

**THE UNHEARD STORIES OF ADOLESCENTS
INFECTED AND AFFECTED BY HIV/AIDS
ABOUT CARE AND/OR THE LACK OF CARE**

by

Marinda van Niekerk

submitted in the fulfillment of the requirements for the degree of

PHILOSOPHIAE DOCTOR

in

PRACTICAL THEOLOGY-

In the

FACULTY OF THEOLOGY

at the

UNIVERSITY OF PRETORIA

Supervisor: Prof JC Müller

October 2004

SUMMARY

Adolescents living in the inner-city of Pretoria have their own special challenges that they must face everyday. These challenges entails a poverty context, communities of violence, difficult family circumstances and a developmental phase in which they struggle with their own identity.

The focus of this research is to listen to the stories of adolescents that have not being listened to before, concerning HIV/AIDS and their experiences regarding care. These young people is infected and/or affected by HIV/AIDS. The researcher does this research in the Narrative therapeutical paradigm, listening Practical Theologically to the stories of young people infected and/or affected by HIV/AIDS regarding care. Other stories about adolescents and care will also be listened to. The research process is social-constructionally structured. The researcher is searching for a holistic understanding of care from the perspective of young people. Discourses about adolescents, about care, about the inner city and about AIDS will be discussed.

Two separate groups of young people participated in the research. The researcher also listened to voices of the Sediba Hope AIDS Care Center about care and about young people. Reflection groups were used, consisting of teenagers and people from the academic community. The researcher used the method of reflection and self reflection throughout the research. Care is described after there were listened to the stories of the young people. The role of an African world-view is described as a resource to understand care holistically. The researcher spent time to reflect on the theological implications of the stories of young people and about the role they must play in the church and in the community.

Different care narratives are described as an outcome of the research. Other outcomes are also named and reflected upon.

KEY TERMS

Adolescence

HIV/AIDS

Narratives

Narrative therapy

Social constructionism

Inner city of Pretoria

Disadvantaged

Transformation

Multi-cultural

Poverty

Discourses

African world-view

PEN (Pretoria Evangelism and Nurture)

Sediba Hope AIDS Center

OPSOMMING

Adolesente wat daagliks in die middestad van Pretoria leef, het hul eie besondere kontekstuele uitdagings wat hulle die hoof moet bied. Hierdie uitdagings behels onder andere 'n konteks van armoede, 'n geweldadige samelewing, moeilike gesinskontekste en 'n lewensfase waarin hulle worstel met die forming van hul identiteit.

Die fokus van hierdie navorsing is om te luister na verhale van adolessente wat nog nie voorheen na geluister is nie, rakende MIV/VIGS en hul ervarings rondom sorg. Hierdie jongmense is geïnfekteer of geïmmuniseer deur MIV/VIGS. Daar word vanuit die Narratiewe paradigma, Prakties Teologies gekyk na hul ervaring van sorg rakende MIV/VIGS. Daar is ook geluister na ander persone en instansies se verhale rakende adolessente en sorg. Die proses van die navorsing is sosiaal konstruksionisties beplan. Daar is deurlopend gesoek na 'n holistiese verstaan van sorg vanuit die perspektief van adolessente. Diskoerse rakende adolessente, sorg, die middestadskonteks en VIGS is bespreek.

Twee afsonderlike groepe jongmense het deelgeneem aan die navorsing. Daar is ook geluister na verhale van sorg van die Sediba Hope Vigs Sentrum. Die navorser het gebruik gemaak van refleksie groepe wat bestaan het uit tieners sowel as mense in die akademiese omgewing. Die navorser het baie gefokus op die proses van refleksie en selfevaluering tydens die verloop van die navorsing.

Sorg is beskryf vanuit die verhale van die jongmense en ander mense rondom hulle. Die rol van 'n Afrika wêreldbeeld is ontgin as 'n bron in die holistiese verstaan van sorg. Daar is teologies besin oor die rol van jongmense in die kerk en in die samelewing. Sorg narratiewe is beskryf as 'n uitkoms van die navorsing, tesame met ander uitkomstes.

SLEUTEL BEGRIPPE

Adolesente

MIV/VIGS

Narratiewe

Narratiewe terapie

Sosiale konstruksionisme

Middestad van Pretoria

Minder bevoorreg

Transformasie

Multi-kultureel

Armoede

Diskoerse

Afrika wêreldbeeld

PEN (Pretoria Evangelisering en Nasorgaksie)

Sediba Hope VIGS sentrum

DEDICATION

This work is dedicated to every young person infected and/or affected by HIV/AIDS who live in the inner city of Pretoria. I want to thank every young person for accompanying me on my journey to look at the world through their eyes. I want to honour them for allowing me to experience God through their love and their commitment. I have seen God in every one of you, you taught me new ways of believing in God like a child. Your narratives have enriched my life and transformed me as person.

Thank you.

INDEX

CHAPTER ONE: POSITIONING AND RESEARCH METHODOLOGY

| PAR. | HEADING | PAGE |
|-------|---------------------------------------|------|
| 1 | MY INTEREST IN THIS FIELD OF RESEARCH | 1 |
| 2 | POSITIONING | 3 |
| 2.1 | Practical Theology | 4 |
| 2.2 | Narrative Approach | 8 |
| 2.2.1 | Co-researcher | 9 |
| 2.2.2 | Position of the researcher | 9 |
| 2.2.3 | Focus of the research | 10 |
| 2.3 | Post-modern paradigm | 10 |
| 2.4 | The social-constructionist paradigm | 16 |
| 2.5 | Qualitative Research | 17 |
| 2.6 | Care | 18 |
| 3 | THE CONTEXT OF THE RESEARCH | 19 |
| 4 | RESEARCH METHOD | 20 |
| 4.1 | The action field of the story | 24 |
| 4.1.1 | The action or fields of action | 24 |
| 4.1.2 | Possible questions | 24 |
| 4.1.3 | Data collection | 25 |
| 4.2 | Background of the story | 26 |
| 4.3 | Story Development | 29 |
| 4.4 | Climax of the story | 31 |
| 4.5 | Ending of the story | 33 |
| 5 | IN CLOSING | 35 |
| 5.1 | Index | 35 |

CHAPTER TWO: UNHEARD STORIES OF ADOLESCENTS

| PAR. | HEADING | PAGE |
|----------------|--|-------------|
| 1 | THE STORY OF THE INNER CITY AND PEN | 36 |
| 1.1 | Four areas of ministry | 40 |
| 1.2 | PEN believe | 41 |
| 2 | MY JOURNEY WITH THE CO-RESEARCHERS | 47 |
| 2.1 | Putting plans into action | 47 |
| 2.2 | How did I choose the co-researchers | 48 |
| 2.3 | How did I go about capturing information | 48 |
| 2.4 | How did I invite people to become co-researchers | 48 |
| 2.4.1 | Names of the main group of teenagers | 49 |
| 2.5 | How did I involve the parents | 49 |
| 2.6 | Sessions with the care institutions in the area | 49 |
| 2.7 | Sessions with the Sediba Hope Aids Center personnel | 50 |
| 2.8 | Sessions with the Academic Reflection Teams | 50 |
| 2.9 | My first encounter: baby research with baby teens | 50 |
| 2.9.1 | Session 1 | 52 |
| 2.9.2 | My reflection | 60 |
| 2.10 | The research team | 61 |
| 2.10.1 | Session 2 | 61 |
| 2.10.2 | My reflection | 67 |
| 2.10.3 | Session 3 | 68 |
| 2.10.4 | My reflection | 78 |
| 2.10.5 | Session 4 | 79 |
| 2.10.6 | My reflection | 88 |
| 2.10.7 | Session 5 | 89 |
| 2.10.8 | My reflection | 97 |
| 2.10.9 | Session 6 | 98 |
| 2.10.10 | My reflection | 107 |
| 2.10.11 | Session 7 | 109 |

| PAR. | HEADING | PAGE |
|-------------|---|-------------|
| 2.10.12 | The drama script | 109 |
| 2.10.13 | My reflection | 111 |
| 3 | SOME REFLECTION THAT WILL GUIDE THE REST OF MY THESIS | 111 |
| 4 | IN CLOSING | 113 |

CHAPTER THREE: WEAVING THE BACKDROP: MIXING DIFFERENT VOICES TO COME TO A DEEPER UNDERSTANDING

| PAR. | HEADING | PAGE |
|-------------|--|-------------|
| 1 | RESEARCH DONE IN AFRICA | 116 |
| 1.1 | Understanding world-view | 117 |
| 1.2 | The African world-view, its understanding of adolescence and its relevance to this study | 118 |
| 1.3 | An African world-view in an narrative, socio-constructionist approach | 120 |
| 1.4 | African Theology | 120 |
| 2 | THE DISCOURSE OF MULTI-CULTURALITY | 124 |
| 3 | THE INNER CITY OF PRETORIA: TRANSITIONAL DISCOURSES | 124 |
| 4 | DISCOURSES ON HISTORICAL INFLUENCE IN PRETORIA | 127 |
| 4.1 | Focusing on the inner city | 127 |
| 4.2 | The Dutch Reformed Church Bosman Street | 129 |
| 5 | THE ROLE AFRICAN FAMILIES PLAY IN BUILDING VALUES IN YOUNG PEOPLE | 131 |
| 6 | DISCOURSES ABOUT ADOLESCENCE | 132 |
| 6.1 | General adolescent discourses | 132 |
| 6.2 | Discourses about young people living in the inner city | 133 |
| 6.3 | Discourses of my co-researchers about adolescence | 134 |
| 6.4 | In the narrative paradigm, a new description of adolescence is required | 134 |
| 7 | CARE DISCOURSES | 136 |
| 7.1 | Young people caring about themselves and their future | 136 |

| PAR. | HEADING | PAGE |
|-------------|---|-------------|
| 7.2 | The message sent by the media | 142 |
| 7.3 | Medical care provided by the government | 143 |
| 7.4 | Illness discourses | 144 |
| 7.5 | Healing discourses | 144 |
| 7.6 | Caring about care | 144 |
| 8 | SEX DISCOURSES IN AFRICA | 145 |
| 9 | IN CLOSING | 146 |

CHAPTER 4: THE CIRCULAR MOVEMENT IN THE PROCESS OF INTEGRATING HEARD STORIES AND LISTENING TO NEW STORIES

| PAR. | HEADING | PAGE |
|-------------|--|-------------|
| 1 | OTHER STORIES OF YOUNG PEOPLE IN SOUTH AFRICA | 147 |
| 2 | LISTENING TO THE STORIES OF CARE INSTITUTIONS AND HOW YOUNG PEOPLE EXPERIENCED IT | 149 |
| 3 | DISCUSSIONS WITH THE SEDIBA HOPE AIDS CENTER PERSONNEL | 149 |
| 4 | FEEDBACK FROM THE REFLECTION TEAMS | 153 |
| 4.1 | Reflection team 1 | 153 |
| 4.2 | Reflection team 2 | 155 |
| 5 | VOICES IN MY HEAD AND AIDS IN MY FACE | 156 |
| 5.1 | My understanding of the church and my own challenge | 156 |
| 5.2 | An African world-view meeting globalization | 157 |
| 5.2.1 | Globalization in the inner city of Pretoria | 157 |
| 5.2.2 | Young people experiencing globalization | 158 |
| 5.2.3 | Is it love at first sight, or will it end in divorce | 159 |
| 5.3 | I see AIDS in my face, but who cares? | 159 |
| 5.3.1 | Care narratives | 160 |
| 5.3.1.1 | Weingarten | 160 |
| 5.3.1.2 | Pienaar | 160 |
| 5.3.1.3 | Baart | 160 |

| PAR. | HEADING | PAGE |
|---------|--|------|
| 5.3.2 | Care narratives developed from this research | 162 |
| 5.3.2.1 | Fearful care | 162 |
| 5.3.2.2 | Paralyzing care | 162 |
| 5.3.2.3 | Legal care | 162 |
| 5.3.2.4 | Nurturing care | 163 |
| 5.3.2.5 | Communal care | 163 |
| 5.3.2.6 | Present care | 164 |
| 5.3.2.7 | Advocative care | 164 |
| 5.3.2.8 | Storying care | 165 |
| 6 | COLLECTING MY THOUGHTS | 165 |
| 6.1 | New places of understanding | 165 |
| 7 | IN CLOSING | 166 |

CHAPTER 5: OUTCOME OF MY RESEARCH

| PAR. | HEADING | PAGE |
|------|--|------|
| 1 | THE PROCESS OF ARRIVING AT THESE OUTCOMES | 168 |
| 2 | SOME OF THE <i>UNIQUE</i> and <i>LESS UNIQUE</i> OUTCOMES OF THE GROUP SESSIONS | 169 |
| 2.1 | The power of spiritual discourses | 169 |
| 2.2 | Individual stories | 169 |
| 2.3 | Reframing | 169 |
| 2.4 | Therapeutic outcomes | 170 |
| 2.5 | Learning to be “HIV positive” | 170 |
| 2.6 | The reality of an “HIV negative” world | 171 |
| 2.7 | Living with “AIDS in my face” | 171 |
| 2.8 | Descriptions of the reality of the lack of accessible health care for young people | 171 |
| 2.9 | Descriptions of the reality of the inner city context and of growing up in communities of violence | 172 |
| 2.10 | “Love them enough to talk about sex” | 172 |
| 2.11 | Silent narratives | 172 |

| PAR. | HEADING | PAGE |
|-------------|--|-------------|
| 2.12 | The drama | 172 |
| 2.13 | Institutions | 173 |
| 3 | NEW PLACES OF UNDERSTANDING | 173 |
| 3.1 | African knowledge as a resource for care narratives | 173 |
| 3.2 | Academic outcome | 173 |
| 3.3 | A narrative description of adolescence | 173 |
| 3.4 | Hearing the reframed discourses of young people about themselves | 174 |
| 3.5 | Valuing the role young people can and must play in co-constructing their own futures | 174 |
| 3.6 | Taking young people serious | 174 |
| 3.7 | Practical Theological implications | 174 |
| 3.8 | A narrative outcome | 175 |
| 3.9 | A personal outcome | 175 |
| 4 | IN CLOSING | 176 |

CHAPTER 6: GROWING UP: IN PERSON AND IN RESEARCH

| PAR. | HEADING | PAGE |
|-------------|--|-------------|
| 1 | THINGS I WOULD HAVE DONE DIFFERENTLY | 177 |
| 2 | AN ETHICAL REFLECTION | 177 |
| 3 | FUTURE FOCUSES FOR RESEARCH | 179 |
| 4 | CRITICAL EVALUATION OF THE RESEARCH PROCESS | 179 |
| 4.1 | Reliability | 179 |
| 4.2 | Validity | 180 |
| 4.3 | Credibility | 180 |
| 4.4 | Transferability | 180 |
| 4.5 | Consistency | 181 |
| 4.6 | Confirmability | 181 |
| 5 | NARRATIVE EVALUATION QUESTIONS | 182 |
| 5.1 | Did the research create space for new stories and for restorying | 182 |

| PAR. | HEADING | PAGE |
|-------------|--|-------------|
| 5.2 | Did the researcher have integrity in listening to and reporting the stories | 182 |
| 5.3 | Did the researcher interpret or ask for interpretation | 183 |
| 5.4 | Did the research process bring transformation/reframing | 183 |
| 5.5 | How is the researcher going to disseminate the research | 183 |
| 6 | IN CLOSING | 184 |
| | WORDS OF THANKS | 187 |
| | BIBLIOGRAPHY | 188 |
| | APPENDICES | 194 |
| | Appendix A | 194 |
| | Appendix B | 195 |
| | Appendix C | 197 |
| | Appendix D | 201 |
| | Appendix E | 204 |
| | Appendix F | 209 |
| | Appendix G | 211 |
| | Appendix H | 212 |