The Relationship Between Internalized Stigma and Functional Disability in Schizophrenia: a Cross-Cultural Comparison of India and the United States

by

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# Table of Contents

Acknowledgements........................................................................................................4

1: Abstract.........................................................................................................................5

2: Introduction..................................................................................................................6
  2.1: Schizophrenia........................................................................................................6
  2.2: Prevalence.............................................................................................................7
  2.3: Diagnosis...............................................................................................................7
  2.4: Symptoms and Clinical Features.........................................................................8
  2.5: Etiology................................................................................................................10
    2.5.1: Genetics.........................................................................................................11
    2.5.2: Maternal Immune Activation and Immune System Compromise......................12
  2.6: Neuropathology....................................................................................................13
    2.6.1: Structural Brain Pathologies.........................................................................13
    2.6.2: Neurochemical Dysfunction.........................................................................14
      2.6.2.1: Dopamine...............................................................................................15
      2.6.2.2: Glutamate..............................................................................................15
  2.7: Stigma....................................................................................................................16
    2.7.1: The Mechanism of Stigma............................................................................17
    2.7.2: Stigma and Mental Illness............................................................................18
    2.7.3: The International Pilot Study of Schizophrenia and Differences in Outcome of Schizophrenia Across Cultures........................................................................21
    2.7.4: Cross-Cultural Comparisons of Stigma and the Implications for Functional Outcome..........................................................................................23
    2.7.5: Stigma in India.............................................................................................25
    2.7.6: Stigma in the United States..........................................................................26
  2.8: Hypotheses of the Pilot Study................................................................................28

3: Methods......................................................................................................................29
  3.1: Design..................................................................................................................29
  3.2: Participants...........................................................................................................30
  3.3: Measures..............................................................................................................31
    3.3.1: The Internalized Stigma of Mental Illness Inventory.....................................31
3.3.2: The World Health Organization Disability Assessment Schedule………………………………………………………32
3.3.3: The Self-Efficacy Scale……………………………………………………33
3.4: Data Analysis and Statistics……………………………………………………33

4: Results…………………………………………………………………………………..34
  4.1: Stigma………………………………………………………………………………..34
  4.2: Functional Disability………………………………………………………………35
  4.3: Stigma and Functional Disability………………………………………………36
  4.4: Self-Efficacy, Stigma, and Functional Disability……………………………38

5: Discussion………………………………………………………………………………..40
  5.1: Limitations…………………………………………………………………………..43
  5.2: Future Directions……………………………………………………………………45

6: References………………………………………………………………………………..49

7: Appendix…………………………………………………………………………………57
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Abstract

Stigma against schizophrenia is one of the largest barriers to treatment seeking and subsequent recovery. Stigmatization is the discrimination and loss of status triggered by negative stereotypes about the mentally ill, which impedes recovery by degrading individuals’ social status, social network, and self-esteem. International studies of schizophrenia have consistently found that patients with schizophrenia in developing countries have better course and outcome than those in developed countries, a disparity which could at least be partially explained by differences in the levels of stigmatization of mental illness across cultures. This pilot study compared the levels of stigma between an American and an Indian sample of patients with psychotic disorders using standardized, self-report measures of internalized stigma and functional disability. Participants in the United States sample also received measures of self-efficacy. The results revealed that individuals with schizophrenia in the United States had more internalized stigma than their Indian counterparts. The Indian sample was more functionally impaired than the American sample, and only the American sample demonstrated a significant association between the degree of internalized stigma and functional disability. This latter finding suggests that the effects of stigma in the United States might be mediated by beliefs around the ability to successfully complete key activities of daily living. Our results also revealed that self-efficacy mediates the relationship between stigma and disability in the American sample. These findings help to elucidate the complex nature of stigma and its relationship to other psychological and functional features of schizophrenia.
2. Introduction

2.1: Schizophrenia

Schizophrenia is a debilitating mental illness that is found worldwide (Sartorius, Gulbinat, Harrison, Laska, & Siegel, 1996). Emil Kraepelin (1856-1926) differentiated this disease from other forms of psychosis and, centuries later, it still remains an enigmatic and costly psychiatric illness that exacts its toll in the form of both societal expenditure and personal suffering (van Os & Kapur, 2009). Kraepelin referred to this psychotic disorder as “dementia praecox”, meaning “dementia of the young”. This designation included hebephrenia, paranoia, and catatonia, which had all previously been assumed to be distinct psychiatric illnesses. The word schizophrenia was not used until the early twentieth century, when it was introduced by Swiss psychiatrist Eugen Bleuler in 1911 (Peralta & Cuesta, 2011). Two Greek words comprise this term: “schizo” meaning to split apart, and “phren” meaning the mind. Such tearing apart of the mind, what Bleuler viewed as a separation of the intellectual from the emotional, speaks to the turbulent emotional and mental state of the patient (Walker, Kestler, Bollini, & Hochman, 2004).

The disorder is characterized by delusions (fixed and irrational beliefs that are incongruous with everyday life), hallucinations (experiences that feel like real world perceptions, but are not triggered by external stimuli), other disordered thoughts, and cognitive and social deficits. Schizophrenia cripples many fundamental cognitive and emotional processes (Ross, Margolis, Reading, Pletnikov, & Coyle, 2006). In addition to internal deterioration, people with schizophrenia are also highly
stigmatized by others, largely due to prevailing negative stereotypes about individuals with this condition, which are created and modulated by sociocultural factors.

2.2: Prevalence

Schizophrenia affects approximately 20 million people worldwide (Hopper, 2007). In industrialized societies, such as Canada, parts of Europe, the United States, and Australia, the average prevalence is approximately 0.9% (Frangou, 2008). The World Health Organization ranked schizophrenia as the seventh largest cause of disability worldwide (Organization, 2001), although the manifestations and consequences of the disorder are experienced uniquely from person to person, and are also expressed somewhat differently according to economic, social, and cultural circumstances (Frangou, 2008). One of the many serious complications of the disorder is suicidal ideation and behavior, which accounts for 5% of the deaths related to schizophrenia (Palmer et al., 2005). In the United States alone, an estimated 3,600 individuals with schizophrenia commit suicide annually, which is over 20 times higher than the rate of suicidal behavior seen in the general population (Meltzer, 1999). The median age of onset of schizophrenia is around 23 years old in men, and 28 in women, and onset is rare before 16 and after 50 years of age (Lieberman, Stroup & Perkins, 2012). Schizophrenia is also slightly more common in men than in women, with an approximate incidence of 1.4:1 (Abel, Drake, & Goldstein, 2010).

2.3: Diagnosis
Schizophrenia presents with a very diverse range of symptoms that affect most domains of psychological function (Walker et al., 2004). The disease is unidentifiable through any medical diagnostic test at present (Ross et al., 2006), and instead is determined based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM) on a syndromal basis. Schizophrenia is diagnosed according to the presence of at least two pathologies out of five symptom domains: delusions, hallucinations, disorganized thinking, grossly disorganized or abnormal motor behavior, and negative symptomology, which is the absence of normal behaviors, such as effective social interaction and emotional expression (American Psychiatric Association, 2000). These symptoms have to be present for at least six months with one month of continuous symptomology for a diagnosis of schizophrenia. Additionally, there must be social and occupational dysfunction that accompanies the clinical symptoms (Walker et al., 2004).

Multiple subtypes of schizophrenia have been defined: paranoid schizophrenia, disorganized or hebephrenic schizophrenia, undifferentiated schizophrenia, residual schizophrenia, and catatonic schizophrenia (Lieberman et al., 2012). However, these subtypes were eliminated from the most recent edition of the DSM.

2.4 Symptoms and Clinical Features

Schizophrenia and related psychotic disorders are heterogeneous syndromes, all of which lack a single characteristic feature. Symptoms of schizophrenia are categorized as either positives or negatives, which vary in presence and intensity.
throughout the course of the illness (Freedman, 2003). The term *positive symptoms* refer to a group of symptoms whose presence is abnormal, including hallucinations, disorganized and disordered thought patterns, and delusions. Hallucinations are experiences that feel like real perceptions, but occur in the absence of external stimuli. Auditory hallucinations, such as hearing voices that are perceived as distinct from those the patient identifies as internal thought processes, are the most common in schizophrenia, but hallucinations can occur in any sensory modality, including visual, tactile, olfactory, and gustatory (American Psychiatric Association, 2000). They often are perceived as not being under voluntary control. Delusions are fixed, irrational beliefs that cannot be changed in response to contradictory evidence, and prevalent types include persecutory (believing that something or someone means to harm the individual), referential (ascribing meaning to the actions and statements of other people and objects when there is none, such as believing that the TV is specifically communicating with the individual), somatic (the belief that one’s body has been altered), religious (often misguided notions about one’s relation to religious entities, for example, believing oneself to be the reincarnation of Jesus Christ), and grandiose delusions (thoughts that stem from the belief that one is of extreme importance and fame, such as being a world leader or a celebrity; Lieberman et al., 2012). Delusions are further classified as bizarre if they are objectively implausible, are incomprehensible to peers of the same sociocultural group, or are not derived from typical life experiences (American Psychiatric Association, 2000).

*Negative symptoms*, in contrast, reflect the absence of behaviors and emotions that are classified as normal (Frangou, 2008). Negative symptoms include anhedonia
(decreased ability to experience pleasure, or diminishment in the expectation or recollection of pleasurable experiences), apathy, decreased motivation, decreased emotional expression and reaction (known as blunted affect), social withdrawal, and disorganization of thoughts and speech (Freedman, 2003). Although negative symptoms are less obvious clinically than positive symptoms, they can be less responsive to treatment and more closely tied to function, thus being more disabling (Ross et al., 2006).

Cognitive dysfunction is a third domain of impairment in schizophrenia, and includes impairments in working memory (a system that provides short term storage and processes information necessary for cognitive processes, such as learning, reasoning, and language comprehension), verbal fluency, attention, and aspects of executive functioning (a broad term that encompasses the cognitive processes required to achieve certain goals; Ross et al., 2006). Dysfunction in this realm has long been recognized as a major feature of schizophrenia, which leads to diminished functional capacity by impairing basic adaptive and social skills (Bowie & Harvey, 2005). Cognitive deficits remain largely stable throughout the course of the illness (Harvey et al., 2003), and are a strong predictor of occupational and social disabilities (Freedman, 2003).

2.5: Etiology

Like many psychiatric disorders, the exact causal factors for schizophrenia are currently unknown. Schizophrenia is a complicated and multifaceted psychiatric disorder, the etiology of which is thought to be a combination of various
susceptibility genes, stochastic, epigenetic, and environmental factors (Escudero & Johnstone, 2014). There are several proposed mechanisms that may contribute to the etiology of the disease.

2.5.1: Genetics

Recent advancements in genomic technology have supported genetics as one of the principal causes of this psychiatric disorder (Escudero & Johnstone, 2014). Through research using family, twin, and adoption studies (Kendler & Diehl, 1993), schizophrenia has been determined to have a heritability score of approximately 0.8 (Ross et al., 2006), indicating that inherited genetic variants play a substantial role in the etiology of the disease (Ripke et al., 2014).

Much of this genetic research has focused on monozygotic and dizygotic twin studies, as monozygotic twins share nearly 100% of their genetic information, while dizygotic twins share about half. Monozygotic twins have the highest concordance rate for schizophrenia, and if one twin has the psychiatric disorder, the other has a 25-50% chance of developing the illness as well. Additionally, studies of dizygotic twins have shown that about 10-15% of co-twins of patients of schizophrenia will become ill as well (Walker et al., 2004). However, these results are highly elevated relative to the 1% chance of developing the disorder in the general population.

A growing body of genetic epidemiological research, including over 30 genome-wide linkage and association studies, has begun to delineate the genetic architecture of schizophrenia. However, no specific genomic region has emerged that has been replicated across other studies and that exceeds genomic wide significance.
Major findings have suggested that schizophrenia is a dynamic polygenic disorder with a complex array of risk loci (Escudero & Johnstone, 2014). 1q, 5q, 6p, 8p, 13q, 15q, and 22q have emerged as susceptibility loci that in sum confer risk (Charney & Nestler, 2004). The genes associated with this psychiatric disorder likely exert pathogenic effects in multiple different domains, such as altering neuronal development, signal transduction, and neuronal plasticity (Ross et al., 2006).

2.5.2: Maternal Immune Activation and Immune System Compromise

Research in immunology, neuropsychiatry, and epidemiology has hypothesized infectious etiologic factors for many major mental illnesses, including schizophrenia (Yolken, Karlsson, Yee, Johnston-Wilson, & Torrey, 2000). A wealth of research has also demonstrated an association between events that occur during pregnancy and increased risk for schizophrenia in the child (Walker et al., 2004). These include stressful life events and infections, culminating in the release of stress hormones from the mother, such as cortisol, which can cause hyperthermia, hypoxia, or malnutrition (Verdoux, 2004). Schizophrenia is considered to be a neurodevelopmental disorder, and growing evidence suggests that developmental abnormalities in the central nervous system are due to the effects of maternal immune activation (MIA). Prenatal stress catalyzes the release of pro-inflammatory cytokines from the mother’s immune system that affect fetal development (Gilmore & Fredrik Jarskog, 1997) by causing neuroinflammation that can result in permanent structural changes in the developing brain that may contribute to subsequent pathologies (Garay
& McAllister, 2010). For instance, excessive release of cortisol can disturb the functioning of the hypothalamic-pituitary-adrenal axis, which can influence cognitive and behavioral patterns later on in life (Welberg & Seckl, 2001).

The effects of pro-inflammatory cytokines are also observed in the association between schizophrenia and influenza, rubella, cytomegalovirus, poliovirus, Herpes Simplex Virus-1 and -2, and Toxoplasma gondii (Brown & Susser, 2002). It has been theorized that these viruses exert their pathologic effect only indirectly, affecting the developing fetal brain by activating the mother’s immune system, with the cytokines released by the mother in response to the virus hypothesized to cause the damage (Patterson, 2010).

2.6: Neuropathology

2.6.1: Structural Brain Pathologies

Over 200 post-mortem and neuroimaging studies conducted in the past two decades have revealed structural brain pathologies in patients with schizophrenia. The findings that have been most consistently replicated are enlargement of the third and lateral ventricles, limbic system pathology (Cannon & Marco, 1994), medial temporal lobe (hippocampal formation, subiculum, and parahippocampal gyrus) volume reductions, and superior temporal gyrus volume reductions, which are most often seen in the left hemisphere (Ross et al., 2006). Other important findings include decreases in gray matter in the left parahippocampus, cingulate gyrus, fusiform, and orbital and cerebellar cortices (Pantelis, Yücel, Wood, McGorry, & Velakoulis, 2003). Additionally, relative to healthy controls, reductions in brain volume have also
been observed in the frontal lobe, especially in the orbitofrontal and prefrontal regions, which are involved in adapting to unexpected rewards or adversities, and higher order cognitive abilities, respectively (Ross et al., 2006). Some studies have suggested that these structural changes may happen slowly over time, prior to the onset of schizophrenia, but are likely catalyzed by events that occur during fetal brain development (Rapoport, Addington, Frangou, & Psych, 2005).

Partially due to these structural brain pathologies, patients often experience difficulties in processing sensory information, such as exhibiting impaired responses to their environment. Research has shown that the initial processing of visual stimuli is slower in these patients (F, H, B, & J, 1999). Furthermore, monitoring of brain activity during the presentation of visual or auditory stimuli to non-medicated patients demonstrates a marked reduction of activity in the prefrontal cortex, parietal lobe, and thalamus (Braus, Weber-Fahr, Tost, Ruf, & Henn, 2002) during processing of elementary sensory stimuli.

2.6.2: Neurochemical Dysfunction

Contemporary pharmacology used to control the symptoms of schizophrenia has been devised based off of research done on yet another etiological mechanism: dysfunctional neurotransmission. A number of different neurotransmitters have been implicated in schizophrenia, including dopamine, glutamate, and mechanisms that control neurotransmission, such as catechol-O-methyltransferase (Harrison & Weinberger, 2005).
2.6.2.1: Dopamine

The dopamine hypothesis of schizophrenia was derived from a proposed etiologic mechanism stating that schizophrenia is the result of excess dopaminergic activity in the brain (Escudero & Johnstone, 2014). Many different lines of research support this as a potential contributor to the etiology of the disease. Both post-mortem and functional MRI studies of the brains of patients with schizophrenia have demonstrated a greater number of type 2 dopaminergic receptors relative to healthy controls (Kestler, Walker, & Vega, 2001), especially in the striatum (Horga & Abi-Dargham, 2014).

Further support for the dopamine hypothesis is that drugs that increase dopamine levels, such as amphetamines, can temporarily induce psychotic symptoms in healthy individuals (Escudero & Johnstone, 2014). Conversely, dopamine receptor antagonists are the main therapeutic agents for the positive symptoms of schizophrenia, which act by blocking type 2 dopaminergic receptors (Ripke et al., 2014). These medications, while often effective, are not curative and can have detrimental side effects.

2.6.2.2: Glutamate

Glutamate dysfunction has been consistently observed in patients with schizophrenia. The etiological theory of glutamatergic hypofunction is based on the finding that antagonists of the glutamate protein channel N-methyl-D-aspartate receptors (NMDA-R) given to healthy individuals results in symptomology similar to the positive, negative, and cognitive symptoms of schizophrenia (Escudero &
Furthermore, evidence of diminished activity at glutamatergic receptors in a number of brain regions implicated in schizophrenia, including the prefrontal cortex, hippocampus, and thalamus, has been found in patients with the disorder (Goff & Coyle, 2001). Other biochemical experiments on the human post-mortem tissue of patients with schizophrenia have suggested that NMDA receptor function may be repressed due to enhanced neuregulin 1 signaling (Hahn et al., 2006), which is in agreement with decreased glutamatergic function being an etiologic mechanism of the disorder (Ross et al., 2006).

2.7: Stigma

Erving Goffman (1963) was one of the first scholars to define stigma (Wahl, 1999). In describing the condition of patients released from the federal psychiatric hospital in Washington D.C., he employed the term “stigmatization” to explain how one’s position in the social hierarchy becomes permanently altered due to his or her association with an institution that bestows unfavorable status (Goffman, 1961). Later, in Stigma: Notes on the Management of a Spoiled Identity (1963), Goffman provided what continues to be accepted as the basic definition of stigma: a mark that symbolizes the possession of a certain attribute or quality that renders a person tainted and not a whole, worthy individual. He moreover articulated his view that stigma can only be enacted through social interaction, and that it reaches critical mass once the stigmatized individual has been excluded from his or her society. Goffman also stipulated that stigma is a dynamic force, not a static entity (Goffman, 1963), and that it changes based upon larger sociocultural contexts (Pescosolido, 2013).
Consequently, similarly dynamic methodologies are necessary to combat the ever-changing manifestations of stigmatization of the mentally ill, because stigma is specific to relationships and contexts. It lives in social interactions and society at large, not within the person (Heatherton, 2000), who is more often than not made to feel at fault for inspiring such negative attitudes, which leads to the internalization of stigma.

2.7.1: The Mechanism of Stigma

Mental illness is a concealable stigmatized identity, meaning that it may not always be markedly apparent that an individual has a psychiatric disorder. Due to this fact, hiding aspects of one’s identity in order to be perceived as belonging to a more valued social group is a primary coping strategy for individuals with mental illness. Interestingly, research has demonstrated that hiding a concealable stigmatized identity actually decreases feelings of social inclusion and belonging, as compared to when the identity is revealed (Newheiser & Barreto, 2014).

In some cases, however, it is not possible to conceal having a psychiatric disorder, during, for instance, episodes of prominent positive symptoms of schizophrenia. This is much of what contributes to the stigma against schizophrenia, which is comprised of negative stereotypes, such as that individuals with schizophrenia are the people who can be seen talking to themselves on the street, or that they commit senseless acts of violence. While it is true that aggression and hostility can be present in schizophrenia, it is predominantly first episode, young unmedicated men who are violent, and such behavior can be effectively curbed with
proper treatment (Cesková, Prikrýl, Kasparek, & Kučerová, 2008). If seeking treatment for schizophrenia was not so stigmatized, perhaps help could be sought early on, thereby curtailing symptoms that are aligned with the negative conceptions about having this mental illness, and avoiding having to bear this label that is all consuming. Even when a patient is not symptomatic, association with a socially denigrated group overshadows other aspects of identity. All that they are is subsumed under this label, and, per the rules of stigmatization, that is who they are.

2.7.2: Stigma and Mental Illness

Stigma against the mentally ill is one of the most challenging barriers to recovery that patients face. While the expression and prevalence of prejudicial attitudes vary in different contexts, the stigma projected upon the mentally ill is a universal reality. Stigma effectively limits the full integration and participation of patients in society and deprives them of dignity. It robs someone diagnosed with a mental illness of autonomy, and relegates the individual in his or her entirety to a skewed stereotype. The actualization of stigma and its related consequences leads to labeling of the mentally ill, negative emotional reactions, loss of status, and discrimination (Link, Yang, Phelan, & Collins, 2004), which impedes recovery by degrading individuals’ social status, social network, and self-esteem. All of these factors contribute to poor outcomes, including isolation, delayed treatment seeking, prolonged course, and additional hospitalizations (J. B. Ritsher, Otilingam, & Grajales, 2003). Thus, social stigma can prevent an individual with mental illness from obtaining both housing and
work and, on a psychological level, prompt patients to adhere to self-fulfilling prophecies of failure (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007).

The literature has articulated three main components of stigma, whose axes of intersection construct the full experience of stigmatization. These include social stigma (Corrigan, Kerr et al., 2005), structural stigma (Herek, 2007), and internalized stigma (Watson, Corrigan, Larson, & Sells, 2007). All of these constituent factors are tightly intertwined with access to economic, political, and social power that makes one subject to identification as an outsider, enforced isolation, the imposition of stereotyping, discrimination and rejection (Link et al., 2004). While the interpersonal consequences of stigma are damaging to one’s quality of life, stigma can become even more disabling once it becomes internalized. Such self-stigma occurs when patients integrate structural and social stereotypes about the mentally ill into their consciousness and behavior (Lauber & Rossler, 2007). A prolific amount of research has demonstrated that patients commonly internalize stigma, and that this subsequently worsens their prognoses.

A meta-analysis by Livingston and Boyd (2010) found internalized stigma to be positively associated with psychiatric symptom severity and impairments in occupational functioning, and to be negatively associated with adherence to treatment regimes and social integration. Furthermore, in a majority of the studies considered, internalized stigma was significantly associated with self-efficacy, and it is possible that the confluence of these two factors contributes to a higher degree of functional disability, such as not being able to socialize effectively or hold down a job.
As such, stigma against individuals with psychiatric disorders has been a major subject of interest in psychological research. There are several predominant ways in which stigmatization is explored in a scientific manner. These include surveys of the general public to index their perceptions of mental illness, the use of vignettes in which participants rate descriptions of mentally ill people, analog behavioral studies that gauge how individuals interact with someone who they know has a psychiatric disorder, surveying community members about how they perceive the mentally ill, or interviewing the family members and caregivers of patients with mental illness. Notably absent from these popular methodologies is researching the perceptions of stigma from the individual diagnosed with a psychiatric disorder. This lack of first-hand reporting could in fact be a representation of the endemic stigma against mental illness, even amongst researchers and medical professionals (Wahl, 1999), and thus reinforces the need for further investigation on how people with psychiatric disorders experience stigmatization.

Increased comprehension of the various components of stigma could allow for the development of mechanisms through which to combat it; an integral goal because the stigma against mental illness is a verified component of psychiatric disorders that negatively affects ones’ quality of life (Sibitz, Unger, Woppmann, Zidek, & Amering, 2011). In addition to understanding how stigma manifests, a thorough understanding of what is consequently associated with it is likewise necessary (Park, Bennett, Couture, & Blanchard, 2013).
2.7.3: The International Pilot Study of Schizophrenia and Differences in Outcome of Schizophrenia Across Cultures

The International Pilot Study of Schizophrenia (IPSS), led by the World Health Organization (WHO) in 1972, was one of the first studies that demonstrated differences in the outcome and course of schizophrenia across different nations. This seminal project involved over 20 leading institutions in 9 countries across the world, and included 1,202 patients with schizophrenia at a baseline and two- and five-year follow up studies. The research considered factors such as the presence of psychiatric symptoms over the past month, functional disability, substance abuse, residential and treatment status, social functioning, and an immediate family member’s perception of factors that may influence the outcome of schizophrenia in his or her ill relative (Sartorius et al., 1996). The IPSS demonstrated that large-scale cross-cultural investigations of mental illnesses can be successfully carried out, and that transculturally applicable instruments for such research can be produced and verified (Hopper, 2007).

One of the most striking findings was that patients with schizophrenia in developing, low-income countries have a better course and overall outcome than patients living in developed, high-income countries. In addition to demonstrating more favorable results on the measures included in the study, half of the patients surveyed in developing countries had periods of complete illness remission, punctuated only by episodic relapses (Sartorius et al., 1996). Two regions that were included in this study were Agra, India, and Washington, D.C. Participants in Agra had the second best course and outcome for most of the factors considered in the
research. Conversely, those in Washington D.C. had poor overall outcomes (Hopper, 2007).

This contributed to the industrialization hypothesis of mental illness, which postulates that industrial economies and attendant lifestyles engender institutionalization, isolation, segregation, rejection, and poor support of those diagnosed with psychiatric disorders (Jadhav et al., 2007). In developed countries with high levels of industrialization, there is often greater value placed on personal autonomy, which effectively accentuates the social exclusion and functional disability of the mentally ill.

The International Study of Discrimination and Stigma Outcomes was another important project that investigated schizophrenia stigmatization on a global scale. A total of 732 individuals with schizophrenia participated in the study, which was carried out in 27 different countries. Using the Discrimination and Stigma Scale (DISC), researchers found that negative discrimination in making and maintaining relationships was experienced by 47% of the sample, 64% expressed anticipated discrimination with respect to applying for jobs, training, or education, and 29% had trouble finding as well as keeping jobs (Thornicroft et al., 2009). Difficulty or inability to perform these activities of daily living is known as disability, and within schizophrenia, this is predominantly expressed in an occupational and social context (Thirthalli & Kumar, 2012). A patient’s degree of functional disability necessitates higher health costs, because greater functional deficits and symptom severity often require more health services (Moreno-Küstner et al., 2011). For all factors considered in this cross-national study, including functional disability and stigma, there was
significant variation among patients in different countries: participants with schizophrenia in Brazil, France, and the United States expressed the most stigmatization, whereas those in Spain, Poland, and India reported the least (Thornicroft et al., 2009).

2.7.4: Cross-Cultural Comparisons of Stigma and the Implications for Functional Outcome

Stemming from the IPSS and other related studies, the hypothesis that there is a better prognosis for individuals diagnosed with schizophrenia in developing as opposed to developed countries has become a common axiom in international psychiatry. A developing country is classified as one with a low-income average, underdeveloped infrastructure, and characterized by a poor human development index in comparison to the global norm. Conversely, a developed country is delineated by a modern infrastructure, and steadily decreasing value placed upon sectors like natural resource extraction and agriculture as ways of life. These countries, sometimes referred to as “first-world” countries, have economic systems that are predicated on self-sustaining and continuous economic advancement. This sharply contrasts the “third-world” countries, in which the majority of the population tends to live below the poverty line, resulting in health, social, and economic problems due to the mass influx into urban centers from rural areas (Lauber, 2007) that causes overpopulation and limited access to critical resources.

Because long-term global studies have cumulatively indicated a better prognosis for patients living in developing, low income nations, industrialization is
hypothesized to increase stigma against the mentally ill (Littlewood, Jadhav, & Ryder, 2007). While this theory may seem counterintuitive on the basis of access to mental health care, reasons behind these findings rely more so on sociocultural factors as opposed to medical ones. Because high-income countries tend to have capitalist systems predicated on self-reliant economic growth (Lauber & Rossler, 2007), impressions of peers are largely based upon self-efficacy and occupational success. Therefore, the inability to work and participate in milieus deemed culturally requisite is especially detrimental to one’s social hierarchical standing.

Perhaps greater stigmatization in developed countries could be partially attributed to the fact that, on average, those living in developing countries are not exposed to the same onslaught of media, which often portrays the mentally ill in a negative light that is conducive to the generation and propagation of stigmatizing attitudes. Moreover, research has indicated that such experiences of “indirect” stigma, which include negative comments and media depictions of the mentally ill, are rather common and damaging in developed economies (Wahl, 1999). In fact, the literature has stipulated that internalized stigma is often comprised of negative self-statements and themes that arise through exposure to specific stereotypes that predominate in one’s sociocultural demographic (Calabrese & Corrigan, 2005). Internalized stigma has been shown to be associated with decreased levels of self-esteem and self-efficacy (B. G. Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001), and impairments in vocational functioning (Jennifer Boyd Ritsher & Phelan, 2004), which is especially detrimental in developed economies.
2.7.5: Stigma in India

India is one of the most populous countries in the world, with current census estimates of the population exceeding 1.1 billion people, among which the prevalence of schizophrenia is approximately 3 out of every 1,000 individuals (Loganathan & Murthy, 2011). The cultural psychology of India, including factors such as one’s family, village, hierarchical social order, and religious practices, strongly influences how mental illnesses are expressed and received in a social context (Fabrega, 2009).

Results from the IPSS indicated that patients with schizophrenia in India had better course and outcome than those in the United States (Hopper, 2007). A number of potential hypotheses have been suggested why this may be the case, many of which are derived from the differences in their respective social structures. Traditional societies, such as those found in parts of India, are predominantly rural and emphasize the collective group over the individual person. Consequently, these communities tend to be characterized by higher rates of social stability compared to developed nations, resulting in slower implementation of widespread social change (Lauber, 2007). Additionally, in rural societies, individuals are not as inundated with prejudicial media representations of the mentally ill, which could be a way in which people living in low-income countries are more shielded from stigma than those in high-income countries.

Regardless of religious practices and beliefs, mental illness in India is commonly perceived as the consequence of fate, being possessed by evil spirits, poisoned food or drink, or of spells cast by enemies. More specifically, some Hindus believe that psychiatric disorders are caused by sins committed in a previous life, and
that the mental illness is a way of atoning for these past sins (Hopper, 2007). The influence of these and other cultural factors is widespread in India, and must be taken into account when determining how stigma is experienced by the mentally ill. In other words, psychiatric disorders, how they are both experienced and perceived, are modulated by the meanings and conventions of the socioeconomic, religious, and cultural norms about where one lives (Fabrega, 2009). In India, most previous studies have focused predominantly on assessing stigma when projected upon the family members or caretakers of a mentally ill individual, or on the perceptions of the population at large (James & Kutty, 2014). In order to truly understand how stigma manifests itself and the ways in which it affects those with schizophrenia, researchers need to hear directly from those who face stigmatization everyday (Wahl, 1999). Thus, a study of the multifaceted phenomenology of stigma in India that actually examines the mentally ill participants themselves provides a relevant example to add to the growing body of literature regarding cultural stigma around the globe.

2.7.6: Stigma in the United States

Stigma against the mentally ill is widespread in the United States (Office of the Surgeon General, 2001). The largest study of stigma in the North America was conducted in 1996 and found that participants typically conceptualized the mentally ill, especially those with schizophrenia, as being dangerous and not competent enough to handle their own affairs (B. A. Pescosolido, Monahan, Link, Stueve, & Kikuzawa, 1999), including societal and vocational duties.
Employment is an integral component of self-esteem and identity in Western societies, and the inability of individuals with schizophrenia to work engenders further social marginalization and stigmatization (Lieberman et al., 2012). The most consistent and reliable predictor of future employment is previous work history, which is problematic for individuals with schizophrenia. Since the age of onset for the disorder is so early, it is unlikely that patients will have had previous work experience that would enable them to get a job, or that could overshadow their mental illness in the eyes of employers. This poses a large problem for patients in developed economies, where securing a job is dependent on resumes, interviews, and working history. Being unemployed is damaging to health and self-esteem, and this status is a critical part of the social exclusion faced by individuals with psychiatric mental illness (Marwaha & Johnson, 2004).

There are often additional factors that account for individuals with schizophrenia not being employed. First of all, those in the throes of psychosis are often not nearly stable enough to hold down a job. Moreover, once diagnosed, the stigma against mental illness is a substantial barrier to gaining meaningful employment, and research indicates that internalized stigma is associated with self-efficacy (Corrigan et al., 2006), which is important in presenting oneself with the confidence and reliability needed to secure employment. In fact, individuals with schizophrenia commonly find that stigma is one of the most difficult barriers to overcome in finding and sustaining a job (Marwaha & Johnson, 2004).

Unemployment among persons with schizophrenia has damaging ramifications for the individual, his or her family, and society at large, including the
patient living in poverty and becoming vulnerable to increased victimization (Walsh, Moran, & Scott, 2003) and stigmatization. Research has demonstrated that internalized stigma heightens social avoidance (Yanos, Roe, Markus, & Lysaker, 2008), which could be linked to negative symptomology, thereby making the search for employment challenging. The role of negative expectations in schizophrenia involves appraisals of reduced likelihood of future pleasure or success (Beck et al., 2009). Such beliefs have been found to be positively associated with defeatist performance attitudes (Couture et al., 2001). While previous research has uncovered a relationship between internalized stigma and perceptions of self-efficacy and confidence (J. B. Ritsher et al., 2003), this line of questioning has not been extended into the domain of functional disability.

2.8: Hypotheses of the Pilot Study

This pilot study was conducted in two separate geographical and temporal phases—the first part in Gujarat, India, in 2012, and the second part in Middletown, Connecticut, in 2015. The aims of the research were to: (1) investigate and compare levels of internalized stigma and functional disability in schizophrenia in both India (low-income country) and the United States (high-income country), (2) compare the relationship of internalized stigma to functional disability in these two samples, and (3) evaluate the specific relationship between internalized stigma, self-efficacy, and functional disability in the United States sample.

In light of epidemiological research indicating that patients in low-income countries consistently have a more favorable course of the illness than their
counterparts in high-income countries (Sartorius et al., 1996), first, it was hypothesized that the Indian cohort would have lower levels of internalized stigma and better psychosocial functioning as compared to the American cohort. Second, due to the immense value placed on self-efficacy and autonomy in American culture, we hypothesized that the relationship between internalized stigma and functional disability would be stronger in the American cohort. Third, we hypothesized that higher levels of internalized stigma would be associated with poorer perceptions of self-efficacy and functional disability, with self-efficacy mediating the relationship between internalized stigma and functional disability.

3: Methods

3.1: Design

All procedures received relevant Institutional Review Board (IRB) approval at both Dhiraj Hospital in Vadodara, Gujarat, India, and Wesleyan University, in Middletown, Connecticut. All participants had the nature and aims of the study explained to them and completed written, informed consent forms. In the same visit, participants provided demographic information and were administered the Internalized Stigma of Mental Illness inventory (J. B. Ritsher et al., 2003) as an index of internalized stigma, the World Health Organization Disability Assessment Schedule (Üstün et al., 2010) to assess the participant’s level of functional disability, and the American cohort completed the Self-Efficacy Scale (McDermott, 1995), which provides a measure of how confident the participant feels in his or her ability to function in social situations, as well as to control positive and negative symptoms.
3.2: Participants

In India, 24 participants who has a DSM-IV chart diagnosis of schizophrenia (n= 13), schizoaffective disorder (n= 5), bipolar disorder with psychotic features (n= 4), or major depressive disorder with psychotic features (n= 2) participated in the study. Participants were either on the in-patient psychiatric unit (n= 9) at Dhiraj Hospital, or were outpatients (n= 15) who had been treated at the facility. Outpatients were interviewed in their homes across a total of 10 villages outside of Vadodara, Gujarat. Participants were gathered from multiple different locations, and the diagnostic criteria was expanded from just schizophrenia spectrum disorders to include other psychiatric disorders characterized by psychotic symptoms in order to obtain as large a sample size as possible in such a remote area.

The American sample consisted of 20 participants who had chart diagnoses of DSM-IV defined schizophrenia (n= 8), schizoaffective disorder (n= 10), or bipolar disorder with psychotic features (n=2), and were mental health consumers at Gilead Community Services in Middletown, Connecticut. This center has a sizable population of individuals with schizophrenia-spectrum disorders. All participants were interviewed at Gilead’s Social Rehabilitation Center, and were recruited from flyers and consultation with staff at the facility.

Participants in the two respective samples were statistically different from one another on all demographic variables considered except for age (Table 1). Participants in Connecticut had, on average, significantly longer duration of illness (25.6 ± 9.6 years) than did participants in the Indian sample (3.6 ± 2.2 years), and also had an
average of twice as many years of education \((12.25 \pm 3.2\) years) compared to participants in India \((6.1 \pm 4.2\) years). Furthermore, a higher percentage of the sample in Connecticut was male \((70\%, 58.3\%\) in India). There was also a higher percentage of the American sample that was unemployed due to mental health reasons \((66.7\%)\) than in the Indian sample \((36.8\%)\).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Indian Cohort ((n=24), \text{Mean} \pm \text{SD})</th>
<th>Connecticut Cohort ((n=20), \text{Mean} \pm \text{SD})</th>
<th>t-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (% male)</td>
<td>58.3 \pm 3.3</td>
<td>70</td>
<td>-3.31</td>
<td>0.00**</td>
</tr>
<tr>
<td>Average age (years)</td>
<td>41.9 \pm 21.8</td>
<td>45.8 \pm 8.5</td>
<td>0.82</td>
<td>0.42</td>
</tr>
<tr>
<td>Duration of illness (years)</td>
<td>3.6 \pm 2.2</td>
<td>25.6 \pm 9.6</td>
<td>9.50</td>
<td>0.00**</td>
</tr>
<tr>
<td>Percent unemployed due to mental health reasons</td>
<td>36.8%</td>
<td>66.7%</td>
<td>2.95</td>
<td>0.01*</td>
</tr>
<tr>
<td>Education (years)</td>
<td>6.1 \pm 4.2</td>
<td>12.25 \pm 3.2</td>
<td>5.14</td>
<td>0.00**</td>
</tr>
<tr>
<td>Percent out-patient</td>
<td>62.5%</td>
<td>100%</td>
<td>3.71</td>
<td>0.00**</td>
</tr>
<tr>
<td>Percent diagnosed with schizophrenia</td>
<td>54.2%</td>
<td>40%</td>
<td>7.36</td>
<td>0.00**</td>
</tr>
</tbody>
</table>

Table 1: Demographics of participants in the Indian and Connecticut cohorts.
Note: *= p<0.05; **= p<0.01

3.3: Measures

3.3.1: Internalized Stigma of Mental Illness (ISMI) Inventory

The ISMI inventory was developed by Jennifer Ritsher and colleagues (2003) as a way to quantify feelings of internalized stigma. This questionnaire consists of 29 items and utilizes a 4-point Likert scale that ranges from 1 (“strongly disagree”) to 4.
(“strongly agree”). Five subscales are incorporated into the ISMI to measure different components of stigmatization, which include discrimination experience (“People discriminate against me because I have a mental illness”), stereotype endorsement (“People with mental illness cannot live a good, rewarding life”), alienation (“I feel out of place in the world because I have a mental illness”), social withdrawal (“I avoid getting close to people who don’t have a mental illness to avoid rejection”), and stigma resistance (“I can have a good, fulfilling life, despite my mental illness”). The latter category is reverse-coded and provides an index of how patients can withstand and overcome stigmatization. The full ISMI and all subscales were selected for analysis.

### 3.3.2: The World Health Organization Disability Assessment Schedule (WHODAS)

The WHODAS was selected as a measure to index functional disability. According to the World Health Organization, disability is defined as “a difficulty in functioning at the body, individual, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors.” Consequently, the WHODAS includes questions about physical, personal, and societal functionality with a focus on the past 30 days. Participants respond using a scale that ranges from 1 (none) to 5 (extreme/ cannot do) to indicate the degree of difficulty that they experience in completing a certain task. This scale has been translated and modulated to over ten languages and many studies have demonstrated the reliability of its psychometric properties in different pathologies and across
different cultures (Guilera et al., 2012). The 12 questions that comprise the functional disability assessment in the measure were analyzed.

3.3.3: The Self-Efficacy Scale (SES)

The Self-Efficacy Scale was only used for the American sample. This measure was designed specifically for individuals with schizophrenia, and assesses attitudes about their ability to control their symptoms in order to achieve a variety of socially-desired and self-care behaviors (Kurtz, Olfson, & Rose, 2013). Each question is preceded by the phrase “I feel confident in my ability to,” followed by the specific example, including to “Ask someone out on a date,” to “Go shopping for groceries,” and to “Ignore voices you might hear”. Participants respond with a rating on a scale from 0 to 100, in which a rating of 0 means that the participant has no confidence in his or her ability to successfully accomplish the task in question, and a rating of 100 indicates complete confidence. The 57-question scale is divided into three parts, each 19 questions, which measure confidence in one’s ability to manage positive symptoms, negative symptoms, and to perform certain social behaviors. The overall self-efficacy score represents the mean of the three sections. Testing of this measure has demonstrated its reliability and construct validity (Pratt, Mueser, Smith, & Lu, 2005). The composite self-efficacy scale score and all subscales were analyzed.

3.4: Data Analysis and Statistics

The data gathered in this study was analyzed using R (Team, 2013). Demographic, clinical, and scale data was inspected for normality with two-group t-
tests. Analysis of Variance (ANOVA) and two-group t-tests were implemented to compare demographic and clinical variables, as well as ratings from different scales from the Indian and American samples (Table 1). Pearson correlations were used to compare the associations between ratings on different scales within the two samples. To assess if self-efficacy learning potential mediated the relationship between internalized stigma and functional disability in the American cohort, we would expect that, according to the methods of Baron & Kenny (1986): (a) internalized stigma assessments would be related to functional disability, (b) self-efficacy measures would be related to everyday life skills, (c) internalized stigma would be related to self-efficacy, and (d) when self-efficacy was controlled for statistically, the relationship between stigma and functional disability would be reduced or removed.

All statistical tests were two-tailed and alpha was set at .05.

4: Results

4.1: Stigma

With the exception of 5 participants in the Indian sample who completed the ISMI did not complete the WHODAS, all participants completed all scales. Comparison of the results obtained for the two different geographical cohorts failed to show a difference on overall mean ratings on the ISMI and the stereotype endorsement section of the ISMI. The other ISMI subscales (alienation [p= 0.04], discrimination experience [p= 0.00], social withdrawal [p= 0.04], and stigma resistance [p= 0.00]) were different between the two samples. Ratings for the American cohort were higher than that of the Indian cohort, with the exception of the
stigma resistance subscale, in which the mean for the Indian cohort was higher, indicating that they are better at resisting stigmatizing attitudes (Table 2).

In the Indian sample, there was a significant association between internalized stigma and in-patient or outpatient status (p= 0.01), with the in-patients having lower average ISMI scores (1.94 ± 0.69) than the outpatients in the sample (2.71 ± 0.25).

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean for Indian Cohort</th>
<th>Mean for USA Cohort</th>
<th>t-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full ISMI</td>
<td>2.23 (± 0.69)</td>
<td>2.45 (± 0.375)</td>
<td>1.35</td>
<td>0.18</td>
</tr>
<tr>
<td>Alienation</td>
<td>2.15 (± 1.06)</td>
<td>2.71 (± 0.66)</td>
<td>2.13</td>
<td>0.04*</td>
</tr>
<tr>
<td>Stereotype endorsement</td>
<td>2.08 (± 1.12)</td>
<td>2.15 (± 0.45)</td>
<td>0.27</td>
<td>0.79</td>
</tr>
<tr>
<td>Discrimination experience</td>
<td>2.00 (± 1.07)</td>
<td>2.81 (± 0.59)</td>
<td>3.18</td>
<td>0.00**</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>2.11 (± 1.09)</td>
<td>2.69 (± 0.73)</td>
<td>2.09</td>
<td>0.04*</td>
</tr>
<tr>
<td>Stigma resistance</td>
<td>2.94 (± 1.09)</td>
<td>1.91 (± 0.39)</td>
<td>-4.29</td>
<td>0.00**</td>
</tr>
</tbody>
</table>

Table 2: Means and standard deviations of the two measures and subscales used for both cohorts (ISMI and WHODAS), and t- and p-values between the two groups. Note: *= p<0.05; **= p<0.01

4.2: Functional Disability

Subjects in the Indian cohort on average had more functional disability (34.26 ± 13.21) when compared to the American cohort (24.4 ± 7.56, t= -2.84, p= 0.00). However, only 36.85% of the Indian participants were unemployed due to mental
health reasons. Those in this sample reported having paid jobs (10.5%), being self-employed, such as owning a farm or business (26.3%), being a homemaker (21.1%), or being retired (5.3%). In contrast, 80% of the American sample was unemployed due to having a psychiatric disorder, with only 10% having a paying job, 5% doing non-paid work, such as volunteering, and 5% that were unemployed for other reasons. Analysis of variance of this data showed that there was no association between functional disability and work status in the Indian sample (p= 0.08), whereas this relationship was significant in the American sample (p= 0.01).

4.3: Stigma and Functional Disability

The levels of functional disability, as indexed by the results of the WHODAS, were not statistically associated with the degree of internalized stigma, nor with any of the subscales of the ISMI, for the Indian cohort. However, in the American cohort, there was a positive association between stigma and functional disability (r= 0.59, p= 0.01; Figure 1). Several subscales of the ISMI were also associated with the WHODAS; alienation and the WHODAS were positively correlated (r= 0.73, p= 0.00), as was the WHODAS and social withdrawal (r= 0.47, p= 0.03). The associations between the WHODAS and stereotype endorsement, discrimination experience, and stigma resistance were not statistically significant (all ps> .29; Table 3).

For the American sample, the association between the ISMI and the WHODAS differed depending on the length of illness duration. There was a significant relationship between internalized stigma and functional disability for
participants with illness duration less than 25 years (r= 0.73, p= 0.02), whereas this relationship was not significant for participants that had been diagnosed for over 25 years (r= 0.56, p= 0.07). Similarly, participants younger than 46 (the average age of the sample) showed a significant correlation between stigma and functional disability (r= 0.71, p= 0.04), and those over 46 years of age did not (r= 0.51, p= 0.09).

<table>
<thead>
<tr>
<th>Measures</th>
<th>Indian Cohort</th>
<th>USA Cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISMI and WHODAS</td>
<td>r= -0.01</td>
<td>r= 0.59</td>
</tr>
<tr>
<td></td>
<td>p= 0.96</td>
<td>p= 0.00**</td>
</tr>
<tr>
<td>WHODAS and ISMI (alienation)</td>
<td>r= -0.18</td>
<td>r= 0.73</td>
</tr>
<tr>
<td></td>
<td>p= 0.45</td>
<td>p= 0.00**</td>
</tr>
<tr>
<td>WHODAS and ISMI (stereotype endorsement)</td>
<td>r= 0.12</td>
<td>r= 0.25</td>
</tr>
<tr>
<td></td>
<td>p= 0.63</td>
<td>p= 0.29</td>
</tr>
<tr>
<td>WHODAS and ISMI (discrimination experience)</td>
<td>r= -0.12</td>
<td>r= 0.23</td>
</tr>
<tr>
<td></td>
<td>p= 0.62</td>
<td>p= 0.33</td>
</tr>
<tr>
<td>WHODAS and ISMI (social withdrawal)</td>
<td>r= -0.22</td>
<td>r= 0.47</td>
</tr>
<tr>
<td></td>
<td>p= 0.38</td>
<td>p= 0.03*</td>
</tr>
<tr>
<td>WHODAS and ISMI (stigma resistance)</td>
<td>r= 0.42</td>
<td>r= 0.03</td>
</tr>
<tr>
<td></td>
<td>p= 0.07</td>
<td>p= 0.89</td>
</tr>
</tbody>
</table>

Table 3: Pearson’s R Correlation statistical analyses between the WHODAS and subscales of the ISMI; r and p-values.
Note: *= p<0.05; **= p<0.01
Figure 1: Scatterplot with trend line of the ISMI scores vs. WHODAS scores for the American cohort, $R^2 = 0.34783$.

4.4: Self-Efficacy, Stigma, and Functional Disability

Secondary analyses in the American cohort revealed that the WHODAS was negatively associated with the composite Self Efficacy Scale (SES) score as well as all three of the subsections: the individual’s sense of confidence in carrying out social tasks ($r = -0.54$, $p = 0.01$), managing negative symptoms ($r = -0.48$, $p = 0.03$), and controlling positive symptoms ($r = -0.74$, $p = 0.00$). Furthermore, internalized stigma was found to be negatively associated with the social ($r = -0.6$, $p = 0.01$), negative ($r = -0.58$, $p = 0.01$), and positive ($r = -0.67$, $p = 0.00$) subsections of the SES, and the overall SES composite score ($r = -0.71$, $p = 0.00$; Table 4).
The effects of the ISMI on the WHODAS were mediated by self-efficacy. The association between internalized stigma and functional disability in the American sample was positive ($r = 0.69$, $p = 0.01$), as was the association between the WHODAS and ISMI ($r = 0.59$, $p = 0.00$), and the association between the SES and the WHODAS was negative ($r = -0.69$, $p = 0.00$). In a linear regression of the relationship between the ISMI and the WHODAS, the relationship was no longer significant when the self-efficacy composite score was added to the regression (Figure 2).

<table>
<thead>
<tr>
<th>Measures</th>
<th>$r$ and $p$-values for the American cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISMI and SES (composite)</td>
<td>$r = -0.71$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.00**$</td>
</tr>
<tr>
<td>ISMI and SES (Social)</td>
<td>$r = -0.60$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.00**$</td>
</tr>
<tr>
<td>ISMI and SES (Negative)</td>
<td>$r = -0.58$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.00**$</td>
</tr>
<tr>
<td>ISMI and SES (Positive)</td>
<td>$r = -0.67$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.00**$</td>
</tr>
<tr>
<td>WHODAS and SES (composite)</td>
<td>$r = -0.69$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.00**$</td>
</tr>
<tr>
<td>WHODAS and SES (Social)</td>
<td>$r = -0.54$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.01*$</td>
</tr>
<tr>
<td>WHODAS and SES (Negative)</td>
<td>$r = -0.48$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.03 *$</td>
</tr>
<tr>
<td>WHODAS and SES (Positive)</td>
<td>$r = -0.74$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.00**$</td>
</tr>
</tbody>
</table>

**Table 4**: Associations between self-efficacy, functional disability, and internalized stigma in the American Cohort.

Note: *$=p<0.05$, **$=p<0.01$


**Figure 2:** The relationships between internalized stigma, self-efficacy, and functional disability in the American sample.

5: **Discussion**

Stigma is a reality that individuals with mental illness have to contend with on a daily basis, and has consistently been cited as one of the most deleterious consequences of schizophrenia. While the roots and manifestations of stigmatization are unquestionably a multifaceted entity, elucidating what leads to the internalization of stigma could lead to generating better anti-stigma interventions, especially ones that are socially and culturally specific. The current study was undertaken to investigate what factors are associated with the internalization of stigma, and to see
how these factors differ between low-income (India) and high-income (United States) countries.

The International Pilot Study of Schizophrenia found that patients with schizophrenia in developing countries had better outcome and overall course compared to patients in developed countries (Sartorius et al., 1996). Agra, India, had the second best outcome and course out of all countries considered, whereas patients in Washington D.C. had some of the poorest outcomes overall (Hopper, 2007). This research adds further support to those findings, and suggests stigmatization as a possible explanation as to why the outcomes are so different in India versus the United States.

The current study included 24 participants from Gujarat, India, and 20 from Middletown, Connecticut. While the differences in overall internalized stigma between the two cohorts was not statistically significant, there were significant differences on a number of the subscales of the ISMI. Participants in Connecticut consistently had higher scores on the alienation, discrimination experience, and social withdrawal subscales, indicating that these individuals suffer from these phenomena to a greater extent, all of which are components that the literature has attributed to the eventual internalization of stigma (J. B. Ritsher et al., 2003). Additionally, participants in the American cohort had lower levels of stigma resistance compared to the Indian cohort, suggesting that they are less adept at repelling predominant stigmatizing attitudes about mental illness that are present in their sociocultural groups.
The IPSS gave rise to the industrialization hypothesis, which states that industrial societies and economies, such as are found in developed countries, contribute to more isolation, segregation, and rejection of the mentally ill, and that these phenomena are not as common in developing, non-industrialized countries (Jadhav et al., 2007). The present research posited that this could potentially be attributed to the high value that is placed on personal autonomy and success in the workforce in developed countries, particularly in the United States, and that higher levels of functional disability in patients with schizophrenia would render them more isolated and stigmatized as a result of not being able to work.

Participants in the Indian sample were more functionally disabled than their American counterparts. However, a greater proportion of the American sample was unemployed due to mental health reasons, and only this sample demonstrated a significant association between work status and functional disability. These results indicate that impairments in social interaction, completing activities of daily living, self-reliance in normal physical domains, all of which are assessed with the WHODAS, are not impediments to gaining employment in India, but that they are significant barriers in the United States.

To explore the association between functional disability and internalized stigma, the results of the ISMI and the WHODAS were compared. As hypothesized, there was a positive association between internalized stigma and functional disability in the American cohort, suggesting a relationship between high levels of functional disability and increased internalized stigma. Interestingly, this association was not statistically significant in the Indian cohort, even though participants in the Indian
sample had much higher levels of functional disability than the American participants. These results reveal that even moderate amounts of functional disability are sufficient enough to predict increased internalized stigma in the United States.

Associations were also found between self-efficacy, internalized stigma, and functional disability in the American sample. Internalized stigma was negatively associated self-efficacy overall, as well as with the social, negative, and positive sections of the scale. These results suggest that the amount to which someone with schizophrenia internalizes stigma is associated with his or her feelings of self-efficacy in managing facets of social interaction, and controlling symptomology on the positive and negative ends of the spectrum.

While previous research has investigated the relationship between stigma and dysfunctional attitudes, it has not been extended to explore how these negative attitudes manifest. The current study found a significant association between high levels of functional disability and low perceptions of self-efficacy, suggesting the presence of a relationship between internalized stigma and functional disability with low perceptions of self-efficacy. Results from this study additionally showed that the relationship between internalized stigma and functional disability is mediated by self-efficacy.

5.1: Limitations

The largest limitation to this pilot study was the small sample size of 44 participants. However, the fact that numerous significant results were obtained from such a small pool of participants indicates that investigating the association between
stigma and functional disability is a worthwhile avenue of research. Another limitation was that the surveys used in India were not translated into Gujarati or Hindi, and were instead translated each time by an interpreter. It is possible that there were differences in how the questions were read to participants, and thus how their answers were given. The same interpreter was used almost every time to try and eliminate the amount of deviation in translation.

A substantial confound in the research was the differences in demographic and clinical variables found between participants in the respective cohorts. The largest disparity between the two samples was the duration of illness—participants in the American cohort were predominantly patients with chronic schizophrenia, whose duration of illness ranged from 3 to 43 years (mean= 25.6 years), whereas participants in India had much shorter illness durations (1 month to 15.5 years, mean= 3.6 years). Having a diagnosis of a psychotic mental illness for a longer period of time could have allowed the individual to develop additional mechanisms to resist stigma. Alternatively, a longer course of illness could render the individual more vulnerable to internalized stigma since they have had a longer time to be exposed to negative attitudes, which seems more likely, given the fact that the American sample had higher levels of stigma in multiple different dimensions. While these discrepancies in duration were indeed a methodological concern in terms of standardization, duration was not statistically related to internalized stigma or functional disability in either cohort, or with self-efficacy in the American sample. However, the duration of illness did influence the association between internalized stigma and functional disability in the American sample. Another substantial difference between the two samples was
that the American cohort consisted of entirely outpatient participants, whereas participants in the Indian cohort included both in- and outpatients.

The final limitation is that not all relevant variables that could contribute to perceptions of stigmatization were included in this study, such as any correlated delusions, depressive symptoms, or cognitive deficits.

5.2: Future Directions

While it has been consistently demonstrated that individuals with schizophrenia have worse outcomes and courses of illness in the United States as compared to low-income countries, the causal factors as to why this occurs have yet to be fully investigated. This research posits that the disparity in course between the United States and India can be partially attributed to patients in the United States internalizing stigma more than those India. However, stigma is a complex phenomenon that likely is born, propagated, and modulated by numerous factors, especially in different sociocultural contexts. Future studies on the stigmatization of schizophrenia-spectrum disorders is needed to understand the situations people affected by these conditions live with on a daily basis. Such research could be a component of situational analyses, for public health interventions, or to monitor and evaluate the effectiveness of interventions taken to reduce stigma, both through the methodologies of increasing education in communities and to decrease feelings of self-stigmatization (van Brakel, 2007). Additional research will be needed to assess the effectiveness of techniques that help patients with schizophrenia cope with stigma (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002).
According to psychiatrist Horacio Fabrega, “psychiatric disorders, including their signs and symptoms, are not language- or culture-free phenomena. Rather, they are permeated with meanings, conventions, and understandings that stem from the individual’s social group, religion, social class, ethnic background, and the like” (Fabrega, 2009). Research on internalized stigma has primarily focused on how a single status or factor affects and shapes subjective experiences of stigma, even though individuals with mental illness belong to multiple different axes of difference that intersect with one another, including gender, class, race, and disability status (Livingston & Boyd, 2010). The current research attempted to broaden the narrow lens through which stigma is often studied by comparing two different cultural and geographical samples, but further analyses on a larger scale are still necessary to uncover the interrelated effects that stigma has on personal experiences.

Therefore, further comprehension of the different levels of, and factors associated with, stigma is needed in order to create socially and culturally applicable anti-stigma intervention programs. In India, psychiatrists and other mental health professionals predominate in urban areas, which makes seeking care more challenging for patients who live in rural communities, including those who participated in this study. According to a report from the World Health Organization, the total number of human resource personnel working in the mental health field per 100,000 population is 1.43 in India (Organization, 2006).

However, the key to eliminating stigma and improving the lives of patients in India will require more than just easier access to psychiatrists. The Westernization of medical practices in India impose requisite conformation to healing in a strictly
biomedical capacity, which for many still living in rural communities, stands in direct conflict with more traditional methods of addressing emotional disorders (Fabrega, 2009). While some scholars who have written about the applicability of Western models of psychotherapy in India have come to the conclusion that the two methodologies are incompatible with one another, there likely exists a happy medium in which stigma and other facets of schizophrenia can be treated with Western models and interventions, and spiritual practices can play a role in healing as well. In the Indian sample, since there was no association found between internalized stigma and functional disability, anti-stigma interventions will need to be focused on milieu other than in the functional realm.

The case in the United States is radically different, and will thus require different ways to reduce stigmatization. The present research found significant associations between functional disability, self-efficacy, and internalized stigma. As such, anti-stigma interventions could be successful by focusing on improving patients’ functional capabilities, which in the long run would heighten self-esteem and self-efficacy.

Reducing self-stigmatization, however, is no easy task (Staring, Van der Gaag, Van den Berge, Duivenvoorden, & Mulder, 2009). A 16-session group intervention, conducted by Link et al. (2002), in which participants were given information about the effects of the stigma against mental illness and provided with behavioral strategies for coping with stigma, as well as outlets to discuss their experiences, did not reduce stigma, depressive symptoms, or self-esteem. Other factors need to be addressed in concert with stigmatization, since this phenomenon is
so broad and can take many different forms. As opposed to just learning about stigma, and being able to more clearly notice it in everyday life, which would likely be damaging to self-esteem, patients could concurrently work to improve in functional domains where they do not feel confident, in order to begin repelling stigmatization by increasing their functional-, and thus self, efficacy.
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7: Appendix

Internalized Stigma of Mental Illness Inventory (ISMI)

We are going to use the term "mental illness" in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it.

For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel out of place in the world because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Mentally ill people tend to be violent.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. People discriminate against me because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I avoid getting close to people who don’t have a mental illness to avoid rejection.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I am embarrassed or ashamed that I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Mentally ill people shouldn’t get married.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. People with mental illness make important contributions to society.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I feel inferior to others who don’t have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I don’t socialize as much as I used to because my mental illness might make me look or behave “weird.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. People with mental illness cannot live a good, rewarding life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I don’t talk about myself much because I don’t want to burden others with my mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Negative stereotypes about mental illness keep me isolated from the “normal” world.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>----------</td>
<td>-------</td>
</tr>
<tr>
<td>13.</td>
<td>Being around people who don’t have a mental illness makes me feel out of place or inadequate.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14.</td>
<td>I feel comfortable being seen in public with an obviously mentally ill person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15.</td>
<td>People often patronize me, or treat me like a child, just because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16.</td>
<td>I am disappointed in myself for having a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17.</td>
<td>Having a mental illness has spoiled my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18.</td>
<td>People can tell that I have a mental illness by the way I look.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19.</td>
<td>Because I have a mental illness, I need others to make most decisions for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20.</td>
<td>I stay away from social situations in order to protect my family or friends from embarrassment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21.</td>
<td>People without mental illness could not possibly understand me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22.</td>
<td>People ignore me or take me less seriously just because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23.</td>
<td>I can’t contribute anything to society because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24.</td>
<td>Living with mental illness has made me a tough survivor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25.</td>
<td>Nobody would be interested in getting close to me because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26.</td>
<td>In general, I am able to live my life the way I want to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27.</td>
<td>I can have a good, fulfilling life, despite my mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28.</td>
<td>Others think that I can’t achieve much in life because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29.</td>
<td>Stereotypes about the mentally ill apply to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Reference:

ISMI Scoring Key

The ISMI contains 29 items which produce 5 subscale scores and a total score. Each score is calculated by adding the item scores together and then dividing by the total number of answered items. If any items are not answered, the total number to be divided by is reduced. The resulting score should range from 1-4. For example, if someone answers 5 of the 6 Alienation items, the Alienation score is produced by adding together the 5 answered items and dividing by 5.

Alienation (6 items)
1. I feel out of place in the world because I have a mental illness
5. I am embarrassed or ashamed that I have a mental illness
8. I feel inferior to others who don’t have a mental illness
16. I am disappointed in myself for having a mental illness
17. Having a mental illness has spoiled my life
21. People without mental illness could not possibly understand me

Stereotype Endorsement (7 items)
2. Mentally ill people tend to be violent
6. Mentally ill people shouldn’t get married
10. People with mental illness cannot live a good, rewarding life
18. People can tell that I have a mental illness by the way I look
19. Because I have a mental illness, I need others to make most decisions for me
23. I can’t contribute anything to society because I have a mental illness
29. Stereotypes about the mentally ill apply to me

Discrimination Experience (5 items)
3. People discriminate against me because I have a mental illness
15. People often patronize me, or treat me like a child, just because I have a mental illness
22. People ignore me or take me less seriously just because I have a mental illness
25. Nobody would be interested in getting close to me because I have a mental illness
28. Others think that I can’t achieve much in life because I have a mental illness

**Social Withdrawal (6 items)**

4. I avoid getting close to people who don’t have a mental illness to avoid rejection
9. I don’t socialize as much as I used to because my mental illness might make me look or behave “weird”
11. I don’t talk about myself much because I don’t want to burden others with my mental illness
12. Negative stereotypes about mental illness keep me isolated from the “normal” world
13. Being around people who don’t have a mental illness makes me feel out of place or inadequate
20. I stay away from social situations in order to protect my family or friends from embarrassment

**Stigma Resistance (5 items – reverse code before including in total score)**

7. People with mental illness make important contributions to society
14. I feel comfortable being seen in public with an obviously mentally ill person
24. Living with mental illness has made me a tough survivor
26. In general, I am able to live my life the way I want to
27. I can have a good, fulfilling life, despite my mental illness

As they are shown in the questionnaire, higher scores on these questions indicate more resistance to stigma and therefore less internalized stigma. If you wish to include them in the total score, you must reverse the scores before doing so. To reverse the scores, subtract them from 5. Thus, a score of 1 becomes a 4 and a score of 4 becomes a 1.

**Total Score (29 items)**
Add together all the answered items and divide by the total number of answered items. (If the person answered every question, divide by 29). Make sure to use reverse-coded Stigma Resistance items.
Total Score without Stigma Resistance (24 items)
Same as above, but do not include the Stigma Resistance items. You may choose to interpret these items separately or to leave them out altogether (Lysaker et al., 2007).

**World Health Disability Assessment Schedule**

SAY TO RESPONDENT:
This interview is about difficulties people have because of health conditions. *(HAND FLASHCARD #1 TO RESPONDENT).* By health conditions I mean diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

I remind you to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about *(POINT TO FLASHCARD #1).*

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

*(POINT TO FLASHCARD #1).* When answering, I’d like you to think back over the last 30 days. I also would like you to answer these questions thinking about how much difficulty you have, on average over the past 30 days, while doing the activity as you usually do it.

*(HAND FLASHCARD #2 TO RESPONDENT).* Use this scale when responding. *(READ SCALE ALOUD):* None, mild, moderate, severe, extreme or cannot do.

In the last 30 days how much difficulty did you have in:

S1 Standing for long periods such as 30 minutes?

S2 Taking care of your household responsibilities?
S3 Learning a new task, for example, learning how to get to a new place?

S4 How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

S5 How much have you been emotionally affected by your health problems?

S6 Concentrating on doing something for ten minutes?

S7 Walking a long distance such as a kilometer [or equivalent]?

S8 Washing your whole body?

S9 Getting dressed?

S10 Dealing with people you do not know?

S11 Maintaining a friendship?

S12 Your day to day work?

Flashcard #1

Health Conditions:

- Diseases, illnesses or other health problems
- Injuries
- Mental or emotional problems
- Problems with alcohol
- Problems with drugs

Having difficulty with an activity means:

- Increased effort
• Discomfort or pain
• Slowness
• Changes in the way you do the activity

Flashcard #2

1 2 3 4 5
None Mild Moderate Severe Extreme/ Cannot Do

Self-Efficacy Scale

Instructions

I am going to be reading several descriptions of behaviors. People with emotional disorders (past or present) sometimes consider these behaviors to be difficult for them. After each statement, I would like you to tell me how confident you are in your ability to perform each behavior on a scale from 0 to 100.

A score of 0% means that you have no confidence in your ability to do the task or behavior. A score of 100% means that you feel totally confident in your ability. All listed numbers between 0 and 100 may be used to accurately express your feeling of confidence in your abilities. For example, if you think that you can probably do the specific task with a great deal of effort, and you are still unsure, you might rate your confidence as 10 or 20%. In contrast, if you are generally fairly sure, but are not 100% certain, you might rate your confidence as 70 or 80%. Remember, all numbers
between 0 and 100 listed on the scale may be used. Try to rate each item according to how you feel about your ability to do it, whether or not you are doing each one at this time. Although you may feel some items do not apply to you, try to imagine how you would rate your confidence if they did apply.

Before responding to the items, let’s complete an example to make sure you understand how to answer each one.

Using this scale, please tell me how confident you are in your ability to get up in the morning without using an alarm clock. If you generally think you can do this, but are unsure, you might say 40 or 50%. However, if you are certain that you cannot do this, say 0%. If this is something you regularly do without any trouble, say 100%. Go ahead.

Do you have any questions before we start?

Client Interview

HOW CONFIDENT ARE YOU IN YOUR ABILITY TO:

W1 Go out on a date
W2 Use your free time for activities other than watching TV
W3 Go to a party with friends
W4 Ask someone out on a date
W5 Go out when a friend calls and invites you
W6 Get regular exercise
W7 Ask a friend for advice
W8 Stop thoughts that others are controlling what you think
W9   Go to a job interview
W10  Go shopping for clothes
W11  Stop feelings of being frightened of people
W12  Stop any feeling that your insides are rotting
W13  Have your family visit you
W14  Go shopping for groceries
W15  Stop any feeling that your mind is racing
W16  Ignore feelings of wanting to kill yourself
W17  Stop yourself from hurting someone
W18  Stop any feeling that the TV in communicating with you
W19  Attend classes
W20  Concentrate when you read
W21  Remember to pay your bills
W22  Trust your friends
W23  Go out even if you don’t want to
W24  Trust your family
W25  Get rid of bad thoughts of ideas
W26  Get along with your neighbors
W27  Stop feelings of fearfulness
W28  Stop feelings of nervousness or shakiness
W29  Stop thought that others can control what you think
W30  Visit your family
W31  Ignore bad thoughts or ideas
W32  Accomplish your occupational goals
W33  Stop feelings of irritability or anger
W34  Find someone to talk to when you feel lonely
W35  Look for a job in the newspaper
W36  Remember to take your medications
W37  Enroll in a class you are interested in
W38  Make friends
W39  Concentrate on your work
W40  Begin a conversation with a friend
W41  Talk to people in a group
W42  Get ride of feelings of wanting to kill yourself
W43  Stop any feeling that others are watching you
W44  Call and ask a friend to go out
W45  Get out of the house enough to stay active

W46  Ignore voices you might hear

W47  Have sex with someone in a way that you and the other person can enjoy

W48  Make decisions

W49  Keep your living quarters clean

W50  Stop thoughts that outside forces are controlling your behavior

W51  Introduce yourself to someone you don’t know

W52  Shake hands when you meet someone

W53  Maintain interest in your job or schoolwork

W54  Ignore any feeling that someone may be trying to hurt you

W55  Begin a conversation with a stranger

W56  Control your temper

W57  Enjoy things as much as others do