A Comprehensive HIV Stigma-reduction and Wellness-enhancement Community Intervention: A Case Study



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We describe the implementation of a comprehensive HIV stigma-reduction and wellness-enhancement community intervention that focused on people living with HIV (PLWH), as well as people living close to them (PLC) from six designated groups. A holistic multiple case study design was used in urban and rural settings in the North West Province, South Africa. Purposive voluntary sampling was used to recruit the PLWH group; snowball sampling was used for the PLCs. Data were analyzed by means of open coding and text document analysis. The comprehensive nature of the intervention ensured enhancement in relationships in all groups. The increase in knowledge about stigma, coping with it, and improved relationships led to PLWH feeling less stigmatized and more willing to disclose. PLCs became aware of their stigmatizing behaviors and were empowered to lead stigma reduction in their communities. Many community members were reached through these initiatives.

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Our study was developed as part of a larger, comprehensive HIV stigma-reduction and wellness-enhancement community intervention study and focused on describing the implementation of the intervention in an urban and a rural setting in the

North West Province, South Africa. We aimed to build upon existing HIV stigma-intervention research, as well as the work initiated by a group of researchers who executed a broad HIV-stigma study in the African context, working over a 5-year period (Holzemer et al., 2007; Uys et al., 2009).

For the purpose of this research, the definition of stigma as conceptualized by Alonzo and Reynolds (1995) and supported by Holzemer et al. (2007) was used. Stigma has been referred to as a "powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons" (Alonzo & Reynolds, 1995, p. 304). In the literature, various models describe HIV stigma (Alonzo & Reynolds, 1995; Herek, 1990; Parker & Aggleton, 2003). Most models have described stigma as a social construction that radically affects the lived experience of people

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living with HIV (PLWH) and their partners, families, and friends (Alonzo & Reynolds, 1995). Herek (1990) further emphasized social processes and suggested that the etiology, symptoms, and course of any stigmatized disease be viewed as a process that involves social interactions among physicians, epidemiologists, patients, and their families. Furthermore, Parker and Aggleton (2003) pointed out that stigmatization and discrimination must be conceptualized as social processes that can only be understood in relation to broader notions of power and domination.

However, few of these models focus specifically on the unique social processes involved in stigma within the African context (Holzemer & Uys, 2004). The conceptual model of HIV stigma from five African countries was designed to ensure a better understanding of HIV stigma in Africa (Holzemer et al., 2007) and was used as the theoretical framework for our study. According to the model, stigma is a complicated process that arises within a context of the environment, health care system, and different agents. The stigma process itself comprises triggers of stigma, stigmatizing behaviors, types of stigma, and outcomes of stigma. The stigma process can be triggered by a variety of factors, of which HIV disclosure is an example. The types of stigma identified in the conceptual model include received stigma, internal stigma, and associated stigma. Outcomes of stigma are mainly negative in nature and form the last aspect discussed in the model.

The same group of researchers has also developed a health setting-based HIV stigma-reduction intervention focusing on PLWH and nurses (Uys et al., 2009). They found that the intervention led to mutual support between nurses and PLWH and created momentum in the settings involved for continued activity. PLWH reported fewer stigma experiences and an increase in self-esteem. Nurses did not report a reduction in stigma or increased self-esteem, but were more willing to get tested for HIV. Our study extended this work into a comprehensive HIV stigma-reduction and wellness-enhancement intervention in the community focusing on PLWH and people living close (PLC) to them in one urban and one rural setting.

A considerable amount of research has been done on stigma and related issues in different health fields, and some programs have implemented stigma-reduction interventions (Scambler & Paoli, 2008). Yet the effectiveness and impact of stigma-reduction interventions are rarely evaluated (Brown, Macintyre, & Trujillo, 2003). More HIV stigma-reduction interventions seem to focus on segmented areas of HIV stigma, such as skills building, counseling, contact with affected groups, and awareness campaigns (Brown et al., 2003). Sengupta, Banks, Jonas, Miles, and Smith (2011) reviewed the literature to evaluate the effectiveness of HIV-related interventions to reduce stigma. Data were extracted from 19 studies: 14 of the studies demonstrated effectiveness in reducing HIV stigma. However, based on research quality and the extent to which the intervention focused on reducing HIV stigma, only 2 of the 14 studies were considered to be good studies (Sengupta et al., 2011). From their results, it becomes clear that more comprehensive HIV-related interventions that focus on reducing HIV stigma in the African context are needed. One of the aims of our study was to describe the implementation of a comprehensive HIV stigma-reduction and wellnessenhancement community intervention to reduce HIV stigma by targeting PLWH and PLC.

Some interventions have been target specific, such as those focused on partners (Manyedi, Greeff, & Koen, 2010), children (Benotsch et al., 2008), family members (Mohanan & Kamath, 2009), and friends. The latter category is limited and does not specifically refer to friends, but does include them (Nyblade, Stangl, Weiss, & Ashburn, 2009). Some stigma-reduction interventions have focused on spiritual leaders and community members (Blignault, Woodland, Ponzio, Ristevski, & Kirov, 2009), but none included PLWH and PLC together in a comprehensive manner within a community context.

Even as these interventions exist, stigma still negatively impacts various aspects of the lives of PLWH. PLWH are affected negatively in areas such as disclosure, health care-seeking behaviors, antiretroviral therapy adherence, emotional wellness, and life satisfaction (Charles et al., 2012; Simbayi et al., 2007). Stigma also impacts individuals, groups, and communities to which PLWH are related (Greeff & Phetlhu, 2007). PLC play a major role in the stigma process because they are most often the parties involved in stigmatizing acts (Greeff et al., 2008; Holzemer et al., 2007). PLC are, however, often

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