

***THE UNTOLD STORIES OF WOMEN IN
HISTORICALLY DISADVANTAGED
COMMUNITIES, INFECTED AND/OR AFFECTED
BY HIV/AIDS, ABOUT CARE AND/OR THE LACK
OF CARE***

by

SUNETTE PIENAAR

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SUPERVISOR: PROF J C MÜLLER

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ABSTRACT

Black women in historically challenged communities in South Africa carry the burden of triple oppression: (a) the social engineering policies synonymous with apartheid have marginalised women economically and socially, (b) patriarchy, embedded in cultural and religious discourses, has rendered women voiceless and powerless and (c) HIV/AIDS targets the most vulnerable: women and children. Not only are women carrying the brunt of HIV infections, but they also carry the extra burden of caring for the sick and the orphaned.

The main aim of this research was to reach a holistic understanding of the untold stories of women in historically challenged communities, infected and/or affected by HIV/AIDS, and specifically about their experiences of care and the lack of care. The two secondary aims were: 1) to research alternative ways and means of making the unheard stories known in South African society; and 2) to disseminate research findings on the stories of these women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in the South African society.

A family of three women and a translator participated as co-researchers with the writer in this research experience. The researcher reflected on the research experience with volunteers from two home-based care programs in the community. The researcher uses drama as metaphor to document her 'colourful' research experience and to make sense of the many intricate and intertwined narratives and discourses, documented over a period of six months in her research diary, through recorded interviews, through her participation with the co-researchers and through the ethnography she had engaged in.

The research experience has found that to be able to 'care someone else into existence'; it is paramount that you as carer experience 'empowering care' yourself. 'Empowering care' is not possible if injustice prevails. This research experience challenges Government to investigate the ethical implications of the policy of placing the burden of care for the dying and the orphans on the shoulders of women in historically challenged communities.

Key terms:

HIV/AIDS; care; injustice; African women; feminist theology; post-modern theology, power; pastoral therapy; narrative therapy; social construction; stigma & discrimination; patriarchy; poverty; religion; 'caring into existence'; 'empowering care'

OPSOMMING

Swart vroue in histories-benadeelde gemeenskappe in Suid-Afrika dra die las van driedubbele onderdrukking: (a) vroue is deur die segregasiebeleid van die apartheidsregering ekonomies en sosiaal gemarginaliseer, (b) patriargie asook kulturele en godsdienstige diskoerse laat vroue stemloos en magteloos, en (c) MIV/Vigs teiken die mees kwesbare lede van die gemeenskap: vroue en kinders. Nie alleen is vroue meer kwesbaar vir die MIV virus as mans nie, as tradisionele versorgers, is hulle ook verantwoordelik vir die duisende siekes en kinders wat weesgelaat word deur die epidemie.

Die hoofdoelwit van hierdie navorsing was om tot 'n holistiese verstaan te kom van die onvertelde stories van vroue, geïnfekteer en/of geaffekteer deur MIV/Vigs, in histories-benadeelde gemeenskappe, en hulle belewenisse oor sorg en/of die afwesigheid van sorg. Die twee sekondêre doelwitte was: 1) om die onvertelde stories op alternatiewe wyses bekend te maak in Suid-Afrika en 2) om navorsingsresultate op so 'n wyse te versprei dat ontwikkelingsbeleid daardeur beïnvloed kan word en dat verstaan oor alternatiewe, holistiese stories van sorg in Suid-Afrika verbreed kan word.

'n Gesin van drie vroue en 'n vertaler het as medenavorsers deelgeneem aan die navorsingservaring saam met die skrywer. Die navorser het gereflekteer op die navorsing saam met twee tuisversorgingsprogramme in die betrokke gemeenskap. Die navorser gebruik drama as metafoer om haar kleurvolle navorsingservaring te dokumenteer en om sin te maak uit die baie verweefde en interafhanklike narratiewe en diskoerse wat sy oor 'n tydperk van ses maande in haar navorsingsdagboek gedokumenteer het. Hierdie narratiewe en diskoerse het ook te voorskyn gekom deur onderhoude, deur die navorser se deelname aan die stories van die medenavorsers en deur die etnografie wat sy onderneem het.

Die navorsingservaring het daarop gewys dat dit slegs moontlik is om vir iemand om 'skeppend' te versorg as die versorger self 'bemagtigende sorg' ervaar. Bemagtigende sorg is egter nie moontlik waar ongeregtheid seëvier nie. Die navorsingservaring daag die regering van die dag uit om die etiese implikasies van 'n beleid wat die versorgingslas van die siekes en die wees op vroue in histories-benadeelde gemeenskappe plaas, te ondersoek.

Sleutelbegrippe:

MIV/Vigs; sorg; ongeregtigheid; swart vroue; feministiese teologie; post-moderne teologie, mag; pastorale terapie; narratiewe terapie; sosiale konstruktivisme; stigma & diskriminasie; patriargie; armoede; godsdiens; 'skeppende versorging'; 'bemagtigende sorg'

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