

**A systematic review: The impact of stigmatisation on HIV/AIDS orphans
psychological health**

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Abstract

Since the inception of the HIV/AIDS epidemic, millions of individuals of all ages have been affected. To date, more than 15 million people have died from HIV/AIDS, resulting in a substantial increase in the number of orphans worldwide. AIDS orphans are not spared from the catastrophic outcomes of the virus but rather are critically affected by the presence of familial HIV/AIDS. They have come to be seen as a vulnerable population of the youth who are neglected and ineffectively educated and cared for. Numerous risk factors and outcomes have been identified for AIDS orphans, such as parental bereavement, poverty, financial strain, the loss of educational opportunities, and stigmatisation. Although these risk factors and outcomes may be present among all orphaned youth, AIDS orphans display higher levels of psychological difficulties and distress than youth orphaned by other causes. Scholars have begun to investigate the association of AIDS orphans with a highly stigmatised disease in the hope of uncovering possible explanations. This research has become a challenging task as there is insufficient filtered information examining the effects of HIV-related stigma on the psychological well-being of AIDS orphans. With limited knowledge, it is impossible to accurately illustrate or address the risk that HIV-related stigma poses to the psychological well-being of AIDS orphans. The present study aimed to examine and report on the effects of HIV-related stigma on the psychological well-being of AIDS orphans who have lost one or both of their parents to HIV/AIDS.

The study employed a systematic review methodology which identified and critically evaluated relevant literature for inclusion and provided a descriptive meta-synthesis of findings. The review considered studies reporting on the effects of HIV-related stigma on the psychological well-being of AIDS orphans that were published during the period 2004–2015. The review was conducted in four systematic steps. Firstly, potential titles were identified using predetermined

sets of keywords in databases available at the University of the Western Cape. Secondly, the abstracts of potential titles were screened for relevance to the study and were promoted to the next level of review. Thirdly, the full text of the studies of all eligible abstracts were retrieved and evaluated for methodological quality using a critical appraisal tool. Eligibility for inclusion was determined by a predetermined threshold score of 80%. Lastly, studies included in the present study were subjected to a process of data extraction. Subsequently, the title search yielded 5473 prospective titles of which 96 titles were identified for possible inclusion. Abstract screening excluded 59 titles, and the difference of 37 studies were included. Critical appraisal of potential studies excluded 28 studies, and the remaining 9 studies were deemed eligible for the purpose of the present study, achieving the threshold score of 80% and above and have been included in the review. The theory explication meta-synthesis and line of argument forming the discussion of findings revealed that AIDS orphans are critically affected by various measures of HIV-related stigma. The central feature extracted from the included studies was the increase of psychological distress and poor psychological functioning of AIDS orphans resulting from HIV-related stigma. Stigma acted to perpetuate poverty, the loss of educational opportunities and the process of bereavement, while leading to an increase in depression, anxiety, post-traumatic stress, conduct disorder, adjustment disorder and delinquency among AIDS orphans. In conclusion, AIDS orphans experienced all measures of HIV-related stigma resulting in an increase of psychological distress accompanied by lower levels of poor-psychological functioning.

Keywords

HIV/AIDS

Stigma

Discrimination

AIDS orphans

Psychological distress

Children

Mental health

HIV-related stigma



Declaration statement

I hereby declare that the dissertation ‘A systematic review: The impact of stigmatisation on HIV/AIDS orphans psychological health’ is my own work and that all resources that were used or during the research study are indicated by means of a complete reference and acknowledgement.

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Date: 22 November 2015

Dedication

This dissertation is dedicated to my loving fiancé, Shane Craig Burns, who has devotedly supported and encouraged me throughout my academic career.



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List of Acronyms

Human immunodeficiency virus (HIV)

Acquired immune deficiency syndrome (AIDS)

People living with HIV and AIDS (PLWHA)

Socioeconomic status (SES)

Preferred reporting items for systematic reviews and meta-analyses (PRISMA)

The critical appraisal tool (CASP)



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CHAPTER ONE

Introduction

1.1 Background and Rationale

Since the inception of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), millions of individuals, including children, have been affected of whom more than 15 million have died (Foster & Williamson, 2000). Worldwide efforts to counteract and prevent the spread of HIV/AIDS and reduce its effects have been implemented. Despite these efforts, the prevalence of infections and mortality rates continue to grow, leading to severe social ramifications (Zhao, Li, Kaljee, Zhang, Fang, Zhao, Lin, Lin, & Stanton, 2009). Owing to the catastrophic outcomes of HIV/AIDS, a large population of children has lost one or both parent/s to HIV/AIDS (UNICEF, 2006). Boyes & Cluver (2013) stated that the HIV/AIDS epidemic has resulted in a substantial increase in orphanhood worldwide. Additionally, UNICEF estimates that 40 million youths will be orphaned by the year 2020 (Maughan-Brown, 2010).

HIV/AIDS orphans have been described as a vulnerable population of the youth (Boyes & Cluver, 2013; Delva, Vercountere, Loua, Lamah, Vansteelandt, De Koker, Claeys, Temmerman, & Annemans, 2009), who have been neglected; ineffectively educated, socialised and cared for; and overlooked as much more focus was placed on the adult population, and the transmission of the virus and its treatment (Wild, 2001). Recent literature (Thupayagale-Tshweneagae, 2011) has begun to acknowledge children orphaned by HIV/AIDS and have recognised that children are critically affected by their parents' HIV status. Cluver, Gardner & Operario (2007) stated that HIV/AIDS orphans are at higher risk of

experiencing psychological distress owing to the psychosocial consequences placed upon them by parental HIV/AIDS. Numerous risk factors and outcomes for HIV/AIDS orphans have been identified, such as bereavement, poverty, financial strain, poor healthcare, inadequate educational opportunities and stigma (Zhao, et al., 2007). Furthermore, studies (Thupayagale-Tshweneagae, 2011; Zhao, et al., 2007) have suggested that HIV/AIDS orphans attain higher levels of psychological difficulties than non-orphans or individuals orphaned by other causes. However, such distress may be brought about by one's exposure to innumerable risk factors (Zhao, et al., 2009). Unmistakably, stigmatisation has been identified as a risk factor affecting the well-being of HIV/AIDS orphans (Deacon & Stephney, 2007). However, with limited knowledge about HIV-related stigma directed at AIDS orphans, it becomes a daunting task to accurately identify the physical and psychological outcomes for AIDS orphans (Cluver, et al., 2007). To accurately illustrate the risk of HIV-related stigma as a predisposing factor for the development of psychological distress amongst AIDS orphans, an adequate understanding of the development and maintenance of stigma needs to be achieved (Deacon, 2006).

Owing to the lack of a common theoretical perspective on stigma and its multifaceted nature, it has become a challenging task to define the concept of stigma (Link & Phelan, 2001). Likewise, Earnshaw & Chaudoir (2009) identified the lack of a comprehensive framework for understanding HIV-related stigma as the fundamental reason for the maintenance of stigma and discrimination. Generally, stigma is defined as an attribute that discredits, differentiates and marks the victim as bad, dangerous or weak (Goffman, 1963). Such negative value judgments made by society lead to the view that stigmatised individuals pose a threat to society's values and safety (Stuenkel & Wong, 2009). These stigmatised individuals evoke a sense of anxiety and apprehension as they remind society of their morality and its

vulnerability. As it is within human nature that individuals strive to protect themselves against threats within society, it comes as no surprise that stigmatised individuals are subjected to moral judgment leading to social exclusion, stigmatisation and discrimination (Stuenkel & Wong, 2009). Discredited individuals are viewed as less worthy and valuable within society as they have been labeled as different or deviant. It is significant to note that stigma is interwoven with the concepts of self-worth and self-esteem (Stuenkel & Wong, 2009).

Furthermore, stigma has been identified as a socially constructed concept, which is constantly negotiated and renegotiated, and may be viewed as the discrediting of others which arises from beliefs about personality, behaviour, traits and illness that are communicated to others through the process of socialisation (Stuenkel & Wong, 2009). Although this explanation accounts for the process of socialisation in the development and maintenance of stigma, it fails to account for the political, economic and psychological facets that ground the existence of stigma (Parker & Aggleton, 2003).

Stigma has been acknowledged as a social and cultural phenomenon grounded in social conditions to construct and maintain social inequalities (Parker & Aggleton, 2003). The complexity of stigma outlined by the views of these scholars contributes to the inability of reaching a consensus when defining stigma and HIV-related stigma. Likewise, scholars have not reached a clear consensus when defining HIV-related stigma; however, it may be defined as ‘prejudice, discounting, and discrediting directed at people living with HIV/AIDS (PLWHA), and groups and communities with which they are associated’ (Lin, Zhao, Stanton, Zhang, Hong, Zhao & Fang, 2010, p. 545).

HIV/AIDS has been recognised as one of the most stigmatising diseases in history (Boyes & Cluver, 2013). This is largely because of the virus’ infectious nature which is considered self-

inflicted by an individual's engagement in socially unacceptable behaviour (Stuenkel & Wong, 2009). HIV-related stigma is often experienced by individuals living with the virus but is frequently extended to those related to people living with HIV/AIDS (Pomeroy, Rubin, & Walker, 1995). HIV-related stigma has been extended to youth who have lost either one or both of their parents to HIV/AIDS. A pressing question arises of how can we ensure the psychological health, well-being and positive development of HIV/AIDS orphans when we cannot grasp the social concept of HIV-related stigma.

Psychological distress among AIDS orphans may be exacerbated by the consequences of parental illness and death, which have been identified as: financial burden, household poverty, food insecurity and unemployment (Booyesen, 2002). However, AIDS orphans are susceptible to vulnerability and may frequently experience stigma and discrimination. Bauman, Camacho, Silver, Hudis & Draimin (2002) suggest that AIDS orphans may encounter hostility from their community and extended family, leading to rejection, and limited access to education, health care and social support. These experiences of discrimination and stigmatisation are independent of stressors associated with parental illness and death, resulting in a heavier psychological burden for AIDS orphans (Delva, et al., 2009). HIV-related stigma has been identified as a chief dissimilarity between HIV/AIDS orphans and individuals who are orphaned by other factors (Boyes & Cluver, 2013). HIV/AIDS orphans have reported experiencing high levels of HIV-related stigma in various forms such as rejection, verbal abuse, physical assault and even homicide (Boyes & Cluver, 2013).

Although limited studies exist that examine the relationship between HIV-related stigma and psychological distress among HIV/AIDS-orphans, few studies (Kheswa & Duncan, 2011; Bougart, Cowgill, Kennedy, Ryan, Murphy, Elijah & Shuster, 2008; Adejuwon & Oki, 2011; Zhao, et al., 2009; de Witt & Lessing, 2010; Lin, et al., 2010; Louw, Mokhosi, & van den

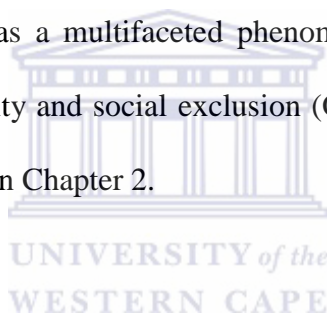
Berg, 2012; Boyes & Cluver, 2013) suggest the development of psychological distress as a result of HIV-related stigma. However, one cannot assert that such findings are an accurate reflection of psychological outcomes among AIDS-orphans for numerous reasons. Foremost, there is no existing theoretical framework that examines the effects of HIV-related stigma on the psychological well-being of people living with HIV/AIDS (PLWHA) or those affected by the virus (Earnshaw & Chaudoir, 2009). The lack of such a theoretical framework presents a gap in current literature hindering our ability to accurately capture HIV-related stigma's contribution to the development of psychological distress among AIDS orphans (Link & Phelan, 2001; Deacon, 2006).

Considering the rapid spread of HIV/AIDS internationally, the present study aims to vigorously review primary literature in order to establish a pragmatic base of knowledge by using a systematic review methodology. This base of knowledge explores the social construction and implementation of HIV-related stigma, and the effects of HIV-related stigma on the psychological well-being of HIV/AIDS orphans, and also fosters an understanding of how the presence of HIV-related stigma contributes to the development of psychological distress. The knowledge generated by the study could be used to inform further research, intervention programmes and psycho-educational strategies aimed at combating HIV-related stigma and reducing its effects.

1.2 Theoretical Framework

The modified hidden distress model proposed by Steward, Herek, Ramakrishna, Bharat, Chandy, Wrubel & Ekstrand (2009) and Goffman's (1963) work on stigma is extended and used interchangeably to provide an adequate theoretical framework for understanding HIV-related stigma and its effects on the psychological health of AIDS orphans. Although, neither

of the frameworks are developed for understanding HIV-related stigma it may be used to shed light on HIV-related stigma and increased levels of psychological distress. While Goffman (1963) aims to explain the social creation and enactment of stigma, Steward, et al. (2009) provides an understanding of how various types of stigma arouse psychological distress. Four types of stigma were identified, namely enacted stigma, vicarious stigma, felt stigma and internalised stigma, as predisposing factors to the development of psychological distress in stigmatised individuals (Steward, et al., 2009). Unlike the work of Goffman (1963), the hidden distress model accounts for HIV-related stigma's contribution towards psychological distress experienced by PLWHA and those with whom they are associated. Although these theories focus on different aspects of stigma and the process of stigmatisation, both theorists recognise stigma as a multifaceted phenomenon, cultivated by society, and leading to deviance from normality and social exclusion (Goffman, 1963). These theoretical frameworks are further explored in Chapter 2.



1.3 Problem Statement

Insufficient filtered information examining the relationship between HIV/AIDS orphans, psychological health and HIV-related stigma exists. It has become challenging to accurately illustrate the nature and severity of the problem both locally and internationally. An initial search of studies revealed that there is no other systematic review on the topic. Therefore, there is a lack of filtered articles whose methodologies have not been rigorously and systematically evaluated along predetermined criteria. Together with insufficient filtered literature and much uncertainty, we cannot attempt to understand or adequately address the impact that HIV-related stigma has on the psychological development of HIV/AIDS orphans. Although there are existing studies of the phenomenon, it is a rather challenging task to amalgamate existing evidence when a rigorous assessment has not been carried out. The

present study aimed to provide a body of knowledge comprising high-quality studies focusing on the effects of HIV-related stigma on the psychological well-being of HIV/AIDS orphans.

1.4 Research Questions

- What is the prevalence of HIV-related stigma among AIDS orphans?
- What are the outcomes of HIV-related stigma on the psychological well-being of HIV/AIDS orphans?
- What is needed for the reduction of HIV-related stigma experienced by AIDS orphans?

1.5 Aim and Objectives

1.5.1 Aim of the Study

The aim of the current systematic review is to examine and report on the effects of HIV-related stigma on the psychological well-being of orphans who have lost one or both of their parents to HIV/AIDS.



1.5.2 Objectives of the Study

The objectives of the present research study were:

- to assess the prevalence of HIV-related stigma among AIDS orphans
- to identify the effects of HIV-related stigma on the psychological wellbeing of AIDS orphans
- to systematically appraise the methodological rigour of studies exploring the relationship between HIV-related stigma and the psychological well-being of AIDS orphans.

1.6 Research Methodology

The study used a systematic review methodology, which is defined as an explicit and systematic method used to integrate evidence reported by a group of inter-related studies on a specific phenomenon to yield reliable and unbiased findings (Higgins & Green, 2011). A systematic review is regarded as the cornerstone of empirical research as it strives to provide deductions from a broad range of inter-related studies in order to address the current problem under examination. This promise is achieved by filtering through relevant studies for the identification of existing evidence, the shortfall of literature and the variance of findings across studies (Higgins & Green, 2011; Sandelowski, 2008). The present systematic review critically filters and evaluates peer reviewed, full-text studies in the English medium, between the years 2004 and 2015, and includes studies of qualitative, quantitative and mixed methodologies. These studies were retrieved from databases available in the library of the University of the Western Cape and that report on the effects of HIV-related stigma on the psychological health of HIV/AIDS orphans between the ages of 6 and 18 who have lost one or both of their parents to HIV/AIDS.

The study's assessment strategy is divided into a four-step process, namely Identification, Screening, Eligibility and Inclusion. Meta-synthesis is then used to amalgamate findings extracted from various included studies within an inter-related group of studies to provide a holistic and deeper understanding of the phenomena while forming a pragmatic body of knowledge from which conclusions may be drawn (Finfgeld, 2003). The detailed explanation of the systematic procedure and data collection is in Chapter 4. The results and the discussion of the systematic review are set out in Chapters 5 and 6 respectively.

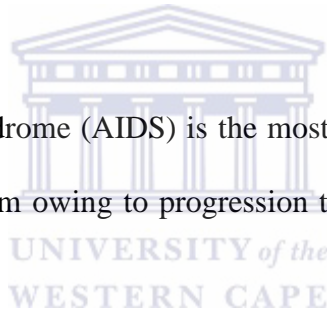
1.7 Definition and Descriptions of Key Concepts and Terms

1.7.1 Human immunodeficiency virus (HIV)

HIV is an intractable retrovirus that causes acquired immunodeficiency syndrome (AIDS), the most advanced stage of HIV infection. There are two strands of HIV, namely HIV-1 and HIV-2. Both types are transmitted through direct exposure and contact with HIV-infected body fluids such as blood, semen and genital secretions. Additionally, transmission may occur by HIV-positive mother-to-child transmission during the processes of pregnancy, birth and breastfeeding. HIV destroys CD4 lymphocytes, leaving the body vulnerable to life-threatening infections, diseases and cancers by weakening an individual's immune system and causing immunodeficiency (AIDSinfo, 2011).

1.7.2 Acquired immunodeficiency syndrome

Acquired immunodeficiency syndrome (AIDS) is the most advanced stage of HIV. It results in a disease of the immune system owing to progression to the final stage of HIV infection (AIDSinfo, 2011).



1.7.3 Hidden Distress Model

Scambler's (1989) hidden distress model is a theoretical framework that considers the development of psychological distress as a response to the experience of enacted and felt stigma and discrimination. Steward, et al. (2009) extend the hidden distress model to include both intrapersonal experiences and interpersonal actions of stigma, surpassing the idea that psychological distress is the result of felt stigma. They proposed four types of stigma, namely enacted stigma, vicarious stigma, felt stigma and internalised stigma, that contribute to the development of psychological distress experienced by PLWHA (Steward, et al., 2009).

1.7.4 People living with HIV and AIDS

PLWHA refers to 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).

1.7.5 Psychological distress

Psychological distress is defined as a state of emotional suffering characterised by symptoms of depression and anxiety, such as sadness, hopelessness, restlessness, etc. along with the presence of somatic symptoms (Drapeau, Marchand, & Beaulieu-Prévost, 2012), or as the exposure to a stressful event that threatens an individual's physical and mental well-being, or the inability to effectively deal with encountered stressors leading to emotional distress (Horwitz, 2007).

1.7.6 AIDS orphans

HIV/AIDS orphans can be defined as children, adolescents or youth whose parents have died as a result of HIV/AIDS infection. These orphans may be categorised as either single or double orphans. Youth who have lost one parent are regarded as single orphans while those who have lost both parents are classed as double orphans (Zhao, et al., 2009).

1.7.7 HIV-related stigma

HIV-related stigma refers to the prejudice, discounting and discrediting directed at PLWHA and may be extended to individuals, groups and communities with whom these individuals are associated (Steward, et al., 2009; Herek, 2005). Four types of stigma are often discussed in relation to HIV-related stigma, namely enacted stigma, vicarious stigma, felt stigma and internalised stigma.

1.7.7.1 Enacted stigma embodies the real actions and experiences of stigmatisation and discrimination by the target of stigmatising beliefs, behaviours and attitudes (Steward, et al., 2009; Goffman, 1963).

1.7.7.2 Vicarious stigma is consistent with the social learning theory and refers to the witnessing or hearing about the experiences of enacted stigma of others which is likely to result in an increase in felt stigma (Bandura, 1979).

1.7.7.3 Felt stigma (also known as received stigma) refers an individual's perception of all types of stigmatising attitudes and behaviours directed towards PLWHA and individuals or groups with whom they are associated (Steward, et al., 2009).

1.7.7.4 Internalised stigma refers to the thoughts, beliefs and behaviour resulting from the individual's personal negative perceptions about themselves which are believed to be true because of their HIV status or their association with the target of stigmatisation and discrimination which are believed to be true (Steward, et al., 2009).

1.8 Structure of Thesis

Chapter One introduces the concept of HIV-related stigma and questions its contribution to the development of psychological distress in AIDS orphans. It covers the introduction, background, problem statement, rationale, purpose of the study, research questions, an overview of the methodology, a brief outline of the theoretical framework, defining concepts and the significance of the undertaken study.

Chapter Two comprises the theoretical framework, with an in-depth overview of the theoretical underpinnings of the study. It introduces the hidden distress model revised by Steward, et al. (2009) and the works of Goffman (1963) in order to provide an understanding of the creation of HIV-related stigma and its associated psychological consequences for

AIDS orphans. Lastly, this chapter offers an extension of these theoretical frameworks to the epidemic of HIV-related stigma of AIDS orphans.

Chapter Three introduces a review of relevant literature that focuses on HIV/AIDS, the increase of orphanhood, stigma and HIV-related stigma, psychological distress and HIV/AIDS-orphanhood. Moreover, it considers the psychosocial effects of AIDS orphanhood and leads a compelling discussion regarding the effects of HIV-related stigma on the psychological well-being of AIDS orphans and its relevance for current research and intervention programmes.

Methodology is outlined in **Chapter Four**. It presents the systematic steps undertaken to assess the relationship between HIV-related stigma and the poor psychological well-being of AIDS orphans, resulting in a justified base of pragmatic knowledge from which conclusions may be drawn. The methodology is divided into 11 subsections, namely aims, objectives, research design, review questions, method of review, retrieval strategy, levels of review, data analysis and ethics considerations.

Detailed tabulated and descriptive accounts of the results obtained in the present systematic review are outlined in **Chapter Five**. This chapter takes the form of a descriptive meta-synthesis which includes the process of results and data extraction presenting the data collected at the various levels of review and all data extracted from included studies.

Chapter Six comprises a theory explication meta-synthesis that provides an integrated discussion of findings, theoretical underpinnings and relevant literature. The discussion is presented in three distinct sections, namely reciprocal translations, refutational synthesis and the line of argument.

In **Chapter Seven**, the conclusions of the study are propounded, which include the executive summary, significance of the study, limitations of the research study and recommendations for future research.

CHAPTER TWO

Theoretical Framework

2.1 Introduction

This chapter provides the theoretical underpinnings for the understanding of HIV-related stigma both as a multi-faceted phenomenon and as a socially constructed process. The work of Goffman (1963) on stigma and the modified hidden distress model adapted by Steward, et al. (2009) has been used interchangeably to provide an adequate framework to guide our thinking on HIV-related stigma and the discussion of our research findings. Goffman (1963) focuses on attributes of an individual rendering them as deviant and different in society while Steward, et al. (2009) critically evaluate the development of the facets comprising stigma and their contribution to one's experience of psychological distress. Both theories account for stigma, an individual's deviance, social exclusion and protective strategies employed to counteract HIV-related stigma. For the purpose of the present research study, both views are significant for understanding HIV-related stigma in relation to the psychological distress experienced by AIDS orphans.

2.2 HIV/AIDS and Stigma

HIV/AIDS has brought about various challenges within societies worldwide, such as HIV prevention, access to health services, human rights protection and appropriate working conditions for infected individuals. Another epidemic, one of stigma which reaches beyond that of the biological facets of the virus, has accompanied these challenges (Varas-Diaz,

Serrano-Garcia, & Toro-Alfonso, 2005). HIV-related stigma has increased significantly along with the steady increase of HIV infections and consequently, owing to the predicted increase in HIV infections, by the year 2020, stigma associated with the virus is likely to have intensified (Varas-Diaz, et al., 2005). HIV-related stigma has formed a barrier to adequate HIV treatment and prevention, which leads to physical and mental health problems for individuals who are both infected and affected by the virus (Earnshaw & Chaudoir, 2009; Steward, et al., 2009; Parker & Aggleton, 2003). Considering the increase and effects of HIV-related stigma, it is imperative that we understand how HIV-related stigma is produced, enacted and contributes to psychological distress. However, the lack of a sustainable theoretical framework hinders our ability to understand how HIV-related stigma is created and enacted (Earnshaw & Chaudoir, 2009). In addition to the lack of a theoretical framework, scholars have not reached a consensus in understanding HIV-related stigma, resulting in various conceptual frameworks that have been developed and extended to understand HIV-related stigma (Link & Phelan, 2001). Reviewing conceptual frameworks that have been developed and extended to understand the effects of HIV-related stigma highlights the lack of a sustainable framework needed to foster an adequate understanding of HIV-related stigma (Link & Phelan, 2001; Deacon, 2006). Some popular conceptual frameworks are briefly discussed below.

Parker & Aggleton (2003) developed a conceptual framework to explain the forming of HIV-related stigma and posed an influential argument that HIV-related stigma arises from the social and political facets that govern and control much-needed resources within society. The focus shifts from stereotyping as a static attribute assigned to an individual, to structural and cultural conditions that produce exclusion from both social and economic life (Parker & Aggleton, 2003; Link & Phelan, 2001). Although this conceptual framework proves valuable

for understanding the multi-faceted underpinnings of HIV-related stigma by examining the relationship between power, inequality and social exclusion, it overlooks the production and experience of psychological distress by stigmatised individuals (Parker & Aggleton, 2003). Likewise, Holzemer, et al. (2007) and Campbell, Foulis, Miamane & Sibiya (2005) have drawn from the works of Parker & Aggleton (2003) to explain HIV-related stigma, arguing that discrimination and stigmatisation needs to be understood as social processes in relation to patterns of power and domination. These extensions of Parker & Aggleton's (2003) conceptual framework have accounted for the social development of HIV-related stigma; however, they continue to overlook the psychological well-being of its victims (Campbell, et al., 2005; Holzemer, et al., 2007). Deacon (2006) attempted to provide a sustainable theory by drawing on the works of Goffman (1963) and Parker & Aggleton (2003). Deacon (2006) stressed the need for an all-encompassing framework in order to foster a deeper understanding of this complex social phenomenon, its origin and the effects on the psychological health of AIDS-orphans. Goffman (1963) provided a social interactionist theory for understanding the origin of stigma and its social nature. He expressed the attribution of difference to individuals and clearly distinguished between the stigmatised, the non-stigmatised and their relation to one another. However, Goffman did not explicitly account for psychological distress experienced by stigmatised individuals (Goffman, 1963).

To explain stigma's contribution to the development of psychological distress, Link, Cullen, Struening, ShROUT & Dohrenwend (1989) formulated a modified labeling approach that draws on Scheff's (1966) model but surpasses its basic elements by asserting that labels are derived from the negative social beliefs held towards behaviour or deviant attributes leading to social exclusion, devaluation and discrimination. However, Link et al. (1989) attributed the increase of psychological distress to felt and internalised stigma. To formulate an all-encompassing

framework for understanding HIV-related stigma, an evaluation of all strands of stigma needs to be conducted to accurately illustrate the effects it has on its victims' lives.

Steward, et al. (2009) provided a modified hidden distress model that accounts for all types of stigma and its contribution to psychological distress experienced by stigmatised individuals. They adapted the notion of felt, enacted and internalised stigma from Scambler's (1989) hidden distress model. After inspection Steward, et al. (2009) felt that these three domains were insufficient and added the notion of vicarious stigma.

Like so many scholars (Varas-Diaz, et al., 2005; Parker & Aggleton, 2003; Deacon, 2006; Steward, et al., 2009; Earnshaw & Chaudoir, 2009), we have drawn on the works of Goffman (1963) and Steward, et al. (2008) to provide a sustainable theoretical framework to guide the understandings and thinking about the effects of HIV-related stigma on the psychological health of AIDS-orphans. As Goffman (1963) accounts for the origin and process of assigning difference to stigmatised individuals, Steward, et al. (2009) provides an understanding of how the origination and production of HIV-related stigma has contributed to the experience of psychological distress of stigmatised individuals. These two theories combined point towards an insightful understanding of the manner in which HIV-related stigma affects the psychological well-being of AIDS orphans.

2.3 Goffman and Stigma

It is important to recognise the HIV/AIDS virus as a multi-faceted phenomenon that far surpasses its biological aspects in order to foster an adequate understanding of how HIV/AIDS has infiltrated and affected our society (Parker & Aggleton, 2003). Parker & Aggleton (2003) recognised three phases of the HIV/AIDS epidemic within a general community. Firstly, HIV-infection occurs while being unnoticeably introduced and

misunderstood within society as it develops over many years. Secondly, as AIDS, the result of HIV infection becomes conceivable within society and lastly, AIDS is followed by the socio-economic, cultural and political responses to HIV/AIDS. However, this third phase is characterised by an epidemic of stigma, discrimination and prejudice as individuals remain in denial, struggling to grasp the rapid change within society (Parker & Aggleton, 2003). HIV/AIDS has affected individuals, households, communities, vulnerable youth and adults, economic growth, stability, private sectors and governmental structures (Attell, 2013). It becomes apparent that HIV/AIDS is both a multi-faceted phenomenon and possessed of a social nature. However, it is a pressing problem that the rate of HIV-related stigma continues to grow. To grasp an understanding of the effects of HIV-related stigma, one must seriously evaluate its origination and implementation within society.

HIV-related stigma has come to be defined as the discrediting, discrimination and exclusion directed towards people living with HIV, or perceived to have HIV, and the individuals, groups and communities with whom they are associated (Herek, 2005). This definition has become elusive in providing a conceptual definition of HIV-related stigma as it fails to account for the geographical and historical factors necessary to understand this phenomenon within the present day. Such a conceptual understanding may be gained by revisiting the work of Goffman (1963), a renowned sociologist who provided a conceptualisation of stigma in his book *Stigma: Notes on the Management of Spoiled Identity*. Although, the works of Goffman (1963) is based on the stigmatisation of individuals suffering from epilepsy, it may be extended to offer an understanding for HIV-related stigma experienced by AIDS orphans.

2.3.1 Defining Stigma

Goffman (1963) defined stigma as a deeply discrediting attribute that a person holds which renders them different and less desirable than the rest of society. He provided the traditional

definition of stigma as a ‘significantly discrediting attribute’ that serves to reduce the stigmatised individual, resulting in a spoiled identity (Goffman 1963, p. 3). A spoiled identity denotes the whole self as bad or not fully human because of the discrediting attribute, condition or behaviour that fails to meet the standards set out by society (Varas-Diaz, et al, 2005; Goffman, 1963).

As there are many reasons for assigning difference and deviance, Goffman (1963) proposed three primary types of stigmatisation, namely abnormalities of the body, blemishes of individual character and tribal stigma. Abnormalities of the body are physical deformities that are visible to others. Contrastingly, blemishes of individual character refer to characteristics of one’s life that are discrediting or simply one’s way of being, such as homosexuality, substance abuse or strong political views. Tribal stigma derives from one’s association with heritages, groups or individuals. Likewise, Major & O’Brien (2005, p. 395) identified similar types of stigma within their study: ‘... 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’. Moreover, Goffman (1963) suggests that stigma is constituted by a discrepancy between the stigmatised individual’s virtual and actual social identity. Virtual identity refers to one’s conformity with the social expectations presented to one within a specific situation and timeframe, while actual identity refers to persons as they truly are. This discrepancy results in stigma, as individuals are branded as different, and devalued within society (Earnshaw & Chaudoir, 2009). Although stigma is constituted by difference, it does not manifest within isolation but rather within social relationships that are referred to as mixed contacts (Goffman, 1963).

Here, Goffman (1963) has accounted for the notion of difference upon which stigma is built. While the work of Goffman (1963) fails to directly account for psychological distress

resulting from stigma, it proves valuable in presenting us with an understanding of how HIV-related stigma is created and assigned to stigmatised individuals, as stigmatisation and its associated effects are described as the most essential and central feature within their lives. This understanding is necessary for conceptualising the manner in which HIV-related stigma has infiltrated the lives of AIDS orphans and contributed to their experience of psychological distress. Although such an understanding is necessary, the pressing question of how stigmatised individuals learn to accept and manage the effects of stigma and their perceived deviance remains (Attell, 2013; Goffman, 1963).

During the process of stigmatisation, stigmatised individuals are forced to manage the causes and effects of stigmatisation when socialising with others categorised as ‘normal’, and in turn learn to accept their perceived deviance (Attell, 2013; Goffman, 1963). Similarly, such acceptance is acknowledged by Crocker, Major & Steele (1998) who declared that stigmatised individuals hold shared understandings of the manner in which the dominant view of their devalued social status is perceived and understood within society. Victims of stigmatisation and discrimination are knowledgeable about the manner in which society perceives and devalues them, based on the dominant cultural and social stereotypes about their identity (Crocker, et al., 1998; Goffman, 1963).

Stigmatisation and deviance arises within the process of socialisation between two broad groupings, namely the own – a group of individuals who have been excluded and stigmatised within society, who form a sense of compassion and understanding amongst each other – and the normal; and those who do not possess the socially devalued characteristic or social deviance, thus placing them in a superior group within society while in turn separating them from ‘the own’ (Attell, 2013). A further group is identified by Goffman (1963) as ‘the wise’: individuals who do not possess the devaluing attribute but are sympathetic and understanding

toward those stigmatised. Through these mixed contacts, stigmatised individuals consciously learn how to socialise with others seeking acceptance and support from the own, and care and support from the wise (Goffman, 1963). Goffman (1963) furthermore explains that stigmatisation does not occur in isolation but rather between social contacts between groups of individuals, and continues to theorise that stigmatised individuals seek acceptance and support. Such acceptance could be described by Goffman's (1963) formulation of a moral career which refers to a structured and patterned way of socialising for individuals who are stigmatised.

2.3.2 The Moral Careers

Principally, there are four moral careers outlined by Goffman (1963). Firstly, an individual may be born with stigma or may be raised in an environment that consciously warns them of their difference. Here an individual learns about the stigmatising beliefs and norms held by society, and consequentially learns to anticipate stigmatising behaviour from others because of their perceived deviance. Equally, an individual may be socialised by society or families that serve as protective capsules against the stigmatised. The support and acceptance received from others acts as a protective factor ensuring the well-being and positive development of the stigmatised. Thirdly, an individual may attain stigma later in life where they must learn to accept their difference. Lastly, an individual who comes of age may leave their safe and protective environment and adapt to the requirements placed on them by the new environment they find themselves in (Attell, 2013; Goffman, 1963). Evidently, Goffman's (1963) conceptualisation of the moral career allows us to understand how a stigmatised individual interacts and socialises within their environment. This concept outlines the importance of social interaction and interpersonal relations for the positive development and central well-being of stigmatised individuals.

2.3.3 Defense Mechanisms Associated with Stigmatisation

Examining the importance of social interactions between designated groupings within society raises a fundamental question of how differences are attributed in order to create social diversions and social exclusion. It is important to understand the manner in which stigma has contributed to social diversions and exclusion when evaluating the effects of stigmatisation on the lives of its victims. Goffman (1963) suggested that differences are perceivable because of information or signs such as prestige symbols, stigma symbols and dis-identifiers carried by individuals throughout their daily lives which may be used by others to assert judgements about those individuals. These judgements may be of both a positive or negative nature; however, the latter results in the formation of stigma (Attell, 2013). Goffman (1963) proposed that individuals maintain power over such information and may control the information that is presented to others to avoid judgement and the attainment of stigma by three core means, namely disassociating from biographical others, passing and covering. Altering or hiding characteristics about oneself may be perceived as methods employed by an individual to avoid or minimise their experiences of overt stigmatisation and discrimination from others. We may disassociate ourselves from biographical others which may be the leading cause of stigma. By escaping the context in which 'the own' co-exist with biographical others, an individual in turn escapes stigmatisation, leaving behind their tainted identity which allows them to construct a new social identity. Passing is an individual's effort to purposively hide a discrediting attribute that may be known about them within various contexts. This form of control relates to one's personal and social identity. Social identity may include an individual's physical activities, professional or occupational roles, and concept of themselves (Markowitz, 1998). The task of passing allows one to meet the social conditions needed to embody a social identity while hiding one's true self in order to avoid

stigmatisation (Attell, 2013; Goffman, 1963). Unlike passing, covering refers to physically hiding an aspect of oneself to avoid stigmatisation. However, the process of controlling information is likely to result in two rather contrasting and ambivalent identities, namely one's personal and social identity. Such ambivalence within an individual may prove troublesome within their lives.

Although disassociation, passing and covering are used by stigmatised individuals to avoid and protect themselves from stigmatising behaviour and attitudes, their use may result in the social isolation and exclusion of stigmatised individuals. Disassociation from biographical others results in inaccessibility of social support, as stigmatised individuals abandon the social support structure currently available to them. Covering and passing cause difficulty in reaching out for support without disclosing threatening information about oneself. Therefore, disassociating oneself from biographical others, covering and passing lead to the inaccessibility of much-needed support, social exclusion and an increase in perceived stigmatising norms and beliefs (Attell, 2013; Goffman, 1963; Steward, et al., 2009). Steward, et al., (2009) suggested that it is important to understand these mechanisms of protection employed by stigmatised individuals as isolation and social exclusion may lead to the development of psychological distress and poor psychological functioning presented by stigmatised individuals. Here it is significant to note that being knowledgeable about the creation and enactment of stigma and the responses of individuals towards stigmatising behaviour and attitudes contributes to the understanding of how such stigmatisation has operated to heighten levels of psychological distress for stigmatised individuals.

Evidently, we can see how Goffman's conceptualisation regarding the creation and enactment of stigma may prove worthy when extending his framework to HIV-related stigma, as living with HIV may potentially be an undesirable attribute or trait within society (Goffman, 1963).

The physical effects, symptoms and deterioration of the body caused by HIV/AIDS may be identified as abnormalities of the body. As HIV is mostly spread through sexual transmission, individuals may be stigmatised simply because of their way of being; this may refer to their sexuality, promiscuity, prostitution and sexual deviance (Parker, Aggleton, Attawell, Pilerwitz, & Brown, 2002). This strand of stigma has been identified as blemishes of individual character (Major & O'Brien, 2005). Tribal stigma focuses on the current study's sample population as stigma is extended to vulnerable children and AIDS orphans simply because of their association with parental HIV/AIDS (Attell, 2013). These orphans are often stigmatised and devalued within society because of their association with the virus rather than their actual HIV status. Social meanings are created and assigned to HIV and individuals infected or affected by the virus. They are perceived as 'invasive [risk] agents within a healthy society' which results in the social exclusion and isolation of the stigmatised (Varas-Diaz, et al., 2005, p. 170; Bunting, 1996). Although Goffman provides an adequate framework for understanding the development of HIV-related stigma, his view of stigma as a stagnant social phenomenon has been largely criticised (Parker & Aggleton, 2003; Attell, 2013). Goffman (1963) views stigma as an attribute that is placed on an individual and causes a spoiled identity and social exclusion. Contrastingly, scholars are urged to recognise that stigma is not a static notion but rather an ever-changing and evolving phenomenon grounded in social and cultural processes and beliefs (Parker & Aggleton, 2003). Therefore, stigma is not an independent operation but rather is dependent on the social, cultural and contextual facets that binds its existence.

Although Goffman does not account for the increase in psychological distress resulting from HIV-related stigma, he provides a theory that is insightful and necessary for understanding the manner in which stigma is created and operates in the lives of those perceived as deviant.

It is only with such an understanding that the ability to conceptualise stigma's contribution towards psychological suffering and distress becomes possible. Steward, et al.'s (2009) modified hidden distress model offers a more compelling extension in understanding the enactment and effects of HIV-related stigma. The use of the modified hidden distress model as a framework for understanding stigma and psychological distress regarding HIV/AIDS indicated a significant impact of stigma on the lives of individuals living with HIV (Burris, 1997; Gupta, 2013; Steward, et al., 2009; Scambler, 1993).

2.4 The Hidden Distress Model

Steward, et al. (2009) extended the hidden distress model coined by Scambler (1989) for the development of a theoretical framework for understanding HIV-related stigma and its effects on the lives of PLWHA in India. The model consists of four components - namely, enacted stigma, vicarious stigma, felt normative stigma and internalised stigma - directed at understanding the production of psychological distress. Understanding of the development of psychological distress experienced by AIDS orphans speaks to the overreaching goal of the present research study.

Generally, the hidden distress model focuses on the manner in which stigma contributes to the development of psychological distress for individuals who are perceived to possess socially undesirable attributes (Scambler, 1993). Scambler's (1989) hidden distress model centres on the concept of stigma and the distinction between enacted stigma and felt stigma in the production of psychological distress and poor mental health outcomes for stigmatised individuals. Similarly to the work of Goffman (1963), Scambler (1993) understands stigma as an 'ontological deficit' which is defined as an encroachment against the social norms of identity or being. Scambler (1993) suggested that, individuals who possess medical

conditions are viewed as deviant and undesirable within society, leading to either the enactment of stigmatising and discriminating behaviour or the fear thereof. Enacted stigma refers to the actual occurrence of negative experiences of discrimination of individuals based on socially unacceptable difference or deviance, while felt stigma refers to an internalised feeling of shame and the fear of enacted stigma (Scambler, 1989; Scambler, 1993).

Scambler's theory unfolds in three distinct parts. Upon diagnosis, individuals develop a special view of the world created by felt stigma (Scambler, 1993). During this stage, diagnosed individuals create an acute sense of felt stigma before the occurrence of enacted stigma. Adults develop an acute sense of felt stigma either immediately or shortly after diagnosis (Steward, et al., 2009). However, children develop an acute sense of felt stigma through a process known as stigma couching. As children are not able to perceive stigmatising beliefs, therefore they are couched by adults through the process of socialisation to incorporate felt stigma. Such beliefs are engrained by phrases such as 'do not use the word epilepsy' or 'why invite trouble' (Gupta, 2013, p. 5; Steward, et al., 2009).

The fear of enacted stigma and feelings of shame about their stigmatised status results in a first choice strategy consisting of non-disclosure and concealment about their stigmatising status (Scambler, 1993; Scambler, 1989). The first choice strategy results in the reduction of experiences of enacted stigma for individuals with stigmatised social statuses. Lastly, felt stigma becomes eminent and more disruptive in the lives of the stigmatised rather than the actual occurrence and experiences of discrimination and stigma. Individuals live in fear of discrimination, leading to complications in the management and treatment of their condition and a decrease in medical and social support (Steward, et al, 2009).

2.5 The Modified Hidden Distress Model

Steward, et al. (2009) extends Scambler's (1989) hidden distress model to include both intrapersonal experiences and interpersonal actions of stigma, surpassing the idea that psychological distress is the result of felt stigma. In contrast, they theorised that four types of stigma (i.e. enacted, vicarious, felt and internalised stigma) would result in the development of psychological distress for diagnosed individuals.

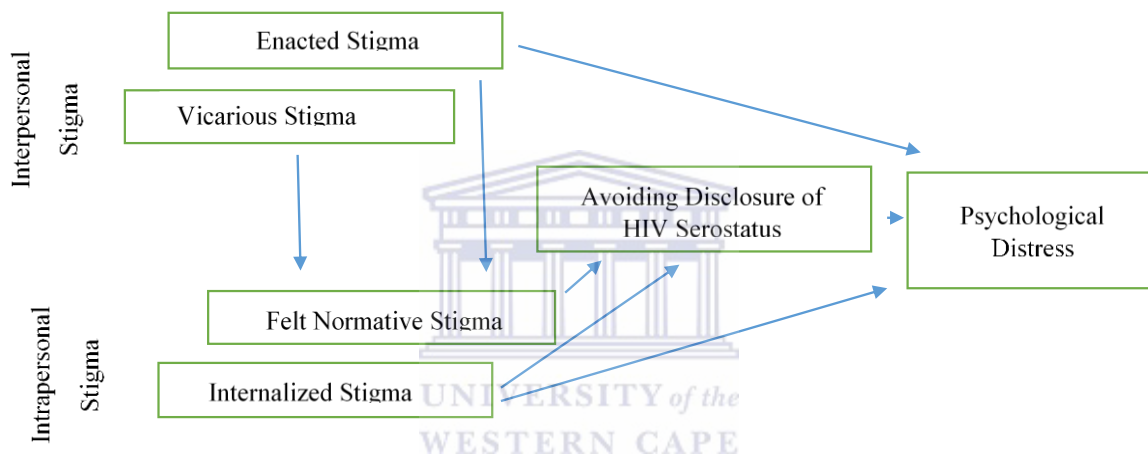


Figure 1. Modified Hidden Distress Model (Steward, et al., 2009)

2.5.1 Interpersonal Actions

2.5.1.1 Enacted Stigma

Interpersonal actions refers to enacted stigma which may be defined as 'overt acts of discrimination and hostility directed at a person because of his or her perceived stigmatized status' (Steward, et al., 2009. p. 3). The experience of discrimination and hostility may lead to the development of psychological distress as an individual becomes socially excluded and devalued within society while experiencing traumatising behaviour from others. However,

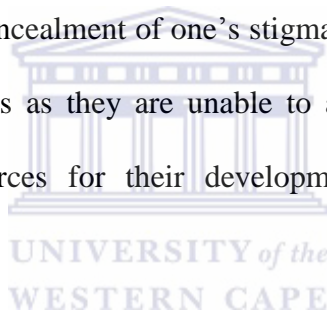
Steward, et al. (2009) theorised that the prevalence of enacted stigma would be far less than that of felt and internalised stigma among people living with HIV.

Steward, et al. (2009) draws conclusions from the work of Goffman (1963) to explain the low prevalence of enacted stigma. Goffman (1963) argues that undesirable characteristics such as abnormality of the body are visible to society, unlike blemishes of the individual character and tribal stigma that may be concealed from society in the hope of reducing enacted stigma. Although HIV/AIDS is not immediately apparent to society, enacted stigma may still occur. Likewise, Steward, et al. (2009) theorise that, because HIV/AIDS is not visibly apparent to society until the development of somatic symptoms, which are typically related to the virus, it brings about the reduction of enacted stigma.

Furthermore, Steward, et al. (2009) deduced the notion of discredited and discreditable identities that are based on the visibility of an individual's condition from the original works of Goffman (1963). A discredited identity develops when an individual is unable to conceal their stigmatised condition or attribute and is known within society, resulting in the development of coping mechanisms to counteract discrimination and prejudice. In contrast, discreditable identities are formed when information about stigmatising conditions and attributes are not readily apparent and may be concealed from society. The central feature for stigmatised individuals who develop discreditable identities is the management of stigma information in order to minimise the occurrence of stigmatisation and discrimination (Steward, et al., 2009). Discredited identities are associated with enacted stigma which is recognised as a direct cause of psychological distress. However, discreditable identities are associated with felt stigma which results in strategies of non-disclosure and concealment of stigmatised social status and has been recognised as an indirect cause of psychological distress (Steward, et al., 2009).

2.5.1.2 Vicarious Stigma

Steward, et al. (2009) introduced a critical aspect of stigma, named vicarious stigma, to explain the development of psychological distress despite the decrease in enacted stigma. Vicarious stigma is consistent with the social learning theory which holds that individuals witnessing or hearing about the experiences of others is likely to result in an increase of perceived norms of stigma, which has come to be known as felt stigma (Bandura, 1979). Observations and stories convey information about the reality of enacted stigma along with the perceived consequences of being identified as possessing a stigmatised status. Upon the basis of such information, enacted stigma becomes salient and the driving force for the management and concealment of information regarding their stigmatising status (Steward, et al., 2009). Non-disclosure and concealment of one's stigmatised status leads to the arousal of psychological distress for victims as they are unable to attain social and medical support along with much-needed resources for their development, functioning and well-being (Steward, et al., 2009).



2.5.2 Intrapersonal Stigma

2.5.2.1 Felt Stigma

Both enacted stigma and vicarious stigma influence an individual's perception about the stigmatising norms and the prevalence of stigmatising attitudes within their community. Although enacted stigma may result in the development of psychological distress, vicarious stigma indirectly contributes to its development by resulting in an increase in felt stigma. The belief that stigma is perceived as normative within a society is regarded as felt stigma. These perceptions motivate individuals with stigmatised social statuses, conditions and attributes to protect themselves against enacted stigma through the use of a disclosure-avoidance strategy, which is the inclined tendency to conceal one's diagnosis or status and withdraw. This

strategy may be carried out in a variety of ways. Scambler (1993) identified secrecy as a method of concealment in order to minimise risk of discrimination. Secrecy may be displayed by an individual through avoidance of others, social withdraw, pragmatic and selective disclosing, and a defiant avowal of normality which is more commonly referred to as the process of passing (Scambler, 1993). According, to Scambler (1993), the practice of passing is the most extreme form of concealment as the individual attempts to be identified as a member of the non-stigmatised society.

Disclosure-avoidance strategies may reduce the opportunities for the occurrence of enacted stigma while simultaneously disrupting the lives of stigmatised individuals by limiting medical and social support, causing psychological distress (Burris, 1997; Gupta, 2013; Steward, et al., 2009). Similarly, Goffman (1963) proposed three mechanisms – namely disassociating oneself from biographical others, passing and covering – that enable stigmatised individuals to control information presented to society through concealing or altering their true self in the hope of reducing enacted stigma. However, Goffman (1963) also expressed the production of psychological distress as individuals experience ambivalence – by attaining a personal and social identity – within themselves and limited support. However, Steward, et al. (2009) recognised that disclosure-avoidance strategies may not always fulfil their intended purpose, thus prompting higher levels of psychological distress and, more specifically, depression.

2.5.2.2 Internalised stigma

The extent to which beliefs about the norms and prevalence of stigmatising attitudes are regarded as valid and truthful is known as internalised stigma. Stigma may be internalised by non-stigmatised and stigmatised individuals within a community. The internalisation of stigma by non-stigmatised individuals cultivates prejudice and stigmatisation towards the

stigmatised. Contrastingly, internalisation of stigma by stigmatised individuals results in self-stigma. Self-stigma denotes the acceptance of a discredited status as valid and truthful (Gupta, 2013; Steward, et al., 2009). Personal internalisations of stigma are partially driven by normative stigmatising perceptions held within society. These individuals' self-concept are congruent with the stigmatising attitudes and beliefs of others. Internalised stigma has been identified as directly eliciting psychological distress (Steward, et al., 2009).

The modified hidden distress model is significant as it addresses stigma's contribution to the development of psychological distress for stigmatised individuals. It goes beyond actual experiences of overt discrimination to evaluate the various measures of HIV-related stigma regarding an increase in psychological distress for PLWHA. This understanding is necessary for evaluating the manner in which HIV-related stigma has contributed to elevated levels of psychological distress experienced by AIDS orphans. Although this model provides a comprehensive explanation for stigma's role in the development of psychological distress such as Goffman's (1963), Steward, et al. (2009) are concerned about the well-being and functioning of stigmatised individuals and questions how they manage to function effectively. Stigma reduction has been identified as a key factor in reducing psychological distress and increasing the effective functioning of stigmatised individuals (Steward, et al., 2009; Scambler, 1993). To explain the effective functioning of stigmatised individuals through the reduction of mediating factors Steward, et al. (2009) drew on Scambler's (1993) dimensions of coping.

2.5.3 Scambler's dimensions of coping

Fundamentally, there is a great desire to reduce stigma in order to bring about an increase in life satisfaction for stigmatised individuals. Satisfaction of life is defined as 'a complex amalgam of satisfactory functioning in terms of physical, social, psychological and

vocational well-being' (Scambler, 1993, p. 149). Similarly to Goffman's (1963) concept of a moral career, Scrambler (1993) proposed five dimensions for coping with conditions to increase life satisfaction, namely accommodation, rationalisation, conception of self, sociability and fulfilment. However, Scambler (1993) discussed these dimensions with regards to epilepsy which was the central stigmatised condition of his research. These dimensions, although designed for the management of epilepsy, may be extended to HIV/AIDS management, the reduction of HIV-related stigma and psychological distress (Steward, et al., 2009).

Accommodation refers to a stigmatised individual's psychical reaction to their medical condition. In the same way that individuals diagnosed with epilepsy respond to recurrent seizures and antiepileptic drugs, so do HIV individuals react to physical changes in their bodies and anti-retroviral treatment (Scambler, 1993; Moskowitz, 2016).

Rationalisation is the need to make sense of what is currently occurring and to solve any problems that are posed by chronic illness or diseases that the individual possesses. HIV-infected individuals attempt to make sense of their condition and resolve the problems that result from their condition, such as poor health, antiretroviral treatment and its associated effects, social exclusion, discrimination and stigmatisation (Scambler, 1993).

Conception of self focuses on an individual's sense of self or self-esteem. Stigma and discrimination may contribute significantly to the manner in which individuals view themselves within society. HIV-positive individuals and their immediate families may internalise the stigmatised view held within society, resulting in a low self-esteem or a negative self-concept (Scambler, 1993). Although Goffman (1963) fails to directly address individual self-esteem, he indirectly discusses the stigmatised individual's acceptance of deviance as true that results in self-hatred, shame and self-isolation.

Sociability refers to social interaction for diagnosed individuals. It examines the extent and quality of social relationships formed by diagnosed individuals. Therefore, social exclusion caused by labelling, discrimination and stigma may cause impairment in the physical, psychological and social well-being of stigmatised individuals (Goffman, 1963; Parker & Aggleton, 2003; Steward, et al., 2009; Scambler, 1993; Attell, 2013). Similarly, the importance of healthy social interaction may be outlined by Allport's (1958) social contact theory. Social contact theory argues that healthy social interaction and awareness result in a reduction of prejudice aimed at labelled individuals. A reduction in prejudice ultimately reduces one's experiences of psychological distress (Allport, 1958; Attell, 2013).

Lastly, fulfilment describes a diagnosed individual's sense of fulfilment through the completion of sociability. Such achievement is expressed through the multiplicity of an individual's healthy social roles within various contexts. HIV-positive individuals and their families who experience discrimination and stigmatisation may improve their overall well-being by the attainment of positive social roles and healthy social interactions within their community. The attainment of positive social roles and activities may operate to decrease levels of psychological distress through healthier social interaction (Scambler, 1993; Louw, et al., 2012).

2.5.4 A hidden distress model for understanding HIV-related stigma

There are many similarities between Scambler's (1989) hidden distress model and the work of Goffman (1963), such as their conceptualisation of stigma, the moral career and the various types of stigma. Although Goffman (1963) aimed at outlining the formation of stigma, Steward, et al. (2009) provided an understanding of the effects of stigma regarding the social, physical and psychological well-being of stigmatised individuals. The hidden distress framework proves insightful for the purpose of the present research study as it allows

one to grasp how HIV-related stigma acts as a fundamental factor in the increase of psychological distress experienced by AIDS orphans.

Enacted stigma is the direct occurrence of discrimination and stigmatisation towards AIDS orphans. Enacted stigma may manifest in the form of physical, verbal and emotional abuse; isolation; social exclusion; and a lack of much-needed resources such as shelter, food, education, medical assistance, and financial and social support (Goffman, 1963; Steward, et al., 2009). According to Steward, et al. (2009), the experiences of enacted stigma result in a direct increase in psychological distress and predispose AIDS orphans to experience an increase in felt stigma as they anticipate discriminating and stigmatising behaviour from others within society.

Steward, et al. (2009) recognise enacted stigma's direct impact on psychological distress; however, their theory accounts for an increase in psychological distress in the absence of enacted stigma. They introduced the concept of vicarious stigma which brings into being the burden of secrecy for AIDS orphans (Steward, et al., 2009), who are likely to employ non-disclosure strategies regarding the truth about parental death and illness to avoid enacted stigma. Non-disclosure strategies limit much-needed available resources and support for AIDS orphans, leading to an increase in psychological distress (Goffman, 1963; Attell, 2013; Steward, et al., 2009). Similar ideas were expressed by several scholars (Thupayagale-Tshweneagae, 2011; Kheswa & Duncan, 2011; Ishikawa, Pridmore, Carr-Hill, & Chaimuangdee, 2010; Bougart, et al., 2008) who have recognised the negative consequences such as withdrawal, isolation and a lack of social support and needs resources resulting from the culture of silence.

The anticipation of discrimination and stigmatisation introduces faulty beliefs about the prevalence and normality of stigmatising beliefs and attitudes in society. As a result of felt

stigma, AIDS orphans act to protect themselves against HIV-related stigma by employing disclosure-avoidance strategies. These strategies allow AIDS orphans to conceal stigmatising information regarding the death and illness of their parents and to withdraw from social interaction in order to control such information (Steward, et al., 2009). Once again, the act of avoidance, social withdrawal, selective disclosure and passing oneself off as a member of the non-stigmatised group, perpetuates factors associated with parental death, such as poverty, lack of education, and social and medical support. The lack of social, financial and medical support, coupled with the fear of discrimination, leads to an increase in psychological distress experienced by AIDS orphans (Steward, et al., 2009; Scambler, 1989).

Lastly: AIDS orphans may internalise stigmatising perceptions held within society as truthful and valid, leading to self-stigma. AIDS orphans accept their devalued and stigmatising social status as true and valid; consequently, they develop low self-esteem and negative self-concept. AIDS orphans who develop a devalued and stigmatised view of themselves are likely to experience higher levels of psychological distress. Steward, et al. (2009) recognised that members of the non-stigmatised group may also internalise these perceptions as truthful and valid, resulting in discriminating and prejudiced behaviour towards AIDS orphans.

Although Steward, et al. (2009) thoroughly account for the development of psychological distress experienced by PLWHA and their families as a result of HIV-related stigma, it is not without shortcomings. Like Goffman (1963), the hidden distress model does not account for the socio-political factors which may be the driving force of stigmatisation and discrimination (Parker & Aggleton, 2003). Parker & Aggleton (2003) have stressed the importance of socio-political factors in the process of stigmatisation and discrimination. Individuals in power will reinforce stigmatising beliefs and attitudes to create social inequality, which results in disproportionate allocation of much-needed resources. Individuals who are stigmatised

remain marginalised, lacking the much-needed resources and support services required for life improvement and holistic well-being (Parker & Aggleton, 2003). The modified hidden distress model fails to explain how the acceptance of stigmatising beliefs is not consistently accepted by diagnosed individuals. It may be internalised by some individuals who are diagnosed, and dismissed by others. However, no explanation is offered for this inconsistency (Steward, et al., 2009). Furthermore, Steward, et al. (2009) have clearly identified a need for challenging the views and perceptions of stigmatised individuals to bring about a reduction in psychological distress for PLWHA and, more significantly, AIDS orphans.

2.6 Conclusion

The theories developed by Goffman and Steward, et al. provide an insightful understanding of the creation and enactment of stigma and the manner in which it may contribute to the psychological distress experienced by AIDS orphans. Goffman discusses the creation and enactment of stigma and proposes ways by which an individual may cope with its associated social stressors. Contrastingly, Steward, et al., provide an in-depth understanding of stigma's contribution to psychological distress as experienced by the stigmatised. These theories, combined with the relevant literature discussed in Chapter Three, inform and substantiate the discussion of findings outlined in Chapter Six.

CHAPTER THREE

Literature Review

3.1 Introduction

Fundamentally, the present chapter sheds insight into the current epidemic of HIV/AIDS, stigma and its associated social ramifications. The text explores the experience of AIDS orphanhood and its associated adversities by firstly describing the severe extent to which AIDS orphanhood accounts for the number of children who have been misplaced or neglected. The text continues to explore the negative psychosocial consequences associated with AIDS orphanhood that might contribute to psychological distress. Lastly, the epidemic of stigma in relation to AIDS orphanhood is examined.

3.2 HIV/AIDS, Orphanhood and Psychological Distress

Mortality rates owing to HIV/AIDS continue to increase along with the prevalence of new infections, despite awareness campaigns and the accessibility of treatment (Andrews, Skinner, & Zuma, 2006; Zhao, et al., 2009). Although much focus has been placed on the adult population and the transmission and treatment of HIV/AIDS, it is significant to note that children are not protected from the major social ramifications associated with parental illness and death (Ishikawa, et al., 2010). In contrast, children have been critically affected by the rapid increase in mortality rates as this has led to an international increase in orphanhood. A large population of the youth have lost either one or both of their parents to HIV/AIDS (Zhao, et al., 2009). The United Nations Children's Fund (UNICEF) estimates that 40 million

children and adolescents will have lost either one or both of their parents to HIV/AIDS by the year 2020 (Boyes & Cluver, 2013; Cluver, Gardner & Operario, 2009).

The accelerating increase in orphanhood as a result of HIV/AIDS infections and deaths has led to the categorisation known as AIDS orphans. However, this term has come to be viewed as driving the stigmatising label attached to orphaned youth and has been rendered politically incorrect (Lalthapersad-Pillay, 2008). Consequentially, the term AIDS orphans has been replaced by orphans and vulnerable children as it is conceived to be an appropriate and dignified label for referring to AIDS-orphaned youth (Lalthapersad-Pillay, 2008; Deacon & Stephney, HIV/AIDS, 2007). For the purpose of the present study, the term AIDS orphans is used to refer to youth orphaned by HIV/AIDS as the categorisation of vulnerable children has come to encompass children affected by HIV/AIDS, and includes groups of children who experience negative outcomes such as loss of educational opportunities, sickness and malnutrition (Lalthapersad-Pillay, 2008; World Bank, 2005).

As more parents succumb to HIV/AIDS, orphans are rendered vulnerable and left without parental care. As a result, AIDS orphans are either left to fend for themselves, cared for by extended family, or rely on foster care and community-based organisations for support (Lalthapersad-Pillay, 2008; Delva, et al., 2009). However, the rising rates of orphaned youth, the diminishing number of adults who may resume the role of a caregiver, the financial responsibilities associated with caring for orphaned youth especially in impoverished communities, and the growth of nuclear families who refuse to care for AIDS orphans have placed immense pressure on family and governmental structures to care adequately for orphaned youth (Lalthapersad-Pillay, 2008; Adejuwon & Oki, 2011; Louw, Mokhosi, & van den Berg, 2012). Evidently, such support structures for AIDS orphans are exhausted and are unable to adequately satisfy the needs of orphaned youth and vulnerable children. As a result,

AIDS orphans are placed in the difficult position of having to struggle with financial, social and emotionally disturbing conditions owing to inadequate care (Lalthapersad-Pillay, 2008) and, associated with this, their experiences of aggravated poverty, physical abuse, the loss of educational opportunities, exploitation and poor mental health (Ishikawa, et al., 2010; Foster, 2006; Louw, et al., 2012). AIDS orphans are therefore regarded as a vulnerable population whose lives are characterised by significant difficulties, unforeseen life changes, fear, emotional distress, discrimination and loss (Deacon & Stephney, 2007).

Although the plight of AIDS orphans has been noted, research has done little to investigate the psychosocial and psychological effects emanating from AIDS orphanhood (de Witt & Lessing, 2010). Therefore, little is known about the lives of AIDS orphans and factors which may negatively affect their well-being while perpetuating the psychological consequences and struggles associated with bereavement (de Witt & Lessing, 2010; Louw, et al., 2012; Ishikawa, et al., 2010). A similar view is expressed by Zhao, et al. (2009) who indicate that research regarding AIDS orphans' experiences of HIV/AIDS regarding economic, social and psychological well-being remains limited, particularly in Asian countries. Moreover, despite the evident need to provide support for AIDS orphans and vulnerable children, this area of research has been largely neglected as little empirical evidence regarding the psychological and psychosocial consequences of AIDS orphanhood in particular exists (Cluver, et al, 2007; de Witt & Lessing, 2010; Ishikawa, et al., 2010).

The few existing studies (Delva, et al., 2009; Zhao, et al., 2009; Cluver, et al., 2009; Cluver, et al., 2007) often revolve around child bereavement and the psychosocial consequences thereof, as the underlying cause of poor well-being. Further investigation conducted by Cluver, et al. (2009) indicated that AIDS orphans are at elevated risk for the development of psychological distress and adverse mental health difficulties. However, these and similar

studies (Delva, et al., 2009; Zhao, et al., 2009; Cluver, et al., 2009; Cluver, et al., 2007) fail to account for the elevated levels of psychological distress experienced by AIDS orphans in comparison with other groups of vulnerable or orphaned children.

Again the lack of pragmatic knowledge regarding the AIDS orphan crisis is highlighted by the results of a few comparative studies conducted among AIDS orphans and youth orphaned by other causes, as initial studies often compared AIDS orphans with non-orphans (Cluver, et al., 2007; Cluver, et al., 2009, Delva, et al., 2009). Wild, Fisher, Laas & Robertson (2005) have identified the lack of appropriate control groups as the chief problem when evaluating the difference and severity of the effects of bereavement and psychosocial facets on AIDS orphans in comparison with adequate control groups. Therefore, facilitating and moderating factors affecting the well-being of AIDS orphans and vulnerable children are poorly accounted for and controlled. Considering the lack of empirical knowledge and poor study designs, the effects of AIDS orphanhood on the psychological health of AIDS orphans in comparison with general parental bereavement cannot be established. The death of a parent is undoubtedly multi-faceted as youth experience numerous losses and socio-economic struggles (Deacon & Stephney, 2007). However, the orphaning experience also fails to explain the evaluated levels of psychological distress experienced by AIDS orphans as discussed above. As HIV/AIDS is a highly stigmatised disease, researchers turn to HIV-related stigma to explain the poor psychological well-being of AIDS orphans in comparison with youth orphaned by other causes (Kheswa & Duncan, 2011; Adejuwon & Oki, 2011; Bougart, et al., 2008; Lin, et al., 2010). To be thorough, it is important that we account for all psychosocial factors that may contribute to the increase in psychological distress experienced by AIDS orphans before introducing HIV-related stigma as a possible cause.

3.3 Structural and Social Factors resulting in Psychological Distress

3.3.1 Parental loss and child bereavement

Orphanhood commences with parental illness as vulnerable children witness the physical suffering and deterioration of their parents (Deacon & Stephney, 2007). The period of bereavement is associated with various kinds of loss for AIDS orphans, especially the loss of a parent or parents as they described a profound sense of grief and sadness (Thupayagale-Tshweneagae, 2011). The loss of a parent or both parents brings about immediate change in the lives, roles and responsibilities of AIDS orphans (de Witt & Lessing, 2010). AIDS orphans also expressed the loss of educational opportunities, support, food security, health care, economic stability and property as a result of parental illness and death (Ishikawa, et al., 2010; Lalthapersad-Pillay, 2008; Deacon & Stephney, 2007). Moreover, AIDS orphans were led to prematurely assume adult roles and responsibilities within their household as they cared for their ill parents and siblings. Stein, Riedel, Rotheram-Borus (1999) and Bauman, Foster, Silver, Berman, Gamble, Muchaneta (2006) identified this phenomenon as the process of 'parentification' which begins with parental illness and is carried throughout parental death and living with extended relatives.

This process has led to adverse consequences for AIDS orphans as they are ineffectively cared for, educated and supported (Deacon & Stephney, 2007). In turn, AIDS orphans are often exploited by relatives and forced to live with extended family in small homes that are often unable to fulfill their basic and emotional needs (Lalthapersad-Pillay, 2008; Kheswa & Duncan, 2011; Wild, et al., 2005). A study by Zhao, et al. (2009) and another by Deacon & Stephany (2007) revealed that the process of bereavement itself predisposed AIDS-orphaned youth to numerous stressors arousing psychological distress that acts to increase mental

health problems as they express feelings of depression, sadness, fear, anxiety, isolation and anger.

Consequently, AIDS orphans conveyed a profound sense of sadness and depression when acknowledging the loss of their parent/s (Zhao, et al., 2009). Such loss was expressed in relation to a lack of received affection and social interactions owing to parental death (Zhao, et al., 2009; Ishikawa, et al., 2010). Zhao et al. (2009) reported that AIDS orphans appeared lonely and voiced a need for family intimacy. Moreover, AIDS orphans were often ill-treated by extended family. Owing to these experiences of ill-treatment and discrimination, AIDS orphans maintained a sense of secrecy regarding parental illness and death, leading to feelings of isolation (Zhao, et al., 2009; Thupayagale-Tshweneagae, 2011). AIDS orphans' perceptions of illness and death aroused feelings of anger towards healthcare workers as they believed that insufficient effort was directed towards treating their ill parents (Zhao, et al., 2009). Feelings of fear and anxiety are present for AIDS orphans as they are uncertain about future prospects for themselves and their families, considering the various losses and changes resulting from parental illness and death (Zhao, et al., 2009). The outcomes associated with parental death, such as poverty, an increase in responsibilities, food insecurity and unemployment, has also incited an increase of psychological distress amongst orphans orphaned by AIDS (Booyesen, 2002; Cluver, et al., 2009; Deacon & Stephney, 2007).

Cluver & Gardner (2007) and Deacon & Stephney (2007) have indicated that parental illness and death disrupts the lives of AIDS orphans, which both predisposes and perpetuates AIDS orphans' experience of psychological distress as they encounter adverse life changes. Deacon & Stephney (2007) reported that all orphans are subjected to a greater level of poverty, parentification and loss of educational opportunities, especially those in poor communities. Although all orphaned youth are subjected to the process of parental bereavement and its

associated psychosocial effects, the staggering increase in psychological distress experienced by AIDS-orphaned youth remains unexplained (Lin, et al., 2010). It has become a daunting task to differentiate the psychosocial and psychological effects of AIDS orphanhood from our understanding of children's responses to parental bereavement and the low levels of disclosure among AIDS orphans (Cluver, et al., 2007; Deacon & Stephney, 2007).

3.3.2 Poverty

Parental illness and death are intertwined with a worsening of poverty and a loss of educational opportunities for the resulting orphans. The literature has identified poverty as an additional stressor to parental loss and illness (Cluver, et al., 2009; Delva, et al., 2009; de Witt & Lessing, 2010). AIDS orphans, in comparison with non-orphans and youth orphaned by other causes, experience an overwhelming sense of poverty and greater economical strain. However, worsening poverty precedes actual orphanhood for AIDS orphans (Cluver, et al., 2009; Lalthapersad-Pillay, 2008; Zhao, et al., 2009). AIDS orphanhood is usually characterised by economic and social hardships as children invariably assume the responsibility to care for their sick relatives, while most earnings are spent on their treatment (Zhao, et al., 2009). This situation ultimately results in shortages, identified by Cluver & Gardner (2007), de Witt & Lessing (2010) and Thupayagale-Tshweneagae (2011) as food insecurity, school non-attendance, lack of financial support and social grants, and lower adult employment (Cluver, et al., 2009). AIDS orphans experience a higher degree of psychological distress in lower socio-economic communities, which have less resources and limited availability of support (Zhao, et al., 2009; Deacon & Stephney, 2007; Thupayagale-Tshweneagae, 2011) than more developed communities.

Despite the apparent socio-economic needs presented by this vulnerable population, Thupayagale-Tshweneagae (2011) has indicated that many governments are unable to

provide the financial and social support needed for their well-being and development. Similar views are held in other studies (Delva, et al., 2009; Cluver, et al., 2009; Deacon & Stephney, 2007; de Witt & Lessing, 2010) regarding the socio-economic vulnerability of AIDS-orphaned youth. These studies (Delva, et al., 2009; Cluver, et al., 2009; Deacon & Stephney, 2007) reported harsh economic conditions resulting from financial costs caused by parental illness and death, the loss of income from parental illness, and shortages of food, education and shelter. It is significant to note that the lack of material assets and financial stability among AIDS orphans becomes evident among their peers, producing experiences of social exclusion, differentness and distress (de Witt & Lessing, 2010). Similarly, Cluver, Gardner & Operario (2009) indicated that poverty exacerbates elevated levels of psychological distress in comparison with other groups of vulnerable children; this may be a result of the increase of AIDS orphans' involvement in economic activities, child labour and being exploited (Deacon & Stephney, 2007). Evidently, AIDS orphans have left school and are more economically active as they earn minuscule wages, being employed generally as farm and domestic workers and engaged in child labour to support their families and relieve financial strain (Delva, et al., 2009).

3.3.3 Education

Several studies (Lalthapersad-Pillay, 2008; Cluver, et al., 2009; Delva, et al., 2009; Thupayagale-Tshweneagae, 2011; Adejuwon & Oki, 2011; Louw, et al., 2012; Deacon & Stephney, 2007; Adato, Carther, & May, 2006; Zhao, et al., 2009) have identified the loss of educational opportunities for AIDS orphans. AIDS orphans have reported higher levels of limited educational opportunities and school non-attendance than other orphaned youth and non-orphans (Adejuwon & Oki, 2011; Lalthapersad-Pillay, 2008). School non-attendance is likely to hinder the achievement of scholastic knowledge and life skills necessary for the

well-being of AIDS orphans (Case, Paxson, & Ableidinger, 2004; Delva, et al., 2009; Adejuwon & Oki, 2011). These educational challenges encountered by AIDS orphans impinge on their rights to an education (Adato, et al., 2006; Lalthapersad-Pillay, 2008).

Educational challenges for AIDS orphans result from various factors that are either internally or externally generated, such as the inability to afford school fees, school uniforms and text books, and inappropriate care as orphans relocate from one caregiver to another (Lalthapersad-Pillay, 2008; Adejuwon & Oki, 2011). The disturbance of living routines and the isolation experienced by AIDS orphans as they are uprooted from their homes to reside with caregivers or extended family exacerbates school non-attendance (Louw, Mokhosi, & van den Berg, 2012). Exclusion from school and educationally related activities inhibits the well-being and wellness of AIDS orphans (Louw, et al., 2012) and, without valuable life skills, scholastic knowledge and a basic school education, AIDS orphans are subjected to economic, psychological, social and health problems, perpetuating the vicious cycle of poverty (Adejuwon & Oki, 2011; Delva, et al., 2009).

Poverty and financial strain have been identified as the leading cause of educational challenges among AIDS orphans. The relationship between poverty and the loss of educational opportunities among AIDS orphans is of a bidirectional nature. Poverty-stricken conditions have motivated AIDS orphans to provide economically for themselves and their families through irregular school attendance or non-attendance. As AIDS orphans assume the role and responsibilities of their sick or deceased caregivers, they are likely to enter informal and formal labour markets, mostly earning minuscule wages while increasing their level of school non-attendance (Cluver, et al., 2009). Thupayagala-Tshweneagae (2011) has indicated that AIDS orphans engage in risk-taking and dangerous behaviour such as prostitution and crime to support themselves or their family. However, school non-attendance acts to

perpetuate poverty and psychological distress as education is strongly correlated with sustainable employment and earning potential in adulthood (Adejuwon & Oki, 2011; Delva, et al., 2009). Zhao, et al. (2009) presented a similar argument in a study undertaken in rural China. The authors found that actions taken to alleviate poverty and economic strain, such as selling their blood to medical institutions, have resulted in further economic loss and financial burden, illness and even death. Contrastingly, Deacon & Stephney (2007) have recognised the lack of accesses to a basic education, school non-attendance owing to poverty, and AIDS orphans' participation in paid labour to support overcrowded homesteads, but continue to suggest that the migration of AIDS orphans may be associated with positive aspects, such as increased access to schools, life skills attainment and better nutrition.

Caregiving conditions and extended family were identified as barriers to educational opportunities and scholastic achievement (Delva, et al., 2009). Educational expenses have been identified as the deciding factor in shouldering the responsibility of caring for AIDS orphans by extended family and caregivers (Adejuwon & Oki, 2011). This cost may lead to the rejection and abandonment of AIDS orphans as they are placed either temporarily or permanently in orphanages, resulting in distress and worsened poverty (Adejuwon & Oki, 2011).

The loss of educational opportunities was a fundamental and concerning theme for AIDS orphans as they are rendered vulnerable and are less likely to achieve a proper level of education (Delva, et al., 2009). The lack of scholastic achievement directly impedes AIDS orphans' pedagogic knowledge and the much-required life skills needed for sustainable employment and future prospects, causing immense distress for AIDS orphans (Delva, et al., 2009). Evidently, a basic school education is imperative for normal child development as it significantly influences future prospects for employment and earning potential while granting

AIDS orphans the opportunity to socialise with others (Adejuwon & Oki, 2011). The involvement regarding basic educational needs of AIDS orphans displayed by caregivers and extended family has done little to address the well-being of AIDS orphans through basic educational training, resulting in researchers responding to address the educational rights of children affected by HIV/AIDS (Delva, et al., 2009).

3.3.4 Extended family and caregivers

The caregiving environment hosted by extended family and caregivers is often laced with adversities which can be expected to hinder the well-being and survival of AIDS orphans (Louw, et al., 2012). Poor social relationships between AIDS orphans and extended family and caregivers are identified as a risk factor, as positive values and support are attached to family members and caregivers who are perceived as trustworthy role models (de Witt & Lessing, 2010). Therefore, extended relatives and caregivers are seen as mediating factors of psychological distress for AIDS orphans (de Witt & Lessing, 2010).

Accompanying the death of their parents, AIDS orphans are likely to experience numerous care arrangements, resulting in the prioritisation of the stability and quality of care arrangements over the type of arrangement provided for AIDS orphans (Zhao, et al., 2009). As previously discussed, the depletion of extended family systems and care arrangements owing to the growing number of orphans has placed the majority of AIDS orphans in the care of their grandparents, especially in homes headed by grandmothers (Lalthapersad-Pillay, 2008; Ishikawa, et al., 2010). Grandparents who have lost their own children to HIV/AIDS assume the responsibility of caring for AIDS orphans on a depleted pension (Lalthapersad-Pillay, 2008). Parenting by a grandmother may bring about various challenges in support, communication and financial stability for AIDS orphans (Thupayagale-Tshweneagae, 2011). Grandparents are unable to effectively support and cope with the demands associated with

caring for their orphaned grandchildren, resulting in a population of youth that is inadequately cared for and socialised. The lack of care and supervision provided by grandparents may result in the experiencing of psychological distress by AIDS orphans (Adejuwon & Oki, 2011).

Other than with grandparents, AIDS orphans are often required to reside with extended family members. Such living arrangements are characterised by mistreatment, lack of satisfaction of basic needs, exploitation, abuse and discrimination (Louw, et al., 2012; Lalthapersad-Pillay, 2008; Deacon & Stephney, 2007; Adejuwon & Oki, 2011; Zhao, et al., 2009; Lin, et al., 2010). Significantly, discrimination was identified, as AIDS orphans discussed their poor treatment by caregivers, rejection by relatives and being denied access to basic meals, schooling and proper medical care (Zhao, et al., 2009; Lin, et al., 2010; Deacon & Stephney, 2007). Similar findings were discussed by Deacon & Stephney (2007) as they described the living conditions provided for AIDS orphans by extended family. Discrimination manifested in a variety of ways, namely being assigned a heavier workload than other children in the homestead, needing to work for the care provided, harsh punishments and sexual abuse (Deacon & Stephney, 2007). AIDS orphans were obliged to silently accept mistreatment as they have no other means of acquiring shelter and protection (Adejuwon & Oki, 2011) while finding it impossible to ‘communicate their concerns and anxieties to others’ (Ishikawa, et al., 2010, p. 308).

Although experiences of discrimination are evident among AIDS orphans, not all experiences of residing with extended family and caregivers were regarded as negative and detrimental to the psychological and physical well-being of AIDS orphans. Extended family may act as advocates for AIDS orphans by building trustworthy relationships and in turn deflecting the development of psychological distress despite harsh and complex living conditions

(Thupayagale-Tshweneagae, 2011). Evidently, the social and psychological well-being of AIDS orphans is largely dependent on the quality of interpersonal relationships within positive social environments. Therefore, healthy relationships with extended family who provide a loving and caring environment that facilitates growth, social protection and psychosocial support are likely to counteract the adversities experienced by AIDS orphans (Louw, et al., 2012).

3.4 The Plight of AIDS Orphans

Interestingly, Deacon & Stephney (2007) question the focus placed on AIDS orphans by asking whether they are significantly worse off than other orphans and vulnerable children. Orphanhood is associated with various degrees of vulnerability and negative consequences dependent on the contextual factors associated with parental death. The negative consequences and vulnerability associated with AIDS orphanhood are apparent, yet the plight of AIDS orphans and vulnerable youth has been neglected as they continue to express difficulty in conveying their distress to others (Ishikawa, et al., 2010; Adejuwon & Oki, 2011). Despite the clear need for support of AIDS orphans, little is understood about the arousal of psychological distress in AIDS orphans and how such needs may be adequately addressed (Ishikawa, et al., 2010). Similarly, Adejuwon & Oki (2011) have recognised that no country has responded adequately to match the severity of the crises for orphans posed by HIV/AIDS. The insufficient understanding of AIDS orphanhood and distress, coupled with the lack of appropriate interventions, forms a compelling argument for focusing on AIDS orphans and vulnerable youth.

It may be argued that psychological distress is the result of psychosocial adjustment to the bereavement that is experienced by orphaned youth despite their association with familial HIV/AIDS. However, studies (Cluver, et al., 2009; Zhao, et al., 2009; Delva, et al., 2009)

have indicated that AIDS orphans experience elevated levels of psychological distress in comparison with other groups of orphaned children and vulnerable youth. To address this discrepancy, we turn to the epidemic of stigma in the hope of uncovering a possible explanation for the increased level of distress experienced by AIDS orphans (Louw, et al., 2012).

3.5 The Epidemic of HIV-Related Stigma

The global AIDS epidemic has posed various challenges for both its victims and society. These challenges have come to include HIV prevention, working conditions for HIV-positive individuals, access to health services and human rights laws (Varas-Díaz, et al., 2005). It is imperative to recognise that these challenges have come to surpass the biological traits of the virus and have resulted in an epidemic of stigma against those living with HIV/AIDS, their families and individuals at risk (Varas-Díaz, et al., 2005; Lin, et al., 2010). Considering the prevalence of HIV infections and the rising number of mortalities, the practice of HIV-related stigmatisation is likely to intensify (Varas-Díaz, et al., 2005). Herek & Glunt (1988) suggested that the severity of the epidemic of stigma is reflected in the coining of the term AIDS-related stigma. Roberts (2006) and Kheswa & Duncan (2011) continues to recognise the severity of stigmatisation, as it is regarded as the key challenge for those infected and affected by the virus.

There has been a nation-wide call for the reduction of HIV-related stigma. Such efforts should not only focus on stigma against individuals living with HIV/AIDS but also be extended to all those associated with the virus, including the community (Lin, et al., 2010).

Before addressing the current epidemic, we have to consider the nature of stigma and HIV-related stigma (Surkan, Mukherjee, Williams, Estache, Louis, Lambert, Scahlan, Oswald &

Smith, 2010). Defining HIV-related stigma has not been an easy task as it is often altered to suit the various perspectives of current studies, populations and contexts (Lin, et al., 2010). A similar idea was proposed by Hong, Li, Stanton, Fang, Lin, Wang (2008) as they suggested that the manifestations and expressions of HIV-related stigma are universal and fluid, as they vary between cultures and populations.

Generally, stigma could be defined as the discrediting of an individual on the foundation of social beliefs about a particular personality, behaviour or illness which is enacted through the process of socialisation (Stuenkel & Wong, 2009). This definition is consistent with Goffman's (1963) idea that stigma arises through social interaction between the stigmatised and the non-stigmatised, where difference and deviance is assigned to labeled individuals. A study conducted by Varas-Díaz, et al. (2005) indicated that interpersonal relationships held by HIV-positive participants were characterised by HIV-related stigma leading to social rejection, self-imposed isolation, discrimination, ostracism, segregation, being relocated to another job, refusal of health services or the lack of healthy communication with healthcare workers and the abrupt ending of significant personal and sexual relationships. One may conclude that stigma is made up of various components, namely labeling, stereotyping, isolation, discrimination, and status loss (Link & Phelan, 2001).

Although the body of empirical evidence has largely focused on the negative impact of HIV/AIDS on the adult population, transmission and treatment (Lin, et al., 2010), children are not spared from the challenges posed by the HIV/AIDS epidemic and its associated culture of stigma (Ishikawa, et al., 2010; Lin, et al., 2010). Children orphaned by HIV/AIDS have been overlooked but have recently drawn a significant amount of interest as they are not isolated from the consequences of HIV (Zhao, et al., 2009; Delva, et al., 2009; Lin, et al., 2010). Although limited empirical knowledge is available on the topic, existing studies

(Ishikawa, et al, 2010; Lin, et al., 2010; Lalthapersad-Pillay, 2008; Adejuwon & Oki, 2011; Kheswa & Duncan, 2011; Bougart, et al., 2008; Cluver, et al., 2007; Zhao, et al., 2009) have explored the psychosocial development of children affected by HIV/AIDS.

3.6 AIDS Orphans and the Epidemic of Stigma

It has been identified that AIDS orphans, compared with those orphaned for other reasons, often present with poor psychological well-being (Cluver & Gardner, 2007). It was noted too that orphans located in poor economic societies with limited resources experience a higher degree of psychological distress. It is evident that numerous contextual and individual risk factors may contribute to the development of poor psychological health and an increase in distress for HIV/AIDS orphans (Zhao, et al., 2009).

The experience of HIV-related stigma is the chief distinction between AIDS orphans and children orphaned by other causes (Boyes & Cluver, 2013). HIV-related stigma has been recognised as an understated but key problem for AIDS-orphaned children because of their association with a highly stigmatised illness (Cluver, et al., 2007). Stigma acts to breach the fundamental human rights of AIDS orphans at various levels including political, economic social, psychological and institutional levels (Dube & Ross, 2012). HIV-related stigma lingers long after parental death and is generalised to AIDS orphans, acting to hinder their opportunities to meet basic needs that ensure their long-term well-being (Louw, et al., 2012; Kheswa & Duncan, 2011). In return, AIDS orphans are rendered vulnerable by familial HIV/AIDS and are more likely to experience enmity, rejection and abandonment (Lin, et al., 2010; Bougart, et al., 2008). Cluver & Orkin (2009) indicated that one-fifth of AIDS orphans experience HIV-related stigma which may range from subtle rejection to physical assault and

even homicide (Skinner & Mfecane, 2004). Various manifestations of HIV-related stigma directed towards AIDS orphans have been identified across studies and are discussed below.

3.6.1 Exclusion from educational opportunities and bullying victimisation

Besides the loss of educational opportunities experienced by AIDS orphans, owing to financial constraints (Lalthapersad-Pillay, 2008), AIDS orphans and vulnerable children are often discriminated against in educational settings (Kheswa & Duncan, 2011). A significant consequence of HIV-related stigma is the exclusion of AIDS orphans from educational facilities by being denied admission to schooling (Kheswa & Duncan, 2011; Louw, et al., 2012; Lin, et al., 2010; Ishikawa, et al., 2010). This has been largely enforced by the parents of other school learners out of fear of contamination and the spread of HIV/AIDS within the school sector (Kheswa & Duncan, 2011). De Witt & Lessing (2010) agreed that the source of stigmatising behaviour was probably the fear of illness, contamination and death.

AIDS orphans were not only denied access to educational facilities but also rather discontinued schooling because of stigma (de Witt & Lessing, 2010). HIV-related stigma is manifested as bullying victimisation which remains rampant in schooling facilities, without adult awareness (Ishikawa, et al., 2010). Bullying victimisation was often expressed as teasing by referencing parental illness and death, gossiping, physical beating, being called names, and discrimination by their peers (Ishikawa, et al., 2010; Boyes & Cluver, 2013), which results in social exclusion, rejection and avoidance of friends (Bougart, et al., 2008; Ishikawa, et al., 2010). Adejuwon & Oki (2011) indicated that AIDS orphans – especially girls – were sexually assaulted by their peers and schoolteachers. Consequently, such experiences of enacted stigma lead to an increase in school dropout rates among AIDS orphans. Lastly, extended family may prohibit AIDS orphans from attending school as they are required to fulfill duties around the homestead while their own children continue their

educational career (Lin, et al., 2010). Stigmatisation and discrimination may be the leading factors fueling school non-attendance, which further endangers the livelihood of AIDS orphans (Lalthapersad-Pillay, 2008). However, it is significant to note that such forms of stigmatisation and discrimination are not limited to educational settings but originate from the stigmatising beliefs held by the general community (Lalthapersad-Pillay, 2008).

3.6.2 Social Abuse and Rejection

The cause of parental death becomes a burden for AIDS orphans as they experience stigmatising attitudes from extended family and community members who continue to gossip and discuss the causes of parental illness and death (de Witt & Lessing, 2010). Community and family members frequently feel that such discrimination and stigmatisation is acceptable because of the perception that HIV/AIDS is the result of deviant behaviour that has somehow extended to their children (Kheswa & Duncan, 2011). Many studies (Kheswa & Duncan, 2011; Bougart, et al., 2008; Zhao, et al., 2009; Adejuwon & Oki, 2011; Lalthapersad-Pillay, 2008) discuss the ill-treatment, exploitation and rejection of AIDS orphans by extended family. During parental illness, vulnerable children were rejected by family members who discontinued visitation and support once they became aware of their parents HIV/AIDS status (Kheswa & Duncan, 2011; Bougart, et al., 2008). After parental death, family members often abandoned children who were then left to support themselves (Kheswa & Duncan, 2011; Zhao, et al., 2009; Bougart, et al., 2008).

Similar stigmatising and discriminatory beliefs were held by the communities in which AIDS orphans resided as they were subjected to avoidance, ostracism and verbal insults emanating from community members (Bougart, et al., 2008). Avoidance was discussed in terms of the subtle and abrupt rejection of AIDS orphans by the community and their peers. Parents forbade their children to associate and share toys with AIDS orphans because of their

connection with HIV/AIDS (Zhao, et al., 2009; Kheswa & Duncan, 2011). Lalthapersad-Pillay (2008) suggested that ostracism is reflected by their permanent displacement as AIDS orphans are chased away from a particular area. An apparent form of stigmatisation directed at AIDS orphans is the verbal insults projected by others. Kheswa & Duncan (2011) suggested that members of a community use a range of derogatory terms and gestures when referring to AIDS orphans, such as Z3, AZT, biltong and various hand gestures. These names have come to indicate the socially devalued status held by AIDS orphans within their communities and the psychological deterioration of their parents. Owing to overt acts of discrimination and stigmatisation, AIDS orphans have become fearful of experiencing such forms of hostility and abuse, resulting in a culture of silence (Thupayagale-Tshweneagae, 2011; Zhao, et al., 2009).



AIDS orphans experience significant social abuse and mistreatment in the form of numerous types of abuse, exploitation and neglect (Louw, et al., 2012). They reported being abused and assaulted by extended family members such as uncles and aunts who had been expected to provide a safe and stable environment for them to live. Instead, these AIDS orphans were beaten and pushed around until physical evidence was evident on their bodies (Pienaar, Swanepoel, van Rensburg & Heunis, 2011). Family members exploited AIDS orphans by collecting grants allocated for their care and spending it on things such as alcohol and cigarettes. This led to the neglect of AIDS orphans as they were not adequately cared for (Pienaar, et al., 2011). Furthermore, AIDS orphans were also sexually exploited, forced to engage in dangerous labour, stripped of their inheritances and provided with different meals from the rest of the household, by extended family members (Adejuwon & Oki, 2011; Lalthapersad-Pillay, 2008; Zhao, et al., 2009).

3.6.2 Silence regarding parental death and illness

The discussion of parental illness and death caused by HIV/AIDS was regarded as taboo in developing countries and communities, and was shrouded in secrecy (de Witt & Lessing, 2010). However, a more salient theme was protecting AIDS orphans and vulnerable children from the negative social consequences associated with the virus (Bougart, et al., 2008; Ishikawa, et al., 2010; Kheswa & Duncan, 2011; Thupayagale-Tshweneagae, 2011).

AIDS orphans and vulnerable children are frequently kept from the truth regarding parental illness and death, as parents and caregivers feared that children might disclose such information to others. The disclosure of parents' HIV/AIDS status is likely to result in rejection, hostility, marginalisation, isolation and discrimination from their peers, extended family members and community (Bougart, et al., 2008; Kheswa & Duncan, 2011; Deacon & Stephney, 2007). Parents and caregivers felt the overwhelming need to protect children from stigmatisation and its associated negative consequences (Ishikawa, et al., 2010). When the truth surrounding parental illness and death were disclosed to AIDS orphans and vulnerable children, they were cautioned to anticipate hostile and discriminating responses from others. Such warnings included being insulted, teased and the loss of interpersonal relationships (Bougart, et al., 2008). These children came to exercise their agency through self-isolation and silence as they are rendered vulnerable and fearful of the virus that haunts them (Kheswa & Duncan, 2011).

Contrary to its purpose, the psychosocial health of AIDS orphans and vulnerable children is destructively affected by this wall of silence (Ishikawa, et al., 2010). Silence and self-isolation have placed AIDS-affected youth beyond the reach of adequate social support needed for their well-being (Kheswa & Duncan, 2011). Although they gained support within their immediate family structure, they remained unable to rely on individuals outside their

immediate family for social support owing to fear of disclosure and associated stigma (Bougart, et al., 2008). The wall of silence demonstrates that AIDS orphans are burdened with HIV-related stigma long after the death of their parents, and that it acts to worsen the process of bereavement, thus harming the well-being of AIDS orphans (Thupayagale-Tshweneagae, 2011).

3.7 Addressing the Culture of Stigma

It is evident that many HIV/AIDS orphans have either experienced or are vulnerable to HIV-related stigma. Considering current knowledge on HIV-related stigma, there is an identifiable relationship between HIV-related stigma and poor mental health outcomes (Cluver & Gardner, 2007). However, the nature of this relationship, and the effects and severity, remain unknown (Cluver & Gardner, 2007). With such uncertainty, we cannot address the psychological needs of AIDS orphans, vulnerable children or those living with HIV/AIDS. Consequently, we have to focus our attention on understanding the various dimensions of stigma and its associated effects.

To understand the culture of stigma and its associated effects, it is significant to note that stigma is a socially constructed phenomenon. It is only when the social processes and demographic factors that underlie such a construction are examined, that intervention programmes aimed at improving HIV/AIDS orphans' quality of life may be addressed (Stuenkel & Wong, 2009). Examining HIV-related stigma in the absence of demographic factors may prove the existence of a relationship between HIV-related stigma and poor psychological health. However, HIV-related stigma is not constant, and its severity and effects are dependent on varying demographic factors. According to Lin, et al. (2010), contextual and demographic aspects such as age, sex and social status need to be

accommodated in order for efforts and programmes developed for stigma reduction to be appropriate and effective. Although examining HIV-related stigma in isolation to gain insight on its effects on mental health is anticipated, it is rather elusive and highly improbable. Consequently, the extent to which HIV-related stigma has affected HIV/AIDS orphans remains unknown (Lin, et al., 2010).

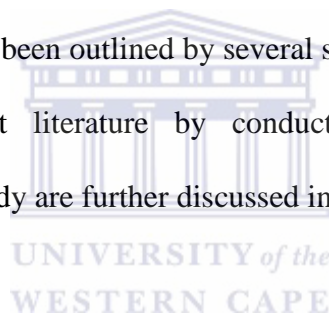
Fundamentally, we strive to account for the role of stigma in the increase of psychological distress experienced by the vulnerable children and orphaned youth who are associated with HIV/AIDS. It becomes a pressing matter to understand and analyse the existing pool of pragmatic evidence in order to foster an understanding of how HIV-related stigma contributes to poor psychological health and distress in AIDS orphans. Such an understanding is imperative for the prevention of negative psychological outcomes and the development of intervention programmes (Cluver, et al., 2009; Cluver, et al., 2007). Additionally, there is a need to examine HIV/AIDS orphans' experiences, perceptions and attitudes regarding HIV-related stigma in order to frame the problem (Surkan, et al., 2010).

It has become a challenging but necessary task to re-evaluate and summarise the current literature to form a valid and reliable pool of knowledge regarding the effects of HIV-related stigma on the psychological well-being of AIDS orphans. Without such information, methods aimed at reducing HIV-related stigma will continue to be poorly informed while perpetuating the negative mental consequences and psychological distress experienced by these orphans. Interventions addressing HIV-related stigma as a risk factor could potentially improve the mental health outcomes of HIV/AIDS children by aiming to reduce HIV-related stigma and its associated negative psychological consequences (Cluver, et al., 2007). However, considering the diversity of HIV-related stigma, the appropriateness of intervention programmes needs to be strongly assessed during their development. Counselors also need to

be aware of HIV-related stigma and its effects on psychological health when assisting HIV/AIDS orphans in their struggles (Lin, et al., 2010).

3.8 Conclusion

Recent literature highlights the effects of AIDS orphanhood and its associated culture of stigma. AIDS orphans have been neglected, abused and exploited within their new homesteads and discriminated against by the general community. Although the problems experienced by AIDS orphans are identified, the existing literature has identified an important gap in research. Few existing studies have focused on the manner in which HIV-related stigma has contributed to the elevated levels of psychological distress experienced by AIDS orphans. This shortage has been outlined by several studies. The present study explores the gap identified in relevant literature by conducting a systematic review. The methodological aspects of the study are further discussed in Chapter Four below.

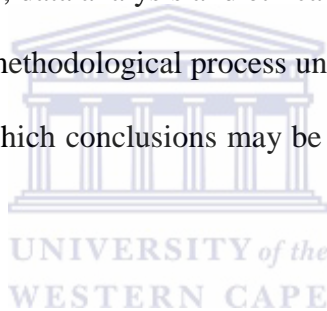


CHAPTER FOUR

Methodology

4.1 Introduction

This chapter outlines the systematic steps followed to assess the relationship between HIV-related stigma and psychological distress experienced by AIDS orphans. It provides a detailed account of the methodological procedures employed during the execution of the present study and is reported in a descriptive manner. The chapter is divided into eleven subsections, namely aims, objectives, research design, review questions, method of review, retrieval strategy, levels of review, data analysis and ethical considerations. Each sub-heading outlines a significant part of the methodological process undertaken by the research, resulting in a justified pool of data from which conclusions may be drawn and a comprehensive body of knowledge may be built.



4.2 Aim

The aim of the current systematic review is to examine and report on the effects of HIV-related stigma on the psychological well-being of orphans who have lost one or both of their parents to HIV/AIDS.

4.3 Objectives

The objectives of the current study were:

- to assess the prevalence of HIV-related stigma among AIDS orphans
- to identify the effects of HIV-related stigma on the psychological wellbeing of AIDS orphans

- to systematically appraise the methodological rigour of studies exploring the relationship between HIV-related stigma and the psychological well-being of AIDS orphans.

4.4 Research Methodology

The study embodies a systematic review methodology. A systematic review is defined as an explicit and systematic method used to amalgamate evidence reported by a group of inter-related studies on a particular phenomenon to produce reliable and unbiased findings (Higgins & Green, 2011). Furthermore, a systematic review is conceived as a cornerstone of empirical research because of its promise to provide valid deductions from a broad spectrum of studies addressing the clinical problem under scrutiny (Sandelowski, 2008). This promise is upheld by the process of identifying current evidence outlined by existing studies, the lack thereof, and the variance of findings across disciplines. Its rigorous and comparative nature provides a comprehensive body of secondary knowledge from which rational and informed decisions can be made as it acts to inform future primary research and intervention programmes (Mulrow, 1994; Higgins & Green, 2011). Its noteworthy ability to capture the depth of various clinical problems and the effectiveness of clinical interventions, which cannot be captured in primary literature alone, renders this research design the most authoritative and credible source of information (Cognetti, Grossi, Lucon, & Solimini, 2015).

The key features of a systematic review are identified by Higgins & Green (2011) as an explicit methodology, clearly defined objectives and criteria of studies, a systematic approach to extracting literature which clearly meets defined criteria, critical assessment of the validity of studies and, lastly, a systematic and comprehensive synthesis of all characteristics and findings of included studies. A systematic review aims to reduce random and systematic errors of bias to increase accuracy, leading to an improved reflection of reality (Mulrow,

1994; Oxman & Guyatt, 1988). Sandelowski (2008) stated a similar claim by suggesting that the structured, rigorous nature and the reduction of bias of a systematic review optimises the validity of outcomes, producing a more realistic view of phenomenon (Sandelowski, 2008).

The systematic review was deemed appropriate as it allows the identification, evaluation and interpretation of inter-related studies examining the effects of HIV-related stigma on the psychological well-being of AIDS orphans. The systematic manner in which studies are identified addresses the core issue of limited empirical evidence, while at the same time allowing the identification of findings and gaps in current literature. The systematic identification, rigorous evaluation and meta-synthesis of findings presented within relevant literature allows the creation of a comprehensive body of literature aimed at addressing the overall aim and objectives of the present study. From this comprehensive body of knowledge, we may construe the prevalence of HIV-related stigma among AIDS orphans and its associated psychological outcomes, and contribute to future research and intervention programmes (Gough, Oliver, & Thomas, 2012).

4.5 Review Questions

This systematic review strives to answer the following questions:

1. What is the prevalence of HIV-related stigma among AIDS orphans?
2. What are the outcomes of HIV-related stigma on the psychological well-being of HIV/AIDS orphans?
3. What is needed for the reduction of HIV-related stigma experience by AIDS orphans?

4.6 Criteria for Inclusion of Studies in the Review

The following criteria were used to determine whether a study should be included in the review for purposes of examining the psychological outcomes of HIV-related stigma among AIDS orphans.

4.6.1 Time period: The time period covers 11 years, from 2004 to 2015. Researchers have recently devoted their attention to the impact of HIV-related stigma on the lives of AIDS orphans, leading to noteworthy developments in contemporary research. Therefore, the selected time period was limited to include the most recent developments in literature examining the effects of HIV-related stigma on the psychological well-being of AIDS orphans (Meline, 2006).

4.6.2 Participants: The inclusion criteria for participants were HIV-negative children between 6 and 18 years of age who had lost either one or both of their parents to HIV/AIDS. The stipulated participant criteria remained broad for the selection of a large range of studies to ensure validity (Meline, 2006). Due to a lack of recent studies focusing on the effects of HIV-related stigma on the psychological well-being of AIDS orphans, sample populations consisting of AIDS orphans along with healthcare professionals and family members were included.

4.6.3 Types of studies: The present study reviewed studies with qualitative, quantitative and mixed-method methodologies. All research designs within these methodologies were considered to ensure that all available studies, latest developments in research and knowledge regarding HIV-related stigma and AIDS orphanhood were covered. Studies included were accessible through electronic databases at the library of the University of the Western Cape. Studies were required to be full text, peer reviewed and in the English medium. Outcomes of studies were allowed to be presented statistically, descriptively or a combination of the two approaches. Studies were eligible for inclusion if they reported on the effects of HIV-related

stigma on the psychological well-being of AIDS orphans who had lost one or both of their parents to HIV/AIDS.

4.7 Criteria for Exclusion of Studies in the Review

Studies were excluded if they had not been published within the designated time period, if they were not accessible on the University of the Western Cape's library data bases, and were not present within the public domain. Studies were further excluded if they were not peer reviewed, full text, if payment was required, and if they were published in languages other than English. Studies that failed to report on the relationship between HIV-related stigma and the psychological health and well-being of AIDS orphans were excluded. As the present study aimed to evaluate and acquire knowledge about the effects of HIV-related stigma on AIDS orphans instead of intervention programmes, all intervention studies were excluded. The review aimed at understanding the manner in which HIV-related stigma has been extended to AIDS orphans. Therefore, studies which explicitly indicated that the sample population was HIV positive or yielded the opinion of caregivers, were excluded to increase the reliability of findings. Literature reviews too were excluded.

4.8 Method of Review

The initial study was conducted independently by the primary researcher using Boolean strings of search terms and keywords at the level of identification. The screening of relevant titles and their abstracts was assessed by the primary researcher. After the removal of duplications across database searches, eligible titles were identified by the primary researcher and considered pertinent to the study. A full-text review of each pertinent study was conducted independently by both the primary researcher and the supervisor, who acted as a

second reviewer. The appraisal of full-text studies were conducted by two independent researchers, aimed to increase the validity and reliability of the study.

Any disputes and disagreements regarding eligibility and inclusion of studies comprising the final set of data were discussed between the reviewers until consensus was reached. However, no disputes regarding the inclusion and appraisal of studies were established, presenting no need for consensus to be reached between the two reviewers, which may be due to the collaborative development of the critical appraisal tools between researchers (Kitchenham, 2004). Reasons for inclusion and exclusion were provided by both researchers and are well documented.

4.9 Search Strategy

The retrieval strategy was adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff & Altman, 2009). The PRISMA flowchart depicts four levels of review and the accompanying operational steps, namely Identification, Screening, Eligibility and Inclusion. The first two levels (identification and screening) were conducted by the primary researcher while the third level of review (eligibility) was conducted by both the primary researcher and the supervisor, who embodied the role of the second reviewer. The level of identification includes the identification of suitable keywords, search terms and Boolean strings, and the retrieval of suitable titles from a comprehensive search across databases in the library of the University of the Western Cape. The level of screening involved the independent review of all abstracts retrieved from eligible titles at the level of identification. The third level of review involved the independent full-text review of all articles deemed eligible at the level of screening. Articles included in the final

set of data were subjected to the process of data collected, conducted by the primary researcher. The PRISMA levels of review are depicted in Figure 2 below.



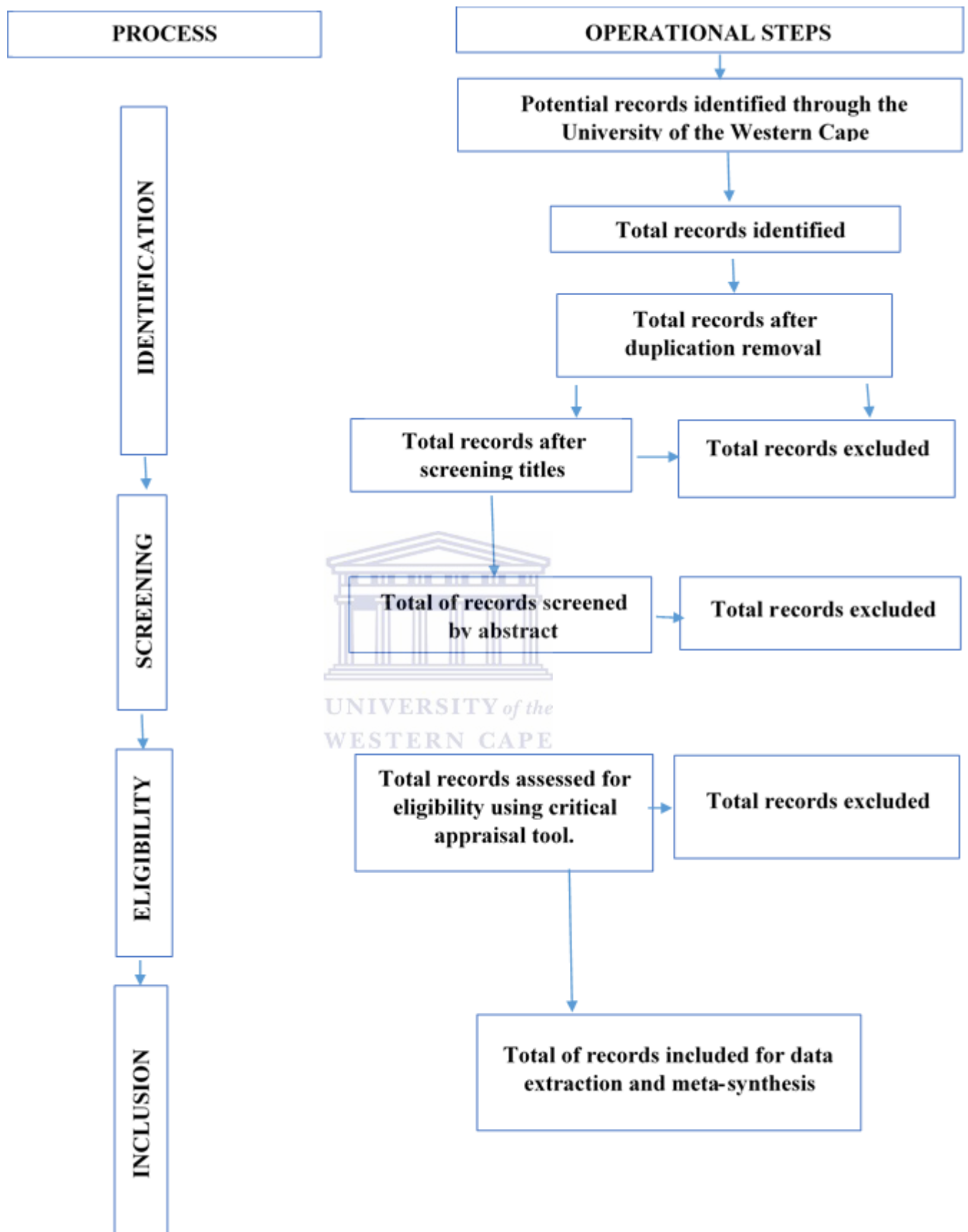


Figure 2: PRISMA levels of review.

4.9.1 Levels of Review

The four levels of review are identified as Identification, Screening, Eligibility and Inclusion (Moher, et al., 2009). A comprehensive description of levels of review and instruments used are discussed below.

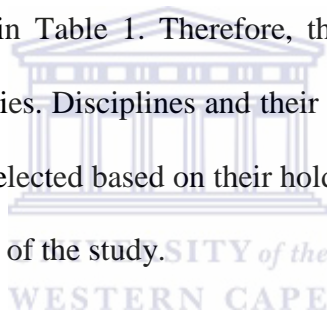
4.9.2 Identification

An initial search was conducted for the identification of appropriate search terms. The preliminary search terms identified in the literature were ‘psychological distress’, ‘AIDS orphans’, ‘HIV-related stigma’ and ‘HIV/AIDS’ and were entered into two electronic databases, namely Academic Search Complete and Medline. The effectiveness of preliminary keywords was determined by the number of hits they produced during initial Boolean searches within the two electronic databases mentioned above. However, these preliminary keywords seemed to restrict searches and yielded a poor amount of data.

Although the initial search was constricted, it provided synonyms for the preliminary keywords and allowed the refinement of keywords. Consequentially, a refined set of keywords and search terms were identified, namely ‘stigma’, ‘discrimination’, ‘orphans’, ‘distress’, ‘children’, ‘mental health’, ‘AIDS related stigma’ and ‘HIV’. Comprehensive searches used the ‘AND’ Boolean operator to further ensure the reliability and efficiency of results. Boolean strings were created for the purpose of a comprehensive search of databases and acted as an essential facet in the identification of relevant data. It restricts searches eliciting potential matches, increasing the prospects of retrieving pertinent data while simultaneously eliminating insignificant studies that fail to address the aims of the current research study. These keywords formed seven sets of Boolean strings necessary for a comprehensive search of electronic data bases, and are set out below:

1. 'HIV' AND 'stigma' AND 'orphans'
2. 'HIV' AND 'stigma' AND 'orphans' AND 'distress'
3. 'AIDS orphans' AND 'stigma'
4. 'HIV' AND 'children' AND 'stigma'
5. 'mental health' AND 'stigma' AND 'orphans' AND 'HIV'
6. 'AIDS related stigma' AND 'orphans' AND 'distress'
7. 'discrimination' AND 'HIV' AND 'orphans'.

The library of the University of the Western Cape has categorised databases according to their relevant disciplines, namely social sciences, education, health and natural sciences. These disciplines are presented in Table 1. Therefore, the selected databases were drawn from the abovementioned categories. Disciplines and their associated databases are presented in Table 2. Databases were also selected based on their holdings of academic material aligned to the outlined aim and objectives of the study.



A comprehensive search was conducted across identified databases in the library of the University of the Western Cape using Boolean strings of search terms and keywords. The primary researcher attained hits from Boolean searches and extracted the relevant titles. Title extraction for eligibility was determined by its relevance and the appearance of specified keywords and search terms outlined in Boolean strings. Titles that failed to meet the inclusion criteria were excluded. The primary researcher screened titles for duplications across databases. Titles extracted for further screening progressed to the next level of review while duplications and inappropriate titles were removed. Included titles and duplications were recorded by the primary researcher on a Title Sheet (Appendix A).

Table 1: Table of disciplines.

Education	Social and Natural Sciences	Health
Education	Sociology	Medicine
	Anthropology	Occupational Therapy
	Psychology	School of pharmacy
	Women and Gender studies	School of Public Health
	Sport Sciences	Nursing
	Human Ecology	Dietetics
		Dentistry

Table 2: Disciplines and associated databases.

Discipline	Databases
Social Sciences	<ul style="list-style-type: none"> • SA ePublications • Academic Search Complete
Natural Sciences	<ul style="list-style-type: none"> • Academic Search Complete (EBSCO) • MEDLINE • PubMed (BioMed Central)
Health	<ul style="list-style-type: none"> • Academic Search Complete (EbscoHost) • BioMed Central • CINAHL (Cumulative Index to Nursing and Allied Health) • MEDLINE (EbscoHost)
Education	<ul style="list-style-type: none"> • PsychARTICLES

4.9.3 Screening

The abstracts of titles deemed appropriate for inclusion during the level of identification were retrieved from the relevant databases and reviewed by the primary researcher. Abstracts were

reviewed according to predetermined inclusion and exclusion criteria set for the present research study. Attention was directed towards the characteristics of sample groups, the accessibility of full texts of studies, study designs, methods of analysis, outcome measures, time period and language of included studies (Abalos, Carroli, Mackey, & Bergel, 2001). Aims and objectives of selected studies were required to be aligned with the aims of the present review. Studies congruent with the inclusion criteria progressed to the next level of review. Those that failed to meet the inclusion criteria were deemed inappropriate and excluded from the next level of review. Assessment information of all abstracts and their associated outcomes was recorded on an Abstract Sheet (Appendix B).

4.9.4 Eligibility

The full texts of all eligible abstracts were retrieved and assessed independently by the primary and secondary researcher for methodological rigour and its suitability for the current study using a self-constructed appraisal tool. The inclusion of studies in the final level of inclusion was determined by a threshold score set by the researcher during a consultation with the supervisor. Additionally, a joint decision was made to exclude studies failing to report on the psychological outcomes of HIV-related stigma for AIDS orphans. The inclusion of studies in the final inclusion of data was further determined by a joint decision-making process between the researchers. Disagreements regarding the eligibility of studies were discussed among the researchers until a consensus was reached regarding the outcome. An in-depth description of the critical appraisal tool and its threshold score for eligibility is presented below.

4.9.4.1 Critical appraisal tool

The present study allowed the review of studies with qualitative, quantitative and mixed-method methodologies. Consequently, qualitative, qualitative and mixed-method appraisal

tools were adapted for the evaluation of methodological rigour and suitability. Appropriate qualitative and quantitative critical appraisal tools were selected and adjusted along the guidelines proposed by Law, Stewart, Pollock, Letts, Bosch, & Westmorland (1998) respectively. The Critical Appraisal Skill Program (CASP) (2014) was identified as a suitable critical appraisal tool for the current study and has been appropriately adapted for the use of full-text reviews. Both qualitative and quantitative critical appraisal tools were divided into eight subsections, namely the study purpose, study design, sampling, data collection, data analysis, findings, conclusion and ethical considerations. The critical appraisal of these subsections guarantees the methodological quality of each subsection, in addition to the quality of studies methodologies as suggested by Siering, Eikerman, Hausner, Hoffman-Eber & Neugebauer (2013). The items of the CASP were examined by the primary researcher who added missing items necessary for evaluation, and deleted extraneous items. This step was conducted to ensure that generic items and specific items were incorporated into the critical appraisal tool. 'Generic items' relates to features of a particular study design – either qualitative or quantitative – such as measuring techniques, sampling methods and analysis. 'Specific items' refers to features relating to the subject area and are necessary for answering the research question (Kitchenham, 2004).

The final set of items were maintained and divided across these sub-sections for a better reviewing process (Siering, et al., 2013). A rating scale rubric was used to assess each item allowing a score of either 1 if the item was present, or 0 if the item was absent. This rating scale allowed a holistic evaluation, resulting in an overall percentage representing the quality of the study under review (Tierney & Marielle, 2004; Law, et al., 1998). As a result, two versions of the CASP tool were developed for the assessment of both qualitative (Appendix C) and quantitative (Appendix D) methodologies. As these appraisal tools were developed for

the review of quantitative and qualitative methodologies, a further appraisal tool was identified for the review of mixed method-methodologies. The Evaluative Tool for Mixed Method Studies (2005) (Appendix E) was identified as suitable for reviewing mixed-method methodologies and adapted accordingly. Similar to the adaptations brought about to the qualitative and qualitative methodologies, the items of the Evaluative Tool for Mixed Method Studies were maintained and divided into eight sub-sections, allowing assessment of the overall quality of the study under review and to facilitate a better reviewing process (Siering, et al., 2013). The rating scale provided an overall percentage representing the quality of the reviewed article by awarding a 1 to items that were present and 0 to absent items.

Three critical appraisal tools were therefore adapted for the independent assessment of quantitative, qualitative and mixed-method studies within the present review. These tools were revised by both the primary and second reviewer, enabling a collective understanding of appraisal tools and scoring techniques. This approach aims to decrease the inconsistency of composite scores awarded by researchers, and to increase standardisation and reliability (Schlosser, 2007). Each tool consisted of 8 sections, namely study purpose, study design, sampling, data collection, data analysis, findings, conclusion and ethical considerations.

These appraisal tools were adapted to assess each section of prospective studies rather than the methodological section alone. Siering and colleagues (2013) suggested that appraisal tools were often focused on examining the methodological quality of studies and in turn overlooked the studies' quality of content. Siering, et al. (2013) stressed the importance of the overall quality of research studies. Therefore, subsections were maintained, allowing the equal contribution of each subsection towards the composite score. This approach allowed assessment of both methodological and content quality. Adapted tools were piloted by the primary researcher, ensuring the tools' reliability and validity. Pilot testing allowed the

identification of measurement error, which allows the refinement of instruments. The process of refinement acts to minimise measurement error, increasing the validity and reliability of the assessment tool (Kimberlin & Winterstein, 2008). Eligible studies progressed to the level of review, namely inclusion by meeting the set threshold score as discussed below.

4.9.4.2 Threshold Score

Each fully reviewed study was awarded a composite percentage indicating its methodological rigor and overall quality from weak (0–30), moderate (31–65), strong (66–80) and excellent (81–100). According to Meline (2006, p. 25), the use of a ‘threshold approach guarantees a minimum level of quality’. The threshold score for the inclusion of eligible studies was set at ‘excellent (81–100)’. Although the comprehensive nature of selected appraisal tools allows a lower threshold score, the present study aimed at including studies of the finest methodological rigour. Studies of the finest methodological rigour provide the best available evidence from which informed decisions may be made (Hemingway & Brereton, 2009). The stringent appraisal and high threshold score for eligibility excludes poorly structured studies with inadequate methodologies and in turn increases the validity and reliability of the current study as it provides the best amalgamated group of findings from which decisions and conclusions may be drawn (Hemingway & Brereton, 2009).

4.9.4.3 Inclusion

All full-text studies meeting the designated threshold score were subjected to the process of data extraction and are included in the final inclusion of studies for the current study. The process of data extraction is outlined below and fully discussed in Chapter Five.

4.10 Data Extraction

Data extraction is the process of describing the overall study by extracting the findings of each primary study in a consistent manner, so that these findings may be synthesised and

interpreted at a later stage (Kitchenham, 2004). The main objective of the data extraction process is to design a data extraction tool to accurately record the findings presented in selected primary studies (Kitchenham, 2004). The primary researcher extracted data from all articles satisfying the stipulated threshold by means of a self-constructed Data Extraction Sheet (Appendix F). The data sheet was constructed along the guidelines outlined in the Cochrane Data Extraction & Assessment Form (Higgins & Green, 2011). This sheet was separated into three distinct sections, namely General Description, Methodology, Findings and Analysis. Extracted data were based on the objectives of the current study and aligned with the various levels of analysis. To reduce bias, the data extraction sheet was piloted by the primary researcher on a random sample before the data extraction process (Kitchenham, 2004). An in-depth account of the data extracted and the self-constructed data extraction sheet is presented in Chapter Five.

4.11 Analysis

The present study uses a meta-synthesis to gain a qualitative account of the effects of HIV-related stigma on the psychological health of AIDS orphans. Stern & Harris (1985) used the term meta-synthesis to describe the joining or uniting of a group of inter-related studies. Similarly, Schreiber, Crooks & Stern (1997, p. 314) defined meta-synthesis as the ‘bringing together and breaking down of findings, examining them, discovering essential features and combining phenomena to form a transformed whole’. This model is grounded in the interpretative paradigm and attempts to synthesise the findings of different studies within an inter-related group of studies, creating a holistic and deeper understanding of the phenomenon under scrutiny (Walsh & Downe, 2005).

Walsh & Downe (2005, p. 204) furthermore argue that the use of a meta-synthesis ‘increases the certainty in cause and effect relationships in a particular area’. Meta-synthesis’

overarching goal is to produce a new and integrative explanation of findings that cannot be deduced from individual studies as it allows the identification of themes, concepts and patterns across studies, the refinement of existing bodies of knowledge, and allows the emergence and alteration of operational models and theories (Finfgeld, 2003; Schreiber, et al., 1997). This comprehensive body of knowledge contributes to the improvement of clinical outcomes, policy and future research (Finfgeld, 2003). Therefore, meta-synthesis does not deduce findings to a single unit but rather aims to attain a higher level of abstraction, contribute to theory development and increase the generalisability of findings, making it more accessible for application and practice (Zimmer, 2006).

A meta-synthesis is deemed appropriate for the present study as it provides a broad description and deep understanding of the relationship between the effects of HIV-related stigma and the psychological health of AIDS orphans (Walsh & Downe, 2005). It further creates a comprehensive base of knowledge that could be readily used for clinical practice and informing future policies and intervention programmes (Finfgeld, 2003). A meta-synthesis lends itself to the critical review and consolidation of existing knowledge outlining eminent themes, concepts, theories and operational models, allowing the development of new theories for practice (Finfgeld, 2003; Sandelowski, 2008). Additionally, a meta-synthesis allows the generalisation of findings so that it may be extended for practical use across various demographic locations and populations, proving useful in intervention and policy development targeting the improvement of mental health for AIDS orphans (Zimmer, 2006). Finfgeld (2003) has identified three types of meta-synthesis, namely descriptive study, theory explication and theory building. Although these types of meta-synthesis are discussed as independent methods, they are rather interconnected and co-dependent (Finfgeld, 2003). All three methods of meta-synthesis are discussed below. The types of meta-synthesis conducted

were motivated by the aim of the current study. Therefore, descriptive meta-synthesis and theory explication was selected. Descriptive meta-synthesis allows an in-depth descriptive account of the findings of the present study, while theory explication allows the amalgamation of pragmatic evidence highlighting shared themes and contrasting themes regarding the effects of HIV-related stigma on the psychological well-being of AIDS orphans. Lastly, it conveys the underlying nature of the research problem across included studies.

4.11.1 Descriptive meta-synthesis

Descriptive meta-synthesis refers to the amalgamation of findings and results that leads to an all-inclusive analysis of phenomena. It refrains from evaluating a single concept or aspect but rather engages in a wide-ranging evaluation of complex phenomena. Therefore, it allows the descriptive amalgamation of findings extracted from included studies (Schreiber, et al., 1997; Finfgeld, 2003). Descriptive meta-synthesis comprises two elements, namely process results and data extraction. Process results refers to a descriptive account of findings extracted at each level of review. The level of findings will be visually presented by means of the PRISMA flow diagram, representing the findings extracted at each level of review. Visual representation of findings offers a clear synopsis of the study's design elements and its associated process findings. Data are extracted by the use of a self-constructed data extraction sheet. Data extraction focuses on the levels of analysis and the objectives of included studies.

The data extraction process unfolds into four distinct categories, namely General Description, Methodology, Findings and Analysis, as mentioned above. The findings of all included studies are first tabulated and then descriptively discussed. The general description of studies includes a description of the target population, geographical location, aim and problem statement of included studies. Methodology outlines the methodological aspects of included

studies descriptively reporting on study designs, theoretical frameworks, sampling methods and size and methods of data collection. Lastly, a descriptive account of data analysis, findings and conclusions of included studies is provided. A descriptive meta-synthesis is used to descriptively amalgamate the findings of the present study and is presented in Chapter Five.

4.11.2 Theory Explication

Theory explication results in the reconceptualisation of original phenomena by fleshing out abstract concepts. Findings across studies are deconstructed, reconstructed and synthesised to illuminate concepts under scrutiny (Finfgeld, 2003). The present study follows three procedural guidelines proposed by Noblit & Hare (1988) for conducting a theory explication. The three guidelines are: **reciprocal translations, refutational synthesis and lines-of-argument synthesis. Theory explication forms the discussion of findings and is presented in Chapter Six.**

4.11.2.1 Reciprocal translations

As suggested by Noblit & Hare (1988), the reciprocal translation stage highlights recurring themes and concepts across studies included in the systematic review. Special focus is diverted towards concepts, themes and metaphors used by researchers to explain phenomena or processes. Therefore, findings and ideas regarding the manner in which HIV-related stigma has infiltrated the lives of AIDS orphans and contributed to their experience of psychological distress were captured. The focus placed on the recurring themes and ideas facilitates the primary researcher's understanding of the research phenomena and allows the synthesis of research findings which may be presented as a pragmatic body of knowledge (Noblit & Hare, 1988; Finfgeld, 2003). Reciprocal translations is represented as the

discussion of findings which are congruent to the theoretical framework and relevant literature outlined in Chapter Two and Three respectively.

4.11.2.2 Refutational synthesis

The refutational stage explicitly identifies and explores contrary findings across included studies in comparison with recent literature and theoretical underpinnings. Therefore, findings extracted from included studies that are incongruent with the theoretical framework and relevant literature outlined in Chapters Two and Three respectively are discussed. Refutational findings are invaluable as they shed light on the gaps in current literature and promote future research. Similarly, Noblit & Hare (1988, p. 49) suggest that ‘explicit refutations holds considerable potential for promoting reflexivity and enriching human discourse’. Although reciprocal translations may not be deduced from refutations as they have to be analysed and explored within their own right, refutations embody a social meaning independent from the study upon which they are based (Noblit & Hare, 1988). An exploration and explanation of differences across studies hinges on situational contexts rather than numerous ethnographic realities captured by included studies.

4.11.2.3 Line-of-argument

The line of argument is regarded as an explicit statement representing all new findings identified within the process of analysis. The statement strives to exemplify a comprehensive nature as it includes identified similarities and differences across included studies and its relation to an array of existing studies focusing on the same phenomena being studied by the current study (Noblit & Hare, 1988).

Theory explication meta-synthesis is deemed appropriate for providing insight regarding the commonalities and differences across inter-related studies. Such insight proves valuable as it allows the reconstruction of phenomena and the synthesising and comparison of findings,

providing a comprehensive base of knowledge deduced from numerous studies reporting on the relationship between psychological outcomes for AIDS orphans and HIV-related stigma (Finfgeld, 2003). Additionally, the researchers may express their views either in agreement or disagreement with the outlined findings.

4.12 Ethical Considerations

Permission to conduct the present systematic review was obtained from the Senate Research Committee at the University of the Western Cape (Appendix G). All studies included in the review were published articles considered to be available in the public domain, so ensuring transparency. Further access to conduct the current study was not required. The primary researcher is a registered student at the institution and has full access to the databases available in the library of the University of the Western Cape. All steps were employed by the researcher to maintain the integrity of the study through the avoidance of misconduct and plagiarism (Wager & Wiffen, 2011). Moreover, the study remains sensitive to the ethical shortfalls of systematic reviews identified by Vergnes, Marchal-Sixou, Nabet, Maret & Hamel (2010) to increase the trustworthiness and reliability of findings and data analysis. It is an ethical obligation that the National Research Foundation be recognised as the primary source of funding for this research project, although all conclusions drawn is the author's own work.

CHAPTER FIVE

Findings

5.1 Introduction

This chapter provides a descriptive account of the findings of all included studies in the current systematic review. A descriptive meta-synthesis was conducted to render descriptive accounts of findings. This chapter consists of the process of results and data extraction. The process of results reports on the findings extracted at the four levels of review, namely identification, screening, eligibility and inclusion. Lastly, the data extraction process extracts data in three distinct categories, namely general description, methodology, and findings and analysis by using a self-constructed appraisal tool.

5.2 Process of Results

The process of results and findings is discussed along the four levels of review adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) as discussed in Chapter Four (Moher, et al. 2009). The four levels of review, namely Identification, Screening, Eligibility and Inclusion are descriptively discussed, outlining the research findings extracted at each level of review respectively. Below is a recapitulation of Figure 2 which has been depicted in Chapter Four. The recapitulation of the PRISMA flow chart (Figure 3) graphically reflects the levels of review and their associated findings while reinforcing the study's structure of data collection methods and design elements.

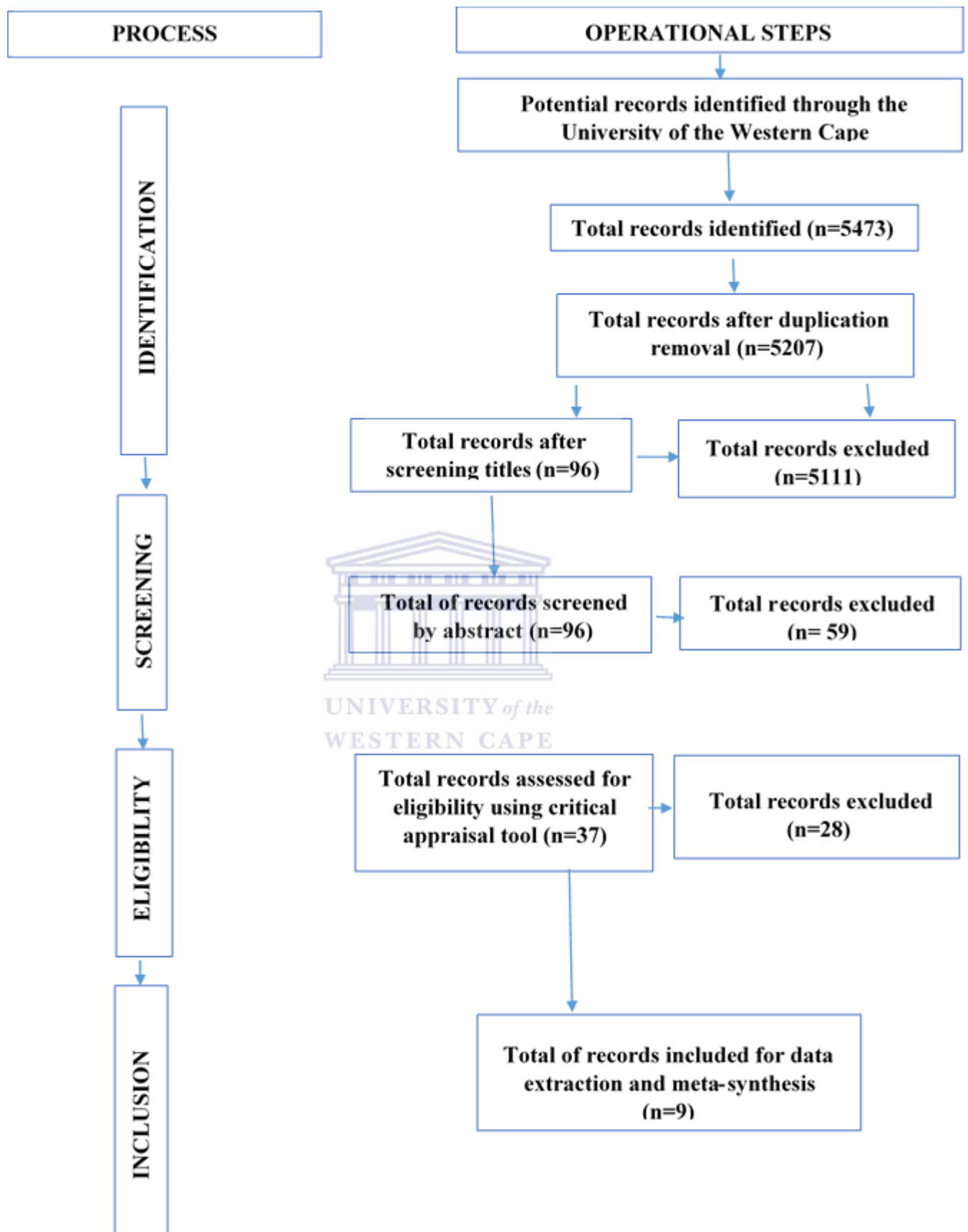


Figure 3: PRISMA levels of review and results.

5.2.1 Level 1: Identification

The title search conducted across the identified databases housed in the library of the University of the Western Cape yielded a total of 5473 hits. A total of 266 duplicated titles were identified across database searches. Duplications were removed from the total number of hits, resulting in a total of 5207 prospective titles. From these, 96 titles were identified as possible inclusions for this study while consequently excluding a total of 5111 titles from the next level of review. Boolean advanced searches were limited to a span of 11 years, ranging from 2004–2015, English medium, peer-reviewed and full-text articles.

5.2.2 Level 2: Screening

The abstracts of all 96 titles identified at the previous level were reviewed, resulting in the inclusion of 37 abstracts that were deemed appropriate for the purpose of the study. The difference of 59 titles was deemed inappropriate and excluded from the next level of review. Reasons for exclusion were as follows: the study did not address the research question and purpose ($n=28$); abstracts were inadequate and poorly written, failing to report on significant elements of the study's design or methodological process ($n=12$); the sample group or target population was inappropriate – focusing on caregivers and guardians rather than AIDS orphans ($n=7$); the study's design was inappropriate, taking the form of either a literature or systematic review ($n=7$); and the full text of articles was inaccessible via open access and were required to be purchased.

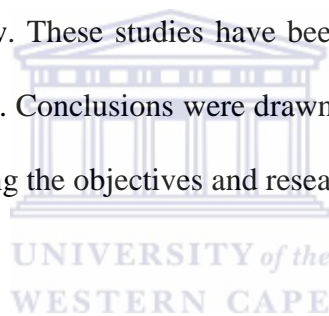
5.2.3 Level 3: Eligibility

The 37 studies included at the previous level were appraised using a critical appraisal tool developed for the respective methodologies. After appraisal, nine studies were included in the final summation of data excluding the remaining 28 studies. There were two main reasons for the exclusion of studies from the final review, namely their inability to meet the

predetermined threshold score for inclusion ($n=14$) and their failure to report on the psychological outcomes of HIV-related stigma for AIDS orphans ($n=9$). Studies excluded attained a threshold score below the 80% cut-off. Studies not meeting the predetermined threshold for inclusion might have placed their focus on the content of discussion, resulting in failure to account for methodological structure. Other reasons for exclusion were the discovery of inappropriate study designs ($n=3$) and target populations ($n=2$) within the full-text review. Nine studies obtained excellent (81%–100%) scores and were included in the final review.

5.2.4 Inclusion

A total of nine studies were identified as appropriate for the purpose of the present study and were included in the final review. These studies have been subjected to the data extraction process which is discussed below. Conclusions were drawn from the findings and the content of these nine studies for addressing the objectives and research questions of the current study.



5.3 Data Extraction

Data were extracted from the nine studies included in the final level of review using a self-constructed extraction tool as discussed in Chapter Four. Data extraction unfolded in four distinct parts, namely general description, methodology, findings and analysis. Each division contains detailed subsections aimed at extracting vital information present within the various sections of each study.

5.3.1 General description

The general description reported on information of the target population, geographical location, demographic factors, aim and the problem statement of included studies. A general description of findings of included studies is represented in Table 3 below.

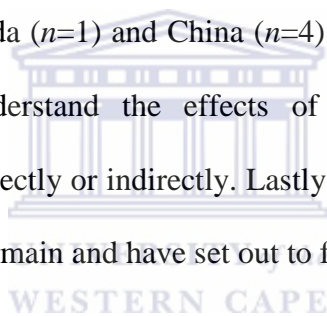
Table 3: General description of studies.

Author/s	General Description			
	Target Population (single/double orphans)	Geographical Location	Aim	Problem Statement
Harms, Jack, Ssebunnya & Kizza (2010)	Single and double AIDS orphans	Uganda, Kampala	To explore the youth's narratives related to 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.
Zhao, Li, Zhao, Zhang & Stanton (2012)	Vulnerable children Single and double AIDS orphans 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	Few studies have examined the relative importance of various measures of HIV-related stigma in predicting psychological outcomes. 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 be a barrier to HIV prevention, treatment and care efforts.
Boyes & Cluver (2015)	Vulnerable children (AIDS orphans & children living with sick parents) Non-orphans	Western Cape and Mpumalanga, South Africa	To determine whether prospective relationships between familial HIV/AIDS and both anxiety symptoms and depressive symptoms operate indirectly via bullying victimisation	To date, no studies have examined whether relationships between familial HIV/AIDS and both symptoms of anxiety and depressive symptoms may operate indirectly via experiences of bullying victimisation.

Chi, Li, Zhao & Zhao (2014)	Single orphans Double orphans Vulnerable children	Rural China	Explore the longitudinal reciprocal effects of depressive symptoms and stigma, specifically enacted stigma and perceived stigma among children affected by HIV/AIDS	Perceived stigma and enacted stigma were reported as robust predictors to internalising and externalising problems not only among children affected by HIV/AIDS but also among HIV-free family in the same community. Limited data were available regarding the impact of different forms of stigma on children's mental health in a longitudinal perspective and in resource limited settings.
Cluver, Gardner & Don Operario (2008)	AIDS orphans Orphans Non-orphans	Cape Town, South Africa	<ul style="list-style-type: none"> • To examine associations between orphanhood and community risk factors • To examine associations between community risk factors and psychological outcomes, and • To examine the extent to which community risk factors mediate associations between AIDS orphanhood (compared with other orphanhood and non-orphanhood) and psychological outcomes 	Research in South Africa shows that AIDS orphanhood is independently associated with heightened levels of psychological problems. The present study is the first to explore the mediating effects of stigma and other factors operating on a community level.
Mo, Lau, Yu & Gu (2015)	Vulnerable children AIDS orphans	Rural Central China	To examine the relationship between associative stigma, optimism, self-esteem and depression and anxiety among children of HIV-infected children in China.	Since the outbreak of the HIV pandemic, PLWH have been subjected to high levels of stigmatisation and discrimination. Stigma has also been found to be significantly associated with adverse mental health outcomes among PLWH. Despite this, relatively few studies have been conducted to explore how stigma affects the children of PLWH.
Cluver & Orkin	AIDS orphans	Cape Town,	To assess how food insecurity, bullying, and	If appropriate services for AIDS-affected children are to be

(2009)	Orphans Non-orphans	South Africa	AIDS-related stigma interact with each other and with the likelihood of experiencing clinical-range disorder.	developed, we need reliable evidence concerning factors which mediate risks of clinical-level disorder. However, few studies to date have investigated interactions of AIDS-orphanhood in particular with risk factors and child mental health. To our knowledge, the present study is the first known study to explore cumulative or interactive effects in relation to child mental health in the developing world.
Xu, Yan, Duan, Wang, Rou & Wu (2009)	AIDS orphans Caregivers Community Informants	Longchuan, County Yunnan Province, China	To explore the psychosocial problems experienced by these children including emotional problems, interpersonal relationships, and stigma and discrimination	More research is needed to profoundly understand the psychosocial impact of HIV/AIDS on children and appropriately indicate the need for interventions. Our study takes the first step toward understanding the psychosocial wellbeing of children in HIV/AIDS-affected families in rural China.
Cluver & Gardner (2007)	AIDS orphans Caregivers Health professionals	Cape Town, South Africa	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. Even less is known about factors in these children's lives that can affect their mental health. Psychological 'risk factors' are defined as variables that increase the likelihood of psychological difficulties, and 'protective factors' as variables that improve outcomes, despite environmental hazards.

As depicted in Table 3, the nine studies have met the predetermined inclusion criteria with regards to the sample groups, as either single orphans, double AIDS orphans or vulnerable children were recruited. Few studies ($n=4$) have used appropriate control groups consisting of AIDS orphans, orphans by other causes and non-orphans to determine whether AIDS orphans are at elevated risk for experiencing psychological distress (Cluver & Orkin, 2009; Cluver, Gardner, & Operario, 2008; Boyes & Cluver, 2015; Zhao, Li, Zhao, Zhang, & Stanton, 2012). Two ($n=2$) studies have sampled caregivers, health professionals and community informants along with AIDS orphans to gain a better understanding of their experience of HIV-related stigma and the associated psychological effects (Cluver & Gardner, 2007; Xu, Yan, Duan, Wang, Rou & Wu, 2009). The geographical locations of the studies were split across South Africa ($n=4$), Uganda ($n=1$) and China ($n=4$). Unvaryingly, studies have aimed to explore, determine and understand the effects of HIV-related stigma and AIDS orphanhood on children either directly or indirectly. Lastly, all studies ($n=9$) have recognised the lack of research within this domain and have set out to fill the gap in the current literature.



5.3.2 Methodology

The methodological level data extraction reports on information regarding the study's design, theoretical framework, sample population, sample size and data collection methods of included studies. All methodological findings were extracted using a self-constructed data collection sheet and are presented in Table 4.

Table 4: Methodology.


Author	Methodology				
	Study Design	Theoretical Underpinnings	Sampling Method	Sample Size	Data collection methods/ Instruments
Harms, Jack, Ssebunnya & Kizza (2010)	Fundamental qualitative descriptive research design	Not specified	Convenience sampling	13 AIDS orphans (Single/double orphan status not explicitly specified)	<ul style="list-style-type: none"> • Individual in-depth semi-structured interviews • Predetermined open-ended questions were used to explore the phenomenon under study • Short written questionnaire for collecting demographic data • Interviews were recorded. Permission to do so was obtained from participants.
Zhao, Li, Zhao, Zhang & Stanton (2012)	Quantitative cross-sectional design	Not specified	Not specified	775 AIDS orphans (consisting of single/double orphans; however, percentages not explicitly identified) 404 non-orphans	<p>Each participant completed an assessment inventory consisting of:</p> <ul style="list-style-type: none"> • Detailed measures of demographic information • Perceived Public Stigma Against PLWHA 10-item scale • Stigma Against Children Affected by AIDS Scale (SACAA) • Personal Stigmatisation Attitudes Against PLWHA Scale

					<ul style="list-style-type: none"> • Enacted Stigma Scale • Centre of Epidemiology Studies Depression Scale for Children (CES-DC) • Childs Rating Scale (CRS)
Boyes & Cluver (2015)	Quantitative longitudinal study design	Not specified	Simple random sampling	<ul style="list-style-type: none"> • 1318 participants were vulnerable children • 2197 participants were non-orphans • 3401 retention of participants • 114 loss of participants 	<ul style="list-style-type: none"> • Questionnaire booklet designed in the style of a teen magazine and including pictures or popular music and television stars. <p>Questionnaire booklets contained the following scales:</p> <ul style="list-style-type: none"> • Children's Depression Inventory- Short Form (CD-SF) • Social & Health Assessment Peer Victimization Scale • Stigma-by-Association Scale • South African School Attitudes Survey
Chi, Li, Zhao & Zhao (2014)	Quantitative longitudinal study design	Not specified	Convenience sampling	<ul style="list-style-type: none"> • 272 AIDS orphans • 249 vulnerable children • 7.5 % loss of participants 	<p>Assessment consisted of 4 measures, namely:</p> <ul style="list-style-type: none"> • Demographic characteristics • Centre for Epidemiological Studies Depression Scale for Children (CES-DS) • Stigma Against Children Affected by AIDS • Self-Constructed Enacted Stigma Scale
Cluver, Gardner	Quantitative Study	Not specified	Non-probability-	<ul style="list-style-type: none"> • 425 AIDS orphans 	<ul style="list-style-type: none"> • Anonymous self-report questionnaires

<p>& Operario (2008)</p>	<p>Design (not further specified)</p>		<p>Purposive sampling</p> 	<ul style="list-style-type: none"> • 241 orphans by other causes • 278 non-orphans 	<ul style="list-style-type: none"> • Interviews with participants • Psychometric measurement tools were: • Child Depression Inventory • Children’s Manifest Anxiety Scale – Revised • Strengths and Difficulties Questionnaire (peer problems and conduct problems subscales) • Child PTSD Checklist • Child Behaviour Checklist (delinquent subscale) • Demographic factors measuring individuals and household factors such as age, gender, migration, age at orphanhood, dwelling type and household size. • Social and Health Assessment Peer Victimization Scale • Self-reports of past year experience of witnessing or having been a victim to establish exposure to community trauma • A brief 4-item scale was devised from the Berger Stigma Scale for HIV-positive youth. Revised for assessing the presence of HIV-related stigma.
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<p>Mo, Lau, Yu & Gu (2015)</p>	<p>Quantitative study design (not further specified)</p>	<p>Not specified</p>	<p>Non-probability – purposive sampling</p>	<ul style="list-style-type: none"> • Total of 195 participants • (Children living in selected villages, between the ages of 9 and 15, whose family had HIV infections or had died from HIV. Children who were HIV positive were excluded from the study). 	<p>Self-administered structured questionnaires consisted of the following psychometric tools:</p> <ul style="list-style-type: none"> • Affiliate Stigma Scale • Rosenberg Self-esteem Scale • Life Orientation Test Revised Scale • Children Depression Inventory (CDI) • Screen for Child Anxiety Related Emotional Disorders
<p>Cluver & Orkin (2009)</p>	<p>Quantitative research design (not further specified)</p>	<p>Not specified</p>	<p>Non-probability sampling – purposive sampling</p>	<ul style="list-style-type: none"> • 425 AIDS orphans • 241 orphaned by non-AIDS causes • 278 non-orphaned • (A further 81 were excluded as cause of orphanhood could not be confirmed.) 	<p>With interviewers, children completed anonymous self-report questionnaires consisting of the following psychometric measures:</p> <ul style="list-style-type: none"> • Child Depression Inventory • Children’s Manifest Anxiety Scale-Revised (R-CMAS) • Child PTSD Checklist • Social and Health Assessment Peer Victimization Scale (adapted from the Multidimensional Peer Victimization Scale)

					<ul style="list-style-type: none"> • No standardised instruments currently exist to measure HIV-related stigma amongst non-infected orphans. A brief 4-item stigma scale was devised, based on items from the Berger Stigma Scale for HIV Youth – Revised • Food insecurity was measured using self-report of 0–7 days without food in the past week
<p>Xu, Yan, Duan, Wang, Rou & Wu (2009)</p>	<p>Qualitative study design (not further specified)</p>	<p>Not specified</p>	<p>Non-probability – purposive sampling and convenient sampling</p>  <p>UNIVERSITY of the WESTERN CAPE</p>	<ul style="list-style-type: none"> • 11 AIDS orphans (5 paternal orphans, 2 maternal orphans & 4 double orphans) • 5 non-orphans • 16 caregivers (7 grandparents, 5 mothers, 3 fathers and 1 uncle) <p>Five key community informants (1 village leader, 1 local health service provider, 1 principal of a local</p>	<ul style="list-style-type: none"> • Semi-structured interviews (duration of each interview ranged from 30 minutes with the younger children to 1.5 hours with the older children and the caregivers) • Drawings regarding their feelings were obtained from children but were not analysed.

				middle school, 1 director of the local Women's Federation and 1 vice-director of the local civil affairs bureau)	
Cluver & Gardner (2007)	Qualitative study design (Grounded Theory Approach)	Not specified	Convenience sampling 	<ul style="list-style-type: none"> • 60 AIDS orphans • 42 caregivers of orphaned children • 20 are professionals 	<ul style="list-style-type: none"> • Worksheet-based semi-structured interviews featuring popular cartoon characters (children opted to answer in relation to themselves (first person) or the cartoon character (third person), and chose to respond in writing, drawings, or verbally, independently or with interviewer assistance) • Caregivers participated in Xhosa and English focus groups

Included studies as reflected in Table 4 above either adopted a quantitative ($n=6$) or qualitative ($n=3$) approach for exploring the psychological distress and poor mental health outcomes of AIDS orphans. Of the six quantitative studies, 2 studies (Chi, Li, Zhao, & Zhao, 2014; Boyes & Cluver, 2015) embodied a longitudinal study design, and one study (Zhao, et al., 2012) embodied a cross-sectional study design. The remaining three studies failed to explicitly report on the study design used within their studies (Cluver & Orkin, 2009; Mo, Lau, Yu, & Gu, 2015; Cluver, Gardner, & Operario, 2008). Of the three qualitative study designs, the study of Harms, Jack, Ssebunnya & Kizza (2010) embodies a fundamental qualitative descriptive research design, and the study of Cluver & Gardner (2007) used a ground theory design. The remaining study (Xu, et al., 2009) failed to explicitly report on the study design used.

Non-probability purposive sampling ($n=4$) and convenience sampling ($n=4$) were equally utilised across studies. However, it is important to note that the study of Xu, et al., (2009) employed both methods of sampling to recruit a justified sample size from the sample population. Simple random sampling was used by one study (Boyes & Cluver, 2015) to recruit participants. The remaining study (Zhao, et al., 2012) failed to explicitly account for the sampling method used. All included studies ($n=9$) failed to explicitly provide a theoretical framework or underpinnings to guide the studies' research findings and the reader's understanding of how such findings are inter-related with current theoretical assumptions. The sample size ranged from 13 participants to 3515 participants respectively (Harms, Jack, Ssebunnya, & Kizza, 2010; Cluver & Gardner, 2007). Self-administered questionnaires consisting of various psychometric measures (Boyes & Cluver, 2015; Zhao, et al., 2012; Chi, et al., 2014; Mo, et al., 2015; Cluver & Orkin, 2009; Cluver, et al., 2008) was the most

commonly used method of data collection, followed by semi-structured in-depth interviews (Xu, et al., 2009; Harms, et al., 2010; Cluver & Gardner, 2007).

5.3.3 Findings and Analysis


Findings and analysis descriptively summarises the findings and authors' conclusions of included studies. This section focuses on information regarding the method of data analysis, findings, conclusion and recommendations extracted from included studies. The data extracted are presented below in Table 5.

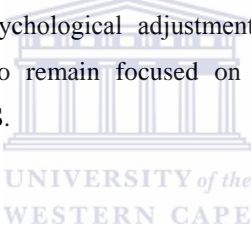


Table 5: Findings and Analysis.

Author	Findings and Analysis		
	Method of Data Analysis	Study's Findings	Author's conclusions
Harms, Jack, Ssebunnya & Kizza (2010)	The computer software package, QSR NVivo 2.0 was used to manage and code data. All transcripts, memos and case summary data were analysed using qualitative content analysis.	<p>Research results suggest the following:</p> <ul style="list-style-type: none"> All participants experienced a loss of their childhood, exposure to extended family conflict and experiencing social stigmatisation. These losses combined contributed to their loss of childhood as they experienced prolonged absence from school, increased manual labour, financial responsibilities and caring for younger siblings. The experience of orphanhood commences during parental illness rather than death. Youth experienced exploitation and conflict with clan/family members over much-needed resources and property. All participants reported their experience of 'okulangira'. This is a verbal exchange where one person is reminded in a derogatory manner about his/her inferior societal position. This form of stigmatisation led to isolation, conflict and heightened levels of psychological distress for AIDS orphans. 	The consequences of parental death by HIV/AIDS led to several struggles for AIDS orphans, namely poverty, lost educational opportunities and living with extended family systems characterised by difficulty and exploitation. AIDS orphans experience culturally specific forms of stigma related to their HIV/AIDS orphan status, making these youth twice and thrice more vulnerable. More needs to be done to understand and address the difficulties experienced by AIDS orphans in order to offer adequate support.
Zhao, Li, Zhao, Zhang & Stanton (2012)	<ul style="list-style-type: none"> Chi-square and ANOVA were employed to assess the group differences in key demographic variables, stigma measures and child psychological problems Post-hoc comparison was performed using the least significant difference 	<p>There were significant group differences in key demographic characteristics, stigma measures and psychological problems among orphans, vulnerable children, and comparison children, namely:</p> <ul style="list-style-type: none"> Comparison children reported a higher family socio-economic status (SES) than both orphans and vulnerable children. Orphans reported a higher family SES than vulnerable children. Orphans scored higher than vulnerable children, who scored higher than 	Various measures of stigma lead to internalising and adjustment problems independent of key demographic factors. All stigma measures do not equally contribute to child psychological problems. There is a need to consider the effect of various forms of HIV-related


	<p>(LSD) criterion to identify pair-wise differences for those continuous variables that show an overall significant difference among three groups.</p> <ul style="list-style-type: none"> • Pearson product moment correlation coefficients were employed to assess the relationship among various stigma and psychological measures among the entire sample • Multiple regression analysis was employed to assess the relative contribution of various forms of stigma measures to both internalising and adjustment problems. 	<p>comparison children on two forms of perceived public stigma (stigma against PLWHA and stigma against children affected by HIV).</p> <ul style="list-style-type: none"> • Orphans reported higher levels of psychology problems than vulnerable children who reported higher levels of psychological problems than comparison children. • The correlation coefficients among measures of stigma and psychological problems were similar for orphans and vulnerable children. • Comparison children displayed lower correlations except a higher correlation between depression and adjustment. • The correlations among the first three stigma measures were in general higher among orphans and vulnerable children than comparison children. • The highest correlations were between two measures of perceived public stigma, followed by enacted stigma and depression. • The weakest correlations were those between personal stigma against PLWHA and depression followed by the correlations between personal stigma and enacted stigma. • Higher scores on perceived public stigma measures are predictive of depression. • Results of regression analysis show that an older age, being an orphan, perceived public stigma and enacted stigma are predictive of depression among children affected by HIV. 	<p>stigma on these children's psychosocial well-being and effectively utilise community resources to mitigate the negative effect of HIV-related stigma on AIDS orphans.</p>
Boyes & Cluver (2015)	<p>Analysis was conducted in four stages in SPSS 22 and Mplus 6, namely</p> <ul style="list-style-type: none"> • Differences in socio-demographic 	<p>The study's findings indicated that:</p> <ul style="list-style-type: none"> • Children and adolescents affected by familial HIV/AIDS experience higher levels of anxiety and depression and an increase in poverty and HIV-related 	<p>Familial HIV/AIDS was associated with symptoms of anxiety and depression both cross-sectionally and longitudinally.</p>

	<p>factors, mental health scores and experiences of victimisation and bullying were assessed between study participants</p> <ul style="list-style-type: none"> Anxiety symptoms, depressive symptoms, bullying victimisation, poverty and HIV-related stigma was assessed at baseline and follow-up assessment Correlational analysis outlined the strength of the relationships between anxiety and depressive symptoms and being HIV affected, bullying victimisation and HIV-related stigma Correlation analysis acts to detect whether there is a relationship between HIV-affected and anxiety and depressive symptoms operate via bullying victimisation, HIV-related stigma and mental health 	<p>stigma.</p> <ul style="list-style-type: none"> There is a significant correlation between familial HIV/AIDS and bullying victimisation resulting in a significant increase in anxiety, depression, poverty and HIV-related stigma scores at baseline assessment. Baseline assessment HIV/AIDS familial association was correlated with follow up anxiety and depressive scores, bullying victimisation, HIV-related stigma and mental health. Familial HIV/AIDS was not directly correlated with anxiety scores but indirectly associated with anxiety via bullying victimisation and HIV-related stigma. 	<p>Children with familial HIV/AIDS experienced significantly higher levels of anxiety and depression. There is a call for more systematic research on group differences in anti-bullying programmes and programme components and their effectiveness, as there is much uncertainty regarding which intervention components are successful and for whom.</p>
<p>Chi, Li, Zhao & Zhao (2014)</p>	<p>Data analysis was performed using SPSS 11.0 Cross Lagged path models were tested</p>	<p>The research findings suggests that:</p> <ul style="list-style-type: none"> Autoregressive effects are stable over time for depressive symptoms, perceived stigma and enacted stigma. 	<p>An increase in both enacted and perceived stigma results in an increase in depressive symptoms. The findings suggests a</p>

	<p>with Mplus Version 5.1</p> <p>Data were analysed in 3 steps, namely:</p> <ul style="list-style-type: none"> • Basic stability models were tested. Autoregressive effects of depressive symptoms, perceived stigma and enacted stigma was estimated. • The hypothesised models were tested: perceived stigma – depressive symptoms; depressive symptoms – perceived stigma; enacted stigma – depressive symptoms; perceived stigma – enacted stigma and enacted stigma – perceived stigma. • Several goodness-of-fit indices were applied to assess the fit of hypothesized models: chi-square, Root Mean Square Error of Approximation, p-value and comparative Fit Index 	<ul style="list-style-type: none"> • Cross-lagged effects depicted a cycle among enacted stigma, depressive stigma, perceived stigma and enacted stigma in a linear direction and demonstrate that perceived and enacted stigma affects the well-being of vulnerable children and AIDS orphans in a variety of ways. • Enacted stigma directly predicted symptoms of depression, aggravating the negative effects of perceived stigma on later symptoms of depression. • Children’s depressive symptoms may be the result of experiences of discrimination, isolation and threatening actions by others and various measures of HIV-related stigma. • Feelings of shame/ embarrassment are caused by enacted stigma inhibiting a child’s psychological adjustment, causing AIDS orphans and vulnerable children to remain focused on negative aspects of living with familial HIV/AIDS. 	<p>longitudinal and bidirectional relationship between enacted stigma, perceived stigma and depressive symptoms. Such findings suggest the need for multilevel interventions to effect a reduction in HIV-related stigma. Further interventions need to emphasise the interrelations of these facets while calling for a rigorous programme evaluation in terms of capacity for stigma reduction to increase the well-being of HIV/AIDS-affected families and children.</p>
<p>Cluver, Gardner & Don Operario (2008)</p>	<p>Data were analysed using SPSS Version 14.0. All tests were two-tailed and significance was set at $p < 0.01$ level.</p>	<p>Findings of the study suggests that:</p> <ul style="list-style-type: none"> • General levels of bullying and experience of community traumas were highly associated but displayed no group differences. 	<p>It is of vital importance that policies are developed to address the psychological distress experienced by AIDS orphans. AIDS-related stigma has shown to be</p>

	<p>Data were analysed in 4 steps, namely:</p> <ul style="list-style-type: none"> • Using Chi-square tests and one-way analysis of variances (ANOVA) to establish differences between orphanhood groups, demographic characteristics and community factors. • Bivariate correlations examined associations between community factors and psychological outcomes. • Associations between orphan status and each psychological outcome were assessed using multivariate linear regression analysis. • Indirect effects associated with stigma were examined using the Sobel test for all psychological outcomes. 	<ul style="list-style-type: none"> • Significant group differences were observed for stigma and positive activities; AIDS orphans experienced higher levels of stigmatisation than other orphans; however other orphans experienced higher levels of stigmatisation than non-orphans. • Victimization bullying and stigma are associated with higher scores of depression, anxiety, peer problems, post-traumatic stress, delinquency and conduct problems which are in turn associated with community violence except for peer problems. • Positive activities acted to bring about the reduction in scores of depression, anxiety, peer problems, post-traumatic stress but not conduct problems. • AIDS orphans displayed higher levels of psychological problems than other orphans and non-orphans. • AIDS orphanhood was highly correlated with depression, peer problems, post-traumatic stress, conduct problems and delinquency. However, no correlation between anxiety and AIDS orphanhood was found. All of the correlations previously discussed are fully mediated by HIV-related stigma. 	<p>significantly relevant to AIDS orphans, having strong predictive outcomes on psychopathology. Some factors need to be introduced at a community level, such as bullying, victimisation and stigma, and there needs to be an increase in positive activities to bring about the reduction of psychological distress experienced by AIDS orphans.</p>
<p>Mo, Lau, Yu & Gu (2015)</p>	<p>Analysis was performed using AMOS version 6.0. Descriptive statistic was conducted to establish demographic variables.</p>	<p>The results of the study indicated that:</p> <ul style="list-style-type: none"> • Participants scored higher than the cut-off for depressive and anxiety disorders such as panic disorder, generalised anxiety disorder, separation anxiety disorder, social anxiety disorder and school avoidance. 	<p>Associative stigma indirectly affect depression and anxiety through lower levels of self-esteem and optimism. This observation may be explained by higher levels of associative stigma that lead to the</p>

	<ul style="list-style-type: none"> • Goodness-to-fit of measurement models was established by a confirmatory factor analysis. • The hypothesised relationship between variables was tested using structural equation modelling. • To examine the indirect effect of associative stigma on depression and anxiety, two paths were added to the model. • χ^2 index, the root mean square of approximation, was used to evaluate the overall model fit. 	<ul style="list-style-type: none"> • Associative stigma is positively correlated with depression and anxiety and negatively correlated with self-esteem. However, self-esteem and optimism has a negative correlation with depression and anxiety disorders. • The Structural Model for Testing Indirect Effects depicts that direct paths of associative stigma on anxiety and depression were non-significant. Therefore full-mediation of self-esteem and optimism on the relationship between associative stigma and depression and anxiety. There were significant indirect effects of associative stigma on depression and anxiety. 	<p>internalisation of the negative views of others. This leads victims to believe that the delinquent label is personally relevant to themselves and that they drain society. The acceptance of negative beliefs and views harmfully affects their view of themselves and their future. Feelings of inadequacy towards oneself and the future may lead to poor mental health. The study recommended that support given to children must address associative stigma and its potential consequences on psychological and mental health.</p>
Cluver & Orkin (2009)	<p>Analysis was performed using SPSS Version 14.0. All tests were two-tailed and significance was set at $p < 0.01$ levels for regression.</p> <ul style="list-style-type: none"> • Hierarchical log-linear modelling was conducted using an unweighted set of data. Significance for log-linear modelling was set more stringently at $p < 0.005$. • Automatic backwards selection 	<p>Findings suggest that:</p> <ul style="list-style-type: none"> • Poverty and HIV-related stigma are risk factors for the development of psychopathology in AIDS orphans. • No differences were present in the median score for bullying among AIDS orphans, non-orphans and other orphans. • Clinical levels of psychological distress ranged from 9.8% for anxiety, 9.7% for depression, 27% for PTSD and 31% for internalising disorders. • Risk factors for the development of psychological disorders for AIDS orphans and vulnerable youth have been identified as: quality of care, stigma, bullying and poverty. • The highest level of psychopathology was caused by stigmatisation and 	<p>The risk factors identified interact to produce a cumulative negative effect on child mental health. AIDS-related stigma, bullying and poverty combine to intensify the vulnerability of AIDS-orphaned and vulnerable children. Youth reported higher levels of distress and social isolation. These findings hold theoretical understanding of the impact of the interacting effects of the factors impinging on child mental health. Implications for further research have been</p>

	<p>provided by SPSS yielded eight variables with associations.</p> <ul style="list-style-type: none"> • Potential risk and protective factors were entered into multivariate logistic regressions alongside orphanhood status, age and gender, and with the dependent variable of any internalising disorder. 	<p>poverty, when controlling for demographic factors.</p> 	<p>drawn from research findings. This research may contribute to the ongoing debate whether interventions should target orphans or AIDS orphans within the wider group of vulnerable children. Policy and programming increasingly recognise risks associated with targeting orphans, such as isolation and re-stigmatisation of children. The findings of the present study suggest that AIDS orphanhood and the experience of AIDS-related stigma interact with factors of more general child vulnerability, such as quality of care, bullying and economic vulnerability, to impact on child mental health.</p>
<p>Xu, Yan, Duan, Wang, Rou, Wu (2009)</p>	<p>Data were analysed using ATLAS ti Version 5.0.</p> <p>The following procedures were conducted:</p> <ul style="list-style-type: none"> • All interviews were transcribed by one research staff member. • The quality of the transcription was double-checked by another staff member. • A local research staff member, 	<p>The findings of the study suggested that:</p> <ul style="list-style-type: none"> • Demographic factors varied according to gender, school attendance and time of orphanhood. • Three themes were identified to represent children’s psychosocial problems, namely emotional issues, interpersonal issues and stigma and discrimination. • All participants were found to suffer from emotional problems such as fear, anxiety and a loss of confidence and self-esteem. • These emotional issues were found to influence participants’ interpersonal relationships with both peers and caregivers. 	<p>AIDS orphans and vulnerable children suffer from a number of psychological problems, consistent with findings from studies conducted in other countries. The participants of our study did not report serious stigma and discrimination. This was beyond their expectations and inconsistent with previous studies conducted in other countries.</p>

	<p>who is fluent in the local dialect, transcribed the interviews in a local dialect.</p> <ul style="list-style-type: none"> • The transcripts were coded and analysed by the first author. • After careful and repeated examination of the transcripts, categories and subcategories of analysis were developed and defined. 	<ul style="list-style-type: none"> • Stigma and discrimination has been identified as the leading cause of participants' emotional issues and associated changes in interpersonal relationships. • Emotional issues were divided into various categories namely: fear & anxiety, sadness and grief, confidence and self-esteem, and stigma and discrimination. • Participants experienced fear and anxiety because of their uncertainty regarding parents' health, illness and future prospects after parental death. • Participants reported feelings of sadness and grief when discussing parental death; however, 3 children reported their ability to express their feelings. • Participants experienced low confidence as they were sensitive to the opinion of others. • Children relied heavily on extended family/adult caregivers to gain economic, emotional and social security. • Peer relationships differed between participants who attended school and drop-outs. Children who dropped out of school were withdrawn, isolated and less involved in peer activities. • All participants experienced stigmatisation by their peers because of the reason of parental illness and death leading to a sense of rejection. Participants reported self-stigma, self-hatred, shame and isolation. 	
Cluver & Gardner (2007)	<p>Content analysis was conducted along the following procedures:</p> <ul style="list-style-type: none"> • Written data, interviewer notes, participant writings and drawings 	<p>Key themes were identified across findings and factors were identified as eliciting both emotional and behavioural difficulties. The key findings and themes of the study are as follows:</p> <ul style="list-style-type: none"> • Bereavement is identified as a key risk for emotional/behavioural problems 	<p>The study reported on factors that are perceived to affect the psychological well-being of AIDS orphans. Many factors remain congruent with the findings</p>

	<p>were read and significant statements were extracted.</p> <ul style="list-style-type: none"> • Meanings from statements were produced to create clusters of themes. • Themes were compared within and across categories to establish consistency. • After comparison, all themes were referred back to original interviews for validation. 	<p>as AIDS orphans experiences substantial anger and grief.</p> <ul style="list-style-type: none"> • The primary caregiver was identified as a significant risk/protective factor for AIDS orphans. Protective factors included support, honesty, praise and closeness, help with homework, reading and stories, advice on education and attending school meetings. Risk factors included multiple moves, caregiver changes, caregiver illness, family conflict, separation, domestic violence and alcohol abuse. • Abuse was a perceived risk factor for emotional and behavioural problems and included: shouting, beating with a stick or belt, neglect and sexual abuse. • Poverty was identified as a substantial risk factor and included: homelessness, unemployment, no medical care, housing problems. Extreme poverty has led to feelings of social exclusion by AIDS orphans, among others. • Stigma and discrimination has been identified as a cause of significant distress among AIDS orphans. Stigma and discrimination manifested through various acts such as gossiping, verbal abuse, being teased and shouted at in public. 	<p>outlined in previous studies. Regarding HIV-related stigma, AIDS orphans reported experiences of gossip and teasing which suggests a possible connection to HIV/AIDS-related stigma that has been supported by examples of gossiping and shouting at surviving parents. The authors have recognised the potential to test identified factors in future research. They also suggest that larger-scale studies would allow exploration of findings in a wider geographical area, with larger samples of AIDS-affected sub-groups.</p>
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As shown in Table 5, numerous methods of analysis have been used for conducting data analysis. Qualitative content analysis has been used by two studies (Cluver & Gardner, 2007; Harms, et al., 2010) to assess descriptive forms of data such as written transcripts, memos, interviews, drawings and case studies. The study by Zhao, et al. (2012) utilised multiple regression analysis to examine the contribution of various measures of associative stigma to the internalising and adjustment issues experienced by AIDS orphans. Boyes & Cluver (2015) examined the relationship between anxiety and depressive symptoms and AIDS orphanhood, bullying victimisation and HIV-related stigma by using correlational analysis. A study by Cluver, et al. (2008) used the Sobel test to establish the indirect effects of stigma on the psychological well-being of AIDS orphans along with a multivariate linear regression analysis. The study by Cluver, Gardner, & Operario (2008) used multivariate linear regression analysis to assess the relationship between various factors associated with AIDS orphanhood and psychological outcomes for AIDS orphans. Three studies (Chi, et al., 2014; Mo, et al., 2015; Cluver & Orkin, 2009) employed statistical analysis to analyse data. Lastly, the constant comparison method was used by one study (Xu, et al., 2009) to analyse descriptive data by reading through data and outlining various themes. This process was repeated by a secondary researcher before themes were placed into categories and sub-categories and compared with original transcripts.

Findings elicited from data analysis procedures conducted by all included studies ($n=9$) have indicated that most participants experienced various measures of HIV-related stigma. Although the stigmatisation of AIDS orphans has been reported in the findings of all included studies, the study conducted by Xu, et al (2009) concluded that AIDS orphans have not experienced significant amounts of HIV-related stigma. In contrast, other studies (Harms, et al., 2010; Chi, et al., 2014) have found that HIV-related stigma has both directly and indirectly contributed to the psychological distress experienced by AIDS orphans. HIV-

related stigma has been identified as resulting in isolation, conflict, shame and embarrassment for AIDS orphans.

The findings of three studies reported a direct relationship between HIV-related stigma and anxiety disorders and depressive symptoms experienced by AIDS orphans (Chi, et al., 2014; Zhao, et al., 2012; Cluver & Orkin, 2009). Stigma has also been identified to indirectly result in psychological distress experienced by AIDS orphans by mediating bullying victimisation, low self-esteem and optimism (Boyes & Cluver, 2015; Cluver & Gardner, 2007; Mo, et al., 2015). The findings of one study (Xu, et al., 2009) indicated that HIV-related stigma has directly led to the development of emotional and internalising problems.

5.4 Conclusion

The present chapter has extracted the necessary data presented in the nine included studies which are needed for addressing the research questions, aim and objectives. The data have been extracted in three consistent steps, namely general description, methodology, and findings and analysis. In-depth descriptive and tabulated accounts of extracted data were provided for each step of the data extraction process; this allows the synthesis and interpretation of extracted data, which is presented in Chapter Six below.

CHAPTER SIX

Discussion

6.1 Introduction

This chapter takes the form of a theory explication meta-synthesis that unfolds in three parts, namely reciprocal translations, refutational synthesis, and the line of argument as discussed in Chapter Four. Reciprocal translations strives to amalgamate evidence by illuminating consisting themes and concepts across the findings of included studies. Contrastingly, the refutational synthesis outlines information that contradicts relevant literature, aspects of the theoretical framework and dominant themes. Line of argument summarises the findings of the current study while emphasising new findings, information and steps for future research in supporting AIDS orphans and reducing HIV-related stigma. The theory explication meta-synthesis is entwined with relevant literature and the theoretical framework adapted from the work of Goffman and Steward and colleagues as outlined in Chapters Two and Three. It allows the findings of this study to be presented and understood alongside the dominant themes, ideas and findings of previous literature and conceptual theories developed for understanding the manner in which HIV-related stigma has contributed to the psychological distress experienced by AIDS orphans.

6.2 Reciprocal Translations

During this phase of analysis, several concepts and themes that are consistent with the work of Goffman (1963) and Steward, et al. (2009) and relevant literature are identified, compared and discussed. Across the nine included studies, various themes regarding the experience of HIV-related stigma for AIDS orphans and its contribution towards psychological distress have been identified as AIDS orphans' experience of HIV-related stigma and psychological

distress. The theme of AIDS orphans' experience of HIV-related stigma has been separated into several sub-themes, namely enacted stigma, vicarious and felt stigma, and internalised stigma. These themes and sub-themes are discussed below.

6.2.1 The prevalence of HIV-related stigma among AIDS orphans

All included studies have reported AIDS orphans' experience of being socially stigmatised owing to familial HIV/AIDS rather than socioeconomic or demographic factors such as poverty, race, education, sexuality, etc. (Boyes & Cluver, 2015; Chi, et al., 2014; Cluver & Gardner, 2007; Cluver & Orkin, 2009; Cluver, et al., 2008; Harms, et al., 2010; Mo, et al., 2015; Xu, et al., 2009; Zhao, et al., 2012). AIDS orphans and vulnerable children reported significantly higher levels of stigmatisation and discrimination than children orphaned by other causes and non-orphaned children (Cluver, et al., 2008; Boyes & Cluver, 2015; Zhao, et al., 2012; Cluver & Orkin, 2009). These findings address the question of “**what is the prevalence of HIV-related stigma among AIDS orphans**”, as it is evident that all studies reported AIDS orphans experience of HIV-related stigma owing to familial HIV/AIDS.

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The extensive social stigmatisation experienced by AIDS orphans is commonly known as HIV-related stigma and may be explained by Goffman's concept of tribal stigma (Goffman, 1963; Herek, 2005). Tribal stigma is the extension of stigmatising behaviour and beliefs to individuals who are associated with others who attain socially undesirable characteristics within a society (Goffman, 1963). Vulnerable children and AIDS orphans are devalued within a society because of their association with familial HIV/AIDS irrespective of their own HIV/AIDS status. Affiliation with the HIV/AIDS virus leads to the social creation of meanings and beliefs that are assigned to AIDS orphans, rendering them as invasive agents of a healthy society (Varas-Diaz, et al., 2005). This concept is consistent with AIDS orphans' internalised belief that they are a 'drain on the society' (Mo, et al., 2015, p. 56). AIDS orphans' experience of numerous measures of HIV-related stigma addresses the first objective

outlined in Chapter Four which questions the prevalence of HIV-related stigma among AIDS orphans.

Similarly to the work of Steward, et al. (2009), several included studies have reported AIDS orphans' experience of numerous measures of HIV-related stigma, namely enacted stigma, vicarious stigma, felt stigma and internalised stigma. It is significant to note that the prevalence of these measures of HIV-related stigma among AIDS orphans differ significantly. These measures of HIV-related stigma experienced by AIDS orphans lead to the following sub-themes presented below, namely enacted stigma, vicarious and felt stigma and internalised stigma.

6.2.1.1 Enacted stigma

Enacted stigma was a reciprocal theme among included studies, being the most reported measure of HIV-related stigma among AIDS orphans. The experience of enacted stigma reported by AIDS orphans was consistent with the conceptualisation of enacted stigma outlined by Steward, et al. (2009). Steward, et al. (2009) described enacted stigma as overt acts of discrimination and hostility directed at an individual because of their stigmatised social status, leading to rejection, social exclusion and traumatising behaviour received from others. AIDS orphans reported being rejected and socially devalued within society as their stigmatising status was openly presented by family members within their community, resulting in isolation, overt discrimination and stigmatising attitudes from community members (Harms, et al., 2010; Mo, et al., 2015). Various manifestations of enacted stigma and its associated consequences experienced by AIDS orphans are discussed below.

Enacted stigma was manifested as the unwilling disclosure of familial HIV/AIDS among AIDS orphans that acts to directly increase overt acts of discrimination and prejudice directed at AIDS orphans (Harms, et al., 2010; Mo, et al., 2015). This relationship has been explained

by Steward, et al's. (2009) concept of a discredited identity which refers to society's knowledge about an individual's stigmatising status that cannot be concealed and its associated increase in overt acts of discrimination and prejudice. Goffman (1963) presented a similar argument, claiming that dis-identifiers carried by individuals present information about themselves to society from which positive and negative judgments may be produced. The latter brings about the formation of stigma against the individual. Therefore, the presentation of AIDS orphans' affiliation to familial HIV/AIDS has directly lead to an increase in AIDS orphans' experience of enacted stigma.

Social rejection and isolation was extensively presented as a consequence of enacted stigma among AIDS orphans. Such rejection and isolation was perceived within interpersonal relationships or mixed contacts as visitations from family members discontinued, and they received substantial rejection from peers who refused to play with them at school or within their residential community (Zhao, et al., 2012; Xu, et al., 2009; Chi, et al., 2014; Boyes & Cluver 2015; Goffman, 1963). This idea was reciprocal with the work of Kheswa & Duncan (2011), Bougart, et al., (2008), Zhao, et al., (2009), Adejuwon & Oki (2011) and Lalthapersad-Pillay (2008). These researchers stated that extended family rejected AIDS orphans, discontinued visitations and withdrew their support once they became aware of the cause of parental illness and death. Two studies (Bougart, et al., 2008; Ishikawa, Pridmore, et al., 2010) support the idea that AIDS orphans are socially excluded and rejected by their peers who refuse to play with them because of their affiliation with the HIV/AIDS virus. Three included studies (Harms, et al., 2010; Boyes & Cluver, 2015; Cluver & Gardner, 2007) reported more extreme acts of overt discrimination, such as physical and sexual abuse against AIDS orphans as they were often beaten, pushed around and sexually assaulted by significant others.

Another form of overt act of discrimination and exploitation resulting from HIV-related stigma was identified by Lin, et al. (2010) and Deacon & Stephney (2007) as the refusal of educational opportunities for AIDS orphans by extended family members and caregivers. AIDS orphans often had to discontinue their educational career to shoulder the burden of excess domestic duties within the homestead. These expressions of enacted stigma are consistent with the findings of the present study which describes the unequal distribution of workload placed on AIDS orphans in comparison with other children in the household. AIDS orphans reported being denied educational opportunities – for example, by being taken out of school – so that they might perform domestic duties while other children within the household continued to attend school (Harms, et al., 2010; Xu, et al., 2009).

The most salient form of enacted stigma presented across six included studies was that of bullying victimisation (Zhao, et al., 2012; Boyes & Cluver, 2015; Chi, et al., 2014; Cluver, et al., 2008; Cluver & Orkin, 2009; Cluver & Gardner, 2007). Although bullying victimisation was partially evaluated as an independent factor from HIV-related stigma, the present study argues that it possesses several qualities consistent with enacted stigma and may, therefore, be recognised as a form of enacted stigma. To substantiate this argument, we give the definition of bullying victimisation which has been referred to as ‘repeated acts of aggressive behaviour intended to cause harm, and it is usually characterised by an imbalance in power between the perpetrator and victim’ (Boyes & Cluver, 2015, p. 848). From this definition, one may deduce the physical and overt nature of discrimination, abuse and harm directed towards AIDS orphans. Secondly, the devalued status attained by AIDS orphans renders them powerless, causing a shift in power between children affected by familial AIDS and others (Parker & Aggleton, 2003). These features of bullying victimisation are consistent with Steward, et al.’s (2009) conceptualisation of enacted stigma as discussed above.

A higher degree of bullying victimisation has been reported by children associated with familial HIV/AIDS in comparison with other orphans and non-orphaned youth (Boyes & Cluver, 2015). Forms of bullying victimisation included being teased, ridiculed, beaten, threatened, called names, treated badly or unfairly, gossiped about and shouted at (Cluver & Gardner, 2007; Cluver & Orkin, 2009; Boyes & Cluver, 2015; Chi, et al., 2014; Cluver, et al., 2008; Zhao, et al., 2012). Relevant literature (Ishikawa, et al., 2010; Boyes & Cluver, 2013) has identified similar acts of bullying victimisation, namely teasing by making reference to parental illness and death, gossiping, physical beatings, being called names, and discernment from their peers. Bullying victimisation was identified as fuelling school non-attendance and strongly correlated with social exclusion, rejection and avoidance of others for AIDS orphans (Ishikawa, et al., 2010; Xu, et al., 2009).

Consequently, the loss of educational opportunities for AIDS orphans resulting from enacted stigma has been well-documented in included studies (Harms, et al., 2010; Xu, et al., 2009; Cluver & Gardner, 2007) and relevant studies (Kheswa & Duncan, 2011; Louw, et al., 2012; Lin, et al., 2010; Ishikawa, et al., 2010; de Witt & Lessing, 2010; Lalthapersad-Pillay, 2008). The loss of educational opportunities for AIDS orphans acts to perpetuate poverty, rendering AIDS orphans vulnerable and powerless (Delva, et al., 2009; Harms, et al., 2010). This is largely because of the earning potential and growth associated with scholastic knowledge and general educational training. Without scholastic knowledge, AIDS orphans lose optimism about their future aspirations.

6.2.1.2 Vicarious and felt stigma

AIDS orphans' experiences of enacted stigma and its associated consequences has led to an increase in felt stigma which has been defined as the anticipation of enacted stigma which results in an increase of one's perceptions about the prevalence and norms of stigmatising behaviours and attitudes from others (Steward, et al., 2009). However, vicarious stigma –

witnessing or hearing acts of stigmatisation against others – has also lead to an increase in AIDS orphans' perceptions of the true nature and prevalence of enacted stigma. The study by Cluver & Gardner (2007) identified the presence of vicarious stigma among AIDS orphans. AIDS orphans bear witness to their HIV-positive parents' experience of enacted stigma from the general community and extended family. They described the verbal abuse and victimisation of their HIV-positive parents as being, shouted at, gossiped about and teased by others (Cluver & Gardner, 2007).

The experience of felt stigma among AIDS orphans was discussed in several included studies (Xu, et al., 2009; Mo, et al., 2015; Cluver, et al., 2008; Harms, et al., 2010). As predicted by Steward, et al. (2009), AIDS orphans' experiences of felt stigma was represented by their silence and methods of non-disclosure around parental illness and death in included studies (Xu, et al., 2009; Mo, et al., 2015; Cluver, et al., 2008; Harms, et al., 2010). The nature of parental illness and death was often concealed and disguised by AIDS orphans (Harms, et al., 2010; Xu, et al., 2009; Mo, et al., 2015). Owing to the highly stigmatising attitudes of the general public, AIDS orphans felt obliged to preserve the dignity of their family and their own social status, and resorted to disclosure-avoidance strategies (Xu, et al., 2009; Mo, et al., 2015).

AIDS orphans feared disclosing their association with familial HIV/AIDS because of associated stigma, and embodied the culture of silence to minimise their experiences of enacted stigma (Mo, et al., 2015). These findings are consistent with Goffman's (1963) suggestion that individuals conceal negative information about themselves in order to protect themselves from stigmatisation and discrimination through disassociating from biographical others, passing and covering. Similarly, related literature (Bougart, et al., 2008; Ishikawa, et al., 2010; Kheswa & Duncan, 2011; Thupayagale-Tshweneagae, 2011) has also indicated that

secrecy is maintained around the nature of parental illness and death in the hope of protecting AIDS orphans from experiences of stigmatisation and discrimination.

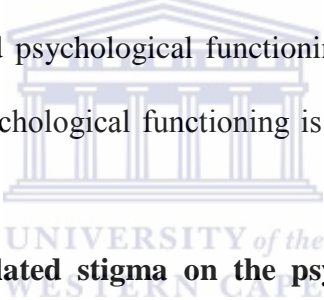
However, the negative consequences resulting from disclosure-avoidance methods employed by AIDS orphans has been recognised by included studies (Mo, et al., 2015; Xu, et al., 2009), previous literature (Ishikawa, et al., 2010; Kheswa & Duncan, 2011; Bougart, et al., 2008; Thupayagale-Tshweneagae, 2011), the theoretical framework adapted by Steward, et al. (2009) and the work of Goffman (1963). Silence and non-disclosure around parental illness and death render AIDS orphans unable to obtain support outside their immediate family structure, leading to withdrawal, social exclusion and self-isolation of AIDS orphans. AIDS orphans have placed themselves beyond the reach of social and psychological support needed for their well-being (Mo, et al., 2015; Xu, et al., 2009; Thupayagale-Tshweneagae, 2011; Bougart, et al., 2008; Kheswa & Duncan, 2011; Goffman, 1963). Self-isolation, withdrawal and social exclusion have acted to worsen the process of parental bereavement (Thupayagale-Tshweneagae, 2011). Two included studies (Xu, et al., 2009; Cluver & Gardner, 2007) have recognised the impact of self-isolation and withdrawal in AIDS orphans' engagement in positive activities. AIDS orphans' withdrawal and self-isolation leads to less engagement in positive social activities needed for the improvement of their well-being and comfort (Xu, et al., 2009; Cluver & Gardner, 2007).

6.2.1.3 Internalised stigma

The presence of internalised stigma was unanimously presented by AIDS orphans as feelings of self-hatred, shame, embarrassment, inferiority and disgrace and beliefs of being tainted and devalued in included studies (Chi, et al., 2014; Mo, et al., 2015; Xu, et al., 2009). The feelings and beliefs held by AIDS orphans are consistent with Steward, et al's. (2009) conceptualisation of internalised stigma. Steward, et al. (2009) has defined internalised

stigma as an individual's internalisation of stigmatising norms and beliefs held by society rendering them as truthful and valid.

Therefore, AIDS orphans believe that delinquent and deviant labels are personally relevant to themselves because of their affiliation with familial HIV/AIDS in spite of their own HIV/AIDS status (Mo, et al., 2015). Such acceptance and beliefs leads AIDS orphans to adopt a negative view of themselves that harmfully affects their well-being by contributing to lower levels of self-esteem, confidence and optimism regarding their future (Mo, et al., 2015; Xu, et al., 2009). AIDS orphans maintain focus on negative aspects of life and their future, and are sensitive to the opinions of others, which evokes a sense of inadequacy (Xu, et al., 2009; Mo, et al., 2015; Chi, et al., 2014). Evidently, internalised stigma has negatively contributed to the well-being and psychological functioning of AIDS orphans. Internalised stigma's contribution to poor psychological functioning is discussed in the theme presented below.



6.2.2 The outcomes of HIV-related stigma on the psychological well-being of AIDS orphans

The discussion below indicates that the experience of HIV-related stigma has resulted in increased levels of psychological distress and numerous mental health problems among AIDS orphans. These findings provided a clear answer to, “**what are the outcomes of HIV-related stigma on the psychological well-being of AIDS orphans**” and are discussed below.

As predicted by Steward, et al. (2009), included studies (Chi, et al., 2014; Harms, et al., 2010; Mo, et al., 2015; Xu, et al., 2009; Zhao, et al., 2012; Boyes & Cluver, 2015; Cluver & Gardner, 2007; Cluver, et al., 2008; Cluver & Orkin, 2009) have identified the presence of HIV-related stigma in the lives of AIDS orphans and acknowledged its contribution to their experiences of psychological distress. AIDS orphans' apparent experience of HIV-related

stigma is associated with increased levels of depression, anxiety, post-traumatic stress and conduct and delinquency problems (Chi, et al., 2014; Harms, et al., 2010; Mo, et al., 2015; Xu, et al., 2009; Zhao, et al., 2012; Boyes & Cluver, 2015; Cluver & Gardner, 2007; Cluver, et al., 2008; Cluver & Orkin, 2009). Although all measures of HIV-related stigma have contributed to the development of these psychological disorders and distress, Zhao, et al. (2012) has indicated that measures of HIV-related stigma do not equally contribute to the development of psychological distress but rather functions differently in the development of psychological distress in AIDS orphans.

Enacted stigma plays a crucial role in the development of psychological distress in AIDS orphans. It acts to inhibit the psychological adjustment of AIDS orphans as they remain focused on the negative aspects of their lives originating from parental HIV/AIDS, such as isolation, discrimination, social exclusion, devaluation and rejection which has been caused by manifestations of enacted stigma (Chi, et al., 2014; Harms, et al., 2010). Manifestations of enacted stigma include bullying victimisation; rejection and abandonment by extended family, peers and community members; social abuse; and the unwilling disclosure of AIDS orphans' affiliation with HIV/AIDS by extended family members (Chi, et al., 2014; Harms, et al., 2010; Mo, et al., 2015; Xu, et al., 2009; Zhao, et al., 2012; Boyes & Cluver, 2015; Cluver & Gardner, 2007; Cluver, et al., 2008; Cluver & Orkin, 2009). Similarly, Steward, et al. (2009) theorised that social exclusion and devaluation resulting from enacted stigma leads to an increase in psychological distress; this is largely because of the limitation of social, financial and mental health support offered to devalued and socially excluded individuals, thus limiting AIDS orphans' access to opportunities needed to meet their basic needs and for their mental well-being (Louw et al., 2012; Kheswa & Duncan, 2011). This dynamic is reciprocal with the findings of included studies (Chi, et al., 2014; Harms, et al., 2010; Mo, et al., 2015; Xu, et al., 2009; Zhao, et al., 2012; Boyes & Cluver, 2015; Cluver & Gardner,

2007; Cluver, et al., 2008; Cluver & Orkin, 2009) that identified social exclusion, isolation and devaluation as the chief result of manifestations of enacted stigma, and results in a lack of much-needed resources. The lack of social support and needed resources includes increased poverty and a lack of educational opportunities and trusting relationships, which is likely to intensify levels of psychological distress in AIDS orphans.

Vicarious stigma has led to an increase in psychological distress in orphans by increasing their perceptions about the norms and prevalence of enacted stigma. The anticipation of enacted stigma has resulted in AIDS orphans feeling anxious and fearful about experiences of hostility, rejection and discrimination (Cluver & Gardner, 2007; Steward, et al., 2009). Felt stigma's contribution to psychological distress operates through AIDS orphans' use of disclosure-avoidance mechanisms (Steward, et al., 2009). Although the disclosure regarding the nature of parental illness and death may result in experiences of enacted stigma, the culture of silence employed by AIDS orphans acts to increase psychological distress by placing them beyond the reach of social, psychological and medical support (Burris, 1997; Gupta, 2013; Steward, et al., 2009; Harms, et al., 2010; Chi, et al., 2014; Xu, et al., 2009). The culture of silence has acted to isolate AIDS orphans as they are unable to convey their distress to trusted advocates in the face of adversities. This isolation prohibits them from seeking the support needed for their psychological well-being (Harms, et al., 2010; Mo, et al., 2015; Chi, et al., 2014). Evidently, HIV-related stigma and the associated consequences of protective mechanisms is a striking concern among AIDS orphans that is likely to increase their experience of psychological distress (Mo, et al., 2015).

AIDS orphans' internalisation of felt stigma contributes to their experience of psychological distress (Steward, et al., 2009). Feelings of self-hatred, shame, embarrassment, inferiority and disgrace are held by AIDS orphans as a consequence of their belief that they are tainted and

devalued (Chi, et al., 2014; Mo, et al., 2015; Xu, et al., 2009). These negative feelings represent the psychological suffering of AIDS orphans caused by HIV-related stigma. This idea is reciprocal with Steward, et al.'s (2009) suggestion that self-stigma directly results in an increase of psychological distress in AIDS orphans. Mo, et al. (2015) suggest that internalised stigma arouses psychological distress indirectly through lower levels of self-esteem and optimism. Lower levels of self-esteem and optimism derive from the negative views held by AIDS orphans, such as believing that they are deviant, delinquent and devalued. The acceptance of such negative feelings harmfully affects the manner in which AIDS orphans view themselves and their future. These harmful effects are manifested as lower levels of self-esteem and optimism. The negative feelings of inadequacy held by AIDS orphans lead to the development of poor psychological health and an increase in psychological distress (Mo, et al., 2015).

HIV-related stigma has adversely affected the psychological health of AIDS orphans and is therefore recognised as a risk factor for the development of psychological distress among AIDS orphans (Mo, et al., 2015). Psychological distress was not a direct result of AIDS orphanhood but rather a result of negative consequences associated with stigmatisation and discrimination directed at AIDS orphans by the general community as a consequence of their affiliation with HIV/AIDS (Boyes & Cluver, 2015). Psychological distress was mainly identified as manifestations of anxiety and depressive symptoms among AIDS orphans (Zhao, et al., 2012; Boyes & Cluver, 2015; Cluver & Gardner, 2007; Cluver, et al., 2008; Chi, et al., 2014; Mo, et al., 2015; Cluver & Orkin, 2009). HIV-related stigma has also been identified as being predictive of peer problems, post-traumatic stress disorder and behaviour problems among AIDS orphans (Cluver & Orkin, 2009; Cluver, et al., 2008). These findings have clearly indicated the contribution of HIV-related stigma to the psychological distress

experienced by AIDS orphans and addresses the objective of the present study that questions the effects of HIV-related stigma on the psychological health of AIDS orphans.

6.3 Refutational Synthesis

The refutational synthesis outlines themes that are contrary to mainstream concepts and ideas presented in relevant literature and the theoretical framework adapted by Steward, et al. (2009), as discussed in Chapters Two and Three respectively. Two refutational themes were identified in included studies, the first being AIDS orphans' experience of HIV-related stigma which explores positive experiences of AIDS orphanhood; and secondly, felt stigma as a predictor of psychological distress which explores a discrepancy in the modified hidden distress model adapted by Steward, et al. (2009).

6.3.1 AIDS orphans' experience of HIV-related stigma

Relevant literature has strongly indicated the presence of HIV-related stigma in the lives of AIDS orphans. Relevant studies (Bougart, et al., 2008; Lin, et al., 2010; Varas-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005; Lalthapersad-Pillay, 2008) have suggested that orphans associated with HIV/AIDS are likely to experience enmity, rejection and abandonment, resulting in various social, educational and financial loss. Moreover, AIDS orphans are likely to be discriminated against and socially abused by extended family members, peers and the general community, resulting in self-isolation and withdrawal (Kheswa & Duncan, 2011; Ishikawa, et al., 2010; Louw, et al., 2012; de Witt & Lessing, 2010; Bougart, et al., 2008). Contrary to this view, Xu, et al. (2014), reported that over 60% of their sample population reported non-discrimination within their extended family structures and in the general community. Significant experiences of HIV/AIDS-associated stigmatisation and discrimination were not reported by AIDS orphans and are inconsistent with the findings of previous studies (Kheswa & Duncan, 2011; Ishikawa, et al, 2010; Louw, et al., 2012; de Witt

& Lessing, 2010; Bougart, et al., 2008). AIDS orphans received more assistance from extended family members, neighbours and peers. Xu, et al. (2014) justified these findings by claiming that there has been an increase in empathy towards AIDS orphans within their community.

Additionally, the low prevalence of HIV-related stigma may be the result of non-disclosure of the cause of parental illness and death (Xu, et al., 2009). Consistent with these findings, Harms, et al. (2010) reported that two paternally orphaned children experienced positive relationships with extended family members who remained trusted advocates and offered a sense of social support to AIDS orphans during challenging times. Harms, et al. (2010, p.8) stated that the '[c]inderella myth' which refers to the exploitation of AIDS orphans in their adopted homes is yet to be empirically validated. No statistical differences were identified among AIDS orphans and other children besides the loss of educational opportunities for AIDS orphans.

6.3.2 Felt stigma as a predictor of psychological distress

Steward, et al. (2009) predicted that felt stigma – one's perceptions about the stigmatising norms and beliefs of the general society – would be a stronger predictor for the development of psychological distress among stigmatised individuals. However, the findings of an included study (Chi, et al., 2014) indicated that felt stigma loses its predictive power in the presence of enacted stigma. This suggests that although felt stigma may contribute to the arousal of psychological distress, enacted stigma is a greater predictor and risk factor for the development of psychological distress among AIDS orphans. This argument may be justified by the findings of the present study as all included studies (Boyes & Cluver, 2015; Chi, et al., 2014; Cluver & Gardner, 2007; Cluver & Orkin, 2009; Cluver, et al., 2008; Harms et al., 2010; Mo, et al., 2015; Xu, et al., 2014; Zhao, et al., 2012) reported the presence of enacted

stigma in the development of psychological distress, while only three included studies recognised AIDS orphans' experience of psychological distress (Chi, et al., 2014; Mo, et al., 2015; Xu, et al., 2009). The reported measure of HIV-related stigma identified in the findings of the present study is inconsistent with Steward, et al.'s (2009) suggestion that AIDS orphans' experience far greater levels of felt stigma than enacted stigma as a result of disclosure-avoidance strategies employed by AIDS orphans.

6.4 Line of Argument

HIV-related stigma remains the chief distinction between AIDS orphans and children or youth orphaned by other causes of parental death. All measures of HIV related stigma – enacted, vicarious, felt and internalised stigma – have characterised the lives of AIDS orphans, subjecting them to experiences of rejection, enmity, abandonment and discrimination (Boyes & Cluver, 2013; Lin, et al., 2010; Bougart, et al., 2008).

HIV-related stigma is a strong predictive factor for psychological distress in AIDS orphans and has been identified as the leading cause of higher levels of psychological distress among AIDS orphans in comparison with other orphaned youth (Chi, et al., 2014; Zhao, et al., 2012). However, all measures of HIV-related stigma do not equally contribute to the development of psychological distress experienced by AIDS orphans (Chi, et al., 2014). Enacted stigma manifests as rejection; abandonment; bullying victimisation; physical, verbal and sexual abuse; unequal treatment in adopted homes; and the loss of educational opportunities (Harms, et al., 2010; Cluver & Gardner, 2007; Boyes & Cluver, 2015; Cluver & Orkin, 2009) and has been identified as the strongest predictor for the development of psychological distress and poor mental functioning among AIDS orphans (Chi, et al., 2014). Enacted stigma directly affects the psychological well-being of AIDS orphans by resulting in self-isolation and withdrawal, leading to limited social support for their psychological well-being (Chi, et al.,

2014; Harms, et al., 2010; Mo, et al., 2015; Xu, et al., 2009; Zhao, et al., 2012; Boyes & Cluver, 2015; Cluver & Gardner, 2007; Cluver, et al., 2008; Cluver & Orkin, 2009).

Felt stigma and internalised stigma are manifested as a culture of silence and feelings of self-hatred, shame, disgrace and inadequacy (Cluver, et al., 2008; Mo, et al., 2015; Xu, et al., 2009; Harms, et al., 2010). These measures of HIV-related stigma indirectly affect the psychological well-being of AIDS orphans through avoidance-disclosure measures employed by AIDS orphans and low levels of self-esteem and optimism respectively. Avoidance-disclosure mechanisms manifest as a culture of silence embodied by AIDS orphans as they refuse to disclose the cause of parental death out of fear of receiving enacted stigma. This acts to inhibit the social support structure of AIDS orphans, resulting in feelings of isolation and loneliness (Burriss, 1997; Gupta, 2013; Steward, et al., 2009; Harms, et al., 2010; Chi, et al., 2014; Xu, et al., 2009). Internalised stigma increases AIDS orphans' sensitivity to the opinions of others, resulting in lower levels of self-esteem and optimism that indirectly affect the mental functioning of AIDS orphans (Mo, et al., 2015). Psychological distress is therefore not a direct result of AIDS orphanhood but is mediated by measures of HIV-related stigma. Psychological distress was identified as an array of feelings such as fear, inadequacy, self-hatred disgrace and shame. Other manifestations of psychological distress among AIDS orphans presented as anxiety, depression, peer problems, delinquency, conduct disorders and post-traumatic stress disorder (Boyes & Cluver, 2015; Mo et al., 2015; Cluver, et al., 2008; Zhao, et al., 2012; Chi, et al., 2014; Cluver & Orkin, 2009).

Positive activities, healthy interpersonal relationships, educational opportunities and the provision of adequate care for AIDS orphans are likely to act as protective factors that cushion the harsh effects of HIV-related stigma on the psychological health of AIDS orphans (Cluver & Gardner, 2007; Cluver & Orkin, 2009; Harms, et al., 2010; Cluver, et al., 2008).

These factors along with an increase in empathy within the community and extended family structures, supportive and trusted relationships and advocates (Xu, et al., 2009) provides us with the solution of reducing HIV-related stigma amongst AIDS orphans. These factors act to explicitly answer the question of “**what is needed for the reduction of HIV-related stigma experiences by AIDS orphans**”. The present review has confirmed that HIV-related stigma remains a significant problem in the lives of AIDS orphans and little has been done to adequately address their concerns and well-being.

6.5 Conclusion

AIDS orphans are not spared the negative consequences associated with parental HIV/AIDS. All measures of HIV-related stigma have substantially affected the well-being and psychological functioning of AIDS orphans as they experience enmity, stigmatisation, discrimination, rejection and social abuse from significant others and the general community. Their experience of HIV-related stigma has operated to limit their structure of social support and opportunities for growth, and lower their levels of self-esteem and optimism about the future, resulting in a significant increase in psychological distress. There is a call for the support of AIDS orphans in order to improve their psychological functioning and physical well-being.

CHAPTER SEVEN

Conclusion

7.1 Introduction

The aim of the present study is to examine and report on the effects of HIV-related stigma on the psychological well-being of orphans who have lost one or both of their parents to HIV/AIDS. The study employed a systematic review methodology to address its aim. A systematic review methodology allows rigorous evaluation of primary literature reporting on the effects of HIV-related stigma on the psychological well-being of AIDS orphans. It also allows the amalgamation of existing evidence on a particular phenomenon resulting in a pragmatic body of knowledge that may be used to address these effects and accomplish a reduction in HIV-related stigma and psychological distress experienced by AIDS orphans.

The present systematic review strove to answer the following research questions:

- what is the prevalence of HIV-related stigma among AIDS orphans?
- what are the outcomes of HIV-related stigma on the psychological well-being of HIV/AIDS orphans?
- what is needed for the reduction of HIV-related stigma experience by AIDS orphans?

The objectives of the current study were:

- to assess the prevalence of HIV-related stigma among AIDS orphans
- to identify the effects of HIV-related stigma on the psychological well-being of AIDS orphans
- to systematically appraise the methodological rigour of studies exploring the relationship between HIV-related stigma and the psychological well-being of AIDS orphans.

A descriptive and theory explicative meta-synthesis was used to analyse the study's findings. The descriptive meta-synthesis was used to descriptively account for the findings of the study while the theory explication meta-synthesis was used to interpret and analyse these findings. Two theoretical frameworks, namely the modified hidden distress model and the works of Goffman, were used along with relevant existing literature to explain and substantiate the findings presented within the study. In addition, to justify the study's findings, these theoretical frameworks and relevant literature were used to find contradictory themes within the findings, which are considered important points of reference for future research.

The current chapter provides an executive summary outlining the manner in which the study has met its predetermined aims and objectives using a systematic review methodology. It discusses the significance of the study and provides an in-depth account of recommendations for future research and interventions aimed at stigma reduction and improving the psychological well-being of AIDS orphans. Although the study has proven beneficial, it is not without limitation. Therefore, the limitations of the study are also outlined in the current chapter.

7.2 Executive Summary

AIDS orphans encounter various challenges posed by the HIV/AIDS epidemic and its associated culture of stigma. The effects of these challenges in the lives of AIDS orphans have become a pressing concern among various scholars; however, only a few existing studies have attempted to understand the psychosocial effects associated with AIDS orphanhood. Even fewer studies are aimed at understanding the psychological outcomes of AIDS orphanhood. The lack of pragmatic knowledge exploring the psychological outcomes on AIDS orphans has resulted in an inadequate body of literature to address the epidemic of AIDS orphanhood.

Poorer psychological well-being among AIDS orphans in comparison with other groups of orphans and vulnerable children has been identified. Although numerous contextual and social factors may contribute to the poor psychological functioning and increase in distress experienced by AIDS orphans, HIV-related stigma remains the core distinction between AIDS orphans and other orphaned youth. To explain the discrepancy between the psychological distress experienced by AIDS orphans and that of other orphans, focus has been placed on HIV-related stigma.

The present study appraised relevant literature reporting on the manner in which HIV-related stigma has resulted in an increase of psychological distress in AIDS orphans, in an attempt to amalgamate existing evidence to provide a body of pragmatic knowledge. Methodological appraisal was conducted on studies published during 2004 – 2015. The methodological appraisal was conducted along the PRISMA levels of review in four systematic steps, namely the identification of relevant studies for inclusion; screening abstracts of potential studies for eligibility; an evaluation of the methodological quality of eligible studies using the adapted appraisal tool for inclusion; and included studies were subjected to a process of data extraction and meta-synthesis, resulting in a pragmatic body of knowledge.

The findings of the present study have indicated the existence of high-quality studies reporting on the psychological outcome of HIV-related stigma experienced by AIDS orphans. Nine studies have successfully attained the predetermined threshold score (81%–100%) for inclusion. The findings of these studies were extracted, descriptively tabularised and synthesised.

Drawing from the research findings, the following objectives were achieved:

1. The first objective was to assess the prevalence of HIV-related stigma among AIDS orphans. The evidence suggests that the majority of AIDS orphans have experienced various measures of HIV-related stigma including enacted stigma, vicarious stigma, felt stigma and internalised stigma. However, the prevalence of enacted, vicarious, felt and internalised stigma is not equally present within the lives of AIDS orphans but, in contrast, vary significantly. Enacted stigma appeared to be the chief form of HIV-related stigma experienced by AIDS orphans, manifesting as forms of outward discrimination and abuse directed towards AIDS orphans. These behaviours included abandonment, rejection, bullying victimisation, exploitation and verbal, physical and sexual abuse.

Vicarious stigma was represented among AIDS orphans as witnessing the stigmatisation of their HIV-positive parents. Parents were verbally abused and discriminated against within their residential communities. Felt stigma was recognised as the culture of silence employed by AIDS orphans in the hope of protecting themselves from enacted stigma. Through experiences of enacted and vicarious stigma, AIDS orphans have developed a perception about social norms and beliefs attached to their stigmatised status. Owing to their fear of experiences of enacted stigma resulting from these beliefs, AIDS orphans employ a culture of silence and non-disclosure. Lastly, internalised stigma was present among AIDS orphans as they accepted stigmatising social beliefs and norms as truthful and valid. As a result, AIDS orphans believed that they were devalued, tainted and a drain on society. Internalised stigma was represented as AIDS orphans feeling shame, embarrassment, disgrace and lower levels of self-esteem and optimism about their future. These feelings result from their beliefs that they are devalued and tainted.

2. The second objective was to identify the effects of HIV-related stigma on the psychological wellbeing of AIDS orphans. The findings suggested that experiences of HIV-related stigma contribute to an increase in psychological distress experienced by AIDS orphans independent of the effects associated with parental bereavement. AIDS orphans displayed higher levels of internalised and adjustment disorders when introducing HIV-related stigma as an independent variable. These disorders included depression, anxiety, post-traumatic stress disorder, delinquency and conduct disorder. HIV-related stigma was also identified as mediating psychological distress through low levels of self-esteem, confidence and optimism about the future.

It is important to note that all measures of HIV-related stigma do not equally contribute to the development of psychological distress in AIDS orphans. Enacted stigma directly arouses psychological distress as AIDS orphans are rejected and discriminated against. Stigmatisation limits the social support and resources available to AIDS orphans, thus arousing psychological distress. Vicarious and felt stigma mediate psychological distress through AIDS orphans' silence and non-disclosure methods. Disclosure-avoidance mechanisms practised by AIDS orphans lead to self-isolation and withdrawal and a lack of social support, resources and opportunities leads to the experience of psychological distress. Felt stigma results in the experience of internalised stigma or felt stigma which results in an increase of psychological distress for AIDS orphans as it operates to reduce levels of self-esteem and optimism. Lower levels of self-esteem and optimism is the result of feelings of shame, embarrassment and disgrace experienced by AIDS orphans as they internalised the negative views and opinions of others as truthful and applicable to themselves.

3. The last objective was to systematically appraise the methodological rigour of studies exploring the relationship between HIV-related stigma and the psychological well-being of AIDS orphans. This objective was achieved in the third level of review, namely eligibility as discussed in Chapter Four as studies identified as eligible for inclusion were retrieved and independently methodologically appraised by two researchers using a critical appraisal tool. Therefore, the methodological rigour of all studies was systematically appraised before adding to the final pool of included studies. From the systematic appraisal, nine studies were deemed methodologically sound for inclusion.

7.3 Significance of the Study

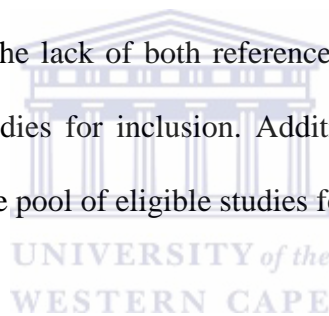
The present study sheds light on the manner in which HIV-related stigma contributes to increased levels of psychological distress experienced by AIDS orphans. It provides a pragmatic base of evidence extracted from high-quality studies that outlines the limitations and gaps in existing literature. Therefore, this pragmatic body of knowledge may positively inform the needs of future research and guide our thinking, the development of policies and interventions aimed at reducing the experiences of HIV-related stigma and its associated psychological consequences for AIDS orphans. This systematic review has outlined the psychological needs of AIDS orphans by highlighting the manner in which HIV-related stigma has operated to arouse psychological distress. These findings may inform the development of programmes and workshops aimed at addressing the needs of AIDS orphans by offering appropriate services and support structures necessary for psychological functioning by the reduction of psychological distress caused by HIV-related stigma

7.4 Limitations of the Study

Publication bias was present. Published studies are limited by specific journal requirements overlooking relevant methodological information. The lack of methodological data might

have resulted in the exclusion of relevant studies. Consequently, this has resulted in publication bias as it operates to limit the sampling frame of potential studies. Language bias was present as database searches for eligible studies were limited to English-medium studies. Relevant studies presented in other languages were omitted, limiting the sampling frame of relevant studies for inclusion, resulting in language bias within the present studies.

Another limitation was the study's failure to evaluate grey literature and conduct a process of reference mining. The study's lack of considering grey literature omits unpublished studies that may valuably contribute to the pragmatic body of knowledge compiled in this study. The lack of reference mining omits studies that are not available in the library of the University of the Western Cape's databases. The lack of both reference mining and grey literature limits the sample frame of eligible studies for inclusion. Additionally, studies not deemed open access were excluded, limiting the pool of eligible studies for inclusion.



Two included studies reported on the psychosocial effects associated with AIDS orphanhood, which has come to include HIV-related stigma. Despite the valuable contribution these studies made, they fail to place sole focus on the effects of HIV-related stigma, resulting in a loss of depth and quality of findings representing the effects of HIV-related stigma on the psychological health of AIDS orphans.

Lastly, the study was limited by low levels of disclosure among participants. It was a difficult task to accurately evaluate the HIV status of AIDS orphans. The HIV status of some participants in included studies was unknown, therefore the present study could not adequately determine whether HIV-related stigma was a consequence of parental HIV/AIDS or the HIV status of surviving orphans.

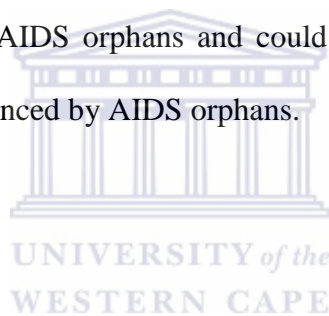
7.5 Recommendations

Based on the findings of the present study, the following recommendations are made:

- Evidence has clearly indicated a need for further research focusing on the experience of HIV-related stigma extended to AIDS orphans who are not infected with HIV/AIDS. Such research needs to consider the effects of various measures of HIV-related stigma on the psychological well-being of AIDS orphans in order to adequately address the current epidemic and to successfully assist AIDS orphans.
- Studies were unable to accurately illustrate the HIV status of AIDS orphans. Future research needs to utilise adequate control groups, increasing the reliability and validity of their research findings. The use of adequate control groups would produce insightful findings to explain the true nature of psychological distress experienced by non-infected AIDS orphans as a result of HIV-related stigma.
- Support structures and programmes developed to assist AIDS orphans need to address their experience of HIV-related stigma and its potential consequences on their psychological functioning. As stigma reduction is a challenging task, intervention may reduce the stigma through focusing on mitigating factors such as low levels of self-esteem and bullying victimisation to bring about change in the psychological well-being of AIDS orphans. Moreover, various policies and interventions aimed at protecting the human rights and well-being of AIDS orphans need to be implemented.
- HIV-related stigma is largely the result of the stigmatising beliefs and attitudes held by the general public; interventions should aim to reduce public stigma directed towards PLWHA and their families to accomplish a reduction in enacted, vicarious, felt and internalised stigma experienced by AIDS orphans.
- Mental health services should be offered to AIDS orphans to address their experience of psychological distress emanating from HIV-related stigma. Cognitive behavioural therapy

may address the psychological needs of AIDS orphans by reinforcing positive attitudes and increasing levels of self-esteem and optimism through correcting irrational beliefs about themselves and HIV/AIDS.

- Findings have suggested that positive activities and healthy interpersonal relationships are likely to result in a decrease in psychological distress. These protective factors should be explored in future research which may bring about an increase in resilience among AIDS orphans affected by HIV-related stigma.
- Furthermore, the lack of the following services were recognised among AIDS orphans, namely quality care arrangements, mental health care services, legal protection of human rights, medical care, an education and a stable support structure. These services may act as protective factors among AIDS orphans and could be implemented to minimise the psychological distress experienced by AIDS orphans.



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Appendix C

Critical Appraisal Tool for Qualitative Studies		
Reviewer: _____ Author: _____ Title: _____ Year: _____		
Study Purpose	Yes (1)	No (0)
<ol style="list-style-type: none"> 1. Has an extensive literature review been conducted to inform the context and background of the study? 2. Has 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 objectives explicitly linked to the research question? <p>Total:</p>		
Study Design	Yes (1)	No (0)
<ol style="list-style-type: none"> 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 their reasoning for the methodology? 5. Is a theoretical framework or underpinning identified? <p>Total:</p>		
Sampling	Yes (1)	No (0)

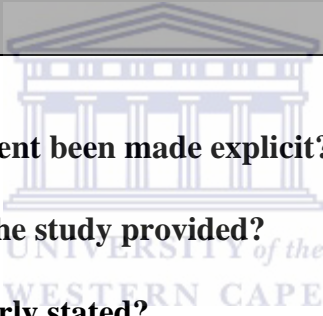
<p>1. Is the source population identified?</p> <p>2. Is there a clear distinction between probability and non-probability sampling?</p> <p>3. Is the sampling method appropriate?</p> <p>4. Did the author/s motivate their sample choice?</p> <p>5. Are inclusion and exclusion criteria clearly stipulated?</p> <p>6. Is the sample representative of the population?</p> <p>7. Has informed consent been obtained from participants?</p> <p>Total:</p>		
Data Collection	Yes (1)	No (0)
<p>1. Is data collected in an ethically sound manner?</p> <p>2. Is the setting of data collection noted?</p> <p>3. Did the authors explicitly indicate the method of data collection (e.g. interviews, focus groups, etc.)?</p> <p>4. Are these methods of data collection appropriate?</p> <p>5. Were any methods modified during the course of the study?</p> <p>6. Is the form of data clear (notes, tape recordings, etc.)?</p> <p>Total:</p>		
Data Analysis	Yes (1)	No (0)
<p>1. Is the method of data analysis clearly stipulated?</p> <p>2. Did the author provide an in-depth description of the process of analysis?</p> <p>3. Are there sufficient data to support the findings?</p> <p>4. Were contradictory data accounted for?</p> <p>5. Has the author/s accounted for bias and influence?</p>		

Total:		
Findings	Yes (1)	No (0)
<ol style="list-style-type: none"> 1. Are the findings made explicit? 2. Is there adequate evidence to support the 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 generalisable? Total:		
Conclusion	Yes (1)	No (0)
<ol style="list-style-type: none"> 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)
<ol style="list-style-type: none"> 1. Has ethical approval been obtained from an identifiable committee? 2. Did the author/s report the method of gaining access from appropriate institutions? 3. Have these ethical issues been reported on: Confidentiality Anonymity Withdrawal Total:		
Total Score/ Percentage	Score	%

<ul style="list-style-type: none"> <input type="checkbox"/> Weak (0–30%) <input type="checkbox"/> Moderate (31%–65%) <input type="checkbox"/> Strong (66%–80%) <input type="checkbox"/> Excellent (81%–100%) <p>(Studies below the threshold stipulated in the Excellent category will be excluded. Studies not focusing on the psychological outcomes of HIV-related stigma will also be excluded.)</p>	(/43)	
Overall Outcome: Include <input type="checkbox"/> Exclude <input type="checkbox"/> Seek Further Info <input type="checkbox"/>		



Appendix D

<p>Critical Appraisal Tool for Quantitative Studies</p> <p>Reviewer: _____ Author: _____</p> <p>Title: _____ Year: _____</p>		
Study Purpose	Yes (1)	No (0)
<div style="text-align: center;">  <p>UNIVERSITY of the WESTERN CAPE</p> </div> <ol style="list-style-type: none"> 1. Has 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 aims and objectives explicitly linked to the research question? <p>Total:</p>		
Literature Review		
<ol style="list-style-type: none"> 1. Has an extensive literature review been conducted to inform the context and background of the study? 2. Are gaps in the literature identified? 3. Is the need for further research addressed? 		

Total:		
Study Design	Yes (1)	No (0)
<ol style="list-style-type: none"> 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 the reasoning for their design selection? 5. Does the research design address the aims and objectives of the study? <p>Total:</p>		
Sampling	Yes (1)	No (0)
<ol style="list-style-type: none"> 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? <p>Total:</p>		

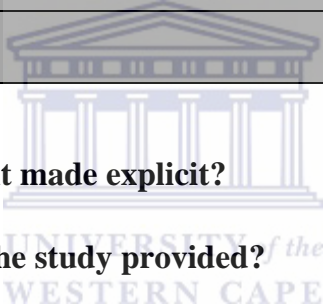
Outcomes	Yes (1)	No (0)
<p>1. Were the instruments used clearly identified with references?</p> <p>2. Are these instruments appropriate?</p> <p>3. Were steps taken to ensure the reliability of outcome measures?</p> <p>4. Did the author/s account for:</p> <p> Sample bias</p> <p> Measurement bias</p> 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

Conclusion	Yes (1)	No (0)
<p>1. Is the conclusion clear?</p> <p>2. Is the conclusion supported by findings?</p> <p>3. Are appropriate recommendations made?</p> <p>4. Are limitations explicitly identified?</p> <p>Total:</p>		
Ethical Considerations	Yes (1)	No (0)
<p>1. Was ethical approval obtained from an identifiable committee?</p> <p>2. Did the author/s report on gaining access to appropriate institutions?</p> <p>3. Have the following ethical issues been reported on: Confidentiality Anonymity Withdrawal</p> <p>Total:</p>		
<p>Total Score/ Percentage</p> <p><input type="checkbox"/> Weak (0–30%)</p> <p><input type="checkbox"/> Moderate (31%–65%)</p> <p><input type="checkbox"/> Strong (66%–80%)</p> <p><input type="checkbox"/> Excellent (81%–100%)</p>	<p>Score (/44)</p>	<p>%</p>

<p>(Studies below the threshold stipulated in the Excellent category will be excluded. Studies not focusing on the psychological outcomes of HIV-related stigma will also be excluded.)</p>		
<p>Overall Outcome: Include <input type="checkbox"/> Exclude <input type="checkbox"/> Seek Further Info <input type="checkbox"/></p>		



Appendix E

<p>Critical Appraisal Tool for Mixed Method Studies</p> <p>Reviewer: _____ Author: _____</p> <p>Title: _____ Year: _____</p>		
Study Purpose	Yes (1)	No (0)
<div style="text-align: center;">  <p>UNIVERSITY of the WESTERN CAPE</p> </div> <ol style="list-style-type: none"> 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? <p>Total:</p>		
Literature Review		
<ol style="list-style-type: none"> 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? 		

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

<ol style="list-style-type: none"> 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.?) <p>Total:</p>		
Findings	Yes (1)	No (0)
<ol style="list-style-type: none"> 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? <p>Total:</p>		
Conclusion	Yes (1)	No (0)



<ol style="list-style-type: none"> 1. Is the conclusion clear? 2. Is the conclusion supported by findings? 3. Are appropriate recommendations made? 4. Are limitations explicitly identified? <p>Total:</p>		
Ethical Considerations	Yes (1)	No (0)
<ol style="list-style-type: none"> 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 <p>Total:</p>		
<p>Total Score/Percentage</p> <ul style="list-style-type: none"> <input type="checkbox"/> Weak (0–30%) <input type="checkbox"/> Moderate (31%–65%) <input type="checkbox"/> Strong (66%–80%) <input type="checkbox"/> Excellent (81%–100%) <p>(Studies below the threshold stipulated in the Excellent category will be excluded. Studies not focusing on the psychological</p>	Score (/41)	%

<p>outcomes of HIV-related stigma will also be excluded.)</p>		
<p>Overall Outcome: Include <input type="checkbox"/> Exclude <input type="checkbox"/> Seek Further Info <input type="checkbox"/></p>		



Appendix F

Author	General Description			
	Target Population (Single/Double Orphan/Both)	Geographical Location	Aim	Problem Statement



Author	Methodology				
	Study Design	Theoretical Underpinnings	Sampling Method	Sample Size	Data collection methods/Instruments

Author	Findings and Analysis		
	Methods of Data Analysis	Study's Findings	Author's Conclusions





UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

18 June 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms Z Yassin (Social Work)

Research Project: A systematic review: The impact of stigmatization of HIV/AIDS orphans on psychological health

Registration no: 15/4/65

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

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*

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A place of quality,
a place to grow, from hope
to action through knowledge

601 Deauville
20 Ednam Road
Rondebosch
7700
22 November 2015

Ms Zeenat Yassin

Dear Ms Yassin

Thesis titled: A systematic review: The impact of stigmatisation on HIV/AIDS orphans' psychological health

I declare that I have read and edited the above document from the standpoint of grammar, syntax, idiom and punctuation according to the norms of British English, which is the style followed in South Africa, and the style and format generally used by academic and scientific publications.

I've worked for many years, and continue to work, as a sub-editor and copy editor for a number of professional South African academic and health-sciences journals produced by HMPG, the publishing division of the South African Medical Association, and by African Online Scientific Information Systems (AOSIS). Googling my name will produce some references to some of the journals that I've worked on.

Yours sincerely



UNIVERSITY of the
WESTERN CAPE

Robert Matzdorff
mobile 084 582 0460