PASTORAL-THERAPEUTIC WORK WITH FAMILY MEMBERS INFECTED AND AFFECTED BY HIV/AIDS: A NARRATIVE APPROACH

by

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DEDICATION

I dedicate this work to all those who are infected and/or affected by HIV/AIDS, of all ages, colours, cultures and beliefs. This study is also dedicated to all those (caregivers) who are committed to show unconditional and compassionate care to the infected and affected. My prayer is that this study may in a small way help caregivers to alleviate the suffering and pain of those infected and affected by HIV/AIDS and points them to the Lord of compassion.

It is not the healthy who need a doctor, but the sick. Go and learn what this text means: I require mercy, not sacrifice. I have not come to call respectable people, but outcasts. (Matthew 9:12-13)



SYNOPSIS

This research reports on narratives of people whose lives had been infected and affected by the devastating disease – HIV/AIDS. The core information, on which this study is based, comes from experiences of those infected and/or affected by HIV/AIDS as well as from caregivers. It sweeps away statistics and places those seeking to offer help in the midst of those seeking to be helped. This mutual *subject-to-subject* relationship becomes the stage on which research/therapy, interviews and conversations are conducted. This study therefore opts for an approach that is informed by the experiences of those infected and/or affected and that addresses the realities of their lives.

Care and/or lack of care is identified as a phenomenon, which is a direct reflection on how therapy (research) is done by those providing the care and perceived by those receiving the care. In the light of the experiences (stories) shared by the companions, it became evident that there is an existing need for alternative therapeutic ways, which seeks to embrace a therapeutic approach, which will minimize the external authority, or power of the therapist and at the same time maximizes the authority of those seeking therapy.

The Narrative approach is explored as a possible therapeutic approach that could be used to empower those infected and/or affected pastorally in a less-knowledgeable fashion that is not-controlling, not-manipulative, not-authoritative and not-knowing – as "guiding" metaphor which will permit the infected and/or affected to use their own thinking, understanding, emotions,



creativity and own resources in a way that best fits them in bringing meaning to their own lives.

The entire study seeks to emphasise the importance of a therapeutic approach, which seeks to symbolically embrace the "clouded" story of the infected and affected in a story of God's hope. In this approach the therapist simply becomes aware of the presence of a person(s) for whom the devastating reality of HIV/AIDS is an every day reality. This research does not claim to have the solutions or quick fix miracle answer to the complex HIV/AIDS phenomenon, and it neither claims to have the power to bring any neat conclusion to the HIV/AIDS story, but rather have the potential to stimulate a new story of hope and purpose in the lives of the infected and affected. This research emphasises a position where the infected and affected can inhabit and lay claim to the many possibilities of their own lives that lie beyond the knowledge, assumptions, expectations, goals and understandings of the therapist. A position in which the therapist simply becomes available to talk, listen and support. A position that will empower those infected and affected to tell:

- the story of need as broadly as possible,
- the story of the past,
- the future story in the story of the past,
- the reinterpreted story of the past,
- the imagined story of the future.

(Muller 1999:84)



OPSOMMING

In hierdie verhandeling word verslag gedoen oor die narratiewe van mense wie se lewens geinfekteer en/of geaffekteer word deur MIV/VIGS. Die kern informasie waarop hierdie studie gebaseer is, kom uit die ervaringswêrelde van die geinfekteer en/of geaffekteer sowel as van beraders. Hierdie navorsing doen weg met statistieke en plaas die terapeut in die midde van die wat berading soek. Die studie kies daarom, 'n benadering wat deur die ervaringswêrelde van die geinfekteerdes en/of geaffekteerdes toegelig word en wat die realiteite soos deur hulle ervaar word, aangespreek.

Sorg en/of gebrek aan sorg word geidentifiseer as 'n fenominaal wat 'n direkte refleksie van hoe terapie (navorsing) gedoen word deur diegene wie die versorging doen, en soos ervaar deur diegene wie sorg ontvang. In die lig van die ervaringe (verhale) soos vertel deur die "vennote", word dit duidelik dat daar 'n behoefte bestaan vir alternatiewe terapeutiese maniere, wat 'n benadering beklemtoon waarin gepoog word om die eksterne outoriteit of mag van die terapeut te verminder en terselfdertyd die outoriteit en mag van diegene wat beraad word te vermeerder.

Die Narratiewe benadering word as 'n moontlike terapeutiese benadering gebruik waarin die geinfekteerde en/of geafekteerde pastoraal begelei word in 'n nie-oorheersend, nie-manipulerend, nie-outoritêre, en nie-wetende manier. Hierdie posisie geld egter as 'n begeleidings metafoor waardeur die



geinfekteerde en/of geaffekteerde toegelaat word om hul eie denke, verstaan,emosies, kreatiwiteit en bronne te gebruik op 'n manier wat hulle bes pas in die meebring van betekenis in hul eie lewens.

Die belangrikheid van 'n terapeutiese benadering wat simbolies die "verduisterde" verhaal, in 'n verhaal van God se hoop plaas, word beklemtoon. In hierdie benadering word die terapeut eenvoudig bewus van die teenwoordigheid van 'n persoon(e) vir wie die vernietigende realiteit van MIV/VIGS 'n daaglikse werklikheid is. Hierdie navorsing maak nie daarop aanspraak dat dit wonderwerkende oplossings of kits herstel antwoorde het vir die gekompliseerde MIV/VIGS probleem nie. Ook maak dit nie daarop aanspraak dat dit die mag het om enige netjies, afgeronde konklusies tot die MIV/VIGS verhaal te bring nie, maar wel die potensiaal het om 'n nuwe verhaal van hoop en doel in die lewens van die geaffekteerdes en/of geinfekteerdes te stimuleer. Die navorsing beklemtoon 'n posisie waar die "vennote" aanspraak maak op die verskeie moontlikhede wat verhewe bo die kennis, verwagtinge, doelwitte en begrip van die terapeut lê. 'n Posisie waar die terapeut hom/haar eenvoudig beskikbaar stel om in gesprek te tree, te luister, vrae te stel en te ondersteun. Die posisie bemagtig die vennote om:

- die noodverhaal so breedvoerig as moontlik te vertel.
- die verledeverhaal te vertel,
- die toekomsverhaal in die verledeverhaal te vertel,
- die herinterpreteerde verledeverhaal te vertel, asook
- die verbeelde toekomsverhaal. (Muller 1999:84)



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