS 4 caregivers 2 local community members 2 adults orphaned during childhood 1 survey interviewer	Each participant completed the following assessment inventory: • The World Health Organization Self-Report Questionnaire on depression and anxiety. • Items were appropriately adapted and have been validated in Zimbabwe and 12 other African countries. For qualitative data collection the following data collection tools and methods were employed: • Focus group discussions were held with participants. • Discussions were held in Shona (the local language). • Discussions were audio-recorded and documented on flipcharts.
Qiao, Li, Zhao, Zhao, & Stanton (2012)	Quantitative study design (not further specified)	Not specified	Non-probability convenience sampling	579 orphans (consisting of double orphans, paternal orphans, and maternal orphans; however, the percentage is not specifically identified) 383 vulnerable children	Each participant completed an assessment inventory consisting of: • A sheet recording demographic information of participants. • Children's perceptions of secondary disclosure were measured using 20-items in terms of intention, openness, and feelings of disclosure. • Center of Epidemiological Studies-Depression Scale for Children (CES-DC). The CES-DC was translated into Chinese and validated with various Chinese populations. • The Chinese version of the Children's Loneliness Scale (CLS). • Perceived social support was measured using a 25-item scale which was a cultural modification of the Medical Outcome Study (MOS) Social Support Survey. • Global feelings of self-worth or self-acceptance was assed using a 10-item Self-Esteem scale. • Perceived public stigma towards people living with HIV and their family was assed using a 10-item scale. • The Stigma Against Children Affected by AIDS (SACAA) scale. • Enacted stigma was assessed using a 14-item list. • The Hopelessness Scale for Children (HSC).

Wei, Li, Harrison, Zhao, & Zhao (2016)	Quantitative cross-sectional study design	Not specified	Non-probability sampling (not further specified)	790 participants (consisting of double orphans, paternal orphans, maternal orphans and vulnerable children; however, percentages were not explicitly identified)	Each participant completed an assessment inventory consisting of: • Enacted stigma was measured with a 14-item scale where children were asked to report whether they had experienced any stigmatization actions after parental HIV infection. • Stigma Against Children Affected by AIDS. • Positive and Negative Affect Schedule (PANAS). The abbreviated version of the PANSA scale consisting of 20 words describing positive or negative emotional states was used. • Emotional regulation was assessed with a 6-item sub-scale of the Social Competence Scale.
Wei, Li, Tu, Zhao, & Zhao (2016)	Quantitative cross-sectional study design	Not specified	Non-probability convenience sampling	790 participants (consisting of double orphans, paternal orphans, maternal orphans, and vulnerable children; however, percentages were not explicitly identified)	Each participant completed an assessment inventory consisting of: • Enacted stigma was measured with a 14-item scale where children were asked to report whether they had experienced any stigmatization actions after parental HIV infection. • Post-Traumatic Growth Scale for children (PTGI-CR). • Hopefulness about Future Scale (Hope). • Perceived social support among children was assessed by a 16-item scale adapted from Zimet's Multidimensional Scale of Perceived Social Support. • Emotional regulation was assessed by a 6-item subscale of The Social Competence Scale. • Informed consent was obtained from all children and their caregivers prior to participation.
Xu, Duan, Wang, Rou, & Wu (2009)	Qualitative exploratory study design	Not specified	Purposive sampling and convenience sampling	11 orphans consisting of double orphans (4), paternal orphans (5), and maternal orphans (2) 5 non-orphans 16 caregivers (consisting of grandparents (7), mothers (5), fathers (3), and an uncle (1) 5 key community informants consisting of the village leader (1), local health service provider (1),	Each participant participated in: • Semi-structured interviews (duration of each interview ranged between 30 minutes with younger children and 1.5 hours with older children and care givers). • Drawings regarding their feelings were obtained from children but were not analysed. • Informed consent was obtained prior to interviews from caregivers and key community informants. • Caregivers provided consent for children.

				principle of a local middle school (1), director of the local Women's Federation, and the vice-director of the local civil affairs bureau	• Confidentiality and voluntary participation was upheld throughout the study.
Zhao, Li, Zhao, Zhang, & Stanton (2012)	Quantitative cross-sectional design	Not specified	Not specified	755 orphans (consisting of double orphans, paternal orphans, and maternal orphans; however, percentages were not explicitly identified) 466 vulnerable children 404 non-orphans	Each participant completed an assessment inventory consisting of: • A sheet recording detailed measures of demographic information of participants. • Perceived Public Stigma Against People Living with HIV/AIDS, 10-item scale. • Stigma Against Children Affected by AIDS Scale (SACAA). • Personal Stigmatization Attitudes against PLWHA Scale. • Enacted Stigma Scale. • Centre of Epidemiological Studies. • Depression Scale for children (CES-DC). • Children's Rating Scale (CRS).

Table 4.4: Findings and Analysis

Finding and Analysis			
Author	**Method of data analysis**	**Study's findings**	**Author's conclusions**
Chi, Li, Zhao, & Zhao (2014)	The following methods of analysis were used to analyse data: • Preliminary data analysis was performed using SPSS 11.0. • Cross-lagged path models were tested with Mplus Version 5.1 • Missing data was efficiently handled through the use of full information maximum likelihood estimation. • The analysis was conducted in three steps: (1) testing a basic stability model in which the autoregressive effects of depressive symptoms, perceived stigma and enacted stigma were estimated; (2) the hypothesised model was tested. A sequence of path models were tested separately, each adding unidirectional cross-lagged paths separately: perceived stigma – depressive symptoms; depressive symptoms – perceived stigma; enacted stigma – depressive symptoms; perceived stigma – enacted stigma, and enacted stigma – perceived stigma; (3) lastly, the potential repeatability of cross-lagged effects over time and the	**Demographic characteristics** • Participants consisted of males (52.8%) and females (47.2%). • The average age of participants was 10.69, although boys were slightly older than girls. • About 70% of children were aware of parental HIV-infection at Time 1 (T1) and increased by 8% at Time 3 (T3). • The percentage of parental death was 52.2% at T1, 58.8% at Time 2 (T2), and 58.6% at T3. Preliminary analyses data • Parental death was correlated with depressive symptoms at T1 (r= 0.09). • Awareness of parental HIV at T1 was significantly correlated with depressive symptoms at T2 (r= 0.10). • Child's age significantly and negatively correlated with depressive symptoms at T1(r= -0.20) and at T2 (r=0.9.) • Perceived stigma and age at T1 (r=-0.21) and T2 (r = -0.09) and with enacted stigma at T1 (r= -0.21). • Some gender differences were found in depressive symptoms at T3, with girls scoring higher than boys. • Differences by care arranges were found in depressive symptoms at T2 (p < .01, Cohen's *d* =0.21), perceived stigma at T1 (p < .01, Cohen's *d* =0.41), and enacted stigma at T1 (p < .05, Cohen's *d* =0.26). • With-in wave correlations between enacted stigma (r = 0.57 to 0.61) were stronger than those between perceived stigma and depressive symptoms (0.17 to 0.28). The research findings suggest that: • Auto aggressive effects are statistically significant and stable over time for depressive symptoms, perceived stigma, and enacted stigma. • Cross-lagged effects depicted a cycle among enacted stigma – depressive symptoms – perceived stigma – enacted stigma in a linear direction and demonstrates that perceived and enacted stigma affects the well-being of children made vulnerable or orphaned by HIV/AIDS in a variety of ways.	The present study is among the first efforts to examine the bidirectional and longitudinal relationship among perceived stigma, enacted stigma, and depressive symptoms among children affected by HIV/AIDS. An increase in both enacted and perceived stigma results in the increase of depressive symptoms for children affected by HIV/AIDS. The findings highlight the importance of considering different aspects of stigma affecting children's psychosocial well-being in future research. The results underscore the needs to mitigate and reduce the negative effects of stigma at the level of the individual and school or community through multilevel interventions and further promote the mental health of children in the context of HIV/AIDS.

	within-wave residual correlations to determine the most parsimonious model that best presents the data was examined. • Several goodness-of-fit indices were applied to evaluate the fit of models: chi-square, p-value, Comparative Fit Index (CFI), and Root Mean Square Error of Approximation (RMSEA).	• T1 perceived stigma predicted T3 depressive symptoms through T2 enacted stigma. • T1 enacted stigma predicted T3 perceived stigma indirectly through T2 depressive symptoms. Enacted directly predicts symptoms of depression, aggravating the negative effects of perceived stigma on later symptoms of depression. • Depressive symptoms predicted T3 enacted stigma indirectly through T2 perceived stigma. Depressive symptoms may result from experiences of discrimination, isolation, enacted/perceived stigma, and threating actions from others.	
Cluver & Gardner (2007)	The following methods of analysis were used to analyse data: • Content analysis was used to analyse written data. • Interviewer notes, participant's writings and drawings were read thoroughly through, and significant statements extracted • Meanings were formulated to produce clusters of themes. • Themes were compared within and across categories to establish consistency and referred back to the original data set for validation. • Priority was given to aspects endorsed by high numbers of participants, caregivers, and professionals.	The key themes and findings are as follows: • Key themes emerged from the data and factors were perceived to elicit both emotional and behavioural difficulties. Key themes are presented below: Bereavement factors • Children (n = 23), caregivers (n = 10), and professionals (n = 6) identified parental bereavement, especially maternal bereavement, as a key risk factor for emotional and behavioural problems, while multiple bereavements resulted in distress. Caregiving factors • The primary caregiver was recognised as a significant risk or protective factor by all participants. • Caregivers (n = 41) perceived care as a critical factor, including support, honesty, praise, closeness, help with homework, reading and stories, advice on education, and attending school meetings. • Professional identified caregiver's mental health, social support, and access to anti-retrovirals as crucial factors affecting children's well-being. • Harmful caregiving was identified by children (n = 29), caregivers (n = 24), and professionals (n = 14), and included multiple moves, caregiver changes, caregiver illness, family conflict, separation, abuse, violence and substance abuse. Abuse • Abuse reported by participants (n = 28) were perceived as risk factors for emotional and behavioural problems. Abuse included shouting (n=23), beating with sticks or belts (n=14), distress and sexual abuse, including rape (n = 7) and witnessing abuse (n = 2). New homes and 'a sense of belonging'	This study identified factors, perceived as affecting the psychological well-being of children affected by HIV/AIDS. Identified factors may have not been previously identified while others are consistent with those presented in previous literature and are particularly significant for children affected by HIV/AIDS. Perceived unequal treatment in new homes especially within the context of stigma and limited rescores may be relevant to children's well-being. Reported experiences of gossip and teasing underscores a possible association with HIV-related stigma. There is a need to test identified needs in future research. Larger-scale study would allow for the exploration of findings in a broader geographical area, with larger samples of AIDS-affected subgroups.

		• Several participants were acutely cognizant of tensions associated with their position as the non-biological child in the home. • Complexities emerge surrounding disclosure of orphanhood to participants. • Caregivers and children (n = 7) described positive factors such as feeling accepted, wanted, and being a 'part of the family'. • Contrastingly, children (n = 10) were particularly unhappy when feeling discriminated against or treated differently to other children in the home. Such discrimination included the unequal distribution of resources, isolation, and loneliness. Contact with extended family • The lack of family contact was identified as a risk for children's well-being. • Children (n = 6) described missing their families, feeling separated, and 'being sent far away'. • Immediate and extended family were perceived as protective factors and recognised as a source of consolation by professionals (n = 3) and children (n=19). Poverty and access to services • Almost all participants (n=75) described poverty as a risk factor mediating emotional and behavioural distress. • Poverty-related risk factors include: homelessness; hunger; unemployment; and no medical care; housing problems, such as overcrowding and burned-down shacks; no toilets, electricity, or water; difficulties around accessing social welfare grants, birth certificates, medical care, and social workers; orphans sense of social exclusion; and concerns around clothing and inadequate school attire. School and peer factors • Both school and peers were important to participants. • Participants (n=10) were distressed and angered at their inability to afford school fees, compulsory equipment, school attire, school transport and outings. • Concerns over educational costs support recent evidence of maternal bereavement affecting educational access. • School attending participants (n=22) identified it as a protective factor. • Participants identified several risk factors, namely: socialising as a protective factor (n=20); friends as a source of comfort (n=29); the lack of friends (n=9); bullying (n=10); teasing and fights (n=8); and being beaten by peers (n=23). Physical safety and crime • Participants (n=16) were distressed or angered by muggings, robbery, and assault. • Others witnessed robberies, imprisonment, and violence towards friends and family. • Participants and caregivers identified the lack of safe play as a risk for behavioural problems.	

		• Participants (n=6) were distressed by poor physical health. Stigma and gossip • Participants (n=14) described stigma and gossip as a risk factor affecting their well-being. • Such acts included: gossiping about the participant, teasing, and being shouted at in public. • Participants distress was associated with others speaking about their parents (n=4), and the spreading of rumours (n=6). • Notably, participants were distressed by verbal abuse towards their surviving (possibly HIV positive) parent. Positive activities • All participants identified activities that improved child well-being and provided comfort. These included: sport (n=23); playing (n=18); television (n=20); singing, music and dancing (n=10); reading (n=12); homework and diary writing (n=5); prayer and church (n=3), and expressed the importance of having a trusted confidant.	
Cluver & Orkin (2009)	The following methods of analysis were used to analyse data: • The software package SPSS version 14.0 was used to analyse data. • Hierarchical log-linear modelling was conducted with an unweighted set of data. The significance for log-linear modelling was stringently set at $p>0.005$. • Automatic backwards selection was used to identify variables and their associations. • Multivariate logistic regression was used and set at $p<0.01$.	The study's findings suggest that: • One third of the participants (n=301) reported having insufficient food at home for one or more days in a week. • One fifth of the participants (n=220) reported experiencing HIV-related stigma. • There was no difference between AIDS-orphaned, other-orphaned, and non-orphaned participants above the median score for being bullied. • Clinical levels for psychological disorder were 9.7% for depression, 9.8% for anxiety, 27% for PTSD, and 31% of participants displayed one or more internalising disorder/s. • Orphanhood was associated with increased likelihood of food insecurity: 50% for COA, and 47% for other-orphans compared to 26% for non-orphans. • Children orphaned by AIDS were more likely to report experiences of stigma: 55% for COA, 27% for other-orphans, and 17% for non-orphans. • Stigma and bullying were associated, as 70% of stigmatised participants reported being bullied compared to 41% of non-stigmatised participants. • Orphaned participants reported better quality of care than non-orphans. Good quality of care was reported by 67% of COA, 73% of other-orphans, and 60% of non-orphans. • The three-way interaction between food insecurity and stigma in relation to disorder. Before food insecurity is brought into the equation, disorder is present amongst 22% of those who are not stigmatised, but present among 69% of those who are stigmatised. • The other three-way interaction between orphanhood, bullying, and disorder. The association between disorder and bullying varies significantly for different categories of	

		orphanhood. Non-orphans presented with low levels of disorder (12%), and with low or no levels of bullying. Other-orphans presented with higher levels of disorder (27%), and with no or low levels of bullying, and doubles (47%) with high levels of bullying. Children orphaned by AIDS presented with the highest level of disorder (38%), with no or low levels of bullying, but increases to a higher level (76%) in the presence of high levels of bullying.	
Harms, Jack, Ssebunnya, &Kizza (2010)	The following methods of analysis were used to analyse data: • The software package QSR NVivo 2.0 was used to manage and code data. • Qualitative content analysis was used to analyse data • Transcripts, memos and case summary data were analysed using qualitative content analysis. • All transcripts were read in the entirety and line-by-line coding was performed • Initial codes were developed from concepts included in the interview guide. • Second level coding involved collapsing initial codes into broader categories, identifying category properties, and establishing the relationship between categories.	**Demographic characteristics** • Thirteen Ugandan youth participated in the current study, consisting of males (5) and females (8); double orphans (7), paternal orphans (5), and a maternal orphan (1). • The mean age of the participants was 15; all youth had completed some level of high school education, but none had completed high school. Six youth were not attending school at the time of the study. • The majority of participants were from the predominant tribe in south-central Uganda, the Baganda tribe, and were from semi-urban homes. Keys themes and findings are presented below: The end of childhood • Several types of loss were described during the time of parental illness and death, including the death of a parent/s, lost educational opportunities, and the loss of familial land and property. Participants' experiences of childhood were changed through absenteeism from school, increased manual work responsibilities, caring for siblings, and an increase in financial burden. Lost education opportunities were strongly associated with hopes for obtaining gainful employment and the provision for basic needs. • Orphanhood begins with parental illness. • All participants discussed their experience of orphanhood beginning with parental illness rather than death. Parental illness resulted in difficult emotional loses as youth witnessed the physical suffering of their parent/s, with the most poignant being the death of a parent. Parental illness resulted in extended periods of school absenteeism, as youth resume being the primary caregiver of the sick parent. Financial difficulties amounted as the result of medical expenses and the lack of adequate resources to pay for food, shelter, and educational costs. Conflict with the clan • The period of parental illness and death was marked by conflict with extended family and relatives regarding property ownership. Property left by the parent was perceived as an opportunity by relatives to exploit orphan's vulnerability and stake claim to these limited resources.	Parental illness and death led to several struggles for orphaned youth namely, financial burdens, the loss of educational opportunities, living conditions characterised by exploitation and abuse and experiences of culturally specific forms of stigmatisation. These experiences and struggles act to increase the vulnerability of youth orphaned or made vulnerable by HIV/AIDS. More needs to be done to understand and address the experiences of AIDS orphaned youth in order to offer the required support.

		• Participants living with extended family (12) described their living situations as difficult circumstances characterised by discrimination and unequal treatment, stigmatisation, not having their basic needs met, and physical abuse. However, two participants described having a trusted family member who remained an advocate for them during difficult living arrangements. Okulangira • Okulangira – one type of stigmatization – repeatedly discussed by participants is a verbal exchange where an individual is reminded in a derogatory manner about their inferior social position. Caregivers engaged in this practice to invoke gratitude from orphaned youth • Stigmatisation led to relationship conflicts and frequent isolation	
Hermenau, Eggert, Landolt, & Hecker (2015)	The following methods of analysis were used to analyse data: • The statistical package IBM SPSS Statistics Version 0.21 was used to analyse data. • To test hypothesis 1 and 2, two MANOVA's were conducted comparing orphans to non-orphans regarding their exposure to maltreatment and psychological distress. • Univariate analysis of variance (ANOVA) was calculated • Bonferroni-correction was applied to avoid x-error due to multiple testing. • To test hypothesis 3, 4 and 5, multiple sequential regression analysis was conducted correlating neglect, abuse, perceived stigmatisation, and the interaction of neglect and stigmatisation on child	**Descriptive statistics** • Orphans (97%) and non-orphans (93%) experienced at least one type of abuse by a caregiver. In total, 50 orphans (56%) and 28 non-orphans (32%) experienced at least one type of neglect Key findings are presented below: Maltreatment and psychological distress • Significant differences between orphans and non-orphans regarding their exposure to maltreatment were identified. • Univariate ANOVA's revealed significant differences with medium effect sizes for neglect types; abuse did not differ significantly. • Univariate ANOVA's revealed significant differences with medium effect sizes in depression, PTSD and aggressive behaviour, no significant differences were present for internalizing and externalising problems. Association of maltreatment and stigmatisation to internalizing and externalising problems. • The effects of neglect, abuse, and stigmatisation positively significantly correlated with orphans internalising and externalizing problems. Stigmatisation as moderator of the relationship between neglect and depressive symptom severity • The main effect of neglect and stigmatization and the interaction term of stigmatization positively significantly correlated with orphans' depressive symptom severity. • Perceived stigmatisation moderated the neglect-depression relationship; the relationship is always positive but stronger in the presence of high levels of perceived stigmatisation. • Simple slope analysis revealed that the relationship between neglect and depression was significantly different at various values for perceived stigmatisation.	The study's findings suggest that orphans in Tanzania are at increased risk of experiencing neglect. Maltreatment and perceived stigmatisation could potentially play a role in orphans' experience of psychological distress. Culturally appropriate and evidence-based intervention may prevent maltreatment and stigmatisation extended to orphans.

	depression, and strengths and difficulties.	High levels of perceived stigmatization resulted in a significant positive relationship between experienced types of neglect and severity of depression. This relationship was insignificant in the presence of low rates of perceived stigmatisation.	
Kumar, Dandona, Kumar, Ramgopal, & Dandona (2014)	The following methods of analysis was used to analyse data: - The statistical package SPSS version 17.0 was used for data analysis. - Differences between groups in socio-demographic characteristics, abuse and violence indicators, and discrimination were assessed using Chi-square tests or one-way analysis of variance tests. - Independent sample Fishers-tests were used to examine the associations between depression and socio-demographic variables and abuse, and violence and discrimination indicators. - Multivariate analysis of the variation in intensity of depression associated with socio-demographic and risk factors for mental health were performed using multiple classification analysis.	**Demographic characteristics** - Participants' age ranged between 12 to 16, with the mean age of 13 years for both girls and boys. - The proportion of boys was higher among children orphaned by AIDS (63.5%), with a higher proportion of girls among children orphaned by other causes (59%). - 397 participants (99.3%) attended school and 200 participants (50.6%) belonged to Hindu religion. The study's findings are presented below: Abuse, violence and discrimination - COA (50.3%) are significantly more likely to report being bullied by friends and relatives than COO (26.8%). - More COA (50.3%) reported witnessing fights between parents when they were alive than COO (35.9%). - A total of 40 orphaned children reported experiencing discrimination of whom the majority were COA (62.5%). - The proportion of children reporting the experiences of abuse at orphanages was higher among COO (23.3%) than COA (19.1%). Depression - The range of depression score was 3 to 56 for COA and 3 to 47 for COO. - The prevalence of depression score of >15 was 74% with a significantly higher prevalence among COA (84.4%) than COO (63.6%). - The mean depression score was higher for COA (34.6) than COO (20.6). - In both groups, the mean depression score was significantly higher in the presence of bullying, ill treatment, and discrimination. - Unadjusted means indicate that the intensity of depression was significantly associated with being orphaned by AIDS, the experience of discrimination, and being bullied by friends or relatives.	A large proportion of orphaned children reported depressive symptoms; however, those orphaned by AIDS-related causes experienced more depressive symptoms than their counterparts. While this study presents mental health issues in orphaned children, particularly COA, there is a lack of specific programmes of policies in India to address care of the large number of COA. These findings may increase attention from policy makers and health care providers to the psychological needs of orphaned children and COA in particular.
Lin, Zhao, Li, Stanton, Zhang, Hong, Zhao, & Fang (2010)	The following methods of analysis was used to analyse data:	Descriptive statistics - The study sample consisted of boys (51%) and girls (49%) with the mean age of 12.85 years.	Children are likely to suffer from numerous AIDS-related stressors including the loss of a parents to AIDS. Stigmatization for parental HIV

	- The statistical package SPSS version 15.0 was used to analyse data. - Cronbach's alpha was employed to examine the internal consistency of stigma scales across the entire sample. - Analysis of variance (ANOVA) was employed to determine the association between stigma measure, demographic characteristics, orphanhood status and psychosocial well-being. - Multivariate analysis using general linear modelling (GLM) assessed the effects of stigma on participants' psychosocial well-being while controlling for orphan status, sex, age and family SES.	- Majority of participants (99%) were of Han ethnicity, while two-thirds of the sample reported good physical health. - Orphans were significantly older than their counterparts and were more unlikely to know their parental educational attainment. - More orphans or vulnerable children reported that their parents mainly engaged in farming than comparison children. Group differences of stigma measures - Perceived public stigma was similar for boys and girls but differed by age group with pre-adolescents and middle adolescents reporting higher levels of perceived stigma than early adolescents. - Perceived public stigma differed significantly across comparison groups with AIDS orphans and vulnerable children experiencing higher levels of perceived public stigma than comparison children. - Personal stigma differed significantly by gender and age with boys reporting higher levels of personal stigma than girls and pre-adolescents, early adolescents, and middle adolescents, respectively. - Family SES was positively associated with children's personal stigma but not public perceived stigma. Association between stigma and psychosocial well-being - Both public perceived and personal stigma scales were positively associated with psychopathological symptoms (depression and lowliness) and negatively associated with psychosocial well-being (self-esteem, positive future expectation, hopefulness about future, and perceived control over future).	and emotional and financial difficulties, Future research should be directed at exploring both individual and contextual factors in mitigating the negative effect of stigma among children affected by HIV/AIDS.
Nyamukapa, Gregson, Wambe, Mushore, Lopman, Mupambireyi, Nhongo, & Jukes (2010)	The following methods of analysis were used to analyse quantitative data: - Psychological distress variables were constructed using factor analysis and psychological distress cores were modelled using Poisson regression. - Multivariate models were developed to (1) measure associations between hypothesized moderating and	The study findings are presented below: Associations between orphanhood and psychological distress - Younger children, girls, and paternal orphans reported higher levels of psychological distress. - For boys, paternal orphans and double orphans reported higher levels of psychological distress. - Paternal orphans displayed greater psychological distress for all duration of parental loss, whereas maternal orphans who lost their parents >4 ago reported less psychological distress, suggesting high levels of resilience. Causal pathways between orphanhood and psychological distress - Associations between immediate and intermediate effects of orphanhood and psychological distress showed strong positive associations for (1) living in a household with a recent	Non-school attendance, inadequate care, child labour, physical abuse, and stigma and discrimination were more common among orphaned children and was associated with psychological distress. When controlling for these factors across causal pathways, the association between orphanhood and psychological distress lost its predictive power. Therefore, programs should be underpinned by community based counselling, training and

	mediating factors and psychological distress; (2) establish whether increased exposure to these detriments accounted for the greater psychological distress in orphaned children. • Logistic regression was used to investigate associations between psychological distress and risk behaviours. The following methods of analysis were used to analyse qualitative data: • Transcriptions were analysed using content theme analysis which involved the coding of recurring themes and the interpretation of coded data.	death; (2) living with a seriously ill adult member; (3) suffering stigma; (4) inadequate care; (5) child labour; (6) physical abuse; and (7) being out of school. Consequences of psychological distress for early sexual risk behaviour and substance abuse in adolescents • Psychological distress was not associated with early sexual behaviours or substance abuse. Measures to reduce children's psychological distress • The careful selection of caregivers for orphaned children were identified as it affects the nature and quality of care for orphaned children and would assist in the prevention of ill-treatment of orphaned youth. • An increase of support for caregivers, such as childcare training which would operate to decrease ill-treatment of children, may act to reduce psychological distress experienced by orphaned children. • Regular school attendance may reduce the psychological distress experienced by orphaned children, as children viewed the school environment as a safe haven in which they could acquire life skills, create a social network, and cope with their grief.	support for caregivers, and stigma reduction to reduce the psychological distress among orphaned children.
Qiao, Li, Zhao, Zhao, & Stanton (2012)	The following methods of analysis were used to analyse data: • The statistical package SPSS version 16.0 was used to analyse data. • Analysis of variance (ANOVA) was used to compare children's individual characteristics. • Frequency distribution was used to compare children's perceptions of disclosure by orphanhood status. • Analysis of variance (ANOVA) was used to compare children's psychosocial and demographic factors by intention, openness,	The study's findings are presented below: Perceptions of secondary disclosure • Orphans living in orphanages (38.2%), orphans in families (20.5%), and vulnerable children (34.4%) have a strong intent to disclose their parental HIV status to others. • Orphans living in orphanages (28.2%), orphans in families (23.9%), and vulnerable children (28.9%) would like to talk about the truth during disclosure. • Over 70% of children reported strong negative feelings associated with secondary disclosure. These negative feelings were distributed across orphans in families (80.4%), orphans in orphanages (72.8%), and vulnerable children (70.9%), respectively. Psychosocial well-being correlated with children's secondary disclosure • Psychosocial measures were associated with children's experiences and perceptions of secondary disclosure. • Weak intention to disclose was significantly associated with higher levels of negative psychological outcomes, including depression, perceived stigma against children affected by AIDS, and enacted stigma.	Various familial, communal and cultural factors that may influence children's perceptions and practices of secondary disclosure and potentially mediate the effects of secondary disclosure on psychological well-being need to be examined. The practice of secondary disclosure and the effects on children's psychological adjustment are important aspects of coping with parental HIV-related infection and death. Further research and interventions are needed to maximize the long-term benefit of secondary disclosure to children affected by AIDS.

	and negative feelings of secondary disclosure. • Multivariate analyses using the general linear model (GLM) procedure were performed to assess the effect of children's intention of secondary disclosure on their psychosocial measures.	• Weak intention to disclose was also associated with higher scores for perceived social support scales, lower hopelessness, and higher self-esteem. • Weak intention to be open during disclosure is significantly associated with higher depression, loneliness, perceived stigma, and enacted stigma. • Weak intention to be open during disclosure is significantly associated with higher scores for perceived social support scales, lower hopelessness, and higher self-esteem. • Strong negative emotions regarding secondary disclosure was more likely to result in high levels of psychological outcomes including depression, loneliness, perceived stigma, enacted stigma, and hopelessness. • Negative feeling of disclosure was associated with high scores for perceived social support scales and self-esteem.	
Wei, Li, Harrison, Zhao, & Zhao (2016)	The following methods of analysis were used to analyse data: • Bivariate correlations were examined to identify significant associations among two types of HIV stigma, emotional status, and emotional regulation. • A three-step regression analysis was performed to test whether emotional regulation mediates the relationship between HIV stigma and negative emotions. • The significance of estimated mediation effects was assessed with Sobel test using the bootstrapping method. • To examine the potential moderating effect of age on emotional status, hierarchical multiple regression analysis was conducted for positive emotions and negative emotions.	Demographic characteristics • Study participants consisted of boys (51.6%) and girls (48.4%). Participants ranged from 6 – 17 years of age with a mean age of 10.51. • The majority (97%) of participants were of Han ethnicity The study's findings are presented below: • Enacted and perceived stigma was positively associated with negative emotion but not positive emotions. • Emotional regulation was associated with positive emotions and negatively associated with enacted stigma, perceived stigma, and negative emotions. • Emotional regulation partially mediated the relationship between negative emotions and both enacted and perceived stigma. • Enacted and perceived stigma had no significant association with positive emotions. • Perceived stigma and age interaction term was significant for negative emotions for the entire sample. Higher age was associated with increased experience of negative emotions. • The effect of perceived stigma on negative emotion is moderated by age in HIV affected children. • A significant relationship between perceived stigma and negative emotions existed at both a younger and older age.	Children affected by HIV may benefit from interventions aimed to enhance their capacity to regulate emotions. Health professionals should be knowledgeable of the association between HIV stigma and negative emotion in childhood and adolescents as such knowledge may inform treatments offered to children affected by HIV

Wei, Li, Tu, Zhao, & Zhao (2016)	The following methods of analysis were used to analyse the data: • The statistical package SPSS version 21.0 was used to analyse data. • The Pearson's correlation analysis was performed to identify significant association among variables. • Multiple regression analysis was performed to evaluate the indirect effects of three mediators, namely, perceived social support, hopefulness, and emotional regulation. • The first regression evaluated the association between enacted stigma and post-traumatic growth. • The second regression evaluated the association between enacted stigma and perceived social support, hopefulness, and emotional regulation. • The third regression examined whether the effect of enacted stigma was reduced when the mediators were introduced into the model predicting post-traumatic growth.	Demographic characteristics • Study participants consisted of boys (51.6%) and girls (48.4%). Participants ranged from 6 – 17 years of age with a mean age of 10.51. • The majority of participants (97%) were of Han ethnicity. The study's findings are presented below: • Greater experiences of enacted stigma were associated with lower post-traumatic growth, less perceived social support, less hopefulness, and poorer emotional regulation. • Greater post-traumatic growth was associated with increased perceived social support, hopefulness, and better emotional regulation. • Post-traumatic growth was negatively associated with enacted stigma. • Perceived social support was negatively associated with enacted stigma. • Emotional regulation was negatively associated with enacted stigma. • Multiple regression analysis indicated statistically significant indirect effects of enacted stigma on post-traumatic growth through each of the three mediating variables, namely, perceived social support, hopefulness, and emotional regulation.	Perceived social support, hopefulness, and emotional regulation offer multiple levels of protection that could mitigate the effects of enacted stigma on post-traumatic growth. Future psychological interventions should develop strategies to reduce stigmatization experienced by children and promote their level of post-traumatic growth. Health professionals should advocate for the development of these protective psychological factors
Xu, Yan, Duan, Wang, Rou, & Wu (2009)	The following methods of data analysis were used to analyse the data:	The study's findings are presented below: • Three themes were identified as relevant to children's psychosocial problems: (1) emotional issues, (2) interpersonal relationship, and (3) stigma and discrimination.	This study illustrated that HIV/AIDS has negatively impacted the psycho-social well-being of children affected by HIV/AIDS. These findings are consistent with research conducted in

	• The software programme ATLAS.ti version 5.0 facilitated the data analysis. • All interviews were transcribed and reviewed by two independent researchers. • Transcriptions were coded and analysed by the first author. After repeated examination of transcripts, codes, categories and subcategories were developed, refined, and defined. • The constant comparative method was used to facilitate theme development. • Through comparison, similarities and differences between groups were compared to identify additional patterns, variation, and concepts, enabling the refinement of themes.	• All participants were found to suffer from emotional issues. Several dimensions of emotional issues were identified, namely, fear, anxiety, and loss of self-esteem and confidence. Emotional issues influenced children’s personal relationships with both caregivers and peers. • Fear resulted from concern regarding parental health and illness and uncertainty about the future following parental death. Sadness and grief was associated with the loss of a parent/s and the truth regarding parental illness and death. Confidence and self-esteem of participants changed as they became sensitive to the opinions of others. • Interpersonal relationships include family and fraternal relationships. Nuclear and extended family members were a source of economic, emotional, and social support for children. Peer relationships differed among attending and non-attending school participants. The former was associated with good peer relationships, while the latter was associated with isolation and feelings of loneliness. • The influence of emotional issues on interpersonal relationships was found to be mediated by stigma and discrimination. Stigma and discrimination were identified as the leading cause of emotional issues resulting in the change in children’s interpersonal relationships with others. • Perceived stigma and discrimination, self-stigma, and perceived non-discrimination was identified. Perceived stigma was characterised by stigmatization from peers because of parental illness and death and resulted in rejection. Children experienced self-stigma, including feelings of self-hatred, shame, and isolation from others. However, a culture of non-discrimination was identified as there was no change in interpersonal relationships as a result of HIV infection or death. However, few participants disclosed parental HIV-infection.	previous countries and may be used as preliminary data to support future research exploring the psychosocial impact of HIV/AIDS on children while appropriately indicating the need for interventions.
Zhao, Li, Zhao, Zhang, & Stanton (2012)	The following methods of analysis were used to analyse data: • Chi-square and analysis of variance (ANOVA) were used to assess group differences in key demographic variables, stigma measures, and child psychological problems. • Post-hoc comparison was performed with use of the least significant difference (LSD)	**Demographic characteristics** • Orphans were older than both vulnerable children and comparison children, and comparison children were older than vulnerable children. • Comparison children reported higher socioeconomic status than both orphans and vulnerable children. Orphans reported higher socioeconomic status than vulnerable children. • Orphans scored higher than vulnerable children, who scored higher than comparison children for two forms of perceived public stigma and psychological problems. • No difference regarding personal stigmatizing attitudes was reported between groups. • There was no difference between orphans and vulnerable children for enacted stigma. The study’s findings are presented below:	Various measures of stigma (perceived public and enacted stigma) were associated with internalising and adjustment problems for children affected by HIV/AIDS, independent of key demographic characteristics. However, all measures of stigma do not equally contribute to psychological problems for affected children. There is a rising need to consider the effects of HIV-related stigma on children’s psychosocial well-being and

	criterion to identify pair-wise differences and present an overall significant difference between three groups. - Pearson Product Moment Correlation Coefficients were employed to assess the relationship among stigma measures and psychological measures for the entire sample. - Multiple regression analysis was performed to assess relative contribution of measures of stigma to both internalising and externalising problems.	- The correlations among three stigma measures were higher among orphans and vulnerable children (ranging from 0.32 to 0.69) than their counterparts (ranging from 0.24 to 0.57). - In terms of strength, the highest correlation was between two measures of perceived public stigma, followed by enacted stigma and depression. - In strength the weakest correlation was between personal stigma against people living with HIV/AIDS and depression, followed by personal stigma and enacted stigma. - Older age, being an orphan, perceived public stigma and enacted stigma was predictive of depression amongst children affected by HIV/AIDS.	effectively utilize community resources to mitigate and reduce the negative effects of HIV-related stigma for children affected by HIV/AIDS.

HIV-related stigma among children orphaned by AIDS

Included studies have unanimously reported that COA are socially devalued as a result of their affiliation with parental HIV/AIDS, regardless of their HIV status, socio-economic status, or other key demographic characteristics associated with orphanhood. COA experienced significantly higher levels of HIV-related stigma than other-orphaned and non-orphaned children (Cluver & Orkin, 2009; Kumar et al., 2014; Lin et al., 2010; Zhao et al., 2012). Xu and colleagues (2009), however, reported a culture of non-discrimination among COA despite the presence of HIV-related stigma, as 60% of the sample population failed to report any stigmatising behaviours within their extended family structures or general community. Various measures of HIV-related stigma were experienced by COA with enacted stigma as the most reported measure of HIV-related stigma (Chi et al., 2014; Cluver & Gardner, 2007; Cluver & Orkin, 2009; Harms et al., 2010; Kumar et al., 2014; Nyamukapa et al., 2010; Qiao et al., 2012; Wei et al., 2016a; Wei et al., 2016b; Xu et al., 2009; Zhao et al., 2012). Cluver and Gardner (2007) reported the presence of vicarious stigma while perceived stigma among COA was well documented by several included studies (Chi et al., 2014; Cluver & Gardner, 2007; Harms et al., 2010; Hermenau et al., 2015; Lin et al., 2010; Qiao et al., 2012; Wei et al., 2016b; Xu et al., 2009). Five included studies (Chi et al., 2014; Hermenau et al., 2015; Lin et al., 2010; Xu et al., 2009; Zhao et al., 2012) consistently indicated the presence of internalised stigma.

HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

All included studies recognised HIV-related stigma’s incremental contribution to the poor psychosocial well-being displayed by COA. Enacted stigma directly impacted the psychosocial well-being of COA, as experiences of overt discrimination resulted in withdrawal, self-isolation, and an increase in internalising disorders (Chi et al., 2014; Cluver & Gardner, 2007; Cluver & Orkin, 2009; Kumar et al., 2014; Lin et al., 2010; Nyamukapa et al., 2010; Qiao et al., 2012; Wei et al., 2016b; Zhao et al., 2012). Similarly, Cluver and Gardner (2007) found that vicarious stigma increased COAs likelihood of psychological distress and internalising disorders as they anticipated experiences of enacted stigma. The development of such internalising disorders ensued an increase in perceived stigma, which indirectly contributed to poor psychosocial well-being through non-disclosure strategies. Non-disclosure strategies encourage a culture of secrecy, silence, isolation and social withdrawal which acts as a barrier to constructing a healthy sense of intimacy with others, negatively affecting COAs perceptions of social support (Harms et al., 2010; Qiao et al., 2012; Wei et al., 2016a; Wei et al., 2016b). The lack of perceived social support negatively impacts COAs capacity for emotional regulation, resulting in a negative emotional status and increased psychological distress (Cluver & Gardner, 2007; Harms et al., 2010; Hermenau et al., 2015; Wei et al., 2016a; Wei et al., 2016b; Xu et al., 2009). Chi et al., (2014) and Hermenau et al., (2015) indicated a bidirectional relationship between enacted and perceived stigma as children with internalising disorders are more sensitive to stigmatising behaviours directed towards themselves or their family and are likely to report higher levels of enacted stigma. However, enacted stigma appeared more powerful in determining poor outcomes for COA as in the presence of enacted stigma, perceived stigma loses its predictive power (Chi et al., 2014; Zhao et al., 2012). Three studies (Hermaneau et al., 2015; Lin et al., 2010; Qiao et al., 2012; Xu et al., 2009) found that COAs experience of internalised stigma resulted in a poor self-concept and lower levels of self-esteem. COAs experiences of enacted, perceived, and internalised stigma severely and negatively impacted the future orientation of COA as they displayed lower levels of optimism, hopefulness, and perceived control over their futures (Harms et al., 2010; Lin et al., 2010; Nyamukapa et al., 2010; Qiao et al., 2012; Wei et al., 2016a; Xu et al., 2009).

Discussion

This study established that HIV-related stigma resulting from parental illness and death inhibited the psychosocial well-being and functioning of COA. Several domains of psychosocial well-being impacted by HIV-related stigma were identified, namely, psychological and social well-being, emotional regulation, emotional status, self-esteem and self-concept, and future orientation. HIV-related stigma has contributed towards COAs increased psychological difficulties, social withdrawal, self-isolation, negative emotional status, poor emotional regulation, low self-esteem, diminished confidence and a lack of hopefulness, optimism, and perceived control over their future.

Experiences of overt discrimination reported by COA are consistent with the definition of enacted stigma. Overt discrimination experienced by COA often manifested as discrimination, rejection, abandonment, bullying victimisation, social isolation, rejection, devaluation, ill-treatment, exploitation, and physical, emotional, and sexual abuse, receiving inadequate food and clothing, and being denied a formal education (Lin et al., 2016; De Witt & Lessing, 2010; Nyamukapa et al., 2010; Adejuwon & Oki, 2011). To avoid future experiences of overt discrimination, COA employed emotion-focused coping strategies (self-isolation and social withdrawal) resulting in increased psychological difficulties, such as feelings of anxiety, depression, and loneliness (Major & O'Brien, 2005). Contrastingly, a culture of non-stigmatisation has been reported by COA, as they receive support from extended family members and the community (Xu et al., 2009). Therefore, when COA receive adequate social support the "Cinderella myth," which refers to COAs experiences of enacted stigma in their adopted homes, may be rejected (Harms et al., 2010). This culture of non-stigmatisation may result from COAs non-disclosure of orphanhood status or parental cause of death due to fear of stigma and discrimination.

Non-disclosure, an outcome of perceived stigma, indirectly affected the psychosocial well-being of COA, as it negatively influenced their perceptions of social support. Perceived social support—the availability of others able to provide social resources necessary to cope with traumatic events and adversities such as parental bereavement and stigmatisation—acts as a protective factor for COA (Cohen & McKay, 1984; Galvan, Davis, Banks, & Bing, 2008; Prati & Pietrantoni, 2009; Wei et al., 2016a; Xanthopoulos & Daniel, 2013). Although the concealment of orphanhood status is met with increased social support needed for the psychosocial well-being of COA, the lack thereof perpetuates emotion-focused coping, impaired social attachments, and psychological difficulties (Major & O’Brien, 2005; Xu et al., 2009, Wei et al., 2016a). Collectively, these factors inhibited COAs ability for healthy emotional regulation as they were unable to healthily express their feelings regarding stressful life events, inevitably leading to a negative emotional status (Cheney, 2015; Cluver & Gardner, 2007; Harms et al., 2010; Hermenau et al., 2015; Wei et al., 2016a; Wei et al., 2016b; Xu et al., 2009). Effective emotional regulation and a positive emotional status are pivotal to the social well-being of COA as it allows for their optimal functioning in secure and affectionate relationships, a necessity for psychosocial well-being (Ritcher et al., 2009).

Negative emotional statuses displayed by COA are maintained by experiences of internalised stigma, as COA accept negative views of themselves as truthful and valid, and foster feelings of disgrace, inferiority, and helplessness. Internalised stigma manifested as chronic feelings of inadequacy and the belief that they are deviant, tainted, and a drain on society (Goffman, 1963; Sandler et al., 2009; Xu et al., 2009). These beliefs represent both the psychological suffering, poor self-concept, and lower levels of self-esteem displayed by COA. The poor self-concept and lower levels of self-esteem of COA are sustained by the lack of intimacy with others. Building trusting relationships presents COA with the opportunity to engage in self-esteem enhancing activities through their interactions with others. With impaired social relationships, a poor self-concept, and lower levels of self-esteem, COA lose confidence in themselves and display a lack of hopefulness, optimism, and perceived control over their future (Adejuwon & Oki, 2011; Harms et al., 2010; Kheswa & Duncan, 2011; Lin et al., 2010; Mo et al., 2015; Qiao et al., 2012; Wei et al., 2016b; Xu et al., 2009). The psychosocial well-being of COA has thus been adversely affected by experiences of HIV-related stigma resulting from parental illness and death.

This is the first known systematic review focusing on HIV-related stigma and the psychosocial well-being of COA and highlights implications for future research and practice. Future research needs to be conducted across a broader geographical area and include a larger sample population. As stigma is culturally and contextually dependent, culturally appropriate interventions are needed to address experiences of stigma and its impact on the psychosocial well-being of COA. Psychological support and counselling services are needed to improve the psychosocial well-being of COA. As the majority of studies have been conducted in China and Africa, the findings are not generalizable. This may result from high prevalence rates of HIV/AIDS reported in these regions and highlights a gap in the literature. Due to non-disclosure strategies, studies failed to report on criteria used for discerning parental cause of death resulting in their exclusion, limiting the pool of included studies.

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4.5 Conclusion

The systematic review (Article 1) presented in this chapter highlights the manifestations of HIV-related stigma and responses to such stigma as experienced and perceived by COA. The findings of the review assisted with the identification of key concepts pertaining to HIV-related stigma and the domains of psychosocial well-being. These will be explored further in the next chapter, contributing to Phase III—where the process of model development unfolds. Chapter 5 therefore presents the results of the second phase of the study involving the lived experiences and perceptions of COA regarding HIV-related stigma and their psychosocial well-being.

Chapter 5

Phase 2: A qualitative exploration of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

5.1 Introduction

The previous chapter presented Phase I (Article 1) outlining the findings of a systematic review. This chapter includes Phase II of the study (Article 2) as depicted in Figure 5.1 below. The qualitative exploration undertaken in Phase II, as presented in this chapter, highlights the experiences and perceptions of HIV-related stigma and the manner in which it has affected the psychosocial well-being of COA. This exploration is facilitated by the findings extracted in Phase I, to inform and guide the explorative process, resulting in the further identification and expansion of concepts and relational statements between concepts.

5.2 Publication details

Article 2 has been published in the journal *Global Social Welfare*, the details of which are presented in Table 5.1 below:

Table 5.8: Article 2 – Publication Details

Title	**HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A systematic review**
Author	Yassin, Z., Erasmus, C. J., & Frantz, J. M.
Year	2019
Journal	Global Social Welfare
Volume	-
Issue	-
Page no.	1-12
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Full citation	Yassin, Z., Erasmus, C. J., & Frantz, J. (2019). Qualitative exploration of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS. *Global Social Welfare*, 1-12. doi.org/10.1007/s40609-019-00147-2

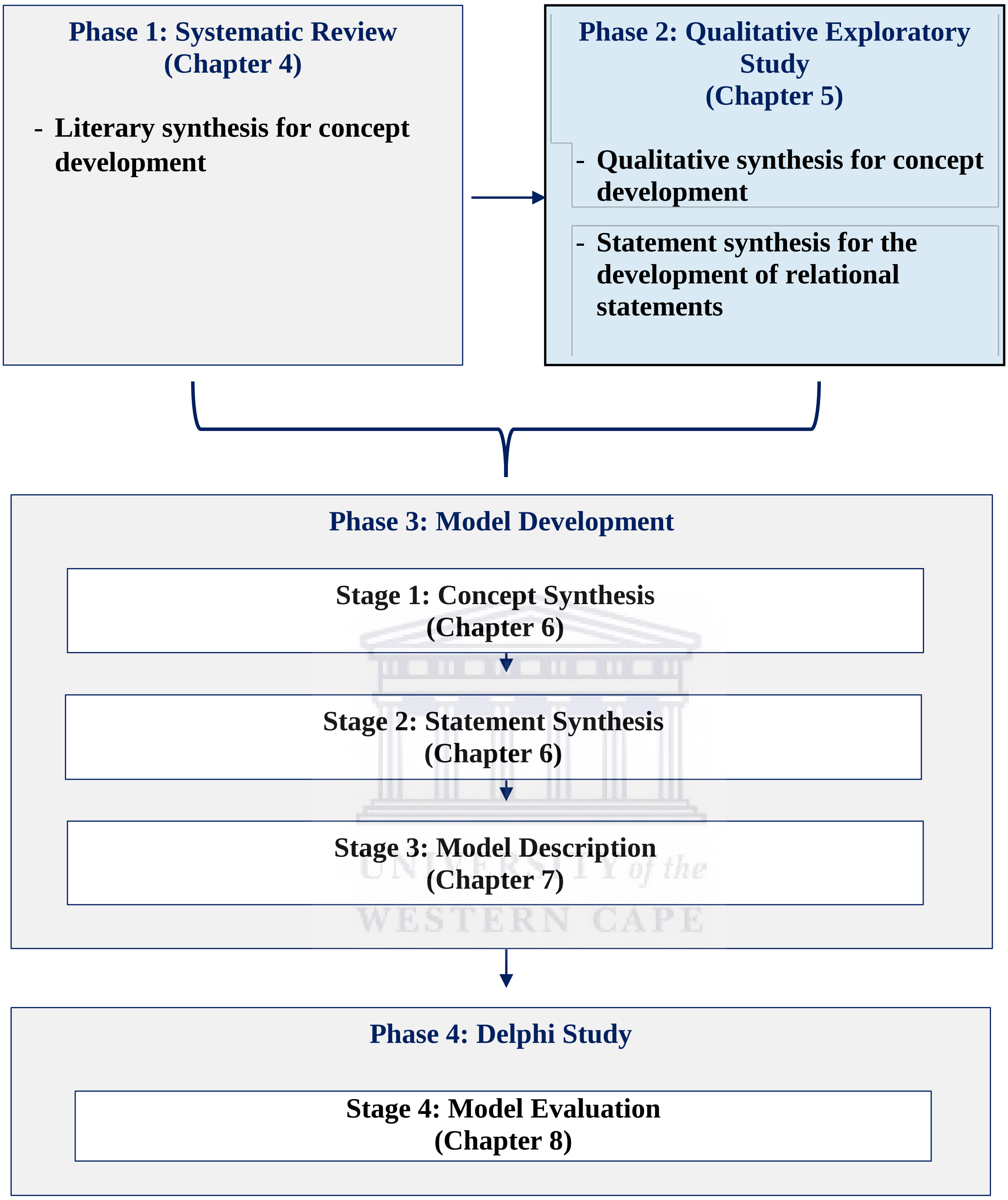

Figure 5.5: Qualitative Exploratory Study

5.3 Journal overview

The *Global Social Welfare* journal maintains an international, interdisciplinary approach focused on applied social work research, policy, and practice. The journal is stored under the Springer Nature publishing house. The journal's publications address shared challenges regarding the well-being of communities, families, and individuals. These shared challenges refer to an array of issues that are considered global threats to well-being, including poverty, food insecurity, housing, social detriments of health, maternal and child health, mental health, trauma, orphans and vulnerable children, and disease and illness, to name a few. Additionally, research published within *Global Social Welfare* is expected to recognize the link between individuals, families, communities, and their external environments, while remaining cognizant of the interconnections between race, culture, and poverty with regards to well-being.

5.4 Phase II: Published article

Qualitative exploration of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

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Abstract

Children orphaned by AIDS continue to display lower levels of psychosocial well-being. While HIV-related stigma has been identified as a risk factor for healthy psychosocial development, there remains an inadequate understanding of orphaned children's experiences and perceptions of HIV-related stigma and its impact on their psychosocial well-being. This study explored children orphaned by AIDS perceptions and experiences of HIV-related stigma and how it has affected their psychosocial well-being. This study used a qualitative exploratory descriptive design. Thirteen participants between 8 and 17 years of age were purposively selected. Data was collected using individual open-ended face-to-face interviews, observations, and field notes. Data was transcribed and analysed using a thematic analysis. Three key themes emerged: (1) children's experiences of stigma and discrimination, (2) children's perceptions of HIV-related stigma, and (3) the psychosocial well-being of children orphaned by AIDS. Children were highly perceptive and experienced HIV-related stigma as a result of their association with parental HIV/AIDS, regardless of their own HIV-status. Experiences and perceptions of HIV-related stigma was identified as negatively impacting the psychological and emotional well-being, social well-being, perceived social support, self-concept and self-esteem, and future orientation of orphaned children. This qualitative study contributes towards an understanding of orphaned children's experiences and perceptions of HIV-related stigma and how it may affect their psychosocial well-being, which is useful for informing future research and policies and programmes guided towards ensuring the well-being of children orphaned or made vulnerable by AIDS.

Keywords: HIV/AIDS, Orphans, HIV-related stigma, Psychosocial well-being, Exploratory design

Introduction

The outcome of the HIV/AIDS epidemic is the emergence of one of the largest orphan populations in the world, as 17.3 million children were parentally bereaved by AIDS-related causes by the year 2011 (Caserta et al., 2016; Chi et al., 2014). Sub-Saharan Africa has been the most severely affected as 15 million orphaned children are located in Sub-Saharan Africa, with 2.5 million orphaned children residing in South Africa (UNICEF, 2013). Children orphaned by AIDS (COA) is defined as a child/ren under the age of 18 years, who have/has lost one (single orphan) or both (double orphan) their parent/s to HIV/AIDS (Tran & Mwanri 2013; Sharp et al., 2015; UNICEF, 2004). COA are likely to experience adversities and stressors associated with orphanhood that may affect them in various ways. These include poverty, food insecurity, inadequate housing, difficult living situations, educational disruption, maltreatment, exploitation, and violence (Harms, Jack, Ssebunnya, & Kizza, 2010; Skovdal et al., 2016; Li, Chi, Sherr, Cluver, & Stanton, 2015). Studies (Skovdal et al., 2016; Doku, Dotse, & Mensah, 2015) suggest that COA experience poorer psychosocial well-being than other-orphaned and non-orphaned children. Psychosocial well-being refers to the amalgamation of mental and social well-being which widely reflects an individual’s thoughts, feelings, behaviours, and reactions to their social environment (Fujishima-Hachiya & Inoue, 2012). Psychosocial well-being thus addresses the holistic well-being of COA (Snider & Dawes, 2006), which is essential for the healthy growth and development of a child and plays a pivotal role in their ability to reach their full potential. Numerous risk factors have been identified in contributing to COAs poorer levels of psychosocial well-being, and these include parental loss and bereavement, financial deprivation, the lack of educational opportunities, social isolation, abuse and exploitation (Ishikawa et al., 2010; Snider & Dawes, 2006; Stein, 2003). Studies (Caserta et al., 2016; Chi et al., 2015) focusing on the psychosocial well-being of COA have also identified HIV-related stigma as a silent stressor.

HIV-related stigma—the “prejudice, discounting, and discrediting directed at people living with HIV/AIDS (PLWHA) and groups and communities with which they are associated” (Lin et al., 2010, p. 544)—transcends beyond individuals infected by HIV/AIDS, and is directed at their families and uninfected children. Children in HIV/AIDS affected families are likely to suffer from stigmatisation at home, at school, and within their leisure environments (Xu et al., 2009). Therefore, the possibility exists that the cause of paternal bereavement leads to the stigmatization of COA, regardless of their own HIV status (Chi et al., 2014; Gamarel et al., 2017; Thurman et al., 2006).

Goffman’s (1963) conceptualisation of tribal stigma represents the devaluation, rejection, and victimisation of COA based on their relationship with a stigmatised individual/s—in this case, being their HIV-positive parent/s. Four primary measures of HIV-related stigma—enacted stigma, vicarious stigma, and perceived and internalised stigma—have been identified as experienced by COA. Enacted stigma captures the interpersonal aspect of stigma—which embodies the prejudicial attitudes and discriminatory behaviours of others directed towards the stigmatised individual—which may be manifested as rejection, avoidance, violence, verbal insults, exploitation, and abuse (Bogart et al., 2008; Scambler, 1989). Witnessing or hearing about acts of enacted stigma of others is referred to as vicarious stigma, which is likely to result in the increase of perceived/felt stigma (Steward et al., 2008). Contrastingly, perceived and internalised stigma captures the intrapersonal aspect of stigma. Perceived stigma refers to an individual's perception and subjective awareness about the prevalence or normativity of HIV-related stigma within society. Internalised stigma is the process of an individual accepting the negative evaluation of society as they regard their discredited status as truthful and valid and incorporate these negative evaluations into their personal values and sense of self (Chi et al., 2014; Steward et al., 2008).

While few empirical studies have been conducted on HIV-related stigma and COA, it has gained much interest as stigma resulting from parental HIV/AIDS remains a key challenge for COA (Adejuwon & Oki, 2011; Kheswa & Duncan, 2011; Sharp et al., 2015; Zhao et al., 2012). COA may experience multiple measures of HIV-related stigma which may be extended to them in a variety of ways, namely, overt discrimination, bullying victimisation, denied access to a formal education, social isolation, and being denied support services as a result of the negative attitudes embodied by healthcare and support providers (Kheswa & Duncan, 2011; Lichtenstein, 2008; Tran & Mwanri, 2013). HIV-related stigma holds the potential to inhibit the psychosocial functioning of COA, setting them apart from their counterparts, as Chi et al., (2015) suggested that HIV-related stigma may adversely affect the feelings, thoughts, and behaviours of an individual, negatively impacting his/her psychosocial well-being. Similarly, reviews conducted by Deacon and Stephney (2007) and Yassin et al., (2018) associated stigma with the poor psychosocial well-being and functioning of COA as they are associated with a highly stigmatised disease, particularly in countries with widespread HIV/AIDS.

Despite substantial efforts to combat HIV-related stigma, it remains prevalent in contemporary day and poses a public health challenge and may negatively hinder healthy psychosocial development in COA (Li et al., 2015; Sharp et al., 2015). Little has been done to understand the manner in which HIV-related stigma affects the psychosocial well-being of COA (Chi & Li., 2013; Deacon, 2006; Sharp et al., 2015). Firstly, to date, there has been a rise in evidence examining the impact of different measures of HIV-related stigma on the psychological health of COA while overlooking the psychosocial and holistic well-being of COA. Secondly, as current knowledge is dominated by statistical studies, few studies have set out to explore and understand COAs experiences of HIV-related stigma with regards to their psychosocial well-being, thus limiting our understanding of COAs experiences and perceptions of HIV-related stigma and its associated impact on their well-being. Lastly, the few studies focusing on the experiences of COA gathered these experiences from relatives, caregivers, and other adults associated with the child. This study, therefore, aimed to explore children orphaned by AIDS perceptions and experiences of HIV-related stigma and the manner in which it has affected their psychosocial well-being.

Methodology

Study Design

A qualitative approach with an exploratory descriptive study design was adopted for the study. This study design allows for an in-depth, rich, and holistic understanding of HIV-related stigma and the manner in which it affects the psychosocial well-being of COA (Polit & Beck, 2004). The study was guided by the research question: “How do children who have been orphaned by

AIDS perceive and experience HIV-related stigma and the manner in which it has affected their psychosocial well-being?”

Study Setting

The study was conducted in a suburb and an informal township in Cape Town, which is situated in the Western Cape, South Africa. South Africa has the highest population of individuals living with HIV/AIDS, with a large population of orphaned youth, estimated at 2.3 million youth (UNICEF, 2015). The high prevalence of HIV/AIDS in South Africa is accompanied by high levels of HIV-related stigma manifesting in various ways from peer rejection and violence to murder (Gamarel et al., 2017). Thirty percent of the Western Cape province’s population consisted of children, of whom 6.7% of children were orphaned either paternally, maternally, or both. The study area had a population of 237, 414 individuals, with children under the age of 18 years amounting to more than 27% of the population (Statistics South Africa, 2011). The study was conducted at two sites: (1) a child and youth care centre founded in 1919. The centre is a registered non-profit organization offering community-based provision for residential care and support for vulnerable children affected by poverty, violence, and orphanhood; and (2) a township area severely affected by poverty, violence, and HIV/AIDS.

Study population

A purposive, criterion non-probability sampling technique was used to recruit participants. This sampling technique allowed for the inclusion of participants meeting a predetermined criterion of importance aligned with the aim of the current study (Patton 1990; 2001). Additionally, this technique allowed for the collection of in-depth information from participants. Children were eligible to participate if they: (1) were between 7 and 17 years of age; (2) have lost one or both parents to AIDS-related causes; (3) are HIV-negative; and (4) have been orphaned for more than 6 months. Children were required to be HIV-negative to ascertain whether their experiences of HIV-related stigma resulted from parental HIV/AIDS rather than the participants own HIV-status. To prevent reactions of acute bereavement and distress, children orphaned in the last six months were excluded from the study (Boyes and Cluver, 2013). Thirteen participants were purposefully recruited for their participation in this study (Pilot et al., 2001) and interviews were conducted between November 2017 and February 2018. The sampling process ended once data reached saturation and no new themes emerged.

Recruitment procedure and data collection

Participants were recruited through the help of the directors of non-profit organizations, social workers, counsellors, and community workers. The recruitment process began with the researcher contacting several non-profit organizations, social workers, and community members assisting orphaned or AIDS affected children to explain the purpose and significance of the study. An information sheet was provided to all respective parties in order to be distributed to potential participants and their guardians to solicit their voluntary participation in the study. Directors, health-service providers, and community workers approached eligible families to ascertain if their children would like to participate in the study. Once approval was attained from guardians or parents, potential participants met with the interviewer to start the process of informed consent. Participants were provided with informed consent, which included information about the aim and purpose of the study, confidentiality, voluntary participation, perceived risks and benefits of the research being undertaken, and contact details of the primary researcher for further queries. Additionally, the aim and purpose of the research study was explained to participants in a language that they understood and all questions regarding the study or process were addressed. No deception was used and correct information was given to participants, legal guardians, and non-profit organisations. The verbal consent of participants was attained and audio-recorded, while consent and assent forms were signed and collected from legal guardian/s before the interviews were conducted.

Data was collected through individual open-ended face-to-face interviews. The interviews were conducted in a private setting and time to the choosing of participants by a trained investigator. The interviews ranged between 20–50 minutes, being no longer than an hour, as suggested by Marshall (1996), and were conducted in English and Afrikaans. With the permission of participants, the interviews were audio-recorded. The purpose of the study, perceived benefits, limitations to confidentiality and the possibility of any risk or harm were reiterated before the interview, affording participants an opportunity to withdraw their participation (National Health Research Ethics Council, 2015; Tsheko, 2007). Pseudonyms were assigned to participants, while no personal descriptors were used throughout the course of the interview.

Considering the high rates of non-disclosure of parental HIV/AIDS, specific questions pertaining to HIV/AIDS or HIV-related stigma were not asked unless mentioned by participants themselves. Engagement techniques were used to establish rapport with younger participants prior to the interview to reduce anxiety and increase their comfortability (Irwin & Johnson, 2005). The researcher acknowledged that participants were regarded as vulnerable children implying an unequal relationship between the researcher and participant. Therefore, trust was maintained by: (1) communicating any changes or amendments to the research project; (2) promoting the best interest of the participant and protecting their well-being; (3) continually reiterating the conditions of participation; (4) refraining from any action that constitutes improper pressure on the participant to participate; and (5) creating a space for the participant to freely discuss their concerns (Human-Vogel, 2007). Safety monitoring through observation was used to identify any sign of distress displayed by participants. Field notes and observational cues were recorded by the researcher at the end of each interview, documenting the context of the interview and highlighting key emerging themes and any adverse events.

Data collection tools

An interview guide consisting of a series of open-ended questions and prompts was adapted along the (1) guidelines proposed by Shaw et al., (2011), and (2) the findings of a study conducted by Yassin et al., (2018). The interview guide served to guide the interviews, promoting the descriptive exploration of COAs perceptions and experiences of HIV-related stigma and its impact on their psychosocial well-being (Barbour & Schostak, 2005). The interview guide was suggestive and flexible rather than rigid and instructional to "improvise fruitful questions and pursue unanticipated lines of inquiry" (Millward, 1995, p. 429). To avoid distress and remain sensitive to the nature of the study, questions did not specifically refer to parental bereavement or HIV/AIDS but remained sensitive to detect experiences of HIV-related stigma and poor psychosocial well-being. As the interview guide was the primary data collection instrument, a pilot study was conducted to: (1) test the quality of the instrument; (2) reduce bias; (3) identify ambiguities; (4) clarify the wording of questions; and (5) identify difficult and unnecessary questions, as suggested by Noor (2008) and Chenail (2011).

Data analysis

Atlas.ti (version 8) was used facilitate the process of data analysis which followed the steps outlined by Braun and Clarke (2006). Given the exploratory nature of the current study, thematic analysis was conducted allowing for a rich and detailed account of the experiences and perceptions of COA to emerge (Braun & Clarke, 2006). The interviews were transcribed verbatim and the quality of each transcription was double-checked by the primary researcher. The transcripts were actively read, and notes were made to establish familiarisation with the data. After repeated reading, 328 initial codes were created and grouped into meaningful clusters resulting in 20 refined codes. The 20 meaningful codes and their extracts taken from the transcriptions were collated giving rise to three primary themes and five sub-themes representing the data. The themes and sub-themes were further refined by re-examining the codes of each theme or sub-theme and their extracts to determine whether the codes and the theme as a whole reflected the true nature and meaning of COAs perceptions and experiences of HIV-related stigma and the manner in which it has impacted their psychosocial well-being. The refinement of the themes resulted in the amalgamation or further breaking down of possible themes. Upon finalisation, each theme was defined by identifying their essence and named accordingly. The findings of the study are reported below.

Ethical Considerations

The study was approved by the University of the Western Cape's Human and Social Sciences Research Ethics Committee under ethics reference number HS17/1/17.

Trustworthiness

The trustworthiness of the study was ensured by credibility, transferability, dependability, and conformability as suggested by Shenton (2004). Credibility was ensured by (1) adopting well-established research methods previously used in qualitative data; (2) a pilot study to gain familiarity with the culture of the participants and organisations prior to the study to establish an understanding of the phenomenon and trust; (3) triangulation of data by using in-depth face-to-face interviews, field notes, and observations; and (4) qualified and experienced investigators. The in-depth account of the study's background and description of the phenomenon allows for transferability. Dependability was ensured through explicitly accounting for the study site, criteria for participant inclusion, sample size, data collection methods, data collection procedure, and the time period in which the study has been conducted so that the study may be replicated. Lastly, conformability was ensured by the reduction of researcher bias through the use of bracketing, provision of in-depth methodological procedures, and the acknowledgement of limitations of the study.

Findings

Sample characteristics

The demographic characteristics of participants are presented in Table 5.2. Thirteen South African children consisting of 9 males and 4 females participated in the study. The age of participants ranged from 8 to 17 with a mean age of 11.85 years. All children included in the sample were HIV-negative, according to their caregivers. Of these orphaned children, 7 were maternally orphaned, 2 were paternally orphaned, and 4 of them were double orphans. The length of time being orphaned ranged from 13 months to 14 years. At the time of the interviews, all of the participants attended school and were receiving a formal education. Majority of the participants received care from a residential care facility run by house mothers and fathers, while the remaining participants resided with extended family. Three primary themes emerged from the data, namely, (1) children's experiences of stigma and discrimination; (2) children's perceptions of HIV-related stigma; and (3) the psychosocial well-being of orphaned children. Each theme has been divided into sub-themes to highlight pertinent aspects of the data.

Table 5.9: Sample Demographics

	Male	*Female*	*Total*	*%*
Children	*(n=9)*	*(n=4)*	*13*	
Age				
8-10 years old	*8*	*0*	*8*	*61.53*
11-17 years old	*1*	*4*	*5*	*38.46*
Orphan Status				
Maternal Orphan	*4*	*3*	*7*	*53.8*
Paternal Orphan	*2*	*-*	*2*	*15.4*
Double orphan	*3*	*1*	*4*	*30.8*
School Attendance				
Yes	*10*	*3*	*13*	*100*
No	-	-	-	
Living arrangements				
With extended family	*1*	*4*	*5*	*38.5*
Residential care facility	*8*	-	*8*	*61.5*
Other	-	-	-	
Caregivers				
Relatives	*1*	*4*	*5*	*38.5*
Residential Care	*8*	*-*	*8*	*61.5*
Relationship with child				
Surviving Parent	*1*	*-*	*1*	*7.7*
Grandparent	*-*	*1*	*1*	*7.7*
Other relatives	*-*	*3*	*3*	*23.1*
Residential care mothers/fathers	*8*	*-*	*8*	*61.5*

Children's experiences of stigma and discrimination

Participants reported that their new living conditions were marked with overt discrimination as they were rejected, excluded, and received differential treatment compared to other children within their residential homes. Participants further expressed that they were not welcomed, they were isolated from others, and they were excluded from events and activities that included other children within the home. This was explained by one participant below:

> *"So when I came here to my grandfather's sister, …I saw that I was shown that I was not from there. Like they would isolate me from the things that they were doing. So sometimes they would go to the mall, all four of them and then I would be left behind I would feel that I'm being picked out and I didn't get much things. They would buy them tekkies and clothes for December and I wouldn't get one." (Female, 16)*

Younger children in residential care reported that they have been abandoned by their extended family, as they left the orphaned child in the care of a residential facility and discontinued all visitation, as indicated below:

> *"They send me here, they don't fetch me. They don't visit me…They can, but they don't." (Male, 9)*

Children living with extended family reported more severe accounts of stigmatisation and overt discrimination, including physical, verbal, and sexual abuse in the homestead compared to children living in residential care. Children were beaten, criticised, and sexually assaulted by others. As explained by participants below:

> *"So after my mother died in 2003, my grandmother raised me until 2011. So I went to stay with my grandfather's sister here at LA44 because my grandmother was abusing me… because sometimes she would beat me for things that, she would take out her stresses and things and beat me." (Female, 17)*

> *"I feel like they are going to, because the kind of situation we live there it's very different. I would say they would criticise me, because even for the good things that happen to me." (Female 16)*

> *"And when I was small, I was almost molested by my grandmother's sister's son. Ja, so he molested me in a way that he made me do oral sex to him, and ja." (Female, 14)*

While children residing in residential care lacked experiences of abuse received from their extended family, they continually reported bullying victimisation received from their peers. Orphaned children were called names, beaten, thrown with stones, sworn at and insulted by their peers. As explained by participants below:

> *"That my friends swear me out …They are thrown stones at me and stuff." (Male, 7)*

> *"They fight with me, they swear my mother out and they kick me." (Male, 10)*

> *"sometimes the other children want to hit me. My friends want to hit me when I do nothing to them… And they swear me out." (Male, 12)*

Experiences of enacted stigma contributed to experiences of internalised stigma, also known as self-stigma, as COA accepted negative views of themselves as truthful and valid. Participants internalised the negative views of others resulting in them developing feelings of shame, embarrassment, self-hatred, dirtiness, and being unworthy and unlovable. As expressed by a participant below:

> *"Grade 9 ja, Grade 9 after my mom passing, I was meeting this boy, but then like whenever he wants to touch me, I wouldn't allow him. I wouldn't allow him because I was like no, I feel dirty or I feel no, I'm not good enough." (Female, 17)*

> *“Yes, I think it’s part of the reason why because I don’t want to feel like I’m dirty, you know? It is, because I feel like it creates that error in other people, because maybe some people would look at themselves and feel disgusted, or maybe I also have this disease, because they never disclosed this to me, maybe I also have this. This disease, my mom had this thing, or my dad has this thing.” (Female, 17)*

Enacted stigma and vicarious stigma alike contributed towards participants’ perceptions of HIV-related stigma associated with parental illness and death. Vicarious stigma acted to convey the existence of HIV-related stigma to orphaned children increasing their perceptions about the risk and likelihood of experiencing overt discrimination. Vicarious stigma was described as talking about the deceased parent/s, the ill-treatment of infected individuals, and acts of stigmatisation directed at children affected by familial HIV/AIDS. Experiencing, witnessing, and hearing about overt discrimination contributed towards COAs perceptions of HIV-related stigma. As two participants explained:

> *“It’s because of the people I grew up around, I’m sure the girls, most of them I grew up with them, because I used to live with them, and I saw how they grew up and how the family members treated them. And not just them, you know, just around me I’m hearing stories from people. I think that’s why I strongly believe that there is stigma around HIV.” (Female, 17)*

> *“Well I don’t know, because I only heard last year that she was positive, so it was not something that I really had in mind, but yes, some children say like your mother passed away from that disease, whose going to do this for you if you come with us and all that stuff.” (Female, 14)*

Perceptions of HIV-related stigma

The results indicated that COA were perceptive of HIV-related stigma and spoke extensively about the nature and prevalence of overt discrimination associated with HIV/AIDS within their communities. These perceptions were associated with the fear of falling victim to acts of overt discrimination from their family, friends, and the community. As one female participant disclosed:

> *"Because I think in society, you know when you have HIV, people look at you differently. I don't know, maybe they look at you like as if you're dirty or you don't belong, or they judge you. I don't know. But based on like TV now and hearing things, I think the normal people when they know you have HIV, they kind of like oh uh-uh don't approach this person. They treat you differently." (Female, 17)*

Non-disclosure of parental infection and death

Perceived stigma was also expressed through COAs accounts of non-disclosure of familial HIV/AIDS. COA expressed negative feelings about the disclosure of parental HIV/AIDS to others and appeared to be concerned about the negative consequences disclosure may yield. These fears were based on their perceptions regarding the nature and prevalence of HIV-related stigma. To avoid experiences of overt discrimination, COA avoided disclosing their association to HIV/AIDS in order to be positively perceived by others, as explained below:

> *"But I don't feel like telling my story. I do tell my story, but to people that I know that it's going to be kept a secret, or it's going to be confidential." (Female, 14)*

> *"I never speak about the HIV part, so if anyone will ask me what happened to your mom, or if it happens, maybe I'm doing an oral in class and I want to share my story, and then I always mention the cancer part. But never that she had HIV, because I'm scared what will they think of me. So I will always mention the cancer and not the HIV part." (Female, 16)*

Many expressed that the cause of parental death was concealed from them by extended family out of fear that they may be ill-treated and rejected by others. Often concealment of parental cause of death caused COA to embody feelings of sadness and anger while contributing to their perceptions of HIV-related stigma, as one female participant stated:

> *"I was very angry and it took a while for me to actually forgive my grandmother, because I feel like even if my mom, why didn't she tell me that she had HIV I knew everything about her, why would she keep this one from me? Maybe she thought I was very young and I wouldn't be able to handle it, or maybe I'd look at her in a different way, I don't know." (Female 16)*

Despite the presence of HIV-related stigma, three participants reported a culture of non-discrimination from extended family and educators. Children noticed no differences in their relationships with others despite their association to parental HIV/AIDS. Contrastingly, children reported an increase in acceptance, support, and love received from family members and educators. However, such support and acceptance was received in the presence of non-disclosure. These experiences are conveyed by the reports of participants below:

> *"My granny, she was the person who was always supporting me, and my family members, they're all supporting me. My dad was very supportive… He showed me love, that's where he was really close to me." (Female, 17)*

> *"They are all nice to me…They share with me, they always talk to me, they help me…They listen to me when I have a question. Help me on the schoolwork." (Male, 9)*

The psychosocial well-being of children orphaned by AIDS

The findings of this study suggested that poor psychosocial functioning may be attributed to experiences and perceptions of HIV-related stigma associated with parental HIV/AIDS. Several domains of psychosocial well-being and functioning affected by experiences and perceptions of HIV-related stigma were outlined in the findings of this study, and includes (1) psychological and emotional well-being, (2) social well-being and perceived social support, (3) self-concept and self-esteem, and (4) future orientation.

Psychological and emotional well-being

As interviews progressed it became evident that the psychological and emotional well-being of COA were indeed affected by experiences and perceptions of HIV-related stigma associated with parental HIV/AIDS. Most participants expressed feeling distressed, depressed, and sad because of overt discrimination received from others and often cried to console themselves, as explained by participants below:

> *"I'm sad, or I'm looking back in my life and everything, I will just lock myself in the room and cry…I close the door, I start crying and crying and crying and then I come and I say everything is going to be fine, and that the Lord knows why all these things had to happen to me." (Female, 16)*
>
> *"I would say depressed, but there are times when I feel happy, but most of the time I feel depressed." (Female, 16)*

Participants reported that they avoided speaking to others about their concerns and problems, as they remained fearful of being stigmatised. To address these fears children employed emotion-focused coping strategies, which includes silence, self-isolation, and withdrawal. As two participants reported:

> *"I sometimes don't talk about everything because now I'm scared of how people are going to look at me. So I wouldn't share some of the things that's happening to me, so it makes me, I don't know, it makes me a person who is quiet sometimes." (Female, 14)*
>
> *"I'm never seen outside, so I don't know what people think; they've never said anything to me. I don't usually get any, I don't have friends in my community, so*

> *I'm always at home. I don't even know my neighbours, like that's how I stay at home." (Female, 16)*

The withdrawal and self-isolation contributed to the psychological distress experienced by COA and negatively impacted their emotional well-being as it restricted their ability to healthily express their feelings and concerns to others (emotional regulation). Poor emotional regulation was met with feelings of sadness, anxiety, depression, and helplessness (poor emotional status). As one participant describes:

> *"I'm not able to communicate to other people easily. I don't communicate with people with my problems. I'm always a smiling person, always keeping what I'm feeling inside. I'm not showing it to other people." (Female, 16)*

Social well-being and perceived social support

Children reported that their social well-being was affected by non-disclosure surrounding parental infection and death. One female participant explicitly acknowledged the role of non-disclosure in limiting the social support she received from others as she stated:

> *"In fact it affects you because you find that there are people who would love to help you, but now because you are silent and you're not talking about it, and then sometimes you won't receive the help that you can receive, and then you end up making decisions on your own, and sometimes decisions are decisions to end up literally repeating even the history, you know. Or making decisions that at a stage you're going to regret." (Female, 17)*

Children struggled to form healthy interpersonal relationships. Their inability to express their feelings or discuss traumatic life events limited the intimacy and connection they felt towards others. Most participants reported that they were unable to form good relationships with their extended family and caregivers from whom they received limited support. A female participant reported:

> *"My family, there's no one that I could say I would sit down and talk like this…they are not like 100 percent there, because most of the time I do my things myself, I apply for school for myself, like I'm the one who is always… And they're not even asking what's happening? I should always be the one who tells them now this is happening." (Female, 16)*

However, another female participant stated that she had good relationships with members of her extended family who provided her with continuous financial and emotional support, as she explained:

> *"My granny, ja, passed away so she was the person who was always supporting me, and my family members, they're all supporting me" (Female, 17)*

Older participants reported healthier fraternal relationships as most had a trusted friend with whom they have formed a connection. These close friends provided COA with the needed social support for them to healthily discuss important life events and stressors they are unable to convey to their extended families. While younger children relied on their educators for social support, educators assumed the role of helping COA. These ideas are presented in the excerpts provided by a female and male participant below:

> *"I'll just be speaking to a friend and the next thing I find myself talking to her about everything that happened, and then after I would feel lighter about the situation." (Female, 16)*

> *"They are all nice to me…They share with me, they always talk to me, they help me…They listen to me when I have a question. Help me on the schoolwork." (Male, 9)*

Self-concept and self-esteem

Upon initial perceptions, participants gave the impression that they were confident about themselves and had high levels of self-esteem. As the interviews progressed, participants' accounts of internalised stigma reflected their lack of self-esteem and the negative view they held of themselves. Participants appeared to believe that they were a burden, unloved, unworthy and dirty, and displayed a lack of uncertainty regarding their decisions, constantly comparing themselves to others. As explained by two participants below:

> *"I would feel as if they don't love me. I think it's because of the situation I grew up in. I'm very sensitive when it comes to the people I care for and what they think, and sometimes maybe it's nature," (Female, 14)*

> *"I feel like I don't love myself, not in terms of, like for me I compare myself with other people and I saw them, the mistakes that I have with the other person that they don't have, and I would say to my mind I thought they are the ones that are brainwashing me and think about things that are inappropriate." (Female, 16)*

Future orientation

Surprisingly, all participants displayed a positive future orientation as they appeared to be hopeful and optimistic about their futures in which they were able to pursue their aspirations and goals, as explained by one female participant:

> *"I see a strong person, I see someone who is going to be successful in life, regardless of what she went through. But now what it has done is that like I told myself that whatever I do in life, I don't also see myself with boys." (Female, 17)*

While younger participants were unable to articulate what they would like to do in the future, they appeared optimistic and reported that they would like to study when they grow up. One male participant explained that he would like:

> *"To be an actor, then I study at college—drama and everything." (Male, 9)*

While older participants appeared ambitious about their future, they lacked consistency and clarity regarding the pursuit of their future aspirations and goals. Instead, participants expressed their desire to pursue several career paths simultaneously, remaining indecisive about their future plans. These ideas are expressed by one female participant:

> *"I wanted to be part of the casting agency and then I had to save up money when I go to my first year, so I know that I have already money in there and then I wanted to study to become an interior designer, and then to be there. And then at a later stage to study more about the human skin, to become a dermatologist and have my own spa and all that." (Female, 16)*

Participants lacked perceived control over their future and often questioned why they have experienced misfortune, as expressed by one female participant below:

> *"I would think my friend maybe got treated in chance and then she went to that school, what about me? What happened? What did I do to deserve this? But at the end of the day I only say God has a reason for everything. So I just think that." (Female, 16)*

Discussion

This study explored COAs perceptions and experiences of HIV-related stigma and how it has affected their psychosocial well-being. The findings of this study highlight the presence of HIV-related stigma in the lives of COA as a result of being parentally bereaved by AIDS-related causes rather than their own HIV-status. COA were rather perceptive of the presence of HIV-related stigma and experienced various measures of HIV-related stigma from their families, friends, and surrounding communities. These perceptions and experiences affected various domains of their psychosocial well-being, including their psychological health, emotional well-being, social well-being and perceived social support, self-concept and self-esteem, and future orientation.

The current study identified enacted stigma, also known as overt discrimination, as the most reported measure of HIV-related stigma experienced by COA. Threatening, discriminatory, and isolating behaviours received from others are consistent with those discussed in previous studies (Chi et al., 2014; Caserta et al., 2016; Harms et al., 2010), as children spoke openly about being rejected, excluded, bullied, victimised, abandoned, abused and being treated unfairly by their extended family, friends, and community members. However, there were key differences in reports of enacted stigma across COA. Younger children living in residential care reported being abandoned, bullied, and victimised, while older children living with extended family reported being treated unfairly and abused within their new homesteads. Despite the variation in experiences of enacted stigma, COA consistently associated feelings of distress, depression, anxiety, and sadness with their accounts of overt discrimination, indicating psychological distress and a negative emotional status. Enacted stigma has been previously identified as a key contributor to the psychological distress experienced by COA, as social exclusion and overt discrimination places COA at increased risk for developing internalizing, emotional, and behavioural issues in comparison to other groups of orphaned youth (Asanbe et al., 2016; Cluver & Gardner, 2007; Cluver et al., 2012; Chi et al., 2014; Zhao et al., 2012).

Fearful of experiencing enacted stigma, COA isolated and withdrew themselves from others. Major and O’Brien (2005) identified self-isolation and withdrawal as emotion-focused coping strategies to protect oneself from traumatic events, like stigmatisation. These emotion-focused coping strategies were similarly associated with COAs experiences of vicarious stigma. Vicarious stigma previously identified by Cluver and Gardner (2007) and Steward et al., (2008) leaves COA fearful of experiencing stigmatisation and discrimination as vicarious stigma contributes to COAs perception of the prevalence of enacted stigma within their communities. Emotion-focused strategies restricted COAs capacity for healthy emotional regulation as they were unable to appropriately expresses their feelings and emotions regarding stressful and challenging life events with others, further contributing to their development of a negative emotional status and psychological distress (Cheney, 2015; Bogart, 2008; de Klerk, 2012; Zhao et al., 2009). As a result of both enacted and vicarious stigma, COA were rather perceptive of the stigmatisation associated with HIV/AIDS within their communities.

Experiences of perceived stigma were conveyed through COAs accounts of non-disclosure and silence as they actively concealed the cause of parental illness and death from others to avoid stigmatisation and discrimination from others. COA experienced a profound sense of anxiety and fear when faced with the disclosure of parental HIV/AIDS, encouraging the acts of non-disclosure and silence among COA. These findings are consistent with Goffman's (1963) suggestion that individuals conceal negative information about themselves through strategies of passing and covering to protect themselves from stigmatisation and discrimination. Similarly, related studies (Mo et al., 2015; Thupayagale-Tshweneagae & Benedict, 2011) indicated that COA often fear disclosing their association with familial HIV/AIDS because of the associated stigma and strive to minimise their experience of enacted stigma. Similar accounts of non-disclosure were adapted by extended family as the cause of parental illness and death was concealed from COA to protect them from HIV-related stigma. However, these attempts were met with the development of feelings of anger and resentment in COA. Strategies of silence and non-disclosure actively hinders COAs ability to form a sense of intimacy and healthy trusting interpersonal relationships with others. In the absence of healthy interpersonal relationships, COA question the perceived social support received from others, which refers to COAs subjective perception of the extent to which others are able to provide the support, resources, and assistance necessary to cope with stressors and adversities, including parental bereavement and discrimination (Cohen & McKay, 1984; Galvan et al., 2008; Prati & Pietrantoni, 2009; Wei et al., 2016; Xanthopoulos & Daniel, 2013). The availability or perception of social support has been identified as a protective factor and an effective critical resource able to reduce psychological distress and enhance the coping-skills of COA (Doku et al., 2015). Doku et al., (2015) propose that children who receive inadequate support from their families are depressed, sad, lonely, and withdrawn, while those who receive adequate support display healthier psychosocial development. Therefore, silence and non-disclosure places COA beyond the reach of attaining the social and psychological support needed for healthy psychosocial well-being (Xu et al., 2009).

Despite the lack of familial support and emotion-focused coping strategies, COA were able to form healthy fraternal relationships, as most children reported having at least one close friend. One possible explanation would be that of non-disclosure, as Qiao. Zhao, Zhao and Stanton (2012) suggest that non-disclosure is met with increased perceived support and a reduction in stigmatising behaviours received from others. This ideology may also address the culture of non-stigmatisation reported by participants.

Maintaining healthy trusting relationships largely impacts the psychosocial dimensions of self-esteem and self-concept (Du et al., 2015). Through social support, COA may receive positive appraisal reasserting a positive evaluation of themselves (Du et al., 2015). In its absence, COA displayed lower levels of self-esteem and a poor self-concept, expressing that they are unloved, unworthy, dirty, and a burden to others. These accounts may be identified as experiences of internalised stigma (Mo et al., 2015). With a lack of social support, COA lack the positive appraisal of others and are unable to manage negative actions and feedback received from others (Du et al., 2015). Additionally, the lack of social support may hinder COAs participation in positive social activities negatively affecting their self-esteem and optimism about the future (Adejuwon & Oki, 2011; Ishikawa et al., 2010).

Mo et al., (2015) asserted that the acceptance and internalisation of the negative views of others has detrimental implications for the way COA view themselves and their future, which is manifested by lower levels of self-esteem and a poor future orientation. Self-esteem is deemed vital for maintaining confidence about one's future prospects and orientation (Mo et al., 2015; Xu et al., 2009).

Participants, although optimistic about the future, continued to expressed uncertainty and a lack of confidence regarding their future prospects, and expressed their desire to pursue multiple career paths simultaneously. Surprisingly, all children were enrolled in school and were receiving a formal education. This finding is inconsistent with previous studies that suggested HIV-related stigma limited the educational opportunities available to COA and the adoption of emotion-focused coping strategies resulted in increased school non-attendance which hindered the attainment of scholastic knowledge, consequentially negatively influencing the future orientation of COA (Xu et al., 2009).

This study may have several potential limitations. Non-disclosure and sensitivity surrounding the discussion of parental illness and death restricted the number of participants who were willing to participate in the current study. However, the number of participants remained sufficient to gather rich and full accounts from COA. The study was conducted with participants situated in South Africa; therefore, the results may not be generalizable to other regions, but may allude to issues of HIV-related stigma and its associated challenges in ensuring the well-being of orphaned and vulnerable children in regions severely affected by HIV/AIDS. Lastly, younger participants may be unable to fully express and convey their experiences due to continuing cognitive and emotional development occurring during the phase of pre-adolescence. Despite the highlighted limitations, the study contributes to our understanding of the lived experiences and perception of COA regarding HIV-related stigma and the challenges these experiences pose to their psychosocial development and well-being.

Implications for future research and practice

The findings of this study have several implications for future research and practice. Future studies should focus exclusively on HIV-related stigma and its outcomes on the psychosocial well-being of COA. There is a need for longitudinal studies to measure the long-term effects of HIV-related stigma on the psychosocial well-being and development of vulnerable and orphaned children. Future research should include a larger sample population to provide more generalizable results and a greater understanding of the lived experiences and perceptions of COA. As stigma affects the well-being of COA, it is essential for practitioners and clinicians to remain cognisant of overt discrimination, silence and non-disclosure when working with COA. Considering the association between social support and psychosocial well-being, it is important to strengthen the support system available to children affected by HIV/AIDS to bring about a reduction in psychological distress and improved psychosocial well-being. Resources such as individual counselling and cognitive behavioural therapy may prove beneficial in reducing stigma and correcting irrational beliefs about oneself. These interventions offer COA skills such as stress management, improved coping strategies and an improved self-esteem and self-concept. Family interventions and therapy should be considered as an intervention to reduce stigma, strengthen familial support, and improve the psychosocial well-being of COA. Social welfare services may be able to monitor the living environment and conditions in which a child is placed, ensuring their well-being. The availability of these services serves as a contact point for children to express or report any ill-treatment and abuse or poor living conditions. The findings of this study highlight the continuing need for stigma awareness campaigns and reduction efforts within communities affected by HIV/AIDS. Lastly, there is a need for the development of tailored programmes for children negatively affected by HIV-related stigma to firstly bring about a reduction of stigma and to promote, improve, and support healthy psychosocial well-being of COA.

Compliance with Ethical Standards

Conflict of interest

The authors declare that they have no conflict of interest.

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Ethical approval

All procedures performed in the studies involving human participants were in accordance with the ethical standards of the University of the Western Cape and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the University of the Western Cape's Human and Social Sciences Research Ethics Committee under ethics reference number HS17/1/17.

Informed consent

Informed consent was obtained from all individual participants included in this study.

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5.5 Conclusion

The qualitative exploratory study (Article 2) explored COAs experiences and perceptions of HIV-related stigma. The study concluded that COA experienced HIV-related stigma and discrimination and were largely perceptive of stigmatizing attitudes and behaviors with their surrounding communities and families. These experiences and perceptions were identified as negatively impacting the psychological, emotional, and social well-being of COA, while compromising their self-concept, self-esteem, and future orientation. The following chapter presents Phase III (Stage 1 and 2) of model development, which focuses on concept and statement development, the most basic building blocks of a model.

Chapter 6

Model Development

6.1 Introduction

Chapter 6 marks the beginning of Phase III (Stage 1) of model development, focusing on concept development. Concept development draws on the findings of Phases I and II, as was outlined in Chapters 4 and 5, respectively, to develop both focal and related concepts upon which the developed model is grounded. This chapter consists of three sections, namely: (1) concept identification, (2) concept classification, and (3) the definitions of concepts. Additionally, concept classification contributes to statement development. Figure 6.1 further below illustrates the sequential stages of the study and portrays the first stage of model development—the main focus of this chapter.

6.2 Concept development

Concepts are building blocks that form the basic fabric of a theory. A concept is defined as a "mental image of a phenomenon, an idea, or a construct in the mind about a thing or an action" (Walker & Avant, 2005, p.59). Similarly, Chinn and Kramer (2008) suggest that concepts are a complex mental formulation of experience. In this regard, experience is considered an empiric construct that may be symbolically shared and verified among individuals through sensory evidence. As concepts hold a shared understanding or meaning of a phenomenon, they are essential in conveying the focus and meaning of a theory. The basis of a theory is therefore dependent upon concept development consisting of a three-step process, namely, concept identification, concept classification, and concept definition. Conceptual meaning may be derived from the identification, classification, and definitions of concepts which form the basic tenets of a theory. Conceptual meaning transcends word definitions to convey the thoughts, feelings, and ideas associated with the human experience of a phenomenon.

Fundamentally, it provides a mental image of what a phenomenon is, as well as the human perception and experience of a phenomenon.

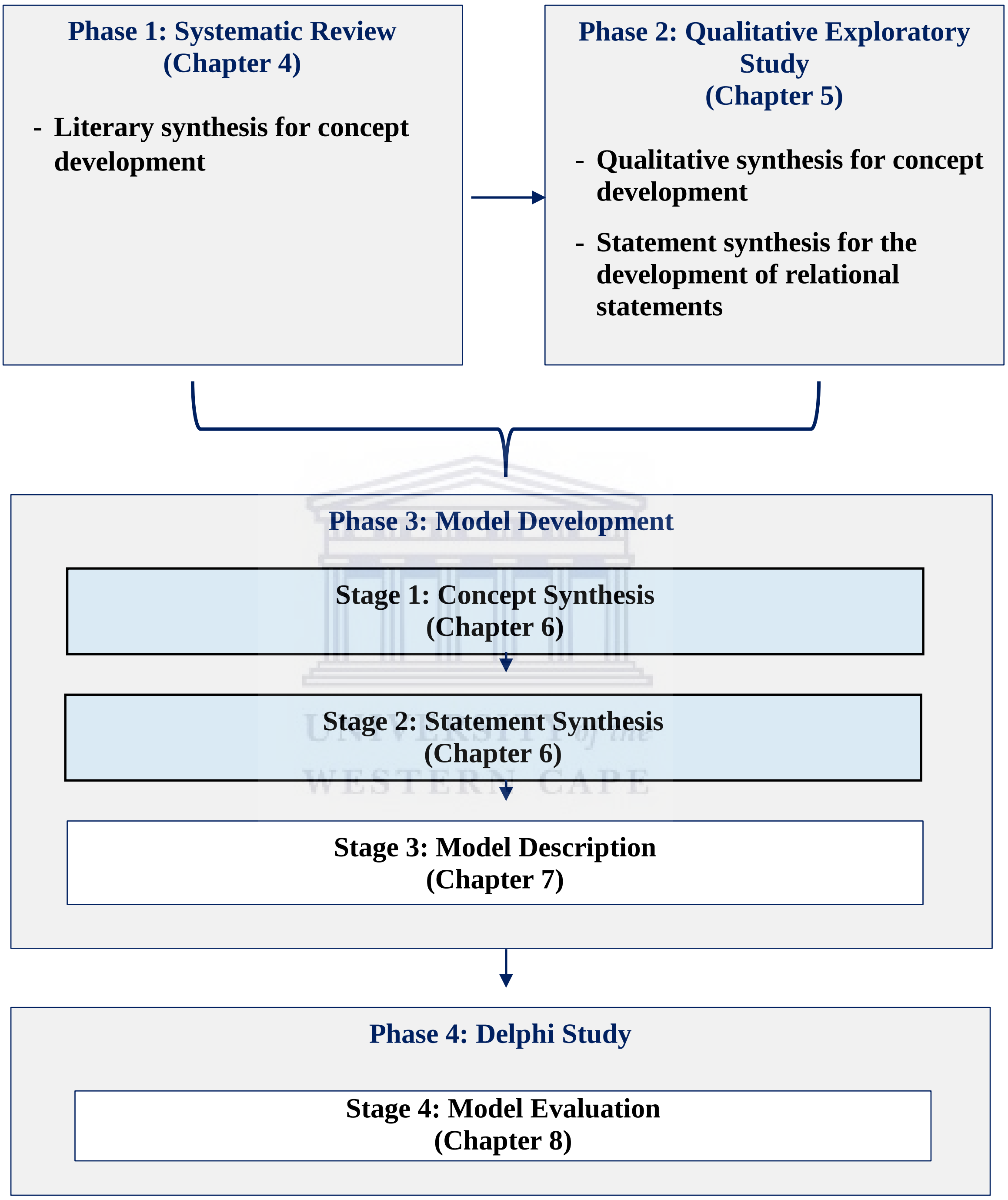


Figure 6.6: Concept and Statement synthesis

6.2.1 Concept identification

As discussed in Chapter 3, a concept synthesis was conducted for the identification of focal and related concepts in this study. A mixed methods approach using (1) life experiences, and (2) existing evidence following the results of a systematic review and a qualitative explorative descriptive study was analyzed for concept identification as suggested by Walker and Avant (2005). Concepts are derived from several sources including life experiences, research, and existing evidence (Chinn & Kramer, 2008). The concepts identified in this study have been guided by the purpose and expressed values relating to the current study which focuses on providing an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA.

The identification of concepts adopted an iterative approach of searching and clustering words or groups of words representing a phenomenon, until theoretical saturation was reached (Chinn & Kramer, 2008; Glaser & Strauss, 1967; Walker & Avant, 2005). Following the results of the literary and qualitative synthesis, 24 concepts were identified. These concepts were further refined through the amalgamation of clusters of concepts considerably overlapping or closely related to each other, resulting in six focal concepts. Additionally, themes appearing across both the literary and qualitative synthesis were documented as horizontal themes which set out to present the prevalence of focal concepts across both sets of data. These focal concepts were utilized for the development of a model for understanding HIV-related stigma and the psychosocial well-being of COA. The focal concepts, providing conceptual meaning and forming the basic tenets of the developed model, are *enacted stigma, perceived stigma, internalized stigma, coping strategies, interpersonal relations, and psychosocial well-being*. These focal concepts, their clustered groupings of concepts and horizontal themes are represented in Table 6.1 below.

Table 6.10: Focal and Related Concepts

Stages	Horizontal themes	Concepts	Focal Concepts
Experiences	- Children orphaned by AIDS reported experiences of several manifestations of enacted stigma because of parental illness and death, regardless of their own HIV status. - Experiences of enacted stigma resulted in increased perceived stigma and psychological distress for children orphaned by AIDS. - Reported manifestations of enacted stigma included overt discrimination, hostility, rejection, exclusion, differential treatment compared to other children within the homestead, isolation, humiliation, abandonment by extended family members, gossiping about and name calling of deceased parent, and victimization.	- *Overt discrimination* - *Rejection* - *Exclusion* - *Victimization* - *Humiliation* - *Abandonment* - *Unfair treatment* - *Hostility* - *Gossip and insults directed at deceased parent*	**Enacted stigma**
	- Shared perceptions of HIV-related stigma, hearing or witnessing the stigmatization of others, and experiences of enacted stigma results in an increased perception of the prevalence and normativity of HIV-related stigma within the social environment or context of COA. - As a result of perceived stigma, COA become increasingly perceptive and fearful of enacted stigma directed at them, whether real or perceived.	- *Shared perceptions of HIV-related stigma* - *Beliefs about the prevalence of HIV-related stigma*	**Perceived stigma**

	• Internalized stigma is presented by COA, as they internalize the negative views and beliefs of themselves as truthful and valid. • These negative beliefs are incorporated into their sense of self, as COA often feel ashamed and guilty, and identify as being tainted, dirty, unlovable, unwanted, a burden or a drain on society.	• *Self-blame* • *Shame*	**Internalized stigma**
Behavioral Response	• COA utilized coping strategies to avoid experiences of HIV-related stigma and/or deal with experiences of HIV-related stigma. • COA concealed their association to HIV/AIDS through a culture of non-disclosure of cause of parental death and illness (problem-focused coping) to prevent being stigmatized by others. • COA engaged in positive re-appraisal, presented a strong sense of faith, assigned external attributes as the reason for stigmatization, engaged in dis-identification with the stigmatized group and/or accepted their stigmatized social status (emotion-focused coping) to cope with experiences of stigmatization. • Children orphaned by AIDS self-isolated and withdrew themselves from others to avoid experiences of enacted stigma (avoidant-coping strategies).	• *Problem-focused coping* • *Emotion-focused coping* • *Avoidant-coping strategies*	**Coping strategies**

Outcomes for Psychosocial Well-being	• COA reported increased levels of psychological distress, depression, and anxiety because of HIV-related stigma, indicating poor psychological well-being. • COA are unable to healthily express their feelings and concerns regarding stressful life events. As a result, they display a negative emotional status, including feelings of sadness, anger, fear, and guilt, indicating poor emotional well-being. • COA have poor interpersonal relationships. Due to avoidant-coping strategies, they are unable to form a healthy sense of intimacy with others, resulting in poor social well-being. • Poor social well-being limits COA opportunity to engage in self-esteem building actives and reappraisal through others. Additionally, internalized stigma affects the confidence, healthy self-concept and self-esteem COA, indicating lower levels of self-esteem and a poor self-concept. • While COA remained optimistic about their futures, they lacked perceived control and hopefulness about their future goals and dreams. Additionally, COA lacked confidence to pursue their future goals, indicating poor future orientation.	• *Psychological well-being* • *Emotional well-being* • *Social well-being* • *Self-esteem and self-concept* • *Future orientation*	**Psychosocial well-being**
Context	• HIV-related stigma occurs through interpersonal interaction between COA and other individuals such as family members, familial friends, and peers within a variety of social environments, for example, the homestead, community, school, etc.	• *Social support* • *Community* • *Interpersonal interaction with others*	**Interpersonal relations**

	• Through interpersonal interaction, enacted stigma and public stigma may be conveyed, increasing COAs perception of HIV-related stigma and lowering their perception of social support that they may receive from others.		

The results indicated that COA experienced stigmatization resulting from parental illness beyond parental death. COA commonly reported experiencing acts of overt discrimination, hostility, rejection, and abandonment—known as ***enacted stigma—***from their extended family members, peers, and members within the surrounding community. Enacted stigma manifests in a variety of ways and includes, but is not limited to, rejection, abandonment, bullying, victimization, exclusion, and differential treatment compared to other children within the homestead. COA expressed that these experiences of enacted stigma affected their *psychological well-being*, as they encounter greater psychological distress accompanied by growing anxiety, depression, and fear. COA fear encountering experiences of enacted stigma and employ ***coping strategies,*** including *emotion-focused*, *avoidant-coping*, and *problem-focused strategies* as a means to reduce their experiences of enacted stigma. These coping strategies hinder the *emotional* and *social well-being* of COA, as it is accompanied by the inability for healthy emotional regulation and emotional status, and a lack of perceived social support. Effective emotional regulation and a healthy emotional status are pivotal to the *social well-being* and healthy functioning of COA. Furthermore, COA are unable to healthily express their emotions regarding important life events or traumatic experiences, leading to a negative emotional status displayed as feelings of anger, sadness, and increased psychological distress.

Coping strategies employed in response to enacted stigma limits the social support—a protective factor—readily available to COA, reducing their resources for their survival and healthy development. In the presence of both reduced social support and varying coping strategies, COA are unable to form healthy interpersonal relationships with others, thus compromising their *social well-being*. The presence of enacted stigma results in a growing increase in ***perceived stigma*** as COA become acutely aware of the nature and prevalence of HIV-related stigma in their surrounding environments. These perceptions are formed based on their personal experiences or hearing and witnessing the stigmatization of others affected by HIV/AIDS. To avoid future stigmatization, COA disassociate themselves from parental HIV/AIDS through the use of non-disclosure strategies by maintaining secrecy, silence, and concealing the nature and cause of parental illness and death. While preventing future experiences of enacted stigma through concealment, secrecy, and silence, the *psychologica*l, *emotional*, and *social well-being* of COA are further deterred.

Poor emotional well-being is maintained by ***internalized stigma***. Internalized stigma entails the acceptance of a stigmatized identity as truthful and valid by the stigmatized individual. Therefore, COA accepted the negative view of themselves as truthful and valid. The results show that internalized stigma manifested as chronic feelings of inadequacy and the belief that they are tainted, different, unworthy, and a burden and drain on society. These negative views of the self held by COA reflects psychological suffering, a poor *self-concept*, and lower levels of *self-esteem*. *Social well-being* forms an important role in developing a healthy *self-concept* and *self-esteem*. Forming a sense of intimacy and building trusting relationship provides COA with the opportunity to engage in self-esteem enhancing activities through interaction with others. However, with limited social support and the absence of trusting relationships, COA are unable to engage in self-esteem enhancing activities through positive interaction with others. As a result, COA lose confidence in themselves and display a lack of *hopefulness, optimism, and perceived control over their future*.

Evidently, HIV-related stigma affects various domains of ***psychosocial well-being*** including *psychological well-being, emotional well-being, social well-being, self-concepts and self-esteem,* and *future orientation.*

6.2.2 Concept classification

Six focal concepts have been identified, namely, ***enacted stigma***, ***perceived stigma***, ***internalized stigma***, ***coping strategies***, ***interpersonal relations,*** and ***psychosocial well-being***. These concepts form the foundation for the development of a model to understand HIV-related stigma and its impact on the psychosocial well-being of COA. The survey list developed by Dickoff et al., (1968) was utilized for the classification of identified focal concepts. The survey list (Dickoff et al., 1968) highlights six significant activity aspects: (1) agency, (2) recipiency, (3) framework, (4) dynamics, (5) procedure, and (6) terminus. Each activity is steered by individual questions which are to be considered and applied for the full exploration of HIV-related stigma and the manner it affects the psychosocial well-being of COA (Dickoff et al., 1968). The application of the focal concepts previously identified above are herewith discussed in terms of the six activity aspects indicated by Dickoff et al., (1968):

1. ***Agency: who or what performs the activity?***

The agents in this model are non-stigmatized individuals who do not possess a spoiled identity or trait that is viewed as undesirable by society. Simply, agents are individuals that are neither infected nor affected by HIV/AIDS. These individuals include, but are not limited to, family members, peers, educators, medical staff, and community members. The non-stigmatized individuals direct overt discriminatory and hostile behaviors toward children who have lost one or both parents to HIV/AIDS. The focal concept categorized according to agency is:

- ***Enacted stigma***

2. ***Recipiency: who or what is the recipient of the activity?***

In the developed model, the recipients are children under the age of 18 who have been orphaned by AIDS-related causes. These children experience enacted stigma from others. In turn, they become increasingly perceptive of HIV-related stigma and begin to internalize and accept the negative view of themselves. The focal concepts categorized in terms of recipiency are:

- ***Enacted stigma***
- ***Perceived stigma***
- ***Internalized stigma***

3. *Framework: In what context is the activity being performed?*

The context of the model will include social environments in which both the recipients and agents are present. These environments include the homestead, organizational care settings, school settings, and local communities. The focal concept categorized according to framework is:

- ***Interpersonal relations***

4. *Dynamics: What is the energy source of the activity?*

Dynamics refers to the power source of an activity (Dickoff et al., 1968). Power sources may be psychical, chemical, biological, or psychological. In this study, the agent possesses physical power as they engage in acts of overt discrimination and humiliation against the recipient. The recipient possesses both physical and psychological power sources as they experience and perceive manifestations of stigmatization and embody behavioral responses to these experiences. The focal concepts categorized according to dynamics are:

- ***Coping strategies***
- ***Enacted stigma***

5. *Procedure: What is the guiding procedure, technique, or protocol of the activity?*

According to Dickoff et al., (1968), “procedure” refers to general patterns, paths, or sets followed for the accomplishment of a goal. In this study, the procedures, namely, interpersonal interaction between the agent and recipient through the process of experiences, behavioral responses to experiences, and outcomes for well-being are essential for the goal to be achieved, namely, poor psychosocial well-being for COA as a result of their experiences of HIV-related stigma. The focal concept categorized according to procedure is:

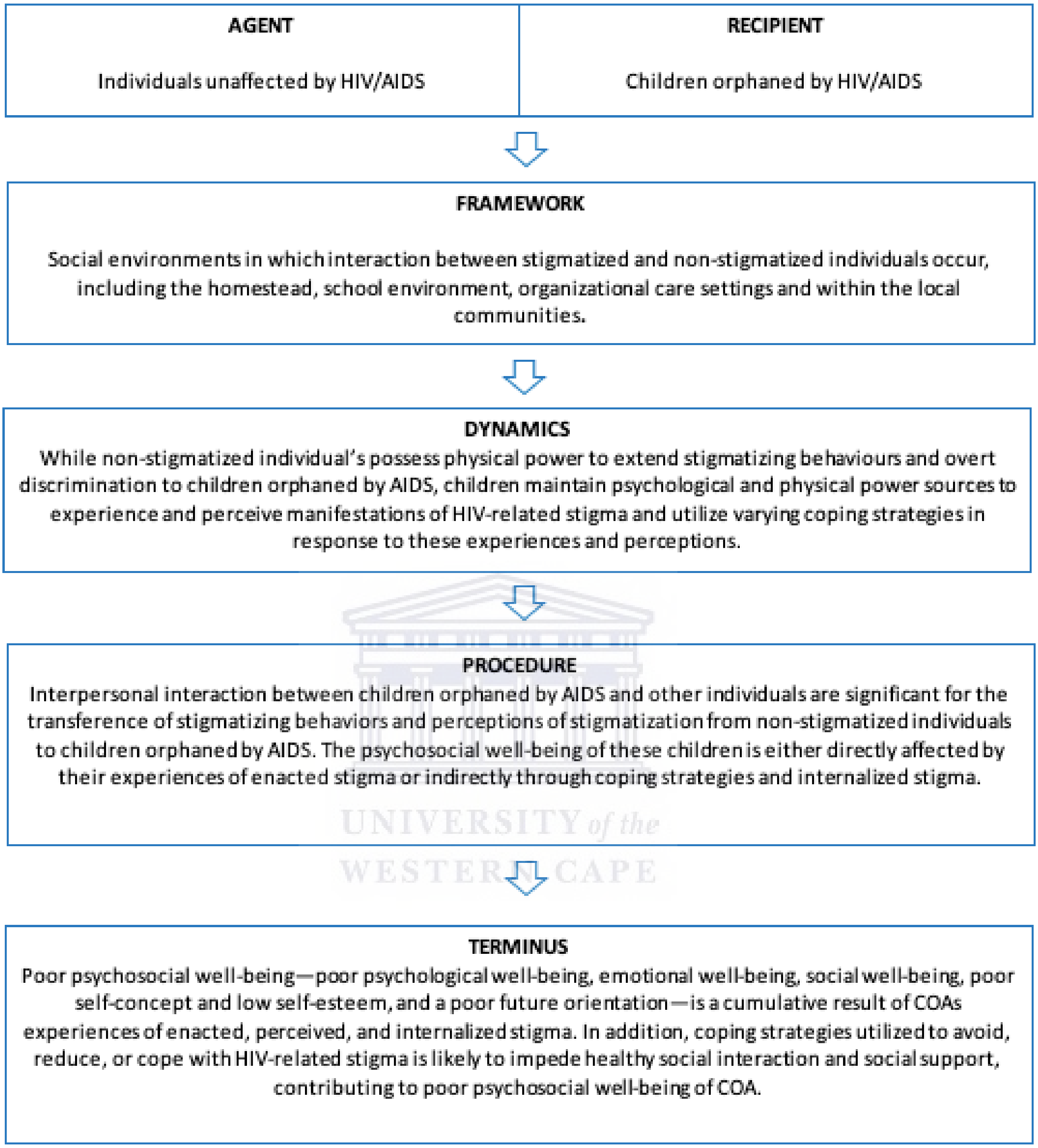
- ***Interpersonal relations***

6. *Terminus: What is the end point of the activity?*

In the present study, the terminus or end point of the activity is the stigmatization and poor psychosocial well-being of COA through the process of social interaction between the agent and recipient. Through the process of social interaction between the non-stigmatized and stigmatized, manifestations of HIV-related stigma are directed at COA. Poor psychosocial well-being presented by COA is a cumulative result of their experiences and perceptions of enacted, perceived, and internalized stigma. The focal concept categorized according to terminus is:

- ***Poor psychosocial well-being***

A thinking map outlining the categorization of focal concepts according to the survey list developed by Dickoff et al., (1968) is depicted in Figure 6.2 below.



Social environments in which interaction between stigmatized and non-stigmatized individuals occur, including the homestead, school environment, organizational care settings and within the local communities.

While non-stigmatized individual's possess physical power to extend stigmatizing behaviours and overt discrimination to children orphaned by AIDS, children maintain psychological and physical power sources to experience and perceive manifestations of HIV-related stigma and utilize varying coping strategies in response to these experiences and perceptions.

Interpersonal interaction between children orphaned by AIDS and other individuals are significant for the transference of stigmatizing behaviors and perceptions of stigmatization from non-stigmatized individuals to children orphaned by AIDS. The psychosocial well-being of these children is either directly affected by their experiences of enacted stigma or indirectly through coping strategies and internalized stigma.

Poor psychosocial well-being—poor psychological well-being, emotional well-being, social well-being, poor self-concept and low self-esteem, and a poor future orientation—is a cumulative result of COAs experiences of enacted, perceived, and internalized stigma. In addition, coping strategies utilized to avoid, reduce, or cope with HIV-related stigma is likely to impede healthy social interaction and social support, contributing to poor psychosocial well-being of COA.

Figure 6.7: Survey List of Focal Concepts

6.2.3 Definition of focal concepts

Focal concepts are defined using theoretical, subject-specific, and dictionary definitions to convey conceptual meaning and clarify ideas and usages associated with the developed concepts (Chinn & Kramer, 2008; Walker & Avant, 2005). This study, therefore, includes (1) dictionary definitions, (2) subject specific definitions, and (3) summary definitions. Summary definitions present an integration of subject-specific and dictionary definitions to provide a synopsis of concept definitions contextually specific to the developed model. These definitions provide conceptual meaning for the developed focal concepts underpinning the model, which offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. The focal concepts and their associated related concepts are given below; however, a full discussion of the model description is provided in Chapter 7.

6.2.3.1 Enacted stigma

The first focal concept—***enacted stigma***—has several related concepts, namely, *overt discrimination, rejection, exclusion, and humiliation.*

Dictionary definition of the concept "enacted stigma"

The word ***enact*** is defined in the Collins English Dictionary as: (1) "to make into an act or statute"; (2) "to establish by law; ordain or decree"; (3) "to represent or perform in or as if in a play: to act out" by the **(**Hanks, Long & Urdang, 1985, p. 481). Similarly, the Merriam-Webster online dictionary declared the word ***enacted*** a transitive verb, simply defined as "to act out."[2] Similarly, the Oxford online dictionary defines the word ***enacted*** as "take place." The Collins English Dictionary provides several definitions for the word ***stigma*** based upon various disciplines, the most applicable being: (1) "a distinguishable mark of social disgrace: *the stigma of having been in prison*"; (2) "any mark on

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[2] 'Enacted,' Merriam Webster Dictionary [Online]. Viewed from https://www.merriam-webster.com

the skin, such as one characteristic of a specific disease"; and (3) "any sign of mental deficiency or emotional upset" (Hanks et al., 1985). Likewise, the Merriam-Webster online dictionary defines stigma as "a mark of shame or discredit" and "an identifying mark or characteristic" or a "stain" associated with "a specific diagnostic sign of a disease." The definition of ***stigma,*** as described above, is applied to the focal concepts—perceived stigma and internalized stigma—presented below.

Subject-specific definition of the concept "enacted stigma"

According to HIV-related stigma research, ***enacted stigma*** captures the interpersonal aspect of HIV-related stigma, which involves acts of overt discrimination and humiliation directed at individuals infected or affected by HIV/AIDS as a result of their stigmatized status (Chi et al., 2014; Wei et al., 2016). Gilbert and Walker (2010) theoretically define ***enacted stigma*** as actual cases of discrimination or discrimination by others towards individuals infected or affected by HIV/AIDS.

Summary

In its totality, ***enacted stigma*** in this study refers to the manifestation of HIV-related stigma that represents the interpersonal aspect of stigmatization. ***Enacted stigma*** refers to acts of overt discrimination, humiliation, and rejection directed at an individual because of his/her stigmatized status resulting from their association with HIV/AIDS.

6.2.3.2 Perceived stigma

The focal concept ***perceived stigma*** has two related concepts, namely, *shared perceptions of HIV-related stigma* and *beliefs regarding the prevalence of HIV-related stigma*.

Dictionary definition of the concept "perceived stigma"

The Merriam-Webster online dictionary describes "**perceived"** as "to attain awareness or understanding of" or to "become aware of through the senses, especially: see or observe." Similarly, the Collins English Dictionary defines **perceive** as "to become aware of (something) through the senses, esp. the sight; recognize or observe." The Collins English Dictionary provides several definitions for the word ***stigma*** based upon various disciplines, the most applicable being (1) "a distinguishable mark of social disgrace: *the stigma of having been in prison*"; (2) "any mark on the skin, such as one characteristic of a specific disease"; (3) and "any sign of mental deficiency or emotional upset" (Hanks et al., 1985). Likewise, The Merriam-Webster online dictionary defines ***stigma*** as "a mark of shame or discredit" and "an identifying mark or characteristic" or a "stain" associated with "a specific diagnostic sign of a disease."

Subject-specific definition of the concept "perceived stigma"

In HIV-related stigma research ***perceived stigma*** captures the intrapersonal aspect of stigma and refers to "the subjective awareness of social stigma" (Chi et al., 2014, p. 1055). Perceived stigma also refers to "all types of stigmatizing behaviours towards people living with HIV/AIDS, as perceived by themselves" (Zhao et al., 2012, p. 276). Steward et al., (2008, p. 1226) provide an all-inclusive definition of ***perceived stigma*** which refers to "the subjective awareness of stigma" which represents "the belief about the prevalence of stigmatizing attitudes among people in the local community, or the degree to which stigma is perceived as normative."

Summary

In this study, ***perceived stigma*** is regarded as an individual's subjective awareness of HIV-related stigma including their perception or belief regarding the normativity and prevalence of stigmatizing beliefs, behaviors, and attitudes within the local community about HIV/AIDS and those infected and affected by HIV/AIDS.

6.2.3.3 Internalized stigma

The focal concept ***internalized stigma*** has two related concepts, namely, *self-blame* and *shame*.

Dictionary definition of internalized stigma

According to the Merriam-Webster dictionary, the word ***internalized*** is "to incorporate (values, patterns of culture, etc.) within the self as conscious or subconscious guiding principles through learning or socialization."[3] The Collins English Dictionary similarly defines the word ***internalized*** as "to make internal, esp. to incorporate within oneself (values, attitudes, etc.) through learning or socialization" (Hanks et al., 1985). The Collins English Dictionary provides several definitions of the word ***stigma*** based upon various disciplines, the most applicable being: (1) "a distinguishable mark of social disgrace: *the stigma of having been in prison*"; (2) "any mark on the skin, such as one characteristic of a specific disease"; and (3) "any sign of mental deficiency or emotional upset" (Hanks et al., 1985). Likewise, the Merriam-Webster online dictionary defines ***stigma*** as "a mark of shame or discredit" and "an identifying mark or characteristic" or a "stain" associated with "a specific diagnostic sign of a disease."

Subject-specific definition of internalized stigma

HIV-related stigma research defines ***internalized stigma*** as "the extent to which an individual accepts stigma as valid" (Steward et al., 2009, p. 3). ***Internalized stigma*** "involves the thoughts and behaviours stemming from the persons own negative perceptions about themselves because of their HIV status" (Zhao et al., 2010, p. 1303). Internalized stigma, often known as self-stigma in current research, may be considered a subject-specific definition of ***internalized stigma***. *Self-stigma* is defined as the internalization of stigma and the acceptance of its validity which is "manifested in negative affect toward and belief about the self" (Herek, Saha, & Burak, 2013, p. 42).

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[3] 'Internalize,' Merriam-Webster Dictionary [Online]. Viewed from https://www.merriam-webster.com

Summary

In this study, internalized stigma refers to the internalization of the negative and stigmatizing views associated with HIV/AIDS into one's values and beliefs about the self. In totality, ***internalized stigma*** is the acceptance of stigmatizing beliefs and values by COA as truthful and valid, in turn these accepted values and beliefs are incorporated into the self.

6.2.3.4 Coping strategies

The focal concept ***coping strategies*** has three related concepts: *emotion-focused coping, avoidant-coping strategies,* and *problem-focused coping.*

Dictionary definition of coping strategies

The focal concept ***coping strategies*** is divided and defined in two separate parts, namely, coping and strategies, allowing for the emergence of conceptual meaning for the current focal concept. Both the Collins English Dictionary (Hanks et al., 1985, p. 331) and the Merriam-Webster online dictionary provide the first known definition for the word ***coping*** as follows: "the sloping top course of a wall, usually made of masonry or brick" and "the covering course of a wall usually within a sloping top," respectively. According to the online Oxford English Dictionary, the word ***coping*** originated in the mid 16th century from the verb cope, originally meaning "dress in a *cope*," "to cover."[4] Therefore, the definition of 'cope' is considered and used to define and understand the word ***coping***. *Cope* is defined as: (1) "to deal with and attempt to overcome problems and difficulties"; and (2) "to maintain a contest or combat usually on even terms or with success."[5] Alternatively, the Collins English Dictionary defines *cope* as: (1) "to contend," and (2)"to deal successfully with or handle a situation: manage" (Hanks et al., 1985, p. 331).

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[4] 'Cope,' Oxford English Dictionary. Viewed from https://www.lexico.com/en/definition/coping

[5] 'Cope,' Merriam-Webster Dictionary [Online]. Viewed from https://www.merriam-webster.com

Strategies is the plural of *strategy*; therefore, the word *strategy* is used to define the term ***strategies***. The Merriam-Webster online dictionary provides the following definitions for the word *strategy*, namely: (1) “a careful plan or method;” (2) “the art of devising or employing plans or stratagems toward a goal”; and (3) “the adaption or complex of adaptions (as of behavior, metabolism, or structure) that serves or appears to serve an important function in achieving evolutionary success.” Similarly, the Collins English Dictionary defines *strategy* as “the practice or art of using stratagems” and “a plan or stratagem” (Hanks et al., 1985, p. 1437). According to the definitions presented above, the word *strategy* is closely associated with the use of the word stratagem, which is defined as “a cleverly contrived trick or scheme for gaining an end; skill in rues or trickery.”[6] The Collins English Dictionary defines stratagem as “a plan or trick, esp. one to deceive an enemy.”

Subject-specific definition of the concept “coping strategies”

In HIV/AIDS research, ***coping strategies*** are regarded as “specific actions that people use to manage stress,” including “affective (e.g. emotional regulation), behavioural (e.g. distraction), and cognitive (e.g. remuneration) responses that people use to cope with environmental stressors” (Chaudoir et al., 2011, p. 2384). Additionally, coping strategies or processes are “typically characterized as relatively stable, individual difference measures that characterize the general strategies that people use to cope with stressors” (Chaudoir et al., 2011, p. 2384).

Summary

In this study, ***coping strategies*** refer to specific actions that are stable over time and involves the complex adaption of affective, behavioral, and cognitive responses of an individual to successfully deal with stressors, in this case being the experiences and perceptions of HIV-related stigma.

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[6] ‘Stratagem,’ Merriam-Webster Dictionary [Online]. Viewed from https://www.merriam-webster.com

6.2.3.5 Interpersonal relations

The focal concept of ***interpersonal relations*** has several related concepts including, *family*, *friends*, *community*, and *social support*.

Dictionary definition of interpersonal relations

The word ***interpersonal*** is simply defined by the Merriam-Webster online dictionary as "being, related to, or involving relations between people."[7] Similarly, the online Oxford Dictionary defines ***interpersonal*** as "relating to relationships or communication between people."[8]

The Collins English Dictionary defines ***relations*** as: (1) "social, political, or personal connections or dealing between or among individuals, groups, nations, etc.," and (2) "family or relatives" (Hanks et al., 1985, p. 1232). Furthermore, the Merriam-Webster online dictionary defines ***relations*** as: (1) "the way in which two or more people or things are connected; a things effect on or relevance to another"; (2) '"he way in which two or more people or groups feel about and behave towards each other"; (3) and "a person who is connected by blood or marriage; a relative."[9]

Subject-specific definition of interpersonal relations

According to the psychology of ***interpersonal relations*** discussed by Heider (1958, p. 1), interpersonal relations "denotes relations between a few, usually two people. How one person thinks and feels about another person, how he perceives him and what he does to him, what he expects him to do or think, and how he reacts to the actions of the other."

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[7] 'Interpersonal,' Merriam-Webster Dictionary [Online]. Viewed from https://www.merriam-webster.com
[8] 'Interpersonal,' Oxford Dictionary [Online]. Viewed from https://www.lexico.com
[9] 'Relations,' Merriam-Webster Dictionary [Online]. Viewed from https://www.merriam-webster.com

Summary

In this study, the focal concept of ***interpersonal relations*** refers to the social interaction between the stigmatized—children orphaned by AIDS—and their social environment with other individuals. This includes the stigmatized relationship and interaction with surviving relatives, extended family, friends, and the surrounding community or others present within their social environment. Additionally, in the context of this study ***interpersonal relations*** include the stigmatized interaction with non-stigmatized groups of individuals and their perception of others, including their perception of social support offered by others.

6.2.3.6 Psychosocial well-being

The focal concept of ***psychosocial well-being*** has five related concepts, namely: (1) *psychological well-being*, (2) *social well-being*, (3) *emotional well-being*; (4) *self-esteem and self-concept*, and (5) *future orientation*.

Dictionary definition of the focal concept "psychosocial well-being"

The focal concept is defined in two separate parts to give rise to conceptual meaning, namely, ***psychosocial*** and ***well-being,*** as described below.

The Oxford Online Dictionary defines ***psychosocial*** as "of or relating to processes or factors that are both social and psychological in origin" (Hanks et al., 1985, p. 1179). The Merriam-Webster online dictionary similarly defines ***psychosocial*** as "involving both psychological and social aspects; relating social conditions to mental health." The Oxford English Dictionary expands on the previously provided definitions, defining the word ***psychosocial*** as "relating to the interrelation of social factors and individual thought and behavior."

The Collins English Dictionary defines ***well-being*** as “the condition of being contended, healthy, or successful: welfare” (Hanks et al., 1985; p. 1645). Similarly, the Merriam-Webster online dictionary and the Oxford Online English dictionary defines ***well-being*** as “a state of being happy, healthy, or prosperous: welfare” and “a state of being comfortable, healthy, happy,” respectively.[10] The word ***well-being*** is unanimously defined as being ‘healthy’ by all sources as presented in the definitions provided above (Hanks et al., 1985; the Oxford Online English dictionary; Merriam- Webster online dictionary). The Collins English Dictionary defines the word “healthy” as “enjoying good health; functioning well or being sound” (Hanks et al., 1985, p. 676). The Merriam-Webster online dictionary expands on the definition of healthy as “free from disease or pain: enjoying healthy and vigor of body, mind, or spirit; showing physical, mental or emotional well-being: evincing health.”[11]

Subject-specific definition of the concept ‘psychosocial well-being’

The term ***psychosocial well-being*** is generally regarded as the “physical, psychological, social and cognitive well-being” of an individual (Dadialla, He, & Wang, 2014, p. 23). While there remains little consensus among scholars for defining the term psychosocial well-being, a holistic definition was provided by Fujishima-Hachiya and Inoue (2012), who define psychosocial well-being as the amalgamation of psychological and social well-being, encompassing well-being to include social inclusion and resilience, that reflects an individual’s thoughts, behaviors and reactions to the social environment. This conceptual definition is consistent with the measures used in several studies focusing on orphaned children and HIV/AIDS to determine psychosocial well-being and the related concepts identified following the findings of the current study.

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[10] ‘Well-being,’ Merriam-Webster Dictionary [Online]. Viewed from www.merriam-webster.com; ‘Well-being,’ Oxford English Dictionary. Viewed from https://www.lexico.com/definition/well-being

[11] ‘Healthy,’ Merriam-Webster Dictionary [Online]. Viewed from www.merriam-webster.com

Summary

In summary, psychosocial well-being in this study refers to the holistic, healthy functioning and well-being of children who have been orphaned by AIDS, encompassing their psychological well-being to include psychological, social, and emotional well-being that reflects their thoughts, behaviors, and their reactions to their social environments. Psychosocial well-being in this regard consists of five crucial domains, namely, psychological well-being, emotional well-being, social well-being, self-concept and self-esteem, and future orientation, comprising the holistic well-being of a given individual.

6.3 Conclusion

This chapter delineated the focal concepts upon which the social transactional model of HIV-related stigma and the psychosocial well-being of COA has been founded. The focal concepts developed within this chapter form the basic building blocks of the developed model and provides conceptual meaning for the model presented in the next chapter. Furthermore, these focal concepts are integrated in the model description of the developed model as presented Chapter 7.

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Chapter 7

Model Description

7.1 Introduction

This chapter presents the social transactional model of HIV-related stigma and the psychosocial well-being of COA. It covers stage three of model development—namely, model description as indicated in Figure 7.1 below. As suggested in the theory generative framework, model description follows concept and statement development and is presented as (1) the overview of the model, and (2) model description. Model description is further separated into six core aspects essential for description, namely: purpose, concepts, definitions, relationships, structure, and assumptions of the Social Transactional Model of HIV-related Stigma and the Psychosocial Well-being of Children Orphaned by AIDS. Additionally, the aspect of context has been added to the description of the model.

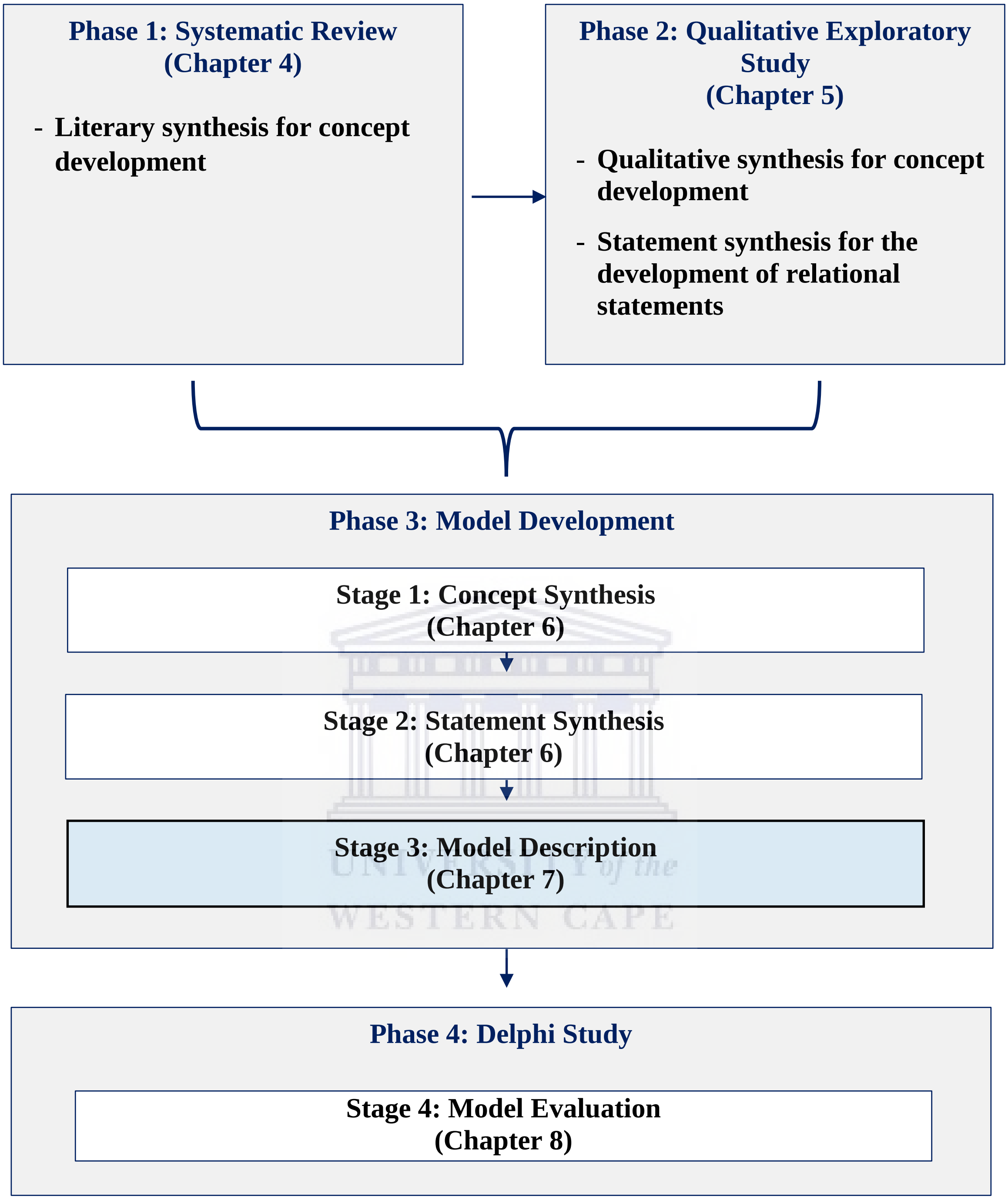

Figure 7.8: Model Description

7.2 Overview of the model

The overview of the model represents a brief discussion of the social transactional model of HIV-related stigma and the psychosocial well-being of COA. The model serves as a framework for understanding the manner in which HIV-related stigma affects the psychosocial well-being of HIV negative COA, either directly or indirectly. Throughout the study it became evident that COA experienced various manifestations of HIV-related stigma because of their association to familial HIV/AIDS. Both interpersonal (enacted stigma) and intrapersonal (perceived and internalized stigma) aspects of HIV-related stigma were captured and varied in the way it affected the psychosocial well-being of COA. Experiences of HIV-related stigma directly influenced the domains of psychosocial well-being of COA. Their experiences and perceptions of HIV-related stigma led to their use of maladaptive coping strategies, a mediator which may contribute towards the poor psychosocial well-being exhibited by COA. Maladaptive coping strategies simultaneously provides protection against and relief from experiences of stigmatization endured by COA, while negatively affecting their psychosocial well-being. The model captures five core domains of psychosocial well-being commonly emerging across the findings of this study, thus representing the poor psychosocial well-being exhibited and described by COA. The model is thought of as a social interactional model as it denotes that a child's interactions with their social environment (friends, family and community) shapes their behavior and well-being. The model is therefore entitled the social transactional model of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS.

As both the concepts of stigmatization and psychosocial well-being are complex, it is rather challenging to include all concepts relating to HIV-related stigma and associated psychosocial outcomes for children. As a result, the model depicts the process of HIV-related stigma for poor psychosocial well-being among COA and anticipates that these processes may be limited, representing a contextual reality of phenomenon. The social transactional model of HIV-related stigma and the psychosocial well-being of COA consists of three stages in which HIV-related stigma acts to affect the psychosocial well-being of COA, as discussed below:

7.2.1 Stage 1: Experiences

The first stage, namely, experiences, focuses on the interpersonal and intrapersonal experience of HIV-related stigma and the interrelationship between these manifestations of HIV-related stigma.

7.2.2 Stage 2: Responses

During stage two, COA respond to experiences of interpersonal and intrapersonal stigma through the use of maladaptive coping strategies. These maladaptive coping strategies include behavioral and psychological responses to stigmatization and consist of avoidant, emotion-focused, and problem-focused coping, and may be adopted by COA, either individually or in combination, to defend against experiences and future encounters of HIV-related stigma.

7.2.3 Stage 3: Outcomes

Stage three describes the outcomes of the model which focuses on the domains of psychosocial well-being negatively affected by experiences and perceptions of HIV-related stigma and associated behavioral reactions adopted by COA. Here, stages one and two may, either directly or indirectly, affect the domains of psychosocial well-being presented in stage three.

7.3 Model description

7.3.1 Purpose of the model

The purpose of the model is guided by the question, “What is the purpose of the theory which addresses why the theory was formulated and reflects the contexts and situations in which the developed theory may be applied?” (Chinn & Kramer, 2004; 2008). Watson (1985) proposes that a theory is created to enhance our understanding of a given phenomenon. Aligned with Watson (1985), this model serves a theoretic purpose as it enhances the understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children who have been orphaned by AIDS-related causes. The model fosters an understanding of two sources of phenomenon and their relation to one another. Firstly, HIV-related stigma as experienced or perceived by COA is presented and explored, followed by the dimensions of psychosocial well-being of COA as affected by experiences, perceptions, and behavioral responses to stigmatization. While the model might not directly affect practice or contribute towards practice goals, it adds to the body of knowledge focusing on health-related—specifically HIV-related—stigma as directed towards children who have been orphaned. Therefore, the understanding offered within the discipline of social science enhances researchers, policy makers, practitioners and organizational members' understanding of research findings and their ability to develop appropriate programs and interventions to reduce HIV-related stigma and its influence on the psychosocial well-being of COA based upon their improved understanding.

7.3.2 Context of the model

According to Chinn and Kramer (2004), contexts may be broad or rather narrow to address the range of applicability of the developed theory. Theoretical relationships must be situated within a context if it were to be useful and meaningfully applied (Chinn & Kramer, 2008). In this study, the context of the model highlights the environment in which phenomenon, namely, HIV-related stigma, is likely to occur. The context of the social transactional model of HIV-related stigma and psychosocial well-being of COA is any social environment in which COA are present. These environments include, but are not limited to, the home, school, health facilities, and local and surrounding communities. It is within social environments that HIV-related stigma may be extended to COA through the process of social interaction between COA and non-stigmatized individuals. While this model development took place within the South African context, it was based on national and international findings, as presented in this study (Phase I). Consequentially, from a cultural perspective, the model may be applied within varying contexts, which includes individuals from diverse ethnic and cultural backgrounds. Despite the model's relevance in various contexts, the use of the model needs to be applied with caution and sensitivity towards the social environment in which HIV-related stigma is being enacted and experienced by COA. Such caution and sensitivity is required because of the nature of stigmatization, which is not constant but rather in flux, and is largely governed by cultural backgrounds and social environments in which it exists.

7.3.3 Assumptions of the model

The assumptions of the model are guided by the question, “On what assumptions does the theory build?” Assumptions are regarded as the basic givens or truths that are accepted and assumed to be factual (Chinn & Kramer, 2004). These assumptions form the grounding of a theory and influences its structure and conceptualization (Chinn & Kramer, 2004). Chinn and Kramer (2004) state that the soundness of assumptions is not to be empirically evaluated but may be philosophically challenged and empirically assessed. The developed model is based on philosophical assumptions drawn from the conceptual framework presented in Chapter 2 and serves as a starting point for the assumptions of the developed model. The assumptions of the model are:

- Stigmatization is a social construct embedded within the social environment of COA and is dependent on the process of dyadic social interaction occurring between COA and non-stigmatized individuals. It is through dyadic social interaction that the cultural and social understandings of HIV-related stigma are conveyed and enacted.
- COA acutely experience HIV-related stigma as a result of their association with parental HIV/AIDS and are awarded the same discredited identity as their parents.
- COA experience both interpersonal and intrapersonal forms of stigma. Interpersonal forms of HIV-related stigma are represented by social interaction between COA and others that is characterized by discrimination, rejection, and hostility. Intrapersonal forms of HIV-related stigma represent COAs psychological and internal experience and response to HIV-related stigma.
- COA experience various components of HIV-related stigma that are both interrelated and interdependent, including enacted stigma, perceived stigma, and internalized stigma.
- Each component of HIV-related stigma uniquely contributes to poor psychosocial well-being and psychosocial distress among COA. These components of HIV-related stigma may, either directly or indirectly, via maladaptive coping strategies, negatively affect the psychosocial well-being of COA.

- The various domains of psychosocial well-being of COA are affected, including the psychological well-being, social well-being, self-esteem and self-concept, emotional well-being, and future orientation.
- Domains of psychosocial well-being are codependent and interrelated, as a change in one domain results in a change in another, resulting in overall poor psychosocial well-being.

7.3.4 Theoretic definitions of focal concepts in the model

According to Chinn and Kramer (2004, p. 83), “Theoretic definitions form the basis for and reflect empiric indicators and operational definitions for concepts that are needed for research and convey the general meaning of a concept.” Therefore, the concepts of theory are to be clearly identified and defined and are crucial for understanding the purpose, structure, assumptions and nature of theoretic relationships of a theory (Chinn & Kramer, 2004; 2008). This section outlines the theoretical definitions of the focal concepts and related concepts that were outlined in Chapter 6 as presented in the social transactional model of HIV-related stigma and psychosocial well-being.

- ***Enacted stigma*** within the context of this study, enacted stigma refers to the interpersonal aspect of stigmatization as it occurs within the social interaction or communication between the stigmatized and non-stigmatized—COA and other individuals—within their social environment. Enacted stigma is regarded as the experience of overt discrimination, humiliation, and rejection as received from others because of ones’ devalued status resulting from their association with HIV/AIDS.
- ***Perceived stigma*** refers to the intrapersonal aspect of stigmatization drawing on the perceptive reality of an individual. Therefore, perceived stigma is regarded as an individual’s subjective awareness of HIV-related stigma. This awareness includes their perceptions and beliefs regarding the normativity and prevalence of stigmatizing beliefs, behaviors, and attitudes held by the community about HIV/AIDS and those infected and affected by

HIV/AIDS. In essence, perceived stigma presents a stigmatized individual’s expectation or anticipation of experiencing stigmatization from others.

- ***Internalized stigma,*** commonly known as self-stigma, refers to the intrapersonal aspect of stigmatization. Internalized stigma denotes the acceptance of stigmatizing beliefs and values which are regarded as truthful and valid by stigmatized individuals—in this case, COA. These accepted beliefs and values are incorporated into the self and manifested as feelings of guilt, shame, unworthiness, and the view of oneself as being unworthy, dirty, or a drain on society. Two main related concepts—self-blame and shame—are also defined. Janoff-Bulman’s (1979) conceptualization of characterological self-blame, which is esteem related, serves to offer an adequate conceptualization for the related concept “self-blame.” Here, self-blame is attributed to one’s character and is associated with one’s belief that past negative outcomes is a result of personal deservingness. The related concept “shame” represents an internal state of regret, dishonor, or inadequacy. COA often express shame because of their devalued social status and being associated with HIV/AIDS, which is often regarded as taboo within social and cultural settings. The experience of internalized stigma, self-blame, and shame is evidenced by a poor sense of self.
- **Coping strategies** refers to a process whereby stigmatized individuals adopt complex affective, behavioral and cognitive responses to successfully deal with stressors and negative life experiences. The manner in which stigmatized individuals adopt these coping strategies are relatively stable and consistent over time. Stigmatized individuals attempt to mitigate the negative impact of HIV-related stigma through the adoption of various coping strategies. These coping strategies are identified as the following related concepts, namely: (1) emotion-focused coping, (2) avoidant-coping strategies, and (3) problem-focused coping. Problem-focused coping strategies seek to alter the relationship between stigmatized individuals and their social environment and may be directed at oneself, others, or the presented situation. Generally, these strategies are aimed at problem solving and may include non or selective

disclosure, compensation, activism, social support, or disengagement. Alternatively, emotion-focused coping refers to strategies that seek to regulate negative emotions and is aimed at reducing or managing the emotional distress accompanied by stressful situations or cues. These strategies include downward spiral comparisons, external attributions for stigmatizing behaviors, like the ignorance and denial of others, disidentification, and the positive reappraisal of experiences. Lastly, avoidant-coping refers to the cognitive and behavioral efforts of the stigmatized individuals to avoid or minimalize dealing with stressors and negative situations, such as withdrawal or isolation.

- ***Interpersonal relations,*** in the context of this study, refers to the social environment in which stigmatized individuals exist and function. Interpersonal relations in this sense extends beyond the social environment in which the individual is present to include social interaction between the stigmatized individual and non-stigmatized individuals, including family, friends, community members, service providers, and others present within the social environment. HIV-related stigma is extended, directed at, or conveyed to COA through social interaction within the social environment.
- ***Psychosocial well-being,*** in this study, is regarded as the holistic functioning and well-being of a child. In this sense, psychosocial well-being encompasses the domain of psychological well-being to include social and emotional well-being, self-esteem and self-concept, and future orientation, which reflects the thoughts, behavior, and an individual's reactions towards their social environment. Five domains of psychosocial well-being are to be defined for a comprehensive understanding of the focal concept as applied within this study. *Psychological well-being* is a multidimensional concept that centers on the mental health or state of an individual and is developed through life experiences, personal identity, and emotional regulation. In the context of this study, poor psychological well-being is represented by depression, anxiety, and post-traumatic stress. *Emotional well-being* is closely related to psychological well-being and refers to positive or negative affect. In the context of

this study, emotional well-being refers to the emotional affect of the stigmatized individual which is negatively affected by psychological distress. Poor *emotional well-being*, in this study, is detected by the presence of poor emotional regulation and a negative emotional status presented by the stigmatized individual. *Self-concept* and *self-esteem*, which is affected by emotional well-being, presents a way to think about oneself, and refers to the conscious reflection of an individual regarding their being or identity that remains separate from the environment and others. *Self-concept* refers to a multifaceted system of learned beliefs, attitudes, and opinions, which are regarded as true by the stigmatized individual about their personal existence. Self-concept is associated with *self-esteem*, which presents the affective or emotional aspect of the self, or the way an individual feels about and values themselves. In the context of the study, individuals are mutually dependent upon their social environment; therefore, *social well-being* refers to social inclusion, a sense of belonging, and the interpersonal relationships held with others. Stigmatized individuals, who are socially excluded, rejected, and unable to form healthy interpersonal relationships with others, display poor social well-being. Lastly, the related concept *future orientation* broadly refers to the extent that an individual think about their future and includes optimism, hopefulness, and perceived control over the future.

7.3.5 Relationship statements of the model

The relationship statements of the model were guided by the question, “What is the nature of relationships?” Chinn and Kramer (2004) stated that relationship statements provide links between identified concepts and may provide structure which is central to the developed theory. The purpose of “relationship statements are to describe, predict or explain the nature of interactions between the concepts of the theory” (Chinn & Kramer, 2004, p. 86). Statements range from simply relating two concepts to complex statements, relating three or more concepts. Similarly, Walker and Avant (2005) indicate that statements are aimed at specifying relationships between two or more concepts based on evidence. Evidence includes drawing from quantitative, qualitative, or literary methods to establish relationship statements. The relationship statements of this model were developed upon the results of the systematic review and the qualitative exploratory descriptive study (Phases I and II) presented in Chapters 4 and 5, respectively.

The relationship statements of the social transactional model of HIV-related stigma and psychosocial well-being are presented below:

1. COA experience enacted (F1), perceived (F2), and internalized stigma (F3). These experiences are facilitated by the stigmatized child's interpersonal relations (F6) with other individuals and their social environment.
2. There is a bidirectional relationship between enacted (F1) and perceived stigma (F2). When children encounter enacted stigma (F1), their experience of perceived stigma—the perception of the normativity and prevalence of stigmatization associated with HIV/AIDS—is heightened. Perceived stigma (F2) is accompanied by increased enacted stigma (F1) as the stigmatized child anticipates the experience of enacted stigma and becomes increasingly sensitive to the actions of others. Enacted and perceived stigma leads to internalized stigma (F3)—the incorporation of negative beliefs and views about the self that are regarded as valid and truthful by COA.
3. Poor psychosocial well-being (F6) is the direct consequence of enacted (F1) and internalized stigma (F3). Enacted stigma negatively affects the domains of psychological and social well-being. Internalized stigma has detrimental outcomes for the domains of self-concept and self-esteem and future orientation.
4. In the absence of social support, negative outcomes associated with enacted, perceived and internalized stigma are mediated by maladaptive coping strategies (F4) adopted by COA. These coping strategies are adopted to minimize and deal with the consequences of HIV-related stigma or avoid future experiences of enacted stigma.

5. Poor psychosocial well-being (F5) is the accumulative outcome of enacted stigma (F1), perceived stigma (F2), experienced internalized stigma (F3), and coping strategies (F4) adopted by COA.
6. The psychosocial well-being (F5) of COA are comprised of five interconnected domains of well-being, which are negatively and uniquely affected by each other.

Figure 7.2 below presents the graphic representation of the focal concepts and their relationship statements, illustrating the social interaction model of HIV-related stigma and the psychosocial well-being of COA, and the structure and process of the developed model.

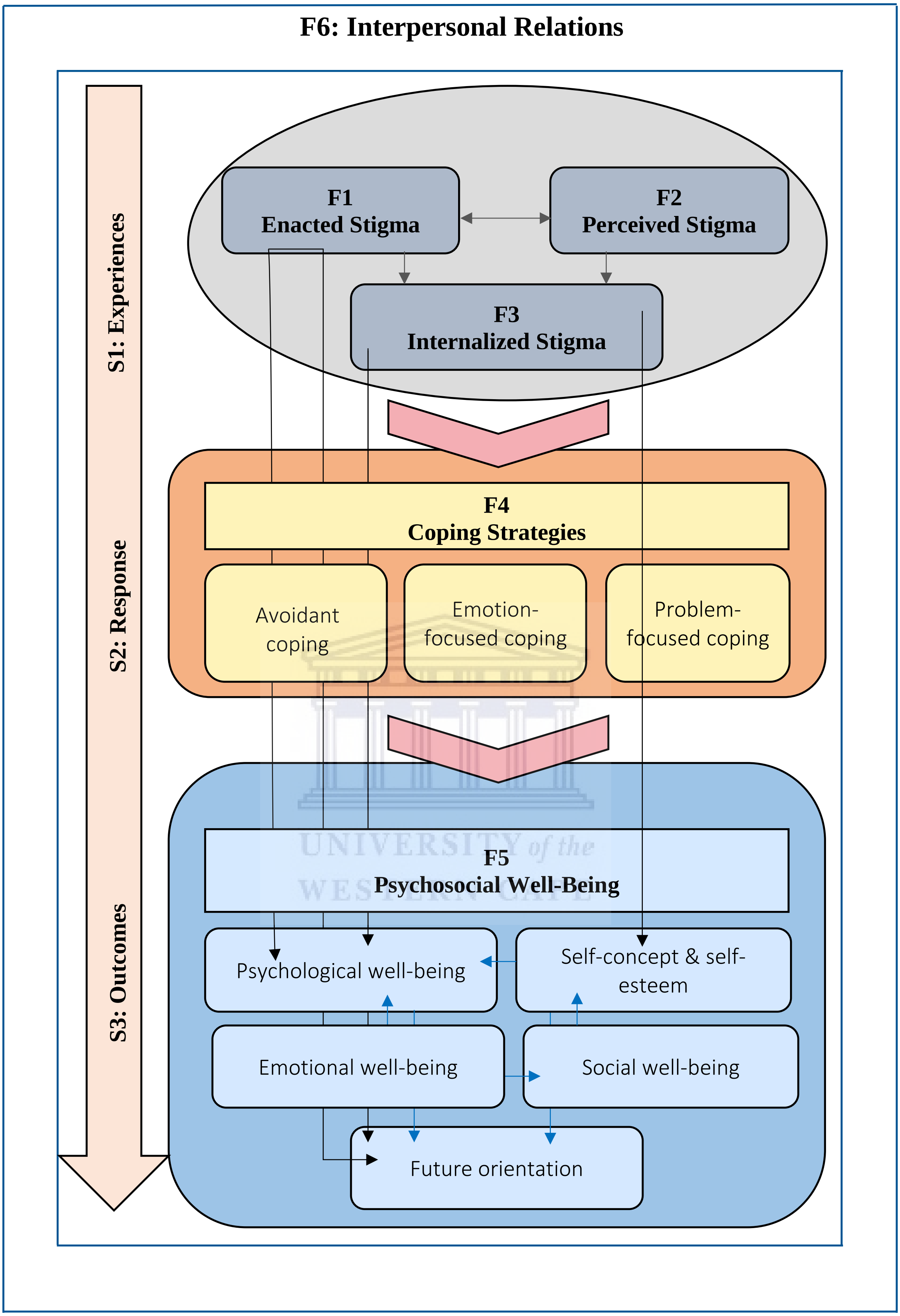

Figure 7.9: The Social Transactional Model of HIV-Related Stigma and The Psychosocial Well-being of COA

7.3.6 Process structure of the model

Chinn and Kramer (2008) posit that structural forms are powerful for shaping the perception of reality and provides the overall form of conceptual relationships within it. The structure of the developed model is guided by the question, “What is the structure of the theory?”, and emerges from the relationship statements between the six focal concepts of the model, namely, enacted stigma, perceived stigma, internalized stigma, coping strategies, psychosocial well-being, and interpersonal relations. The structure of the developed model consists of three stages according to the main concepts to facilitate a discussion and explanation of the interaction between focal concepts and stages of the model. The structure of the social interactional model of HIV-related stigma and psychosocial well-being is depicted in Figure 7.2 above.

The stages of the model are illustrated by the letter “S” to represent the word “stage,” i.e. stage one is presented as “S1: Experiences,” and is therefore representative of the first stage of the model. The numbering of the stages is significant as it depicts the linear structure of the model, moving from HIV-related stigma to the impact on the psychosocial well-being of COA. Their positioning within a vertical downward pointing arrow suggesting movement from HIV-related stigma to psychosocial well-being indicates the linear progression of the stages. Focal concepts are depicted by the letter “F,” meaning “focal concept,” such as “F1” for enacted stigma. Unlike the stages presented in the model, the numbering of focal concepts holds no significance, as concepts are rather iterative, involving bidirectional and linear relationships. Secondly, focal concepts form the basic fabric of the model and are presented in bold text to draw attention to the importance of main concepts setting them aside from related concepts. Related concepts attached to focal concepts that facilitate understanding of the model are included in plain italicized text underneath presented focal concepts.

Interpersonal relations (F6) encapsulated the experiences, responses and psychosocial outcomes for COA. Interpersonal relations represent the social environment in which COA exist and function, affecting them throughout the three stages of the model. The social environment in the context of this study comprises the homestead, school, community, health care facilities, and local organizations. For the process of stigmatization to unfold, social interaction between the stigmatized child and non-stigmatized individuals— referred to as mixed contact in the social environment— needs to be present (Goffman, 1963). Forms of mixed contact would include interaction between the stigmatized orphaned child and family members, friends, children within the surrounding community, educational staff, community members, health service providers, and organizational staff. While it is envisioned that interpersonal relations would be present throughout the model, it is most influential during stage one as stigmatization is extended to or perceived by COA through mixed contact. Interpersonal relations, or rather the absence thereof, perpetuates poor psychosocial well-being and the adoption of maladaptive coping strategies by COA.

Stage One: Experiences

During stage one (S1), COA experience both interpersonal and intrapersonal forms of stigmatization, conveyed through the process of social interaction within their social environment. **Enacted stigma (F1),** an interpersonal form of HIV-related stigma, is characterized by overt discrimination and hostility resulting in social exclusion, placing COA at a disadvantage (Major & O'Brien, 2005). Manifestations experienced by COA include rejection, hostility, exclusion, ill or unequal treatment, devaluation, victimization, exploitation and abuse. There is a direct relationship between **enacted stigma (F1), psychosocial well-being (F5)** and intrapersonal forms (F2, F3) of stigma. Firstly, the direct relationship between enacted stigma and psychosocial well-being is presented by black vertical arrows pointing towards the domains of **psychosocial well-being (F5)** that are negatively affected. Experiences of enacted stigma inhibits the *psychological well-being* of COA, increasing their levels of distress and the formation of psychopathological symptoms, such as depression, anxiety, adjustment problems, post-traumatic stress, fear, and distress. Enacted stigma leads to the obstruction of formal education and educational access. Such obstruction coupled with the presence of overt discrimination within the schooling environment, negatively affects future orientation, as COA present a lack of optimism, confidence, and perceived control over their future.

There is a bidirectional relationship between **enacted (F1)** and **perceived (F2)** stigma as presented by a double arrow between the two focal concepts. Firstly, as children experience enacted stigma, they become increasingly aware of the HIV-related stigma. This contributes to the development of **perceived stigma (F2),** which is regarded as the belief about the prevalence and normativity of HIV-related stigma within one's environment. Secondly, psychopathological symptoms ensued from enacted stigma predicts perceptions of discrimination—perceived stigma (Major & O'Brien, 2005)—as children with internalizing problems are increasingly sensitive and perceptive to stigmatizing behaviors, increasing experiences of enacted stigma over time. Perceived stigma fails to directly affect the psychosocial well-being of COA, but like enacted stigma contributes to the development of **internalized stigma (F3).** The arrows pointing towards internalized stigma (F3) from enacted and perceived stigma present this relationship.

Internalized stigma (F3), a product of enacted and perceived stigma, is the internalized belief of being devalued and tainted and results in feelings of self-hatred, guilt, inferiority, shame and embarrassment for COA. Internalized stigma inhibits psychosocial well-being, specifically the *self-concept* and *self-esteem*, and *psychological well-being* of COA. COA hold a negative view of themselves and lack self-esteem and confidence because of their belief that they are devalued, consequentially resulting in distress and psychopathological symptoms.

Stage Two: Response

Stage two (S2) focuses on COAs response to HIV-related stigma and its related distress and negative affect. Experiences of HIV-related stigma is followed by **coping strategies (F4)** and is presented by a horizontal downward chevron. Coping strategies is labeled "F4" and has three related concepts: (1) *avoidant-coping*, (2) *emotion-focused coping, and* (3) *problem-focused coping,* which are represented by three smaller rounded rectangles. These related concepts are illustrated by smaller yellow boxes and are encapsulated by the focal concept “coping strategies” (F4). **Coping strategies (F4)** include behavioral and psychological responses to stressful events, such as interpersonal and intrapersonal forms of stigmatization, and are used either alone or in combination. Both avoidant and problem-focused coping strategies are behavioral responses to HIV-related stigma and affects psychosocial well-being. *Avoidant coping strategies* involve disengagement, presenting the social withdrawal and self-isolation of COA to avoid experiences of enacted stigma. Disengagement exacerbates psychological distress, bringing about loneliness and actively undermines the healthy development of meaningful social relationships and networks (Schibalski et al., 2017). Problem-focused coping, which is fueled by perceived stigma, involves secrecy, selective disclosure, and non-disclosure of the cause of parental bereavement (Stutterheim et al., 2012). In addition, these coping strategies prohibit the formation of healthy relationships and reduces the opportunity for COA to healthily express their feelings and discuss stressful life events. *Emotion-focused coping* is a psychological response to HIV-related stigma and aims to reduce negative emotional responses to stigma. COA are rather avoidant of healthily expressing their feelings and suppress the negative feelings associated with enacted, perceived, and internalized stigma. The coping strategies adopted by COA are rather maladaptive and despite their use for defending against HIV-related stigma and emotional responses, negatively affect their psychosocial well-being. The impact of coping strategies on psychosocial well-being is illustrated by a horizontal downward chevron representing the progression from coping strategies towards the psychosocial well-being of COA.

Stage Three: Psychosocial well-being

Stage three (S3) presents the progression of COAs experiences and responses of HIV-related stigma to its associated outcomes for psychosocial well-being, presented by a horizontal downward chevron. Through experiences of HIV-related stigma and the adoption of maladaptive coping strategies, the **psychosocial well-being (F5)** of COA are negatively affected. Psychosocial well-being is regarded as the holistic well-being of COA, which included their psychological, emotional and social well-being, self-esteem and self-concept, and future orientation. These domains of psychosocial well-being reflect COAs thoughts, behaviors and reactions towards their social environment and others. Psychosocial well-being is presented by a rounded rectangle presenting the holistic psychosocial well-being of a child orphaned by AIDS. The rounded rectangle consists of a smaller regular rectangle set above five smaller rounded rectangles. The smaller regular rectangle presents the focal concept "**psychosocial well-being" (F5),** while the smaller rounded rectangles below present related concepts forming the psychosocial well-being, namely, *psychological well-being, social well-being, emotional well-being, self-concept and self-esteem, and future orientation.* The order in which related concepts are presented hold no relevance as the dimensions are interconnected, related, and influence each other. The relationship between the related domains of psychosocial well-being are indicated through the use of blue arrows pointing in the direction of the affected domain.

Enacted stigma (F1) negatively affects the psychosocial well-being of COA. Experiences of enacted stigma acts to increase psychological distress, contributing to the development of internalizing and externalizing disorders, such as anxiety, depression, PTSD, and aggressive and risk-taking behavior. The self-isolation and social withdrawal of COA (*avoidant coping strategies*) to prevent future experience of HIV-related stigma contributes to the psychological distress and suffering of these children, exacerbating poor *psychological well-being*. Similarly, the *future orientation* of COA is negatively affected by the disadvantage cultivated by **enacted stigma (F1)** manifesting as actions of overt discrimination and rejection. COA are stripped of their resources, unfairly treated, and discriminated against, both within the homestead and the schooling environment, resulting in school dropout. Without scholastic knowledge and social support, a child orphaned by AIDS lacks optimism, confidence, and perceived control over their future. There is also a direct relationship between *psychological well-being* and *future orientation* presented by a solid blue arrow leading from psychological well-being towards future orientation. Poor psychological well-being leads to poor future orientation for COA.

Perceived stigma (F2) causes a child orphaned by AIDS to embody a culture of secrecy, non-disclosure or selective disclosure of the cause of parental death. The use of *problem-focused coping strategies* to conceal the cause of parental death actively limits a child's ability to form healthy interpersonal relationships, which are essential for receiving the social support necessary to cope with stressful life events. Therefore, perceived stigma indirectly negatively affects the *social well-being* of COA through their use of *problem-focused coping*. A direct relationship exists between *social well-being*, *self-concept and self-esteem*, and is presented by a solid blue arrow. Poor *social well-being* exhibited by a child orphaned by AIDS restricts their opportunity to engage in self-esteem enhancing activities that occurs through their social interaction with others. Through minimal interpersonal engagement COA cannot receive self-validation from others, resulting in a poor *self-concept* and lower levels of *self-esteem* as they lose confidence in themselves and their capabilities. Non-disclosure and secrecy prohibits an orphaned child from healthily expressing their emotions and concerns about stressful events, contributing to poor *emotional well-being*.

S*elf-esteem and* the *self-concept* are similarly affected by **internalized stigma (F3)**. COA hold a negative view of themselves as being devalued, tainted, and dirty. This not only presents the poor self-concept embodied by COA, but also represents their psychological suffering. A solid blue arrow signifies the relationship between *poor self-concept*, *self-esteem* and *psychological well-being*. A poor self-esteem cultivates a lack of confidence in a stigmatized child, ultimately negatively influencing their *future orientation*.

Consequentially, all forms of HIV-related stigma results in emotional distress for COA, negatively affecting their *emotional well-being*. To efficiently deal with and minimize emotional distress, COA adopt *emotion-focused coping strategies* likely to hinder healthy emotional regulation and reinforce a negative emotional status. In the absence of social support and healthy interpersonal relationships combined with experiences and perceptions of HIV-related stigma, these children are unable to healthily express themselves and continue to suppress their emotions, leading to poor emotional regulation and a negative emotional status, indicating poor *emotional well-being*.

Emotional well-being directly affects *psychological well-being*, perpetuating psychological distress and internalizing psychopathological symptoms. A solid blue arrow directed towards psychological well-being indicates this direct relationship.

7.4 Conclusion

This chapter constituted the second and third stages of model development and presented the social transactional model of HIV-related stigma and the psychosocial well-being of COA. The six core aspects of the developed model were discussed at length, namely: purpose, context, assumptions, concepts, definitions of focal and related concepts, relationship statements, and process of structure. Next, Chapter 8 introduces the last stage of model development, presented as a critical evaluation.

7.5 References

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Chapter 8

Model Evaluation

8.1 Introduction

The previous chapter focused on the social transactional model of HIV-related stigma and the psychosocial well-being of COA, providing an overview followed by a graphical and narrative description of the model. Model description was further separated into six components, namely: (1) purpose, (2) concepts, (3) definitions, (4) relationship statements, (5) structure and process, and (6) assumptions of the model for effective description. This chapter evaluates the developed model using the proposed criteria of Chinn and Kramer (2008) in the form of a modified Delphi technique. Specific focus is given to the consensus reached among a panel of experts regarding the model and is presented along the five evaluative categories of: (1) clarity, (2) simplicity, (3) generalizability, (4) accessibility, and (5) importance.

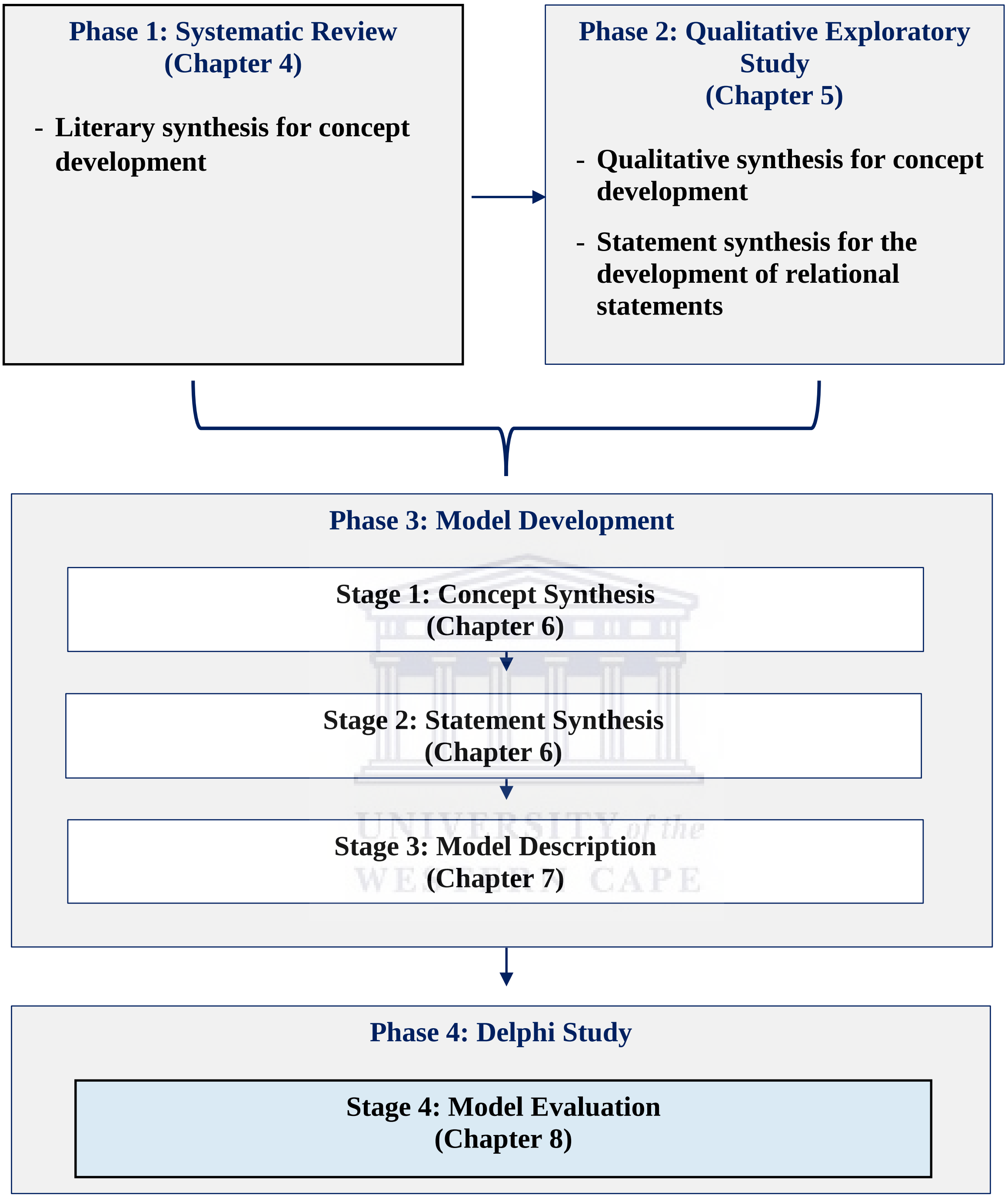

Figure 8.10: Model Evaluation

8.2 Methodology

8.2.1 Design

A modified Delphi study design—a consensus developing technique—was used to determine the functionality of the social transactional model of HIV-related stigma and the psychosocial well-being of COA according to various stakeholders. The Delphi technique is regarded as a systematic approach that seeks to obtain concordance on the opinions of key stakeholders and experts through a series of structured questionnaires, namely, “rounds” (Hasson et al., 2000; Young & Jamieson, 2001). Rounds are held until group agreement is reached (Green, Jones, Hughes, & Williams, 1999). Unlike traditional consensus-seeking methods, a modified Delphi design does not seek to consult an expert panel to generate answers during the first round (Avella, 2016). Rather, the modified design allows for the researcher to present previously elicited answers to an expert panel, initiating the consensus-seeking process (Avella, 2016). Correspondingly, the methodological design used to develop the presented model previously gathered answers from (1) a relevant systematic review, and (2) a qualitative exploration. Additionally, the theory generative approach to model development is accompanied with an evaluative questionnaire that held the potential to illicit agreement regarding the aspects, description, and formulation of the developed model (Chinn & Kramer, 2008).

The Delphi technique was regarded as suitable for the current study as it (1) allowed for a verified method of consensus building to ensure the functionality of the developed model; (2) it is applicable in an area of interest where there is limited evidence, such as HIV-related stigma and its impact on the psychosocial well-being of COA; (3) is suited for application to large complex problems or situations which may be contested, such as the conceptualization of stigma; and (4) is able to gather collective subjective judgements of experts that is beneficial to understanding a phenomenon in the light of limited research (Avella, 2016; Hasson et al., 2000; Hejblum et al., 2008; Young & Jamieson, 2001). In this study, expert opinion is combined to produce group consensus regarding the functionality of the developed model. The modified Delphi technique implemented in this study follows the guidelines prescribed by Boulkedid et al., (2011) which specifies five quality indicators for optimal use and reporting of a Delphi method.

8.2.2 Participant selection

According to Boulkedid et al., (2011), the selection of experts is one such quality indicator. Purposive and snowball sampling techniques were used to gather a sample population. Initially, non-probability purposive sampling was used to identify and recruit a panel of experts meeting a predefined criterion. A predefined criterion allowed for the selection of knowledgeable, competent key stakeholders to participate in the study. Duffield (1993) states that the strategic selection of expert panel members is vital if the group consensus method is to work. As a result, participants were required to be competent, knowledgeable, and interested in the topic, and generated a model focusing on HIV-related stigma and how it impacts the psychosocial well-being of COA. To be included, participants were required to be (1) healthcare professionals; (2) organizational members; (3) scholars focusing on stigma, discrimination, and child well-being; (4) renowned experts in the field; and (5) informal caregivers (Hsu & Sandford, 2007). The initial respondents selected via purposive sampling facilitated the further selection of participants through snowball sampling. Candidates considered appropriate for participation in the current study were identified and invited by participants.

8.2.3 Sample population and size

As suggested by Boulkedid et al., (2011), a list of prospective participants and their contact information was compiled and an invitation to participate in the study was extended in December 2018. The invitation furnished potential participants with an information sheet informing them of the purpose, benefits, and risks of the study. Additionally, the invitation elicited the willingness of potential panel members to participate. Participants' informed consent to participate in the study were obtained via email, aligned to the quality indicator of sending the Delphi questionnaire electronically (Boulkedid et al., 2011). A total of 35 identified panel experts were invited to participate in the study.

These potential panel experts were geographically diverse and held varying roles and expertise within the field of interest, allowing for the recruitment of a heterogenous sample. According to Hsu and Sandford (2007), the sample size is justified, sufficient, and reliable to undertake a consensus generating technique, such as a Delphi study. Participants were informed of the right to anonymity, confidentiality, and withdrawal from participation at any time without any repercussions. Aligned with the indicators of quality, the selected panel of experts were heterogenous in nature, speaking to the creditability and acceptance of quality indicators as the panel reelects a full range of stakeholders who are interested in the developed model and the empirical evidence upon which it is based. The diverse views of the panel of experts enriched the results of the Delphi procedure (Boulkedid et al., 2011).

8.2.4 Data collection

According to Hsu and Sandford (2007), the Delphi technique should consist of a series of iterations until a consensus is reached. During the first round, experts expressing their willingness to participate in the study were provided with a self-administered questionnaire via email (Appendix 8). This procedure is consistent with the quality indicator provided by Boulkedid et al., (2011) who suggests that questionnaire dispersion via email increases dissemination and saves time. The self-administered questionnaire consisted of three sections, namely: (A) a full narrative description of the developed model, (B) biographical information, and (C) a 30-item adaptation of the model evaluative guide provided by Chinn and Kramer (2008). For section A, a full narrative description which outlines the structural process, concepts, and relationship statements of the developed model was provided (under Phase III). This description was developed upon the empirical findings of a systematic review and a qualitative explorative descriptive study undertaken in Phases I and II, respectively. In Section B, the following biographical information was elicited from the panel of experts, namely, demographic details, gender, institution, occupation, and area of interest. Section C presented 30-items pertaining to the (1) clarity, (2) simplicity, (3) generalizability, (4) accessibility, and (5) importance of the social transactional model of HIV-related stigma for child psychosocial well-being as suggested by Chinn and Kramer (2008). These items were important for evaluating the functionality of the model and acts as a critical reflection of the conceptual theory as developed within this study. However, the evaluative questionnaire was adapted by removing items pertaining to semantic clarity, structural clarity, and structural consistency. These adaptions were deemed appropriate as the graphical structure of the model was not presented to expert panels. A further three items were removed as they pertained to the nursing discipline from which the theory generative methodology carried out in Phase IV was adopted. Items were rated using a 4-point Likert scale ranging from (1) Strongly Disagree, (2) Disagree, (3) Agree, and (4) Strongly Agree to determine the consensus among participating panel experts. The data was collected in a singular round between January and July 2019. As consensus was reached among participating experts during the first round. This indicated theoretical saturation, concluding the data collection procedure (Skulmoski, Hartman, & Krahn, 2007).

Round 1 undertook a survey using a self-administered questionnaire, which was distributed to participating experts electronically via email as an editable word document to be completed and returned. The participating experts were instructed to rate their agreeableness of the 30 items included in the 4-point Likert scale. Once completed, the respondents returned the questionnaire, and the responses were populated into an excel spreadsheet. From a preliminary analysis, it was evident that consensus among the participating experts had been reached.

8.2.5 Data analysis

The collected data were subject to extraction and a process of data analysis. A descriptive statistical analysis was computed using the SPSS (version 26). The researcher checked the raw data for completeness and correctness before carrying out the statistical analysis. In line with the quality indicators, descriptive statistics and levels of dispersion are most used to present the collective judgments of responding experts (Hasson et al., 2000). For consensus to be reached, 70% of respondents are to rate 3 or higher on a 4-point Likert scale and obtain a median of 3,24 or higher (Boulkedid et al., 2011; Hsu & Sandford, 2007). In adherence with these suggestions, the 4-point Likert scale was dichotomized into two categorical sections, namely: (1) non-consensus, and (2) consensus. Non-consensus comprises the ratings “Strongly Disagree” and “Disagree,” while consensus comprises the ratings “Agree” and “Strongly Agree.” A consensus is thus reached when the collective rating percentages within a dichotomized category represents 80% or more of participating expert responses (Yeh, Van Hoof, & Fischer, 2016). The median is calculated to determine expert consensus which is strongly favored and inherently appears to best reflect the convergence of opinion among the experts (Hill & Fowles, 1975; Hsu & Sandford, 2007). Additionally, levels of dispersion—the interquartile range—was identified and calculated to reflect respondent consensus. These methods are regarded as best practice.

8.3 Results

8.3.1 Biographical information

Of the 35 potential participants, 14 experts agreed and participated in the current evaluation, resulting in a 40% response rate. The majority of participants (78.57%) resided in South Africa, followed by Zimbabwe (7.14%), England (7.14%), and Dubai (7.14%). Eight participants (57.14%) were male with the remaining six participants (42.86%) being female. More than half of the participants (64.29%) indicated that they had a background in psychology, followed by backgrounds in social work (28.57%) and nursing (7.14%). Participants (57.14%) were academic staff members at institutions of higher education, directors (14.28%) of university centers, and practitioners (14.28%) (one was a psychologist and another a social worker). The remaining two participants were an organizational member and a postgraduate student, respectively. While participants’ occupations remained heterogeneous in nature, they unanimously maintained a key interest in health-related stigma, HIV/AIDS, and child well-being. The following results present the combined consensus of participants as indicated below.

8.3.2 Clarity

There was a consensus among participants regarding the clarity of the concepts, relationship statements, and the order and structure of the developed model. Overall, six items relating to clarity attained the highest agreement indicated by a median ranging from 3.50 to 4 with responses ranging from 3-4. As depicted in Table 8.1 below, all the participants indicated that the focal concepts were well defined, and that explanations of the focal concepts were appropriate and useful. For the element of clarity, participating experts (100%) indicated that (1) the view of the person and the environment are compatible, and (2) the focal concepts and relationship statements of the model were both identifiable and explicit. Additionally, all participating experts (100%) supported definitions describing focal concepts included in the model by agreeing that they were specific and applicable and that all relationships within the model are appropriate. The majority of participating experts (92.85%) agreed that the model is easily comprehendible. These results are indicated in Table 8.1 below.

Table 8.11: Clarity

Item	Statement	Range	Consensus	Mean	Median	Interquartile Range
1	Focal concepts of the model are made explicit and identifiable.	3-4	100	3.80	3.50	1
2	Focal concepts within the model are well defined.	3-4	100	3.64	4	1
3	Definitions of concepts in the model are specific and applicable.	3-4	100	3.50	3.50	1
4	The explanation of concepts is appropriate and useful.	3-4	100	3.64	4	1
5	The view of person and environment is compatible.	3-4	100	3.43	3	1
6	Relationships within the model are identifiable.	3-4	100	3.57	4	1
7	All relationships are appropriate and fit within the model.	3-4	100	3.43	3	1
8	The order of the model is easily comprehended.	2-4	92.85	3.43	3.50	1

8.3.3 Simplicity

A consensus was reached among the participating experts regarding the simplicity of the developed model as indicated by a consensus rate ranging from 85.71 to 100%. Two items relating to the differentiation of concepts and the purpose of the model reached the highest agreement as indicated by a median score of 4. All participants (100%) strongly agreed that concepts were differentiated into focal and related concepts within the model. Participants (100%) strongly agreed that the model is aligned with its purpose to describe, explain, and predict phenomenon. Participants (100%) agreed that for simplicity, concepts could be merged without the loss of theoretic meaning and that the model is well organized. While the participating experts agreed on the organization of relationship statements within the model, only 92.85% indicated that such relationships are easily identified. Additionally, most of the participating experts indicated that the developed model offers a clear and simplistic understanding of the phenomenon throughout. These results are presented in Table 8.2 below:

Table 8.12: Simplicity

Item	Statement	Range	Consensus	Mean	Median	Interquartile Range
1	The relationships within the model are easily identified.	2- 4	92.85	3.21	3	1
2	The relationships within the model are organized.	3-4	100	3.36	3	1
3	Concepts are differentiated into focal concepts and related concepts.	3-4	100	3.71	4	1
4	Concepts can be combined without losing theoretic meaning.	3-4	100	3.43	3	1
5	The model is simplistic and fosters a clear understanding throughout.	2-4	85.71	3.29	3	1
6	The model aims to describe, explain, or predict phenomenon.	3-4	100	3.57	4	1

8.3.4 Generalizability

The participants agreed upon the generalizability of the model despite its development within a South African context. Generalizability received the highest level of agreement across the evaluation, which is demonstrated by the median score of 4 and a 100% consensus rate across all items pertaining to generalizability. All the participating experts (100%) strongly agreed that the (1) purpose of the model was clear and specific regarding its application; (2) concepts of HIV-related stigma may be applied meaningfully as presented within the developed model, and (3) that the model is both specific to areas of health-related stigma and child well-being. Additionally, participating experts (100%) indicated that the developed model may be utilized by a wide range of professionals and researchers within the area of interest or specialty. These results are indicated in Table 8.3 below:

Table 8.13: Generalizability

Item	Statement	Range	Consensus	Mean	Median	Interquartile Range
1	The purpose of the model is clear and specific.	3-4	100	3.64	4	1
2	The model can be applied to all practice areas dealing with HIV-related stigma and child psychosocial well-being.	3-4	100	3.57	4	1
3	The model is specific to the interest area of health-related stigma and child well-being.	3-4	100	3.57	4	1
4	A wide range of professionals and researchers may use the developed model.	3-4	100	3.57	4	1
5	Concepts of the model may be meaningfully applied.	3-4	100	3.71	4	1

8.3.5 Accessibility

While receiving 100% consensus among participating experts, the element of accessibility received the lowest median scores ranging from 3 to 3.50. Participating experts (100%) indicated that concepts within the model were identifiable in experience and/or practice. While the remaining item for accessibility received a median of 3, 100% of the participants agreed that the definitions of the concepts adequately reflected their meanings. These findings are represented in Table 8.4 below:

Table 8.14: Accessibility

Item	Statement	Range	Consensus	Mean	Median	Interquartile Range
1	Concepts are identifiable in experience/practice.	3-4	100	3.50	3.50	1
2	Definitions provided for the concepts adequately reflect their meanings.	3-4	100	3.36	3	1

8.3.6 Importance

Agreement was reached among participating experts regarding the importance of the developed model as indicated by a consensus rate ranging from 85.71% to 100% with six items scoring a median score of 3.50 or higher. In terms of importance and relating to the purpose of the developed model, participating experts indicated that the model would facilitate an understanding of the subject area and its importance to the field of health-related stigma and child well-being. The developed model was also identified by participating experts (100%) as a general framework to predict the phenomenon of HIV-related stigma and outcomes for child psychosocial well-being. Participating experts (100%) agreed that given the purpose and orientation of the developed model, included factors have been accounted for. Additionally, the participating experts (100%) identified the usage of the model as being helpful in the respective fields and research relating to HIV-related stigma and child psychosocial well-being, retaining its ability to influence current understanding and practice. The participants also strongly agreed that the model would provide answers to important questions and all (100%) unanimously agreed that the model would resolve issues in research, programs, and practice. While the model was deemed important for the subject area for which it was developed, only 85.71% of the participating experts agreed that it was futuristic and future oriented. These results are indicated in Table 8.5 below.

Table 8.15: Importance

Item	Statement	Range		Mean	Median	Interquartile Range
1	The model has potential to influence current understanding and practice.	3-4	100	3.57	4	1
2	The model may be used to understand the subject area for which it is developed.	3-4	100	3.71	4	1
3	The model provides a general framework in which to act or a means to predict phenomena.	3-4	100	3.64	4	1
4	Given the purpose of the model and its orientation, significant factors have been adequately covered.	3-4	100	3.43	3	1
5	The stated purpose is one that is important to health-related stigma and the well-being of vulnerable children.	3-4	100	3.79	4	1
6	The use of the model will be helpful in respective fields and research.	3-4	100	3.79	4	1
7	The application of the model will resolve issues in research, programs, and practice.	3-4	100	3.29	3	1
8	The model is futuristic and future looking.	2-4	85.71	3.21	3	1
9	Research based on the model will provide answers to important questions.	3-4	100	3.50	3.50	1

8.4 Discussion

The purpose of this modified Delphi study was to determine the functionality of the social transactional model of HIV-related stigma for child psychosocial well-being. The aim of the developed model was to foster an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. Thus, the modified Delphi technique as employed here served to obtain the consensus of key stakeholders regarding the quality and purpose of the developed model. All items included for the evaluation of the developed model gained the highest level of consensus among key stakeholders as presented by the mode, as suggested by Boulkedid et al., (2011), and Hsu and Sandford (2007). These items relate to five core elements of the theory generative approach outlined by Chinn and Kramer (2008) in relation to the reflective evaluation and functionality of the developed model. Each element of evaluation is discussed according to its level of consensus below.

The findings of the current modified Delphi indicated that the highest level of agreement among the experts was attained for the element of generalizability. This element centers around the question, “To whom/what and when does the theory apply?” (Chinn & Kramer, 2008). While the manifestation, enactment, and experience of HIV-related stigma are subjective to the social and cultural climate in which it occurs, experts believed that the model may be meaningfully applied. Models that address human experience and associated outcomes often lack the characteristic of generality; however, the specificity of the model is useful in guiding its application (Chinn & Kramer, 2008). Aligned with the suggestion put forth by Chinn and Kramer (2008), experts have agreed that the developed model is specific to the field of HIV-related stigma and child well-being. In addition, participating experts strongly agreed that despite its specificity the model may be applied by a range of professionals and researchers.

While participating experts agree that the model is generalizable, the element of accessibility needs to be considered. Accessibility is characterized by the questions: “Can empiric indicators for concepts be identified?” and “Can the purpose of the theory be attained?” The participating experts indicated a consensus regarding empiric indicators which are presented in practice, namely, focal concepts, related concepts, and relationship statements. Similar to the consensus reached by experts, evidence-based studies (Boyes & Cluver, 2013; Chi et al., 2014; Lin et al., 2010; Lin et al., 2016; Mason & Sultzman, 2019) have recognized COAs experience of various manifestations of HIV-related stigma and the manner it affects their psychosocial well-being. These studies reflect the empiric indicators of focal and related concepts and their relationships within the developed model, reflecting its measurement. As a result, participating experts agreed that the model is accessible and the manifestations of HIV-related stigma, coping strategies, the domains of psychosocial well-being and their interpersonal relations are visible within practice and may be formally measured. For the measurement of empiric indictors, concepts and relational statements need to be clear and explicitly defined and presented within the developed model, thus drawing on the element of clarity.

Clarity refers to how well a model is understood and how consistently ideas—including concepts and relationships—have been conceptualized (Chinn & Kramer, 2008). The participating experts reached a consensus that the concepts, relationships, and overall structure of the model are explicit, identifiable, and clearly defined. As concepts form the basis of a theory and are to be effectively used within a discipline, clear definitions are necessary (Chinn & Kramer, 2008; Florom-Smith & De Santis, 2012). Florom-Smith and De Santis (2012) identified issues surrounding the complexity of the concept "HIV-related stigma" stating that despite various studies' efforts to examine the impact of stigma, the concept remains largely unclear. Kontomanolis, Michalopoulos, Gkasdaris and Fasoulakis (2017) supported these ideas, outlining the multifaceted nature of HIV-related stigma which continues to create a barrier for the effective conceptualization, evaluation, and practical measurement of the concept. The importance of concept exploration for examining HIV-related stigma is therefore highlighted by Florom-Smith and De Santis (2012). Similar challenges arose for the concept of psychosocial well-being as Tsang, Wong, and Lo (2011) too identified the construct as one with multiple components, questioning its varying definitions and means of measurement. Clear and explicit concepts and relationships as presented in this model, addressing the challenge of varying definitions and applications of concepts while establishing empiric meaning (Chinn & Kramer, 2008). Additionally, experts indicated that the overall structure of the model is identifiable and clear, representing the comprehensibleness of the developed model.

Although concept and relationship statements within the model are explicitly identified and clearly defined, only 92.85% of participating experts agreed that the model is easily comprehendible and simplistic throughout. These findings may indicate theoretic complexity (Chinn & Kramer, 2008). The theoretic complexity of the developed model alludes to the value it may contribute to enhancing an understanding of extremely complex processes or phenomenon, such as HIV-related stigma. Pescosolido and Martin (2015, p. 96) support these ideas by asserting that HIV-related stigma is a multi-dimensional construct that is "more complex than either proponents or critics conceptualize." Such theoretic complexity draws on the importance of understanding complex processes and issues that affect child well-being, reinforcing the evaluative element of importance.

Importance centers around the question, "Does the model create an understanding that is important for a specific phenomenon or discipline?" (Chinn & Kramer, 2008). Aligned with its purpose, the study's findings indicate that the developed model provides an adequate understanding of HIV-related stigma and its influence on the psychosocial well-being of COA. The results indicate that the outlined purpose of the developed model is important to the field of health-related stigma and child well-being, specifically with regards to orphaned children. Such importance is expressed in the call for a more adequate understanding of HIV-related stigma that may guide future research and the development of interventions and programs that are geared towards addressing HIV-related stigma (Chi & Li, 2013; Florom-Smith & De Santis, 2012). A systematic review conducted by Chi and Li (2013) indicated that two studies included in the review utilized a theoretical framework to guide their analysis. As a result, Chi and Li (2013) recommended that future studies focusing on orphaned and vulnerable children be informed by adequate theoretical frameworks that guide the analysis and dissemination of findings. Similarly, Bos, Pryor, Reeder, and Stutterheim (2013) also identified the inadequate usage of theory and appropriate methodologies for the development of effective interventions. Consistent with this view, several studies (cf. Parker & Aggleton, 2003; Deacon, 2006; Misir, 2015; Pantelic, Sprague, & Stangl, 2019) have called for a more adequate and comprehensive understanding of HIV-related stigma for the effective reduction of HIV-related stigma and its associated outcomes for affected individuals.

While Pantelic and colleagues (2019) have alluded to the development of a model that moves beyond psychological frameworks to include social, structural, and intersectional conceptualizations of stigma, this model is grounded in a microlevel perspective to address the need of understanding HIV-related stigma with regards to the psychosocial well-being of COA. The developed model, therefore, offers an understanding specific to the experience and psychosocial needs and outcomes of COA. This purpose is similarly expressed by Chi and Li (2013) who have called for a theoretical or conceptual framework that may assist in either identifying or addressing the specific needs of children facing parental HIV-infection and bereavement. These ideas are supported by the study's findings, as experts have agreed that the model provides a general framework to predict phenomenon and is suitable to understand the subject area for which it has been developed. The high levels of consensus attained by these items allude to the model's potential to guide the development of future research and empirical evidence and inform future intervention adaption and development.

Evidently, experts have largely reached a consensus regarding the five elements of evaluation in terms of clarity, simplicity, generalizability, accessibility, and importance. Focal and related concepts are regarded as applicable, explicit, and well-defined in the developed model. These are accompanied by a structural description consistent with the narrative description of the developed model. Drawing from the evaluation, the model presents theoretic complexity aligned with the multifaceted nature of the included concepts of HIV-related stigma and psychosocial well-being. Despite theoretic complexity, the model remains comprehensible and simplistic to foster an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. Regardless of the mentioned theoretic complexity, the focal and related concepts are relevant for the discipline of HIV-related stigma and child well-being, and may, therefore, be widely applied by researchers and practitioners alike across a variety of settings. The model is important as it provides an evidence-based understanding of HIV-related stigma and how it affects the psychosocial well-being of COA, which is largely absent within the discipline.

8.5 Conclusion

This chapter provided a critical model evaluation presented as a modified Delphi technique following the suggested elements proposed in theory generative research designs. These conclusions are, therefore, drawn from expert consensus and previous studies. The social transactional model of HIV-related stigma and the psychosocial well-being of COA was considered by the experts to be clear, generalizable, accessible, and important. While the model displays theoretic complexity, it remains simplistic enough for understanding and application within the discipline of HIV-related stigma and child well-being. The next chapter presents a submitted manuscript which offers a summary of the stages of model development and the social transactional model of HIV-related stigma and the psychosocial well-being of COA.

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Chapter 9

A model to understand HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

9.1 Introduction

In the previous chapter, functionality of the social transactional model of HIV-related stigma and the psychosocial well-being of COA was examined through the implementation of a modified Delphi technique. The functionality of the model centered around five key elements, namely: (1) clarity, (2) simplicity, (3) generalizability, (4) accessibility, and (5) importance. This chapter presents the final publication (Article 3) of the dissertation which summarizes Phases III and IV, and provides a comprehensive overview of the developed model. The manuscript (Article 3) presented here reiterates the methodological design implemented in this study, followed by the model description and evaluation.

9.2 Publication details

Article 3 has been submitted for publication to *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, the details of which are presented in Table 9.1 below:

Table 9.16: Article 3 – Publication Details

Title	**A model to understand HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A theory generative approach**
Author	Yassin, Z., Erasmus, C. J., & Frantz, J. M.
Year	2020
Journal	SAHARA-J: Journal of Social Aspects of HIV/AIDS
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Issue	-
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Full citation	Yassin, Z., Erasmus, C. J., & Frantz, J. (2020). A model to understand HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A theory generative. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 1-33. (Submitted)

9.3 Journal overview

The *SAHARA-J: Journal of Social Aspects of HIV/AIDS* maintains a focus on disseminating research on the social factors relating to the HIV/AIDS pandemic. The journal's scope highlights stigma and discrimination as one such social aspect amongst others, such as care, support, behavioral change, counseling, culture, health communication, and environmental intervention. The journal is published under the Taylor and Francis publishing house on behalf of the Social Aspects of HIV/AIDS Research Alliance (SAHARA) that forms part of the Human Sciences Research Council in South Africa. This partnership seeks to conduct, support, and utilize social sciences research to prevent the spread of HIV and mitigate the impact of the HIV/AIDS pandemic in SSA. The journal aims to influence policy and responses to the HIV/AIDS pandemic through the dissemination of evidence-based research focusing on the social aspects of HIV/AIDS and provides a publication source for all aspects of HIV/AIDS in Africa.

9.4 Article submitted for publication

A model to understand HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A theory generative approach

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***Article has been submitted to** SAHARA-J: Journal of Social Aspects of HIV/AIDS*

Abstract

HIV-related stigma has negatively impacted the psychosocial well-being of children who have been orphaned by AIDS-related causes. Response to reducing stigma and ensuring child well-being is hindered by the limited understanding of HIV-related stigma and how it affects the psychosocial well-being of children. Due to the call for a comprehensive understanding of HIV-related stigma, this study aimed to develop a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS. The study implemented a mixed method, exploratory, sequential design within a theory generative approach that included concept development, statement development, model description, and model evaluation. The developed model indicated that HIV-related stigma is embedded in social interaction and mediated by children orphaned by AIDS response to stigma. HIV-related stigma and maladaptive coping strategies collectively affect several domains of child psychosocial well-being and elevates psychosocial distress. This is the first model to provide a child-centered understanding of HIV-related stigma and its consequences for psychosocial well-being. The model may be used to guide future research and inform the development of appropriate interventions.

Keywords: HIV-related stigma, children orphaned by AIDS, psychosocial well-being, model development, theory generative approach

Introduction

Stigma has been recognised as a key driver of the human immunodeficiency virus and the acquired immunodeficiency syndrome (HIV/AIDS) pandemic (Treves-Kagan et al., 2016). HIV/AIDS's association to premature mortality, debilitation, and behaviour deemed immoral and deviant within society has resulted in a second epidemic of HIV-related stigma that is both malicious and long-term (Link & Phelan, 2001; Parker & Aggleton, 2003; Treves-Kegan et al., 2016). HIV-related stigma has been defined as a social phenomenon by which an individual is considered to possess a discrediting attribute and thus deemed tainted, spoiled, or flawed by others (Stutterheim, Pryor, Bos, Hoogendijk, Muris, & Schaalma, 2009, p. 2354). The definition of HIV-related stigma offered by Stutterheim et al., (2009) draws on Goffman's (1963) conceptualisation of stigma. Goffman (1963) described three forms of stigma: (1) abnormalities of the body, such as deformations or physical signs of illness; (2) stigma associated with blemishes of the individual character, referring to individuals engaging in immoral activities or exhibiting immoral behaviour such as promiscuity or dishonesty; and (3) tribal stigma, which signifies the stigmatisation of an individual as a result of their membership to a social group or individual.

People living with HIV/AIDS (PLWHA) are likely to be subjected to experiences of HIV-related stigma, including prejudicial actions received from family members, colleagues, employers, health care providers, communities, and governments (Dahlui, Azahar, Bulgiba, Zaki, Oche, Adekunjo, & Chinna, 2015). While focus is maintained on the adult population, current evidence has suggested that HIV-related stigma stretches beyond infected individuals to exhibit a negative outcome for their families and children. This is supported by the increase in evidence focusing on the impact of HIV-related stigma on the well-being of children who have been orphaned by AIDS (COA) (Cluver, Orkin, Boyes, Sherr, Makasi, & Nikelo, 2013; Skovdal, 2012; Sherr, Cluver, Betancourt, Kellerman, Richter, & Desmond, 2014; Campbell, Skovdal, Mupambireyi, & Gregson, 2010).

The stigmatisation of COA by extended family, peers, communities, and health and social services has been documented consistently (Chi, Li, Zhao, & Zhao, 2014; Deacon & Stephney, 2007; McAteer, Truong, Aluoch, Deathe, Nyandiko, Marete, & Vreeman, 2016; Mo, Lau, Yu, & Gu, 2015; Zhao, Li, Zhao, Zhang, & Stanton, 2012). HIV-related stigma functions to undermine the well-being of COA leading to reduced access to support, increased poverty and exploitation, victimisation and bullying, poor mental health, and increased psychosocial distress (Campbell et al., 2010).

While there has been a global call for an adequate response to reduce HIV-related stigma, the phenomenon remains poorly understood (Stangl, Lloyd, Brady, Holland, & Baral, 2013). HIV-related stigma has long been regarded as culturally and contextually specific and too sensitive to be addressed in a meaningful may. Ogden and Nyblade (2005) suggest that HIV-related stigma shares common traits across diverse contexts and cultures presenting viable avenues for addressing HIV-related stigma through the development of appropriate interventions and programmes. Varying understandings of HIV-related stigma and the lack of an appropriate framework outlining the manner in which individuals are affected by their experiences of HIV-related stigma forms a significant barrier to understanding and adequately addressing HIV-related stigma to produce better outcomes for orphaned children (Genberg et al., 2009; Campbell & Gibbs, 2016). This study, therefore, aimed to develop a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of COA.

Process of Model Development

A mixed methods, exploratory, sequential design grounded in a theory generative approach was implemented for model development as undertaken in this study. The design followed the four stages of theory generation as proposed by Chinn and Kramer (2008), Walker and Avant (2011), and Dickoff, James, and Wiedenbach (1968), which includes: (1) concept development, (2) statement development, (3) model description, and (4) model evaluation.

Concept development

Concepts are the basic building blocks that form the fabric of a theory. A "concept" is defined as a "mental image of a phenomenon, an idea, or a construct in the mind about a thing or action" (Walker & Avant, 2005, p. 59). This study adopted a concept synthesis strategy as suggested by Walker and Avant (2005) for the (1) identification, (2) classification, and (3) defining of concepts.

Concept identification

Concepts were extracted from the first two empirical phases of the study, namely, (1) a systematic review (Yassin, Erasmus, & Frantz, 2018), and (2) a qualitative, exploratory, descriptive study (Yassin, Erasmus, & Frantz, 2019). The systematic review acted as a literary synthesis towards concept development and systematically reviewed existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of COA. From the meta-synthesis analysis undertaken, focal and related concepts were identified in the review to produce study findings. The findings of the review indicated that COA experienced four measures of HIV-related stigma, namely: enacted stigma, vicarious stigma, perceived stigma, and internalised stigma. COAs experiences of HIV-related stigma negatively influenced several domains of psychosocial well-being, including their psychological, social, and emotional well-being, self-concept and self-esteem, and future orientation. The complete methodological design and study's findings have been published elsewhere (Yassin et al., 2018). The findings of the review guided the qualitative, exploratory, descriptive study that constitutes the secondary empiric study, and acts as a qualitative synthesis as suggested by Walker and Avant (2008).

The objective of the qualitative, exploratory, descriptive study was to explore COAs perceptions and experiences of HIV-related stigma. The in-depth exploration served to further expand and refine focal and related concepts as distilled within the systematic review. The study conducted in-depth face-to-face interviews with 13 children between of the ages of 7 and 17 years. Data was transcribed and thematically analysed. The complete methodological design and study's findings have been published elsewhere (Yassin et al., 2019). The focal concepts and related concepts extracted from the qualitative findings were consistent with those identified during the meta-synthesis analysis. However, the findings of the qualitative exploration highlighted various coping strategies and the role of social interaction and perceived social support in mediating the impact of HIV-related stigma on the psychosocial well-being of COA.

The findings of the empiric studies were merged for further analysis. An iterative approach was implemented for the process of concept synthesis and involved the searching and clustering of words representing the phenomenon, until theoretical saturation was reached (Chinn & Kramer, 2008; Glasser & Strauss, 1967; Walker & Avant, 2005). A total of 24 concepts were identified. These were further refined through the amalgamation of clusters of concepts that overlapped considerably resulting in a total of six focal concepts: **enacted**

stigma, perceived stigma, internalised stigma, coping strategies, interpersonal relations, and psychosocial well-being. These focal concepts provided conceptual meaning and formed the basic tenets of the developed model. Additionally, horizontal themes evolving across the data set emerged during the analysis of the combined data set, contributing towards statement development. The focal concepts alongside the related concepts and horizontal themes are presented in Table 9.2 below.

Table 9.2 Focal and Related Concepts

Focal Concepts	Related Concepts	Horizontal Themes
Enacted stigma	• Overt Discrimination • Rejection • Exclusion • Victimization • Humiliation • Abandonment • Unfair treatment • Hostility • Gossip and insults directed at deceased parent/s	• Children orphaned by AIDS reported experiences of several manifestations of enacted stigma because of parental illness and death, regardless of their own HIV status. • Experiences of enacted stigma resulted in increased perceived stigma and psychological distress for children orphaned by AIDS. • Reported manifestations of enacted stigma included overt discrimination, hostility, rejection, exclusion, differential treatment compared to other children within the homestead, isolation, humiliation, abandonment by extended family members, gossiping about and name calling of deceased parent, and victimization.
Perceived stigma	• Shared perceptions of HIV-related stigma • Beliefs about the prevalence of HIV-related stigma	• Shared perceptions of HIV-related stigma, hearing or witnessing the stigmatization of others, and experiences of enacted stigma results in an increased perception of the prevalence and normativity of HIV-related stigma within the social environment or context of COA. • As a result of perceived stigma, COA become increasingly perceptive and fearful of enacted stigma directed at them, whether real or perceived.
Internalised stigma	• Self-blame • Shame	• Internalized stigma is presented by COA, as they internalize the negative views and beliefs of themselves as truthful and valid. • These negative beliefs are incorporated into their sense of self, as COA often feel ashamed and guilty, and identify as being tainted, dirty, unlovable, unwanted, a burden or a drain on society.

Coping strategies	• Problem-focused coping • Emotion-focused coping • Avoidant-coping strategies	• COA utilized coping strategies to avoid experiences of HIV-related stigma and/or deal with experiences of HIV-related stigma. • COA concealed their association to HIV/AIDS through a culture of non-disclosure of cause of parental death and illness (problem-focused coping) to prevent being stigmatized by others. • COA engaged in positive re-appraisal, presented a strong sense of faith, assigned external attributes as the reason for stigmatization, engaged in dis-identification with the stigmatized group and/or accepted their stigmatized social status (emotion-focused coping) to cope with experiences of stigmatization. • Children orphaned by AIDS self-isolated and withdrew themselves from others to avoid experiences of enacted stigma (avoidant-coping strategies).
Psychosocial well-being	• Psychological well-being • Emotional well-being • Social well-being • Self-esteem and self-concept • Future orientation	• COA reported increased levels of psychological distress, depression, and anxiety because of HIV-related stigma, indicating poor psychological well-being. • COA are unable to healthily express their feelings and concerns regarding stressful life events. As a result, they display a negative emotional status, including feelings of sadness, anger, fear, and guilt, indicating poor emotional well-being. • COA have poor interpersonal relationships. Due to avoidant-coping strategies, they are unable to form a healthy sense of intimacy with others, resulting in poor social well-being. • Poor social well-being limits COA opportunity to engage in self-esteem building actives and reappraisal through others. Additionally, internalized stigma affects the confidence, healthy self-concept and self-esteem COA, indicating lower levels of self-esteem and a poor self-concept. While COA remained optimistic about their futures, they lacked perceived control and hopefulness about their future goals and dreams. Additionally, COA lacked confidence to pursue their future goals, indicating poor future orientation.
Interpersonal relations	• Social support • Community • Interpersonal interaction with others	• HIV-related stigma occurs through interpersonal interaction between COA and other individuals such as family members, familial friends, and peers within a variety of social environments, for example, the homestead, community, school, etc. • Through interpersonal interaction, enacted stigma and public stigma may be conveyed, increasing COAs perception of HIV-related stigma and lowering their perception of social support that they may receive from others.

Concept classification

Focal and related concepts distilled from the empirical phases were classified using the survey list developed by Dickoff et al., (1968) that highlights six significant activity aspects, namely: (1) agency, (2) recipiency, (3) framework, (4) dynamics, (5) procedure, and (6) terminus.

- *Agency* refers to the individual performing an activity. In this model, *agents* are non-stigmatised individuals that are neither infected nor affected by HIV/AIDS, and include, for example, family members, peers, educators, medical staff, and community members. Agents direct overt discriminatory and hostile behaviours towards COA. Enacted stigma is categorised according to agency.
- The *recipient* refers to the individual/s receiving the activity. In this model, the recipients are children under the age of 18 who have lost one (single orphan) or both (double orphan) parents to AIDS-related causes. These children experience enacted stigma and become increasingly perceptive of HIV-related stigma. Orphaned children then internalise and accept the negative view of themselves. Enacted stigma, perceived stigma, and internalised stigma are categorised in terms of recipiency.
- *Framework* is the context in which an activity is performed. *Context* in terms of this model refers to the social environment in which both the recipients and agents are present, and include the homestead, organisational care settings, school settings, and local communities. Interpersonal relations are classified in terms of framework.
- *Dynamics* is the energy or power source of the activity, which may be physical, chemical, biological, or psychological. Both agents and recipients serve as an energy and power source in this model. Agents possess physical power as they engage in acts of overt discrimination and humiliation against the recipient. The recipient possesses both physical and psychological power sources as they experience and perceive

manifestations of stigmatisation and embody behavioural responses to these experiences. Enacted stigma and coping strategies are categorised in terms of dynamics.

- *Procedure* refers to general patterns, paths, or sets followed for the accomplishment of the goal. The procedure in this model unfolds within interpersonal interaction between the agent and recipient. It is through interpersonal interaction that COA may receive, experience, perceive, and respond to HIV-related stigma, resulting in poor psychosocial well-being. Interpersonal relations are categorised for procedure.
- *Terminus* or the end point of the activity is the stigmatisation and poor psychosocial well-being of COA through the process of interpersonal interaction between the agent and recipient. Through the process of interpersonal interaction between the non-stigmatised and stigmatised, measures of HIV-related stigma are directed at COA. Poor psychosocial well-being presented in COA is a cumulative result of their experience and perceptions of enacted, perceived, and internalised stigma. Psychosocial well-being is categorised in terms of terminus.

Defining of concepts

Adequate concepts are to be defined as they convey conceptual meaning and clarify the ideas and usages associated with the presented concepts (Chinn & Kramer, 2008; Walker & Avant, 2005). To define the concepts adequately, various sources, including dictionaries, subject textbooks, and published works were screened to fully understand the identified concepts. In this model, dictionary and subject-specific definitions were utilised to provide a synopsis of definitions contextually specific to the current model as suggested by Walker and Avant (2005). Consequentially, contextually specific definitions were created and assigned to focal concepts that were identified, categorised, and defined, and then placed in relation to each other through the development of relationship statements.

Statement development

Statements serve to specify the relationship/s between two or more concepts to provide structure that is central to the developed model (Walker & Avant, 2005). Furthermore, developed statements provide the ability to describe, predict, and explain the nature of the interactions between the focal concepts and are guided by the question, “what is the nature of the relationships?” (Chinn & Kramer, p.86). As statements may be derived from quantitative, qualitative, and literary methods, as proposed by Walker and Avant (2005), this study utilises a statement synthesis strategy that derives relationship statements from evidence emerging from the systematic review and qualitative exploration in combination with the survey list utilised for the categorisation of concepts. The relationship statements of the developed model are as follows:

- COA experience enacted, perceived, and internalised stigma. These experiences are facilitated by the stigmatised child’s interpersonal relations with other individuals within their social environment.
- There is a bidirectional relationship between enacted and perceived stigma. When children encounter enacted stigma, their experience of perceived stigma—the perception of the normativity and prevalence of stigmatisation associated with HIV/AIDS—is heightened. Perceived stigma is accompanied by increased enacted stigma, as the stigmatised child anticipates the experience of enacted stigma and becomes increasingly sensitive to the actions of others. Enacted and perceived stigma leads to internalised stigma—the incorporation of negative beliefs and views about the self that are regarded as valid and truthful by COA.
- Poor psychosocial well-being is the direct consequence of enacted and internalised stigma. Enacted stigma negatively affects the domains of psychological and social well-

being. Internalised stigma has detrimental outcomes for the domains of self-concept and self-esteem, and future orientation.

- In the absence of social support, negative outcomes associated with enacted, perceived, and internalised stigma are mediated by maladaptive coping strategies adopted by COA. These coping strategies are adopted to minimise and deal with the consequences of HIV-related stigma or avoid future experiences of enacted stigma.
- Poor psychosocial well-being is the accumulative outcome of enacted stigma, perceived stigma, experienced internalised stigma, and coping strategies adopted by COA.
- The psychosocial well-being of COA are comprised of five interconnected domains of well-being, which are negatively and uniquely affected by each other.

Model description

This description of the model provides an overview and centres around the six descriptive components proposed by Chinn and Kramer (2008), namely: (1) purpose, (2) concepts, (3) definitions, (4) relationships, (5) structure, and (6) assumptions of the social transactional model of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS. The six key questions identified by Chinn and Kramer (2008) further guided the description of the model, which facilitates a clear understanding of the nature and flow of the model for use in research and practice (Chinn & Kramer, 2008).

Overview of the model

The model serves as a framework for understanding the manner in which HIV-related stigma affects the psychosocial well-being of COA. Both interpersonal (enacted stigma) and intrapersonal (perceived and internalised stigma) measures of HIV-related stigma varied in the way they affected the psychosocial well-being of COA. The experiences and perceptions of

HIV-related stigma led to their use of maladaptive coping strategies—a mediator contributing to the poor psychosocial well-being exhibited by COA. Maladaptive coping strategies simultaneously provide protection against and relief of experiences of stigmatisation experienced by COA, while negatively affecting their psychosocial well-being. The model captures five core domains of psychosocial well-being, holistically encompassing the poor psychosocial well-being exhibited and described by COA. It is viewed as a social interactional model as it denotes that a child's interactions with their social environment (friends, family, and community) shapes their behaviour, development, and well-being. Therefore, the social transactional model of HIV-related stigma and the psychosocial well-being of COA consisted of three stages in which HIV-related stigma acts to affect psychosocial well-being, namely (1) experiences, (2) responses, (3) and outcomes. A graphical representation of the social transactional model of HIV-related stigma and the psychosocial well-being of COA is presented in Figure 9.1 further below.

Purpose of the model

Watson (1985) proposes that theory is generated to enhance the understanding of a given phenomenon. Aligned with Watson (1985), this model serves a theoretic purpose as it provides a framework that enhances the understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. The model fosters an understanding of two sources of phenomenon and its relation to one another—related stigma and the psychosocial well-being of COA.

Context of the model

The *context* of the model is any social environment in which COA are present, such as the homestead, school, health facilities, and local and surrounding communities. While the model was developed within the South African context, it was based on national and international empirical findings. From a cultural perspective, the model may be applicable in various contexts, which includes individuals from diverse ethnic and cultural backgrounds.

Assumptions of the model

Assumptions of the model are regarded as the basic givens or truths that are accepted and assumed to be factual (Chinn & Kramer, 2008), and that influence the structure and conceptualisation of the model (Chinn & Kramer, 2004). The assumptions of the social transactional model of HIV-related stigma and the psychosocial well-being of COA are described below:

- Stigmatisation is a social construct embedded within the social environment of COA and is dependent on the process of dyadic social interaction occurring between COA and non-stigmatised individuals. It is through dyadic social interaction that the cultural and social understandings of HIV-related stigma are conveyed and enacted.
- COA acutely experience HIV-related stigma as a result of their association with parental HIV/AIDS and are awarded the same discredited identity as their parents.
- COA experience both interpersonal and intrapersonal forms of stigma. Interpersonal forms of HIV-related stigma are represented by social interaction between COA and others that is characterised by discrimination, rejection, and hostility. Intrapersonal forms of HIV-related stigma represent COAs psychological and internal experience and response to HIV-related stigma.
- COA experience various components of HIV-related stigma that are both interrelated and interdependent, including enacted stigma, perceived stigma, and internalised stigma.

- Each component of HIV-related stigma uniquely contributes to poor psychosocial well-being and psychosocial distress among COA. These components of HIV-related stigma may, directly or indirectly, via maladaptive coping strategies, negatively affect the psychosocial well-being of COA.
- The various domains of psychosocial well-being of COA, such as the psychological, social, and emotional well-being, self-esteem and self-concept, and future orientation, are affected.
- Domains of psychosocial well-being are codependent and interrelated, as a change in one domain results in a change in another, resulting in overall poor psychosocial well-being.

Definitions of key concepts

Definitions have been developed to provide conceptual meaning and clarity to focal concepts which formed the basic building blocks of the social transactional model of HIV-related stigma and the psychosocial well-being of COA.

Enacted stigma

Enacted stigma within the context of this model refers to the interpersonal aspect of stigmatisation as it occurs within the social interaction or communication between stigmatised and non-stigmatised COA and other individuals within their social environment. Enacted stigma is regarded as the experience of overt discrimination, humiliation, and rejection of an individual because of his/her devalued status resulting from their association with HIV/AIDS.

Perceived stigma

Perceived stigma refers to the intrapersonal aspect of stigmatisation drawing on the perceptive reality of an individual, thus being regarded as an individual’s subjective awareness of HIV-related stigma. This awareness includes their perceptions and beliefs regarding the normativity and prevalence of stigmatising beliefs, behaviours, and attitudes held by the community about HIV/AIDS and those infected and affected by HIV/AIDS. In essence, perceived stigma presents a stigmatised individual’s expectation or anticipation of experiencing stigmatisation from others.

Internalised stigma

Internalised stigma, also commonly known as self-stigma, is the intrapersonal aspect of stigmatisation. Internalised stigma denotes the acceptance of stigmatising beliefs and values, which are regarded as truthful and valid by stigmatised individuals, in this case, COA. These accepted beliefs and values are incorporated into the self and manifested as feelings of guilt, shame, unworthiness, and the view of oneself as being unworthy, dirty, or a drain on society. Two main related concepts—self-blame and shame—are also defined. Janoff-Bulman’s (1979) conceptualisation of characterological self-blame, which is esteem related, serves to offer an adequate conceptualisation of the related concept ‘self-blame.’ Here, self-blame is attributed to one’s character and is associated with one’s belief that past negative outcomes is a result of personal deservingness. The related concept “shame” represents an internal state of regret, dishonour, or inadequacy. COA often express shame because of their devalued social status and being associated with HIV/AIDS, which is regarded as taboo within social and cultural settings. The experience of internalised stigma, self-blame, and shame is evidenced by a poor sense of self.

Coping strategies

Coping strategies is a process whereby stigmatised individuals adopt complex affective, behavioural, and cognitive responses to successfully deal with stressors and negative life experiences. The manner in which stigmatised individuals adopt these coping strategies are relatively stable and consistent over time. Stigmatised individuals attempt to mitigate the negative impact of HIV-related stigma through the adoption of various coping strategies. These coping strategies are identified as the related concepts of: (1) emotion-focused coping, (2) avoidant-coping, and (3) problem-focused coping. *Problem-focused coping* strategies seek to alter the relationship between stigmatised individuals and their social environment and may be directed at oneself, others, or the presented situation. Generally, these strategies are aimed at problem solving and may include non or selective disclosure, compensation, activism, social support, or disengagement. Alternatively, *emotion-focused coping* refers to strategies that seek to regulate negative emotions and strive towards reducing or managing the emotional distress accompanied by stressful situations or cues. These strategies include downward spiral comparisons and external attributions for stigmatising behaviours, like the ignorance and denial of others, dis-identification, and the positive reappraisal of experiences. Lastly, *avoidant-coping* refers to the cognitive and behavioural efforts of the stigmatised individuals to avoid or minimalise dealing with stressors and negative situations, such as withdrawal or isolation.

Interpersonal relations

Interpersonal relations are the social environments in which stigmatised individuals exist and function. In this sense, interpersonal relations extends beyond the social environment in which the individual is present to include social interaction between the stigmatised individual and non-stigmatised individuals, such as family, friends, community members, service providers, and others present within the social environment. Through social interaction in the social environment, HIV-related stigma is extended, directed at, or conveyed to COA.

Psychosocial well-being

Psychosocial well-being is the holistic functioning and well-being of a child, which encompasses the domain of psychological well-being and includes social and emotional well-being, self-esteem and self-concept, and future orientation, which reflects the thoughts, behaviour, and an individual's reactions towards their social environment. Five domains of psychosocial well-being were defined for a comprehensive understanding of the focal concept as applied within this study. *Psychological well-being* is a multidimensional concept that centres on the mental health or state of an individual, and is developed through life experiences, personal identity, and emotional regulation. In the context of this study, poor psychological well-being is represented by depression, anxiety, and post-traumatic stress. *Emotional well-being* is closely related to psychological well-being and refers to positive or negative effects. In the context of this study, emotional well-being refers to the emotional affect of the stigmatised individual, which is negatively affected by psychological distress. Poor *emotional well-being,* in this study, is detected by the presence of poor emotional regulation and a negative emotional status presented by the stigmatised individual. *Self-concept* and *self-esteem,* affected by emotional well-being, presents a way to think about oneself, and refers to the conscious reflection of an individual regarding their being or identity that remains separate from the environment and others. *Self-concept* refers to a multifaceted system of learned beliefs, attitudes, and opinions, which are regarded as true by the stigmatised individual about their personal existence. Self-concept is associated with *self-esteem*, which presents the affective or emotional aspect of the self, or the way an individual feels about and values themselves. In the context of the study, individuals are mutually dependent upon their social environment; therefore, *social well-being* refers to social inclusion, a sense of belonging, and the interpersonal relationships held with others. Stigmatised individuals who are socially excluded, rejected, and unable to form healthy interpersonal relationships with others, display poor social well-being. Lastly, the related concept *future orientation* broadly refers to the extent that an individual thinks about their future and includes optimism, hopefulness, and perceived control over the future.

Model structure

The structure of the social transactional model of HIV-related stigma and the psychosocial well-being of COA consists of three linear stages according to the identified focal concepts, which facilitates a discussion and explanation of the interaction between focal concepts and stages of the model. The description of the structure of the model as presented here corresponds with the graphical representation of the model presented in Figure 9.1 below[12].

The stages of the model are illustrated by the letter "S" to represent the word "stage," i.e. stage one is presented as "S1: Experiences." The numbering of the stages is significant as it depicts the linear structure of the model, while their positioning within a vertical downward pointing arrow suggests movement from HIV-related stigma to psychosocial well-being, indicating the linear progression of the stages. Focal concepts are depicted by the letter "F," such as "F1" for enacted stigma. Unlike the stages presented in the model, the numbering of focal concepts holds no significance, as concepts are rather iterative, involving bidirectional and linear relationships. Focal concepts are presented in bold text to draw attention to the importance of main concepts, setting them aside from related concepts. Related concepts attached to focal concepts that facilitate understanding of the model are included in plain italicised text underneath the presented focal concepts.

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[12] Figure 7.2 is repeated in the article submitted for publication in Chapter 9. (It is renumbered Figure 9.1 for the purpose of the chapter).

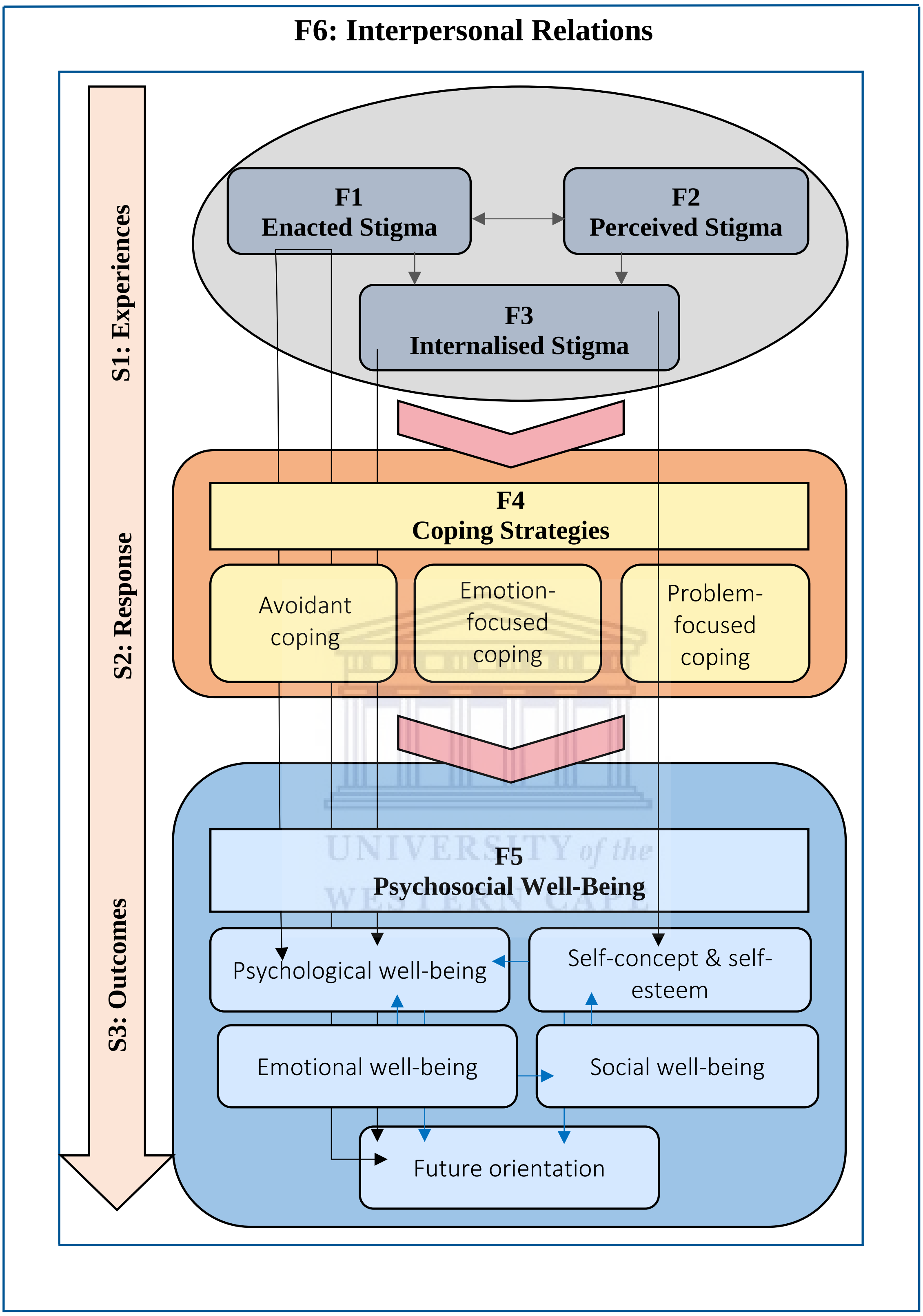

Figure 9.1: The Social Transactional Model of HIV-related Stigma and the Psychosocial Well-being of COA

Interpersonal relations (F6) encapsulated the experiences, responses, and psychosocial outcomes for COA. Interpersonal relations represent the social environment in which COA exist and function, affecting them throughout the three stages of the model. The social environment in the context of this study comprises the homestead, school, community, health care facilities, and local organisations. For the process of stigmatisation to unfold, social interaction between the stigmatised child and non-stigmatised individuals—referred to as mixed contact in the social environment—needs to be present (Goffman, 1963). Forms of mixed contact would include interaction between stigmatised orphaned child and family members, friends, children within the surrounding community, educational staff, community members, health service providers, and organisational staff. While it is envisioned that interpersonal relations would be present throughout the model, it is most influential during stage one as stigmatisation is extended to or perceived by COA through mixed contact. Interpersonal relations, or rather the absence thereof, perpetuates poor psychosocial well-being and the adoption of maladaptive coping strategies by COA.

Stage One: Experiences

During stage one (S1), COA experience both interpersonal and intrapersonal forms of stigmatisation, conveyed through the process of social interaction within their social environment. **Enacted stigma (F1),** an interpersonal form of HIV-related stigma, is characterised by overt discrimination and hostility resulting in social exclusion, placing COA at a disadvantage (Major & O’Brien, 2005). Manifestations experienced by COA include rejection, hostility, exclusion, ill or unequal treatment, devaluation, victimisation, exploitation, and abuse. There is a direct relationship between **enacted stigma (F1), psychosocial well-being (F5)** and intrapersonal forms (F2, F3) of stigma. Firstly, the direct relationship between enacted stigma and psychosocial well-being is presented by black vertical arrows pointing towards the domains of **psychosocial well-being (F5)** that are negatively affected. Experiences of enacted stigma inhibits the *psychological well-being* of COA, increasing their levels of distress and the formation of psychopathological symptoms, such as depression, anxiety, adjustment problems, post-traumatic stress, fear, and distress. Enacted stigma leads to the obstruction of formal education and educational access. Such obstruction coupled with the presence of overt discrimination within the schooling environment, negatively affects future orientation, as COA present a lack of optimism, confidence, and perceived control over their future.

There is a bidirectional relationship between **enacted (F1)** and **perceived (F2)** stigma as presented by a double arrow between the two focal concepts. Firstly, as children experience enacted stigma, they become increasingly aware of HIV-related stigma. This contributes to the development of **perceived stigma (F2),** which is regarded as the belief about the prevalence and normativity of HIV-related stigma within one's environment. Secondly, psychopathological symptoms ensued from enacted stigma predicts perceptions of discrimination—perceived stigma (Major & O'Brien, 2005)—as children with internalising problems are increasingly sensitive and perceptive to stigmatising behaviours, increasing experiences of enacted stigma over time. Perceived stigma fails to directly affect the psychosocial well-being of COA, but like enacted stigma contributes to the development of **internalised stigma (F3).** The arrows pointing towards internalised stigma (F3) from enacted and perceived stigma indicate this relationship.

Internalised stigma (F3), a product of enacted and perceived stigma, is the internalised belief of being devalued and tainted and results in feelings of self-hatred, guilt, inferiority, as well as shame and embarrassment for COA. Internalised stigma inhibits psychosocial well-being, specifically the *self-concept* and *self-esteem,* and *psychological well-being* of COA. COA hold a negative view of themselves and lack self-esteem and confidence because of their belief that they are devalued, consequentially resulting in distress and psychopathological symptoms.

Stage Two: Response

Stage two (S2) focuses on COAs response to HIV-related stigma and its related distress and negative affect. Experiences of HIV-related stigma is followed by **coping strategies (F4)** and is presented by a horizontal downward chevron. "Coping strategies" is labelled "F4" and has three related concepts: (1) *avoidant-coping*, (2) *emotion-focused coping*, and (3) *problem-focused coping*, which are represented by three smaller rounded rectangles. These related concepts are illustrated by smaller yellow boxes and are encapsulated by the focal concept "coping strategies" (F4). **Coping strategies (F4)** include behavioural and psychological responses to stressful events, such as interpersonal and intrapersonal forms of stigmatisation, and are used either alone or in combination. Both avoidant and problem-focused coping strategies are behavioural responses to HIV-related stigma and affects psychosocial well-being. *Avoidant-coping strategies* involve disengagement, presenting the social withdrawal and self-isolation of COA to avoid experiences of enacted stigma. Disengagement exacerbates psychological distress, bringing about loneliness and actively undermines the healthy development of meaningful social relationships and networks (Schibalski et al., 2017). Problem-focused coping, which is fuelled by perceived stigma, involves secrecy, selective disclosure, and non-disclosure of the cause of parental bereavement (Stutterheim, Bos, Shiripinda, de Bruin, Pryor, & Schaalma, 2012). In addition, these coping strategies prohibit the formation of healthy relationships and reduces the opportunity for COA to healthily express their feelings and discuss stressful life events. *Emotion-focused coping* is a psychological response to HIV-related stigma and aims to reduce negative emotional responses to stigma. COA are rather avoidant of healthily expressing their feelings and suppress the negative feelings associated with enacted, perceived, and internalised stigma. The coping strategies adopted by COA are rather maladaptive and despite their use for defending against HIV-related stigma and emotional responses, negatively affect their psychosocial well-being. The impact of coping strategies on psychosocial well-being is illustrated by a horizontal downward chevron representing the progression from coping strategies towards the psychosocial well-being of COA.

Stage Three: Psychosocial well-being

Stage three (S3) presents the progression of COAs experiences and responses of HIV-related stigma to its associated outcomes for psychosocial well-being, presented by a horizontal downward chevron. Through experiences of HIV-related stigma and the adoption of maladaptive coping strategies, the **psychosocial well-being (F5)** of COA are negatively affected. Psychosocial well-being is regarded as the holistic well-being of COA, which included their psychological, emotional and social well-being, self-esteem and self-concept, and future orientation. These domains of psychosocial well-being reflect COAs thoughts, behaviours and reactions towards their social environment and others. Psychosocial well-being is presented by a rounded rectangle presenting the holistic psychosocial well-being of a COA. The rounded rectangle consists of a smaller regular rectangle set above five smaller rounded rectangles. The smaller regular rectangle presents the focal concept '**psychosocial well-being' (F5),** while the smaller rounded rectangles below present related concepts forming the psychosocial well-being, namely, *psychological well-being, social well-being, emotional well-being, self-concept and self-esteem,* and *future orientation.* The order in which related concepts are presented hold no relevance as the dimensions are interconnected, related, and influence each other. The relationship between the related domains of psychosocial well-being are indicated through the use of blue arrows pointing in the direction of the affected domain.

Enacted stigma (F1) negatively affects the psychosocial well-being of COA. Experiences of enacted stigma acts to increase psychological distress, contributing to the development of internalising and externalising disorders, such as anxiety, depression, PTSD, and aggressive and risk-taking behaviours. The self-isolation and social withdrawal of COA (*avoidant-coping strategies*) to prevent future experience of HIV-related stigma contributes to the psychological distress and suffering of these children, exacerbating poor *psychological well-being*. Similarly, the *future orientation* of COA is negatively affected by the disadvantage cultivated by **enacted stigma (F1)**, manifesting as actions of overt discrimination and rejection. COA are stripped of their resources, treated unfairly, and discriminated against, both within the homestead and the schooling environment, resulting in school dropout. Without scholastic knowledge and social support, a child orphaned by AIDS lacks optimism, confidence, and perceived control over their future. There is also a direct relationship between *psychological well-being* and *future orientation,* presented by a solid blue arrow leading from psychological well-being towards future orientation. Poor psychological well-being leads to poor future orientation for COA.

Perceived stigma (F2) causes a child orphaned by AIDS to embody a culture of secrecy, non-disclosure, or selective disclosure of the cause of parental death. The use of *problem-focused coping strategies* to conceal the cause of parental death actively limits a child's ability to form healthy interpersonal relationships, which are essential for receiving the social support necessary to cope with stressful life events. Therefore, perceived stigma indirectly negatively affects the *social well-being* of COA through their use of *problem-focused coping*. A direct relationship exists between *social well-being, self-concept and self-esteem,* and is presented by a solid blue arrow. Poor *social well-being* exhibited by a child orphaned by AIDS restricts their opportunity to engage in self-esteem enhancing activities that occurs through their social interaction with others. Through minimal interpersonal engagement COA cannot receive self-validation from others, resulting in a poor *self-concept* and lower levels of *self-esteem* as they lose confidence in themselves and their capabilities. Non-disclosure and secrecy prohibits an orphaned child from healthily expressing their emotions and concerns about stressful events, contributing to poor *emotional well-being*.

S*elf-esteem and* the *self-concept* are similarly affected by **internalised stigma (F3)**. COA hold a negative view of themselves as being devalued, tainted, and dirty. This not only presents the poor self-concept embodied by COA, but also represents their psychological suffering. A solid blue arrow signifies the relationship between *poor self-concept and self-esteem,* and *psychological well-being*. A poor self-esteem cultivates a lack of confidence in a stigmatised child, ultimately negatively influencing their *future orientation*.

Consequentially, all forms of HIV-related stigma results in emotional distress for COA, negatively affecting their *emotional well-being*. To efficiently deal with and minimise emotional distress, COA adopt *emotion-focused coping strategies* likely to hinder healthy emotional regulation and reinforce a negative emotional status. In the absence of social support and healthy interpersonal relationships combined with experiences and perceptions of HIV-related stigma, these children are unable to healthily express themselves and continue to suppress their emotions, leading to poor emotional regulation and a negative emotional status, indicating poor *emotional well-being*. *Emotional well-being* directly affects *psychological well-being,* perpetuating psychological distress and internalising psychopathological symptoms. A solid blue arrow directed towards psychological well-being indicates this direct relationship.

Model evaluation

A modified Delphi technique was implemented to evaluate the developed model and assess the functionality of the social transactional model of HIV-related stigma and the psychosocial well-being of COA. The functionality of the model was assessed according to the points of critical reflection outlined by Chinn and Kramer (2008), including (1) simplicity, (2) clarity, (3) generalizability, (4) accessibility, and (5) importance. These points seek to contribute to an understanding of how well a developed model relates to practice, research, and/or educational activities (Chinn & Kramer, 2008).

Fourteen experts indicating a 40% response rate critically evaluated the model. The majority of participants (78.57%) resided in South Africa, followed by Zimbabwe (7.14%), England (7.14%), and Dubai (7.14%). Eight participants (57.14%) were male with the remaining six participants (42.86%) being female. More than half of the participants (64.29%) indicated that they had a background in psychology, followed by backgrounds in social work (28.57%) and nursing (7.14%). Participants (57.14%) were academic staff members at institutions of higher education, directors (14.28%) of university centres, and practitioners (14.28%) (one was a psychologist and another a social worker). The remaining two participants were an organisational member and a postgraduate student, respectively. While participants' occupations remained heterogeneous in nature, they unanimously maintained a key interest in health-related stigma, HIV/AIDS, and child well-being.

The panel of experts reached consensus for each point of critical reflection as proposed by Chinn and Kramer (2008), thus indicating that the developed model is simplistic, clear, generalisable, accessible, and important. The model is therefore regarded as functional and satisfies the 6-point criteria of critical reflection outlined within the theory generative approach.

Conclusion

The social transactional model of HIV-related stigma and the psychosocial well-being of COA provides an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. It contributes to the empirical body of knowledge and is the first known model to provide an understanding of HIV-related stigma that is specific to orphaned children and their well-being. It is envisioned that the developed model would guide future research focusing on children in the context of HIV/AIDS. Considering the unique understanding of HIV-related stigma with regards to children, the model may assist with future research studies focusing on the impact of HIV-related stigma on COA and the dissemination of findings. The understanding conveyed by the model would allow for child specific strategies geared towards HIV-related stigma reduction to be appropriately developed and implemented. Furthermore, interventions geared towards equipping COA with healthy coping strategies to lessen the impact of HIV-related stigma on their psychosocial well-being needs to be implemented. As a multidisciplinary approach was used to develop the model, it is accessible and understandable to all disciplines interested in understanding the impact of HIV-related stigma on the psychosocial well-being of COA. The model would enable both policy makers and practitioners to understand COAs experiences of HIV-related stigma and aid the establishment of policies and legislation that addresses the unique needs of COA, affording them sufficient protection against adverse effects and adequate policies addressing their psychosocial needs and challenges. While the developed model makes a noteworthy contribution, it has not been scientifically tested. Therefore, further research assessing the validity of the model is needed.

Compliance with Ethical Standards

Conflict of interest

The authors declare that they have no conflict of interest.

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Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of the Western Cape and with the 1964 Helsinki declaration and its later amendments and comparable ethical standards. The study was approved by the University of the Western Cape's Human and Social Sciences Research Ethics Committee under ethics reference number HS17/1/17.

Informed consent

Informed consent was obtained from all individual participants included in this study.

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9.5 Conclusion

This chapter presents the last article (Article 3) of the dissertation, fulling the requirement for a doctoral thesis by publication. Article 3 draws on evidence presented through the eight chapters within the dissertation and explicitly outlines the theory generative approach as undertaken in Phases III and IV towards model development. Furthermore, Article 3 presents the graphical and narrative description of the social transactional model of HIV-related stigma and the psychosocial well-being of COA. The next chapter serves to conclude the dissertation by presenting a summary of the study's methodological aspects and findings, including the limitations of the study, followed by recommendations for research, practice, and policies and programs.

Chapter 10

Summary, Limitations and Recommendations

10.1 Introduction

This chapter serves to conclude the dissertation by discussing the key findings of each phase of the study. The summary part outlines the main objective of each phase, each phase's contribution to the development of the ***social transactional model of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS,*** and their related key findings. This is followed by a presentation of the limitations of the study and recommendations for research, policy, and practice, and a final conclusion section that closes the chapter.

10.2 Summary

This study found that the HIV/AIDS pandemic has consistently been recognized as inhibiting the healthy development, well-being, and survival of children both infected and affected by the virus. Overwhelming research has alluded to the displacement and orphaning of children due to the pandemic, exposing children to psychosocial stressors. The focus on AIDS-related orphanhood in particular has gained popularity over the past decade, dominating research fields focusing on child health and well-being. AIDS-related orphanhood is associated with varying degrees of loss and imposes financial, material, and social stressors on COA. Despite these stressors, one noteworthy risk factor separating COA from other groups of orphaned children is their perceptions and experiences of HIV-related stigma. The stigmatization and discrimination resulting from parental AIDS-related illness and death introduces a differing dynamic to the orphaning experience for COA, by producing increased marginalization and the layering of stigma. COAs experience of HIV-related stigma along with other stressors inhibits their psychosocial well-being. While easily stated, it is important to recognize the complex and multifaceted nature of the concepts of HIV-related stigma and psychosocial well-being. Both of these concepts hold varying connotations and are context specific. However, due to its complex nature, the need to comprehensively understand HIV-related stigma and its influence on the psychosocial well-being of COA is needed. This study therefore set out to foster a compressive understanding of the phenomenon with the overall aim of this study being to develop a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS. The aim of this study was achieved through the satisfaction of the study's objectives, which were to:

1. Systematically review existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS.
2. Explore children orphaned by AIDS perceptions and experiences of HIV-related stigma.
3. Develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS.
4. Determine the functionality of the developed model through the use of the Delphi technique.

The results of this study are discussed below according to the associated Phase and related objectives of the study.

10.2.1 Phase 1 (Chapter 4): HIV-related stigma and the psychosocial well-being of children orphaned by AIDS: A systematic review

Phase I of this study was employed to satisfy the first objective of this study, which was to “systematically review existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS,” achieved through the implementation of a systematic review methodology. The review was guided by the research question, “what are the effects of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS?” The review, regarded as pivotal for concept development, served as a literary synthesis by identifying and expanding concepts upon which the developed model was based. Phase I informed the qualitative exploration carried out in Phase II by informing the development of an interview guide to facilitate the exploration of concepts and the development of relationship statements.

The identified studies found that COA experienced and perceived greater levels of stigmatization and discrimination than other groups of orphaned and vulnerable children due to their association with HIV/AIDS. COA were found to experience HIV-related stigma regardless of their HIV-status, socio-economic status, and other key demographic characteristics.

Four measures of HIV-related stigma experienced by COA emerged, namely, enacted, vicarious, perceived, and internalized stigma, which manifested in a variety of ways and depended on the environment in which COA found themselves. Stutterheim and colleagues (2009) postulated that the impact of specific manifestations of HIV-related stigma on the psychological health of PLWHA in specific settings remains largely unexplored. Considering these findings, it is argued that HIV-related stigma needs to be recognized as a multifaceted concept whose conceivability depends on the socio-economic and cultural environment in which it is experienced and/or perceived.

While measures of HIV-related stigma appeared characteristically different, they remained interconnected and interdependent, and the findings of this review highlighted a connection between measures of HIV-related stigma. The presence of one measure of HIV-related stigma was likely to contribute towards the development, reinforcement, and sustainment of other measures of HIV-related stigma. Enacted and vicarious stigma sought to increase perceived stigma. Collectively, these measures resulted in experiences of internalized stigma among COA. The findings disseminated by Chi et al., (2014) were consistent with that of the current review and they recognized the longitudinal and bidirectional relationship between enacted and perceived measures of stigmatization. These authors further postulated that in the presence of perceived stigma, COA are likely to be more susceptible to experiencing the actions and judgements of others as stigmatizing and discriminatory (Chi et al., 2014).

Mirroring the unique characteristics of HIV-related stigma, measures of HIV-related stigma were identified to uniquely affect the psychosocial well-being of COA. Several domains of psychosocial well-being of COA were negatively influenced by measures of HIV-related stigma which include psychological-, social-, and emotional well-being, self-concept and self-esteem, and future orientation. Enacted stigma was strongly found to directly affect the psychological domain of psychosocial well-being, while internalized stigma acted to influence the self-esteem and self-concept of COA. Measures of HIV-related stigma indirectly affected the psychosocial well-being of COA through the adoption of maladaptive coping strategies. Specifically, non-disclosure strategies mediated the influence of perceived stigma, resulting in diminished psychosocial well-being among COA. Non-disclosure strategies attained the tendency to restrict the social support structures available to COA while limiting their engagement or participation in social activities. Other coping strategies involved self-isolation and withdrawal from participating in social activities. These strategies were identified as restricting COAs opportunity to engage in self-esteem enhancing activities vital for the preservation of the self-concept and self-esteem.

The review highlighted the pivotal role of social support for the establishment of social and material resources available to COA when dealing with traumatic events. An included study by Harms, Jack, Ssebunnya, and Kizza (2010) suggested that COA reported a culture of non-stigmatization in the presence of perceived social support received from family members and peers. Social support structures available to COA are, therefore, able to diminish experiences of HIV-related stigma and its influence on their psychosocial well-being. Casale and colleagues (2019) asserted that social support might be a significant protective factor able to moderate the influence of HIV-related stigma on the psychosocial well-being of adolescents.

The findings outlined above indicates that the review undertaken in Phase I has satisfied the first objective "to systematically review existing literature focusing on the relationship between HIV-related stigma and the psychosocial well-being of children orphaned by AIDS," and also answered the research question, "what are the effects of HIV-related stigma on the psychosocial well-being of children orphaned by AIDS?" Evidently, HIV-related stigma is composed of four measures of stigma that uniquely operate to diminish healthy psychosocial well-being among COA. Experiences and perceptions of HIV-related stigma has resulted in poor psychological health, diminished emotional and social well-being, a poor self-concept, lower levels of self-esteem, and lower levels of optimism, hopefulness, and perceived control over the future among COA. The findings of this phase were used to guide and inform the qualitative exploration in Phase II and contribute towards concept and statement synthesis as undertaken in Phase III, respectively.

10.2.2 Phase II (Chapter 5): Qualitative exploration of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

Phase II of this study achieved the second objective of the study, which was "to explore children orphaned by AIDS perceptions and experiences of HIV-related stigma," and also answered the research question, "how do children who have been orphaned by AIDS perceive and experience HIV-related stigma?" The objective and research question in Phase II were achieved through the implementation of a qualitative, exploratory, descriptive study. An in-depth exploration was undertaken to deeply engage with and understand COAs experiences and perceptions of HIV-related stigma concerning their psychosocial well-being. In doing so, Phase II expanded the findings outlined in Phase I and a qualitative approach to concept synthesis was deemed appropriate. Phase II contributed towards the development of concepts and relationship statements underpinning the model as outlined in Phase III.

In-depth face-to-face interviews conducted were thematically analyzed. Three key themes emerged from the data: COA experiences of stigma; COA perceptions of HIV-related stigma; and the influence of HIV-related stigma on the psychosocial well-being of COA. These themes largely reinforced the findings extracted during Phase I, coining enacted, perceived, and internalized stigma—core concepts upon which the model was based. COA spoke extensively about their experiences and perceptions of HIV-related stigma, regardless of their gender, age, level of formal education, and living arrangements. Enacted stigma was predominantly reported by COA as they described instances of differential treatment, abandonment, abuse and bullying victimization enacted by family members and peers. These experiences resulted in an increase in perceived stigma and internalized stigma. Notably, despite the variation in manifestation of HIV-related stigma, COA attributed feelings of psychological distress to their experiences and perceptions of HIV-related stigma.

Significantly, the narratives of COA drew attention to the mediating role of maladaptive coping strategies and the process of social interaction. While both maladaptive coping strategies and social interaction independently affect the psychosocial well-being of COA, they remain interlinked to produce an incremental negative outcome for child psychosocial well-being. Sandstrom and Dunn (2014) suggests that daily social interaction and interpersonal relationships held with others are related to the social and emotional well-being of individuals. These findings support the view that HIV-related stigma occurs through "mixed contacts," plainly known as social interaction with others, negatively influencing the psychosocial well-being of COA. Moreover, social interaction characterized by HIV-related stigma resulted in COAs adoption of maladaptive coping strategies, such as self-isolation, withdrawal, non-disclosure, and secrecy, as previously suggested by Bos, Pryor, Reeder, and Stutterheim (2013). These coping strategies further limits received social support and diminishes healthy interpersonal relationships held by COA, which are perceived as valuable resources for ensuring the psychosocial well-being of COA. The statement by Doku, Dotse, and Mensah (2015), that received social support is a protective factor and an effective resource, and attains the ability to reduce psychosocial distress and enhance the coping skills of COA, supports the above findings.

Notability, the findings of Phase II are similar in nature to those presented in Phase I, while placing continuing emphasis on the mediating role of coping strategies and interpersonal relationships held by COA. The similarity in findings affirms the sentiments held by Deacon (2006) that HIV-related stigma is a universal concept experienced by those affected and infected by HIV/AIDS, despite its variations in manifestation, appearance, or expression. While the variation in the manifestation of HIV-related stigma—which is dependent on cultural and national settings—has resulted in difficulties for defining and measuring HIV-related stigma (Mahajan et al., 2008). The triangulation of findings resulted in the identification of common meanings assigned to HIV-related stigma and several common forms of manifestation transcending culture and location. The findings of Phase II led to the development of horizontal themes across the findings of Phases I and II, and the further expansion, development, and identification of focal and related concepts and relationship statements, as explored in Chapters 6 and 7. During Phase II, the second objective of the study—"to explore children orphaned by AIDS perceptions and experiences of HIV-related stigma"—was realized, and the research question "how do children who have been orphaned by AIDS perceived and experience HIV-related stigma and the manner in which it has affected their psychosocial well-being?" was answered. COA experienced enacted, perceived, and internalized stigma. These perceptions and experiences of HIV-related stigma have negatively affected the psychosocial well-being of COA, either directly or indirectly through limited social support and maladaptive coping strategies. COA reported poor psychological, emotional, and social well-being while displaying a poor-self-concept and lower levels of self-esteem.

10.2.3 Phase III (Chapters 6 and 7: Model development)

Phase III achieved the third objective of the study, which was "to develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS," and also answered the research question, "what factors should be considered for the development of a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS?" This was accomplished through the implementation of a theory generative design, using a concept and statement synthesis strategy. This design served to highlight factors that precede or influence HIV-related stigma; indicate the manner in which HIV-related stigma affects the psychosocial well-being of COA; and categorize discrete and scientific information as extracted in Phases I and II into a theoretically organized form. Model development was further separated into four stages, namely: (1) concept synthesis, (2) statement synthesis, (3) model description, and (4) model evaluation. The first three stages of model development were completed within Phase III, and presented in Chapters 6 and 7, respectively.

The findings of Phases I and II were assimilated to produce an extensive list of concepts refined through a process of clustering. A total of 24 concepts were identified and further clustered to form six focal concepts, namely: enacted stigma, perceived stigma, internalized stigma, coping strategies, psychosocial well-being, and interpersonal relations. Enacted stigma captures overt acts of discrimination as received from others, including rejection, exclusion, victimization, humiliation, hostility, unfair treatment, abandonment, gossip, and insults directed at the deceased parent/s. Perceived stigma captures COAs perception of the normativity and prevalence of HIV-related stigma within their social environments. Internalized stigma denotes COAs internalization of HIV-related stigma, including self-blame and shame. These three focal concepts—enacted stigma, perceived stigma, and internalized stigma—were further categorized to indicate the experiences of COA.

Coping strategies, which includes problem-focused coping, emotion-focused coping, and avoidant-coping strategies, were categorized as a behavioral response. This focal concept captures the prominence of maladaptive coping strategies, which mediates the negative influence of HIV-related stigma on the psychosocial well-being of COA. Psychosocial well-being reflects domains of well-being adversely affected by COAs experience of HIV-related stigma and is categorized as outcomes for psychosocial well-being. These domains transcend beyond the psychological domain to include the emotional well-being, social well-being, self-esteem and self-concept, and future orientation of COA. Lastly, interpersonal relationships, categorized as the context, captures the social interaction and environment in which the process of HIV-related stigma may unfold. This focal concept captures the community, interpersonal interaction with others, and the social support available to COA.

These focal concepts formed the foundation for the developed model and were further classified according to six aspects, namely: agency, recipiency, framework, terminus, procedure, and dynamics enabling statement synthesis. The statements developed through this categorization displayed in Chapter 7 enabled the process of statement synthesis for the development of relationship statements. Relationship statements served to project interrelations between concepts, which accounts for the interaction and relation among multiple concepts. These statements support concepts by providing form and structure to the developed model, resulting in the developed model.

The model description (Chapter 7) marks the third stage of model development. The developed ***social transactional model of HIV-related stigma and the psychosocial well-being of COA*** is graphically presented and provides a comprehensive overview of the model, alongside five descriptive components, namely: (1) purpose, (2) concepts, (3) definitions, (4) relationships and structure, and (5) assumptions of the social transactional model of HIV-related stigma and child psychosocial well-being in Chapter 7.

During Phase III, the researcher developed, presented, and fully described a ***social transactional model of HIV-related stigma and the psychosocial well-being of COA,*** therefore meeting the objective of this phase, which was “to develop a model that offers an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS.” The process of concept and statement synthesis, as carried out during this phase, served to answer the research question, “what factors should be considered for the development of a model to understand the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS?”

10.2.4 Phase IV (Chapter 8): Model evaluation

Phase IV presented the final stage of model development and thus concluded the study. In Phase IV, a modified Delphi technique was implemented to satisfy the objective "to determine the functionality of the developed model through the use of the Delphi technique," and answer the research question, "what is the functionality of the developed model according to various stakeholders?" This phase moved beyond gathering consensus among stakeholders to establish the nature and value of the developed model. This phase, therefore, served as a critical reflection and an evaluation of the functionality of the developed model.

Experts evaluated the developed model according to five pertinent elements: (1) clarity, (2) simplicity, (3) generalizability, (4) accessibility, and (5) importance, with generalizability achieving the highest level of consensus. This confirmed that a range of professionals and researchers may meaningfully apply the developed model. Importantly, such application was achievable, despite the variations in manifestations of HIV-related stigma. These views held by key stakeholders supported the previously presented argument that HIV-related stigma is to be recognized as a universal concept based on the commonality of features despite variations in its manifestation (Deacon, 2006).

Considering the element of accessibility, the experts reached a consensus that focal concepts, related concepts, and relationship statements, as presented in the developed model, are visible in both empiric literature and practice (Boyes & Cluver, 2013; Chi et al., 2014; Lin et al., 2010; Lin et al., 2016; Mason & Sultzman, 2019). Empiric indicators may, therefore, be formally identified and measured. One significant finding is that the experts reported high rates of consensus for the elements of clarity and simplicity. They further indicated that the concepts, relationship statements, and the order and structure of the developed model was clear, while the model remained simplistic, offering an understanding of the manner in which HIV-related stigma affected the psychosocial well-being of COA throughout. HIV-related stigma, in particular, has previously been identified as embodying a multifaceted nature, which creates a barrier for effective conceptualization, measurement, and evaluation of the concept (Chi & Li, 2013, Florom-Smith & De Santis, 2012; Kontomanolis, Michalopoulos, Gkasdaris, & Fasoulakis, 2017).

The understanding provided by the model lends itself to the element of importance, as the inability to understand HIV-related stigma has resulted in an ineffective response to combat HIV-related stigma (Parker & Aggleton, 2003; Deacon, 2006; Misir, 2015; Pantelic, Sprague, & Stangl, 2019). As the developed model facilitates an understanding of HIV-related stigma and its influence on the psychosocial well-being of COA, experts have acknowledged the importance of the model for the field of health-related stigma. Importantly, the model was recognized for its ability to resolve issues in research and practice.

The findings of Phase IV indicates that the ***social transactional model of HIV-related stigma and the psychosocial well-being of COA*** serves to provide an understanding of HIV-related stigma and its influence on the psychosocial well-being of COA, thereby satisfying the fourth objective, which was ‘to determine the functionality of the developed model through the use of the Delphi technique,’ and also answered the research question, ‘what is the functionality of the developed model according to various stakeholders?’

10.3 Limitations

In the current research study, several research limitations emerged across the implemented studies, namely, (1) systematic review, (2) qualitative study, (3) model development, (4) and model evaluation. These limitations were:

- The systematic review conducted in Phase I failed to (1) include grey literature, and (2) asses included studies for publication bias during the methodological assessment undertaken during the level of eligibility. Since a meta-synthesis was employed rather than a meta-analysis, publication bias was not assessed, as suggested by Dwan, Gamble, Williamson, and Kirkham (2013). These authors caution against the overestimation of study results and the production of unreliable evidence for decision-making (Dwan et al., 2013). While the omission of publication bias may be a limitation, a comprehensive tool and the PRISMA guidelines and checklist were utilized to provide substantial transparency in the section of included studies, thus improving reporting quality of the systematic review (Knobloch, Yoon, & Vogt, 2011).

- With COA being regarded a stigmatized and vulnerable population, restricted access to the sample population was encountered. Millum and colleagues (2019) similarly recognized stigma as a significant barrier to the recruitment of participants, thus hindering research needed to reduce stigma. The primary researcher acknowledges the sensitivity, secrecy, and non-disclosure strategies accompanying parental illness and death due to AIDS-related causes, and its role restricting the participation of COA in the qualitative exploration carried out in Phase II. While restricted participation is an identified limitation, the sample size remained sufficient for the exploration of the complex phenomenon—HIV-related stigma—and allowed the primary researcher to make meaningful inferences from the dataset (Polit et al., 2001).
- The qualitative exploration was conducted in South Africa, therefore, the findings may not be generalizable to other regions, as HIV-related stigma is largely “socially constructed and deeply rooted in social culture” (Zhang, Guida, Sun, & Liu, 2014, p. 452). While the generalizability should be carefully considered in application, the results provided an insightful view and highlighted issues relating to HIV-related stigma and its associated outcomes for orphaned and vulnerable children within regions severely affected by the HIV/AIDS pandemic. Leung (2015) states that generalizability is an unexpected attribute of qualitative research, as the methodology’s key

characteristic is the exploration of a phenomenon within a specific population and context, thus emphasizing a focused locality. While this limitation has been recognized for the study's findings depicted in Phase II (Chapter 5), it may not apply to the developed model. The triangulation of the results from the systematic review (Phase I) and the qualitative exploration (Phase II) addressed the pertinent issue of generalizability, and revealed noteworthy similarities between the findings of each study as represented by the horizontal themes presented in Phase III (Chapter 6). Finfgeld-Connett (2010) and Leung (2015) suggest a pragmatic approach to assessing the generalizability of qualitative studies and have advocated for the use of triangulation and meta-synthesis as utilized in Phases II and III of this study.

- Furthermore, pre-adolescent participants participating in the qualitative explorative study may have been incapable of fully expressing their experiences and perceptions of HIV-related stigma and its associated consequences for their well-being because of their continuing cognitive and emotional development. Previous studies have similarly cautioned against the developmental vulnerability (intellectual immaturity and emotional dependency) of COA, due to complicated and unresolved bereavement (Li et al., 2008; Snider & Dawes, 2006; Thupayagale-Tshweneagae, 2011).
- During Phase III, a theory generative design was utilized for model development. The ***social transactional model of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS*** was theoretically developed in this study. Further research is, however, needed to empirically validate the theoretical assumptions put forth in the developed model. While empirical evaluation is beyond the scope of this study, empirical investigations (systematic review and qualitative exploration) were conducted for the development and clarification of concepts—the building blocks of theoretical models—and relationship statements. Likewise, Botes (2002) suggests that

empirical investigation is needed to enhance the quality of the developed concepts. Moreover, the developed model does not possess a practical nature but rather a theoretical one as it serves to provide an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of COA. The model may, therefore, enhance researchers and practitioners' understanding of the phenomenon, rather than be generally applied.

10.4 Recommendations

In light of the study's findings and limitations that emerged during the research process, the following recommendations for (1) research; (2) practice, and (3) policies and programs are presented below, discussed under each heading, respectively.

10.4.1 Research

- The current study provided a theoretical underpinning from which HIV-related stigma and the manner in which it influences the psychosocial well-being of COA may be understood. The findings from the systematic review (Chapter 4) highlighted the lack of a sound theoretical framework (or underpinnings) in published research studies. As suggested by Deacon (2006), the use of a sustainable theory is critical to understand the phenomenon under investigation and meaningfully address HIV-related stigma. Prospective researchers are urged to adopt a theoretical lens that will guide their research practices and influence the interpretation of their findings. In future research, the use of an appropriate theoretical lens will provide a means to fully understand the phenomenon and bridge the gap between theory and practice.
- There is a lack of HIV-related stigma frameworks and models specific to the experiences, challenges, and needs of children who have been affected by the

HIV/AIDS pandemic, including COA. Consequentially, it has been commonplace to adopt theoretical underpinnings designed for the adult population, especially regarding HIV testing, treatment, and care. Bos et al., (2013) share these sentiments as they identify the inadequate usage of theory. However, children affected by HIV/AIDS may have unique experiences of stigma, particularly in regions severely affected by the pandemic (Domlyn, Jiang, Harrison, Qiao, & Li, 2019), that are markedly different to that of the adult population. Future studies need to remain cautious when making inferences to theoretical models or underpinnings developed from empirical studies focused on adult populations. The use of a conceptual framework that frames the theoretical understanding of HIV-related stigma from a child-centered perspective may be ideal. Conceptual frameworks will contribute to the existing body of knowledge offering an understanding of HIV-related stigma and the manner it affects the psychosocial well-being of COA.

- Similarly, instruments developed for the assessment of HIV-related stigma among the adult population are often utilized in research studies focusing on children. Emerging evidence needs to consider the use of appropriate measures for examining and understanding HIV-related stigma among COA. These limitations may be addressed through the appropriate adaptation of measures for use with COA. Moreover, evidence-based research needs to be conducted to establish the validity and reliability of measures originally developed for the adult population for use with children. As HIV-related stigma remains culturally and contextually dependent (Mahajan et al., 2008), further consideration should be given to the production of evidence-based studies to establish the validity of measures in varying regions influenced by unique social and cultural norms.

- Study findings in Phase I suggest the interchangeable use of the concepts “psychosocial well-being” and “psychological well-being.” This study therefore highlights that it is imperative to understand psychosocial well-being as a distinct concept that surpasses psychological well-being to include several domains of well-being. The two concepts—psychological and psychosocial well-being—while entwined, are distinctly different. It is recommended that scholars acknowledge the multifaceted nature of the concept psychosocial well-being (Tsang et al., 2011). Recognition of such would allow for the emergence of evidence-based research focusing on the various domains of psychosocial well-being, as identified in this study, to address the paucity of research focusing on the psychosocial well-being of COA.
- The field of HIV-related stigma is dominated by evidence-based studies situated within SSA and China. The recommendation is that a broader exploration of HIV-related stigma as perceived and experienced by children be undertaken to establish a better understanding of HIV-related stigma among children in diverse regions. Considering the cultural and contextual dependence of HIV-related stigma, evidence-based research from other regions would allow for more generalized findings that supports a deeper and clearer understanding of how the psychosocial well-being of COA is affected by their perceptions and experiences of HIV-related stigma.
- A further recommendation is for more qualitative studies exploring the concept of HIV-related stigma among children. The current body of knowledge is dominantly quantitative in nature, which limits our ability to make sense of complex phenomenon and social processes. To deeply understand the manner in which HIV-related stigma affects the well-being of COA, it is necessary to develop an adequate understanding of the phenomenon that is derived from the experiences, perceptions, beliefs, and opinions of COA themselves. These explorations added to the current body of knowledge by

offering a detailed description of the experiences and perceptions of HIV-related stigma from the standpoint of COA (Hammarberg, Kirkman, & de Lacy, 2016).

- This study highlights the need for longitudinal research to be conducted to ascertain the long-term impact of HIV-related stigma on the well-being of COA. As most studies embody a cross-sectional design, they allow for a limited understanding of HIV-related stigma and its impact on the psychosocial well-being of COA at a specific point in time. Longitudinal studies serve to measure the long-term impact of HIV-related stigma on the psychosocial well-being of COA. Therefore, an increase in longitudinal studies would largely contribute to the body of empirical evidence and inform the design, development, and implementation of interventions addressing the psychosocial well-being of COA and HIV-related stigma.
- This study reflects the need for the inclusion of COA in research studies, thus advancing the principles conveyed by the United Nations Convention on the Rights of the Child (UNCRC) (UNICEF, 1989). The UNCRC considers children as active agents, who are able to construct knowledge and make valid contributions towards their own well-being. The examination of HIV-related stigma from the perspectives of caregivers and guardians are limited as it serves to convey their interpretation and meaning of the phenomenon as experienced by COA. To provide adequate care and support to COA, future research studies should be geared to fully understand the needs, experiences, and perceptions of COA themselves. Research conducted with COA (despite their vulnerability), would allow for the adequate identification of their encountered challenges and needs.

10.4.2 Recommendations for practice

- The developed model indicates that HIV-related stigma operates to negatively affect the psychosocial well-being of COA. It is therefore essential for communities of practice, including practitioners, clinicians, and social workers, to remain cognizant of HIV-related stigma, discrimination, and issues surrounding non-disclosure when working with COA. It is imperative that professionals be provided with an understanding of the origin, root causes, and manifestations of HIV-related stigma via professional training, workshops, seminars, conferences, and programs. Building knowledge capacity among professionals working with COA is to ensure that they are able to adequately identify and respond to issues and challenges experienced by COA. This would ultimately allow professionals working with COA to produce tailored interventions and measures to support COA and influence referral procedures, as well as determine the affected child(dren)'s need for extensive resources, care, or support.
- Considering the psychosocial distress caused by perceptions and experiences of HIV-related stigma, COA should have access to individual counseling. A health service provider, such as a counselor and/or psychologist, may appropriately assist COA with managing the challenges they experience, specifically within the domain of psychological well-being, self-esteem and self-concept, and emotional well-being. Health care professionals offer COA a safe space in which they may express their concerns, receive social support, and build healthy interpersonal relationships that may bolster their self-esteem. Counselors and psychologists need to remain cognizant of HIV-related stigma and gather a deeper understanding of its impact on identity formation, self-esteem and self-concept, and psychological well-being of COA. Addressing perceptions and experiences of HIV-related stigma remains vital in ensuring the healthy psychosocial well-being of COA. As perceived stigma is

considered to be the belief regarding the normativity of HIV-related stigma in one's social environment, techniques such as cognitive behavioral therapy may prove beneficial in correcting irrational beliefs about HIV-related stigma and reduce their experiences of overt discrimination.

- Evidence suggests that COA are often stigmatized within their living environments, therefore the living conditions of COA should be closely monitored by social welfare professionals. These professionals often maintain close contact with both children and the families with whom they stay, therefore enabling them to monitor the living environment and conditions in which a child is located. Additionally, social welfare professionals are to support extended families providing them with the necessary resources and skills to care for COA. As COA are recognized to experience both stigmatization and marginalization, social welfare services ought to be widely available to COA, offering a contact point should COA need to report instances of ill-treatment, abuse, or poor living conditions.

10.4.3 Recommendations for policy and programs

- Evidently, stigma reduction efforts need to be prioritized in the global response to combat the HIV/AIDS pandemic and to enhance the well-being of orphans and vulnerable children affected by HIV/AIDS. For these reduction efforts of stigma to be effective, a multifaceted response needs to be adopted, requiring the collaboration of policy makers, program developers, and practitioners. This multidisciplinary approach to stigma reduction may combine the knowledge, expertise, and skill sets of a wide range of professions, thus strengthening the capacity to address HIV-related stigma and improve the well-being of the most vulnerable populations affected by the HIV/AIDS pandemic, including COA.

- The findings of this study highlight the continuing need for stigma reduction efforts and awareness campaigns to be employed globally. Despite HIV/AIDS being classified as a manageable illness, HIV-related stigma continues to remain prevalent within society. Awareness campaigns and programs need to be developed and implemented in regions severely affected by HIV/AIDS to bring about a reduction in stigma. This holds especially true for the educational sector. Across the study’s findings, COA reported experiencing stigma and discrimination from their peers resulting in school dropout, increased non-attendance, and psychosocial distress. There is a need to address HIV-related stigma among children, offering them factual information regarding the transmission and treatment of HIV/AIDS, and an understanding of HIV-related stigma and its consequences. These efforts aim to reduce the stigma extended to COA by their peers and increase levels of received social support, which is regarded as vital for healthy psychosocial well-being.
- Child-based interventions and programs should be designed to equip COA with psychosocial resources to effectively cope with HIV-related stigma and enhance their psychosocial well-being. Included content should focus on self-esteem and self-concept, emotional regulation, optimism, coping strategies, and social skills. Importantly, these measures should be developed to equip COA with the necessary skills and coping strategies that may enhance their well-being. The developed model highlights the mediating role of maladaptive coping strategies and its negative influence on child psychosocial well-being. It is suggested that content dealing with healthy coping strategies and skills be embedded in the design of such programs to capacitate COA with the necessary coping skills and strategies that promote healthy psychosocial well-being.

- Social support has been identified as offering the necessary resources that may enhance the psychosocial well-being of COA. As COA are firstly embedded in the social structure of the family, programs should be developed to strengthen and support the immediate and extended family system to support COA. Family level and/or centered interventions may be set in place to bolster the interpersonal resources available to COA, such as social networks, social support, interpersonal trust, and empathy. Interpersonal resources influence COAs capacity to cope with stressful events and situations, such as being stigmatized. While these interventions may enhance the psychosocial well-being of COA, there remains a need to reduce stigma and capacitate caregivers with the necessary resources tools, these may include but are not limited to financial resources, accurate information about HIV/AIDS, an understanding of HIV-related stigma, and capacitating caregivers with the necessary parenting skills and tools to support COA. These recommendations are set out to strengthen the interpersonal relationships COA hold with others within their immediate social environment. The ability to engage in meaningful relationships that are regarded as healthy, supportive, nurturing, and positive, provides COA with the necessary support structure to successfully deal with experiences of HIV-related stigma and parental illness and death.
- Interventions geared towards stigma reduction should remain culturally and contextually specific to uniquely address stigma within various settings. HIV-related stigma, while common at its core, remains a socially constructed phenomenon that is culturally and socially dependent. Therefore, HIV-related stigma may manifest in a variety of ways, which may negatively affect the psychosocial well-being of COA.

10.5 Conclusion

This final chapter summarized the key findings extracted at each phase and discussed their contribution to the developed model. The chapter then considered the research process and study's findings in its entirety, followed by an explanation of the limitations, and a presentation of recommendations for future research, practice, and the development and planning of policies and programs. This concludes the study.

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APPENDICES

Appendix 1: Critical Appraisal Skills Program for Qualitative Studies

Critical Appraisal Tool for Qualitative Studies **Reviewer: ________________ Author: ________________** **Title: ________________________________ Year: _______**		
Study Purpose	**Yes (1)**	**No (0)**
1. Has an extensive literature review been conducted to inform the context and background of the study? **2. Is the problem statement been made explicit?** **3. Is a clear rationale for the study provided?** **4. Have the Aims been clearly stated?** **5. Are the objectives clearly stated?** **6. Are the aims and objective explicitly linked to the research question?** **Total:**		
Study Design	**Yes (1)**	**No (0)**
1. Does the article seem to explore/interpret the subjective experiences of participants? **2. Is the methodology suitable for the proposed objectives?** **3. Does the research design address the aims and objectives of the study?**		

4. Did the authors indicate reasoning for the methodology? **5. Is a theoretical framework or underpinning identified?** **Total:**		
Sampling	**Yes (1)**	**No (0)**
1. Is the source population identified? **2. Is there a clear distinction between probability and non-probability sampling?** **3. Is the sampling method appropriate?** **4. Did the author/s motivate their sample choice?** **5. Are inclusion and exclusion criteria clearly stipulated?** **6. Is the sample representative of the population?** **7. Has informed consent been obtained from participants?** **Total:**		
Data Collection	**Yes (1)**	**No (0)**
1. Is data collected in an ethically sound manner? **2. Is the setting of data collection noted?** **3. Did the authors explicitly indicate the method of data collection (e.g. interviews, Focus groups, etc.)?** **4. Are these methods of data collection appropriate?** **5. Were any methods modified during the course of the study?**		

6. **Is the form of data clear (notes, tape-recordings, etc.)?** **Total:**		
Data Analysis	**Yes (1)**	**No (0)**
1. **Is the Method of data analysis clearly stipulated?** **2.** **Did the author provide an in-depth description of the process of analysis?** **3.** **Is there sufficient data to support the findings?** **4.** **Was contradictory data accounted for?** **5.** **Has the Author/s accounted for bias and influence?** **Total:**		
Findings	**Yes (1)**	**No (0)**
1. **Are the findings made explicit?** **2.** **Is there adequate evidence to support findings?** **3.** **Has the researcher discussed credibility of findings (e.g. triangulation, another analyst, respondent validation)?** **4.** **Are findings linked to the research question?** **5.** **Are findings generalizable?** **Total:**		

Conclusion	**Yes (1)**	**No (0)**
1. Is the conclusion clear? **2. Is the conclusion supported by findings?** **3. Are appropriate recommendations made?** **4. Are limitations explicitly identified?** **Total:**		
Ethical Considerations	**Yes (1)**	**No (0)**
1. Is ethical approval obtained from an identifiable committee? **2. Did the Author/s report of gaining access from appropriate institutions?** **3. Have these ethical issues been reported on:** **Confidentiality?** **Anonymity?** **Withdrawal?** **Total:**		
Total Score/ Percentage ☐ **Weak (0-30%)** ☐ **Moderate (31-65%)** ☐ **Strong (66-80%)** ☐ **Excellent (81-100%)**	**Score** **(/41)**	**%**

(Studies below the threshold stipulated in the category strong shall be excluded. Studies not focusing on the relationship between HIV-related stigma and the psychosocial well-being of children who have been orphaned by HIV/AIDS shall be excluded.)		
Overall Outcome: Include ☐ Exclude ☐ Seek Further Info☐		

Appendix 2: Critical Appraisal Skills Program for Quantitative Studies

Critical Appraisal Tool for Quantitative Studies **Reviewer: ________________ Author: ________________** **Title: __________________________________ Year: _______**		
Study Purpose	**Yes (1)**	**No (0)**
1. Is the problem statement been made explicit? **2. Is a clear rationale for the study provided?** **3. Have the Aims been clearly stated?** **4. Are the objectives clearly stated?** **5. Are the objectives clearly stated?** **6. Are the aims and objective explicitly linked to the research question?** **Total:**		
Literature Review		
1. Has an extensive literature review been conducted to inform the context and background of the study? **2. Are gaps in literature identified?** **3. Is the need for further research addressed?**		

Total:		
Study Design	**Yes (1)**	**No (0)**
1. Is the research design clearly identified (e.g. RCT, Cohort design, case study, cross-selection, etc.)?		
2. Are the essential features of the design stipulated?		
3. Is the study design appropriate?		
4. Have author/s indicated reasoning for their design selection?		
5. Does the research design address the aims and objectives of the study?		
Total:		
Sampling	**Yes (1)**	**No (0)**
1. Is the source population identified?		
2. Is there a clear distinction between probability and non-probability sampling?		
3. Did the author/s motivate their sample choice?		
4. Is the sampling method appropriate?		
5. Is the sample representative of the population?		
6. Is the sampling size justified?		
7. Has informed consent been obtained from participants?		
Total:		

Outcomes	**Yes (1)**	**No (0)**
1. Where the instruments used clearly identified with references?		
2. Are these instruments appropriate?		
3. Were steps taken to ensure the reliability of outcome measures?		
4. Did the Author/s account for:		
Sample bias?		
Measurement bias?		
Performance bias		
5. Which psychometric properties were reported on:		
Did they report on psychometric properties?		
Psychometric properties on the scale of the sample?		
Type of data produced by instrument?		
Did the data produced support the proposed analysis?		
Total:		
Findings	**Yes (1)**	**No (0)**
1. Is the statistical significance of results indicated?		
2. Is such statistical significance justified?		
3. Are analysis methods appropriate?		
4. Are results correctly interpreted in relation to the research question?		

Total:		
Conclusion	**Yes (1)**	**No (0)**
1. Is the conclusion clear? **2. Is the conclusion supported by findings?** **3. Are appropriate recommendations made?** **4. Are limitations explicitly identified?** **Total:**		
Ethical Considerations	**Yes (1)**	**No (0)**
1. Is ethical approval obtained from an identifiable committee? **2. Did the Author/s report of gaining access from appropriate institutions?** **3. Have these ethical issues been reported on:** **Confidentiality?** **Anonymity?** **Withdrawal?** **Total:**		
Total Score/ Percentage ☐ **Weak (0-30%)** ☐ **Moderate (31-65%)** ☐ **Strong (66-80%)** ☐ **Excellent (81-100%)**	**Score (/45)**	**%**

(Studies below the threshold stipulated in the category strong shall be excluded. Studies not focusing on the relationship between HIV-related stigma and the psychosocial well-being of children who have been orphaned by HIV/AIDS shall be excluded.)		
Overall Outcome: Include ☐ Exclude ☐ Seek Further Info☐		

Appendix 3: Evaluative Tool for Mixed Method Studies

Critical Appraisal Tool for Mixed Method Studies **Reviewer: ________________ Author: ________________** **Title: ________________________________ Year: _______**		
Study Purpose	**Yes (1)**	**No (0)**
1. Is the problem statement made explicit? **2. Is a clear rationale for the study provided?** **3. Have the aims been clearly stated?** **4. Are the objectives clearly stated?** **5. Are the aims and objectives explicitly linked to the research question?** **Total:**		
Literature Review		
1. Has an extensive literature review been conducted to inform the context and background of the study? **2. Has a theoretical framework been identified?** **3. Are gaps in the literature identified?** **4. Is the need for further research addressed?** **Total:**		

Study Design	**Yes (1)**	**No (0)**
1. Is the research design clearly identified (e.g. RCT, cohort design, case study, grounded action theory, etc.)? **2. Are the essential features of the design stipulated?** **3. Has author/s indicated reasoning for their design selection?** **4. Does the research design address the aims and objectives of the study?** **Total:**		
Sampling	**Yes (1)**	**No (0)**
1. Is the source population identified? **2. Is the method of sampling clearly identified?** **3. Are the inclusion and exclusion criteria explicitly identified?** **4. Is the sampling method appropriate for the aims and objectives outlined in the study?** **5. Is the sample representative of the population?** **6. Is the sampling size justified?** **Total:**		
Outcomes	**Yes (1)**	**No (0)**

1. **Were the instruments used clearly identified?** 2. **Are these instruments appropriate?** 3. **Were steps taken to ensure the reliability of outcome measures?** 4. **Did the author/s account for potential bias?** 5. **Has the researcher accounted for their role in the current study?** 6. **Were psychometric properties reported on (scale of sample, data produced by instruments, etc.?** **Total:**		
Findings	**Yes (1)**	**No (0)**
1. **Are the results clearly stipulated?** 2. **Are outcomes justified by adequate findings (both statistical and descriptive findings)?** 3. **Are methods of analysis appropriate?** 4. **Are results correctly interpreted in relation to the research question?** 5. **Are qualitative and quantitative results integrated?** **Total:**		
Conclusion	**Yes (1)**	**No (0)**
1. **Is the conclusion clear?** 2. **Is the conclusion supported by findings?**		

3. Are appropriate recommendations made? **4. Are limitations explicitly identified?** **Total:**		
Ethical Considerations	**Yes (1)**	**No (0)**
1. Was ethical approval obtained from an identifiable committee? **2. Did the author/s report on gaining access from appropriate institutions?** **3. Have the following ethical issues been reported on:** **Informed consent** **Confidentiality** **Anonymity** **Withdrawal** **Total:**		
Total Score/Percentage **6. Weak (0–30%)** **7. Moderate (31%–65%)** **8. Strong (66%–80%)** **9. Excellent (81%–100%)** **(Studies below the threshold stipulated in the category strong shall be excluded. Studies not focusing on the relationship between HIV-related stigma and the psychosocial well-being of children who have been orphaned by HIV/AIDS shall be excluded.)**	**Score (/41)**	**%**

Overall Outcome: Include ☐ Exclude ☐ Seek Further Info☐		

Appendix 4: Systematic Review Data Extraction Sheet

General Description

Author	Sample Population	Geographical location	Aim	Problem Statement

Methodology

Author	Study design	Theoretical Underpinning	Sampling Method	Sample Size	Data Collection Methods/Instruments

Findings and Analysis

Author	Method of Analysis	Study Findings	Author Conclusion

Appendix 5: Qualitative Interview Guide

QUALITATIVE INTERVIEW GUIDE

NB: Ensure written consent and assent form is signed and collected before the interview commences

Research Introduction: This study is conducted in fulfilment of the requirements to obtain a Doctoral degree in Child and Family Studies at the University of the Western Cape. The study seeks to find out your experiences and perceptions about stigmatisation related to your parents' illness and death. Your experiences and suggestions will go a long way to inform the development of a model that will help increase the understanding of how stigma affects your well-being and will create/improve programmes and policies that addresses the stigmatisation experienced by orphaned children.

Respondent Code: ……………………………………

Gender: ………………………………………………

Age: …………………………………………………

How long have you been an orphan (if applicable): ……………….

Facility/NGO (if applicable): …………………………

1. Can you tell me what a regular day for [insert name] would be like?

   [prompts: daily activities and routines]

2. Do you feel you can talk to others about your day?

   [Prompt: If no, why?; If yes, Who?; Are they accessible all the time?; Can you talk to your parent/ guardians/friends?; What bothers/excites you?]

3. Can you tell me about school

[Prompts: What do you do at school?; How do you feel about school?; Do you have friends at school?; How are you treated at school?; Do you do well in school?, If no, why?; What do you enjoy about school?, if nothing, why?]

4. What do you do in your free time/hobbies?

   [Prompts: Interpersonal relationships; access to positive activities; engagement in self-esteem enhancing activities; religious activities]

5. Can you tell me about your friends?

   [Prompts: Do you have friends?, If no, why?; Do you make friends easily?; What do you and your friends do for fun?; How do your friends treat you?; Are your friends supportive?]

6. What would you like to be when you grow up one day?

   [Prompts: Goals and dreams?; What are the feelings about the future?; What are your aspirations?; Outlook for the future?]

7. Can you tell me about how you feel in general?

   [Prompts: Why do you feel that way?]

8. Can you tell me about your health?

   [Prompts: Do you feel healthy? If no, why?; Psychological health and physical health; e.g crying, headaches, sleepiness, stomach ache?]

Appendix 6: Theory Descriptive Guide

Guide for the Description of Theory	
1	**Purpose**
	1.1.Why was this theory formulated
	1.2.Is there an overall purpose for the theory? A hierarchy of purposes? Separate numerous purposes?
	1.3.Is there a purpose for a nurse? The person receiving care? Society? Environment?
	1.4.How broad or narrow is the purpose?
	1.5.What is the value orientation of the purpose? Positive, Negative, Neutral?
	1.6.Does achieving the purpose require a nursing context?
	1.7. Does (do) the purpose(s) reflect understanding? Creation of meaning? Description, explanation, and prediction of phenomena?
	1.8.When would the theory cease to be applicable? What is the end point?
	1.9.What purpose not explicitly embedded in the matrix of the theory can be identified?
2	**Concepts**
	2.1. Is there one major concept with subconcepts organized under it?
	2.2. How many concepts are there?
	2.3. How many major ones?
	2.4. How many minor ones?
	2.5. Can the concepts be order, related? Arranged into any configuration?
	2.6. Are there concepts that cannot be interrelated?
	2.7. Are concepts broad in scope? Narrow?
	2.8. How abstract or empiric are the concepts?
	2.9. What is the balance between highly abstract and highly empiric concepts?
	2.10. Do concepts represent objects, properties or events? Can you say there are concepts that are closely related?
3	**Definitions**
	3.1. Which components are defined? Which are not?
	3.2. Which concepts are defined explicitly? Which are implied?
	3.3. How much meaning need to be inferred?

	3.4. Which concepts are defined specifically? Generally?
	3.5. Are there competing definitions for some concepts? Are there similar definitions for some concepts?
	3.6. Do any explicitly defined concepts not need definition?
	3.7. Are any concepts defined contrary to common convention?
4	**Relationships**
	4.1. What are the major relationships within the theory?
	4.2. Which relationships are obvious? Which are implied?
	4.3. Do relationships include all concepts? Which are not included?
	4.4. Are some concepts included in multiple relationships?
	4.5. Is there a hierarchy of relationships? Do relationships create meaning and understanding? Do they do this by describing, explaining? Predicting? What mix of each?
	4.6. Are relationships directional? What is their direction? Are they neutral?
	4.7. Are there mixed, competing, or incongruous relationships?
	4.8. Are relationships illustrated?
5	**Structure**
	5.1. How are overall and individual ideas organised?
	5.2. If outlined, what would the theory look like?
	5.3. Do relationships expand concepts into larger wholes or vice versa? Do they link concepts in a linear fashion?
	5.4. Does the structure move concepts away from or towards the purpose?
	5.5. Are there several structures that emerge? What is their form? Do they fit together?
	5.6. Could more than one structure represent the overall structural relationships?
	5.7. Where is there no structure?
6	**Assumptions**
	6.1. What assumptions underlie the theory? Are assumptions explicit, implicit or derivable from context or meaning?
	6.2. What are the individual, nurse, society, environment and health assumed to be like?
	6.3. Do assumptions have an obvious value orientation? What is it?
	6.4. Could assumptions be factually verified?

	6.5. Where are the assumptions located within the structure – before, within, or after theoretic reasoning?
	6.6. Can assumptions be hierarchically arranged or otherwise ordered?
	6.7. Do assumptions have any identifiable relationship or theoretic relationships or structure?
	6.8. Are there competing assumptions?

Appendix 7: Critical Reflection Guidelines

Guide for Critical Reflection of Theory
HOW CLEAR IS THE THEORY? ***Sematic Clarity***
Are major concepts defined? Are definitions explicit? Implicit? Inferable?
Are significant concepts not defined? Are definitions clear?
How general are definitions? How specific?
Are words coined? Are coined words defined?
Is the amount of explanation appropriate and useful? Too much? Not enough?
Are examples meaning and helpful? Need and not present?
Semantic Consistency
Are definitions consistent with one another?
Are the same terms defined differently?
Are different terms defined similarly?
Are implied or inferred meanings different from explicit meanings?
Is the view of person and environment compatible?
Are words borrowed from other disciplines and used differently in this context?
Are assumptions and purposes compatible with other elements of the theory?
Are competing assumptions or purposes present?
Are examples consistent with one another?
Structural Clarity
Do all relationships fit within the structure of the theory?
Can the order of the theory be comprehended?
Can an overall structure be diagrammed?
Where, if any, are gaps in the flow? Do all concepts fit within the theory?
Structural Consistency
Do diagrams and visual structures provide support, or compete with one another?
Is there one structural form or several? If more than one form, do they complement, or compete, with one another?
Are examples consistent with one another?
Are basic assumptions consistent with one another? With purposes?
Are compatible and coherent structures suggested for different parts of the theory?

Are there any ambiguities as a result of sequence of presentations?
HOW SIMPLE IS THIS THEORY?
How many relationships are contained within a theory?
How are the relationships organized?
How many concepts are contained in the theory?
Are some concepts differentiated into subconcepts and others not?
Can concepts be combined without losing theoretic meaning?
Is the theory complex in some areas and not in others?
Does the theory tend to describe, explain, or predict? Impart understanding? Create meaning?
HOW GENERAL IS THE THEORY?
How specific are the purposes of this theory? Do they apply to all or only some practice areas? When?
Is this theory specific to nursing? If not, who else could use it why?
Is the purpose justifiably a nursing purpose?
If subconcepts exist, do they reflect nursing actions? How broad are the concepts within the theory?
HOW ACCESSIBLE IS THE THEORY?
Are the concepts broad or narrow?
How specific or general are definitions within the theory?
Are the concepts' empiric indicators identifiable in experience? Are they within the realm of nursing?
Do the definitions provided for the concepts adequately reflect their meanings?
Is a very narrow definition offered for a broad concept? A broad meaning for a narrow concept?
If words are coined are they defined?
HOW IMPORTANT IS THE THEORY?
Does the theory have potential to influence nursing actions? If so, to what end? Is that end desirable?
Is the theory used? Does the theory guide nursing education? nursing research? Nursing practice? All three? If so to what end is that end desirable?
How specific are the purposes of the theory? Do they provide a general framework in which within which to act or a means to predict phenomena?
Is the theory's position about people, about nursing, and about the environment consistent with nursing philosophy?

Given the purpose of the theory and its orientation, what significance factors for nursing or health care have been omitted?
Is the stated or implied purpose one that is important to nursing? Why?
Will use of the theory help or hinder nursing in anyway? If so how?
Will application of this theory resolve any important issues in nursing? Will it resolve any problems?
Is the theory futuristic and forward-looking?
Will research based on the theory answer important questions?
Are the concepts within the domain of nursing?
Do I like this theory? Why?

Appendix 8: Self-Administered Delphi Questionnaire

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A Social Transactional Model of HIV-related Stigma and the Psychosocial Well-being of Children Orphaned by AIDS

Delphi Study

Zeenat Yassin-Burns

Dear Participant

Thank you for agreeing to partake in a survey for this PhD research project. Your participation will be confidential, and your identity will remain anonymous throughout the process. The data gathered within this survey is not subject to any public disclosure, the findings of the research project will be published at a later stage and no personal information will be included within this publication.

The PhD project aimed to develop a model that fosters an understanding of the manner in which HIV-related stigma affects the psychosocial well-being of children orphaned by AIDS. This survey represents stage 1 of the Delphi study, which aims to reach a common understanding about the feasibility of the developed model among experts. Your personal opinion relating to five key areas of the developed model namely: (1) Clarity; (2) Simplicity; (3) Generalizability; (4) Accessibility; (5) and Importance, is required.

In round One a full description of the developed model is provided to be read through. A survey, ***provided below,*** consists of questions relating to the five key areas, requires your response.

Participation in round Two of the Delphi study will be required at a later stage. Round Two will consists of your answers from Round One which will be summarized and formulated into a series of more specific questions, that needs to be responded to.

The identity of all participants will remain confidential at all times.

Thank you for your assistance

A Social Transactional Model of HIV-related Stigma and the Psychosocial Well-being of Children Orphaned by AIDS

Model Description

The stages of the model are illustrated by the letter '**S**' i.e. stage one is presented as, ***S1: Experiences*** and is therefore, representative of the first stage of the model. The numbering of the stages is significant as it depicts the linear structure of the model moving from HIV-related stigma towards the impact on the psychosocial well-being of children orphaned by AIDS. Focal concepts are depicted by the letter 'F' i.e. **enacted stigma (F1).** The numbering of focal concepts holds no significance as concepts are rather iterative. Focal concepts are presented in bold, setting them aside from related concepts which are presented in italics i.e. *social well-being.*

Interpersonal relations (F6) encapsulated the experiences, behavior and psychosocial well-being of children orphaned by AIDS. Interpersonal relations represent the social environment in which children orphaned by AIDS exist and function and may impact them throughout the three stages of the model. The social environment in this study includes the homestead, school, community, health care facilities and local organizations. For the process of stigmatization to unfold social interaction between the stigmatized child and non-stigmatized individuals within the social environment needs to be present. While it is envisioned that interpersonal relations would be present throughout the model, it is most influential during stage one as stigmatization is extended to or perceived by children orphaned by AIDS through their contact with others.

Stage 1: Experiences

During **S1: Experiences** children orphaned by AIDS experience interpersonal and intrapersonal forms of stigmatization, conveyed through the process of social interaction within their social environment. **Enacted stigma (F1)** an interpersonal form of HIV-related stigma is characterized by overt discrimination and hostility resulting in social exclusion placing children orphaned by AIDS at a disadvantage. Manifestations experienced by children orphaned by AIDS include rejection, hostility, exclusion, ill or unequal treatment, devaluation, victimization, exploitation and abuse. There is a direct relationship between **enacted stigma (F1)** and **psychosocial well-being (F5)** and intrapersonal forms of stigma.

There is a bidirectional relationship between **enacted (F1)** and **perceived (F2)** stigma. As children experience enacted stigma, they become increasingly aware of the HIV-related stigma being **perceived stigma (F2)** which is regarded the belief about the prevalence and normativity of HIV-related stigma within one's environment. Psychopathological symptoms ensued form enacted stigma predicts perceptions of discrimination as children with internalizing problems are increasingly sensitive and perceptive to stigmatizing behaviours, enacted stigma over time. Perceived stigma fails to directly affect the psychosocial well-being of children orphaned by AIDS, but like enacted stigma contributes to development of **internalized stigma (F3).**

Internalized stigma (F3), is the internalized belief of being devalued and tainted resulting in feelings of self-hatred, guilt, inferiority, shame and embarrassment for children orphaned by AIDS. Internalized stigma inhibits the psychosocial well-being, specifically the self-concept and self-esteem and psychological well-being of children orphaned by AIDS.

Stage 2: Response

Stage two focuses on children orphaned by AIDS response to HIV-related stigma its associated outcomes. Experiences of HIV-related stigma is followed by **coping strategies (F4)** which has three related *concepts namely,* (1) *avoidant-coping;* (2) *emotion-focused coping; and* (3) *problem-focused coping*. Both *avoidant* and *problem-focused coping strategies* are behavioural responses to HIV-related stigma and affects the psychosocial well-being. Avoidant coping strategies involve disengagement presenting the social withdrawal and self-isolation of children orphaned by AIDS to avoid experiences of enacted stigma. *Problem-focused coping* fuelled by **perceived stigma (F2)**, involves secrecy, selective disclosure and non-disclosure of the cause of parental bereavement. *Emotion-focused coping* is a psychological response to HIV-related stigma and aims to reduce negative emotional responses to stigma. The **coping strategies (F4)** adopted by children orphaned by AIDS are rather maladaptive and despite their use for defending against HIV-related stigma and emotional responses negatively affect their psychosocial well-being.

Stage 3: Psychosocial well-being

Through experiences of HIV-related stigma and the adoption of maladaptive coping strategies the **psychosocial well-being (F5)** of children orphaned by AIDS are negatively affected. Psychosocial well-being is regarded as the holistic well-being of children orphaned by AIDS which included their *psychological well-being, social well-being, emotional well-being, self-concept and self-esteem and future orientation*. These domains of **psychosocial well-being (F5)** reflect their thoughts, behaviours and reactions towards their social environment and others. The order in which related concepts are presented hold no relevance as the dimensions are interconnected, related and influence each other.

Experiences of **Enacted stigma (F1)** acts to increase psychological distress and contribute to the development of internalizing and externalizing disorders such as, anxiety, depression, post-traumatic stress disorder, aggressive and risk-taking behaviour. The *avoidant coping strategies* - self-isolation and social withdrawal – used by children orphaned by AIDS to prevent future experience of HIV-related stigma contributes to the psychological distress and suffering, exacerbating poor *psychological well-being*. The *future orientation* of children orphaned by AIDS are negatively affected by the disadvantage cultivated by enacted stigma. Children orphaned by AIDS are stripped of their resources, unfairly treated and are discriminated against both within the homestead and the schooling environment resulting in school dropout. Without scholastic knowledge and social support, a child orphaned by AIDS lack optimism, confidence and perceived control over their future.

Perceived stigma (F2) causes a child orphaned by AIDS to embody a culture of secrecy, non-disclosure or selective disclosure of the cause of parental death. The use of *problem-focused coping strategies* to conceal the cause of parental death actively limits a child’s ability to form healthy interpersonal relationships which are essential for receiving the social support necessary to cope with stressful life events. Therefore, perceived stigma indirectly negatively affects the *social well-being* of children orphaned by AIDS through their use of *problem-focused coping*. A direct relationship exists between *social well-being* and *self-concept and self-esteem*. Poor *social well-being* restricts a child’s opportunity to engage in self-esteem enhancing activities that occurs through social interaction with others. Through interpersonal engagement children orphaned by AIDS cannot receive self-validation from others resulting in a poor *self-concept* and *lower levels of self-esteem* as they lose confidence in themselves and their capabilities. Non-disclosure and secrecy prohibit an orphaned child from healthy expressing their emotions and concerns about stressful event contributing towards poor *emotional well-being*.

The *self-esteem and self-concept* are similarly, affected by **internalized stigma (F3)**. Children orphaned by AIDS hold a negative view of themselves as being devalued, tainted and dirty. This not only presents the poor *self-concept* embodied by children orphaned by AIDS but represents their psychological suffering. A poor *self-esteem* cultivates a lack of confidence in a stigmatised child ultimately, negatively impacting their *future orientation*.

Consequentially all forms of HIV-related stigma results in emotional distress for children orphaned by AIDS negatively affecting the *emotional well-being*. To efficiently deal with and minimize emotional distress, children orphaned by AIDS adopt *emotion-focused coping strategies* likely to hinder healthy emotional regulation and reinforce a negative emotional status. In the absence of social support and healthy interpersonal relationships combined with experiences and perceptions of HIV-related stigma these children are unable to healthily express themselves and continue to supress their emotions leading to poor emotional regulation and a negative emotional status indicating poor *emotional well-being*. Emotional well-being directly affects the psychological well-being perpetuating psychological distress and internalizing psychopathological symptoms.

Biographical Information	
Name:	**Surname:**
Gender:	**Sex:**
Institution:	
Occupation:	
Area of interest/specialization:	

The **survey,** presented below, evaluates the (1) Clarity; (2) Simplicity; (3) Generalizability; (4) Accessibility; (5) and Importance of the developed model.

Indicate your response with one of the following options: ***(1) strongly disagree; (2) strongly disagree; (3) agree; (4) strongly agree.***

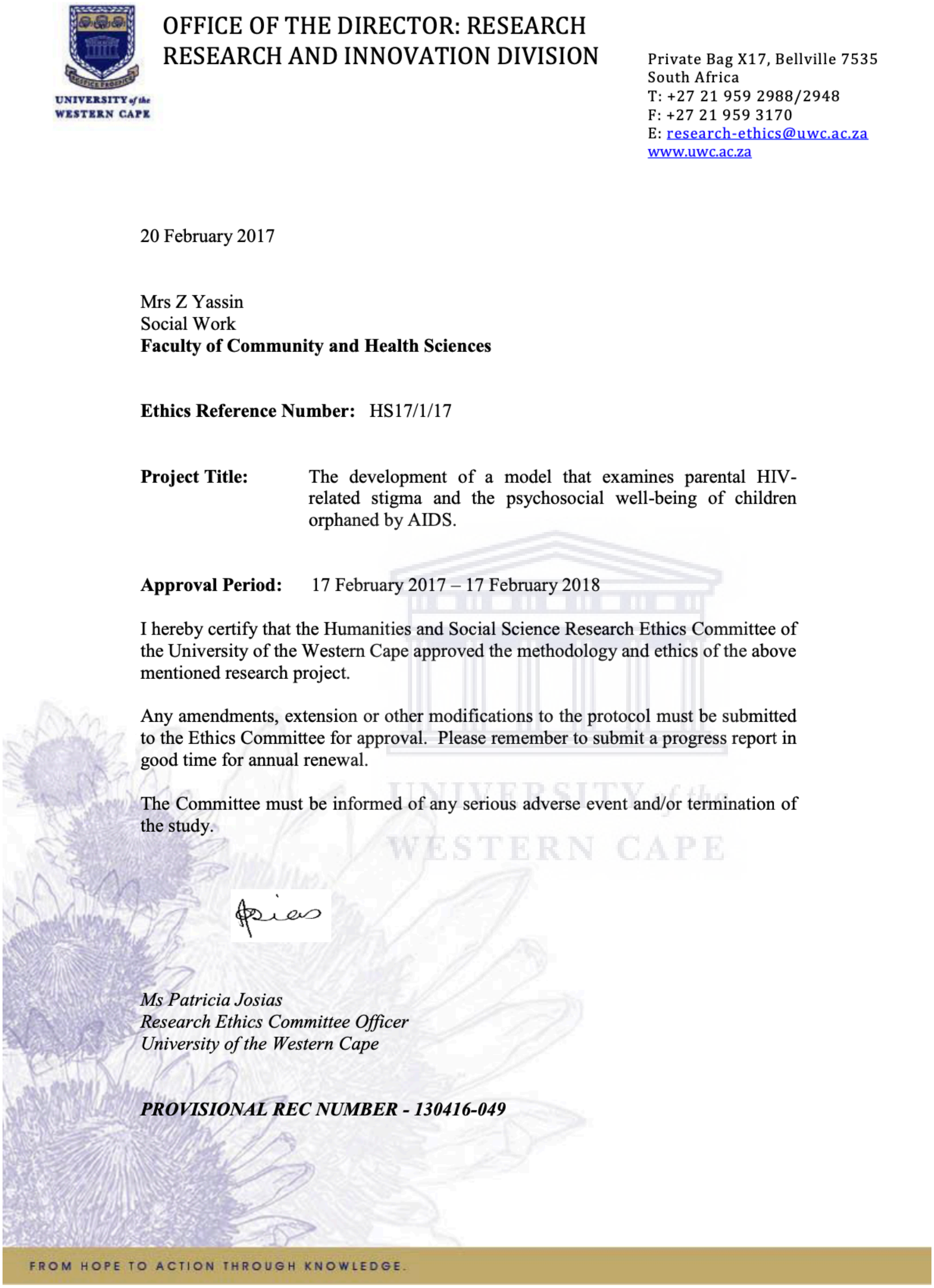
EVALUATION OF A SOCIAL TRANSACTIONAL MODEL OF HIV-RELATED STIGMA AND THE PSYCHOSOCIAL WELL-BEING OF CHILDREN ORPHANED BY AIDS				
CLARITY OF THE MODEL	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
Focal concepts of the model are made explicit and identifiable				
Focal concepts within the model are well defined				
Definitions of concepts in the model are specific and applicable				
The explanation of concepts is appropriate and useful				
The view of person and environment is compatible				
Relationships within the model are identifiable				
All relationships are appropriate and fit within the model				
The order of the model is easily comprehended				
SIMPLICITY OF THE MODEL				
The relationships within the model are easily identified				
The relationships within the model are organised.				
Concepts are differentiated into focal concepts and related concepts.				
Concepts can be combined without losing theoretic meaning				
The model is simplistic and fosters a clear understanding throughout				

The model aims to describe, explain, or predict phenomenon				
GENERLIZABILITY OF THE MODEL				
The purpose of the model is clear and specific				
The model can be applied to all practice areas dealing with HIV-related stigma and child psychosocial well-being				
The model is specific to the interest area of health-related stigma and child well-being				
A wide range of professionals and researchers may use the developed model				
Concepts of the model may be meaningfully applied				
ACCESSIBLITY OF THE MODEL				
Concepts are identifiable in experience/practice				
Definitions provided for the concepts adequately reflect their meanings				
SIGNIFICANCE OF THE MODEL				
The model has potential to influence current understanding and practice				
The model may be used to understand the subject area for which it is developed				
The model provides a general framework in which to act or a means to predict phenomena				
Given the purpose of the model and its orientation, significant factors have been adequately covered				

The stated purpose is one that is important to health-related stigma and the well-being of vulnerable children				
The use of the model will be helpful in respective fields and research				
The application of the model will resolve issues in research, programmes and practice				
The model is futuristic and future looking				
Research based on the model will provide answers to important questions				

THANK YOU FOR YOUR PARTICIPATION

Appendix 9: Ethics Clearance Letter



UNIVERSITY of the WESTERN CAPE

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20 February 2017

Mrs Z Yassin
Social Work
Faculty of Community and Health Sciences

Ethics Reference Number: HS17/1/17

Project Title: The development of a model that examines parental HIV-related stigma and the psychosocial well-being of children orphaned by AIDS.

Approval Period: 17 February 2017 – 17 February 2018

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER - 130416-049

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 10: Information Sheet

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INFORMATION SHEET

Project Title: The development of a model that examines HIV-related stigma and the psychosocial well-being of orphaned children

What is this study about?

This is a research project being conducted by Zeenat Yassin at the University of the Western Cape. We are inviting your child to participate in this research project because they have experience of being orphaned as a result of HIV/AIDS**.** The purpose of this research project is to understand their experience of any stigmatisation resulting from parental illness or death and how it has acted to affect their psychosocial well-being. Participants will assist in the development of a model to understand the manner in which HIV-relate stigma has affected the psychosocial well-being of children orphaned by HIV/AIDS.

What will I be asked to do if I agree to participate?

Participants will be expected to participate in individual interviews with the researcher and will have to answer questions that the researcher will ask them. The questions will deal with HIV-related stigma and psychosocial health of children orphaned by AIDS. The interviews will be held in a non-threating environment, preferably at the facilities of the non-profit organisation through which you have been contacted. The interview will be no longer than an hour long**.**

Would my participation in this study be kept confidential?

The researchers undertake to protect their identity and the nature of their contribution. To ensure their anonymity pseudonym names will be used so that participant's identity may be kept anonymous, and no documents will be recorded under your name. An identification key will be linked to your identity and will only be available to the researcher. To ensure your identity remains anonyms all information is kept in a locked cupboard and identification codes will be placed on the data. If a report or an article is written, your identity will be protected. This research study will use a tape recording. The reports will be kept in a locked compartment with only the researcher and research supervisor having access to the information. The research findings will not include any of your personal details.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities' information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities

What are the risks of this research?

There may be some risks from participating in this research study. All human interaction and conversations about others and yourself may pose certain risks. We will try to minimize the risks as best as possible and will provide the necessary support if you have any discomfort, either psychologically or otherwise during your participation in the study. If necessary, will be a reference is made to an appropriate professional for support

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about HIV-related stigma and its impact on children who have been orphaned. We hope that, in the future, other people might benefit from this study through improved understanding of the how HIV-related stigma has affected the livelihoods, social and psychological well-being of children orphaned by AIDS-related causes.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. If the participant displays any signs of psychological distress or non-verbal cues of unwillingness to participate, participation shall be terminated.

What if I have questions?

If you have any questions regarding the study and your rights as a participant or if you experience any problems regarding the study, please contact the following persons

This research is being conducted by Zeenat Yassin at the University of the Western Cape. If you have any questions about the research study itself, please contact Zeenat Yassin at: 061 411 7267 or 3119420@myuwc.ac.za.

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

Head of Deparetment: Prof Schenk
Social Work Department
University of the Western Cape
Private Bag X17
Bellville 7535
Email: schenck@uwc.ac.za

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

This research was approved by the University of the Western Cape 's Senate Research and Ethics Committee.

UNIVERSITEIT VAN DIE WES-KAAP

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592459, Fax: 27 21-9593686
E-mail: cjerasmus@uwc.ac.za

INLIGTINGSBLAD

Projek Titel: **Die ontwikkeling van 'n model wat MIV- verwante stigma en die psigososiale welstand van weeskinders ondersoek**

Waaroor handel die studie?

Hierdie is 'n navorsingsprojek deur Zeenat Yassin gedoen aan die Universiteit van die Wes-Kaap . Ons nooi jou kind om deel te neem in hierdie navorsingsprojek, want hulle het ondervinding van weeskinders as gevolg van MIV/vigs. Die doel van hierdie navorsingsprojek is om hul ervaring van enige stigmatisering as gevolg van ouers se siekte of dood en hoe dit opgetree het om hul psigososiale welstand beïnvloed te verstaan . Deelnemers sal help met die ontwikkeling van 'n model om die wyse waarop MIV - verband stigma het die psigososiale welstand van kinders wat deur MIV/vigs geraak word verstaan .

Wat sal van my verwag word as ek deelneem aan die studie?

Deelnemers sal verwag word om deel te neem in individuele onderhoude met die navorser en sal vrae wat die navorser hulle sal vra beantwoord . Die vrae sal hanteer MIV-verwante stigma en psigososiale gesondheid van kinders wat wees gelaat deur vigs . Die onderhoude sal gehou word in 'n nie - threating omgewing , verkieslik by die fasiliteite van die nie-winsgewende organisasie waardeur jy gekontak is . Die onderhoud sal nie langer as 'n uur lank wees .

Word my deelname in die studie vertroulik gehou?

Die navorser onderneem om u identiteit en die aard van u bydrae te beskerm. U sal anoniem gehou word, ʼn skuilnaam sal gebruik word en geen dokumentasie sal onder u naam aangeteken word nie. ʼn Identifikasie sleutel sal aan u identiteit gekoppel word en sal slegs aan die navorser bekend wees. Om u identiteit te verseker sal allle inligting in ʼn geslote kas gehou word en identifikasie kodes sal op die data geplaas word.

Indien ŉ verslag of ŉ artikel geskryf word, sal u identiteit ook beskerm word. Hierdie navorsingstudie sal gebruik maak van ŉ band opname. Toestemming sal van u verkry word om u op te neem en die onderhoude sal beskerm word deur ŉ wagwoord te plaas op die rekenaars wat vir die doel gebruik gaan word.

Na aanleiding van die regs vereistes en professionele standaarde word dit verwag dat enige inligting met betrekking to kinderverwaarlosing, mishandeling of moontlike skade aan persone aangemeld word by die toepaslike professionele persone. U sal dan ingelig word dat indien die vertrouens verhouding verbreek sou word, en ook indien hierdie inligting aan die betrokke owerheid gerapporteer word.

Wat is die risikos in die navorsing?

Daar mag risikos wees in die navorsing. Alle menslike interaksie en gesprekke oor ander en jouself mag sekere risikos inhou. Ons sal egter probeer om die meesste risikos te minimaliseer en sal die nodige ondersteuning bied indien u enige ongemak, hetsy psigologies of andersins ervaar gedurende u deelname in die studie. Indien noodsaaklik, sal `n verwysing gemaak word na ŉ geskikte professionele persoon vir ondersteuning.

Wat is die voordele van die navorsing ?

Die navorsing is nie ontwikkel om jou persoonlik te bevoordeel nie, maar die resultate sal egter die navorser help om HIV stigma en die invloed daarvan, te verstaan. Ons hoop dat ander persone in die toekoms baat sal vind by hierdie studie .

Moet ek deel wees van die studie en mag ek my enige tyd van die studie onttrek?

Jou deelname in die navorsing is heeltemal vrywilliglik. Jy mag kies om nie deel te neem aan die studie nie. Indien jy besluit om nie deel te wees nie of om enige tyd jou te onttrek van die studie, mag jy nie gepenaliseer word nie en sal jy dus nie enige voordele verloor nie.

Wat indien ek enige vrae het?

Hierdie navorsing word uitgevoer deur Zeenat Yassin by die Universiteit van Wes-Kaap. Indien u enige vrae het oor die navorsing studie, kontak Zeenat Yassin: 0761098511.

Indien u enige vrae het met betrekking tot die studie en jou regte as `n deelnemer of indien u enige problem ervaar met betrekking tot die studie, kan u die volgende persone kontak:

Hoof van die Departement: Prof Schenk
Departement van Maatskaplike Werk
Universiteit van Wes-Kaap
Privaatsak X17
Bellville 7535
Epos:schenck@uwc.ac.za
Tel: 021 09592011
Dekaan van die Fakulteit Gemeenskap en Gesondheids Wetenskappe:
Prof José Frantz
Universiteit Wes-Kaap
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Hierdie navorsing is goedgekeur deur die Universiteit van Wes-Kaap se Senaat Navorsing en Etiese Komitee.

Appendix 11: Informed Consent

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2459, Fax: 27 21-959 3686
E-mail: cjerasmus@uwc.ac.za

CONSENT FORM

Title of Research Project: The development of a model that examines HIV-related stigma and the psychosocial well-being of orphaned children

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my child's participation will involve and I agree to their participation of my own choice and free will. I understand that their identity will not be disclosed to anyone. I understand that my child may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Parent/ Legal Guardian name………………………..

Parent/ Legal Guardian signature……………………………….

Date……………………

UNIVERSITEIT VAN WESKAAP

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2459, Fax: 27 21-959 3686
E-mail: cjerasmus@uwc.ac.za

TOESTEMMINGS VORM

Titel van die Navorsings Projek: Die ontwikkeling van 'n model wat MIV- verwante stigma en die psigososiale welstand van weeskinders ondersoek

Die studie is beskryf in die taal wat ek verstaan. My vrae oor die studie is beantwoord. Ek verstaan wat my deelname sal behels en ek kom ooreen dat ek vrywilliglik en uit eie keuse deel neem aan die studie. Ek verstaan dat my identiteit nie bekend gemaak sal word nie. Ek verstaan dat ek enige tyd mag onttrek van die studie sonder om `n rede te verskaf en sonder om enige vrees of negatiewe gevolge of skade te lei.

Ouer/wettige voog se naam………………………..

Ouer/wettige voog se handtekening……………………………….

Datum………………………

Appendix 12: Informed Assent

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2459 Fax: 27 21-959 3686
E-mail: cjerasmus@uwc.ac.za

ASSENT FORM

Title of Research Project: The development of a model that examines HIV-related stigma and the psychosocial well-being of orphaned children

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Parent/legal guardian's name………………………..

Parent/legal guardian's signature……………………………….

Date………………………

UNIVERSITEIT VAN WESKAAP

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2459, Fax: 27 21-959 3686
E-mail: cjerasmus@uwc.ac.za

INSTEMMINGS VORM

Titel van die Navorsings Projek: Die ontwikkeling van 'n model wat MIV- verwante stigma en die psigososiale welstand van weeskinders ondersoek

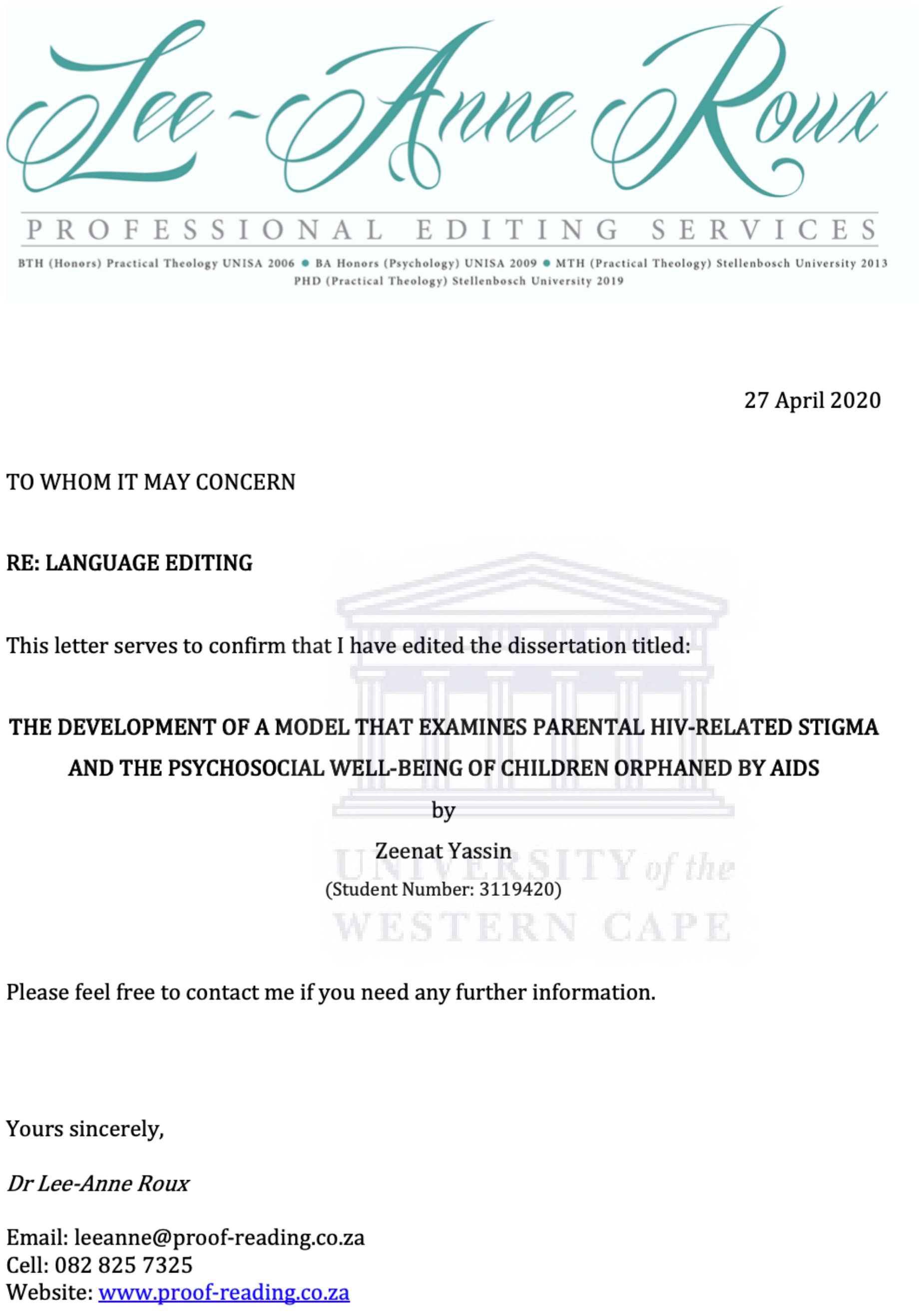
Die studie is beskryf in die taal wat ek verstaan. My vrae oor die studie is beantwoord. Ek verstaan wat my deelname sal behels en ek kom ooreen dat ek vrywilliglik en uit eie keuse deel neem aan die studie. Ek verstaan dat my identiteit nie bekend gemaak sal word nie. Ek verstaan dat ek enige tyd mag onttrek van die studie sonder om `n rede te verskaf en sonder om enige vrees of negatiewe gevolge of skade te lei.

Ouer/wettige voog se naam………………………..

Ouer/wettige voog se handtekening……………………………….

Datum………………………

Appendix 13: Editor's Letter



Lee-Anne Roux
PROFESSIONAL EDITING SERVICES
BTH (Honors) Practical Theology UNISA 2006 ● BA Honors (Psychology) UNISA 2009 ● MTH (Practical Theology) Stellenbosch University 2013
PHD (Practical Theology) Stellenbosch University 2019

27 April 2020

TO WHOM IT MAY CONCERN

RE: LANGUAGE EDITING

This letter serves to confirm that I have edited the dissertation titled:

THE DEVELOPMENT OF A MODEL THAT EXAMINES PARENTAL HIV-RELATED STIGMA AND THE PSYCHOSOCIAL WELL-BEING OF CHILDREN ORPHANED BY AIDS

by

Zeenat Yassin
(Student Number: 3119420)

Please feel free to contact me if you need any further information.

Yours sincerely,

Dr Lee-Anne Roux

Email: leeanne@proof-reading.co.za
Cell: 082 825 7325
Website: www.proof-reading.co.za