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# HIV stigma experiences and stigmatisation before and after an intervention

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## ABSTRACT

This study focuses on one aspect of a more extensive SANPAD-funded HIV stigma reduction research project. The study addresses not only the continuous burden of HIV stigma, but more specifically on the low rate of participation in healthcare opportunities and HIV stigma reduction interventions by people living with HIV (PLWH). This study tested both change-over-time in HIV stigma experiences of PLWH and change-over-time in the HIV stigmatisation behaviour of people living close to them (PLC) in an urban and rural setting in the North-West in South Africa. These aspects were measured before and after the comprehensive community-based HIV stigma reduction intervention. A quantitative single system research design, with a pre-test and four repetitive post-tests, and purposive voluntary and snowball sampling were used. Findings did not indicate significant differences between urban and rural settings, but demonstrated some significance in change-over-time in the HIV stigma experiences of PLWH as well as the HIV stigmatisation behaviour of PLC after the intervention. Recommendations include the continuation of this intervention, following the same guidelines that were implemented during the study.

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## 1. Introduction

HIV infection remains a globally stigmatised condition (Greeff et al., 2008) and HIV stigma remains a complex concept (Mbonye et al., 2013) associated with blame, shame, disgrace and social unacceptability (Mandal, 2013). Fifty years ago Goffman (1963) described stigma as a deeply discrediting personal phenomenon and forty years later, Deacon and Stephney (2007) argued for an even stronger term to more

accurately describe stigma. They suggested that a term similar to racism be found that would strongly portray public disapproval of discriminatory and stigmatising behaviour.

HIV stigma manifests as the assertion of a socially constructed “undesired differentness” through acts of ostracism, discrimination, social control, marginalisation and social domination (Herek, Saha, & Burack, 2013). Earlier authors have described it as a disempowerment of PLWH through labelling, stereotyping, separation, diminishing and discrimination (Link, Yang, Phelan, & Collins, 2004). Moreover,

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according to Kohi et al. (2006), stigma manifests in the violation of human rights which may take the form of refusing to care for PLWH within health facilities, verbal and physical abuse, food deprivation, denial of employment or income opportunities, denial of leadership positions and a so-called justified breach of confidentiality regarding the HIV status of PLWH. Further aspects of psychological distress experienced by stigmatised PLWH include increased physical distance, awkward social interaction, indifference, avoidance, blaming, exaggerated kindness, aggression, exclusion, excessive hygienic measures and being told to disclose or not (Stutterheim et al., 2009).

These complexities led to Holzemer et al. (2007) proposing a four-dimensional process model to facilitate a better understanding of HIV stigma in Africa. The model served as a basic framework for this study as it acknowledges that HIV stigma occurs within an interactive context where environment, the healthcare system as well as people all play a role in the everyday stigma reality. In this model there are four interactive processes of HIV stigma, namely triggers, behaviours, types and outcomes of HIV stigma. This suggests that an HIV test can trigger certain behaviour, lead to a specific type of stigma and result in a definable outcome of stigma for the PLWH.

The types and outcomes of HIV stigma are broadly covered in the literature and are summarised in Fig. 1 to enhance understanding. Internal stigma seems to refer to self-stigmatising (Holzemer et al., 2007) by PLWH or their insider view (Rensen, Bandyopadhyay, Gopal, & Van Brakel, 2011). Received stigma (Holzemer et al., 2007) relates to concepts like perceived/anticipated, outsider-view/external or felt stigma as mentioned by Mak et al. (2007), Weiss et al. (1992) and Herek et al., (2013) respectively, and as such experienced by PLWH as directed towards them. Lastly, associated stigma (Holzemer et al., 2007) or secondary stigma (Ogden & Nyblade, 2005) relates to stigma that stems from someone's association with PLWH and often includes PLC (people living close to PLWH). It

is important to understand that stigma may in some instances also arise from PLC participating in stigmatising behaviour towards PLWH.

The experiences of PLWH with the above types of HIV stigma directed at them can be devastating with life-inhibiting emotional, psychological, relational or material outcomes. Repeated experiences of abuse and discouragement to participate in treatment programmes and attend care facilities could lead to diminished physical and mental health (Greeff et al., 2008). Isolation or decreased social participation of PLWH stems from living while fearing stigma and thus minimising their exposure to others (Gilbert & Walker, 2010) which in turn leads to poor participation in healthcare as well as in personal and employment relationships (Greeff et al., 2010). A further outcome of HIV stigma for PLWH relates to self-isolating behaviour to prevent HIV-transmission to others and to minimise secondary (associated) stigma directed at those living close to them (Salter et al., 2010). PLWH often experience personal and emotional frailty coupled with internalised self-stigmatisation, shame and a compromised self-efficacy (Naidoo et al., 2007). This leads to social avoidance, real or perceived loss of friends, perceived discomfort of those they are in contact with, symptoms of depression and feelings of anxiety, hopelessness and unattractiveness (Cahill & Valadez, 2013). All these aspects contribute to a decreased quality of life as an outcome of HIV stigma for PLWH and poor disclosure practices, poor sexual choices or quality-of-life decisions driven by a debilitating, internalised fear of losing significant relationships and losing their source of income/livelihood. Other fears include the fear of losing out on marriage, child-bearing, family care, hope, self-worth and reputation (Kasapoglu, Saillard, Kaya, & Turan, 2011; Rensen et al., 2011). However, HIV stigma could be turned around and lead to positive outcomes if PLWH become involved in actively reducing stigma, accept their HIV status, demonstrate a pleasant disposition, choose positive interpretations of social interactions, refuse the victim role and focus on health,

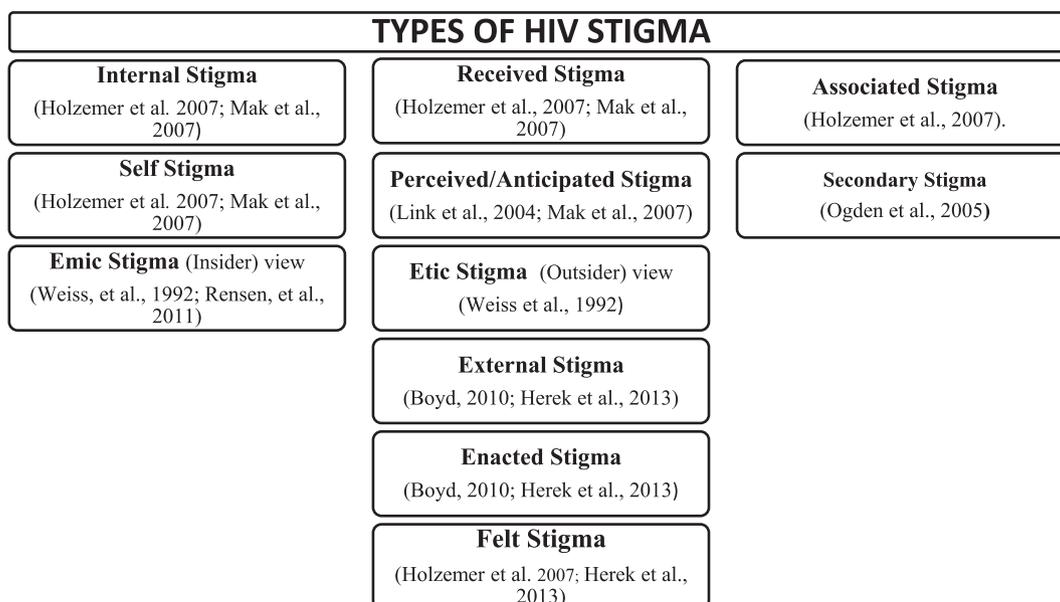


Fig. 1 – Types of HIV stigma.

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