

STIGMA EXPERIENCE AMONG CHINESE AMERICAN IMMIGRANTS WITH  
SCHIZOPHRENIA

A dissertation submitted in partial fulfillment of the degree of Doctor of Philosophy from  
New York University Silver School of Social Work

GRACE YING CHI LAI

January 2018

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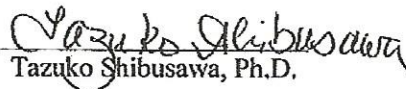


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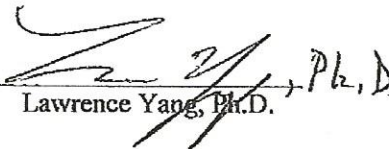
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Grace Ying Chi Lai

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Date

This dissertation is dedicated to my always-supportive parents,  
my husband, and our sweet, thoughtful children.

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Stigma has profound consequences on individuals with mental illness, specifically schizophrenia. Individuals who suffer from internalized stigma further struggle with self-esteem, quality of life, and their recovery from mental illness. To avoid rejection and being the target of discrimination, these individuals often practice coping strategies such as secrecy and withdrawal. However, these coping strategies can eventually lead to poor self-image, restricted opportunities in life, and other negative outcomes. Cultural beliefs relating to the concept of *face* and Confucianism further exacerbate the effects of stigma among Chinese American individuals who suffer from mental illnesses.

This study examined the experiences of stigma and coping strategies used by Chinese Americans with schizophrenia spectrum disorders. The associations between internalized stigma, experienced stigma, loss of face, and coping strategies were also analyzed. Unlike previous studies, this study found that internalized and experienced stigma were not associated with coping strategies used by the Chinese American participants; instead, the cultural construct of loss of face was associated with secrecy as a coping strategy. This study calls for further research on the effects of this cultural construct on one's recovery.



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## Chapter 1

### Statement of the Study Issue

#### **Purpose of the Study**

Stigma has profound consequences on individuals with mental illness including negative stereotyping, discrimination, limited access to life opportunities, and social exclusion (Haraguchi, Maeda, Xiao, & Uchimura, 2009; S. Lee, Chiu, Tsang, Chui, & Kleinman, 2006; Spriggs, Olsson, & Hall, 2008; Yang, 2007). Although individuals with socially unattractive physical disabilities and illnesses such as HIV/AIDS, epilepsy, and obesity experience stigma, it is mental illness, specifically schizophrenia, that has been identified by public-attitude surveys as one of the most stigmatized conditions (Angermeyer & Schulze, 2001; Westbrook, Legge, & Pennay, 1993). Despite an increase in public education and general knowledge regarding mental illness, stigmatizing attitudes toward people with mental illness have not improved. A systematic review and meta-analysis examining 16 studies on public attitudes toward mental illness across countries revealed that although literacy about mental illness has increased, attitudes toward individuals with mental illness have not changed for the better, and have even deteriorated toward people with schizophrenia (Schomerus et al., 2012). At the same time, a 2006 study of 5,251 individuals in the United States regarding their attitudes toward mental illness indicated that 70% did not believe a person with a mental illness could pull himself or herself together if they wanted to, and about 30% did not think that a person with a mental illness could eventually recover (Kobau, DiIorio, Chapman, & Delvecchio, 2010). Not only do individuals with a mental illness face discrimination from the general public, they also experience unfair treatment by their families and social networks. These

negative experiences, in addition to internalized stigma, directly contribute to individuals' struggles with self-esteem (Livingston & Boyd, 2010; Wahl, 1999), quality of life (Depla, de Graaf, van Weeghel, & Heeren, 2005; El-Badri & Mellsop, 2007; Livingston & Boyd, 2010; Lundberg, Hansson, Wentz, & Björkman, 2008; Rosenfield, 1997) and their recovery from mental illness (Yanos, Roe, Markus, & Lysaker, 2008). For these reasons, stigma needs to be addressed and reformed to facilitate the recovery of individuals with mental illness.

The harmful label of mental illness, specifically schizophrenia, causes rejection and discrimination at three levels: individual, structural, and internal. Individuals with chronic mental illness are often shunned or avoided (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). In addition, many are treated as less competent, and are less likely to be employed (Dickerson et al., 2002; S. Lee et al., 2006). Furthermore, individuals with mental illness experience structural forms of stigma such as hurtful media representation and unequal treatment by healthcare providers or health insurers because of their psychiatric conditions (Forrester-Jones & Barnes, 2008; Link & Phelan, 2001b). Stigmatized individuals also suffer from the harmful effects of internalized stigma (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Once stigmatized individuals internalize the belief that they will be devalued and the target of discrimination, they may fear rejection from others and may use coping strategies such as secrecy and withdrawal to avoid such discrimination (Link et al., 1989). However, these coping strategies could eventually lead to poor self-image, restricted opportunities in life, and other negative outcomes (Corrigan & Watson, 2002; S. Lee et al., 2006; Watson & River, 2005).

Although researchers have studied mental health stigma widely among diverse populations in Australia, China, India, Japan, Sweden, and the United Kingdom (e.g., Björkman, Angelman, & Jönsson, 2008; Blignault, Ponzio, Rong, & Eisenbruch, 2008; Forrester-Jones & Barnes, 2008; Haraguchi et al., 2009; Saravanan et al., 2008), few researchers have examined the experiences of stigma among Chinese with severe mental illness in the United States. Cultural beliefs relating to the concept of *face* and Confucianism further worsen the effects of stigma among the Chinese. In the United States, Chinese Americans form the largest subgroup among Asian Americans (27%) with a population of 4 million, and their numbers continue to increase (U.S. Census Bureau, 2010). Therefore, it is important to expand knowledge on the issue of mental health stigma among the Chinese American population to aid the affected individuals and benefit society at large.

The purpose of this study is to examine (a) the experience of internalized stigma among Chinese American immigrants with schizophrenia spectrum disorders, (b) the effects of internalized stigma on these individuals and their coping strategies in managing the illness, (c) the extent to which Chinese immigrants with schizophrenia spectrum disorders experience loss of face and how this loss influences their coping strategies, and (d) the association between different coping strategies and level of experienced stigma among this population. Examining the stigma experience among these individuals will provide valuable direction for implementing multilevel interventions to counter the negative effects of stigma for this group. Findings will further suggest specific avenues for culturally competent clinical and community interventions. A comprehensive understanding of people's stigma experience will inform mental health professionals with



constructive ideas to work with individuals, communities, and larger legislative organizations to improve the well-being of Chinese immigrants who suffer from severe mental illness.

### **Significance of the Study**

The 2005 National Comorbidity Study (Kessler, Chiu, Demler, & Walters, 2005) estimated that 30% of U.S. citizens aged 18 and older suffered from a diagnosable mental disorder in a given year. When using the 2010 census, about 70.3 million U.S. adults were affected with a mental disorder. To emphasize the omnipresent effects of stigma, the 1999 *Surgeon General's Report on Mental Health* placed overcoming the effects of stigma at the forefront of the nation's efforts to promote mental health (U.S. Department of Health and Human Services, 2001). Schizophrenia, among other mental illnesses, has been associated with the most negative reactions, with those afflicted often labeled as dependent, dangerous, and unpredictable (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). Schizophrenia, a chronic severe brain disorder, affects approximately 1.1% of the U.S. population aged 18 or older in any given year (National Institute of Mental Health, 2008). Although the National Institute of Mental Health (2013) reported a 1.1% lifetime prevalence rate of schizophrenia in the U.S. adult population (those over 18 years of age), an estimated 1.0% 1-month prevalence rate of psychotic disorders was found in only four provinces in China (Phillips et al., 2009); China has 34 provincial-level administration units. The National Latino and Asian Americans Study estimated that Asian American groups to have a 17.91% lifetime prevalence rate of any mental disorder (Takeuchi, Hong, Gile, & Alegría, 2007). In fact, Chinese American women have the highest lifetime prevalence of depression among all Asian American groups. However, because the

Composite International Diagnostic Interview (the measure of psychopathology in the National Latino and Asian Americans Study) has not been found to be reliable for diagnosing psychotic disorders, no adequate prevalence estimate of schizophrenia exists among Chinese Americans. Migration is a major factor that affects individuals' mental health. One study (Bourque, van der Ven, & Malla, 2011) found that first-generation immigrants were 2.5 times more likely to develop a psychotic disorder than their native-born counterparts, suggesting that first-generation Chinese Americans may be at a higher risk of developing a psychotic disorder.

The effect of stigma among Chinese immigrant groups is further magnified due to cultural, linguistic, and structural barriers that relate to immigration and acculturation experiences. Chinese immigrants with mental illness and their family members frequently experience pervasive stigma that may stem from Chinese historical and cultural influences such as Confucianism and the centrality of face (C. H. Ng, 1997; Yang, 2007). Confucian practices emphasize social harmony and social order. In Confucian ideology, members of a society are obligated to fulfill their roles in society to achieve personal harmony with others, and one's inability to meet his/her responsibility will bring social discord and disorder. In addition, face directly aligns with one's social power in the Chinese community. Traditionally, having a chronic mental illness such as schizophrenia signifies the loss of face for the individual and the family, thereby diminishing social power to engage in the interpersonal world among other Chinese individuals (Yang & Kleinman, 2008). To be denied participation in the interpersonal world is to be denied full personhood, which then reduces access to essential life opportunities such as work

and marriage (Yang et al., 2007). As a result, these community attitudes severely marginalize individuals with mental illness and their families.

As mentioned above, this study provides key data to understand the stigma experience among Chinese American immigrants with schizophrenia spectrum disorders. Although stigma is a significant problem among the Chinese-immigrant group, insufficient information is available to properly understand the nature of stigma among this group, or about culturally appropriate responses. This group warrants attention from the social work profession to reduce stigma and decrease the negative consequences related to stigma.

## Chapter 2

### Literature Review

Stigma and its consequences are multifaceted. The disciplines of sociology, psychology, and social work, worldwide, have all contributed to the study of this complex issue. This study focused on the little-known stigma experience of Chinese American immigrants who suffer from a severe mental illness. This chapter will review current literature regarding stigma, its related social theories, common coping strategies regarding mental illness, and salient aspects of Chinese cultural beliefs that align with stigma.

#### **Definitions of Stigma**

In the seminal book, *Stigma: Notes on the Management of Spoiled Identity*, Goffman defined stigma as a deeply discrediting attribute that reduces the bearer “from a whole and usual person to a tainted, discounted one” (1963, p. 3). People with a stigmatizing condition are often treated as “not quite human” (Goffman, 1963, p. 5) and suffer from various kinds of discriminations that reduce life opportunities. Goffman (1963) categorized three types of stigma: (a) abomination of the body such as any type of physical deformity, (b) deviations of individual character traits including mental disorders, unemployment, and drug addiction, and (c) tribal stigma, which addresses traits based on race, ethnicity, nationality, and religion that are considered to deviate from social norms. Building on Goffman’s description that stigma is an association between an attribute and a stereotype, social psychologists Jones and colleagues (1984) conceptualized stigma as a mark that connects a person to undesirable characteristics, which in turn produces negative reactions and discrimination from the majority. Jones et

al. illustrated the following six dimensions that determine the public's reaction to individuals with stigmatizing conditions: (a) the concealability of the condition, meaning that the visibility of the condition to others influences the production of negative societal reactions; (b) the course of the condition in that the actual or perceived alterability of the stigmatizing condition plays a major role in how the person would be treated; (c) disruptiveness, which is the degree to which the person's stigmatizing condition hinders the ability to socially interact with others; (d) the aesthetic qualities of the condition, which refers to those with certain physical disabilities who are often rejected and seen as disgusting; (e) the origin of the condition, such as if an individual is seen as responsible for creating or causing the condition, the person is treated worse than those who are seen as not responsible for their condition; and (f) the peril of the condition, which signifies that the greater the fear or threat one feels toward a condition, such as violence or contagiousness of a condition, the more a stigmatizing attitude emerges. According to Jones and colleagues, these six factors play critical roles in shaping and influencing the stigma experiences and the interpersonal interactions of individuals with stigmatizing conditions (Link & Phelan, 2001b).

To bridge the gap of existing stigma research, Link and Phelan (2001a) and Link, Yang, Phelan, and Collins (2004) proposed another stigma conceptualization that includes six interrelated components. This sociological framework focuses on how stigma manifests on stigmatized individuals when all six components are present. In the first component, human differences are distinguished and labeled but not all human differences are identified. However, once a group or an individual has been labeled (e.g., labeled as having mental illness), the effects of stigma begin. In the second component,

labeled persons are linked to undesirable attributes and negative stereotypes; for example, individuals with mental illness are believed to be incapable. Third, a separation emerges between “us” and “them,” a distinct segregation of the labeled persons who are seen as completely different from other citizens. Fourth, emotional responses stem from the result of stigma experienced by the stigmatized (e.g., shame) and the stigmatizers (e.g., fear and pity). In the fifth component, the labeled persons experience status loss and discrimination due to stigma that further leads to unequal outcomes. The last component involves the use of power (e.g., social, economic, or political) by the stigmatizers in the stigmatizing process that eventually results in harmful effects on the labeled persons. Link and colleagues (2001a, 2004) proposed that when power co-occurs with the other stigma components, negative consequences arise and cause harmful effects on the stigmatized individuals.

Many conditions or disabilities such as physical deformities, addictions, homosexuality, HIV/AIDS, and mental illness are considered to be stigmatizing (Goffman, 1963). According to public-attitude surveys (Angermeyer & Schulze, 2001; Westbrook et al., 1993), mental illness is the most stigmatizing condition among these disabilities. Furthermore, schizophrenia has often been at the forefront of stigmatized mental illnesses, and those who are diagnosed are often labeled as dependent, dangerous, and unpredictable (Angermeyer & Schulze, 2001; Crisp et al., 2000). People with schizophrenia often face worse attitudes from the public than people with depression (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999; Nordt, Rössler, & Lauber, 2006). Symptoms among people with schizophrenia such as bizarre behaviors, disheveled appearance, disorganized behaviors, and poor social skills serve as marks that produce

negative stereotypes (Corrigan & Kleinlein, 2005). People who endorse these stereotypes often react emotionally with feelings of fear and resentment, which in turn can result in prejudicial attitudes against individuals who appear to fit the negative stereotype. This prejudicial attitude can then lead to the behavioral response of discrimination (Corrigan & Kleinlein, 2005; Corrigan, Larson & Kuwabara, 2010; Yang, Kleinman, & Cho, 2008).

However, not everyone who possesses traits described above has a mental illness, nor do people with mental illness necessarily exhibit these traits. Some individuals with mental illness are able to conceal their symptoms and perform routine functions. Goffman (1963) described these differences as discredited and discreditable stigma. Individuals with discredited stigma are those who possess characteristics that are readily observable to the public such as a person with a physical disability. In contrast, those who are able to conceal traits have discreditable stigma and often experience less stigma and discrimination than those who have discredited traits. Because not all symptoms are readily noticeable by others, scholars have suggested the concept of labeling as the mark that identifies an individual as a psychiatric patient which results in their becoming stigmatized (Link et al., 1989; Scheff, 1974). When individuals are labeled as having a psychiatric disorder, people may immediately associate them with the negative stereotypes of mental illness and they will then become victims of stigmatization.

### **Mechanisms of Stigma**

#### **Labeling Theory**

Labeling theory is a major sociological perspective often used to describe stigma. Labeling theory rests on symbolic-interaction theory, which highlights the importance of

the socially constructed nature of values, and the significance of interpersonal actions on stigma (Yang et al., 2008).

Scheff applied labeling theory to mental illness in his 1966 book, *Being Mentally Ill*. Scheff (1966) proposed an alternate explanation of mental illness based more on a cultural model than the traditional medical model. The psychiatric perspective of the traditional medical model asserts that individuals who are labeled as mentally ill are, in fact, mentally ill. These individuals exhibit symptoms of mental illness in their behaviors and are therefore marked as mentally ill (Gove, 1980a). In contrast, Scheff claimed that individuals who are labeled with mental illness are, in fact, no different from those who are not labeled, and that it is the culture that defines mental illness. Labeling theory emphasizes the effects of societal attributes on the labeling of mental illness (Gove, 1980b), and suggests a direct link between social reactions and the emergence of mental illness (Link et al., 1989).

According to labeling theorists, when individuals exhibit behaviors that differ from societal norms, society will react to these behaviors by either denying or labeling them (Scheff, 1975). Denying those behaviors means to normalize the behaviors and provide a rationale for them. When denying occurs, labeling theory hypothesizes that the deviant behaviors will subside or be channeled into more acceptable forms by society. However, when the behaviors and the individuals are labeled as deviants, the behaviors persist. Labeling theory suggests that when individuals are labeled as deviant, society subsequently treats these individuals as deviants (Corrigan & Kleinlein, 2005). For example, when individuals are labeled as having mental illness, society will respond to such a label with fear, disgust, and avoidance. Subsequently, when the individuals with



mental illness internalize these negative societal conceptions through a system of punishments and rewards, they adopt those negative beliefs and continue to become chronically mentally ill (Scheff, 1966). For instance, when the “labeled deviant” attempts to resume his or her previous self and status, he or she will at least be distanced by society, possibly be the target of discrimination or even penalized (Scheff, 1966). Such punishment would be the inability to find gainful employment or appropriate housing for which the person is qualified. In contrast, when these individuals show insight about their mental illness and are able to identify their symptoms, they will be rewarded, such as being praised by psychiatrists (Scheff, 1966).

These kinds of punishments and rewards not only constrain individuals to their deviant roles, the individuals will then further internalize these roles into their central identity, which results in chronic mental illness (Scheff, 1966). This internalization is considered secondary deviance, which further contributes to or exacerbates mental illness and symptoms. Individuals who are labeled as deviants are then forced into the deviant group and the group’s subculture (Becker, 1963). Such group membership further enforces the individual’s deviant identity, forming an irreversible socialization process (Gove, 1980b).

Because of its assertion that mental illness is a manifestation of societal influence, labeling theory has received severe criticism over the last few decades. Numerous critics have refuted Scheff’s claims that labeling causes mental illness (Gove, 1980a; Ruscio, 2004). Gove (1980a) believed that people form their perceptions about individuals with mental illness based on their observations of the individuals’ behaviors, not because of the label given. Because mental health stigma has been a serious social issue even before

the formal establishment of any classification of psychopathology, it appears a weak link of causality that the label of mental illness would, in itself, have caused stigma (Ruscio, 2004). Rather, critics of Scheff's claims asserted that the label of mental illness facilitates individuals to access treatment that eventually minimizes the severity of the disorder and reduces the associated stigma (Gove, 1980b; Ruscio, 2004). Gove (1980b) claimed that the effects of hospitalization are not long lasting, and that the stigma does not affect individuals' functioning in the community after their discharge (Link et al., 1989).

Although labeling theorists contend that society is inclined to hinder deviant individuals to resume their previous normal roles, Gove (1980b) emphasized positive aspects of societal reaction that could facilitate the return of labeled individuals to their normal state. For example, society may be more inclined to provide support during the labeled individuals' treatment or training process that helps correct the deviant behaviors. Additionally, labeling may create a positive influence (Ruscio, 2004). When people use a label to explain an individual's deviant behaviors, it is less likely that society will blame the individual for these personality traits, thereby lowering social rejection and blame of the deviant individuals.

An empirical study by Gove and Fain (1973) demonstrated the positive impact of psychiatric hospitalizations and labeling. Extensive interviews with 429 individuals with mental illness illustrated that a large number of participants experienced positive outcomes of their psychiatric hospitalizations and the resulting labeling. They further reported that the hospitalization helped improve social relationships and increase capabilities in problem-solving skills. Additionally, a study with more than 800 college

students showed that most participants agreed that deviant behaviors, not labels, caused social rejection and stigma (Kirk, 1974).

### **Modified Labeling Theory**

Link and colleagues (1989), in contrast, argued that critics of labeling theory downplayed the long-term negative effects and consequences of stigma by overlooking deep-seated prejudices toward people with mental illness. Based on empirical research, *modified labeling theory* addresses the damaging consequences of labeling (Link et al., 1989). Building on Scheff's theory, modified labeling theory focuses on discrimination (i.e., social distance) and devaluation (i.e., loss of status) and outlines a five-step process of the consequences of labeling (Link et al., 1989). First, modified labeling theorists suggested that once individuals are officially labeled with a mental illness through contact with psychiatric treatment, negative societal concepts regarding people with mental illness become relevant to them. Second, once the negative societal perceptions regarding mental illness become relevant to the labeled individuals, they internalize the negative thoughts and believe they are devalued and the target of discrimination. Third, as a result, they respond in three ways toward their stigmatizing status: (a) secrecy in which patients conceal their treatment history, (b) withdrawal or limiting their interactions to those who are aware and accepting of their condition, and (c) educating by disclosing their condition to change negative views at the risk of discrimination (Link et al., 1989). Fourth, modified labeling theorists focus on the negative outcomes of the stigma process. When individuals with mental illness cope with stigma by being exposed to negative community attitudes (Step 1) or respond to their stigma (Step 3), they may feel shame and embarrassment or face discrimination, which results in social isolation,

low self-esteem, and restricted opportunities in life such as un- or underemployment, and delayed or noncompliance with mental health treatment. The four steps can result in a state of vulnerability that, in turn, may increase the chances of repeated episodes of mental illness (Step 5; Link et al., 1989).

Studies conducted based upon the modified labeling theory appear to confirm the negative effects of internalized stigma (Kleim et al., 2008; Link, Cullen, Frank, & Wozniak, 1987; Lundberg, Hansson, Wentz, & Björkman, 2007; Yow & Mehta, 2010). For example, in a study of 593 respondents, Link and colleagues (1987) found that study respondents were inclined to believe that psychiatric consumers would face discrimination and devaluation. In addition, study participants agreed that psychiatric consumers would be rejected by most people and would be excluded from social situations such as friendships, jobs, and intimate relationships despite the absence of deviant behaviors. Psychiatric consumers were likely to endorse one of the coping strategies such as withdrawal and secrecy that modified labeling theory suggested. Furthermore, repeat-treatment-contact consumers had fewer social supports when compared with nontreatment community respondents and untreated cases (those who met the criteria of a *Diagnostic Statistical Manual of Mental Disorders* diagnosis, but were not being treated or officially labeled) after controlling for sociodemographic factors. Another study (Lundberg et al., 2007) found that a majority of study participants (73%) believed employers would disregard applications from former mental health consumers, favoring applications from other applicants. In addition, study participants thought mental health consumers were viewed by others as less trustworthy (67%) and less intelligent (50%) when compared to average citizens. More than half of the study participants

believed psychiatric consumers would face severe devaluation and discrimination. These studies support the notion of modified labeling theory that psychiatric consumers tend to receive less social support from people outside their family, due to the stigma of mental illness.

## **Definitions of Concepts**

### **Internalized Stigma**

Internalized stigma, sometimes called perceived stigma or self-stigma, arises when individuals with mental illness believe in and internalize the negative stereotypes of mental illness endorsed by the general public. The internalization of stigma damages the quality of life of mental health consumers and delays their recovery. According to labeling theory, individuals form conceptions of mental illness such as viewing those with mental illness as being less intelligent, less capable, and undependable by internalizing cultural stereotypes through family teachings, education, and media portraits early on in life (Link, 1987; Scheff, 1966). These conceptions become particularly relevant for individuals who become psychiatric consumers. For example, a study of 127 individuals with a diagnosis of schizophrenia found that 64% of study participants believed they would be seen as societal failures after psychiatric hospitalization (Kleim et al., 2008). In addition, studies of individuals with schizophrenia found that a majority of respondents believed employers would favor other applicants over mental health consumers, and that mental health consumers would not be hired to care for children (Lundberg et al., 2007; Yow & Mehta, 2010). A systematic review that examined eight studies on stigma experienced by individuals with schizophrenia indicated that individuals suffer from internalized stigma especially regarding work, dating, and social

interactions, and believed others in society view them unfavorably (Tan, Klainin-Yobas, & Creedy, 2011).

### **Negative Impacts of Internalized Stigma**

Internalized stigma and its processes may exacerbate one's existing mental illness and cause additional damage including restricted social networks, low self-esteem, low self-efficacy, poor quality of life, and depressive symptoms (Kleim et al., 2008; Rosenfield, 1997; Yanos et al., 2008; Yow & Mehta, 2010). A meta-analysis of 45 studies examining internalized stigma among people with mental illness supported this finding that self-esteem, empowerment, self-efficacy, quality of life, and social support all negatively aligned with internalized stigma (Livingston & Boyd, 2010). This meta-analysis also concluded that high levels of internalized stigma significantly associated with hopelessness ( $r = -.58, p < .001$ ), poorer self-esteem ( $r = -.55, p < .001$ ), decreased quality of life ( $r = -.47, p < .001$ ), and weakened social support ( $r = -.28, p < .05$ ). Internalized stigma linked to greater psychiatric symptom severity ( $r = .41, p < .001$ ) and poor treatment adherence ( $r = -.38, p < .001$ ). A study in Sweden found a positive correlation between internalized stigma and perceived devaluation and discrimination experiences ( $r = 0.45, p = .001$ ; Lundberg et al., 2007).

In contrast, other researchers contended that people have divergent reactions to stigma and not all mental health consumers internalize stigma or experience loss of self-esteem (Watson, Corrigan, Larson, & Sells, 2007; Watson & River, 2005). Some consumers become empowered through group identification as "persons with mental illness" and by believing that the stigma is unjust (perceived legitimacy). Furthermore, noting only a modest association between stigma and self-esteem, Thoits (2011) asserted

the need to incorporate stigma resistance into classical and modified labeling theory. Thoits (2011) found evidence of stigma resistance from previous research. For example, about 50% of hospital patients with severe psychiatric disorders did not identify themselves as mentally ill whereas another 35–45% of clubhouse participants did not feel different or ashamed because of their mental illness (Doherty, 1975; Estroff, Lachicotte, Illingworth, & Johnston, 1991; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2002; Warner, Taylor, Powers, & Hyman, 1989). Moreover, a study by Ritsher and Phelan (2004) reported high level of stigma-resisting beliefs such as mental health consumers can also have a good and fulfilling life, among 25% of a Veterans Administration outpatient sample. Thoits (2011) suggested two forms of stigma resistance: challenging and deflecting to protect individuals from devaluation. Challenging involves “pushing back” others’ negative views or actions, whereas deflecting means “deliberately blocking an outside force” without engaging in conflict (p. 11). Thoits (2011) asserted that challenging others’ negative beliefs reinforces a sense of empowerment and may raise one’s self-esteem; however, confronting others may also risk damaging interpersonal relationships. When one uses deflecting to resist stigma, he or she forms a “cognitive shield” against discriminatory behaviors and is able to maintain self-esteem (Thoits & Link, 2016, p. 3). I discuss these stigma-resisting coping strategies and their effects further in the coping strategies section.

### **Experienced Stigma**

It has long been recognized that the harmful labels of mental illness, specifically schizophrenia, result in rejection and discrimination of people with the illness in addition to internalized stigma. People with mental illness often experience stigma on an

individual level (also known as public stigma or social stigma) and a structural level (also known as institutional stigma). On an individual level, some of the most cited sources of stigma include employers, family members, and general community members (Świtaj et al., 2012). Employers and supervisors treat many people with mental illness are treated as less competent by employers and supervisors, and are less likely to be employed (Arthur, Knifton, Park, & Doherty, 2008; Dickerson et al., 2002; S. Lee et al., 2006; Link et al., 2002; Świtaj et al., 2011). A national survey of 1,301 mental health consumers showed that even when people with mental illness were employed, they often found their coworkers or supervisors were unsupportive and unaccommodating after learning of their illness (Wahl, 1999). In addition, individuals with mental illness often experience being shunned and avoided by others (Dickerson et al., 2002; El-Badri & Mellsop, 2007; Wahl, 1999). Link and colleagues (2002) found, in their study of 88 consumers in a community-based psychiatric rehabilitation clubhouse, that half of the respondents reported being treated differently after being hospitalized, whereas 45% of them were being avoided by people with whom they normally associated.

Regarding stigma from community members, studies reported that mental health consumers often heard others speaking unfavorably about people with mental illness (Depla et al., 2005; El-Badri & Mellsop, 2007; Świtaj et al., 2011). These stigma experiences on an individual level have a damaging impact on the affected person's mental health. Stigma negatively aligns with stigmatized people's quality of life (Depla et al., 2005; El-Badri & Mellsop, 2007; Lundberg et al., 2008; Świtaj, Wciórka, Smolarska-Świtaj, & Grygiel, 2009) and self-esteem (Wahl, 1999). These experiences also triggered social avoidance (Wahl, 1999) and emotional distress (S. Lee, Lee, Chiu, & Kleinman,



2005; Wahl, 1999). Wahl (1999) found that 95% of study participants reported feeling a lasting negative impact from stigma and over half experienced diminished self-esteem.

In addition to experiencing stigma on an individual level, people with mental illness experience structural forms of stigma, a driving force of health disparity (Hatzenbuehler, Phelan, & Link, 2013). Similar to discrimination relating to race, ethnicity, and sexual orientation, several stigma-induced processes, including the availability of resources, interpersonal relationships, psychological and behavioral responses, and stress, contribute to adverse health outcome among people with mental illness. They experience reduced resources in the areas of employment, wages, housing, education and health care. For example, individuals with mental illness receive fewer overall insurance benefits than the general public (Druss, Allen, & Bruce, 1998; Tovino, 2012), and many health insurance companies offer only minimal mental health coverage to consumers at large (Cohn, 2015). For example Medicare Part A, a public healthcare program that provides medical insurance for individuals over age 65 or those under 65 with certain disabilities restricts beneficiaries to a lifetime maximum of 190 days of inpatient mental health treatment in a psychiatric hospital. However, this program does not restrict nonpsychiatric inpatient treatment (Tovino, 2012). Moreover, individuals with mental illness generally receive less medical services than those who do not have a diagnosed mental illness perhaps due to inadequate health insurance (Druss et al., 1998, Sipe et al., 2015). About one-third of study participants had been turned down for health insurance because their mental illnesses were considered “preexisting conditions” (Wahl, 1999, p. 472). In addition, these individuals were often denied psychiatric treatment because their health insurance was not sufficient to pay for the treatment (Wahl, 1999).

In addition, stigma has a negative effect on one's status and interpersonal influence. Evidence also shows that stigma causes social isolation, which is linked to poor health outcomes. Moreover, having to cope with stigma would, over time, diminish individuals' ability to effectively regulate their emotions, and people with mental illness can engage in maladaptive mechanisms to cope with stigma. Lastly, being exposed to chronic conditions, such as discrimination and unfair treatment, leads to increased stress that compromises the individual's health. Two major sources of discrimination and unfair treatment faced by people with psychiatric conditions are hurtful media representations and unequal treatment by healthcare providers (Arthur et al., 2008; Forrester-Jones & Barnes, 2008; Link & Phelan, 2001b). While people in society hold damaging stereotypes relating to schizophrenia, media sources such as films, newspapers, and television programs further portray and label individuals with this illness as crazy killers, incompetent beings, "psychos" and "nut cases" (Arthur et al., 2008; Sullivan, Hamilton & Allen, 2005, p. 305; Watson & Corrigan, 2005). The media plays a major role in contributing to mental health stigma and providing misinformation about mental illness (Wahl, 2003). The sensationalism in the media's portrayal of people with psychiatric disorders often attracts public attention and brings the media industry financial rewards and acclaim (Wahl, 2003). These messages further intensify and reinforce the negative treatment people with mental illness receive in their daily lives.

Although many assume that mental health professionals hold more positive attitudes toward people with mental illness because of their education and frequent contacts with mental health consumers, studies have found otherwise. Many mental health professionals' beliefs are no different from those of the general public, and may be

even more negative (Jorm et al., 1999; Lauber, Anthony, Ajdacic-Gross, & Rossler, 2004; Servais & Saunders, 2007). Psychiatrists often hold negative stereotypes specifically of consumers diagnosed with schizophrenia as dangerous and incapable (Lauber et al., 2004; Üçok, Polat, Sartorius, Erkoc, & Atakli, 2004), and are also likely to maintain social distance from them (Lauber et al., 2004; Nordt et al., 2006). Other medical professionals including nurses and psychologists also hold negative attitudes about social distance, marrying, or working with someone with schizophrenia (Ishige & Hayashi, 2005; Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2004). These mental health professionals often believe people with mental illness are ineffective, undesirable, and unable to control their emotions, and that people in the society risk harm from those who have a mental illness such as schizophrenia (Ahmead, Rahhal, & Baker, 2010; Servais & Saunders, 2007).

Stigma negatively influences individuals in the areas of interpersonal relationships, material resources, rights and identity, discrimination, and stereotypes by community, families, friends, colleagues, mental health professionals, and media portrayals (Hatzenbuehler et al., 2013; Tan et al., 2011). These stigma processes increase the risk for adverse health outcomes that ultimately contribute to health inequality among people with mental illness.

### **Coping With Stigma**

Individuals with stigmatizing statuses respond to and cope with their situations differently. Individuals with mental illness have three main coping responses: secrecy, withdrawal, and educating others (Goffman, 1963; Jones et al., 1984; Link et al., 1989; Schneider & Conrad, 1980). One coping resource is the management of information

about mental illness. Using secrecy, individuals with mental illness conceal their mental illness and treatment history from relatives, friends, and employers to avoid rejection (Goffman, 1963; Link, Mirotznik, & Cullen, 1991). Goffman (1963) described the act of concealing one's stigmatizing condition as "passing" (p. 42). Goffman believed most people would choose to disguise their condition on some occasions due to the assumed societal virtue and reward in being considered normal. Another coping strategy is withdrawal, such that people limit their social interactions with those who have similar conditions and those who would accept their mental illness. Goffman classified people who are accepting into two groups: "the own" and "the wise" (p. 19), who are people who share the same condition and people who accept and sympathize with people with the stigmatizing condition. The "wise" could be people who work with the stigmatized individuals such as nurses, doctors, or therapists. When individuals employ the strategy of withdrawal, they could avoid rejection from others in society. However, the use of secrecy and withdrawal as coping strategies often results in negative outcomes such as discrimination, social isolation, low self-esteem, restricted opportunities in life such as employment, and delayed or in adherence to mental health treatment (Link et al., 1989).

Although some individuals respond to their illness with secrecy and withdrawal, others choose to educate others regarding mental illness. This "preventive telling" aims to provide others with accurate information about mental illness to decrease negative attitudes toward individuals with mental illness (Link et al., 1991; Schneider & Conrad, 1980). Secrecy and withdrawal as coping strategies positively correlated with a higher degree of perceived stigma, whereas educating others negatively aligned with a higher degree of perceived stigma (Kleim et al., 2008; Yow & Mehta, 2010). Educating others

necessitates self-disclosure of one's own mental illness. However, whether to disclose one's illness is not a clear-cut decision because of the potential cost and benefit associated with disclosure.

Drawing from research on the lessons learned from revealing one's orientation in the lesbian, gay, bisexual, and transgender community, Corrigan (2005) made some parallel comparisons with disclosure among persons with mental illness. Corrigan suggested that experiences with social disapproval or isolation could cause a negative impact on one's self-esteem and self-efficacy. In addition, people with mental illness who choose to disclose may experience job and housing discrimination. Furthermore, individuals who have disclosed their mental illness may be coerced to receive mandated, involuntary psychiatric treatment, possibly due to preconceived impressions or misunderstandings. In contrast, advantages also accrue from disclosing one's mental illness. Jones and colleagues (1984) believed that stigmatized persons were less adversely affected, felt more at ease, and felt less tense and less self-conscious if their condition were known by those with whom they interacted. In addition, Corrigan et al. (2010) found that individuals who disclosed their mental illness generally felt better about themselves and that the shame associated with mental illness decreased. Furthermore, individuals who disclosed their mental illness received more support from those who shared a similar illness, as well as from other people (Corrigan et al., 2010).

Amid the advantages and disadvantages of disclosing, many individuals with mental illness continue to avoid telling others about their conditions (also see Table 1). Wahl (1999) found that the majority of respondents (74%) avoided telling others outside their immediate families about their illness. However, they remained fearful that their

illness would be discovered. Another study of 500 mental health consumers revealed that the majority of consumers were unwilling to disclose their mental health conditions to acquaintances and colleagues because of their perceived high level of stigmatization from this group (Bos, Kanner, Muris, Janssen, & Mayer, 2009).

Table 1

*Advantages and Disadvantages of the Different Coping Strategies*

Coping strategies	Pros	Cons
Social Avoidance and Secrecy	Avoid potential rejection and discrimination	Remain fearful that their condition would be found out Higher level of anxiety Feel guilty and shameful Restricted social network Possibly increased rate of relapse
Selective Disclosure/Concealment	Receive support	Being shunned Experience discrimination
Indiscriminant Disclosure	Less anxiety Less self-conscious Receive support	Experience discrimination May be coerced to receive mandated psychiatric treatment
Broadcasting/Educating/Political Activism	Feel empowered	Experience discrimination May be coerced to receive mandated psychiatric treatment

As with the decision to disclose, coping with secrecy and withdrawal also has its costs and benefits. As stated earlier, individuals who decide to keep their mental illness a secret or withdraw from people may be able to avoid potential rejection and discrimination. However, harmful outcomes from these coping strategies also may accrue. Individuals who choose to hide their illness may feel guilty for not revealing their situation to intimate others (Goffman, 1963). The feeling of guilt and shame for hiding the stigmatizing conditions may lead to fear of being discovered, and therefore negatively influence social interactions (Jones et al., 1984). Withdrawal and secrecy as coping strategies are widely considered dysfunctional coping in that they reduce social contacts

and constrict social networks (Kleim et al., 2008). Social withdrawal often aligns with worse outcomes in individuals with schizophrenia (Robinson et al., 1999). In addition, these dysfunctional coping strategies often lead to an increased rate of relapse and rehospitalization (Larsen, Johannessen, & Opjordsmoen, 1998; Robinson et al., 1999), and tend to lead to a higher level of anxiety (Vauth, Kleim, Wirtz, & Corrigan, 2007; Yow & Mehta, 2010).

Recently, Thoits and Link (2016) proposed alternative stigma-resisting strategies that could lead to higher self-esteem and lower depressive symptoms. A study of 65 individuals with severe mental illness from four psychiatric hospitals in New York City (NYC) and New Jersey found that study participants who used secrecy or avoidance strategies had poorer self-esteem and more depressive symptoms. In contrast, participants who challenged devaluation and discrimination had higher self-esteem and those who used deflection as a strategy had higher self-esteem and a more satisfactory quality of life. It is crucial to examine the association between stigma and these coping strategies, which is the focus of this dissertation. Results may allow professionals to design appropriate interventions to minimize negative consequences.

Because people experience advantages and disadvantages from keeping their illness a secret rather than disclosing, the choice of disclosure or secrecy is a difficult decision for those suffering from mental illness. An ethnographic study conducted by Herman (1993) comprehensively examined four types of information management in coping with the stigma of mental illness: selective concealment, therapeutic disclosure, preventive disclosure, and political activism. Individuals who practice selective concealment have to make decisions about to whom to disclose their illness. They make

their decision based on their perception of who they consider “safe others” or “risky others” (Herman, 1993, p. 307). They base their decisions on prior experiences with different types of people with whom they have shared the information. Herman described a hierarchical pattern of selective disclosure, according to the degree of closeness. For example, people with mental illness generally share the information regarding with family members first, followed by close friends and then acquaintances. Some common selective concealment strategies include avoidance of selected “normals,” withdrawal, the use of disidentifiers, and the avoidance of stigma symbols. For avoidance of selected “normals,” one would avoid interacting with “risky others” as well as redirecting conversations to mask the mental illness. Others who choose to withdraw would choose not to interact with others. Those who use disidentifiers would make jokes about people with mental illness or protest against them. Another form of selective concealment is through the avoidance of stigma symbols such as avoiding contact with friends who also have mental illness and avoiding treatment. Herman asserted that selective concealment is a temporal process and the majority of mental health consumers would move from secrecy to alternative disclosure strategies.

The next step, therapeutic disclosure involves disclosing a discreditable attribute to some trusted others including family members, close friends, and other mental health consumers. Therapeutic disclosure helps relieve anxieties and frustrations, elevate one’s self esteem, and allow for “renegotiation of personal perceptions of mental illness as a discreditable attribute” (Herman, 1993, p. 312).

Third, preventive disclosure means disclosing a discreditable attribute to selected individuals who do not have a mental illness to influence others’ attitudes toward people



with mental illness. For example, one would disclose mental illness early in a relationship to prevent future rejection as the relationship moves forward. People commonly use four methods of preventive disclosure: medical disclaimers, deception or coaching, education, and normalization. When using medical disclaimers, individuals explain their mental illness through a medical interpretation that focuses on the biochemical aspect of the illness to transfer the responsibility out of the self and to evoke sympathy. Another method of preventive disclosure is deception or coaching that involves being coached by people such as parents, close friends, spouses, and other individuals who share the same conditions in distorting one's condition to present their illness in the least stigmatizing manner. Education is the third kind of preventive disclosure that aims to inform people, providing accurate information about mental illness. However, the effort to educate others may not be successful for certain individuals in that people with mental illness have to make judgments as to whom to educate. Last, mental consumers may use normalization as a form of preventive disclosure. They would participate in various activities to show they are capable of performing like people without mental illness. They also attempt to get people to focus on their positive attributes instead of their stigmatizing condition.

The last type of information management of mental illness is political activism. With the goal of self-affirmation, political activism has a threefold function: (a) to reject the labels placed on individuals with mental illness, (b) to provide people with mental illness with a positive identity and to enhance a new sense of purpose, and (c) to produce a new and positive image to others in the society. In contrast to other management strategies that cope with an individual's own perceptions about mental health stigma,

political activism considers stigma a societal issue. Activists attempt to promote social change by countering or removing the stigma attached to mental illness through activities such as demonstrations, rallies, and attending conferences regarding consumers' rights, for example. Through participation in such activist groups, individuals with mental illness internalize beliefs that reject societal values and negative stereotypes that are placed on people with mental illness; instead, they adopt a more positive identity.

A growing number of studies have focused on internalized stigma, experienced stigma, and coping strategies among individuals with mental illness (e.g., Depla et al., 2005; Dickerson et al., 2002; El-Badri, & Mellsop, 2007; Fung, Tsang, & Corrigan, 2008; Kleim et al., 2008; Lauber et al., 2004; Lundberg et al., 2008; Świtaj et al., 2011; Vauth et al., 2007; Yanos et al., 2008). However, a paucity of studies investigated the experiences of stigma and accompanying coping strategies among Chinese-immigrant populations with mental illness. Given the rapid increase in the number of Chinese immigrants to the United States, it is imperative for mental health professionals to understand how Chinese immigrants cope with the stigma associated with mental illness to facilitate effective services to support their recovery. It is particularly important to understand how culture shapes stigma experience and coping responses. The diagnoses of mental illness and its stigma deeply tie to culture, and when studying mental illness stigma, researchers should be cautious to resist grouping everyone as if they share the same experience (Abdullah & Brown, 2011). Stigmatizing attitudes and related behaviors toward mental illness vary by culture (Abdullah & Brown, 2011; Rao, Feinglass, & Corrigan, 2007). Specific cultural beliefs shape public views and self-stigma about mental illness. One's cultural history, socialization and culturally informed attitudes

toward mental illness determine whether one endorses a stereotype. In addition, once one endorses a stereotype of mental illness, such cultural values influence whether one expects discrimination and stigmatization. Therefore, understanding how culture influences stigma is essential when researchers examine mental illness stigma.

In the following section, I first present an overview of Chinese immigrants and mental illness in the United States. Because of the paucity of studies on Chinese immigrants with mental illness, I review specific cultural aspects of stigma and coping in this population by reviewing studies that have been conducted in the United States, China, and Taiwan.

### **Chinese Immigrants in the United States**

Chinese Americans form the largest subgroup among Asian Americans (27%) with a population of 4 million (U.S. Census Bureau, 2010). The U.S. Chinese population has increased by 40% since the year 2000. New York City (NYC) has the largest Chinese population of any city outside of Asia (New York City Planning, 2016). An average of 552,550 Chinese (including Chinese, Taiwanese, Hong Kongese, or Cantonese), about 7% of the city's overall population, lived in NYC between 2010 and 2014 (New York City Department of Health and Mental Hygiene, 2017). About 33.6% of Chinese immigrants in NYC came to live in the United States in the year 2000 or later (Asian American Federation, 2013). Chinese residing in NYC had less schooling than the citywide population. In the adult Chinese population in 2011, 38% did not have a high school diploma, compared with 21% of the citywide population. In addition, 61% of Chinese reported having limited English proficiency (someone who spoke English "well,"

“not well,” or “not at all”) in 2011, significantly higher than the citywide figure of 23% (Asian American Federation, 2013).

Chinese also had a lower income than the general population in NYC. Their per capita income was \$23,315, lower than the citywide figure of \$30,717. They also tended to have larger households (averaging 3.12 people) compared to 2.63 of the average NYC household. About 15% of Chinese households had more than one occupant per room compared to 9% of general NYC households that had more than one occupant per room (Asian American Federation, 2013)

Despite no adequate prevalence estimates of schizophrenia among Chinese Americans, one study found that Chinese Americans have the highest lifetime prevalence of depression (10.1%) among all Asian American groups (Takeuchi, Alegria, Jackson, & William, 2007). In addition, migration was identified as a major factor that affects individuals' mental health. A study found that first-generation immigrants are 2.5 times more likely to develop a psychotic disorder compared with their native-born counterparts (Bourque et al., 2011).

Although mental illnesses affect Asian Americans similar to their effects on other ethnic groups, Asian Americans are less likely to seek mental health services compared to European Americans (S. Y. Lee, Martins, Keyes, & Lee, 2011; U.S. Department of Health & Human Services, 2001). Several cultural and structural factors can be attributed to the underuse of services among this population (Weng & Spaulding-Givens, 2017): (a) cultural, language, knowledge, and transportation barriers; (b) impact of the model-minority myth; and (c) service and policy needs of immigrants. Many Asian Americans find mental health issues to be shameful and embarrassing and are reluctant to talk and

express their feelings. In addition, they fear being ostracized, losing the respect of others, and losing face, thereby bringing dishonor to the family. Moreover, the language barrier is a reason Asian Americans, especially older adults who migrated to the United States later in life, do not seek services. Linguistically appropriate services may not be readily available for the many subgroups of Asian Americans who speak different dialects.

Another barrier is the lack of knowledge of available mental health services in the community and ways to access the complicated mental health system. Lack of transportation can also be in issue for people who live in areas where public transportation is not readily available.

The model-minority myth, in which Asian immigrants are stereotyped as being successful and wealthy, often leads to the perception that the Asian community has minimal needs (Weng & Spaulding-Givens, 2017). This minimization of needs can lead to the invisibility of this racial minority in the areas of policymaking and program development.

Moreover, refugees, older adults, and undocumented immigrants have specific challenges that affect their ability to access mental health services (Weng & Spaulding-Givens, 2017). Many refugees lack health and mental health education and therefore may not be able to seek assistance when issues arise. Older adults who moved to the United States later in life also have a more difficult time integrating into mainstream society, due to language barriers and limited social interactions. Last, undocumented immigrants experience additional stress due to their legal status. They fear being caught and face pressure to pay off smuggling debts. Employers, immigration lawyers, and landlords may

have taken advantage of them. These cultural and structural factors negatively impact Asian Americans' use of mental health services.

### **Stigma Experiences Among Chinese Individuals With Severe Mental Illness**

Studies conducted in China reported similar types of discrimination toward people with mental illness as those reported in the United States (Chien, Yeung, & Chan, 2012; Chung & Wong, 2004; S. Gao, Phillips, & Wang, 2005; S. Lee et al., 2005). Researchers indicated that these individuals experience stigma on individual and structural levels. A study in Hong Kong, examining employers' attitudes toward hiring people with psychotic disorders, found that 86% of the 30 employers queried expressed concern about safety threats posed by individuals with psychotic disorders to fellow employees or customers (Tsang et al., 2007). In addition, 50% of employers also worried about unpredictable and erratic behaviors of individuals with mental illness. A study in Hong Kong revealed that more than a third of the 480 participants reported being treated negatively by friends and employers after revealing their mental illness (S. Lee et al., 2005). Furthermore, more than half of participants reported they perceived their families and spouses regarded them as highly violent. Another study in mainland China among individuals with schizophrenia disclosed that a majority of participants reported moderate to severe effects of stigma on their lives (Phillips, Pearson, Li, Xu, & Yang, 2002).

Other studies in China (Chung & Wong, 2004; Chien et al., 2012) also found that mental health consumers experienced structural discrimination including offensive media portrayal of mental illness and negative stereotype beliefs among mental health professionals. Mental health professionals in Hong Kong held negative stereotypes against individuals with severe mental illness (Chien et al., 2012). Some major

stereotypes professionals held were that people with mental illness were unpredictable, weird, abnormal, and emotional. In addition, mental health professionals believed individuals with severe mental illness should be admitted to psychiatric hospitals against their will, have their driving licenses revoked, and enforce abortion in case of pregnancy.

In addition to experiencing stigma on individual and structural levels, Chinese individuals with severe mental illness also suffer from internalized stigma. In Hong Kong, researchers found that many psychiatric consumers believed employers would not hire people with a history of mental illness and their chance of a promotion at work would be greatly affected if their mental illness were revealed (Chung & Wong, 2004; S. Lee et al., 2005). Some also believed they would be fired if their employers found out about their history of mental illness. Moreover, many individuals with severe mental illness felt they were being despised or disliked by family members, believed friends would distance themselves, and anticipated partners would end their relationship.

Another study in China found that 70% of participants experienced mild to moderate level of internalized stigma (Lv, Wolf, & Wang, 2013). More than half of study participants reported feeling out of place in the world because of their mental illness, and more than 60% of them believed mental illness has spoiled their lives. Another 50% disagreed or strongly disagreed that people with mental illness make important contributions to society. A more recent study conducted in Taiwan found that Taiwanese participants diagnosed with schizophrenia had a higher level of internalized stigma than their counterparts in Western societies (Hsiao, Lu, & Tsai, 2017). In addition, stressors relating to stigma aligned with diminished quality of life and family sense of coherence.

Interestingly, a number of studies noted that Chinese consumers did not report high rates of direct discrimination and rejection (Chien et al., 2012; Chung & Wong, 2004). One hypothesis is that these individuals are more inclined to keep their mental illness a secret and are more likely to withdraw from social situations, resulting in less direct discrimination (Chien et al., 2012; Chung & Wong, 2004).

One of the few studies that examined Asian Americans with mental illnesses revealed similarity and differences in their stigma experience compared to other ethnic groups (Wong, Collins, Cerully, Seelam, & Roth, 2016). Asian Americans comprised 7% of the total of 1,066 study participants. Asian Americans reported higher level of self-stigma and were less hopeful than White participants that people with mental illness could make a contribution to society. Asian Americans also were more likely to feel alienated because of their mental health issues comparing to Whites. This study found that 95% of Asian American participants felt inferior to those who did not have a mental health problem. In contrast, a significantly higher number of Asian American participants agreed that individuals with mental illness can lead a normal life, with treatment, when compared to White participants.

### **Coping Strategies Among Chinese Individuals**

Studies identified secrecy as one of the most frequently endorsed coping strategies among Chinese individuals suffering from severe mental illness (Chien et al., 2012; Chung & Wong, 2004; S. Lee et al., 2005; Lv et al., 2013). In addition, this population commonly practiced avoidance and withdrawal. For example, Lv and colleagues (2013) found that 70% of study participants in China avoided telling those outside their immediate family about their psychiatric illness, whereas S. Lee et al. (2005),



in a study conducted in Hong Kong, indicated that more than half of participants deliberately concealed their mental illness from friends and coworkers. Moreover, a study of 90 mental health consumers with schizophrenia in Singapore (with close to 80% of the participants being Chinese) found that among the five studied coping strategies, secrecy was the most highly endorsed strategy adopted by respondents; educating others was the least endorsed strategy (Yow & Mehta, 2010). In a Taiwanese study, participants chose to withdraw from others to keep their illness private (Hsiao et al., 2017). These studies suggested that Chinese individuals with severe mental illness and their families choose not to disclose or disclose only to a limited number of friends and relatives to preserve the face of the individuals and their families.

### **Chinese Traditional Beliefs and Stigma**

Confucianism and its principles especially influence Chinese populations and people frequently experience pervasive stigma that stems from these historical and cultural influences. Confucian practices emphasize social harmony and social order above the individual. Only when societal values are met first, individual needs will be served. Members of society must fulfill their family and work roles and responsibilities in society to achieve personal harmony with others (C. H. Ng, 1997; Yang, 2007). One's inability to meet one's responsibility will bring social discord for individuals and their families. For example, society expects an individual to perform his/her duty in a family by providing material and emotional support. This tenet of society perceives a person diagnosed with mental illness, particularly schizophrenia, as dependent and unable to fulfill this role; consequently, the individual is seen as unproductive to society and therefore censured and rejected by others. In addition to stigma jeopardizing interpersonal

engagement, mental illness and its stigma also threaten *what matters most* to Chinese immigrants. For these immigrants, their core lived values and motivation include making money, supporting their family in China, continuing their family lineage, and attaining U.S. citizenship (Lai et al., 2013). Being excluded from partaking in these engagements with their acquaintances because of mental illness stigma diminishes one's sense of connectedness with the community.

In a study of Chinese Americans with severe mental illness, study participants expressed that not being able to engage in gainful employment intensified stigma and social vulnerability against them (Yang et al., 2014). In addition, their inability to work could also negatively affect other aspects of their lives such as marriages and relationships with family members (Yang et al., 2014). Some Chinese view mental illness as a result of moral transgressions against ancestors, thus the family is also held liable (C. H. Ng, 1997). Another study reported that Chinese American participants were more likely to believe that people with mental illness should not get married or have children, compared to their European American participants (Yang et al., 2013). Chinese American participants were also more likely to endorse genetic screening before marriage, and that it was critical to know their potential marriage partner's family history of mental illness (Yang et al., 2013). Mental illness is regarded as hereditary; therefore, individuals with mental illness and even their siblings may be excluded from marriage (C. H. Ng, 1997). Not being able to marry means individuals would be unable to perpetuate the family line, which causes further disgrace and guilt.

## Loss of Face

Face is another element critical to functioning and socializing in the Chinese community. The idea of face is of Chinese origin (Ho, Fu, & Ng, 2004). It is described as tree bark in an old Chinese saying, implying its protective and essential role for an individual (G. Gao, 1998). Face has two major components: *lian* and *mianzi*. *Lian* refers to one's social conduct, acquired by an individual behaving appropriately to meet social standard or norms. *Lian* is respect given to someone with a good moral reputation (Hu, 1944). Furthermore, *lian* represents personal and familial dignity (Earley, 1997), viewed as a prerequisite to participating in special relationship networks known as *guanxi* (Lai et al., 2013). One gains *mianzi*, in contrast, through one's own effort and performance, and is bestowed by others in society (Huang, 2004; Hwang, 1997). One achieves *mianzi* through success and ostentation, accumulated through personal effort or careful planning (Hu, 1944). Individuals who are high on the social ladder are more likely to have greater *mianzi* than those who occupy a lower social status. *Mianzi* is a representation of social power that allows individuals to partake in the interpersonal world (Lewis-Fernandez & Kleinman, 1994). Face directly aligns with one's social power in the Chinese community. Having face allows individuals and their families to extend social networks, thereby increasing the family's social standing and influence in the community (Yang, 2007).

Losing face is "a condemnation by the group for immoral socially disagreeable behavior" (Hu, 1944, p. 46). Losing face is a damaging social event in which one is judged by others, and has unfavorable implications for one's social functioning (Ho et al., 2004). In addition, losing face always affects the reputation of the whole family, not only the individual who is being judged (Hu, 1944). Despite occasions when an individual

does not associate losing face with dysphoric emotions (e.g., the individual being in denial or emotionally detached), feelings of shame, embarrassment, humiliation, and guilt often relate to losing face (Ho et al., 2004; Yue, 1994). Shame often accompanies the fear of being humiliated by others due to one's failure and weakness, although the failures or weaknesses may not be under the control of the individual (Ho et al., 2004). Shame also often ties to loss of face in some Asian languages. Similarly, embarrassment is considered a loss of composure comparable to a minor loss of face (Ho et al., 2004). When individuals with mental illness are regarded as useless and crazy, they are seen as being unable to fulfill their personal responsibilities to meet the cultural norm (socially agreeable behavior), and therefore lose face (*lian*). In addition, others in society are unlikely to grant these individuals any *mianzi*, making it impossible for them to participate and engage in interpersonal relationships.

The stigma and the shame involved in mental illness causes the loss of face for the entire family, accompanied by their inability to participate in what matters most in their community, thereby losing their social power to engage in the interpersonal world among other individuals (Yang & Kleinman, 2008). As a result, these community attitudes severely marginalize individuals with mental illness and their families, viewing them as less than human. These traditional beliefs and the importance of face in participation in social relationships and engagement shape the specific meaning of stigma in the Chinese cultural group in the United States.

Studies indicate that Stigma and the desire to keep one's mental illness a secret directly aligns with the underuse of and poor adherence to mental health services (Fung et al., 2008; Shea & Yeh, 2008; Yang & Kleinman, 2008; Yang, Phelan, & Link, 2008).

This phenomenon is particularly acute among Chinese American individuals with severe mental illnesses. Given the seriousness of the issue of stigma and its harmful consequences, further compounded by cultural factors, examining stigma among Chinese immigrants with mental health issues is crucial. It is imperative for the social work profession to explore the stigma experience and its manifestation in the specific cultures and subcultures of the Chinese-immigrant population. This study, therefore, focuses on the stigma experiences of Chinese American immigrants with mental illness.

Understanding how this group copes with stigma will not only assist in the development of more culturally appropriate services and interventions but will facilitate treatment adherence and successful recovery among this understudied and hard-to-reach population.

## Chapter 3

### Methodology

In this chapter, I present the research questions and hypotheses of the study. In addition, I discuss the research design, recruitment procedure, measurements, and data analyses.

#### **Research Questions and Hypotheses**

##### **Research Questions**

- RQ1 What are the characteristics of internalized stigma and experienced stigma that are reported by Chinese American individuals with schizophrenia spectrum disorders?
- RQ2 What types of coping strategies do Chinese American individuals with schizophrenia spectrum disorders adopt in managing the disclosure of their mental illness?
- RQ3 To what extent do Chinese American individuals with schizophrenia spectrum disorders report the experience of loss of face?
- RQ4 What are the associations between the study participants' levels of internalized stigma and coping strategies?
- RQ5 What are the associations between coping strategies and levels of experienced stigma?
- RQ6 What are the associations between the participants' experience of loss of face and coping strategies?

## **Hypotheses**

- Ho1 Chinese American individuals with schizophrenia spectrum disorders will be more likely to report stigma experiences related to interpersonal relationships, especially those relating to intimate relationships.
- Ho2 Chinese American individuals with schizophrenia spectrum disorders will adopt coping strategies that are secretive with limited disclosure regarding their mental illness.
- Ho3 Chinese American individuals with schizophrenia spectrum disorders will report experiencing a high level of loss of face.
- Ho4 A high level of internalized stigma will be associated with higher levels of secrecy and limited disclosure about their mental illness among Chinese American individuals with schizophrenia spectrum disorders.
- Ho5 A high level of experienced stigma will be associated with higher levels of secrecy and limited disclosure about their mental illness among Chinese American individuals with schizophrenia spectrum disorders.
- Ho6 A high level of experience of loss of face will be associated with higher levels of secrecy and limited disclosure about their mental illness among Chinese American individuals with schizophrenia spectrum disorders.

## **Research Design**

This study uses data from a study on stigma and expressed emotions among Chinese American immigrants with psychosis, funded by the National Institute of Mental Health (Yang et al., 2014). Data accrued using a cross-sectional survey design with face-to-face semi-structured interviews to examine experiences of stigma among Chinese

American immigrants with schizophrenia spectrum disorders. Interviews took place between 2006 and 2010.

### **Study Participants**

Participants meeting the following criteria participated in the study:

1. Adults 18 years or older of Chinese descent
2. Mandarin and/or English speaking
3. Hospitalization within 1 month of the interview
4. Co-residing with a family member after hospitalization
5. Diagnosed with schizophrenia, schizoaffective or psychotic disorder not otherwise specified as determined by the Structured Clinical Interview for DSM-IV Diagnoses (SCID, Spitzer, Williams, Gibbon, & First, 1992) or the Chinese-bilingual SCID (So et al., 2003). The Chinese-bilingual SCID was tested to be reliable and valid among Chinese individuals (So et al., 2003; Zhou, Zhang, Peng, Lie, & Zhu, 1997).

The research team recruited participants simultaneously from inpatient psychiatric units at two major NYC hospitals. A total of 56 participants participated in the study. Because of the severe stigma attached to mental illness among Chinese immigrants, this is the largest-known sample of Chinese immigrants with psychosis available to examine stigma. Hospital psychiatrists who were unaffiliated with the study determined participants' capacity to consent. The research team presented written consent in Chinese or English to participants and verbally explained a brief description of the study and its procedure. Further, the research team explained the risks and benefits associated with participating in the study and the voluntary nature of participation. In addition, the team



emphasized confidentiality by informing study participants that no identifying data would be revealed in any published results from the study.

### **Procedures**

This study was approved by the University Committee on Activities Involving Human Subjects at New York University. Using Mandarin Chinese or English, whichever participants preferred, two bilingual interviewers who were psychologists conducted face-to-face structured and semi-structured interviews. The interviewers filled out participants' responses on the questionnaires. Study participants first responded to the survey questions by giving an ordinal ranking, and for one scale, the interviewers asked participants to explain their responses to obtain narrative data. All questionnaires and the interview guide were translated by a professional translator into Mandarin Chinese and then back translated to English to ensure accurate interpretation. The team audiotaped all interviews and transcribed them verbatim. Bilingual and bicultural graduate students studying social science translated interviews conducted in Mandarin Chinese into English. Each participant received \$80 upon completing the study and being discharged from the inpatient unit.

### **Presentation of Variables**

#### **Participant Demographics**

Collected participant demographics included (a) gender, (b) age, (c) years of education, (d) country of birth, (e) marital status, (f) religious affiliation, (g) employment status, (h) participant income, (i) onset age of illness, (j) duration of illness, (k) number of psychiatric hospitalizations, and (l) duration of the most recent hospitalization.

### **Internalized Stigma**

Internalized stigma means individuals with a mental illness believe and internalize negative stereotypes regarding mental illness that the general public endorses (Link et al., 2002).

### **Experienced Stigma**

Experienced stigma is when individuals with mental illness experience negative attitudes and behaviors such as rejection and discrimination from others in society (Corrigan et al., 2010).

### **Coping Strategies**

Individuals with a mental illness develop coping methods such as secrecy, withdrawal, and educating others to avoid or reduce the possibility of rejection (Link et al., 2002). Secrecy is defined as concealment of mental illness and treatment history from relatives, friends, and employers. Withdrawal means limiting one's social interactions to those who have similar mental health conditions and to those who would accept their mental illness. Educating others indicates providing accurate information to others to decrease negative attitudes toward individuals with a mental illness.

### **Loss of Face**

In Chinese culture, face symbolically refers to an individual's dignity (Chen, Lai, & Yang, 2013), and represents one's ability to engage in social relationships. Therefore, when an individual loses face, the person becomes powerless to partake in local social networks (Yang, 2007). Moreover, feelings of shame and embarrassment often accompany losing face (Ho et al., 2004; Yue, 1994). The feeling of shame accompanies

the fear of being humiliated whereas embarrassment is a loss of composure, similar to a minor loss of face (Ho et al., 2004)

## **Measurements**

### **Demographic Characteristics Questionnaire**

The questionnaire gathered information on (a) gender, (b) age, (c) years of education, (d) country of birth, (e) marital status, (f) religious affiliation, (g) employment status (h) participant income, (i) onset age of illness, (j) duration of illness, (k) number of psychiatric hospitalizations, and (l) duration of the most recent hospitalization (see Appendix A).

### **Internalized Stigma**

I measured internalized stigma among study participants using an adapted 9-item version of the Devaluation-Discrimination Scale (DDS, Link, 1987; see Appendix B). This is the oldest and most commonly used measure of internalized stigma among people with mental illness (Livingston & Boyd, 2010). Researchers constructed this measure to test hypotheses associated with modified labeling theory (Link et al., 2004) and to assess the extent to which respondents believe a person with mental illness would be devalued and the target of discrimination (Link et al., 2004; Livingston & Boyd, 2010). Some examples of the questions included the following: (a) Most people in your community think a person with a serious mental illness is dangerous and unpredictable, (b) Most people in your community would accept a person who once had a serious mental illness as a close friend, and (c) Most young women would not marry a man who has been treated for a serious mental disorder. The research team added one question especially pertaining to the Chinese culture—“Most people in your community think that having

mental illness would cause a person to lose face”—to measure a culturally specific construct. Items on the DDS were rated on a 4-point Likert-type scale ranging from 1 = “strongly disagree” to 4 = “strongly agree,” summed for a total score that ranged from 9 to 36. Two items on the scale were in the reverse direction; therefore, I reversed scores before adding to the rest of the items. A higher score on the DDS indicated a higher level of internalized/perceived stigma. Internal consistency reliability ranged from .82 (Link et al., 1991) to .86 (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). The DDS has adequate construct validity (Brohan, Slade, Clement, & Thornicroft, 2010). The Chinese version of the DDS has good content validity (content validity index = .95 by an expert panel) and satisfactory internal consistencies (Cronbach’s  $\alpha = .70-.77$  for overall scale and subscales) among Chinese psychiatric consumers (Chien et al., 2012). Cronbach’s alpha for this study was .70 after removing Item Number 2: “Most people in your community feel that having a mental illness is worse than being addicted to drugs,” with a total score ranging from 8 to 32.

### **Experience of Stigma**

I used an adapted version of the Mental Health Consumers’ Experience of Stigma Scale (CES-Q, Wahl, 1999; see Appendix C) to measure the experience of stigma. The adapted version has a total of 23 items that measure interpersonal experiences regarding others’ negative attitudes such as being shunned or being treated as less competent due to mental illness and structural stigma experiences such as employment, education, and housing. The measure used 17 of the original CES-Q items that were most pertinent to the direct discrimination experienced by the Chinese group. Six additional questions were included as part of the CES-Q for inquiry regarding nonverbal forms of discrimination

(Yang et al., 2010), and discrimination associated with language, finance, citizenship, and health insurance barriers. Items on the original instrument are rated on a 4-point Likert-type scale ranging from 1 = “strongly agree” to 4 = “strongly disagree.” A higher score on the CES-Q indicated a higher level of experienced stigma. However, in this study, I only asked participants if they had experienced the various types of stigma with an answer of “yes” or “no.” I coded an answer of “yes” as 1 and an answer of “no” as 0. The total score of this measurement ranged from 0–23 (the range became 0–13 after taking away 10 items for statistical analyses), with a higher score representing more experienced stigma. The instrument has been shown to have a positive rating of content validity; however data on reliability were not reported (Brohan et al., 2010). The original Wahl’s instrument was administered in a paper-and-pencil format. However, for this study, the interviewers filled out participants’ responses. Cronbach’s alpha for this study was .69 after removing 10 items from the scale, with a total score ranging from 0 to 13. The 10 items were

1. Have you been in situations where you have heard others say unfavorable or offensive things about people who have mental illness?
2. Have you seen or read things in the mass media (e.g. television, movies, books) about people who have mental illnesses that you find offensive?
5. Have you been treated fairly by others who know that you have this condition?
6. Have people been supportive and understanding when they learned that you have this condition?

7. Have you been excluded from volunteer or social activities by others when it was known that you have this condition?
9. Have coworkers or supervisors at work been supportive and accommodating when they learned that you have this condition?
12. Have doctors or other health professionals treated you fairly and respectfully while treating you for this condition?
13. Have you had a spouse or romantic partner break up with you because of this condition?
16. Have you had the fact that you have this condition used against you in legal proceedings (such as child custody or divorce disputes)?
17. Have you been treated disrespectfully or unfairly by law enforcement officers when they learned that you have this condition?

### **Experience of Loss of Face**

Modeled after a validated measure of emotions related to stigma (Link et al., 2002), we asked three questions to assess participants' feelings of loss of face (see Appendix D). We asked participants to rate from 1–7 whether they experienced loss of face, shame, and embarrassment. I added the scores of the three questions together to obtain a total score that ranged from 3–21. The higher the total score on these three items, the greater the sense of loss of face, shame, and embarrassment. Cronbach's alpha for this study was .80.

### **Coping Strategies**

I adapted the stigma section of the Subjective Experience of Medication Interview (SEMI), a semi-structured qualitative evaluation of subjective experience of mental

illness (Jenkins et al., 2005), to measure coping strategies. For this study, I assessed coping strategies using the following questions (see Appendix E):

1. Regarding your most recent hospitalization, do people know that you have been hospitalized? Do people know that you have this condition?
2. Did you tell other people or did the person find out by accident?
3. Do you feel that you are better off not telling people about this and why?  
—Follow up question: “Are there certain people who you might tell and certain people who you might not tell?”
4. If other people know, how do you think that they will view this or act towards you?
5. Does anybody act differently towards you because of your condition, or because you take medication?

Narrative responses to the questions were coded to create a quantitative measure of coping strategies (Greene, 2007), and they were also used to illuminate study participants’ coping styles.

### **Data Analysis**

I used the SPSS 22 statistical package to analyze quantitative data. A power analysis, using the G\*Power 3.1 statistical power analysis program (Faul, Erdfelder, Lang, & Buchner, 2007), determined the effect size to avoid type II errors in the study. Based on 56 participants with power set at 0.80 and with alpha set at .05, an effect size ( $f^2$ ) of .26 emerged, indicating a medium effect size (Cohen, 1988). Other studies in Chinese groups indicated a similar medium effect size of stigma on related outcomes (Fung, Tsang, & Cheung, 2011; Yang & Singla, 2011), indicating adequate power for the study.

This study included use of descriptive statistics, correlation analysis, and regression. Descriptive statistics summarized participants' characteristics and examined the extent of internalized stigma, experienced stigma, and loss of face experienced by participants.

For the qualitative data obtained from the SEMI, I created two scales to measure secrecy coping and disclosure and used thematic analysis to further illuminate findings on coping styles through the creation of codes and themes. Researchers have used content analysis and thematic analysis to transform qualitative data into quantitative data or to organize qualitative data in meaning ways (Rubin & Babbie, 2008; Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Working with a bilingual–bicultural graduate psychology student, I coded English transcripts of the interviews (see Appendix F). We primarily used the English transcripts for coding; however, we referred to the Chinese transcripts when we needed clarification of the texts. We met weekly for more than 2 months to conduct content analysis (open coding). I read through the first 10 transcripts and identified main codes. For example, “not a bright thing” and “a shameful thing” were coded as “loss of face,” and “it’s normal to take medicine” was coded as “normalization.” We then analyzed the remaining transcripts by applying the codes from the first 10 interviews. We also noted other emerging codes such as “ambivalent” in the rest of the transcripts, and revised our initial codes accordingly. We then sorted the codes into different categories such as “coping strategies,” and “reasons for secrecy.”

To create the scale, we assigned a numerical value to each participant’s secrecy coping and level of disclosure. When discrepancies arose in our ratings, we discussed our rationales and came up with a compromise. The process of transforming qualitative data into quantitative data is called quantizing (Sandelowski, Voils, & Knafl, 2009). To



enhance the credibility of the analysis, we first used peer debriefing to keep our assumptions in check. The graduate student and I discussed our coding weekly and asked each other questions to ensure the analyses had minimal biases. In addition, we kept a written record of our coding process, and our discussions of points of disagreement. We used Cohen's  $k$  to determine agreement between the two raters in the level of secrecy and disclosure. We had substantial agreement on the secrecy scale ( $k = .811, p < .000$ ) and the disclosure scale ( $k = .766, p < .000$ ).

Herman (1993) described observations of how people with mental illness managed mental illness stigma by strategizing who and when to disclose their illness. The construction of the secrecy and disclosure scales builds on Herman's framework. The secrecy scale focuses on the selective-concealment element of the model to explore with whom mental health consumers are willing to share information about their mental illness. In contrast, the disclosure scale concentrates on the kinds of information consumers are willing to disclose.

We used the following criteria to construct the rating scale for participants' secrecy coping:

1. **No secrecy:** The participant actively shared his/her mental illness with **everyone** he or she knew.
2. **Minimal secrecy:** The participant **did not mind** others in his or her social network (including family members, friends, and acquaintances) knowing about his or her illness; however, he or she may **not have actively shared** the illness with them. This category also included participants who had the **intention to share** with others, though may not have done so.

3. **Some secrecy:** The participant **shared with some** family members and one or more friends regarding his/her mental illness. This also included participants who had the **intention to share** with close friends and significant others, though may not have done so.
4. **Substantial secrecy:** Due to the fear of loss of face or feeling shameful, the participant only shared his or her illness with a **very small number of family members**. However, family members may have shared the illness with others despite the participant's preference.
5. **Total secrecy:** With extreme fear of loss of face, the participant **did not share** the illness with anyone.

Once we quantified the data, participants received a score of 1 to 5, representing the range of no secrecy to total secrecy in their disclosing preference. For example, a participant who shared his or her illness history with everyone he or she met was considered to have no secrecy (coded as 1). Those participants who shared their illness with only a select number of people, such as friends who also suffered from mental illness or treatment providers, were considered as keeping their illness a medium level of secrecy (coded as 3). To be regarded as highly secretive, participants did not share their illness or treatment history with anyone; not even their spouses or significant others.

For the study participants' disclosure preferences, we constructed the following 5-point scale:

1. **No Disclosure or Denial:** Participants denied having any illness and did not share knowledge of their illness with others.

2. **Deception or Coaching:** Participants told distant relatives, friends, or acquaintances they **had an illness such as headache or depression without mentioning psychosis;** however, they told family members about the mental illness.
3. **Therapeutic disclosure:** Participants shared some **basic and accurate information about their mental illness and treatment when asked** by some trusted, others including family members, relatives, and a limited number of friends or acquaintances such as other church members or mental health consumers.
4. **Education:** Participants were willing to **actively educate** others by providing additional information regarding their mental illness and treatment.
5. **Advocacy or Political Activism:** Participants **advocated** for people with mental illness such as supporting people with mental illness publicly through demonstrations, rallies, or attending conferences and promoting social change.

Each study participant received a score of 1 to 5, representing the degree of their mental illness disclosure. Once we quantified the coping-strategies data, I analyzed the associations between coping strategies and internalized stigma, experienced stigma, and loss of face using Pearson's correlation and linear regression. Codes and narrative statements further illuminated participants' coping strategies.

## Chapter 4

### Results

This chapter presents the findings of the stigma experience and coping among Chinese American immigrants with schizophrenia spectrum disorders. First, I present an overview of the data, including a description of participants' demographics, as well as the mean, medium, and range of scores for the five scales: Link's DDS, Wahl's CES-Q, Experience of Loss of Face, and Coping Strategies (secrecy and disclosure). Then, I discuss the results aligned with each of the research questions and hypotheses.

#### **Description of the Sample**

A total of 56 Chinese immigrants residing in the United States participated in the study. Overall, the average age of the participants was 34.3 ( $SD = 11.0$ ), and they had 9.9 ( $SD = 3.0$ ) years of education. Participants had lived in the United States for an average of 12.6 ( $SD = 11.9$ ) years.

Table 2 shows the frequency distributions of participants' gender, place of birth, legal status in the United States, diagnosis, court-ordered treatment, religion, and employment information. Among study participants, 36 (64.3%) were men and 44 (78.6%) were unmarried, defined by the categories of never married, separated, or divorced. Most participants (41, 73.2%) were born in mainland China. Forty-six (82.1%) participants used Mandarin Chinese during the interview and 10 spoke English or a combination of the two languages. In legal status, almost half (26, 46.4%) were resident aliens.

Table 2

*Frequency Distributions of Participants' Demographic Characteristics*

Variable		<i>n</i>	%
Gender	Male	36	64.3
	Female	20	35.7
Place of birth	Mainland China	41	73.2
	Hong Kong or Macau	6	10.7
	Taiwan	1	1.8
	Other Asian Countries	3	5.4
	United States	5	8.9
Language	Mandarin	46	82.1
	English	9	16.1
	Combination	1	1.8
Legal status	U.S. citizen	15	26.8
	Resident alien (green card)	26	46.4
	Legal visa holder (student, work etc.)	1	1.8
	Pending court case	2	3.6
	Undocumented	11	19.6
	Awaiting green card	1	1.8
	Unknown	4	7.1
Diagnosis	Schizophrenia	32	57.1
	Schizoaffective disorder	12	21.5
	Bipolar disorder with psychotic features	1	1.8
	Depressive disorder with psychotic features	1	1.8
	Psychotic disorder not otherwise specified	6	10.7
	Unknown	4	7.1
	Unknown	8	14.3
Court-ordered treatment	None	41	73.2
	Assisted outpatient treatment	4	7.1
	Assertive community treatment (ACT)	2	3.6
	Transfer to long-term care (State inpatient unit)	1	1.8
	Unknown	8	14.3
Religion	Buddhism	15	26.8
	Catholicism	3	5.4
	Christianity (other than Catholicism)	14	25.0
	Traditional folk belief	2	3.6
	None	17	30.4
	Other	2	3.6
	Unknown	3	5.4
Employment	Unemployed	38	67.9
	Full time	15	26.8
	Part time	3	5.4
Field of employment	Service (restaurants, housekeeping)	32	57.1
	Factory	7	12.5
	Construction	1	1.8
	Student (full-time)	5	8.9
	Sheltered workshop	1	1.8
	Professional (white collar)	6	10.7
	Never worked	4	7.1
	Unknown	8	14.3
Income (annual)	No income	19	33.9
	> \$5000	13	23.2
	\$5000–\$11,999	11	19.6
	< \$12,000	13	23.2

A total of 32 (57.1%) participants were diagnosed with schizophrenia, 12 (21.5%) with a schizoaffective disorder, and eight (14.3%) with other disorders (e.g., bipolar disorder with psychotic features, major depressive disorder with psychotic features, and psychosis not otherwise specified). Participants had an average duration of 8.5 ( $SD = 8.3$ ) years of mental illness, and a total of 4.9 ( $SD = 3.7$ ) hospitalizations. Duration of mental illness was determined by year of first psychiatric hospitalization until the present time. The majority of the participants (73.2%) did not have any court-mandated treatment

Furthermore, 17 (30.4%) of the 53 participants (three were missing data) had no religious affiliation, whereas the rest reported having a religious belief such as Buddhism, Christianity, or traditional folk belief. The questionnaire divided Catholicism and Christianity because for many Chinese people, Catholicism usually indicates the Roman Catholic Church, of which the Pope is the head. In contrast, Christianity usually refers to evangelical Christianity. In employment, 38 (67.9%) participants were unemployed at the time of the interview, with the majority (57.1%) of those employed having worked in a service-sector job such as restaurant and housekeeping. Among participants, a third (33.9%) reported no income. On average, households comprised 3.5 people.

Overall, the majority of study participants were mostly first-generation Mandarin-speaking immigrants from China. On average, they had less than a high school education and more than half were unemployed. Those who worked had low-income jobs and the majority lived under the poverty line. Participants duration of mental illness and number of hospitalizations reflect severity and chronicity. All participants lived with family members.

## Descriptive Findings of the Major Variables

Table 3 illustrates the mean, standard deviation, and range of scores of the scale, used to examine internalized stigma, experienced stigma, experience of loss of face, and coping strategies.

Table 3

### *Statistics on the Five Scales*

Variables/Scales	Mean	Std. deviation	Range of scores
Internalized Stigma Link's Devaluation Discrimination Scale	21.59	2.81	8–32
Experienced Stigma Wahl's Mental Health Consumers' Experience of Stigma Scale	2.77	2.31	0–13
Experience of loss of face	8.15	4.43	3–21
Coping Strategy—Secrecy	3.19	0.69	1–5
Coping strategy—Disclosure	2.56	0.50	1–5

## Characteristics of Participants' Experiences of Stigma

### **Internalized Stigma**

The mean of Link's DDS was 21.59 ( $SD = 2.81$ ). Among the nine items, Item 8, "Most young women would not marry a man who has been treated for a serious mental disorder," had the highest mean ( $M = 3.00$ ,  $SD = .64$ ) with 73% of participants endorsing it; this was followed by Item 9, "Having a mental illness would cause a person to lose face" ( $M = 2.77$ ,  $SD = .64$ ), with 60% of participants having endorsed it. Item 6, "Most people think less of a person who has been a patient in a mental hospital," had an average score of 2.76 ( $SD = .44$ ) with 63% of participants agreeing to it, whereas the first item, "Most people in your community think that a person with a serious mental illness is

dangerous and unpredictable,” had an average of 2.76 ( $SD = .56$ ) with 60% of participants having endorsed it. Table 4 presents the item statistics on the DDS.

Table 4

*Statistics on the Devaluation–Discrimination Scale*

Link’s Devaluation–Discrimination Scale (DDS)	Mean	Std. deviation	% of endorsement
1) Most people in your community feel that a person with a serious mental illness is dangerous and unpredictable.	2.76	0.56	58.90
3) Most people in your community would accept a person who once had a serious mental illness as a close friend. (Reverse item)	2.54	0.59	44.70
4) Most people in your community look down on someone who once was a patient in a mental hospital.	2.71	0.64	57.10
5) Most employers will hire a person who once had a serious mental illness if he or she is qualified for the job. (Reverse item)	2.44	0.69	39.30
6) Most people in your community think less of a person who has been a patient in a mental hospital.	2.76	0.44	62.50
7) Most people in your community feel that entering psychiatric treatment is a sign of disgrace.	2.61	0.71	51.70
8) Most young women would not marry a man who has been treated for a serious mental disorder.	3	0.64	73.30
9) Most people in your community think that having a mental illness would cause a person to lose face.	2.77	0.64	58.90

**Experienced Stigma**

Of participants, 24 reported they most frequently experienced being shunned or avoided (Item 4) and being disdained by family members (Item 11), once they revealed their mental health condition. In addition, 21 participants experienced being treated as less competent (Item 3) by others, whereas 20 experienced having more difficulty in finding a romantic partner because of their mental illness (Item 14). Table 5 shows the most frequently reported stigma-experience items.



Table 5

*Frequency of the Most Experienced Stigma*

	Experienced of stigma	Frequency	%
4	Being shunned or avoided	24	42.9
11	Being looked down on by family members	24	42.9
3	Being treated as less competent	21	37.5
14	Having more difficulty finding romantic partner	20	35.7
11A	Family members tell participants not to tell others about his/her condition	15	26.8
18	People “give off” a sense of stigmatization even if something is not explicitly said	15	26.8

Overall, study participants reported low incidence of experienced stigma.

However, close to half reported being disdained by family members and over one third reported difficulty in finding a romantic partner. Furthermore, study participants reported the highest level of internalized stigma on Items 8 and 9 on the internalized-stigma scale related to marriage and loss of face. Thus, the first hypothesis that Chinese American individuals with schizophrenia spectrum disorders would be more likely to report stigma in their interpersonal relationships, especially those relating to intimate relationships, was supported.

**Types of Coping Strategies Adopted by Participants**

**Secrecy.** I constructed the secrecy scale by coding qualitative data obtained from semi-structured interviews as part of the adapted SEMI questionnaire. The secrecy scale focused on people with whom participants were willing to share their mental health status. For negative coping strategy, no participants reported having no secrecy (a score of 1). All participants fell into three categories: minimal secrecy (eight participants, 14%), some secrecy (26 participants, 46%), followed by substantial secrecy (18 participants, 32%). See Table 6 for a detailed illustration.

Table 6

*Frequency of the Secrecy Scale*

	Frequency	%
No secrecy	0	0
Minimal secrecy	8	14.3
Some secrecy	26	46.4
Substantial secrecy	18	32.1
Total secrecy	0	0
Missing	4	7.1
Total	56	100.0

When conducting content analysis of the coping strategies data, valuable qualitative information emerged. To illuminate the coping methods used by study participants, I present comprehensive qualitative information below. A majority of study participants, mostly those in the *some secrecy* and *substantial secrecy* groups, were only willing to disclose their illness to a few family members and close friends. Many chose to share the information with those they felt could empathize with and support them, such as fellow individuals who shared the same mental illness status. Three main reasons emerged for why participants decided to keep their mental health status a secret.

**Reasons for secrecy.**

***Fear of rejection and discrimination.*** Some participants shared their fears and experiences with rejection and discrimination. One 30-year-old single participant diagnosed with schizoaffective disorder stated, “The illness affects my whole life. If my sister doesn’t tell anyone, it would be better for me.” Another 22-year-old female participant, originally from China, echoed the same sentiment, expressing that she is

better off not telling others about her mental illness because “it might affect my future” and others “would look down on me.”

Although these participants expressed frustration that, from their perspective, mental illness will affect their future, one 28-year-old male from China was upset about the possibility of not being able to get married. He said he used to have many girlfriends, but his neighbors told girls not to date him after they realized he had a mental illness. He said, “[The neighbors] said to those women there, ‘How would you be with a person with mental illness? He is mentally ill, he is this and that.’” This mental health consumer lamented that the news about his mental illness from “one spreads to one hundred” and “I will not find a wife for the rest of my life.”

Other participants also worried about family and friends avoiding them and treating them differently. A 19-year-old single female participant with schizophrenia disorder reported having experienced discrimination. She said the people in the restaurant “refused to “sell me things because they knew [about my mental illness] and would tell me to go away” because they “fear contagiousness” of her illness. Similarly, an 18-year-old full-time student diagnosed with psychosis not otherwise specified reported he had not told anyone about his mental illness, but then news about his illness spread. The participant said his friends would distance themselves from him, laugh at him, and discriminate against him when they learned of his illness. Another 27-year-old single male expressed having encountered stigma in this family.

One of my family members found out that I had this, this condition, they, they start to look at you funny ... they don't look at me the same anymore. They look at me like there might be something wrong with me. ... you're thinking, “Hey is this guy going to do something crazy?” [laughter] you know what I mean? ... they look at you like you might be dangerous ... they pay more attention to you,

looking at you, like maybe see if you are acting in a threatening manner. Anyway, they pay more attention to that.

*Loss of face.* Many study participants felt they were better off not telling others about their psychiatric illness because of their belief that having a mental illness makes them less of a person, and that others will also see them as inferior, causing them to lose face. One 42-year-old female participant who had been ill for 22 years stated that her mother told other relatives about her mental illness and she felt “I have no face to be a person.” In addition, she believed her sister stopped interacting with her after she was diagnosed with her psychiatric illness and her sister “looked down on me.” She believed she would be better off not telling others about her illness because “I still have to have face.” Likewise, a 28-year-old male diagnosed with schizophrenia expressed feeling ashamed to meet with people who know of his illness. He also stated that he did not want others to know of his psychiatric illness because he did not “want to affect [others’] impression of me in their minds.”

Losing face is not only a concern for the individual who has the illness; it is equally important to preserve the family’s face. The 19-year-old female participant mentioned earlier also reported fear of losing face. She expressed, “I am not normal” and feels “shameful and dirty.” Her family has told her not to tell others about her mental illness “[so we] will not lose face.” Two other participants also reported their families refused to disclose their mental illness to other people. One said, “My family prevents [the mental illness] from letting others know,” while another said, “I hate other people knowing. ... My mom and I definitely could not tell anybody else.”

*Unnecessary to disclose (i.e., prioritize receiving treatment and recovery).* Many participants did not want others to know about their mental illness, especially those

outside of the family, because they believed it was better to focus on seeking treatment and recovery. According to the 18-year-old participant previously mentioned, he preferred not to share his mental health status with others because he would rather focus on getting better. He said, “I receive treatment. ... I am young and I am willing to seek treatment; it’s likely I will recover.” He also believed “if I receive treatment, others will think better of me.” Likewise, a 28-year-old single male who had been hospitalized six times in the past 5 years said, “most important thing is that the doctor could find adequate remedy for the disease.” Furthermore, he believed that getting a mental illness is normal among his peers because of the huge pressure many immigrants like him face daily.

Many study participants focused on becoming “normal” and being able to work. A 33-year-old married male participant opined, “I am still young and I have hands and feet, I can work in any field, no problem.” Similarly, another 35-year-old divorced man with schizophrenia believed in the importance of getting treatment and returning to work.

It’s not necessary to tell others or not to tell others. The most important thing is that one has to get one’s illness treated well. My thought is that I’m already well now. Just to say that I can do other things. Nothing more to it, nothing.

**Disclosure.** I constructed a disclosure scale to measure participants’ disclosure preference. The scale focuses on what participants are willing to share about their mental health status. None of the participants reported having no disclosure (score of 1), education (score of 4), or advocacy or political activism (score of 5). Over half of the study participants (29, 52%) used some kind of therapeutic disclosure in sharing their mental health status to selected groups of people such as family, close friends, church friends, and bosses whereas 23 (41%) used deception or coaching when disclosing their mental illness. See Table 7 for the scale’s frequencies.

Table 7

*Frequency of the Disclosure Scale*

	Frequency	%
No disclosure	0	0
Deception or coaching	23	41.1
Therapeutic disclosure	29	51.8
Education	0	0
Advocacy or political activism	0	0
Missing	4	7.1
Total	56	100.0

Additional qualitative data further enriched understanding of participants’ disclosure pattern: reason for disclosure, strategies for disclosure, and involuntary disclosure.

**Reasons for disclosure.** The results suggested three main reasons participants were willing to disclose their illness.

*Social support.* Participants expressed that others showed greater empathy and understanding after learning about their illness. A 31-year-old single man with a history of three psychiatric hospitalizations stated, “You should talk to your friends (when you encounter difficulties) ... because it is too severe, can lighten my mood [by sharing with others about my mental illness].” He also said that friends would call and console him. At the same time, another 26-year-old male diagnosed with schizoaffective disorder was not afraid to share his illness with others, and expressed that “true friends will remain loyal.”

Since that I got this illness, it is the fact, right? ... I am not afraid that the others know about it. ... I am not afraid that they will know about my situation. If they know it, they know it ... friends are about friendship, they won’t look down on me.

Moreover, some participants found it useful to share with fellow mental health consumers because they “have connections” and understand each others’ struggles and needs.

In addition to receiving emotional support from others who know about the participant's mental illness, some reported getting instrumental help. A 34-year-old married man with schizophrenia said others had greater sympathy if they knew of his mental illness, and they encouraged him to take medication. Another 29-year-old woman who had been diagnosed with schizoaffective disorder for 4 years said her friends had helped her receive psychiatric treatment including hospitalization when she needed it. Likewise, another male participant said his friends loaned him money after learning about his hospitalization to help him pay off his smuggling debts.

**Honesty.** In addition to receiving support from disclosing mental illness, some reported they disclosed their mental illness to close friends or intimate others to be genuine and to build a trusting relationship. A 29-year-old woman believed it was good to share something private with others and become friends, even though she felt vulnerable about being honest.

I guess there's like a weird, conflicting feeling. Sometimes I do want people to know but there's also the flip side ... that's a little bit scary. But I feel if I need to cross the barrier, then I have to let them know ... It's like, somebody reading a diary, they know everything about you ... but sometimes it feels good to have people know, so that's the flip side of that ... So if I could share something with them, then they are my friend.

Some participants maintained they would tell their intimate others about their mental illness if they were to get involved in a romantic relationship. A 26-year-old single woman with schizophrenia said, "I told [previous boyfriends] directly [about my mental illness] so that they could choose whether to stay with me or leave." She believed it was important to be honest if they were to get serious in the relationship. Another 30-year-old single man also said, "I would have to, I don't know when I would have that discussion, but definitely prior to having a relationship with a female I guess I would

have to have some kind of discussion [about his mental illness].” In contrast, despite the desire to be honest and truthful with friends, some others said they would still prefer to maintain a certain level of privacy by “tell[ing] them a little about mental illness, not too much, still keep my private life.”

***Acceptance of their illness.*** Participants stated that having a mental illness was a normal part of life, like having a physical illness, and they had no need to hide it. As one participant stated, “It’s ok if they don’t want to be friends, I have this illness, illness exists.” At the same time, another 21-year-old, single, male participant wanted to focus on recovery and future achievement. He said, “I don’t think there is anything to be laughed at. If I am cured, then there’s nothing wrong. It’s not something incurable.” In contrast, a single man who had been ill for 5 years stated that he wanted to hide his psychiatric illness at first, but after the third hospitalization, he felt that it was “impossible to hide.”

**Strategies for disclosure.** In addition to the reasons participants were willing to disclose their mental illness, many also discussed the various strategies they used for such disclosure.

***Humor.*** Although some participants were willing to discuss basic facts about their mental illness, some preferred to share it jokingly, to add levity to their situation. A 21-year-old single man who was having his first psychiatric hospitalization said he was willing to tell some people about his mental illness, but to some others he would tell about it as a joke: “When they asked me what a mental disease was, I answered that I have something wrong in my head and mind ... I would tell them also, but in a way like



jokes.” Another 30-year-old male participant also said, “I would joke about mental illness; hospitalization is not a big deal.”

**Concealment.** To not reveal their mental health status, some study participants concealed it by giving other reasons for their behaviors and absence from their community. For example, one participant with schizophrenia who suffered from medication side effects including fatigue and sleepiness said he would tell his coworkers he did not sleep well because he worried that he would be fired from his job if his boss discovered he had a mental illness and was taking medication. Another female participant would tell others that she had gone to study elsewhere if asked about her absence from home and her community. Furthermore, a participant said, “but finally I have to face it. I just change the way to tell [people] ... just say [I had a] headache.

**Involuntary disclosure.** However, participants experienced some situations in which they did not choose to disclose their mental health status, but it was revealed by others. It was not uncommon for family members to share participants’ mental illness with other relatives or those in their *guanxi*. Family shared some of these situations to receive assistance or support from their support network. For example, the wife of a 57-year-old participant needed help to get to the prison where the participant was staying at the time. In another instance, a girlfriend of another study participant told more than 100 church friends about his condition, and although the participant states he would have told the friends on his own, he thought his girlfriend should have gotten his consent before sharing the news. In addition, several occasions arose of “gossiping,” when information was spread from person-to-person in the same village. As one participant put it, “one spread to ten, then ten spread to a hundred.” In other incidents, participants’ illness was

revealed through a very public episode. For example, a 57-year-old male participant was reported in the newspaper for grabbing a knife, whereas another 59-year-old female participant with schizophrenia was in the newspaper for jumping out of a window. Another 44-year-old participant with schizophrenia felt that people in her church should have known about her illness because she was yelling in church during one of her relapse episodes.

The second hypothesis, that Chinese American individuals with schizophrenia spectrum disorders would tend to adopt coping strategies such as secrecy and withdrawal, was supported. According to findings from the quantitative and qualitative data, most participants were inclined to keep their mental illness to a certain level of secrecy. Although some were willing to disclose their mental illness to others, they restricted such disclosure mostly to family and close friends. Findings supported the second hypothesis.

**Experience of loss of face.** On average, participants had a mean of 8.15 ( $SD = 4.43$ ) on the Experience of Loss of Face scale. When considering individual items, feeling shame was highest ( $M = 2.92$ ,  $SD = 1.88$ ), followed by experiencing loss of face ( $M = 2.65$ ,  $SD = 1.85$ ), and embarrassment ( $M = 2.58$ ,  $SD = 1.49$ ). The third hypothesis, that Chinese Americans with schizophrenia spectrum disorders would report experiencing a high level of loss of face, was not supported. The overall score on the loss-of-face scale was below average and more than one third of study participants did not feel loss of face.

### **Association Between Participants' Internalized Stigma and Coping Strategies**

I ran a Pearson correlation to determine the relationship between participants' levels of internalized stigma and level of secrecy; however, no association emerged ( $r =$

-.06,  $p = .66$ ). I also ran a Pearson correlation to determine the relationship between participants' levels of internalized stigma and level of disclosure. No correlation emerged ( $r = -.01, p = .97$ ). As an exploratory analysis, I conducted an item-by-item analysis and no association emerged between coping strategies and each individual item on Link's DDS, determined by Pearson correlations.

The fourth hypothesis, which assumed that a high level of internalized stigma would be associated with higher secrecy level and limited disclosure, was not confirmed. No significant findings emerged on the association between the participants' internalized stigma and coping strategies.

#### **Association Between the Participants' Experienced Stigma and Coping Strategies**

A Pearson correlation showed that level of secrecy and experienced stigma did not significantly correlate ( $r = .05, p = .72$ ). Furthermore, participants' level of disclosure did not significantly correlate with their experienced stigma ( $r = .02, p = .89$ ). In a set of exploratory analyses to determine if participants' secrecy level and disclosure level was associated with the individual items on Wahl's CES-Q, I ran point-biserial correlation and phi coefficient, respectively. However, no significant correlation emerged among one's secrecy level, disclosure level, and individual items on the Experienced Stigma Scale. Because no significant correlation emerged between participants' secrecy level and level of experienced stigma, Hypothesis 5, which states that higher secrecy coping would be associated with a low level of experienced stigma, was not confirmed.

#### **Experience of Loss of Face and its Association With Coping Strategies**

Using Pearson correlations, no significant correlation emerged between one's secrecy level and the Experience of Loss of Face scale ( $r = .25, p = .08$ ); however, a

positive trend can be observed between the two variables. In addition, participants' level of secrecy significantly correlated with their feelings of shame ( $r = .27, p = .05$ ) but not with feelings of embarrassment ( $r = .23, p = .11$ ) or the single item loss of face ( $r = .14, p = .33$ ).

In contrast, no significant correlation emerged between the participants' disclosure level and experience of loss of face ( $r = -.13, p = .37$ ). Furthermore, no significant correlation arose between the participants' level of disclosure and the individual items on the Experience of Loss of Face scale.

A significant correlation did emerge between one's secrecy level and the feeling of shame, and a trend toward significant correlation arose between one's secrecy level and the Experience of Loss of Face scale. However, Hypothesis 6, which states that a high level of loss of face would be significantly associated with higher levels of secrecy and limited disclosure, was not confirmed.

### **Bivariate Correlations Among the Key Variables**

Bivariate correlations showed a significant association between one's internalized stigma and experience of loss of face ( $r = .29, p = .04$ ). In addition, one's experienced stigma was also significantly associated with experience of loss of face ( $r = .46, p = .00$ ). One's secrecy level was also significantly associated with disclosure ( $r = -.72, p = .000$ ). However, no other significant association arose among the key variables. See Table 8 for correlations among the variables.

I also conducted bivariate correlations among the key variables stratified by participants' employment status and religious affiliations and found several significant correlations. For the unemployed participants, experienced stigma ( $r = .54, p = .001$ ) and

secrecy ( $r = .40, p = .02$ ) were significantly correlated with loss of face. There was also a significant correlation between secrecy and disclosure ( $r = -.78, p = .000$ ). For participants who had employment, only secrecy was found to be significantly correlated to disclosure ( $r = -.57, p = .02$ ). Bivariate correlation analysis revealed that internalized stigma was significantly associated with loss of face ( $r = .53, p = .001$ ) among participants who followed an Eastern religion. On the other hand, experienced stigma was significantly associated with loss of face among participants who endorsed a non-Eastern religion ( $r = .64, p = .01$ ). Secrecy and disclosure were significantly correlated with each other for all participants ( $r = -.65, p = .000$  (Eastern religion;  $r = -.72, p = .001$ , non-Eastern religion). See Appendices G and H for tables.

Table 8

*Bivariate Correlations Among Key Variables*

		Internalized stigma	Experienced stigma	Loss of face	Secrecy	Disclosure
Internalized stigma	Pearson correlation	1	.21	.29*	-.06	-.01
	Sig. (two-tailed)		.13	.04	.66	.97
	<i>N</i>	52	52	52	51	51
Experienced stigma	Pearson correlation	.21	1	.46**	.05	.02
	Sig. (two-tailed)	.13		.00	.72	.89
	<i>N</i>	52	56	52	52	52
Loss of face	Pearson correlation	.29*	.46**	1	.25	-.13
	Sig. (two-tailed)	.04	.00		.08	.37
	<i>N</i>	52	52	52	51	51
Secrecy	Pearson correlation	-.06	.05	.25	1	-.72**
	Sig. (two-tailed)	.66	.72	.08		.00
	<i>N</i>	51	52	51	52	52
Disclosure	Pearson correlation	-.01	.02	-.13	-.72**	1
	Sig. (two-tailed)	.97	.89	.37	.00	
	<i>N</i>	51	52	51	52	52

\*Correlation is significant at the .05 level (two-tailed), \*\*Correlation is significant at the .01 level (two-tailed).

## **Associations Between Sociodemographic Correlations and Key Variables**

### **Internalized Stigma**

*T*-test and one-way Analysis of Variance (ANOVA) determined the mean differences on participants' level of internalized stigma, based on their sociodemographics. When comparing employed against unemployed participants, an ANOVA showed a significant difference in the mean,  $F(2,49) = 3.48, p = .04$ , on the DDS between the unemployed ( $M = 20.88, SD = 2.40$ ) and full-time employed participants ( $M = 23.03, SD = 3.26$ ); however, no significant difference emerged between part-time employed and unemployed/full-time employed participants. Also, a significant difference,  $F(2,49) = 3.74, p = .03$ , emerged between participants who received 7–12 years of education, with a mean of 21.18, and those who received 13 and more years of education, with a mean of 24.60. An ANOVA also revealed a significant group difference among participants' diagnosis,  $F(3,44) = 3.40, p = .01$ . Participants who were diagnosed with a schizoaffective disorder had a higher internalized stigma score ( $M = 23.13, SD = 2.93$ ) than those with a psychosis disorder not otherwise specified ( $M = 19.58, SD = 1.74$ ).

### **Experienced Stigma**

No significant difference emerged on participants' experienced stigma level in relationship to their sociodemographic data.

### **Secrecy Level**

*T*-tests determined the mean differences in participants' secrecy level in relation to sociodemographic variables. The tests revealed a significant difference in the mean secrecy score between married and unmarried participants,  $t(50) = -2.54, p = .01$ .

Married participants had a statistically significant higher secrecy score than unmarried participants. Unmarried participants had a mean of 3.07 ( $SD = .65$ ), whereas married participants had a mean of 3.63 ( $SD = .67$ ). Additionally, participants who reported having a traditional Eastern religious affiliation (i.e., Buddhism and traditional folk belief;  $M = 3.47$ ,  $SD = .62$ ) had a statistically significant higher secrecy score than those who did not (i.e., Catholicism and Christianity;  $M = 3.03$ ,  $SD = .67$ ),  $t(49) = -2.26$ ,  $p = .03$ ). Moreover, participants who received any form of mandated treatment had a statistically significant lower secrecy score ( $M = 2.71$ ,  $SD = .76$ ) compared to those who did not receive mandated treatment ( $M = 3.27$ ,  $SD = .65$ ,  $t(42) = 2.02$ ,  $p = .05$ ).

### **Disclosure Level**

Participants' level of disclosure was distributed between only two levels, so the variable was dichotomized for the data analysis. A  $t$ -test indicated a significant difference in the average disclosure score between married and unmarried participants,  $t(18.33) = 3.33$ ,  $p = .004$ ). The average disclosure score for married participants was 2.66 ( $SD = .48$ ), whereas unmarried participants had an average of 2.18 ( $SD = .40$ ). Also, a statistically significant difference emerged in disclosure level between participants who reported having a traditional Eastern religious affiliation compared with those without an Eastern religious affiliation, determined by  $t$ -test,  $t(49) = 2.98$ ,  $p = .004$ ). Participants who had a non-Eastern religious affiliation had a statistically significant higher disclosure score (2.71,  $SD = .46$ ) than those who had an Eastern religious affiliation (2.29,  $SD = .47$ ).

### **Experience of Loss of Face**

No significant difference emerged in participants' experience of loss of face in relationship to their sociodemographic data.

### Regression Analysis of Coping Strategies (Secrecy and Disclosure)

I ran a linear regression even though no correlations emerged between the predictors (internalized stigma, experienced stigma, and experience of loss of face) and the outcome variables (secrecy level and disclosure level). Results showed that participants' internalized stigma, experienced stigma, and experience of loss of face were not significant predictors of their secrecy level as a whole,  $F(3,47) = 1.69, p = .25$ , with a  $R^2$  of .09; however, experience of loss of face was a significant predictor of secrecy level, as shown in Table 9.

Table 9

*Secrecy Level Regressed on Internalized Stigma, Experienced Stigma and Loss of Face*

	Unstandardized coefficients		<i>t</i>	Sig.
	<i>B</i>	Standard error		
Constant	3.68	.76	4.87	.00
Internalized stigma (DDS)	-.04	.04	-1.10	.28
Experienced stigma	-.04	.05	-.76	.45
Experience of loss of face	.06	.03	2.19	.03

$R^2 = .09, p = .25$ , Significant at the  $p < .05$  level.

The regression results also showed that participants' internalized stigma, experienced stigma, and experience of loss of face were not significant predictors of their degree of disclosure,  $F(3,47) = .52, p = .77$ , with a  $R^2$  of .03. Table 10 shows the results.

Table 10

*Degree of Disclosure Regressed on Internalized Stigma, Experienced Stigma and Loss of Face*

	Unstandardized coefficients		<i>t</i>	Sig.
	<i>B</i>	Standard error		
Constant	2.52	.57	4.41	.00
Internalized stigma (DDS)	.01	.03	.26	.80
Experienced stigma	.02	.04	.83	.41
Experience of loss of face	-.02	.02	-1.21	.23

$R^2 = .03, p = .77$ , Significant at the  $p < .05$  level.



## Post Hoc Analysis

I examined employment and religion in the post hoc analysis because they play important roles in a person's well-being. Employment is an essential component in the recovery process for individuals with a mental illness. Not only does employment bring financial independence, it also helps construct one's social identity (Saavedra, López, González, Arias, & Crawford, 2016). Researchers indicated a positive association between a mentally ill individual's employment status and level of internalized stigma (Chee, Ng, & Kua, 2005). Work is also a central element for many Asian cultures, including the Chinese. In addition, religion is a protective factor that promotes health. Researchers found a positive relationship between one's religious involvement and mental health (Dein, 2010; Koenig, 2009; Lake, 2012). Religious involvement often associated with greater purpose of life, increased hope, more optimism, and improved self-esteem (Koenig, 2015). Because the elements of employment and religion are important aspects of life for people with a mental illness, it would be critical to consider them when examining a person's stigma experience.

I conducted bivariate correlation between participants' employment status and religious affiliation. I coded employment status into three categories: 0 as unemployed, 1 as part-time employed, and 2 as full-time employed. I recoded religion into a dummy variable where 1 represents Eastern religion and 0 represents non-Eastern religion. Result showed that participants' employment status and religious affiliation was not significantly correlated,  $r = -.08$ ,  $p = .57$ .

## Regression Models using Employment and Religion as Predictors

I also conducted linear regression analyses to examine the relationships between participants' employment status, religion affiliation, and level of internalized stigma, coping strategies, experienced stigma, and experienced loss of face. I regressed study participants' internalized stigma, measured by Link's DDS, with gender, employment, and religion. In addition to coding employment and religion as stated above, I entered gender as a dichotomous variable with 1 representing male and 2, female. A significant regression equation emerged,  $F(3,47) = 4.88, p = .01$ , with an  $R^2$  of .49. Participants' employment status was a significant predictor of internalized stigma. The regression results appear in Table 11.

Table 11

### *Regression Results for Internalized Stigma*

	Unstandardized coefficients		<i>t</i>	Sig.
	<i>B</i>	Standard error		
Constant	19.03	1.15	16.50	.00
Gender	1.61	.75	2.13	.04
Employment	1.05	.40	2.62	.01
Religion	-.92	.77	-1.20	.24

$R^2 = .29, p = .00$ , Significant at the  $p < .01$  level.

Table 12 shows a significant linear regression predicting participants' secrecy level based on their gender, employment, and religion,  $F(3,47) = 3.25, p = .03$ , with an  $R^2$  of .172.

Table 12

### *Regression Results for Secrecy Level*

	Unstandardized coefficients		<i>t</i>	Sig.
	<i>B</i>	Standard error		
Constant	2.46	.29	8.39	.00
Gender	.37	.19	1.96	.05
Employment	.08	.10	.77	.45
Religion	.50	.19	2.56	.01

$R^2 = .17, p = .03$ , Significant at the  $p < .05$  level.

I conducted a linear regression to predict participants' degree of disclosure, based on their gender, employment, and religion. A significant regression equation emerged,  $F(3,47) = 3.70, p = .02$ , with an  $R^2$  of .19. Table 13 shows the regression results.

Table 13

*Regression Results for Degree of Disclosure*

	Unstandardized coefficients		<i>t</i>	Sig.
	<i>B</i>	Standard error		
Constant	2.96	.21	13.97	.00
Gender	-.14	.14	-1.06	.30
Employment	-.08	.07	-1.05	.30
Religion	-.45	.14	-3.19	.00

$R^2 = .19, p = .02$ , Significant at the  $p < .05$  level.

However, no significant result in a linear regression predicted participants' experienced stigma based on gender, employment, and religion,  $F(3,48) = .65, p = .59$ . Moreover, no significant result in a linear regression predicted participants' experienced loss of face, based on the three predictors,  $F(3,47) = 1.84, p = .15$ .

**Summary**

A total of 56 Chinese American immigrants participated in the study. Participants had an average age of 34 years and an average of close to 10 years of education. They have lived in the United States for nearly 13 years and have had a mental illness for more than 8 years. Over half of the participants have a diagnosis of schizophrenia and a majority (68%) were unemployed.

The participants experienced more internalized stigma than experienced stigma. They reported experiencing internalized stigma higher than the midpoint level. The most commonly experienced internalized-stigma items related to not marrying someone with a mental illness and losing face due to having a mental illness. However, study participants

had a low mean score on the experienced stigma scale. The most experienced stigma areas were being shunned or avoided, being disdained by family members, and being treated as less competent.

In addition, findings indicated that all study participants maintained some level of secrecy regarding their illness. No participants were willing to educate others or advocate for people with mental illness. However, participants did not experience loss of face as was expected. Over one-third of participants expressed not feeling a loss of face due to their mental illness. Those who reported experiencing loss of face had a below average score on the Experience of Loss of Face scale.

In addition, findings revealed that gender and employment status significantly predicted participants' level of internalized stigma, whereas participants' religious affiliation significantly predicted their level of secrecy and disclosure. Moreover, participants' experience of loss of face also significantly predicted their secrecy level after adding internalized stigma and experienced stigma to the model. The discussion that follows demonstrates the significance of the findings and its implication to social work research, practice, and policy.

## Chapter 5

### Discussion and Implications

The purpose of this study was to examine the stigma experiences of Chinese American individuals diagnosed with schizophrenia spectrum disorders. Very few studies have focused on Chinese Americans with psychiatric disorders, and this study sought to understand the association among stigma, experience of loss of face, and disclosure preferences in this population. In this chapter, I discuss the findings of the study in relation to the existing research. Additionally, I consider the implications of the findings for social work practice, policy, and research. I also discuss the limitations of this study.

#### **Stigma Experiences**

Similar to previous studies on stigma among people with severe mental illness (Link, 1987; Link et al., 1989), the mean score of the DDS for this study sample was above the midpoint level. The most prominent internalized-stigma experiences among participants in this study were in the area of marriage and loss of face.

Extending one's family lineage by producing offspring is one of the most significant aspects of the Chinese culture (Kleinman & Kleinman, 1993; Stafford, 2006; Yan, 2003). Chinese individuals believe they are obligated to extend their family lineage through procreating and assuring prosperity. Therefore, being able to get married is a major concern for Chinese people. Being diagnosed with a mental illness, however, threatens one's ability to fulfill this key social responsibility because of concern about the threats of genetic contamination of mental illness (Yang et al., 2013). Mental illnesses are viewed by many in Asian communities as a genetic disease, inherited through family. Thus, mental illness taints not only the individual who is diagnosed with the disorder, but

the whole family, causing them to lose face (Knifton, 2012). Chinese people consider those with a mental illness to be unsuitable for marriage. For example, a public-opinion study in Hong Kong (Chan et al., 2016) indicated that over half of the study participants believed people would not be willing to date someone with psychosis. Increased levels of social restriction and social distance of intimate relationships were associated with a history of mental illness in one's family (Yang et al., 2013). Participants in this study were concerned about negative attitudes toward marrying someone who had been treated for a serious mental disorder, and some had experienced difficulty in finding romantic partners because of their mental illness.

Additionally, studies showed that it is not uncommon for people to believe that individuals with mental illness are dangerous and unpredictable (Chan et al., 2016; Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2006; Mestdagh & Hansen, 2014). This study confirmed such belief in that nearly 60% of the study's participants endorsed the notion that most people feel that a person with a serious mental illness is dangerous and unpredictable.

This study found that participants who had full-time employment before their hospitalization experienced more internalized stigma compared to those who were unemployed. This finding is different from views expressed in other studies. For example, Yang et al. (2014) found that impairment in one's ability to work led to intensified stigma. Moreover, being able to obtain competitive employment is an important component of recovery among people with a serious mental illness, as it brings empowerment, social contact, and increased self-esteem (Marwaha & Johnson, 2005; Tsang et al., 2007). Perhaps employed participants were more aware of the potential of being the target of

discrimination. Some study participants may have previously experienced stigmatization in their employment setting that contributed to our different finding from previous research (Marwaha & Johnson, 2005).

In addition to internalized stigma, previous studies also indicated that mental health consumers often experienced stigma in the area of interpersonal interactions (Jenkins & Carpenter-Song, 2009; Mestdagh & Hansen, 2014; Schulze & Angermeyer, 2003). Just as the findings of other studies suggested (Gonzalez-Torres et al., 2006; Mestdagh & Hansen, 2014; Schulze & Angermeyer, 2003), this study's participants also reported being shunned, ignored, and mocked because of their mental illness. They also experienced a deterioration of social interactions in which the quality of social interactions declined and the frequency of social contacts diminished. A study in Hong Kong indicated that people in the community tended to be reluctant to have people with mental illnesses as neighbors and also believe that people with mental illnesses belonged in psychiatric hospitals (Tsang et al., 2007). Similar to the Chinese American participants in this study, Mestdagh and Hansen's review (2014) found that individuals with mental illness are often being treated as less competent. In contrast, only a small number of participants reported having experienced structural forms of discrimination such as discrimination from mental health professionals and inadequate treatment and services.

An interesting finding from this study is that study participants reported higher internalized stigma than experienced stigma. One reason could be that most study participants did not fully and accurately disclose their mental health condition to others in their social networks; therefore, their mental health condition was mostly known only to their family members and close friends, which contributed to their limited encounter with

experienced stigma. Another reason may be that mental health consumers have limited social networks and have the tendency to avoid social interactions; as a result, they suffered only limited experienced stigma.

### **Coping Strategies**

#### **Secrecy**

Although previous studies portrayed secrecy as a negative coping mechanism that has primarily adverse effects such as anxiety on individuals (Vauth et al., 2007; Yow & Mehta, 2010), the Chinese immigrants in this study expressed positive aspects of keeping their mental illness a secret. Quantitative analyses demonstrated that no participants endorsed no secrecy, and one-third of participants endorsed substantial secrecy. The analyses of narrative data further illuminated the reasons behind the secrecy. For example one reason participants wanted to keep their mental illness a secret was the desire to focus on treatment with a plan to return to work. Moreover, participants' wish to remain normal illustrated their desire to function like those who do not have a mental illness. A study of a group of highly acculturated Chinese individuals with a severe mental illness indicated that mental health stigma conditionally rested on the individuals' functioning (Lin, 2013). If the individual was able to function and work, he or she would be less stigmatized than those who were not as able to function. This notion reflects their use of secrecy in an adaptive manner to preserve face so the consumer could reintegrate into the community when his or her symptoms subsided.

Moreover, participants who received mandated treatment such as Assistant Outpatient Treatment or Assertive Community Treatment were also less secretive about their mental health status. Mental health consumers referenced receive mandated



treatment if their mental illnesses were severe or they had a history of treatment-adherence issue. It is possible that their mental health status was revealed through their behaviors (e.g., bizarre behaviors during decompensation) or media reports (e.g., as one participant reported being in a newspaper article because she tried to jump out of the window) without self-disclosure. As a result, participants were less likely to have to maintain secrecy. Furthermore, frequent visits from case managers also provided some external exposure of their mental illness. Many study participants had restricted social circles; visits from non-Chinese individuals were typically rare. Because most case managers are not of Chinese descent, it is difficult for participants to hide their mental illness from people in their community. Married participants also reported a higher level of secrecy than their unmarried counterparts. This may be because the person with mental illness felt the need to protect the face and reputation of both families and therefore sensed the burden of being secretive about their mental health condition.

### **Disclosure**

Although no study participants endorsed no secrecy, none were willing to fully disclose their mental illness. Similar to a study conducted in Singapore in which study participants were hesitant to engage in initiatives to educate others about mental illness (Yow & Mehta, 2010), none of this study's participants were willing to provide advocacy such as participating in public education. Although a good number of participants were willing to disclose their mental health status, they only shared it with a limited number of people such as family and close friends to protect their own privacy. This result resonates with core Chinese values that focus on the protection of one's face and the safeguarding of their *guanxi*. If their mental illness became known to everyone in their social network,

it could potentially damage their *guanxi*, their families' reputations, and consequently their self-esteem. As a result, study participants perceived they had to strategically disclose their mental illness.

Affiliation with a non-Eastern religion (i.e., Christianity) was associated with levels of disclosure in this study. Participants who endorsed having a non-Eastern religion reported higher disclosure levels than those who endorsed having an Eastern traditional religion. Religious involvement in general positively related to psychological well-being and quality of life (Corrigan et al., 2003; Levin & Chatters, 1998). A number of study participants affiliated with non-Eastern religion expressed willingness to confide in their church friends about their mental health status and reported they felt supported. In this study, I did not examine types of activities related to religious affiliation in this study. However, a Christian church group regularly visits one of the Asian inpatient psychiatric units to support patients. Study participants who are affiliated with Christianity may, therefore, have felt accepted and supported by church members.

### **Experience of Loss of Face**

Although studies about mental illness among Chinese communities in different parts of the world found that loss of face and shame are the most common responses to mental health problems (Knifton, 2012; Lin, 2013), over one-third of this study's participants did not report feeling face loss due to mental illness. One reason study participants did not report experiencing loss of face may be due to the three-question scale used in this study. Knifton (2012) and Lin (2013)'s findings regarding loss of face rests on focus groups and semi-structured interviews, respectively, and neither used a quantitative measure to measure loss of face. Although one scale measures loss of face

among the general population (Zane & Yeh, 2002), no measures exist for loss of face among Chinese with mental illness. This area warrants further study.

In spite of the insignificant finding based on the loss-of-face quantitative measure, study participants' narrative comments expressed feeling a loss of face and therefore wanting to keep their mental illness a secret. It is interesting to note that participants who have been ill for fewer years (0 to 10 years) had a higher loss-of-face score than those who had been ill between 11 and 20 years. This may be due to their continual effort to try to uphold Chinese cultural values during their early years of the illness, causing them to feel more strongly about losing face when they saw the difficulty in fulfilling their expectations. Another reason may be that participants who recently became ill were not yet used to the stigma attached to mental illness and therefore felt more face loss. In contrast, participants who have been ill longer might have accepted the possibility that they may never be able to fulfill the expectations of others, and as a result experience less loss of face.

### **Coping Strategies and the Association With Stigma and Loss of Face**

According to previous studies, mental health stigma experiences affect one's disclosure preference, and lower levels of internalized and experienced stigma is associated with greater comfort in disclosing (Kleim et al., 2008; Rüsçh, Brohan, Gabbidon, Thornicroft, & Clement, 2014; Yow & Mehta, 2010). However, this study's findings did not correspond to these studies' results. Internalized stigma and experienced stigma did not predict secrecy in the regression model. Rather, experiencing loss of face significantly predicted secrecy, and the feeling of shame also significantly correlated to secrecy. A study among some highly acculturated Chinese American individuals with

mental illness also found that shame was a common negative emotional reaction when something improper occurs (Lin, 2013). The construct of loss of face, which affects many individuals in Asian culture, played an important role in shaping study participants' coping strategy in responding to stigma.

### **Limitations**

This study aimed to examine an understudied area: the stigma experience of Chinese American immigrants diagnosed with schizophrenia spectrum disorders. Although the largest known data set that focuses on this population was used for this study (Yang et al., 2014), the study had several limitations. First, the study had a small sample size and geographically restricted sample; thus, the results are not generalizable to all Chinese American immigrants. A larger sample size would allow for further examination of the associations among the variables. Conducting future research in a number of U.S. immigrant enclaves would also allow for a broader understanding of mental health stigma experienced by U.S. immigrants with different levels of acculturation and socioeconomic backgrounds.

In addition, participants in the study were all co-residing with family members at the time of data collection. Individuals who had no family in the United States may have had different stigma experiences and may have experienced loss of face differently from those who resided with family members, given that participants who had closer proximity to their families were more likely to feel pressured to preserve the family's face. Furthermore, those who were willing to participate in research may have held less stigmatizing attitudes about themselves and mental illness, potentially underestimating the effects of stigma. Last, this study was conducted using semi-structured interviews

guided by established stigma measures, which may have restricted participants' responses on their stigma experiences. This study, however, laid out important findings and a method to characterize coping methods among Chinese immigrants that may be used in future studies.

## **Implications for Practice and Policy**

### **Practice Implications**

Despite research that suggested negative outcomes of using secrecy as a coping strategy (Link et al., 1989), this study showed potential benefits of not disclosing one's mental illness. When working with mental health consumers, clinicians should consider the consumers' comfort level regarding how much information and with whom they want to share information about their mental illness. In addition, clinicians should discuss potential positive and negative impacts of disclosing, such as potential discrimination in comparison to additional support one may receive, once their mental health status is known. Core Chinese values such as *guanxi* and the issue of face should be considered as both are fundamental to participants' survival in the community (Chen et al., 2013).

In addition, clinicians should consider incorporating techniques to help cope with stigma into their regular psychiatric treatment. It is essential for mental health consumers to be aware of the negative effects of stigma and effective techniques to handle discriminatory situations. However, it may be difficult to engage consumers in formal ways to address stigma such as anti-stigma campaigns. Therefore, including some basic skills could be useful. Clinicians should consider teaching cognitive-behavioral principles to mental health consumers to help counter internalized stigma and discriminatory behaviors. For example, mental health consumers often have automatic thoughts or

stereotypic thinking about themselves. Using the 3Cs technique—catch it, check it, and change it—consumers can learn to counter their own internalized stigma. Another technique is to help mental health consumers examine their thoughts, feelings, and behaviors when facing discriminatory behaviors. This cognitive-behavioral approach can offer consumers alternative ways to cope with discrimination, thereby preventing others' behaviors to negatively affect them. These techniques were taught to caregivers of mental health consumers in the Chinese American community (Yang et al., 2014), and can also be valuable for mental health consumers.

In addition to helping mental health consumers cope with stigma, it would be beneficial to engage family members to learn about anti-stigma techniques. As studies suggested, family members were also affected by the stigma of mental illness (Koschorke et al., 2017; Mak & Cheung, 2012). Caregivers also experience avoidance and distancing by others in the community and often experience loss of face because of their family member who is diagnosed with a mental illness. It would be helpful for caregivers to learn new ways to handle discrimination. Additionally, helping caregivers counter their own internalized stigma about mental illness would be constructive in facilitating the recovery of individuals with mental illness. Anti-stigma interventions for caregivers of people with mental illness in the mainstream culture have shown efficacy in reducing internalized stigma, increasing acceptance of mental illness, and empowering caregivers (Dixon et al., 2011; Perlick et al., 2011). Additionally, Yang et al. (2014) has piloted a short-term anti-stigma intervention based on established interventions with modifications specifically designed for Chinese caregivers. The pilot intervention has received positive feedback from participants and showed a trend in stigma reduction following the

intervention. The continuation of such anti-stigma interventions would be constructive for caregivers to manage their own stigma experience.

Employment programs can be effective in helping mental health consumers who desire to return to work (Marwaha & Johnson, 2005). Many mental health consumers are concerned with their ability to cope with work-related stress and the risks of decompensation (Marwaha & Johnson, 2005). Employment programs would be a good starting point in which consumers could receive support and assistance to balance work and treatment adherence. An evidence-based practice of supported employment for people with mental illness called Individual Placement and Support has shown to be effective in helping individuals with mental illness maintain employment and improve job retention (Luciano et al., 2014; Marshall et al., 2014). The Individual Placement and Support program has been implemented with different cultural groups such as African Americans and Latino Americans in the United States and internationally (Luciano et al., 2014), and has shown similar results in other parts of the world including Hong Kong (Tsang, Chan, Wong, & Liberman, 2009). Furthermore, programs that cater to the immigrant population are lacking. Therefore, it is important for employment programs to hire bilingual staff with an understanding of the specific challenges immigrants face. Such programs could help improve treatment adherence among Chinese mental health consumers and decrease the discrimination to which consumers are susceptible in traditional work settings.

### **Implications for Social Work Policy and Education**

The recovery model has played an important role in reshaping mental health services since the 1990s (Anthony, 1993). Recovery, as a concept, emerged from

consumers, and is “described as a deeply personal unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles [and] ... is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness” (Anthony, 1993, p. 15). In addition to controlling psychiatric symptoms and regaining functioning, being able to cope with mental health stigma is another significant aspect of the recovery movement (Tse, Siu, & Kan, 2013). Self-disclosure and group identification are crucial means to challenge stigma and gain empowerment (Marino, Child, & Krasinski, 2016); however, self-disclosure and group identification require individuals with mental illness to risk facing discrimination. Despite the potential benefits of disclosing one’s mental health status, study participants expressed reluctance. Similar to findings in a study in Hong Kong (R. M. Ng, Pearson, Lam, Law, Chiu, & Chen, 2008), participants in this study focused on symptom remission and reclaiming life roles in work. Some study participants expressed their belief that it is unnecessary to disclose their mental health status to others; instead, they wish to focus on treatment and finding employment. Researchers (Chiu, Ho, Lo, & Yiu, 2010; R. M. Ng et al., 2008; Yee, 2003) found conflicting results about whether the recovery model from the West can be applied directly to Asian culture. Policymakers need to reconsider the meaning of recovery among service users in minority communities when designing mental health policies and programs. In addition, practitioners should explore and integrate the various definitions of recovery into treatment to promote the well-being of service users.

Public anti-stigma campaigns should emphasize culturally appropriate language, nuances, and concepts if they engage minority communities. Knifton (2012) found that a national anti-stigma campaign in the United Kingdom failed to reach many ethnic-



minority groups because of inappropriate language use and a focus on the use of the Western medical model. For example, participants in the Knifton study felt that the individualistic approach of mental illness used in the public campaign did not correspond with the more community- and group-focused attitude endorsed by their cultural group. Instead Knifton suggested engaging in personal contacts, dialogues, and group discussions in managing stigma that are embedded in one's community. This approach is far more effective than merely receiving written information or an advertisement. This approach can also be used for the Chinese American immigrant population. Having personal contacts or dialogues could address stigma such as threats of genetic contamination or inability to function or work.

Social work educators need to address the issue of mental health stigma in social work curriculum more comprehensively. Although the subject of stigma is infused in courses that teach about mental health, this subject deserves more attention. Social work students are seldom challenged to examine the issue of mental health stigma from personal, institutional, and cultural perspectives (Matsuoka & Thompson, 2009); social work schools should provide greater opportunities and space for such conversations. In addition to understanding the types of stigma regularly experienced by mental health consumers, social work students need to examine their own values, attitudes, and beliefs about mental health consumers. One social work program in Canada designed an anti-stigma program to be incorporated into its social work education. The program uses a strengths-based perspective to integrate consumers of the mental health system as lead instructors to engage in discussions about stigma, creating collaborative contact opportunities for students, teachers, and mental health consumers in equal discussion

(Matsuoka & Thompson, 2009). Such collaborative contact produces positive results in reducing stigma and discrimination (Matsuoka & Thompson, 2009). Social work programs in the United States should consider designing a similar program to increase social work students' awareness about mental health stigma and to equip them with the skills to counter stigma in social work practice at multiple levels.

### **Future Research**

This study is one of only a few research projects that interviewed Chinese immigrants in the United States diagnosed with schizophrenia spectrum disorders. Schizophrenia is a highly stigmatizing illness; therefore, individuals diagnosed with such illnesses tend to be reluctant to engage in this kind of study. This study has generated valuable information concerning the stigma experienced by Chinese American individuals with mental illness. It is crucial to continue to further understanding of the lived experiences of Chinese American individuals with mental illnesses to serve this population effectively. Further studies would benefit from having a larger sample size and samples from multiple immigrant enclaves. In addition, future research study could focus on culture-specific constructs such as the *what matters most* framework to investigate how these cultural concepts protect against or exacerbate Chinese individuals' stigma experience. Moreover, it would be critical to examine how structural stigma produces health inequality among this minority group. Although stigma is a social determinant of population health, most extant research focuses on the effects of stigma on an individual level. Literature that studied the influence of structural forms of stigma on the overall health outcomes among people with mental illness is very limited (Hatzenbuehler et al., 2013). It would be advantageous to understand ways structural

stigma negatively produces health disparity in the Chinese American group that may already be facing discrimination, due to its minority status in the United States.

Furthermore, the secrecy and disclosure scales need to be further tested for their usefulness and robustness. First, they should be tested with a larger sample size and with additional variables. Second, researchers may use them to examine secrecy and disclosure level among other conditions that bear similar stigmatizing traits such as people with HIV/AIDS. Future research can also use these two scales in other ethnic groups and examine if they are appropriate for other populations. The use of a phenomenological study to augment understanding of the day-to-day lived experiences of Chinese American immigrants with mental illness would allow researchers to develop a deep and rich description of the complex issues they face.

### **Conclusion**

This study examined the relationships among internalized stigma, experienced stigma, experienced loss of face, and coping strategies of Chinese American individuals with schizophrenia spectrum disorders. This study demonstrated a unique pathway of culturally distinct constructs that influence Chinese mental health consumers' coping strategies. Although internalized stigma and experienced stigma traditionally have been known as predictors of one's secrecy regarding one's mental illness, this study found that experience of loss of face—a culturally unique construct—significantly predicted participants' secrecy. This finding, in conjunction with the qualitative data collected from participants, illustrated the distinctiveness and complexity of the Chinese mental health consumers' stigma experiences. This finding could guide future researchers to further examine the experience of the loss-of-face construct and how this construct shapes

Chinese individuals' stigma experiences and coping methods. Social workers need to understand the cultural expectations and norms of this population and develop appropriate approaches to reduce mental health stigma, increasing efficacy of treatment and productivity of mental health consumers in the workforce, which will reap benefits for the richly diverse U.S. socioeconomic fabric.

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## Appendix A: Demographic Characteristics Questionnaires

1. Gender
2. Age
3. Years of education
4. Country of birth
  - Years in the U.S. if born overseas
  - Legal status in the U.S.
5. Marital status
6. Religious affiliation
7. Employment status
8. Participant income
9. Onset age of illness
10. Duration of illness
11. Number of psychiatric hospitalizations
12. Duration of the most recent hospitalization

Appendix B: Link's Devaluation –Discrimination Scale (DDS)

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	2.5	3	4

1. Most people in your community think that a person with a serious mental illness is dangerous and unpredictable.
2. Most people in your community feel that having a mental illness is worse than being addicted to drugs.
3. Most people in your community would accept a person who once had a serious mental illness as a close friend.
4. Most people in your community look down on someone who once was a patient in a mental hospital.
5. Most employers will hire a person who once had a serious mental illness if he or she is qualified for the job.
6. Most people in your community think less of a person who has been a patient in a mental hospital.
7. Most people in your community feel that entering psychiatric treatment is a sign of disgrace.
8. Most young women would not marry a man who has been treated for a serious mental disorder.
9. Most people in your community think that having a mental illness would cause a person to lose face.

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Appendix C: Mental Health Consumers' Experience of Stigma Scale

A. Experiences in the General Community

1. Have you been in situations where you have heard others say unfavorable or offensive things about people who have mental illness?

Yes      No

2. Have you seen or read things in the mass media (e.g. television, movies, books) about people who have mental illnesses that you find offensive?

Yes      No

—Direct Negative Treatment:

3. Have you been treated as less competent by others when they learned that you have this condition?

Yes      No

4. Have you been shunned or avoided when it was revealed that you have this condition?

Yes      No

—Direct Positive Treatment:

5. Have you been treated fairly by others who know that you have this condition?

Yes      No

6. Have people been supportive and understanding when they learned that you have this condition?

Yes      No

B. Rejection from General Community

7. Have you been excluded from volunteer or social activities by others when it was known that you have this condition?

Yes      No

C. Education—Negative Treatment

8. Have you been denied educational opportunities (for example, acceptance into schools) when it was revealed that you have this condition?

Yes      No

D. Employment—Positive Treatment

9. Have coworkers or supervisors at work been supportive and accommodating when they learned that you have this condition?

Yes      No

—Negative Treatment

10. Have you been turned down for a job for which you were qualified when it was revealed that you have this condition?

Yes      No

E. Family—Negative Treatment

11. Have family members looked down on you when they found out that you have this condition?

Yes      No

a. Did family members tell you not to tell others about your condition?

Yes      No

F. Doctor/Health Professional—Positive Treatment

12. Have doctors or other health professionals treated you fairly and respectfully while treating you for this condition?

Yes      No

G. Dating/Marriage—Negative Treatment

13. Have you had a spouse or romantic partner break up with you because of this condition?

Yes      No

14. Does having this condition make it more difficult to find a spouse or romantic partner?

Yes      No

H. Housing – Negative Treatment

15. Have you had difficulty renting an apartment or finding other housing when your condition was known?

Yes      No

I. Legal—Negative Treatment

16. Have you had the fact that you have this condition used against you in legal proceedings (such as child custody or divorce disputes)?

Yes      No

J. Police—Negative Treatment

17. Have you been treated disrespectfully or unfairly by law enforcement officers when they learned that you have this condition?

Yes      No

K. Intersubjective Stigmatization

18. Have you encountered situations where people “give off” a sense of stigmatization even if something is not explicitly said to you?

Yes      No

—How is this sense of stigmatization conveyed by others?

L. Structural Discrimination – Negative Treatment

19. Have you experienced difficulty in receiving adequate psychiatric services because of a lack of doctors who can speak your language?

Yes      No

—Due to a lack of insurance

Yes      No

—Due to having an illegal citizenship status?

Yes      No

—Due to a lack of monetary resources?

Yes      No

Reference

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Appendix D: Experience Loss of Face

1. How much loss of face have you experienced due to your condition?

Not at all Very Strongly

1    2    3    4    5    6    7

2. How much shame do you feel due to your condition?

Not at all Very Strongly

1    2    3    4    5    6    7

3. How much embarrassment do you feel due to your condition?

Not at all Very Strongly

1    2    3    4    5    6    7

## Appendix E: Coping Strategies

1. Regarding your most recent hospitalization, do people know that you have been hospitalized? Do people know that you have this condition?
2. Did you tell other people or did the person find out by accident?
3. Do you feel that you are better off not telling people about this?

Why?

—Follow up “Are there certain people who you might tell and certain people who you might not tell?”

4. If other people know, how do you think that they will view this or act towards you?

—Does anybody act differently towards you because of your condition, or because you take medication?

## Appendix F: Code Book

Codes	Themes
Indifference	Coping Strategies
(Doesn't care if illness is known by others)	(Secrecy)
(Illness isn't a big deal)	(Disclosure)
Secrecy	
(It's better that others don't know)	
(won't tell anyone outside of family)	
(I absolutely won't tell anyone)	
Disclosure	
(would tell some friends)	
(church has good people)	
Fear of rejection	Reasons for Secrecy
(sickness will affect my life)	(Fear of rejection)
(others will avoid you and keep distance)	(Loss of face)
Loss of Face	(unnecessary to disclose)
(Not a bright thing)	
(A shameful thing)	
(they will look down on me)	
Unnecessary to disclose	
(ability to do things after getting well)	
(focus on getting treatment)	
(It's one's own business)	
Support from Others	Reasons for disclosure
(will receive assistance from others)	(Social support)
(others offer comfort)	(Honesty)
Genuine relationship	(Acceptance of illness)
(Won't lie to friends)	
(it feels good to have people know)	
Focus on Achievement	
(I am still young and have hand & feet)	
(Keeping dreams alive)	
Humor	Disclosure Strategies
(tell others like a joke)	(Humor)
Concealment	(Concealment)
(didn't sleep well)	(Involuntary disclosure)
(went out of town to study)	
(will change the way in telling people)	
Involuntary disclosure	
(impossible to hide)	
(family members told others)	
(incidents was on newspaper)	

Appendix G: Bivariate Correlations Among Key Variables by Employment

		1	2	3	4	5
Unemployed						
1 Internalized stigma	Pearson correlation	1	.15	.23	.13	-.24
	Sig. (two-tailed)		.39	.19	.47	.17
	<i>N</i>	34	34	34	34	34
2 Experienced stigma	Pearson correlation	.15	1	.54**	.16	-.10
	Sig. (two-tailed)	.39		.001	.38	.56
	<i>N</i>	34	38	34	35	35
3 Loss of face	Pearson correlation	.23	.54**	1	.40*	-.26
	Sig. (two-tailed)	.19	.001		.02	.14
	<i>N</i>	34	34	34	34	34
4 Secrecy	Pearson correlation	.13	.16	.40*	1	-.78**
	Sig. (two-tailed)	.47	.38	.02		.000
	<i>N</i>	34	35	34	35	35
5 Disclosure	Pearson correlation	-.24	-.10	-.26	-.78**	1
	Sig. (two-tailed)	.17	.56	.14	.000	
	<i>N</i>	34	35	34	35	35
Employed						
1 Internalized stigma	Pearson correlation	1	.32	.34	-.46	.42
	Sig. (two-tailed)		.20	.16	.06	.09
	<i>N</i>	18	18	18	17	17
2 Experienced stigma	Pearson correlation	.32	1	.31	-.27	.36
	Sig. (two-tailed)	.20		.22	.30	.15
	<i>N</i>	18	18	18	17	17
3 Loss of face	Pearson correlation	.34	.31	1	-.04	.11
	Sig. (two-tailed)	.16	.22		.87	.67
	<i>N</i>	18	18	18	17	17
4 Secrecy	Pearson correlation	-.46	-.27	-.04	1	-.57*
	Sig. (two-tailed)	.06	.30	.87		.02
	<i>N</i>	17	17	17	17	17
5 Disclosure	Pearson correlation	.42	.36	.11	-.57*	1
	Sig. (two-tailed)	.09	.15	.67	.02	
	<i>N</i>	17	17	17	17	17

Note: \*\*. Correlation is significant at the 0.01 level (two-tailed); \*. Correlation is significant at the 0.05 level (two-tailed).



Appendix H: Bivariate Correlations Among Key Variables by Religion

		1	2	3	4	5
Eastern religion						
1 Internalized stigma	Pearson correlation	1	.30	.53**	-.01	-.04
	Sig. (two-tailed)		.09	.001	.96	.84
	<i>N</i>	34	34	34	33	33
2 Experienced stigma	Pearson correlation	.30	1	.29	.07	.19
	Sig. (two-tailed)	.09		.10	.70	.29
	<i>N</i>	34	35	34	34	34
3 Loss of face	Pearson correlation	.53**	.29	1	.16	.08
	Sig. (two-tailed)	.001	.10		.37	.67
	<i>N</i>	34	34	34	33	33
4 Secrecy	Pearson correlation	-.01	.07	.16	1	-.65**
	Sig. (two-tailed)	.96	.70	.37		.000
	<i>N</i>	33	34	33	34	34
5 Disclosure	Pearson correlation	-.04	.19	.08	-.65**	1
	Sig. (two-tailed)	.84	.29	.67	.000	
	<i>N</i>	33	34	33	34	34
Non-Eastern religion						
1 Internalized stigma	Pearson correlation	1	.12	.15	-.03	-.17
	Sig. (two-tailed)		.64	.57	.90	.52
	<i>N</i>	17	17	17	17	17
2 Experienced stigma	Pearson correlation	.12	1	.64**	-.02	-.18
	Sig. (two-tailed)	.64		.01	.94	.49
	<i>N</i>	17	17	17	17	17
3 Loss of face	Pearson correlation	.15	.64**	1	.24	-.18
	Sig. (two-tailed)	.57	.01		.35	.50
	<i>N</i>	17	17	17	17	17
4 Secrecy	Pearson correlation	-.03	-.02	.24	1	-.72**
	Sig. (two-tailed)	.90	.94	.35		.001
	<i>N</i>	17	17	17	17	17
5 Disclosure	Pearson correlation	-.17	-.18	-.18	-.72**	1
	Sig. (two-tailed)	.52	.49	.50	.001	
	<i>N</i>	17	17	17	17	17

Note: \*\*. Correlation is significant at the 0.01 level (two-tailed).