Violet Naanyu

SOCIAL CONTEXT AND MENTAL ILLNESS STIGMA IN SOUTH AFRICA

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To my beloved daughters,
my true friend Agnes,
and my gracious and loving parents.

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CHAPTER 1

INTRODUCTION: STIGMA AND ASSOCIATED BELIEFS IN CONTEXT

Although recent medical advances have increased our understanding of mental illness, many people living with mental illness experience stigma in the form of rejection. There is a wide range of literature on stigmatization of people living with mental illness. However, most of these studies, originate from the West. Limited studies have attempted to address this topic in Africa. This dissertation uses data from the Stigma in Global Context- Mental Health Study (SGC-MHS) to explore public perception regarding labels and causes of mental illness and its associated social distance in South Africa.

What is Stigma?

Stigma research stems from the scholarly work of Goffman (1963) and Allport (1958) among others. Greeks originated the word 'stigma' to refer to bodily signs designed to expose something unusual and bad about the moral status of an individual, such as a slave or a criminal (Goffman, 1963, p. 1). In ancient Greece, citizens made marks on their slaves using pointed instruments in order to reveal ownership, and to signify that such individuals were unfit for citizenship. The ancient Greek word for prick is 'stig,' and the resulting mark is a 'stigma.' Nowadays, stigma is held to be an invisible mark that signifies social disapproval and rejection (Dovidio, Major, & Crocker, 2000; Goffman, 1963). Stigma therefore is an attribute that is deeply discrediting (Goffman, 1963, p. 11), and the stigmatized are assumed to 'possess undesired differentness' (Goffman, 1963, p. 5). Noteworthy, the term stigma conceals a double perspective: *discredited* implies a stigma is known and evident to others, and *discreditable* means a stigma is unknown and not perceivable to others (Goffman, 1963, p. 4).

Although Goffman's (1963) use of the term stigma refers to a deeply discrediting element, he also acknowledges that it is a *language of relationships* because an attribute that stigmatizes one possessor may not be discreditable to another. Undeniably, recent stigma studies suggest that stigma is a multifarious social process that is linked to social mechanisms of exclusion and dominance (Link & Phelan, 2001; Parker & Aggleton, 2003; Stein, 2003).

Moreover, its pervasiveness and severity varies with whether one is a member of a high or low status group (Lee, Lee, Chiu, & Kleinman, 2005; Major & Eccleston, 2005).

The concept of stigma has become elastic and is used to indicate a vast range of conditions (Prior, Wood, Lewis, & Pill, 2003; Weiss, Ramakrishna, & Somma, 2006). While some attributes are stigmatized universally, stigmatization usually exists in the eye of the beholder rather than in a given odd mark (Major & Eccleston, 2005, p. 65). Researchers have attempted to explore the 'social process of stigma' by distinguishing between stigma, prejudice, and discrimination. Corrigan and colleagues discuss three components to public stigma including stereotypes, prejudice, and discrimination (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003). *Stereotypes* represent collectively agreed upon notions. *Prejudice* is a cognitive and affective response and usually involves endorsement of negative stereotypes. *Discrimination* is a behavioral response based on prejudice towards a minority group (Crocker, Major, & Steele, 1998). It is evident that a more concrete understanding of the difference between prejudice and discrimination, and what we should do to eliminate stigma is needed (Parker & Aggleton, 2003; Weiss et al., 2006).

Some scholars differentiate between diverse types of stigma. Goffman (1963) distinguishes between *felt* and *enacted stigma.* Felt stigma is *perception* of a potentially stigmatizing condition at the individual level, while enacted stigma is directly experienced through various forms of *discrimination*. Usually, as members of social groups whose expectations are known to all members, the stigmatized experience felt stigma as soon as they become aware of their discreditable qualities. Once discredited by others, they become vulnerable to prejudice and discrimination (i.e enacted stigma). Other authors differentiate between instrumental and symbolic forms of stigma. *Instrumental stigma* is intended discrimination based on fear of contracting disease, and resource concerns as members of society make judgments regarding a patients' ability to contribute to the general public (Herek, 1999). On the other hand, *symbolic stigma* includes moral judgments that may lead to prejudice and discrimination. While instrumental stigma is based on risk and resource concerns (e.g. the ill seen as contaminants and draining medical/economic resources), symbolic stigma employs 'othering' and distancing of people, e.g. through blame/causal judgments and negative attitudes towards certain illness labels (Herek, 1999).

Courtesy stigma also known as *associative stigma* is another type of stigma that has received scholarly attention (Goffman, 1963; Gullekson, 1992; Reece, Tanner A., Karpiak, & Coffey, 2007; Zola, 1991). It usually affects those who are close to the stigmatized e.g. care giving teams like nurses and doctors, advocates and relatives of the stigmatized (Goffman, 1963, p. 30). Researchers have examined courtesy stigma associated with the mentally retarded (Birenbaum, 1992), schizophrenia (Angermeyer, Schulze, & Dietrich, 2004), physical disabilities (Goldstein & Johnson, 1997), and HIV/AIDS (Crawford, 1996; Poindexter, 2005; Reece et al., 2007).

This dissertation focuses on disease stigma associated with mental disorders. *Disease stigma* is the ideology that one is different from 'normal' society, more than simply through infection with a disease agent. Usually, resulting categorization depends on the biological nature of the ailment as well as societal responses (Deacon, Stephney, & Prosalendis, 2005). When symbolic stigma and related moralization is added to biological conditions (e.g. association of mental illness to irresponsible behavior), we observe differences in stigma attached to different ailments.

Functions of Stigma

Stigmatization serves society in several ways (Goffman, 1963). First, it has the general social function of enlisting support from society. Secondly, stigmatization highlights bad moral records, thus providing a means of social control. Thirdly, in certain cases (e.g. race, religion, or ethnicity), stigmatization is a means of removing minorities from various avenues of competition. Lastly, stigma associated with bodily disfigurement contributes to a needed narrowing of courtship decisions (Goffman, 1963, p. 135). Some argue that rejection and exclusion are inevitable because excluding stigmatized individuals enhances personal or group self-esteem; alleviates discomfort and anxiety on the part of the 'normals'; and reminds the 'normals' of their own vulnerability and mortality (Major & Eccleston, 2005, p. 67).

Moreover, recent work shows that there are occasions when stigmatization may effectively reduce prevalence of 'undesirable' behaviors (Bayer, 2008; Link & Phelan, 1995; Phelan, Link, & Dovidio, 2008). Bayer (2008) notes that 'there may be circumstances when public health efforts that unavoidably or even intentionally stigmatize are morally defensible' (Bayer, 2008, p. 471). Conversely, others argue that stigma is *always* bad and stigmatizing

harmful health behavior is a losing public health practice (Burris, 2008). As Burris concludes, 'stigma is a barbaric form of social control that relies upon primitive and destructive emotions. And chances are it won't work anyway' (Burris, 2008, p. 475).

Effects of Stigma

The degree to which disease stigma will affect individuals and their daily interactions depends on eight factors; visibility, pervasiveness, clarity, centrality, relevance, salience, responsibility and removability (Elliot, Herbert, Altman, & Scott, 1982; Goffman, 1963). Some stigmas can be removed or their effect can be minimized, e.g. a successful cochlear implant minimizes stigma associated with deafness. However, some offending attributes may be permanent or difficult to remove. When a stigmatized person finds limited options to ward off a negative label, capitulation takes place as she/he realizes that her/his discredited self engulfs all other identities (Elliot et al., 1982).

Although debates on conceptualization, functions, and consequences of stigma remain unresolved, it is clear stigmatization worsens lives of people experiencing illness (Burris, 2008; Link & Cullen, 1986; Link & Phelan, 2001; Mechanic, McAlpine, Rosenfield, & Davis, 1994; Phelan et al., 2008; Yang & Kleinman, 2008). While all members of society have to find ways to interact with the stigmatized, the stigmatized group requires more effort in mixed social encounters; they have to be self-conscious and calculating about the impression they make when in the company of 'normals' (Goffman, 1963, p. 14). Stigma deprives people of their dignity, curtails social interaction, and interferes with participation in society (Dovidio et al., 2000; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Martin, Pescosolido, & Tuch, 2000; Stuart, Arboleda-Flórez, & Dabfp, 2001; Yang & Kleinman, 2008).

Disease stigma, such as HIV-related prejudice and discrimination, not only destroys social relations, impairs disclosure of illness and appropriate care seeking, it is also linked to harmful and unnecessary social policies (Crawford, 1996; Herek & Capitanio, 1998; Herek, Capitanio, & Widaman, 2002). Stigma contributes to under-funding of services and research. Mental health budgets are easily cut because they rarely result in public protests and when additional funding is available, it is allocated to services or research addressing groups that appeal to the public (Sartorius, 2004).

Stigmatizing attitudes can hamper healing and promote disability because they are associated with unemployment/low earnings, lack of housing, diminished self-esteem, weak social support, and new disorders or repeat episodes of existing problems (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Link, Mirotznik, & Cullen, 1991; Markowitz, 1998; Prince & Prince, 2002; Stip, Caron, & Lane, 2001; Wahl, 1999). In addition, 'normals' have low expectations for those with mental illnesses and easily accept low quality of life for them, their families, their communities, and their health care providers (Jones, 2001; Sartorius & Schulze, 2005). For instance, former psychiatric patients in Hong Kong live in poor housing and have a deprived social life (Mak & Gow, 1991). Similarly, former patients living in Singapore report stigma affecting their self-esteem, relationships, and job prospects (Lai, Hong, & Chee, 2001).

Generally, the resulting inferior social status of stigma targets implies that they have less power than the 'normals' and reduced access to shared resources (Herek, 2008; Link & Phelan, 2001). Even though others impose stigma, prejudice and presence of a biological disorder also have negative effects on self-concepts of the stigmatized; they feel devalued, and abnormal (Fife & Wright, 2000). The 'self-isolate' can also become suspicious, depressed, hostile, anxious, and bewildered'(Goffman, 1963, p. 13). Similarly, their family members face fear, loss, lowered family esteem, shame, secrecy, distrust, anger, and helplessness (Gullekson, 1992).

Visibly, when disease stigma sets in, it lingers endlessly and impairs social life. Stigma adds suffering to the primary illness. Worse still, it may be more devastating, life-limiting and long-lasting than the first problem (Schulze & Angermeyer, 2003). Failure to address disease stigma therefore enhances suffering among the ill and their associates. More research designed to examine problems encountered by the stigmatized, their associates, and the 'normals' would move disease stigma agenda forward.

Cross National View of Stigma and the Important Role of Social Context

Stigma is contextual for it varies dramatically across time and place (Crocker et al., 1998; Phelan et al., 2008). The meaning of a condition in a particular context may not apply elsewhere, and the status of the 'patient' vs. 'normals' is determined by culture (Devlieger, 1995, p. 96). Stigma is therefore best understood within specific contexts because it is shaped by cultural norms and values, and by history (Dovidio et al., 2000; Fabrega, 1991; Goffman, 1963). For instance, explanatory models and meanings attached to chronic illnesses are grounded in specific

cultural understandings of health and illness (Lefley, 1990). Consequently, any fruitful future research requires a comparative approach. While locating stigma within local and the larger global context, such studies ought to reflect on social, cultural, political and economic determinants of stigma (Parker & Aggleton, 2003).

Since stigmatization is universal and it evidently worsens lives globally, approaches that enable us build a global understanding of stigma are essential. Useful global stigma research requires collection of data with nationally representative samples of adults in each country. Only then can we get national and international descriptive profiles of mental illness knowledge; familiarity with mental illness; and beliefs and stigmatizing responses toward mental disorders and persons with mental illness. For example, the association between prejudice and discrimination remains an ongoing debate with scholars urgently calling for cross-disciplinary, cross-cultural, multi-conceptual, and multi-level approaches (Pescosolido, Martin, Lang, & Olafsdottir, 2008; Phelan et al., 2008; Stuber, Meyer, & Link, 2008). Such efforts that look at both the individual and the collective will ultimately expand our understanding of stigma, and consequently scientifically inform interventions to prevent stigma and its negative consequences.

Since past studies have documented differences in outcomes for persons with mental illness globally, investigations of stigma across cultural contexts are overdue (Dovidio et al., 2000; Hopper, Harrison, & Wandeling, 2007). One global effort towards a better understanding of mental health stigma is the World Psychiatric Association programme (Sartorius & Schulze, 2005). In their approach, they emphasized the need for targets of stigma, their families, and communities, the media, and advocacy groups to create more awareness and tolerant responses (Sartorius & Schulze, 2005). The Stigma in Global Context Mental Health Study (SGC-MHS) is an ongoing project that seeks to explore how mental illness is understood and stigmatized across countries. Given that the SGC-MHS allows for comparative analysis across countries, and explores the role of culture in mental illness outcome, its importance cannot be overstated.

Future research must identify the collective properties of social, cultural, economic, and physical environments that influence health and disease outcomes (Dovidio et al., 2000; Hopper et al., 2007). To advance our understanding of stigma and the role of social context, this study explores mental illness stigma in the South African Republic. It also examines applicability of the Etiology and Effects of Stigma (EES) Model to mental illness in the South African context. It is limited to mental illness labels, causal attributions, and social distance. The study defines

labels as the indicative category that respondents assign a given problem. Causal attributions reflect individuals' beliefs about etiology of mental illness, and stigmatizing responses comprise prejudice and isolating behavioral tendencies.

Thus, this study expands our knowledge of disease stigma in general; summarizing what is known about Africa, and examining both stigma levels and the Etiology and Effects of Stigma (EES) Model to mental illness in South Africa. This then can begin to shed light on the specificity or universality of the prejudice and discrimination attached to mental illness. In addition, it provides evidence on whether there are similar costs of stigma in terms of public response to different mental health problems by people of different social location. Additionally, the study's examination of factors predicting social distance has potential to inform anti-stigma work in South Africa.

In the following chapter, African public understandings of illness, particularly mental illness is discussed. Special focus is laid on causal attributes and stigma associated with mental illness on the African continent. Knowledge about African endorsement of biogenetic or non-biogenetic causes for mental illness lays a foundation for a better understanding of causal beliefs and stigma in South Africa. The chapter concludes with a discussion on stigma associated with mental disorders in African cultures, excluding South Africa.[1]

[1] The South African scenario is presented in Chapter 5 in anticipation of study hypotheses.