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# Chapter

# Implications of Social Stigma on the Health Outcomes of Marginalised Groups

Jacqueline Carol Matthews-Mthembu and Gadija Khan

#### **Abstract**

Research Focus: Stigma is a longstanding issue for South Africa as it is influenced by a history of typification. Social marginalisation is influenced by a myriad of socially structured norms and those who experience stigma, are often faced with social devaluation within their society. In addition, experiences of discrimination may lead to internalised stigma that may lower the self-esteem and agency as well as negatively affect the well-being of many. *Methods:* This chapter uses current literature to propose that stigma, remain a public health concern. *Recommendations:* The findings suggest recommendations that are likely to enhance programme and policy interventions aimed to decrease stigma. Overview Stigma has been a longstanding issue for South Africa as it is influenced by a history of typification. Social marginalisation is influenced by a myriad of socially structured norms and those who experience stigma, are often faced with social devaluation within their society. This policy brief proposes that stigma, and in particular its association with certain marginalised groups, remain a public health concern. It further discusses possible recommendations that are likely to enhance both programme and policy interventions aimed to decrease stigma or at the least, make individuals aware of their complicity in reproducing and maintaining social stigmatisation.

**Keywords:** social stigma, marginalisation, internalised stigma, mental health, sexual orientation and gender identity, HIV

#### 1. Introduction

The sociologist Erving Goffman [1], provided a widely used definition of stigma which asserts that stigma is a means through which an individual's image is tainted because of a certain characteristic or identity. More recent, definitions suggests that stigma is a concept that is socially constructed and situational; it is shaped by the culture and history of a society and may not transcend time and space [1, 2]. "Rather, the stigmas that prevail about a certain group are located in essentialist stereotypes that have been patterned over time" [3]. Stigmatisation therefore gives root to generalised stereotypes (or ideas) about a person or group which in turn may lead to blatant discriminatory and prejudiced attitudes toward that person or group [4]. There are

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different types of stigma such as public (externalised or experienced stigma) as well as self-stigma i.e. internalised stigma [5].

South Africa's Apartheid history is entrenched in essentialized ideas about its people, with racism at its core. So much so, that it seems like typifying each other in terms of race, gender and sexuality is a normative measure of the 'worth' of an individual. These ideas are socially constructed and ingrained in the fabric of society and has become the yardstick in health-related situations, including attitudes toward people living with HIV and those with mental disorders. As such, social stigma is shown to have a devastating effect on society [4]. Nevertheless, our country, with its progressive Constitution, has made immeasurable strides in the attempt to curb stigma, but much is still to be done to improve the level of tolerance toward those we "other".

Stigma is a major social determinant of health, it is a cross-sectoral phenomenon, which penetrates at various levels of the health care system including interpersonal, organisational and structural levels [6, 7]. Literature documents a variety of social, physical and physiological consequences of stigma such as isolation and rejection, blatant discrimination and ridicule and violence [3, 5, 8, 9]. Stigma has also been found to have direct and indirect effects on health seeking behaviours and health outcomes. As such, there has been calls for increased attention and urgency toward reducing stigma against marginalised groups, considering its implications on health and wellbeing [6, 10, 11]. This brief broadly focus on the public health implications of stigma for three marginalised groups namely: people with mental disorders, people whose sexual orientation and gender identity (SOGI) is different from their assigned sex at birth and people living with HIV (PLHIV).

#### 2. Mental health disorders

There is sufficient evidence to demonstrate the health system defects in terms of mental health users, stigma and negative traumatic experiences (ill-treatment) at health facilities or by health care providers [12]. The health policy framework integrates chronic conditions including mental health care into primary health care (PHC), which in itself, serves as a way to destigmatize people with mental disorders. However, although the PHC 101 guideline, train health care providers on the diagnoses and treatment of people with mental conditions, it fails to address stigma and discrimination attached to these conditions. This shows implications for access and utilisation of mental health services (e.g. delayed health seeking and non-adherence) as well as the quality of life and well-being of those diagnosed with mental disorders [5, 6].

In regard to interventions to reduce mental disorder-related stigma within society, evidence suggest that family focused interventions, specifically, that of psycho-education on the causes, symptoms and how to care for someone with a mental disorder, is imperative. This is particularly important given the shift toward deinstitutionalisation, which renders the involvement of family members and reintegration into society crucial steps toward improving the health outcomes of people with mental disorders [5].

# 3. Sexual orientation and gender identities (SOGI)

Sexual orientation and gender identities or SOGI-related stigma is highly prevalent in South Africa and is often grounds upon which LGBTIQ+ people experience various degrees of abuse at the hand of those who hold heteronormative ideals. In the same

vein, although progressive legislation legally protect the rights of LGBTIQ+ people to health services, it has also been restricted by heteronormative gatekeepers at local health facility level [11]. Furthermore, there is evidence to suggest that the public health care system is non-responsive to the diverse health needs of LGBTIQ+ people [9, 11]. The LGBTIQ+ population is often grouped together, yet they are very diverse groups. For example, the National Strategic Plan for HIV, TB and STIs (2007–2011) acknowledges that stigma reduction for the LGBTIQ+ population make them less vulnerable to HIV while the 2017–2022 plan encourages the scaling up of programmes geared toward zero stigma. However, greater programmatic and legislative commitment is focused on those who identify as gay and men who have sex with men (MSM) [9, 11, 13]. Reportedly, the development of policy that reflect the diversity within LGBTIQ+ and the necessary guidelines needed to offer specialised health care to sub-populations, is still underway. In the interim, there are important lessons to be learned from private healthcare and NGOs/civils society organisations where the majority of LGBTIQ+ users prefer to access services as opposed to public health facilities. The advocacy and activism emanating from LGBTIQ+ civil society organisations emphasises a rights based approach to (health) care to ensure equity and access to appropriate health services – this should be at the core or health provider training country-wide.

#### 4. HIV

There have been breakthroughs in HIV prevention, treatment programme implementation and human rights realisation, which makes "an AIDS free generation" possible. However, the uptake, adaptation, and successful use of these innovations are hindered by ever-persistent HIV-related stigma [14]. To date, only two studies surveyed stigma experienced by PLHIV. Using the Stigma Index, 799 PLHIV were surveyed in the O. R. Tambo district of the Eastern Cape, in 2012. This was followed by the 2014 survey of over 10,000 PLHIV, across 18 districts (2 per province) in South Africa. Both surveys showed continued significant levels of HIV-related externalised (where stigma or unfair treatment is experienced) and internalised stigma (where stigma, discrimination or negative treatment by others is anticipated or expected) reported by PLHIV [15, 16]. The 2017 national population-based household HIV survey showed mainly positive attitudes toward PLHIV [17], which may be reflective of the improved HIV knowledge in the same survey and even the possible awareness of political correctness around reporting stigma. However, HIV-related stigma still persist and those who experience internalised stigma remain silenced due to fear of stigma. In an effort to mitigate stigma, treatment initiation and disclosure is delayed which nullifies positive prevention efforts.

# 5. Intersectionality of stigma

Stigma is often experienced on a continuum where race, HIV status, mental health and SOGI intersects [6, 7]. Experiences of stigma, whether real or imagined may influence an individual's health seeking behaviour, which may result in a diminished quality of life. Thus, while we progress toward effective treatment and management of HIV, a greater understanding of mental illness and a more inclusive society in terms of SOGI, social and structural dynamics and determinants of health including stigma are just as important when aiming to improve health outcomes [6].

The multi-layered nature of stigma makes the design and implementation of stigma-reduction interventions more challenging. Addressing stigma on multiple levels is complex and may require greater resources, and be more burdensome to implement successfully amongst all target groups [7]. The greatest impacts in addressing stigma and discrimination have been observed when national responses employ a range of approaches that are monitored, evaluated and re-designed where necessary [6, 14].

#### 6. Recommendations

In reflecting on the current influence of social stigma on the health of South Africans, the country has institutionalised policies for the reduction of stigma for people with mental health conditions as well as those living with HIV, while we are still in the process of developing progressive policies and laws around health care that promotes all SOGI. In view of continued social stigma, we propose the following recommendations for policy development as well as programmatic implementation.

Policy development level:

- Promote the full inclusion and participation of stigmatised groups in the development of programmes, agenda setting and policy formation. This would empower groups and serve as a social accountability mechanism where public health and social systems are held accountable for the commitments made. We suggest that there is concerted efforts to build capacities of different actors in the health care system (providers, patients, civil society organisations) that would create an enabling environment for advocacy and for user groups. This would include legitimising the role patient and user representative groups in decision-making and policy development spaces.
- We recommend that the ministry of health prioritise LGBTIQ+ inclusive health policy development and implementation, and that these processes be spearheaded by the LGBTIQ+ community.

#### Implementation level:

- Civil society organisations have been at the forefront of advocacy and activism for many marginalised groups. They have been found to mobilise and empower communities and hold government accountable for the infringements of users' rights. We therefore, recommend that civil society organisations be prioritised as implementing partners, receiving support from the ministry to provide appropriate service that marginalised groups find acceptable and accessible.
- The need to improve health provider characteristics (attitudes, beliefs, skills and competencies) to reduce stigma at point of care and facility level. We suggest behavioural and psycho-educational health provider training that goes beyond diagnosis and treatment, to address issues of stigma, fears and attitudes of providers in regard to stigmatised populations. Health professional students should receive more substantive sensitization training during their undergraduate programmes. Continuous in-service training are imperative as well as monitoring the efficacy of the trainings overtime, to determine whether it improves the experiences of users at facilities, as well as the attitudes and culture of facilities.

- Develop an institutional culture of zero tolerance for stigmatisation where providers hold each other accountable and where the statements made in public against stigma must be reflected in action and not be refuted by qualifications and contradictory statements.
- There needs to be greater efforts to obtain feedback about the perceptions, needs and preferences of the health care system for marginalised groups, to create more equitable access to services and improve the inclusivity of services. Within facilities, it is imperative to provide enabling environments for users from marginalised groups to provide feedback regarding their expectations, views and experiences (experiences of care and satisfaction of services) of the health care system without being victimised. More importantly, such feedback should be used to make health care services less stigmatising and more responsive.

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