

poor social well-being. Lastly, the related concept *future orientation* broadly refers to the extent that an individual thinks about their future and includes optimism, hopefulness, and perceived control over the future.

Model structure

The structure of the social transactional model of HIV-related stigma and the psychosocial well-being of COA consists of three linear stages according to the identified focal concepts, which facilitates a discussion and explanation of the interaction between focal concepts and stages of the model. The description of the structure of the model as presented here corresponds with the graphical representation of the model presented in Figure 9.1 below¹².

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

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

Outcomes	Yes (1)	No (0)
<p>1. Where 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 p</p> <p> Did they repo</p> <p> Psychometric</p> <p> Type of data i</p> <p> Did the data i</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>		



Total:		
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. Is ethical approval obtained from an identifiable committee?</p> <p>2. Did the Author/s report of gaining access from appropriate institutions?</p> <p>3. Have these ethical issues been reported on: Confidentiality? Anonymity? Withdrawal?</p> <p>Total:</p>		
<p>Total Score/ Percentage</p> <p><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>	Score (/45)	%

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



Appendix 3: Evaluative Tool for Mixed Method Studies

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

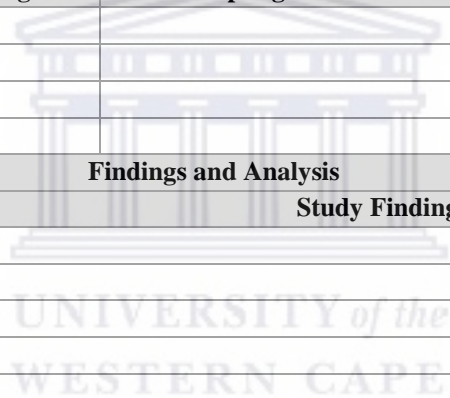
<p>3. Are appropriate recommendations made?</p> <p>4. Are limitations explicitly identified?</p> <p>Total:</p>		
<p>Ethical Considerations</p>	<p>Yes (1)</p>	<p>No (0)</p>
<p>1. Was ethical approval obtained from an identifiable committee?</p> <p>2. Did the author/s report on gaining access from appropriate institutions?</p> <p>3. Have the following ethical issues been reported on:</p> <p style="padding-left: 40px;">Informed consent</p> <p style="padding-left: 40px;">Confidentiality</p> <p style="padding-left: 40px;">Anonymity</p> <p style="padding-left: 40px;">Withdrawal</p> <p>Total:</p>		
<p>Total Score/Percentage</p> <p>6. Weak (0–30%)</p> <p>7. Moderate (31%–65%)</p> <p>8. Strong (66%–80%)</p> <p>9. Excellent (81%–100%)</p> <p>(Studies below the threshold stipulated in the category strong shall be excluded. Studies not focusing on the relationship between HIV-related stigma and the psychosocial well-being of children who have been orphaned by HIV/AIDS shall be excluded.)</p>	<p>Score (/41)</p>	<p>%</p>

Overall Outcome: Include Exclude Seek Further Info



Appendix 4: Systematic Review Data Extraction Sheet

General Description					
Author	Sample Population	Geographical location	Aim	Problem Statement	
Methodology					
Author	Study design	Theoretical Underpinning	Sampling Method	Sample Size	Data Collection Methods/Instruments
Findings and Analysis					
Author	Method of Analysis	Study Findings			Author Conclusion



Appendix 5: Qualitative Interview Guide

QUALITATIVE INTERVIEW GUIDE

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

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

Respondent Code:

Gender:

Age:

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

Facility/NGO (if applicable):

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

[prompts: daily activities and routines]

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

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

3. Can you tell me about school

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

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

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

5. Can you tell me about your friends?

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

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

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

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

[Prompts: Why do you feel that way?]

8. Can you tell me about your health?

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

Appendix 6: Theory Descriptive Guide

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

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

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



Appendix 7: Critical Reflection Guidelines

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

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

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



Appendix 8: Self-Administered Delphi Questionnaire

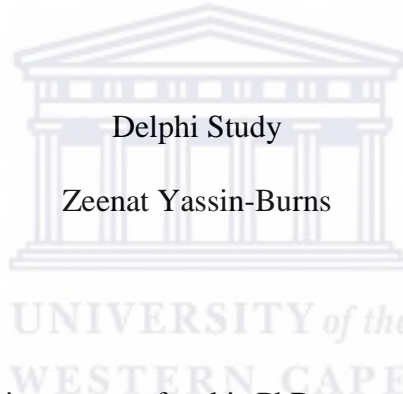


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A Social Transactional Model of HIV-related Stigma and the Psychosocial Well-being of Children Orphaned by AIDS



Dear Participant

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

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

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

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

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

Thank you for your assistance

A Social Transactional Model of HIV-related Stigma and the Psychosocial Well-being of

Children Orphaned by AIDS

Model Description

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

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

Stage 1: Experiences

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

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

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

Stage 2: Response

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

by AIDS are rather maladaptive and despite their use for defending against HIV-related stigma and emotional responses negatively affect their psychosocial well-being.

Stage 3: Psychosocial well-being

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

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

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

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

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

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

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

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

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

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

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

THANK YOU FOR YOUR PARTICIPATION



Appendix 9: Ethics Clearance Letter



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20 February 2017

Mrs Z Yassin
Social Work
Faculty of Community and Health Sciences

Ethics Reference Number: HS17/1/17

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

Approval Period: 17 February 2017 – 17 February 2018

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

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

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

A handwritten signature in black ink, appearing to read 'Josias', on a white rectangular background.

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

PROVISIONAL REC NUMBER - 130416-049

Appendix 10: Information Sheet



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E-mail: cjerasmus@uwc.ac.za

INFORMATION SHEET

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

What is this study about?

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

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

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

Would my participation in this study be kept confidential?

The researchers undertake to protect their identity and the nature of their contribution. To ensure their anonymity pseudonym names will be used so that participant's identity may be kept anonymous, and no documents will be recorded under your name. An identification key will be linked to your

identity and will only be available to the researcher. To ensure your identity remains anonymous all information is kept in a locked cupboard and identification codes will be placed on the data. If a report or an article is written, your identity will be protected. This research study will use a tape recording. The reports will be kept in a locked compartment with only the researcher and research supervisor having access to the information. The research findings will not include any of your personal details.

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

What are the risks of this research?

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

What are the benefits of this research?

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

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

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

What if I have questions?

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

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

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

Head of Department: Prof Schenk

Social Work Department

University of the Western Cape

Private Bag X17

Bellville 7535

Email: schenck@uwc.ac.za

Prof José Frantz

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za



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



UNIVERSITEIT VAN DIE WES-KAAP

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-9592459, Fax: 27 21-9593686

E-mail: cjerasmus@uwc.ac.za

INLIGTINGSBLAD

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

Waaroor handel die studie?

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

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

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

Word my deelname in die studie vertroulik gehou?

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

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

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

Wat is die risikos in die navorsing?

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

Wat is die voordele van die navorsing ?

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

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

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

Wat indien ek enige vrae het?

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

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

Hoof van die Departement: Prof Schenk

Departement van Maatskaplike Werk

Universiteit van Wes-Kaap

Privaatsak X17

Bellville 7535

Epos:schenck@uwc.ac.za

Tel: 021 09592011

Dekaan van die Fakulteit Gemeenskap en Gesondheids Wetenskappe:

Prof José Frantz

Universiteit Wes-Kaap

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

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



Appendix 11: Informed Consent



UNIVERSITY OF THE WESTERN CAPE

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

CONSENT FORM

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

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

Parent/ Legal Guardian name.....

Parent/ Legal Guardian signature.....

Date.....



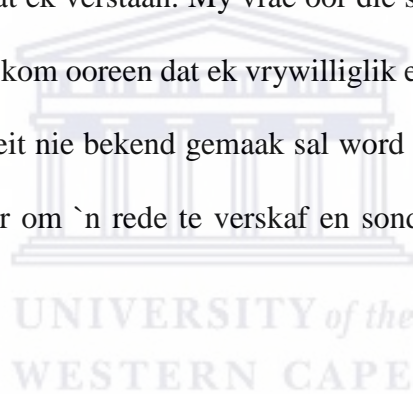
UNIVERSITEIT VAN WESKAAP

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

TOESTEMMINGS VORM

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

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



Ouer/wettige voog se naam.....

Ouer/wettige voog se handtekening.....

Datum.....

Appendix 12: Informed Assent



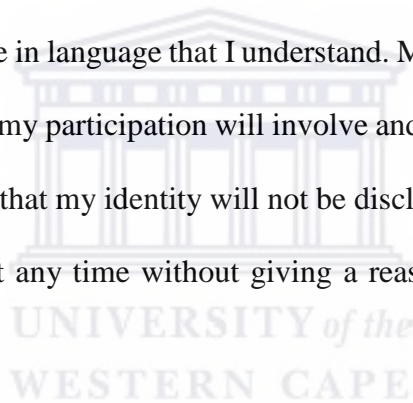
UNIVERSITY OF THE WESTERN CAPE

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Tel: +27 21-959 2459 Fax: 27 21-959 3686
E-mail: cjerasmus@uwc.ac.za

ASSENT FORM

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

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



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

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

Date.....



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INSTEMMINGS VORM

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

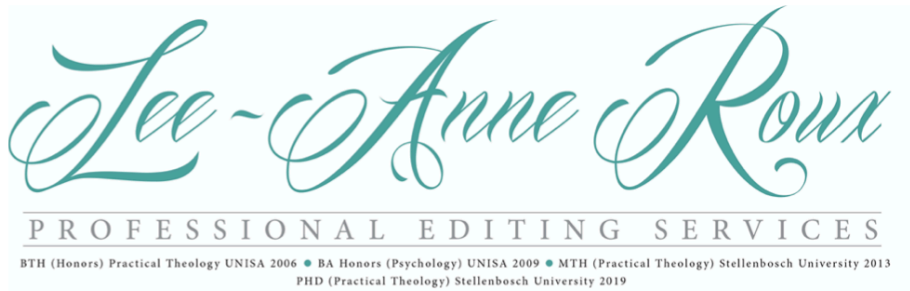
Die studie is beskryf in die taal wat ek verstaan. My vrae oor die studie is beantwoord. Ek verstaan wat my deelname sal behels en ek kom ooreen dat ek vrywilliglik en uit eie keuse deel neem aan die studie. Ek verstaan dat my identiteit nie bekend gemaak sal word nie. Ek verstaan dat ek enige tyd mag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

Ouer/wettige voog se naam.....

Ouer/wettige voog se handtekening.....

Datum.....

Appendix 13: Editor's Letter



27 April 2020

TO WHOM IT MAY CONCERN

RE: LANGUAGE EDITING

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

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

by

Zeenat Yassin
(Student Number: 3119420)

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

Yours sincerely,

Dr Lee-Anne Roux

Email: leeanne@proof-reading.co.za

Cell: 082 825 7325

Website: www.proof-reading.co.za