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A HIV stigma reduction intervention for people living with HIV and their families

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ABSTRACT

Background: The diagnosis of HIV is life-changing that requires people not only to deal with the disease but also to cope with the stigma attached to HIV. People living with HIV (PLWH) as well as their close family members (CFM) are stigmatised; however, CFM also stigmatise PLWH. This interaction affects the relationship between PLWH and their CFM.

Aim: To explore and describe the experiences of PLWH and CFM during and after a community-based HIV stigma reduction intervention in both an urban and rural setting in the North-West.

Method: A qualitative description approach through in-depth interviews was used in both settings. Purposive sampling was used for the PLWH and snowball sampling for the CFM. Data was analysed using open coding.

Results: Both urban and rural groups gained a richer understanding of HIV stigma and how to cope with it. The relationships were enriched by PLWH feeling more supported and CFM realising how they stigmatised PLWH and that they should be more supportive. Leadership was activated in PLWH and CFM through the stigma reduction project that they participated in.

Conclusion: No significant differences were found between rural and urban communities, thus the intervention can be implemented with similar results in both settings. The intervention showed positive outcomes for both PLWH and CFM. Bringing PLWH and CFM together during an intervention in an equalised relationship proved to be useful as PLWH felt more supported and CFM showed much more compassion towards PLWH after the intervention.

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1. Introduction

This study was part of a bigger comprehensive community-based HIV stigma reduction and wellness enhancement intervention study in an urban and rural setting in the North-West of South Africa, and included people living with HIV (PLWH) and people living close to them (partner, child, close family member, close friend, spiritual leader and community member). The focus in this study was only on people living with HIV and their close family members (CFM). CFM in this study refers to a member who is part of the biological family but excludes the partner or children.

The global AIDS epidemic is one of the greatest challenges in the field of global health, affecting the quality of life of many people and the cost of care. PLWH, those close to them, as well as their healthcare providers are affected by stigma and discrimination, particularly in Southern Africa, where so many are infected and the burden of the disease is significant (Greeff et al., 2010). It has therefore become all the more urgent to find a way to address HIV-related stigma in the South African context (Forsyth, Vandormael, Kershaw, & Grobbelaar, 2008; Nicolay, 2008).

Although published many years ago, the definition of stigma as conceptualised by Alonzo and Reynolds (1995) is used for this study. According to Alonzo and Reynolds (1995), stigma is "a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as people" (p. 302). Several conceptual frameworks for understanding HIV stigma and its effects propose that the fear of being identified with HIV prevents people from learning their sero status, changing unsafe behaviours, and caring for PLWH (Wingood et al., 2008).

A number of different frameworks have been published over the years. For instance, Parker and Aggleton (2003) offered a theoretical framework of social inequality as a strategy to understand stigma. The study of Deacon, Stephney, and Prosalendis (2005) focused on social theories of stigma as a problem of fear and blame rather than as a problem of ignorance or a mechanism of social control. Campbell, Foulis, Maimane, and Sibya (2005) proposed a framework regarding the contexts in which stigma occurs: the economic, political, and local community contexts, and the organisational context. The ecological model of human development by Bronfenbrenner (as cited in Asiedu, 2007) stresses the importance of looking at the impacts of HIV and its related stigma on the family members of PLWH. Mak et al. (2007) proposed a social cognitive framework to study the effect of self-stigma on psychological distress. Holzemer et al. (2007) proposed a conceptual model of HIV stigma to understand the stigma process that is specific to HIV in Africa. This model describes HIV-related stigma as a cyclical process within a specific context (the environment, the healthcare system and agents). The stigma process includes four dimensions: triggers of stigma, stigmatising behaviours, types of stigma, and the outcomes of stigma. This model was used as the theoretical framework for the current study.

In the African setting, HIV stigma acts as a powerful barrier to access healthcare as it inhibits HIV testing and disclosure of HIV status (French, Greeff, Watson, & Doak, 2014). Uys et al. (2009) found that HIV stigma is a problem for Africa but that it was more intense and more frequent in South Africa. In addition, it posed a serious problem to PLWH and people associated with them as judgement from family members can be one of the worst personal struggles that PLWH have to deal with (Muhomba, 2007). This often leaves the infected individuals with existential questions about the meaning of their infection, their behaviour, as well as their HIV-positive status as it relates to their family relationships. Research by Holzemer et al. (2007) and Ming-Chu et al. (2009) has also shown that as soon as the diagnosis becomes known, spouses, children and family of the infected person also become targets of stigmatisation. The situation thus becomes very difficult if family support is compromised as a result of disclosure. This is of particular concern as Greeff et al. (2008) found that in the African context, PLWH disclose to families first.

Internationally, the literature has shown that HIV stigma tendencies differ in urban and rural settings due to differences in social structure and the experiences of individuals living in those settings. Literature on this theme is however scarce. In their study in five African countries on urban and rural differences on HIV stigma, Naidoo et al. (2007) found that in general, the urban groups described more incidents of stigmatisation and discrimination than the rural groups did. They thus argued that there was a clear difference in character and intensity of stigma between urban and rural groups. However, their findings contradict the results of some other research studies such as the study by Campbell, Nair, Maimane, and Sibiya (2008) which found that there is significant stigmatisation in rural communities due to anonymity and confidentiality being very difficult to maintain in rural areas. Rankin, Brennan, Schell, Laviwa, and Rankin (2005) found that in many African rural communities a restriction on privacy increased the opportunity for stigmatisation because the lives of individuals and families were closely intertwined with those of others. A common thread throughout the literature on urban and rural differences in HIV stigma is that factors such as social structure, economic status and the level of literacy probably determined the manner in which HIV is perceived (French et al., 2014).

Some available literature on HIV stigma reduction programmes or interventions (Bos, Herman, Schaalma, & Pryor, 2007; Rao et al., 2012) indicates that few effective programmes have been developed and implemented. However, several researchers (Chirwa et al., 2008; Cook, Purdie-Vaughns, Meyer, & Busch, 2014; Mahendra et al., 2007; Uys et al., 2009) argue that HIV-related stigma reduction interventions can be effective. In a review by Sengupta, Banks, Jonas, Miles, and Smith (2011), 14 out of 19 interventions demonstrated effectiveness in reducing the stigma of HIV and AIDS. Uys et al. (2009) explored HIV stigma interventions in healthcare settings and found that stigma can be reduced by increasing contact with the affected group, sharing information on HIV stigma and improving coping through empowerment. Further systematic reviews of interventions to reduce HIV-related stigma conducted by Skevington, Sovetkina, and Gillison (2013) and Stangl, Lloyd, Holland, and Baral (2013) found that most interventions were effective at reducing the aspects of stigma, but most did not look at the impact or outcomes.