Stigma Against Mental Illness and Cerebral Palsy in China

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Stigma against Mental Illness and Cerebral Palsy in China

by Liying Shen

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Abstract

This dissertation examines the stigmatization of two health conditions: mental disability and physical disability in the context of China. In particular, it addresses two main themes: the processes and impacts of stigma, and the variables that moderate the association of stigma with social attributes.

The first paper applied a qualitative approach to identify the sources of burdens of raising a child with cerebral palsy in China and how stigma and "face" as a cultural factor affect children with cerebral palsy and their families. The findings showed that families with children of cerebral palsy report tremendous financial burdens, insufficient educational and medical services, as well as discrimination among family members and communities. An overwhelming majority of caregivers reported to have had the feeling of "loss of face," while family members considered the child with cerebral palsy as "useless" and "burdensome." Their common remarks o "send away the child to orphanage" and "give another birth to a normal child", reinforced caregivers' feeling of helplessness, and put many family relationships to an end.

The second and third papers on stigma and mental illness studied the underlying social determinants of public stigma and the variations in the general public's attitudes and reactions toward people with mental illness. Using a population-based stratified sample of 3703 adults from the Stigma in Global Context-Mental Health Study, paper II investigated social attributes, stigma, and the links between them. Paper III assessed how demographics and geographical location structured public perceptions and reactions towards people with mental illness.

Findings from paper II indicated that Chinese are less willing to interact with people with depression and schizophrenia than those with a physical illness. Depressive disorders had more rejections than schizophrenia in this study. Age, education, and place of residence among respondents had significant association with public stigma. The label of “mental illness” and perception of dangerousness had significant negative association on social stigma. Findings from paper III indicated that social distance had a significant association with regional context, which suggests that public stigma exists at larger cultural levels. Our findings help inform specific factors in the pursuit of tackling structural discrimination.

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Acknowledgements

It is hard for me to imagine that I am completing my doctoral training at Harvard. Five years ago when I started this program, I had never thought that I would study stigma; I never imagined that my doctoral dissertation would be investigating the emotional suffering of human beings associated with disease. Over the past decade, I have been with victims of a “mark”, or the victims of being disabled. I have witnessed people’s sorrow and anger of being someone who seems abnormal or less desired in a society. Honestly, I used to hate to reveal and talk about what I have seen. But they did happen, and I am, inevitably, one of the chosen ones to keep a record of these accounts.

If it were not for Dr. David. R. Williams’ encouragement, I would have pursued other topics. I would therefore like to first give my sincere gratitude to my thesis advisor, Dr. Williams. Over the past five years, David has been more than my thesis advisor. The ways he teaches, analyzes studies, and talks about discrimination related to health, are all very inspiring and enlightening. He is a great example of what a serious scholar should be. David has helped me throughout my journey, not just with academic training, but also by providing feedback about my writing and even correcting language errors. I would not be here without his guidance and help. Secondly, I want to thank my other thesis committee members: Dr. Arthur Kleinman and Dr. S.V. Subramanian. I remember the first time I went to Arthur’s office and presented my idea about studying the stigma of children of cerebral palsy in China. Before that meeting, I had talked to many professors at Harvard and almost gave up this topic; Arthur was my last hope to continue this exploration. After listening to my idea for two minutes, he was very excited about this topic and said to me: “This is a very interesting and important topic. I will support you.

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Paper I: Caring for a child with Cerebral Palsy in China: Understanding the burdens of caregiving in the Chinese Context

Summary

This study aims to understand caregiving experiences of parents of children with cerebral palsy in China, a disease that affects 3 per 1000 Chinese children under seven years old at birth per year. Although studies in the West have been devoted to the consequences of caregiving experiences, little is known little about the effect of having children with cerebral palsy among Chinese parents. In particular, no studies have yet investigated both social and cultural factors that contribute to burdens of caregiving for children of cerebral palsy in current Chinese society. This qualitative study will describe daily experiences of primary caregivers in their taking care of children with cerebral palsy, and examine how "face" as a distinctive cultural factor plays a critical role in the stigmatizing process in Chinese culture.

We collected data with semi-structured interviews with 17 families with children of cerebral palsy recruited from Chengdu No1 hospital rehabilitation center, and Chengdu Women and Children's hospital The results indicate that parents experienced demanding challenges as they cared for their children with cerebral palsy. Tremendous financial burdens, insufficient educational and medical services, loss of social connections, as well as feeling of "loss of face" and stigma among family members and communities were the major themes from parents' stories. Staring, uncomfortable questioning, unfriendly tones, and ignoring and devaluing their children were the major discriminatory behaviors families often suffered. An overwhelming majority of caregivers reported to have had the feeling of "loss of face" when family members labelled the child with cerebral palsy as "useless" and "burdensome." Their common remarks to "send away the child to orphanage" and "give another birth to a normal child" reinforced caregivers' feeling of helplessness, and put many family relationships to an end.

Findings from this study are helpful to medical staff and public health practitioners to assess the needs of the disabled children and their families. It highlights the importance of family interventions that can inform family members' understanding of cerebral palsy and their attitudes towards the afflicted children. Better welfare systems for children with special needs can not only reduce family burdens, but also contribute to a better quality of life. This study also calls for better policy and anti-stigma actions that address stigma against people with disabilities and acknowledge their needs and rights in society.

Background

China is confronting a growing trend of child abandonment. According to the 2010 China Children Welfare Policy Report, nearly 100,000 Chinese newborns are abandoned by their parents each year, and most of the abandoned babies have disabilities or diseases (UNICEF, 2010)

Anyone visiting a Chinese orphanage nowadays will see a substantial number of children with birth defect issues. In 2011, China introduced 25 "baby hatch facilities" around major cities to ensure that parents could abandon infants safely rather than leave them in the streets. This action only ended up increasing the abandonment of disabled children. The Jinan orphanage hatch received 106 children after it opened for 11 days, which was more than 85 babies the orphanage accepted the entire previous year, all of whom were ill or disabled (Connie, 2014). The Guangzhou orphanage hatch facilities were even forced to shut down within two months after becoming overwhelmed with 262 abandoned youngsters (Euan, 2014). Childcare institutions have remained the dominant method of caring for abandoned children in China. Sixty-seven percent of the infants dropped off were less than one year old and most suffered from cerebral palsy, Down's and congenital heart disease, according to the Bureau of Civil Affairs (Kubin, 2014).

In China, children born with disabilities can easily be abandoned by their parents at public toilets, on the streets, or in front of the police office. According to the Second National Sample Survey of Disabled Persons in China conducted in 2006, there were 5.8 million children with some kind of disability (UNICEF, 2011). Among all diseases that contribute to infant abandonment, cerebral palsy (CP) is the most common. In 2012, there were 6 million children with cerebral palsy in China, with an increase of 4 per 1000 new born babies per year. 70% of the affected families were living in poverty and 26% of the families had to give up treatment due to financial restrains (Big River,2013). According to the data from Chinese adoption institutions, 80% of children from Chinese Children Welfare Institution were abandoned by their parents due to disabilities and 60% of children at Chinese orphanages have cerebral palsy (Social Welfare and Charity Promotion Division, 2014). Luo Yang Welfare institute in He Nan province, for example, currently has over 624 orphans, and 90% of them are children with severe cerebral palsy (Luoyang institute of child welfare, n.d.)

While advancements in medicine and social conditions have prolonged life expectancy and increased the overall quality of life in China, children born with disabilities still experience enormous social rejection, even from their own biological parents. It is difficult to surmise the reason for each child abandonment, but the overarching trend shows that parents with a child with cerebral palsy are stigmatized without financial, psychological and medical support, and are thus under tremendous pressure to resort to abandonment.

We investigate these pressures by studying the opposite end of the spectrum of abandonment -- families who decided instead to raise their disabled children. Through their stories we seek to grasp the burdens and limitations they face in raising a child with special needs in an unsupportive cultural context.

Introduction

Cerebral palsy (CP) is defined as a range of non-progressive syndromes of posture and motor impairment, and is the most common cause of disability in childhood (Koman et al.,2004). It is estimated to afflict about 2.1 per 1000 live births per year, and the rates appear to be similar in both developing and developed world (Oskoui et al., 2013). In China, The birth-weight adjusted prevalence of cerebral palsy for children aged <7 years is 2.8 per 1000 children (Liu et al.,1999). It develops in infancy or early childhood and permanently affects motor function (Murphy & Such-Neibar, 2003).

Although cerebral palsy predominantly results in motor system dysfunction, other commonly associated conditions have been identified, such as impaired cognition, sensory deficits, feeding problems, behavioral dysfunction, and emotional problems (Davis, 1997). It is a costly disorder: In the U.S., the lifetime cost of direct care for an individual with cerebral palsy was $921,000 (CDC, 2004). No study has reported the cost of cerebral palsy in China yet, but Chinese scholars have estimated the average cost of raising children with physical disability to be 17,000 RMB per year, and mental disability to be 6,300 RMB per year (Xiong, 2011).

This condition not only affects nearly every aspect of the child's life, but studies worldwide have documented that it has a tremendous effect on the quality of life of parents with children of cerebral palsy as well. Scholars from Europe have reported tremendous loss and sorrow (Fernandez, et al., 2015), crisis and stress (Uldall, P. 2013; Parkes, 2011) among European families with children of cerebral palsy (lversen,A.S. et al., 2013). Australian scholars also reported that caregiving experiences for a child with CP have been associated with feelings related to loss, unresolved grief, experiential avoidance and depression (Whittingham K. et al., 2013). A systematic review of quality of life of parents with children of cerebral palsy found that mothers of children with cerebral palsy report consistently poorer quality of life and higher stress levels and depression, compared to mothers of normally developing children (Pousada, M. et al., 2013). Scholars in Netherland and United States found that the source of stress includes time demands, prolonged burden of care, reduction in social relationships, lack of social support, reduction in professional opportunity, and lack of information and services (Ketelaar,M. 2008; Green,S. 2007; Green et al., 2005, Krstic, 2012). A study from Israel that examined stressors, coping strategies, and social support among parents with a variety of disabilities found that the most stressful aspects for these families included the financial stress and lack of social support (Leyser, Y, 1991). Risdal (2004) in a meta analysis study also learned that parenting CP children is also correlated with a lower marriage quality and lower marital satisfaction among them, as well as an elevated risk of divorce and separation.

In addition to the conventional stress indicators mentioned above, the work of Miller and Major (2000) emphasizes the connections between stigma and all forms of disabilities, and states how the stigmatized status could become a major source of stress in people’s lives. In the early 1960s, Goffman published the book “Stigma: Notes on the Management of spoiled identity” (1963), which provided comprehensive framework and understanding of stigma. According to Goffman’s definition in his book (1963), stigma is a “mark” that signals to others that an individual possesses an attribute reducing him or her from “whole and usual” to “tainted and discounted" (p.3). This devaluation translates into seeing the stigmatized person as "not quite human" and may emanate from "abominations of the body" (physical disabilities), "blemishes of individual character" (mental illness, addiction) and "tribal identities" (race, gender, religion). In his book, Goffman argues that stigma not only affects the experiences of those "in possession of the stigmatizing characteristic", but also their family members and others associated with the stigmatized.

Studies from developed countries have consistently provided evidence between the parental experiences of stigma and stigmatized conditions of their children with disabilities. By studying American families with disabilities, Mehta & Farina (1988) suggested that family members were also afflicted by their children's disabilities. Through their association with disabled children, they themselves were also "marked" by the the society. In order to investigate the parental stress attributed to public stigma and children's stigmatizing conditions, Baxter (1989) interviewed 131 Australian families with children of developmental delay. The study showed that the "noticeability" of the children's physical difference, abnormal speech, and uncontrollable behaviors were significantly associated with parental stress level. Public reaction towards their children, such as staring, displaying discomfort, ignoring, and drawing attention to the child, were also significantly associated with parental stress levels. Angermeyer et al. (1997) assessed the burden and stigma experienced by relatives of mentally ill persons through a random sample of members from the Federal Association of Relatives of the Mentally Ill survey in Germany. Of the sample, 30% reported experiencing discrimination by their environment, and 25% of respondents reported reduced social interactions with other family members due to their illness. Angermeyer also did another focus group study among families with Schizophrenia in

Germany, and it suggests that family relatives who feel stigmatized often experience increased emotional distress, social isolation, and structural discrimination (Schulze & Angermeyer, 2003).

The burden of raising CP children in China

No study in Mainland China has yet focused on the caregiving experiences and stressors of parents with children of cerebral palsy, although a few studies have investigated caregiving experiences in other disabilities. Lim (2013) reported Chinese families with children with Rett Syndrom (learning disabilities) received poor diagnoses, few limited services, and discrimination due to illness. Another study looked into family economic burdens among 227 families of children with disabilities in China found that families with disabled children have significantly higher medical costs and care costs, but lower education costs, clothing costs and entertainment costs than those of families with normal children (Xiong, 2011). Compared to families of CP children from Western developed countries, Chinese families seem more likely to suffer from a greater level of burden from both economical and social structural constraints.

Unsupportive educational environments, inadequate rehabilitation services, and shortfalls in government support are the three major problems that Chinese families with disabled children have to face. The current educational system in China provides limited opportunities for children who need special education. Children with mental retardation and children with multiple disabilities were largely excluded from school due to lack of personnel and resources (Deng & Harris, 2008). In recent years, China is attempting to do much more in the way of educating children with disabilities. However, children with severe and multiple disabilities and many children with moderate disabilities are still lack of opportunities to be enrolled in general public schools (Kritzer, 2011). In addition to the lack of educational resources for children with special needs, there are significantly inadequate rehabilitation services for children with disabilities, along with underdeveloped child welfare institutions and shortfalls in government support to children and their families (UNICEF, 2011). Although some local governments, such as the cities of Guangdong, Zhejiang, Xiamen, have made initiatives to provide rehabilitation facility funds and surgical funds to families with disabled children, there are no national rehabilitation policy mechanisms that subsidize families with disabled children who require day-to-day and long-term therapeutic services (UNICEF, 2011).

An important contextual factor unique to China is the set of unintended consequences of the "one child policy" in China. The one child policy was introduced by Deng Xiaoping in 1979, as a short term solution to curb the population overgrowth and to promote a voluntary small family culture (Nakra, 2012). One of its unintended yet noticeable consequences is the unbalanced male/female ratio in current Chinese society; the Chinese male to female ratio at birth went up from 1.08 in 1980s to 1.18 in 2010 (World Bank, 2012). The reasons behind this asymmetry are sex-selective abortions due to Chinese preference for sons, under-reported female births, and unreported adoptions of baby girls (Greenhalgh, 2008). Simultaneously, a far less noticeable consequence of the one child policy is the increasing trend of child abandonment. According to UNICF China report in 2011, China's orphan population has increased 24%, from 574 thousand in 2005 to 712 thousand in 2010, among which a majority of children are orphaned due to illness and disabilities (UNICEF, 2011). Under the one child policy, the government acquiesced to a moral economy in which the single child was expected to be healthy and "normal". Hence, to a certain degree, the Chinese government has legitimated the practices of giving up disabled children for adoption and even the practice of aborting fetuses expected to be disabled.

In the midst of a Chinese policy transformation that allows for more than one child in a new family, having an abnormal child is still a very big challenge for most families. Not only does the child suffer mentally and physically, but the family members are also stigmatized and lacking financial, psychological and medical support (Xiong, 2011). While acknowledging the key roles that psychological forces play in stigma's manifestation in Western countries, scholars studying stigma in China propose that "face" as a distinctive cultural phenomenon in China plays an important role in the stigmatization process (Yang, 2008). Thus it should be considered while studying stigmatized conditions among the people with the disease and their family members. "Face", according to Yang (2008), is a "physical, emotional, social and moral process" in Chinese society, which functions as a form of symbolic social capital that analogous to "guanxi" within Chinese society. Yan (2003) described "guanxi" in the book *Private Life under Socialism* as "the society", or "local moral world", that served as a platform for "economic, political, social and recreational activities" in the society. Through his study in a North China Village, Yan (1996) suggested that "guanxi" functioned as a social network to reproduce relationships. A person was able to establish "guanxi" through his/her efforts in order to gain support or personal interests, while "face," that combines both moral and social aspects of a person, plays a vital role in allowing an individual to establish "guanxi". Through cultivating and maintaining one's moral face, a person is able to obtain social face that determines the overall social capital and resources the person possesses (Yang, 2008). In the negative example of mental illness, Chinese believe people with mental illness have moral lapses; this leads to family shame, loss of face and social stigma, as it is contrary to the Chinese values that promote being "normal" and fulfilling cultural expectations and standards (Holroy, 2003). Family stigma in China threatens to break social connections (“guanxi wang”) linking family members to social connections, working opportunities, and other social capital resources (Yang, 2008).

The phenomenon of “loss of face” and being stigmatized not only affects family members of people with mental illness in China, but also those with other forms of disabilities. Traditional Chinese beliefs perceive giving birth to a child with disability is a punishment for morally wrongdoings from a previous life, and having a child with disability is shameful (Chiang & Hadadian, 2010). Holroy (2003) interviewed 15 Hong Kong Chinese families and found that fathers in the interviews expressed that they would pay any price to have a normal son or daughter, in order to regain their moral reputation and social status in the community. In a recent study of caregiving for cerebral palsy children in Taiwan, Huang (2011) found Taiwanese mothers received limited or no support among family members whom believed cerebral palsy made them loss face in the family. She concluded that Taiwanese mothers experienced the burdens of caring in an unsupportive environment, as well as structural discrimination against their children with cerebral palsy.

Although previous qualitative studies have described a wide range of stressors related to caretaking of children with cerebral palsy, no studies have yet focused on the parental experiences of caring for a cerebral palsy child in mainland China, and in particular, investigating the social and cultural factors that contribute to burdens of caregiving for children of cerebral palsy. In order to advance our knowledge about the burdens of caregiving, this study explores chronic and daily stressors Chinese families’ experience and perceptions of having a child with cerebral palsy as one form of disability, with the goal of examining how cultural values influence parents’ perceptions of and reactions to stigma. This qualitative study will describe daily experiences of primary caregivers in taking care of children with cerebral palsy, and examine how “face” as a distinctive cultural factor plays a role in the stigmatizing process in Chinese culture.

Methods

Design

A demographic questionnaire and a semi-structured interview guide was developed from a number of studies that had identified major domains of caregiving experiences of children with cerebral palsy in Western countries (Mihaylov, et al., 2004; Masterson, 2010; Burkhard, 2011; Sarkar, 2010) and studies undertaken in China that assess the stigma among mentally ill patients and their family members (Guo, 2008).

Specifically, the interview questions (Table 1.1) were selected based on the domains of literature. It included a mix of structured and open-ended questions. The ***Present situation*** section was used mainly to have some general topics to start the conversation, and to see if parents are able to freely discuss their children’s illness and daily experience. The ***Daily challenges of caregiving*** section was used to generally discuss the amount of time involved in childcare, major life changes, healthcare cost, financial situation and daily challenges of caregiving. The ***Social support and social network*** *section was used to infer whether parents still maintained social interactions with relatives, community members, friends and other people, and the overall quality of their social support.* ***Feeling of loss of face*** was a new section used to understand whether parents and other family members had the feeling of “loss of face” due to their children, and the context of when the feeling occurred. The ***Fairly or unfairly treated by family or non-family members*** section was used to observe whether parents had been discriminated due to the illness of their children within and outside family members and parents were asked to describe the occasions when discrimination happened. The ***What matters to you***

***the most** section was used to* discover what has not been discussed but parents feel very important to share. Four subject matter experts including one rehabilitation clinician in Chengdu and three professors with extensive experience in qualitative studies and stigma research in China, reviewed and provided feedback the interview guide prior to the start of data collection (see Table 1.1).

The demographic questionnaire includes socio-demographic characteristics and levels of independence in caretaking. Age is coded as a continuous measure in years. Gender of both caretaker and the child were collected. Other demographic variables such as education of caretakers, ethnic background, rural/urban residence, and religious background were also collected.

Table 1.1: **Script of the semi-structured interview**

Section I: Present situation of your child

- How many children do you have in your family? Is he/she your first child?
- How do you describe your child's problem? What's the name of this disease?
- What caused it? How serious is it?
- What is it like to care for *(child name)*? (Describe a typical day in your life. What helps you get through the day? What hinders you getting through the day?)

Section II: Daily challenges of caregiving

- Has the experience of caring for (child name) impacted different aspects of your life? For example, your relationships with other people? Your health? Your employment status or work life?
- Tell me about a time when caring for (child name) was particularly meaningful or rewarding for you?
- Tell me about a time when caring for *(child name*) was particularly difficult or challenging for you?
- How much time do you spend everyday to take care of your child?
- How much do you cost to take care of the child, on average per month? What are the components of the cost? Do you have health insurance to cover your cost? how much percentage does the insurance cover the medical cost?

Section III: Social support and social network

- What types of supports do you have caring for your child? (support from family members, relatives, friends, neighbors, community members)? Are you satisfied with their kinds of support, is it helpful?
- On a typical day, do you feel that you have enough support (or all of the support that you need) or do you wish that you had more support?
- How has the illness been treated by medical professionals? (Detail experiences of seeking medical help if possible.
- Do you have any kind of support from the local government? or any welfare benefits? Is it helpful?
- How many close friends does your child have? Who are they? What kind of activities do they like to do together?
- How many close friends do you have? (Who are they) how often do you meet? Does having a CP child change how often you interact with your friends? / Does having a CP child affect the guanxi with your friends?

Table 1.1 (Continued)

Section IV: Feeling of “ Loss of face”

- Do you think that your child or his/her Illness has made you lose face?
- Do you think this Illness had made your whole family lose face?
- How often does your child's condition make you feel loss of face?
- How often does your child's condition make you feel sad?
- How often does your child's condition make you feel angry?
- Can you describe an example of a recent time when those feelings or emotions occurred?
- Has the feeling of loss of face change over the years since you took care of the child?

Section V: Fairly or unfairly treated by family or non-family members

- What do you think other people feel about your child?
- Do family members gossip about your child's condition? (relatives on father&mother sides) What was your reaction?
- Do non family members gossip about your child's condition? (neighbors, friends, colleagues, other etc) what was your reaction?
- Has this illness changed the way that your child has been treated within the family members (including your relatives, grandparents)?
- Can you describe what the changes are?
- Does your child's condition affect how family members treat you? Do they treat you better or worse?
- Does your child's condition affect how non family members treat you?
- Does the concern that your child might treated unfairly/badly by other people make you and your child withdraw from social activities (such as walking outside, go shopping, go to school, social gathering, etc)
- How often does your family receive positive and helpful instances from others because of his/her illness?
- How free do you feel to talk about the problem caused by the illness within the family?
- How free do you feel to talk about the problem caused by the illness among people outside of your family members?

Section VI: What matters to you the most

- We have talked about so many problems about child caregiving. Can you tell me what matters most about your experience of taking care of the child?
- Is there anything we haven’t discussed that you believe is important for nurses and other
  health care providers to know about your experience caring of for an adolescent/young adult with cerebral palsy?

Participants

The Institutional Review Board (IRB) of the Harvard School of Public Health approved the research in 2014. The interviews were conducted from March to May of 2014 in Chengdu, China. Participants were recruited from Chengdu No1 hospital rehabilitation center, and Chengdu Women and Children's hospital. A purposive sampling was performed, with the inclusion criteria composed of (1) a confirmed clinical or genetic diagnosis of cerebral palsy for the child and (2) evidence that the caregiver had a good command of written and spoken Mandarin. By the end of May 2014, 17 families were interviewed and each interview lasted about 90 minutes. Interviews were guided by the semi-structured questions approved by thesis committee members, although the sequence of questions changed according to the flow of conversation. All study materials including interview questions and schedules and consent forms were translated into Mandarin. Before the interviews began, participants were told by the interviewer about the objectives of the study, the voluntary nature of the interview, and the possibility to abandon the study any time at their will. At the end of the introduction, participants were asked for their informed consent.

Analysis

The transcribed data were analyzed using a generative thematic approach (Braun & Clarke, 2006). Data were tape-recorded and transcribed verbatim by the first author into Chinese to ensure subtle meanings were not lost in translation (Neubert, 2003). NVivo 10 Chinese version software (QSR International, 2014) was used to organize data and record notes. Data were coded and grouped by the content area of the question. The first author then read and reread to gain familiarity, organizing data into meaningful groups, forming initial ideas of the data set, sorting different codes into potential themes. The initial coding classifications and analytical schema were built with reference to the existing stigma model for China (Yang, 2008). A summary of the thematic code is shown in Figure 1.1. The major theme were the ones we developed through the semi – structured interview, and the minor themes were pull out from the data analysis. Shared meanings and selected quotes were translated into English.

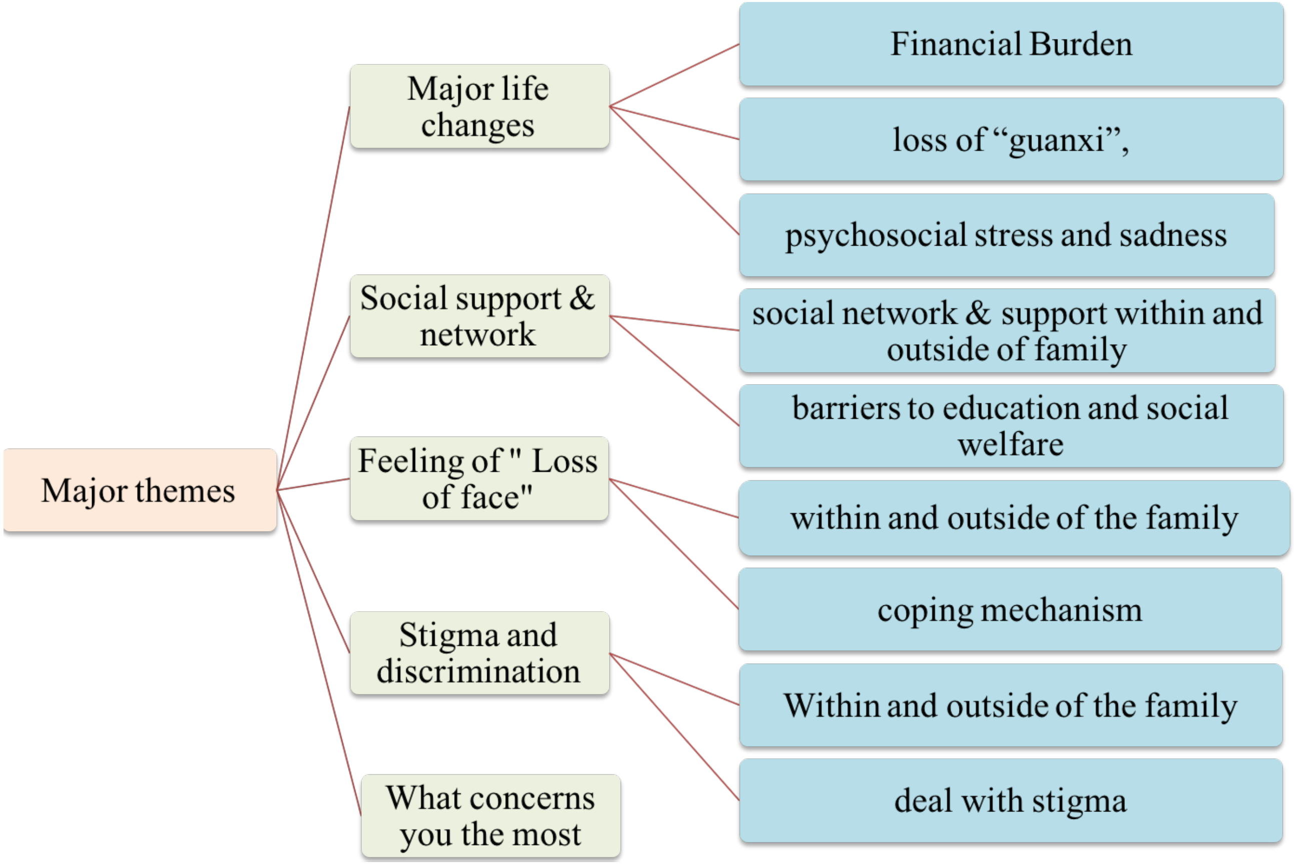


Figure 1.1: Major and minor themes in the study of stigma against family with children of cerebral palsy

Results

Individual family data are showed in Table 1.2. Seventeen families participated in the interviews. Thirteen interviews were completed with the child's mother as the main caregiver, fathers in two cases, and grandmother as the main caregiver in two cases. Ten families lived in Chengdu or in Sichuan province (within 500 km of Chengdu), Seven families came from Henan, Shandong, Inner Mongolia Province (> 1000 km away). Nine families were from rural areas, and eight families lived in urban areas. Five families had only one child; four families had three children; eight families had two children and among them, in three families the child with cerebral palsy was the eldest sibling. One family had twin girls, the younger sister was affected but the older sister was unaffected. The other families had unaffected older siblings. The average age of the main caregiver was 39, and ranged from 27 to 69 years old. Children were aged between 3 to 18 years old at the time of the study. Figure 1.1 includes a summary of the identified thematic codes, which includes major life changes, social support and social network, feeling of "loss of face", stigma and discrimination, and what you concern the most.

Major life changes – Financial Burden

All families interviewed expressed financial burden as a major life challenge after having a child with cerebral palsy. Maternal resignation from the workforce was found to occur more often than for other family members. Among all families, two families reported that the father elected to withdraw from the workforce as mothers were able to generate more income than fathers in the family, two families reported that mothers continued to work to support the rehabilitation cost and grandmothers elected to be the primary caregiver, and thirteen families reported that the mother elected to withdraw from the workforce and served as the sole caregiver.

Table 1.2: Demographic information for participating families

Family ID	Age	Education	Rural/ Urban	Child age at interview	Sex of the child	Number of children at home	Religion	Main Caregiver
1	45	college	Urban	14	Male	2	None	Mother
2	48	high school	Rural	18	Male	2	None	Mother
3	32	high school	Urban	5	Female	2	None	Mother
4	34	high school	Rural	3	Male	2	None	Mother
5	49	high school	Rural	3	Male	2	None	Father
6	48	middle school	Urban	5	Female	3	None	Grandmother
7	35	middle school	Urban	7	Male	1	None	Mother
8	38	middle school	Rural	6	Male	3	Christian	Mother
9	28	middle school	Rural	4	Male	1	None	Mother
10	37	college	Urban	8	Female	1	None	Mother
11	32	elementary school	Rural	5	Female	1	Christian	Mother
12	32	college	Rural	3	Male	1	None	Father
13	35	middle school	Urban	11	Female	3	None	Mother
14	37	middle school	Urban	3	Female	2	None	Mother
15	42	elementary school	Rural	7	Male	2	None	Mother
16	27	high school	Rural	3	Female	2	None	Mother
17	69	elementary school	Urban	12	Female	3	None	Grandmother

Among thirteen families with mother as the primary caregiver, 12 mothers expressed leaving the workforce was their major life change, as their children required extensive medical and therapeutic care. For example, one mother originally from Beijing said quitting her job was a very difficult decision for her and her parents. "*Before I had this child, I worked in a middle position in a bank and my salary was very good compared with my peers. I gave part of my salary to my parents to make their lives better. But I couldn't do that anymore after I knew *** had this disease. When I told my parents I had to quit my job, they were very upset. But there was no better solution."*

Similarly, one grandmother took the interview while her granddaughter was taking the physical therapy, it was her 12th year of caretaking the child. She described herself as "my granddaughter's real mother."

She recounted, *"My husband and I are retired. Generally, retired couples could enjoy a relaxing and stress free life. But we can't. All six adults (parents, and grandparents on both sides) are making money to support her (the CP granddaughter). Her mum is making money now. And we (herself and her husband) take her to do therapies everyday. This is tiring. And we have to save our retirement fund for her." She shook her head. "Alas… This is fate".*

In addition to the financial burdens to the cost of rehabilitation services, the limited and uneven rehabilitation service is another barrier for some parents from limited healthcare services in some isolated areas in China. Among 17 families, 7 families rented a room in the rehabilitation center because they were from other provinces. 6 families have lived in the rehabilitation center for more than a year, and one family stayed in the center for 7 years. These families had to face both the financial challenges to the cost of rehabilitation cost and the housing cost, as well as no day-to-day support from spouses or other family members who lived

1000 km away. As one mother from Henan province (1500 km away from Chengdu) described, "*We went to all hospitals in Henan, there was no good rehabilitation center. So we decided to live here. We are still using the money we saved in the past few years. His father is making money everyday as a construction worker. His job is not stable. I think we can't afford this in a couple of months.*"

" What are you going to do if you can not afford it?" I asked

" We have to go back to our village." She said.

" Are you going to stop therapy for him?" I asked.

" There is nothing I can do. I hope that by the time we leave here, he is able to walk like a normal person. I am also worried everyday, that's why I am not able to sleep every night."

The incurred direct financial burdens mainly related to medical expenses that were not covered or little covered by health insurance. Among families who elected for treatment in rehabilitation centers, the monthly expense (including physical therapy, occupational therapy, and speech therapy, and chinese medicine, and living expense in Chengdu) was around 9,000 - 10,000 RMB (equivalent to $1,451 - $1612) and 25% of the cost was covered by New Cooperative Medical Scheme insurance, whereas families residing in Chengdu, the monthly expense for the child was around 3000 - 5000 RMB (equivalent to $483 - $806) and three months of medical cost per year were covered by Urban Residents Medical Insurance. Participants expressed profound worries due to the cost of rehabilitation services and burden of lifetime course of caregiving. While the physical demands of providing intense levels of care has been challenging and exhaustive, the majority of the participants expressed the financial burden of care as the biggest challenge. One mother summarized, "*Even though we have insurance, but we still need to pay 3000 RMB per month. Two thirds of our family income is on his* *rehabilitation cost. After he was born, we (myself and his father) haven't bought any new clothes."*

Major life changes – Lack of support, and loss of "Guanxi"

Family support was an integral part of the caregiving experience. Mothers expressed a strong need for spousal support, and loss of spousal support among some mothers was a major challenge for them. One mother had an especially strong emotional feeling about the lack of spousal support, and was constantly crying during the interview.

"It does have a big impact on my life, I do not know how to say or how to use language to describe it. Because of this child, I feel my relationship with her father is getting worse. .... (Stopped.... weeping ... we stopped interview for one minute. She could not stop crying... and constantly said "sorry") I've seen too much, ... so many families get divorces because of these kind of children. There are a number of divorced families in this center. They were very supportive to treating their children at first, but gradually they gave up. Her father told me that he would be supportive, but he only financially supports us; I need more spiritual support. Even since she was born, he never really took care of her.

Fifteen families have reported the loss of relatives' "guanxi" (Social connections) as a major change after having a child with cerebral palsy. The stigma of cerebral palsy among families relatives directly affected family interactions, as relatives stopped contacting with afflicted families after knowing the child's disease. During interviews, parents expressed disappointment and frustration with unsupportive family relatives after the child's disease was disclosed.

As one father described, *"Before the child was diagnosed with cerebral palsy, my family still kept a good relationship with our relatives in the village. Because of the child, everything* *has changed. My relatives never called me to see how is my life in Chengdu and how is the child. Of course I am not satisfied with their attitudes, especially (I am not satisfied with) my siblings. Friends are less important, but my family members…. I am not asking your financial support, but at least, spiritually (I am expecting to get your support). Because of him (the child), I have seen through everything.*

One mother reflected on the changes of relative relations*, "My father died a while ago. But his parents (father's parents) live on the outskirt of Chengdu. We asked them if they are willing to help taking care of my child. But his father said, "I don't know how to take care of children." This is absurd. They (parents- in- law) are taking care of my brother-in-law's children now. They are lying. My mother, on the other hand, offered to live with us, so that we can take shifts to take care of her. Going through difficulties helped me understand a deeper level of humanity. It is only through hard times, you can tell who is genuinely helping you, who is not."*

" So your side of the family don't interact with your husband's parents anymore?" I asked.

" We still keep in contact. My parents- in- law still come to stay with us during Spring festival.

"Why? Have they helped you during those times" I asked

"No. Having a son living in a big city is a very proud thing for them (villagers). They can have face if they tell other people in the village that I am going to big city to stay with my son."

Psychological distress: feelings of sadness and loss

Mothers expressed feelings of sorrow and desperation, due to the loss of a normal child, while fathers I interviewed, did not report the same level of sadness due to not having a normal child. The sadness of not having a normal child repeatedly manifested among mothers during the interviews, especially among mothers with younger children of cerebral palsy. Mothers often described feelings of desperation, hopelessness, shame, and loss of confidence, especially during the first year of diagnosis.

"The first year at here (rehabilitation center) was extremely difficult for me. I felt ashamed and didn't want to live. Everyday I had to carry him to get across the bridge. Sometimes when I was walking, looking down from the bridge. I wish I could jump from here and die with my child. I was very sorry to bring him into this world."

Feelings of sorrow were commonly expressed, especially when mothers thought about the future of their children, or when parents saw their children attempting to walk, or when their children are staring at other normal children walking.

*" I always feel sad, usually 2-3 times a week, especially before I go to bed." One mother replied, "I would think about **'s future, think about his brother, thinking about my hard laboring husband, all of these would make me feel very sad."*

A common way mothers managed to cope with sorrow was to dissociate from the environment that could trigger emotional sadness, such as playgrounds with many normal children running around freely, and family gatherings where other normal cousins were around. One mother from Chengdu had a much better financial situation than the rest of families interviewed, and her description of sadness was accordingly different from other families with major financial crisis. She described her moments of sadness occurred while she failed to give her child a normal body : *"We spent a lot of time going to others public places, and I know environmental exposure is very important to her. Sometime, we could have fun when it was only two of us at the playground. But when there are a lot of normal children running around. My child would stare at their feet and then look at her own feet. This makes me very sad. (…. weeping …..)*

Loss of Social connection and Social support

All participants reported reduced social interactions with friends due to caregiving demands from children, or loss of common topics with friends.

"I have been living here (rehabilitation center) for two years now. And no friends, no relatives ever visited us. I generally don't contact with my friends anymore. Sometime we would talk over the phone or send a text. But I never go to the reunion. Some friends know the situation of my child, and our relationship is not that great anymore…. Hmmm… maybe it's not their problems. I just don't like to tell them because we are in different world now."

Only small number of caregivers reported a positive change in their social networks. Two mothers surprisingly reported they have found trustworthy friendships due to the illness of their children. The other 14 caregivers reported reduced social interactions. *"This child made me easily delineates who are my true friends, and who are not. A friend in need is a friend in deed. All my classmates know I have an abnormal child. But only two friends are very supportive. They would ask me out and encourage me to bring my child."*

Among 17 families, seven families reported support (e.g. physical support for activities of daily living, or financial support) from family members from the mother's side. Three families received family support from both sides. Families with grandparents' support expressed great appreciation of their efforts. Seven families did not have any support from any family members. As one father reckoned,

" Because of this child, I realize "guanxi" is not that important to me anymore. When my brother's child had a car accident, I provided financial support to him. But when I had this child, his grandparents, uncles, aunts, my side relatives, no one, none of them came to help me. Not even a phone call in a year. I don't mind if my friends were not supportive. They are my family. We are from the same blood. I don't need their financial support, but at least spiritual support. But not even some comfort. It's only us (me and his mother), we support each other."

Some mothers who only received support from their side of relatives expressed great dissatisfaction with their partner sides of family support.

"When I was pregnant, my mother in law was initially very supportive, and she said she would take care of the child until he (the child) went to school . . . after my son was diagnosed with CP, she only saw my son once when I was still in hospital. He (the cp child) is 4 years now and has only seen his grandparents once. So I haven't visited my parents in law almost 3 -4 years, but my older son (normal child) visits them every year during Spring festival. But my little son (with cp) never visit them. They definitely don't like him."

The mother with twin sisters felt very strongly about her unsupportive husband and unsupportive environments from her husband's relatives. *"Support? So limited. (weeping) only my relatives and my parents helped. My sister helps a lot. But not his (her husband's) family. I am not happy with his relatives. He has a lot of relatives in Chengdu, and they live near by. But nobody would help us."*

Stigma from within the family not only influenced the familial support structure in caring for the child, but it also negatively affected family activities. Fear of being stared at, or fear of harsh comments from their relatives about the child influenced the quality and frequency of family gatherings. *"Before the child was born, we were very close to my husband's relatives. Now we don't interact that much. Because every time we go there, his relatives would keep asking me "when will your child be able to walk?" I felt very embarrassed when I was with them and they also made my baby cry."*

Barriers to special education and rehabilitation resources

The interviewed primary caregivers displayed anger and frustration towards the poor design of public facilities that fail to provide a disability-friendly environment, such as public transportation, public bathrooms, and other public services; this ubiquitous lack of accommodation results in an extreme barrier for the CP children to integrate in social settings.

Compared to their Western counterparts, Chinese children with cerebral palsy do not have equivalent educational programs that cater to their special needs. Among 7 children who were over 6 years old in this study, only two children reported to be enrolled in public general schools where the majority of students were normal. Schools with special educational program or rehabilitation centers that parents had contacted refused to admit the child due to the illness or residential restrictions. For example, mothers from other provinces expressed the anger that their children couldn't receive free therapeutic lessons because they were not registered Chengdu residents.

Even for the two children had opportunities to go to school, the institutional ignorance of the children's disability and special needs made their integration into school life enormously difficult. One grandmother felt powerless when the school ignored her child's personal disability and needs, creating a barrier to school attendance and: *"I have to accompany her at school all the time. Usually when she is in class, I stayed at the back of the classroom. Her classroom is on* *the 3^{rd} floor, but the school does not have elevator to the classroom. We usually spend half an hour every day to climb up the stairs. Usually it takes 5 minutes for a normal student. Also the bathroom only has squat toilet, that my grandchild is not able to use at all. I hope it has one potty toilet at least."*

The attitude of others, especially teachers, could harm family members' dignity and force them to further withdraw from social engagements: "*The teacher asked me to go to school and asked me how I taught my kid to hold a spoon. She said "Your child can not hold a spoon like others. How could this be possible?" I could never forget the way she questioned me and starred at me. We were at the special education school for visual and hearing impaired children, but my child is neither blind nor deaf, he has cerebral palsy. How could teacher judge me that I am not a good mother?....(weeping)… I have tried my best."*

Feeling of "loss of face"

Among 17 families, three caregivers did not have the feeling of "loss of face", and they were in fact the same 3 families that reported having full family support from both sides of parents. 13 caregivers admitted they have or had the feeling of "loss of face", and expressed their greatest moments of emotional distress and strong feelings of shame or "loss of face" during the first few months of diagnosis. "*I did feel "loss of face" in the first few years, but now I don't care anymore. "Face" is a matter of perception, and you need to adjust to it by yourself."*

Especially during the first year of their children's diagnosis, parents had trouble speaking straightforwardly even about the name of the disease. They would avoid the word "cerebral palsy" and used "developmental delay" to describe the disease. The fear of being judged by others affected parents' comments about their children in social settings. When they were asked about their children's disease, they would use vague descriptions such as *"He is sick. He can't* *walk. Some neighbors would say he walks funny, at that time I felt very uncomfortable. Even my child is very different from others, I don't want others to judge my child."*

Among 7 families from rural areas, mothers reported a feeling of "loss of face" for the whole family. 5 reports indicated a child with cerebral palsy made the whole family feel loss of face. One mother reported, *"Yes, this made my whole family loss of face. Before I had xxx, we had a family hostel and our financial situation was so much better. But after I gave birth to him, we spent a lot of money on his illness. We closed the hostel, didn't refurbish the house. Other families in the village have better financial situation than us now. My parents are very old now, but they also have to make money to support his healthcare cost."*

Another mother mentioned moving to a new place because the illness made the whole family lose face. "*Our village is small, everyone knows anyone else. There is nothing you can hide. Elders in the village always spread the rumor. They said my child was born with red skin one day, green skin the other day. They described him as a monster."*

One mother without spousal support also felt this child made her husband "lose face".

"We had a serious talk about the face issue. Because I feel he has the problem. So I talked to him once, but he didn't admit. My child is 5 years old now. Ever since she was diagnosed, my husband never brought her outside of the house. He never brought her to visit his relatives. I feel he wants to hide her. I know he feels embarrassed, can you imagine, a charming guy like him holding a disabled child walking on the street, what a shame."

Fairly/unfairly treated from family members and community members

Mothers described cerebral palsy as the obvious "mark" of their children who deviate from expectations of normal children in Chinese culture. Among 17 families, 12 families reported direct negative or discriminatory words from family members towards their children due to their disease, and five families with a single CP child were told by family members to have a 2nd normal child.

One mother described, *"One time, my husband's father complained that we should not have saved the child's life when he was almost dead a few years ago. He said "if she (the CP child) were dead, and you gave birth to another one. How great it is." I was very angry, I said 'of course we need to try our best to save her, this is human instinct.' This is the main reason I stopped contacting him any more. Even my best friend encouraged me to send her away to the local orphanage. One time she told me, we could secretly drive to the orphanage, cover our car plate number so that no camera can catch us and dropped her off in front of the orphanage. I told her we can't do that. This is a crime and this is my child. "*

Another mother described the experience of visiting her family members: *"Every time when I go home during the spring festival, my parents and relatives would always mention this. They said I am still young, and should have a normal child. My elder relatives feel he is useless, he is a burden. I should give up treating him. It's a waste of money and energy. What they mean is to leave him alone, just give him food, clothes every day. Don't spend energy and money on him. They said "you should have a useful child."*

9 caregivers have heard relatives to ask them give up treating the child. 4 families were told by relatives to send the child to the orphanage. As one mother recalled, *"When he was still in the ICU, my husband's siblings came to visit, and they encouraged my husband to give up this child. They asked us to secretly send the child to the orphanage. But I couldn't do it. We thought he would die soon, so we brought him home. I thought, if he would die, I wanted him to die at home."*

Another mother had a similar experience: "*After we knew the disease, my husband and his relatives all asked me to send him to the local orphanage. I insisted on raising him up. This is my child, it is not a cat, or a dog. If the biological parents don't care about him, who else would?"*

"What do you think other people feel about your child?" I asked,

"Of course everyone believes he is a burden. People think he should not live in this world. They felt this is crucifixion. It is crucifixion for him, also for me. Someone told me …. well…anyway, you can not disclose my identity… someone said just to feed him something, so he will gradually die. There are things like these. Don't be surprised. If this happens here (Chengdu), it is crime. But not in my place (Inner Mongolia).

One mother was told to send her child to local orphanage by her friend: "*My best friend once said, we could drive the car to the orphanage, cover the car plate so that no camera can locate us, and drop the kid in front of the orphanage. I told her this is illegal. We can not do that. But my friend said 'she (the child) has destroyed your life.' I can understand how she feels, but I think I can still bear it."*

Discrimination within family members directly reduced family gatherings, and mothers felt they needed to isolate the children from such environments. *"She (CP child) can freely laugh with my relatives, but not with my husband's relatives. Every time when I visit them, they would ask my child with scolding tone 'when are you able to walk? Why can't you walk!' I have told them my child has feelings. But they say it anyway. I was afraid that my child would have social phobia problem if she countinues visiting them. So I don't bring her to see my husband's relatives anymore."*

Another mother described her most hurtful moment: *"After he was not able to walk a year and a half after birth, my mother went to see a fortuneteller. The fortuneteller said my child should have a godfather. So my mother asked my cousin's husband to be my child's godfather. My cousin's family were very unhappy, they said to my cousin's husband, 'how could you be a godfather for a disabled child?' I was hurt so badly when I heard this, so I never contacted my cousin and her family anymore."*

Discrimination and stigma by strangers and neighbors influenced every aspect of how parents cared for their children and social activities. As one mother described the uncomfortable interactions with her neighbors: *"They don't care about your feelings; they stare at you and your child with that odd look in their eyes. One time a neighbor came to visit me and asked me directly "what's wrong with your child?" I still remember the way she looked at my child. I asked her out. And after that event, my husband and I tried to avoid taking a stroll in our neighborhood, I think subconsciously I am trying to avoid that woman."*

Another mother described the similar experience in her community, *"I usually take a stroll with my husband and my child after dinner. Some middle age women would even come up to me and asked me why my child can't walk. They stared at my child with that odds look in their eyes and talked to each other. I knew they were gossiping about my child. At first I would explain to them what's wrong with my child, but they keep asking more questions, I feel upset and stop talking to them. So now I don't go to places where there are a lot of middle aged people or elderly. They like gossips and I don't want to be their topics."*

Over time, parents had learnt how to deal with unfair reactions and "odd looks" from non-family members. Parents with older CP children said that the "odd looks" did not bother them anymore and they became bolder in talking about their children's illness when unfriendly people stared at their children. As one mother described, *"Now I don't care. When there is some woman staring at my child, I would stare at her back and make her uncomfortable until she stops staring at my child. I found this to be the most effective way to deal with the odd looks."* They manage stigma/unfair treatment by seeking affiliation with considerate individuals, talking to people they trust, and dissociating from inconsiderate individuals. Parents also felt more comfortable living with other parents with CP children:

> *"Sometimes people will give me some comfort, which are much appreciated and I feel more encouraged. When I come to the hospital and look at other children and their parents, I feel more like a normal person, and I feel my child is much happier playing with other sick children. I feel more comfortable at here (rehabilitation center), because I can be myself here. Just like the way I talk to you, I feel we are equal, no discrimination or wired staring at my child or me. This is good."*

What matters the most to you and to your child?

When asked about their vision of future, or what matters the most to you about your child, all families were concerned about their child's need for independence, "trying to be normal," and not becoming a burden for the child's siblings. "*I hope my child can get a little better, so that he can at least take care of himself when we go back to our village, and not to become his brother's burden. Sure I am scared to go back, the difference is relatively large between him and other kids in the village. Of course the village people would not say anything in front of you. However , my greatest fear is that in front of the whole village , and I am not able to keep my head up."*

Parents whose children with higher levels of independence cared more about the emotional well-being of their children: *"My greatest wish is for my child to be able to take care of herself"; " I hope that my child is able to take care of herself even I will be no longer in the world one day"; " My greatest wish is for my child to have dignity;" "Is this a blessing or a curse… well, I can't tell, many things mix together. If I still had my job, my salary would be very high now. But my child's health condition is not reversible, and his physical health will be affected (if I were not at home, taking care of him). Now his health condition is getting better. I can only make sure he looks clean, has dignity, be kind and grateful."*

Discussion

This study is the first to focus on the parental experiences of caring for a cerebral palsy child in China. It provides an overview of the burdens of caregiving and chronic and daily stressors Chinese families have to face, as well as how parents perceive "face" values. This study found that caregiving a child with cerebral palsy had more negative impacts on parental quality of life than positive impacts. Negative impacts included demands on financial burdens, insufficient support services, and discrimination from family members and from the society at large. This study suggests that caregiving for a child with cerebral palsy comes with a host of unexpected and complex burdens, and has a profound impact on all aspects of the families' lives.

The majority of the Chinese families reported tremendous financial burdens of having a child with special needs. Compared with bringing up a normal child, Chinese parents had to face the barriers of treatment cost, caregiving cost, and inadequate access to educational resources. The majority of the families interviewed also needed to give up at least one working salary in order to take care of the child, which caused the family to experience even greater financial difficulty. Most of the families I interviewed had to spend two thirds of their family income on childcare. This placed enormous stress on the budgets of low-income families. The consistency with which these financial issues were reported by the families further highlights the importance of addressing financial constrains to alleviate their burdens.

Mothers in my study were more affected emotionally their children's conditions than fathers interviewed. The most traumatic experience for the mother described was the feeling of loss of a "normal child". The words "normal child" were repeated among mothers, especially when they describe how the playgrounds and watching other children running would make them sad. The majority family reported caregiving help from their husbands and only one family reported father passively engaged in their child's caring activities. And over 58% of caregivers reported some support from family members. Among families with no support from family members, caregivers felt deeply hurt, helpless and powerless when their children and themselves were marginalized due to the illnesses.

In this study, 82% of caregivers reported had or still have the feeling of loss of face. Caregivers felt extremely distressed when family members also had the feeling of loss of face and refused to support treatments and refused to share caretaking duties. However, the feeling of loss of face gradually decreased as caregivers started to worry about the future of the children. Eventually, educational access and training their children to be independent became the major goal for most caregivers.

Families often felt stigmatized by family members, non-family members, and educational institutions. Staring, uncomfortable questioning, unfriendly tones, and ignoring and devaluing their children were the major discriminatory situations families have to face. Some family members' devaluing remarks (such as useless, burden) about the children with cerebral palsy, encouraging parents to send away the child, or give another birth to a normal child, reinforced caregivers' feeling of helplessness, and deteriorate these family relationships.

All families expressed concerns about their children's future. Their concerns were mainly about the accessibility and availability of educational resources in their community, and also the uncertainties associated with parents' or grandparents' ability to sustain their current level of caregiving in the future. Overall, the stories of these families afflicted by the multifaceted burdens of caregiving reflected a deep love and commitment to their child as they managed complicated lives in an unsupportive environment. This study revealed that the challenges experienced by caregivers are compounded when society views children with cerebral palsy as useless and fails to acknowledge their needs and rights in society.

Limitations and Implications

This study has several limitations. In particular, with the purposed sampling, there were small numbers of participants. In March 2014, I conducted a pilot study among a subset of potential participants. I interviewed two primary caregivers in Chengdu. I noticed that during the one on one interview, when a third participant (such as the child, the primary caregiver's partner) was present, the conversation and level of raw honesty, particularly in relation to "loss of face" and primary caregiver's relationship with other family members completely changed. Either the primary caregiver was not able to fully engage in the conversation (i.e. the child was moving and crying all the time), or their spouse's presence did not give them comfort to talk about the family crisis in an honest way. This qualitative study primarily focuses on "life history" which asks participants to reflect on their lives. As a researcher as well as an outsider, I had to be constantly aware of the approach to conduct "life history" interviews, and the environment in which my participants would feel comfortable to provide honest response to my questions.

The other limitation is the qualitative method to study this notion of stigmatization process among children with cerebral palsy and their families. Qualitative approach, of course, is able to describe in rich detail phenomena embedded in local contexts. However, it is impossible to generalize my findings in other context in China. Chengdu resides in the western part of China with rich traditional Chinese culture and it still maintain rich Chinese traditions. Since 1978, China has experienced a transition to a free market economy. The influx of foreign investments and imported cultural media products have led to an evolution in cultural norms and social values among different regions in China. Chinese culture and economic development varies widely across the country, and the knowledge produced in this study may not generalize to other contexts in China – particularly the findings pertaining to financial burdens and educational resources. More developed regions with better social welfare programs might have already mitigated the social constraints and financial burdens for families in those regions. However, the notion of "Easternization" (Marsella & Choi, 1993) suggests that important cultural structures and moral values will not change even in the face of economic and social transformation, as well as unequal development throughout the country. It is important to study the stigma of cerebral palsy in differing social contexts in China, compare how different Chinese populations perceive having a child with cerebral palsy or other forms of mental or severe disabilities.

This study documented a time when China was transforming itself into a middle income economy that aimed to establish a universal medical insurance for major childhood disease, build a child welfare system to meet the multi-faceted development needs of children, and improve legislation and provide a solid legal basis for the provision of child welfare services. Therefore, there exists a backdrop of increasing political activism for social welfare, which is an auspicious context for policy changes addressing the matters brought up in this study. Meanwhile, in 2015, the Communist Party of China finalized the country's 13th Five Year Plan for 2016-2020 and relaxed its 37-year-old one-child policy to allow all couples to have two children. In a setting in which the one child policy no longer holds, families may gradually begin changing the way they perceive having a disabled child.

Overall, this study adds depth and scope to our understanding of the challenges faced by families with children with special needs in the current China. This study demonstrates that families caring for a child with cerebral palsy often have to adapt to quite unexpected parenting challenges, which are multifaceted, divergent from the norm, and ignored in society; it highlights the current systematic underinvestment of resources that force underprivileged families to bear tremendous burdens; it calls for urgent attention on the quality and availability of support and services for families. This issue fits squarely in the domain of public health, as family caregivers are the foundation of an enormous system of care in China, and priority must be given to determine the most useful and effective interventions for these providers. Family members, as well as healthcare professionals, education professionals, and communities at large, all have the potential to play an integral role in building and sustaining support and services to minimize burdens and stresses and optimize family caregiving quality.

Paper II: Public Stigma against People with Mental Illness in China

Summary

Research has revealed pervasive and persistently negative attitudes toward persons with mental illness in Western countries. Yet, few studies have investigated public attitudes against people with mental illness in China, where an overwhelming of 17.5% of the population are afflicted by mental illness, but a majority of them are untreated and undiagnosed due to the public stigma of mental illness.

Using a population-based stratified sample of 3703 adults from the Stigma in Global Context-Mental Health Study, this paper studies the social determinants of public stigma and the variations in the general public's attitudes and reactions toward people with mental illness.

Findings from paper II indicate that mental illness stigma exists in China. Chinese are less willing to interact with people with depression and schizophrenia than those with a physical illness such as asthma. Our analyses found the greatest social rejection manifested as unwillingness to marry persons or take care of children afflicted with mental illness. Differently from countries, depressive disorders had more rejection than schizophrenia in this study. Age, education, and place of residence among respondents had significant association with public stigma. Labels of "mental illness" had a negative impact on people's willingness to socially engage the individuals described in the vignettes. Moreover, the gradient effect between people's perception level and their rejection levels is persistent after controlling all possible covariates. Perception of dangerousness also had a significant negative impact on social stigma. Respondents who had the strongest fear reacted with more rejection towards people with mental illness than people with less fear, or no fear at all.

This study used a national representative sample to advance our understanding of stigma and its social and demographical variations in the Chinese context. Its findings on public belief, perceptions of dangerousness, and the effect of labeling lay the empirical foundations for future policies and interventions. Our findings suggest that restraining people with mental illness from the public, or controlling patients' symptoms, would not be enough to eliminate prejudice and stereotypes in people's minds. It calls for better anti-stigma strategies that fit into the Chinese cultural context and Chinese fundamental beliefs.

Introduction

Mental illness is one of the most critical health problems and the leading cause of ill-health in the global burden of disease, that every one in four people will be affected at some point in their lives (WHO, 2001). Stigma against people with mental illness are widespread, and it remains a serious issue that impedes care seeking and undermines the service system globally. In China, stigma has became a significant barrier to the seeking of mental health services, successful treatment and rehabilitation (Tsang H., et al., 2003). According to the World Health Organization, mental illness has now overtaken heart disease and cancer as the biggest burden on the Chinese health system, affecting 17.5% of the population. It is estimated that 173 million Chinese people experience deleterious effects of a mental disorder recently (Phillips et al., 2009). However, an overwhelming 92% of individuals with mental disorders had never sought any type of professional help or treatment for their illness. Phillips (2013) argues that part of the problem may be due to the shortage of both specialized services and well trained general physicians in mental health care. Another factor, perhaps more importantly, is the unwillingness of community members to seek help for psychological problems, as well as the unsupportive psychological services among health professionals in China.

Research evidence has consistently demonstrated that stigmatizing attitudes towards people with mental illness and their family members in China are pervasive and substantial

(Kleinman, 1977; Phillips, 1993; Phillips, 2002; Gao, 2005; Ying, 2013) For example, Phillips and his colleagues (2002) conducted a study among 608 patients with schizophrenia and their family at 5 locations around China from 1990 – 2000. Sixty percent of family members reported that stigma had a moderate to severe effect on the lives of patients. Twenty eight percent reported that stigma had a moderate to severe effect on the lives of other healthy family members (Phillips, Pearson, Li, Xu, & Yang, 2002). Ying (2013) also found that 70% of schizophrenia patients in Xiangya Hospital of China reported mild or moderate self-stigma. Another survey conducted among health professionals in a psychiatric hospital in Beijing reported that 80% of the clinicians believed social stigma was the most challenging barrier that impeded the community integration of people with mental illness (Tsang, et al., 2000). Among a a sample of mental health patients (N=193) in Hong Kong, 75% patients reported that they have been stigmatized and discriminated, and the most common way of coping with the hostile environment was to hide their mental health conditions (Chung & Wong, 2004). Similarly, another study in Hong Kong and Beijing reported that stigma leads families to deny or hide the mental illness (Lee, et al., 2005; Phillips & Gao, 1999), that the stigmatizing experience and structural discrimination resulted in delays and non-adherence to psychiatric treatment (Lee, et al., 2006).

Unsurprising, covert and overt public endorsement of stigmatizing attitudes against people with mental disorders potentially impede their recovery process and deprive them of rightful life opportunities. In order to understand the pervasive stigma towards people with mental illness and their families in Chinese society, it is important to discuss some unique aspects of Chinese culture.

Chinese culture background

Cultural and philosophical beliefs shared by all Chinese groups are believed to have significant influence on understanding and interpreting mental illness and its stigma (Lam, 2010). In contrast to individualism in Western culture, Confucianism has a profound influence in China and Chinese perceptions about disabilities (Chan et al., 1988). According to Chan (1988), Confucianism places extraordinary emphasis on the maintenance of harmony in social relationships and respect for elders and ancestor worship. This fundamental value is embedded in major aspects of Chinese social behavior that Chinese personal identity is dependent on continued relations with the family and confirmed only through interpersonal relationships. When failing to fulfill a group requirement, one is liable to lose group status (Yang, 2007). A person with mental illness is considered as abnormal, aberrant, or deviant in countries (Haslam, 2005). Chinese lay beliefs on mental illness such as moral lapse (Geaney, 2004), weak character (Parker, et al., 2001), punishment of wrongdoing in this life or previous one (Campbell & Uren, 2011), are considered to contribute to stigmatization of mental illness in China. A person with mental illness in China encountered difficulties in fulfilling his/her role in meeting the expectation of family, such as having a job, marrying and having a child, or taking care of parents when they get old (Phillips, 1999). Furthermore, the perceived unpredictability and dangerousness of people with mental illness is viewed as a serious violation of the Confucian ethics; thus, the individual is stigmatized and ostracized (Yang, 2008). Families with mentally ill members fear being ridiculed and "losing face", and therefore attempt to deny the existence of mental illness or disguise the problem under a more socially acceptable label, such as eccentricity or physical illness. In some extreme cases, inhumane confinement will be initiated by the family or mandated by local government (Fabrega, 1991). According to recent news from

China, there are about 100,000 psychotic patients in the Hebei province alone, and a large number of them are locked in iron cages made by family members (Beijing News, 2013). Family-oriented stigma has undoubtedly become a key barrier to provide optimal mental health care to Chinese communities.

In the past 20 years, awareness of the importance of mental disorders in China has increased and actions have been taken to reduce the burden of mental disorders. On May 1st 2013, the Chinese central government established a national mental health law that were perceived to have a substantial effect on the overall public health of this nation. One major reform is to enhance mental health services among general hospitals and community health clinics in both urban and rural areas. Another change is that it recognizes the need to decrease the stigma: "…individuals and organizations must not stigmatize… persons with mental disorders" (article 5). But scholars believe education alone is unlikely to reduce stigma and change long-standing belief and attitude directly (Phillips, 2013). The stigma attached to mental illness and all that is related to it – patients, family members, psychiatric institutions, and medications – is a major obstacle to better mental health care and better quality of life of people who have the illness, as well as their families and communities (Philips, 2013). There is an urgent need of studies that assess possible determinants of public stigma to establish effective social interventions in the Chinese context.

Role and Impact of Stigma in the Field of Mental Illness

Findings from all over the world have consistently documented the pervasive existence and impact of stigma upon those with mental illness. There is a universal acknowledgement that stigma may negatively delay one's seeking for medical intervention, and further exacerbate the process of recovery and therapeutic outcomes (Corrigan, 2007; Pescosolido, 2007). Empirical work and theoretical studies have been consistently examining the cause of social stigma and its social attributions, such as labeling hypothesis (Nieradzik & Cochrane, 1985; Link et al., 1987; Link et al., 1989; Link et al., 1991; Link et al., 1999; Martin et al., 2000; Link & Phelan, 2001; Angermeyer & Matschinger, 2003; Yang et al., 2012), causal attributes (Link et al., 1999; Martin, J. K., et al. 2000; Naanyu, 2009) and social demographical attributes (Angermeyer et al., 2003; Angermeyer, 2006; Jorm & Griffiths, 2008; Jorm & Oh, 2009).

Scheff (1974) proposed the ‘‘labeling effect” of mental illness, in which the application of deviant labels to individuals leads to changed self-perceptions and social opportunities. It was then modified by Link and his colleagues to study the cause of mental illness stigma in the American population (Link et al., 1987; Link et al., 1989; Martin et al., 2000; Link & Phelan, 2001), Link and his colleagues suggested that the label of “mental illness” triggered significant rejection among the public, and thus disturbed social interactions with the mental ill. Using vignette data from the 1996 General Social Survey, Martin (2000) found that respondents who labeled a vignette as "mental illness" also expressed a preference for greater social distance from the mentally ill. This was believed as one of the reasons that people with mental illness choose to hide their health status (Link et al., 2008; Link & Phelan, 2006).

Causal attributes usually refer to perceptions of underlying causes that affect individual reactions towards mental illness (Martin et al., 2000). However, there is no consistent agreement on the effects of biological (i.e. genetic factor) versus psychosocial (i.e. stress) causal explanations (Jorm & Oh, 2008). Belief that mental disorders are due to genetic inheritance was found to be negatively correlated with social stigma in the U.S. (Martin et al., 2000) and Netherlands (Van’t Veer et al., 2006). However, there is no consistent evidence in this explanation (Jorm & Oh, 2008). Other studies also found that “bad character” was one of the causal explanations positively associated with social distance (Martin et al., 2000; Martin et al., 2007).

Regarding the type of characteristics of mental illness that are associated with social rejection, empirical evidence across different countries found that perceived dangerousness appears to correlate with the level of stigmatization of the mentally ill (Link et al., 1999). The MacArthur Mental Health Module of the 1996 GSS data showed that as much as 61% of the public in the U.S. viewed people with schizophrenia as dangerous, followed by 33% who viewed depression as dangerous (Link et al., 1999). In a comparison of public perception of mental illness in 1950 and 1996 in the U.S., Phelan (2000) found that the perception that mentally ill people are violent has substantially increased in the U.S over the 40 year period. Scholars also found that people in society have different levels of acceptance of various mental disorders. In Germany, respondents reported more social acceptance of an individual with depression than one with schizophrenia (Angermeyer, 2003). Studies investigating public reactions in America also found that people with depression receive less social stigma compared to those with schizophrenia (Pescosolido et al., 2000) or alcohol dependence (Link et al.1999).

Regarding the social demographic factors that are associated with public stigma, findings from multiple countries are also informative. Social rejection is greater for older (in comparison with younger) adults in Germany (Angermeyer et al., 2004). This pattern is also consistent for Asian countries such as Hong Kong (Chou &Mak,1998) and India (Thara & Srinivasan, 2000). Studies from Nigeria, Ghana and Ethiopia have reported that people with higher education were more likely to exhibit positive feelings towards the mentally ill (Mohammed K, 2004; Barke A,2011; Tamirat Y, 2005). However, a Canadian study found that higher education was associated with increased social rejection (Kirmayer et al., 1997).

Studies also found that personal contact was associated with social distance. Angermeyer (1997) found that people with direct contact with mental illness had favorable attitudes and lower level of social distance, compared with people who did not have personal contact. Using a nationally representative sample in the U.S., Phelan (2004) found that respondents with more personal and impersonal contact perceive people with mental illness to be less dangerous. This pattern was found in both eastern and countries (Chung & Chan, 2004; Angermeyer & Matschinger, 1996).

Despite these extensive international studies, we still know relatively little about underlying mechanisms of deep-rooted stigma in China. To advance our understanding of stigma and its association with social context, this study applies the Etiology and Effects of Stigma Model to frame and evaluate the stigma of mental illness in China. Using a population-based stratified multi-staged sample of 3703 adults from the Stigma in Global Context-Mental Health Study, this study aims to expand our knowledge of mental illness stigma in general, and lay the empirical foundations for future policies and interventions in China.

Theoretical Framework

The Etiology and Effects of Stigma Model (EES)

The Indiana Consortium for Mental Health Services Research (ICMHSR) group proposed a multi-disciplinary and multi-level theoretical framework, the Etiology and Effects of Stigma Model (EES)(see Figure 2.1), to systematically study causes and correlates of stigmatizing responses to persons with mental illness. This framework was used in a 16 nation-collaborative study that investigated public stigma of major depression and schizophrenia. These countries included Argentina, Bangladesh, Brazil, Bulgaria, China, Cyprus, Germany, Great Britain, Hungary, Iceland, South Korea, New Zealand, Philippines, South Africa, Spain, and the United

States of America.

The theoretical framework suggests that personal knowledge (e.g. identification, meaning, etc.) and experience (e.g. personal and impersonal contact, etc.) of mental illness are the consequences of socio-demographic characteristics (e.g. education, age, gender, etc.) of both the mentally ill and the respondents in the survey. The social context also shapes personal attributions and perceptions about people with mental illness and their behaviors. These personal assessments and perceptions will lead to various reactions and behaviors towards people with mental illness, and the stigmatizing reactions vary under different social and cultural contexts.

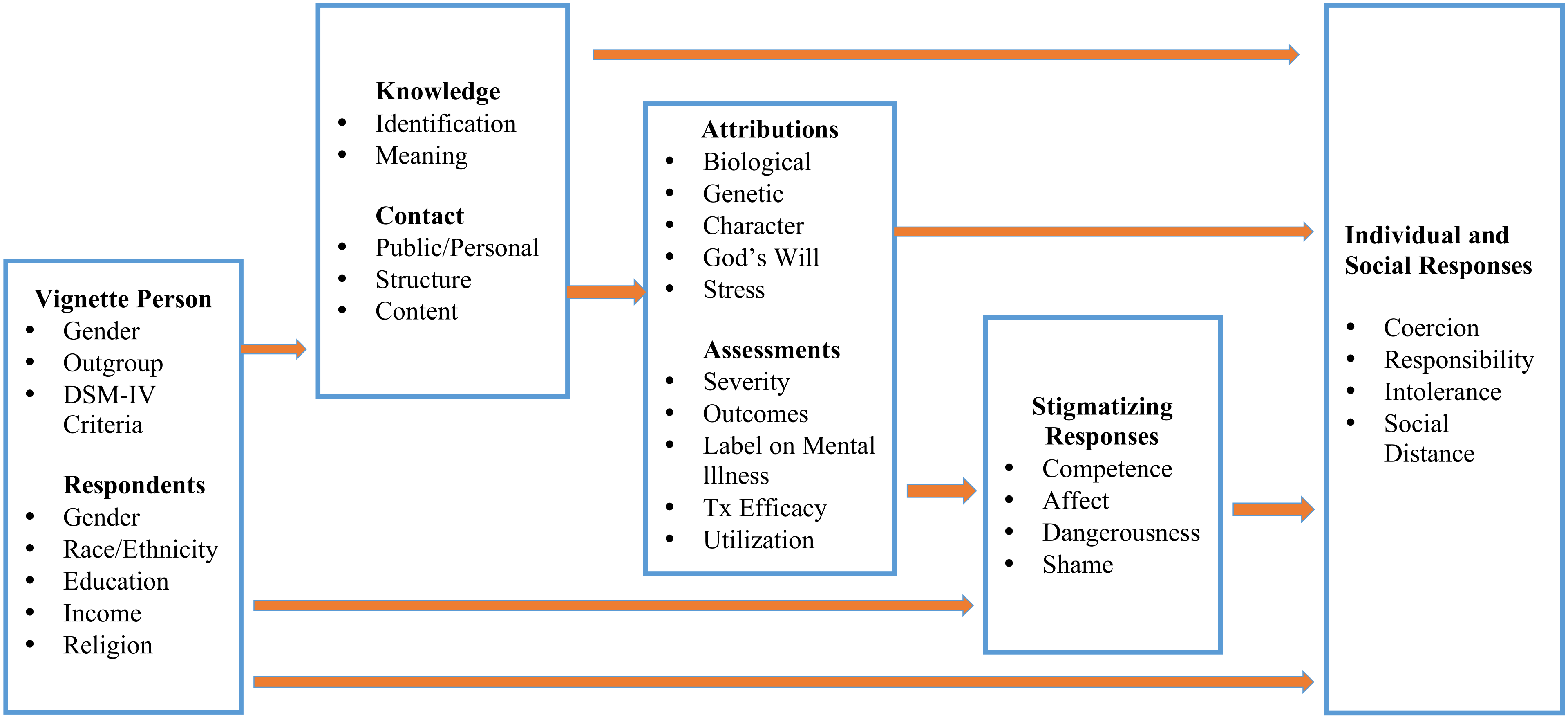


Figure 2.1: The Etiology and Effects of Stigma Model (EES)

Source: Pescosolido, B.A. 2006. Stigma and Mental Illness in Cross-National Perspective.

Having provided the relevant Chinese context and the limitations of available data, as well as empirical evidences of mental illness stigma across the world, I developed a modified version of the EES model to guide my study (Figure 2.2). This model integrates social attribution, causal attribution, labeling hypothesis, and symbolic interaction viewpoints to examine Chinese prejudice and discrimination against mental illness.

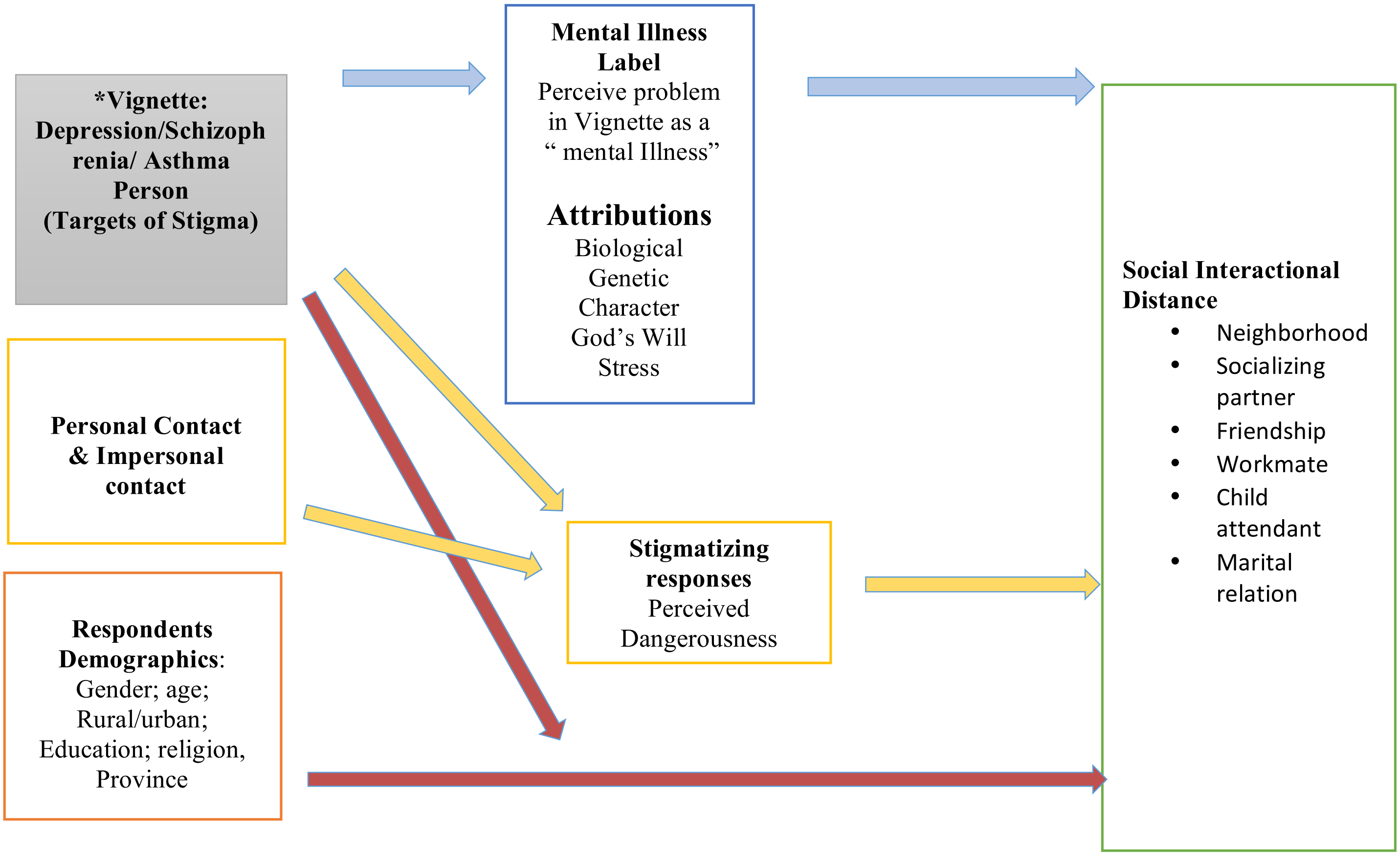


Figure 2.2: The Etiology and Effects of Stigma Model (EES) for China. Adapted for the Context of China and The Stigma in Global Context-Mental Health Study Data

Note: ** A vignette in this study is a fictional account that describe symptoms of certain disease. Respondents are required to answer questions regarding their attitudes, assessment, and reactions towards the person described in the vignette (Naanyu, 2009).*

Method and Analytic Strategy

Study Design and Data Description

This study uses Chinese data from the Stigma in Global Context-Mental Health Study (SGC-MHS). The National Survey Research Center at Renmin University conducted the SGC-MHS from July 2010 to December 2010, which was fielded with the 2010 China General Social Survey (GSS). Data was collected through face-to-face interviews conducted by trained interviewers drawn from the National Survey Research Center at Renmin University. Translation was discussed and checked via group expert discussion among Chinese bilingual scholars and researchers in America.

The survey instrument includes a vignette that describes a series of standard symptoms of either depression or schizophrenia. A third vignette as control group describes a series of standard symptoms of asthma. A vignette is a fictional account that describe symptoms of a certain disease. The vignette approach has been well developed and practiced in psychiatric studies in Western counties. It was able to minimize social desirability bias and obtain fairly accurate respondents' recognition of mental health problems (Nannyu, 2009). See Table 2.1 for the three vignettes used in China.

Vignette 1 represents someone meeting the DSM-IV criteria for depression, Vignette 2 presents a subject with schizophrenia, and Vignette 3 describes a patient with asthma, which was used as the reference (or control) category. Respondents were randomly assigned to listen to one of these three vignettes. They were expected to comprehend the vignette description and then answer follow-up questions. The second part of the survey included questions that tapped into substantive issues of stigma. A set of background variables such as gender, age, marital status, educational degree, household income, province, religion was also collected in the study.

Table 2.1: Vignettes Used in China

Vignette 1

XIAO WANG is a MAJORITY/MINORITY MALE/FEMALE. For the last several weeks XIAO WANG has been feeling really down. He wakes up in the morning with a sad mood and heavy feeling that sticks with him all day long. He isn’t enjoying things the way he normally would. In fact nothing seems to give him pleasure. Even when good things happen, they don’t seem to make XIAO WANG happy. The smallest tasks are difficult to accomplish. He finds it hard to concentrate on anything. He feels out of energy, out of steam and cannot do things he usually does. And even though XIAO WANG feels tired, when night comes he can’t go to sleep. XIAO WANG feels pretty worthless, very discouraged, and guilty. XIAO WANG’s family has noticed that he has lost appetite and weight. He has pulled away from them and just doesn’t feel like talking.

Vignette 2

LILY is a MAJORITY/MINORITY FEMALE /MALE. Up until a year ago, life was pretty okay for LILY. But then, things started to change. She thought that people around her were making disapproving comments, and talking behind her back. LILY was convinced that people were spying on her and that they could hear what she was thinking. LILY lost her drive to participate in her usual work and family activities and retreated to her home, eventually spending most of her time on her own. LILY became so preoccupied with what she was thinking that she skipped meals and stopped bathing regularly. At night, when everyone else was sleeping, she was walking back and forth at home. LILY was hearing voices even though no one else was around. These voices told her what to do and what to think. She has been living this way for six months.

Vignette 3

LIMING is a MAJORITY/MINORITY FEMALE /MALE. LIMING has a history of breathing problems. LIMING often has bouts of coughing at night, and doesn't sleep very well. His family and friends have noticed that these problems seem to be particularly bad during challenging situations, in the spring and fall, and during strenuous activities. LIMING used to enjoy playing soccer but recently gave it up because of these problems. LIMING feels badly about his breathing problems, which seem to be getting worse, and wishes he could "be just like everyone else." LIMING is involved in several activities and hobbies, and shares these activities with several friends.

In an attempt to ensure representativeness, researchers used a multi-stage probability sample from the China General Social Survey in 2010, employing a four-stage stratified sampling scheme with unequal probabilities. After missing data analysis, no systematic biases were found. The final complete sampling consisted of 3703 participants in China.

Variables

Variables selected from the Chinese data for this study are shown in Table 2.2. Detailed descriptions of the variables are as follows:

Dependent Variables: Social distance scale. The social distance scale included six items assessing willingness to interact with the person described in the vignette. Respondents were asked how willing they would be (1) “to have [person in the vignette] as a neighbor;” (2) “to spend time socializing with [person in the vignette];” (3) “to have [person in the vignette] care for your children or children you know;” (4) “to make friends with [person in the vignette];” (5) “to work closely with [person in the vignette] on a job;” (6) “to have [person in the vignette] marry someone related to you.” For each item, the response was a four-point scale ranging from (1) "definitely willing", (2) “probably willing”, (3) “probably unwilling”, to (4) "definitely unwilling." Responses were coded 1 to 4 accordingly and added to produce a summative scale of preferences for social distance. Table 2.2 shows the correlations between the six items in this study which suggests a strong relationship between them. The social distance scale then ranged from 6 as the lowest possible social distance or least social stigma, to 24 as the highest potential social distance or greatest social stigma. The internal consistency reliability coefficient (Cronbach’s alpha) for this six-item scale was 0.87 (Martin, J. K., et al., 2000).

Table 2.2: Social distance scale correlations (N=3703)

	Neighbor	Socialize	Childcare	Friend	Workmate	Marriage
Neighbor	1.00					
Socialize	0.75	1.00				
Childcare	0.44	0.43	1.00			
Friend	0.70	0.75	0.47	1.00		
Workmate	0.59	0.60	0.46	0.68	1.00	
Marriage	0.39	0.38	0.56	0.45	0.46	1.00

Measures of independent variables: Type of Mental Health Problem. Out of the total 3703 adults interviewed, 1,902 (33.8%) randomly received the depression vignette. Another 1844 (33 %) and 1874 (33.35%) received the schizophrenia and asthma vignettes, respectively. The asthma reference group was coded as 1, depression was coded as 2, and schizophrenia was coded as 3

Measures of independent variables: Causal Attributes. The causal attributes include 7 Likert-type items that include biological and psychosocial causes. Respondents were asked how likely they believed the health condition of the [person in the vignette] was caused by: (1) “His/her own bad character;” (2) “A brain disease or disorder;” (3) “The way he/she was raised;” (4) “Stress;” (5) “A genetic or inherited problem;” (6) “God’s will;” (7) “bad luck.” For each item, the response was a four-point scale ranging from "very likely " (1), “somewhat likely” (2), “not very likely” (3) to "not at all likely" (4). For each attribution, responses of "very likely" or "somewhat likely" were coded 1 and responses of "not very likely" or "not at all likely" were coded 0.

Measures of independent variables: Perception of “Mental Illness”. The assessment of the vignette problem was measured by one question: “Is it very likely, somewhat likely, not very likely, not likely at all that [person in the vignette] is experiencing a mental illness.” Response categories “very likely”, “somewhat likely”, “not very likely”, “not at all likely” were coded 1 to 4 respectively.

Measures of independent variables: Perception of dangerousness. Perceived dangerousness was also measured with a single item: "How likely is it that [the person named in the vignette] would so something violent or harmful to other people?" Response categories “very likely”, “somewhat likely”, “not very likely”, “not at all likely” were coded 1 to 4 respectively.

Personal contact was measured with a single item: "Leaving yourself aside, have you personally ever known someone who has received treatment for a mental health situation?" Response “yes” was coded 0, and “No” was coded 1. ***Impersonal contact*** with people with mental illness is measured with one item: "Do you frequently, occasionally, rarely, or never see someone who seems to have a serious mental health problem in a public place?" Responses were "frequently" (1), "occasionally" (2), "rarely" (3), or "never" (4). In this study, "frequently" and "occasionally" was coded as 1, "rarely" or "never" was coded as 0.

Demographic variables. The demographic variables in this study included gender, age, educational attainment, place of residency (rural/urban), province, and religion. Age was a continuous variable that measured the exact age of the respondents interviewed. Gender was coded 1 if the respondent was female and 0 if male. Education was assessed by the highest educational level or degree achieved, and ranged from ‘no formal training’ to ‘college/university.’ Urban residency was coded 0 and rural residency was coded 1. For this study, education was coded 0 if the respondent had “no education,” “complete primary school” or “less than middle school,” 1 if the respondent had “Junior high schools” to “Technical school” or “less than college,” and 2 if the respondent had more than “Higher Education” or “College and more.” There were 26 regions selected in this sample.

Analysis Plan

ANOVA tests and t-tests were conducted to evaluate the mean difference between public stigma and socio-demographic variables and other attributes. Multivariate linear regression models were developed to evaluate the relationship between public stigma and type of mental health disorder, causual attributes, perception of the illness, perceived dangergousness, while adjusted sociogemographic characteristicis. All analyses were conducted using STATA version 13.1 statistical software.

Results

Participants characteristics

Of the 3703 participants in the SGC-MHS survey in china, 51.6% were female. The mean age was 45.2 years old. The majority of the respondents were non-religious (89.6%), and the rest were Roman Catholic (0.35%), Protestant (2.05%), Jewish (0.03%), Muslim (0.97%), Buddhist (4.9%), participants of other eastern religions (1.81%), and participants of other religions (0.24%). 35.2% participants were urban residents, 27.1% were township residents, and 37.7% lived in villages. 32% of respondents finished primary school, 52% finished high school, and 15.1% had a higher education or graduate degrees. 13.8% of all respondents knew someone getting mental health treatment, and 34% of all respondents reported have frequently or occasionally seen people with mental illness in public.

Table 2.3 shows socio-demographic characteristics of the study population for each vignette. Respondents randomized to different vignettes show different percetions towards people with asthma, depression, and schizophrenia. Across dix item that measure social distance, “Childcare” and “marriage” drew higher rejection than other social integreation items. People with depression and people with schizophrenia were perceived (by 37.6% and 40.6% of the sample, respectively) as “somewhat likely” or “very likely” to be dangerous to others, comprared with people with asthma (34.8%). Respondents with depression vignettes, in general, reported higher average social distance score (16.68), than respondents with schizophrenia vignettes (16.54), and asthma vignettes (15.73).

Table 2.3: Descriptive statistics. 2010 Stigma in Global Context – Mental Health China Study (N=3703)

	Asthma	Depression	Schizophrenia
	1239 (33.4%)	1249(33.7%)	1215 (32.8 %)
Stigma average Social Distance (1= definitely willing, 4=definitely unwilling)			
Neighbor	2.25	2.39	2.39
Socialize	2.28	2.44	2.40
Childcare	3.15	3.33	3.27
Friend	2.31	2.49	2.46
Workmate	2.48	2.65	2.64
Marriage	3.24	3.36	3.37
Average sum score	15.73	16.68	16.54
Percentage of people “Definitely” or “ Probably unwilling” to interact with people with mental health problems			
Neighbor	30.1%	36.4%	37.2%
Socialize	32.4%	40.4%	37.9%
Childcare	79.2%	85.8%	83.1%
Friend	33.2%	41.2%	39.9%
Workmate	44.4%	52%	51.9%
Marriage	82%	86.2%	86.2%
Percentage of people responding “ likely” “very likely” as attributing causes to vignette conditions			
Bad character	13.4%	16.3%	17.8%
Brain disease	42.3%	46.5%	49.2%
Way of being raised	41.1%	45.4%	46.4%
Stress	82.7%	88%	86.7%
Genetic	47.8%	40.7%	40.7%
God’s will	12.16%	11.25%	11.3%
Bad luck	20.8%	22.9%	21.1%
Respondent demographics			
Female	633 (51%)	630 (50%)	649 （53%）
Age (mean)	45.04	45.17	45.35
Education			
Less than middle school	387 (31.2%)	411 (32.9%)	410 (33.7%)
Less than college	660 (52.4%)	663 (53.1%)	612 (50.4%)
College and more	192 (15.5%)	175 (14.0%)	193 (15.9%)
Perceived as “mental illness”			
Very likely	346 (27.9%)	426 (34.1%)	435 (35.8%)
Somewhat likely	544 (43.9%)	595 (47.6%)	534 (44%)
Not very likely	260 (21%)	182 (14.6%)	178 (14.7%)
Not at all likely	89 (7.2%)	46 (3.7%)	68 (5.6%)

Table 2.3(Continued)

Perception of dangerousness to others			
Very likely	70 (5.7 %)	87 (7%)	107 (8.9%)
Somewhat likely	361(29.1 %)	382 (30.6 %)	385 (31.7 %)
Not very likely	595(48.0%)	633 (50.7%)	564 (46.4%)
Not at all	213 (17.2%)	147 (11.8%)	159 (13.1%)
Personal Contact			
Personally know someone received mental health treatment	148 (12%)	180 (14.5%)	182 (15 %)
See someone with serious mental health problem in public places	395 (31.9%)	418 (33.5%)	444 (36.6%)

Perferences for Social Distance, Sociodemographic Attributes and Causal Attributes

Table 2.4 shows whether public stigma is influenced by the type of mental health problem, socio-demographic attributes and their perceived causal attribtues. Three independent multivariate models were developed for estimating the effect of social-demographic variables, and causal variables on social distance scale under different vignettes. Model 1 displays the the results of the baseline model that expresses public sitgma, evalutated by social distace scale, as a function of depression and schizophrenia. The coefficients of depression and schizophrenia indicate that the behaivors of different diagnostic categories of mental health problems have a significant relationship with public sitgma. Compared with Asthma as the reference group, respondents have a 0.95 significant higher score on social distance scale when the vignette person is described as having depression, and a 0.81 significant higher score when the vignette person is described as having schizophrenia.

Model 2 adds socio-demogrpahic characteristics to model 1. It indicates that the inclusion of socio-demogrpahic variables does not alter the significance of the association between disorder types and public stigma. The pattern of perferred social distance against depression or szhiciphrenia still exist, that depression drew higher social rejections than schizoprehinia, compared with asthma. Of the five socio-demographic variables considered, age and place of residence, and educational level are found to be statistically associated with public stigma. The analysis also shows that people living in rural area have a significantly lower social distance score than urban participants (β = -0.33, S.E = 0.13). This is consistant with evidence from 1996 GSS MacArthur Mental Health Study, which also showed that residents of urban places were more likely to avoid people with mental illness (Martin,J.K., 2000). Desire for social distance was significantly greater at older ages, that a unit increase in age was associated with significant increase in social distance score (β = 0.03, S.E = 0.004). There was a gradient effect of education on social distance, in that people with college degrees had the highest social distace against people with mental illness, compared to people with less than college, or less than middle school educational attainment. Gender and religion did not appear to be important correlates of social distance attributes.

Model 3 adjusts 7 other causal attribute variables to model 2. The patterns of types of disorders on social distance still remained robust. Age, place of residence, and educational attainment were still significant. Causal attributes "bad charcter," "brain disease," "stress," "Genetic cause" were significantly associated with social distance. People who perceived the "disturbing behaviors" described in the vignette as the result of "bad charcter," "brain disease," "stress," had significantly higher social rejections. People who perceived the "disturbing behaviors" described in the vignette as the result of "genetic" reasons had significantly lower social rejections, even though the magnitude was small (β = -0.31, S.E = 0.12).

Table 2.4: Ordinary Least Squares Estimates for the regression of social distance from people with mental health problems with disorder type, sociodemographic and causal attributes (SGC-MHS China, 2010)

	Model 1		**Model 2**		**Model 3**	
	Coefficient	S.E	Coefficient	S.E	Coefficient	S.E
Types of Disorder (Refer: Asthma)						
Depression	0.95 ***	0.15	0.98***	0.14	0.98***	0.15
Schizophrenia	0.81***	0.15	0.77***	0.15	0.68***	0.15
Background Attributes						
Urban (ref.)						
Rural			-0.33**	0.13	-0.49***	0.13
Religion			-0.19	0.20	-0.06	0.05
Age			0.03***	0.004	0.03***	0.004
Female			0.2	0.12	0.2	0.12
Education						
Less than middle school (ref.)						
Less than college			0.43**	0.13	0.47**	0.15
College and more			0.6**	0.2	0.73**	0.21
Causal Attributes						
Bad character					1.19***	0.18
Brain disease					0.66***	0.13
Way of being raised					0.07	0.57
Stress					0.74***	0.18
Genetic					-0.31**	0.12
God’s will					-0.21	0.24
Bad luck					0.2	0.18
Intercept	15.72	0.11	14.67	0.30	13.08	0.41

Notes:
*P=0.05, *p<.05, **p<.01,***p<.001.*

Psychiatric labeling, perceived dangernouness, and contact

Table 2.5 shows the association between social distance and psychiatric labeling, perceived dangernousnessa and contact, adjusting other covariates discussed. Model 4 in table

2.5 mainly examines the “ labeling effect” on social distance score, adjusted other variables included in model 3. It evaluated whether the labeling the scenario a “ mental illness” would increase public stigma against people with mental illness problems, while adjusting for the type of disorders in vignettes, causal attributes and socio-demogrpahic attributes. There was a gradient labeling effect on social distance, in which respondents who reported “ very likely” had the highest social distance scores, whereas respondents who reported “somewhat likely” (β = -0.73, S.E = 0.13), “not very likely” (β = -1.73, S.E = 0.19), and “not at all” (β = -1.90, S.E = 0.30) had decreasing social distance scores compared with the reference group “very likely”. After including the variable “labeling mental illness”, the coefficients of depression and schizophrenia on social distance attenuated, but people with depression vignettes still reported greater social distance than people with schizophrenia vignettes. Place of residence, age, and educational attainment still remained robust and the inclusion of the labeling effect did not change the pattern of the association. Only causes of “bad charcater” and “brain disease” still showed statistical significance on social rejections.

Model 5 includes “the perception of dangerousness” in the model to assess its effect on social distance, after adjusting type of disorders in vignettes, socio-demographic attributes, causal attributes and “labeling of mental illness”. There was also a gradient effect of perception of dangernouness on social distance, in which respondents who reported that individuals with vignette problem are “very likely” to harm others have the highest score on social distance against people with mental illness, compared with people who reported “somewhat likely” (β = -0.58, S.E = 0.26), “not very likely” (β = -1.44, S.E = 0.25), and “not at all” (β = -2.10, S.E = 0.30). While adding perception of dangerousness to the model, the coefficent of type of disorders have attenuated, while the overall pattern is still the same. Place of residence, age, educational attainment, cause of "bad charcater" still independently associated with social distance. The inclusion of perception of dangerousness altered the pattern of labeling effect, in that respondents who perceived the person in the vignette were "somewhat likely" to have mental illness had the highest social distance (β = -1.46, S.E = 0.20), compared "with not all all" (β = -1.39, S.E = 0.31) and "somewhat likely" (β = -0.64, S.E = 0.14). Part of the variations were explained by perception of dangerousness.

Number of studies have found "familiarity" with people who have experienced mental disorders correlates with social distance. Studies used personal contact with people who received mental health treatement as a way to measure familiarity. Contact has been found to be significantly associated with social distance across a broad range of populations and cultures.Therefore, model 6 aimed to test whether " personal contact" and "impersonal contact" independently associated with social distance. The results from model 6 showed no indication of correlation between "personal contact", "impersonal contact" and social distance against people with mental illness in the China data.

Table 2.5: Ordinary Least Squares Estimates for the regression of social distance from people with meantl health problems with disorder type, sociodemographic attributes, causal attribtues, perception of mental illness, perceived dangernousness, and contacts (SGC-MHS, 2010)

	Model 4		**Model 5**		**Model 6**	
	Coefficient	S.E	Coefficient	S.E	Coefficient	S.E
Types of Disorder (Refer: Asthma)						
Depression	0.86***	0.15	0.78***	0.15	0.80***	0.15
Schizophrenia	0.58***	0.15	0.51***	0.15	0.54***	0.16
Background Attributes						
Rural/Urban (Refer: city)						
Village	- 0.44**	0.14	-0.49***	0.14	-0.48***	0.14
Religion	- 0.05	0.05	-0.06	0.05	-0.06	0.05

Table 2.5 (Continued)

Age	0.03***	0.004	0.03***	0.00	0.03***	0.00
female	0.2	0.12	0.21	0.13	0.20	0.13
Education						
Less than middle school (ref.)						
Less than college	0.45**	0.15	0.35*	0.15	0.38*	0.15
College and more	0.66**	0.21	0.58**	0.21	0.58**	0.22
Causal Attributes						
Bad character	1.15***	0.18	0.99***	0.19	1.02***	0.19
Brain disease	0.41**	0.13	0.20	0.14	0.17	0.14
Way of being raised	-0.05	0.13	-0.12	0.13	-0.11	0.13
Stress	0.34	0.18	0.26	0.19	0.27	0.19
Genetic	-0.16	0.13	-0.10	0.13	-0.08	0.13
God’s will	-0.20	0.23	-0.28	0.24	-0.32	0.25
Bad luck	0.19	0.18	0.24	0.18	0.27	0.18
Labeling of the problem						
“Perceives as mental illness”						
Very likely (ref.)						
Somewhat likely	- 0.73***	0.13	-0.64***	0.14	-0.63***	0.15
Not very likely	-1.73***	0.19	-1.46***	0.20	-1.48***	0.20
Not at all	-1.90***	0.30	-1.39***	0.31	-1.40***	0.31
Perceived “ Danger”						
Perceive individual with vignette problem as a danger to others						
Very likely (ref.)						
Somewhat likely			-0.58*	0.26	-0.56*	0.26
Not very likely			-1.44***	0.25	-1.42***	0.26
Not at all			-2.10***	0.30	-2.07***	0.30
Personal Contact						
Personally know someone received mental health treatment					0.08	0.19
Impersonal						
See someone with serious mental health problem in public places					-0.04	0.13
Intercept	15.60	0.31	15.76	0.49	15.53	0.62

Notes:
*P=0.05, *p<.05, **p<.01,***p<.001.*

Discussion and Limitations

Based on the Etiology and Effects of Stigma Model (EES), this study examined key, theoretically derived compoments of public stigma toward mental illness. The Social distance scale, as a fairly consistent way to measure stigma, was adopted in this national multistage sample of adults in China. A number of attributes - the type of disorders, sociodemographic characteristics of respondents, causal attributes, the stigmatizing label of mental illness, perception of dangerousness, and personal/impersonal contacts - were assessed to measure the effect on overall preferences for social distance. We wanted to study three dimensons of these relationships with public stigma. First we found that people have significantly greater social rejections against people with schizophrenia, depression than people with nomral physical illness. Second, we found that age and place of residence had significant associations with social distance. There was a graident effect of education on social distance. Higher education levels were independely associated with greater social rejections. Third, the perception of dangerousness had a gradient association with social distance.

Our first result, that Chinese are less willing to interact with people with depression and schizophrenia than those with a physical illness such as asthma, is consistent with similar studies that compared a mentally ill person to someone with normal behavior (Ingamells, S., 1996), or physical illness (Martin et al., 2000). However, rejection in this study was greater for depressive disorder than for schizophrenia, which was very different from prior studies in other countries; notably, studies from Western countries found that rejection was greater for schizophrenia than for depression (Angermeyer, M. C., & Matschinger, H., 2003b). This difference in results between varying cultural populations suggests an important role that culture may play in individual perception of mental illness. As some scholars have pointed out, data relating to mental illness in Asian countries must be interpreted with caution and cannot be treated with the same assumptions as those from Western countries (Lauber, 2007). More generally, even regional changes in population culture may exhibit a profound difference in mental health perception; for example, a recent detailed study in Malaysia found out that the perception of mental illness considerably varied across and within regions. (Edman & Koon, 2000). Another factor that helps to explain the finding is the low health literacy of mental illness issues among Chinese (lam et al., 1996). According to Lam's finding in Hongkong, 68% of community memebrs failed to ascribe a schizophrenia vignette as mental illness. It is possible in this study that participants were not able to discriminate the difference between depression and schizophrenia. Taken together, these factors underscore the need to further study how cultural context modulates the perception of mental illness.

Generally, social rejection was consistently greater among people with depression or schizoprenia, compared with people with physical illness, such as asthma in this study. Specifically, our analyses found the greatest social rejection came in the unwillingess to marry or take care of children. More than 50% of respondents were also unwilling to have people with depression or schizophrenia as a workmate. A number of studies have found that employers and employees held negative attitudes towards mental illness (Glozier, N.,1998; Couser, G. P., 2008). These findings suggest the importance of wholistic anti-stigma intervetions among Chinese to increase the public recognition and acceptance of people with mental illness.

Our second major finding was that the strongest demographic predictors of public stigma are place of residence, age and education. People living in cities tended to have greater avoidance of people with mental illness than people who live in rural areas. Despite the observation of an age difference found in this study, there was relative consistency that an increase in age was associated with an increase in social distance in other countries (Angermeyer & Matschinger, H.,2004; Jorm & Oh, 2009). It is not known, however, whether this could be an aging or cohort effect. Education was a significant predictor in this study and the association was robust after controlling for all possible variables. The pattern showed that respondents with higher education levels tended to have greater social distance against people with mental illness. This similar pattern was also found in a nationwide telephone study in Korea (Moon et al., 2008). Another study found that more knowledge about mental illnesses, especially schizophrenia, increased social distance (Lauber et al., 2004). Higher education may indicate higher knowledge, which results in greater social distance. Therefore, at a population level, anti-stigma educational campaign that caters to highly educated groups in China may not be well received and effective.

In our third arm of the study, we found that labels of “mental illness” have a negative impact on people’s willingness to socially engage the individuals described in the vignettes. Moreover, the labeling effect is persistent across all models. This finding suggests that the “mental illness” label has an independent and strong assocation with chinese people’s willingness to interact and socialize with people with mental disorders. One study in China found that respondents given a “non-psychiatric, indigenous label” for schizophrenia conditions endorsed the least social distance (Yang, 2012). Another study had a different finding, that psychiatric labeling did not have a statistically significant main effect on attitude measures (Chung & Chan, 2004). One potential explanation of the contradictory findings are the different population subgroups, that Yang (2012) completed the study among 160 adult (age 18 and older) in urban communities in Beijing, whereas Chung (2004) interviewed 313 students from secondary school in Hongkong. All in all, this study, which employed a population survey among 26 regions across China, may suggest that the effect of labeling on social stigma exists in China. However, more studies should be conducted to provide more evidence on this issue.

Perceived dangerousness remains robust even after controlling for personal contact and interpersonal contact in this study. Respondents who had the strongest fear reacted with more rejection towards people with mental illness, than people with less fear, or no fear at all. In additon to its effect on social distance, after including perceived dangernousness in the model, the coeffienct of labels of "mental illness" attenuated at all levels and the gradient effent still remained. What constitutes the labeling is the belief that people with this illness are dangerous and unpredictable, which generates negative emotional reactions and greater desire for social distance (Socall & Holtgraves, 1992). Persons with mental illness are often perceived as dangerous and disruptive by the public in China (Philips & Gao, 1999). In the U.S, studies have shown that the association of mental illness and perceived dangernousness have increased in recent decades (Phelan et al., 2000). Our findings suggest that confining people with mental illness from the public, or controlling patients' symptoms, would not be able to eliminate public prejudice and stereotypes against people with mental illness. On the contrary, we propose a focus on the origins of perceived dangerousness in the public and a need to initiate a strategic and effective way to communicate the nature of mental illness in order to demystify its connetion with violence.

No significant association was found between contact and social distance in this study, which was consistent with another study that investigated prior personal contact and social distance against people with mental illness in China. That study among northern Chinese indicated that prior personal contact did not independently reduce community attitudes of social distance (Yang et al., 2012). A possible explaination of insignificant association could be the quality of the contact. Scholars argued that only strong and positive personal experience with mental illness people was associated with reduced social distance, and no effect was found if the relationship was unchanged, or worse (Martin et al., 2007).

This study also had several limitations. First, respondents who did not answer all 6 social distance items were not included in the study. Although no systematic missing data was detected in statical analysis, it seems rather unlikely that our sample was completely unbiased. Second, social distance was the only assessment of stigma, which does not include other constructs of stigma, and other discriminatory measures. Finally, this study did not measure respondents' prior knowledge or prior quality of exposure to mental illness. Prior knowledge of mental illness could be a mediator that affect respondents' reactions towards people with mental illness. Further studies could investigate whether prior knowledge leads to unfavorable attitudes towards mental illness.

This study used a national representative sample to advance our understanding of stigma and its social and demographical variations in the Chinese context. Its findings on public belief, perceptions of dangerousness, and the effect of labeling lay the empirical foundations for future policies and interventions

Paper III: Stigma in a specific cultural context: Multilevel Analysis of Public Stigma against Mental illness in 26 regions in China

Summary

Larger cultural contexts of stigma differ significantly, yet empirical studies on stigma variations are predominantly focused on Western countries. No study has thus far empirically documented the contextual effect on public stigma against mental illness in China. Using a population-based stratified sample of 3703 adults clustering across 26 regions from the Stigma in Global Context-Mental Health Study, this study explores the extent to which public stigma varies across different regions in China. Multilevel analysis was used to predict the effect of contextual variable on individual attitudes against people with mental illness in China.

The result suggests that larger cultural contexts, defined as different geographical locations, have significant association with individual attitudes towards people with mental illness, which suggest a critical macro-micro connection of public stigma against people with mental illness in China. Economically advanced regions have higher stigma against people with mental illness than less developed regions. Rural respondents have less stigma than urban respondents. Age is positively associated with public stigma. The label of "mental illness" and perception of dangerousness both have negative impacts on people's willingness to socially engage the individuals with mental illness.

The result of the multi-level analysis on public stigma against people with mental illness suggest that social distance is not only associated with individual factors, but also influenced by social context. This study helps to statistically analyze stigma as a social phenomenon that is shaped by the culture and structure of society. New methodology applied in stigma research could signal new directions for the next phase of study in stigma across different cultural contexts.

Background

Stigma is a “mark” that signals to others that an individual possesses a “label’ that causes the person with this “label” to be abnormal from the public, and thus prone to be the target of discrimination, stereotyping and separation in a society. It is a product of a given cultural heritage (Goffman, 1963; Link& Phelan, 2001). Sigma against mental illness is a well-studied subject worldwide and some characteristics of mental illness are stigmatized universally. However, the manifestation of stigmatization usually varies under different social context; it exists “in the eye of the beholder” rather than “in a given odd mark” (Major & Eccleston, 2005, p. 65). Stigmatization is a social construct that fundamentally causes health disparities (Hatzenbuehler, Phelan, & Link, 2013).

Scholars in social psychology have distinguished several related types and different constructs of stigma. According to Corrigan, *public stigma* refers to the attitudes and reactions of the general public towards a group based on stigma about that group. *Self-stigma* refers to the perception, attitudes and belief of stigmatized groups against themselves (Corrigan, 2002). With reference to Corrigan’s definition of public stigma and self-stigma, the components of *public stigma* and *self-stigma* both include cognitive, emotional and behavioral aspects. Corrigan proposed an attribution model of public stigma against mental illness discussed and discussed that public stigma and self-stigma both include stereotype, prejudice and discrimination (Corrigan et al., 2003). *Stereotypes,* according to Hiton *(1996*), are “collective opinions” and knowledge about a group, which are effective ways to draw an impression. *Prejudice* refers to an emotional response based on stereotypes. *Discrimination* is a set of actual hostile behavioral reactions towards one group based on one’s prejudice (Crocker, Major, & Steele, 1998). In the case of mental illness, the stereotypes that people with mental illness are dangerous and unpredictable are engrained in the public, which generate fear against the stigmatized group, and lead to avoidant behaviors (Phelan et al., 2000; Phelan & Link, 2004). Scholars in America concluded that the most prominent and consistent view of people with mental illness across the world is the idea that people with mental illness are dangerous (Martin, J. K., et al., 2000). Under this notion, fear as one aspect of stigma has been measured in a fairly consistent way. More importantly, surveys in the US have documented an increasing trending of negative prejudice against people with mental illness since 1950 (Phelan et al., 2000). Scholars in America and Europe have applied the social distance scale to measure attitude and acceptance among the general public towards people with mental illness. The association between perceived dangerousness and social distance was supported among studies in Germany (Angermeyer & Matschinger, 2003), America (Corrigan, 2002b) and Russia (Angermeyer et al., 2004).

Culture and Stigma of Mental Illness

The aspects of stigma are socially constructed and closely related to specific social contexts, yet stigma of mental illness is one of few universal stigmas that exist countries across the globe (Stangor and Crandall, 2000). Recently, stigma researchers have increasingly recognized the value of cultural differences and contextual aspects and variations to the individual level of stigma (Pescosolido, B. A., 2013). In this article, Pescosolido also suggested that limited and debatable systematic explanations could be derived from individual socio-demographical variables. As they are unreliable and inconsistent across countries, structural factors, such as institutional discrimination, should also be considered and measured (Pescosolido, 2013).

Despite the acknowledgement that stigmatization pervasively exists in different cultures, we have little evidence to validate the stigma against mental illness differs across cultures. Only a small number of comparative studies tackled the cultural variations against people with mental illness. Westbrook (1993) conducted a study among health practitioners (N = 665) from the Chinese, Italian, German, Greek, Arabic and Anglo in Australian communities. Westbrook asked health practitioners to rate the attitudes of people in their communities toward 20 disability groups (mental disorders, physical disabilities, AIDS, etc.). The results showed significant differences in community attitudes toward people with mental disorders. Overall, the German community expressed the greatest acceptance of people with disabilities, followed by the Anglo, Italian, Chinese, Greek and Arabic groups (Westbrook, 1993). Preliminary findings from the Stigma in Global Context – Mental Health Study also suggest significant variations in public response to mental illness, even in regions such as Europe where countries have relatively similar cultures (Pescosolido, 2013). Respondents across 15 countries (Argentina, Bangladesh, Brazil, Bulgaria,Cyprus, Finland, Germany, Great Britain, Hungary, Iceland, Japan, New Zealand, Philippines, South Africa, Spain, U.S) in various cultures reported unwillingness to have a person in the schizophrenia vignette as a neighbor. The population proportion of unwillingness differs dramatically; for example, less than 25% respondents from Brazil have stigmatizing responses, whereas more than 75% people in Bangladesh reported not being willing to have people with schizophrenia as their neighbors. A recent study, which measured cultural differences in stigma against schizophrenia between Central Europe and North Africa, showed a striking difference between these populations. Respondents in Tunisia expressed more prosocial reactions and less fear against people with schizophrenia than people in Germany (Angermeyer et al., 2015). Ongoing studies have suggested different cultural norms, values, attitudes and behaviors towards people with mental illness within and across social and cultural contexts may play a significant role in such variability. Thus, cross-cultural studies regarding stigma against mental illness play an important role in better understanding the origins, experiences, and consequences of specific cultural contexts.

The unique context of China: Chinese Diverse Culture

Public stigma against mental illness is pervasive and is a significant barrier to the seeking of mental health services (Tsang H., et al., 2003). Although mental illness affects 17.5% of the population, an astounding 92% of individuals with mental disorders had never sought any type of professional help (Phillips et al., 2009).

China is recognized as the world's largest population and an extremely large country with enormous cultural diversity. In fact, multiculturalism in China has been recognized and promoted across many centuries (Magid, 1998). Scholars in social science and cultural comparative studies believe that regional variation within China is considerably large, and that may lead to significant variations in attitudes and behavior across different regions in China (Gong, 2011). In a study that focused on leadership behaviors and value differences across different provinces in China, Littrel (2012) found significant behavioral differences that indicated the existence of "culture areas" in China. What contributed to these behavioral differences, as Littrel concluded, were local dialect differences, unique economic histories, and geographic distance from one another. Gong (2011) also assessed the possible effects of regional differences and cultural diversity in China by examining dialect similarities and differences in work settings. He found that employees' focal dialect speaking skill was positively related to their links in organization and community.

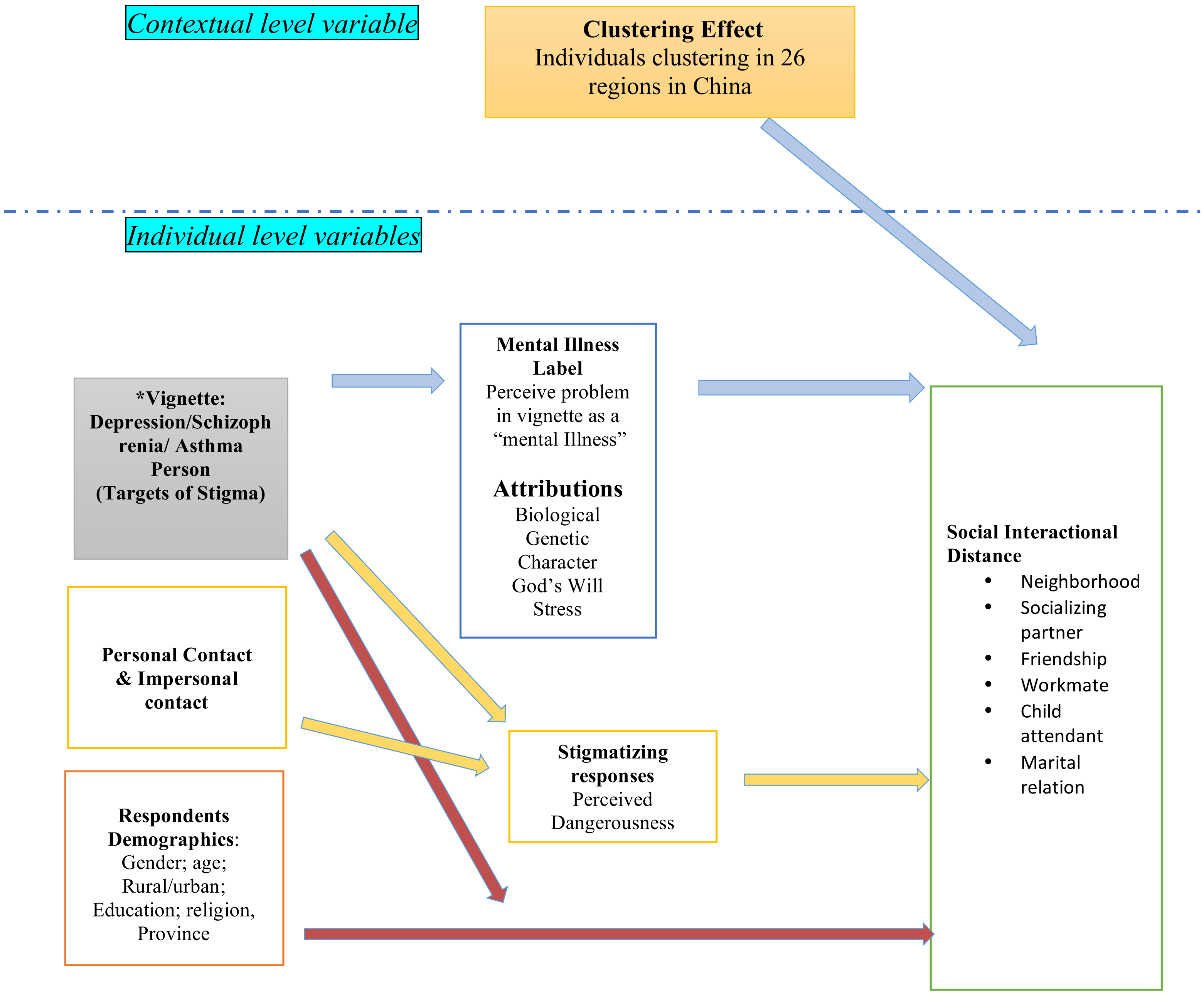
To advance our understanding of stigma and the role of social context in stigma, this exploratory research examined the extent to which public stigma varies across different provinces. Specifically, we focus on the public's willingness or unwillingness to interact with people with mental illness. Differing from the traditional method of measuring contributing factors of public stigma at the individual level, this study identified the variability of public stigma reactions across 26 regions that included provinces and autonomous cities in China, and evaluated the amount of between-province variability of stigmatizing responses that remained significant after the main effect of individual socio-demographic characteristics had been accounted for. The relationships between social demographic attributions (e.g., type of vignettes, respondents' education, religion, place of residence) and social distance towards people with mental illness (neighborhood, socializing partner, friendship, workmate, etc.,) were estimated at both individual and contextual levels. We hope this study may shed light on developing more effective public anti-stigma interventions specifically tailored to Chinese diverse regional cultures and ethnic groups.

Theoretical Framework

This paper is also based on the the Etiology and Effects of Stigma Model (EES) as described explicitly in paper II. The EES model highlights the importance of social location and its influence on individual knowledge and experience regarding mental illness. Further, the EES model suggests that the stigmatizing process occurs within a larger social and cultural context, which sets the parameters for individuals' reactions towards people with mental illness.

Using a population-based stratified multi-staged sample of 3702 adults from 26 provinces and municipal cities in China, we may expect clustering of cultural differences that could be reflected in stigmatizing responses across these regions, as shown in Figure 3.1. Specifically, we expect a contextual effect that independently associates with individual responses against people with mental illness.

Figure 3.1: The Etiology and Effects of Stigma Model (EES) for the Multilevel Analysis



Data and Analytic Strategy

Paper III uses the same raw data as described in paper II. Therefore, the study design, study source, sampling strategy, and instrument development sections have omitted here. Please refer to paper II regarding these methods.

Variables

Dependent Variables: Social distance scale

As discussed in paper II, the social distance scale is a 6 item instrument recognized as a technique to measure public stigma. The social distance scale in this study was summed to measure variability among individuals and regions.

Independent variables

The independent variables in paper III also included type of mental disorders, causal attributes, perception of "mental illness," perception of dangerousness, personal contact, and impersonal contact.

Demographic variables. The demographic variables also included gender, age, place of residence educational degree, and religion. In addition, there was an institutional level variable that indicated geographical location of each participant.

Institutional – Level Variables

Respondents were geocoded to census tracts. Each tract represented one province or municipal city (See Table 3.1).

Table 3.1: Contextual level description:

Province	Number of respondents	Percent	Mean Social Distance Score	Province	Number of respondents	Percent	Mean Social Distance Score
Beijing	315	8.51	17.36	**He Nan**	104	2.81	15.95
Tianjing	113	3.05	16.88	**Hu bei**	237	6.4	16.22
He Bei	204	5.51	16.66	**Hu nan**	63	1.7	16.63
Shan Xi	129	3.48	16.50	**Guangdong**	73	1.97	15.97
Liao Ning	170	4.59	17.13	**Guangxi**	136	3.67	15.55
Ji Ling	283	7.64	16.73	**Chong Qing**	90	2.43	15.18
Hei Long Jiang	201	5.43	16.59	**Sichuan**	64	1.73	16.77
Shanghai	85	2.3	17.07	**Guizhou**	60	1.62	14.78
Jiangsu	77	2.08	17.43	**Yunnan**	97	2.62	14.05
Zhe Jiang	66	1.78	16.11	**Shanxi**	201	5.43	15.64
An Hui	234	6.32	15.85	**Gansu**	127	3.43	15.11
FuJian	61	1.65	16.02	**Qinghai**	85	2.3	16.13
JiangXi	176	4.75	15.77				
ShanDong	252	6.81	16.89	**Total: 3703**			

Statistical Analysis

Prior studies in public stigma mainly evaluated individual characteristics. Moreover, the previous study that took contextual factors into account did not distinguish adequately between individual and group level influences (Evans-Lacko et al., 2012). Unlike the linear regression approach, the multilevel approach applies parameters to vary more than one level. The analysis includes both individual units (at a lower level) nested within contextual/aggregate units (at a higher level). This method is able to take into account regional variation, and model the data in a hierarchical system for both individual-level and group-level variables (Diez, 2002). To study cross-provincial differences in the preferred social distance against people with mental illness, we employed multi-level modeling and use two-level structures, where individuals were nested in provinces. With this method, we could simultaneously estimate differences between provinces and variations between individual respondents. It accounted for a nesting of individuals in province, which enabled us to model heterogeneity and to obtain correct estimations of provincial effects. Given the fact that this study was aimed to investigate public stigma in one country with 26 clustering units, we may expect significant variability of stigmatizing responses (the sum scale of social distance) between provinces than within provinces. The main question and hypothesis are:

> **Question**: Is there provincial patterning in the individual responses of “social distance” once controlling for individual demographic variables (i.e. education, age, religion, and etc).
>
> **Hypothesis**: There is residual between province variability on social distance reactions after main effects are accounted for. Respondents reporting social distance in a province represent the function of the socio-demographic variables, and a differential effect associated with its cultural region).

First, I used general linear regression to model summative social distance score, conditional on age, sex, rural/urban residence, education, religion, causal attributes, personal contact, perceived dangerousness, and province. Province of residence was ‘dummy’ coded and treated as a fixed classification in these models to first examine the significance of provincial variability on social distance. Next, the models were extended and included a random effect for province and specifying two-level multilevel models. Two-level models would be specified with a continuous response for individual i in province j. In this model, the random intercepts for provinces were assumed to be independently and identically distributed with variance σ_{u0}^2.

The Random Intercept Model:

$$Y(Social\ Distance)_{ij} = \beta_0 X_{0\mathrm{ij}} + \beta_1(Personal\ Contact_{ij}) + \beta_2(Demographics_{ij}) + U_{0j}X_{0\mathrm{ij}} + e_{0\mathrm{ij}}X_{0\mathrm{ij}}$$

where $U_{oj} \sim N(0, \sigma_{u0}^2)$, $e_{oij} \sim N(0, \sigma_{e0}^2)$

OLS model and multilevel models were estimated with STATA (version 13).

Results

Participants characteristics

The manjority of the results of participants' characteristics were summarized in Paper II. Figure 3.2 to Figure 3.7 shows the desire for social distace across 3 different vignettes: asthma, schizophrenia and depression. The asthma vignette drew less rejection than depression and schizophrenia across 6 items in social distance scale. As shown in Figures 3.2 to 3.7, respondents were less willing to let the person described in the vignette to "marry" their relatives or to "take care of children." Among items that required greater intimacy, depression drew greater rejections than schizophrenia. Almost 50% of repondents were "definitely not" willing to have people with depression take care of their children, whereas schizoprehnia drew 47% of rejection.

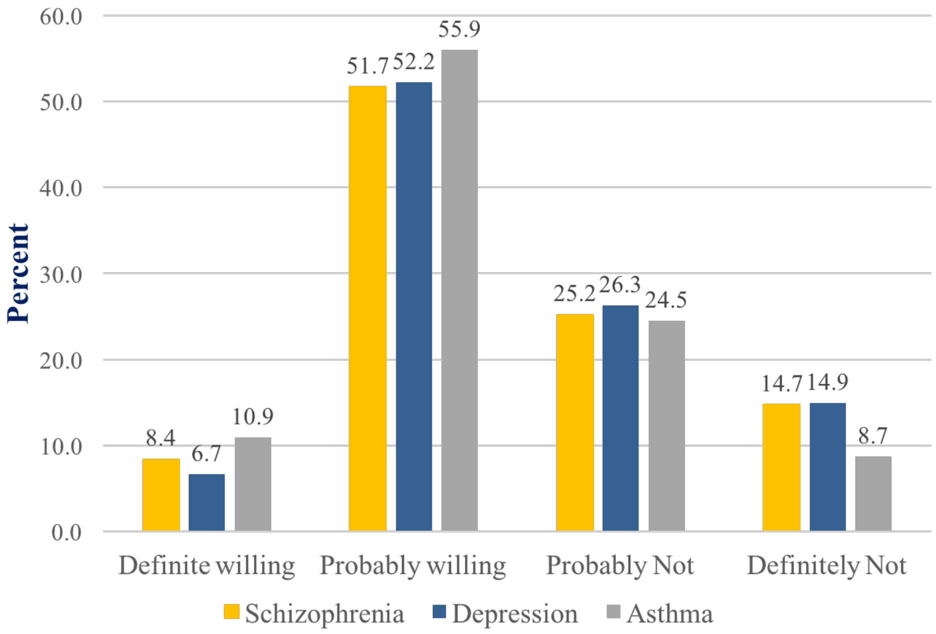


Figure 3.2 Willingness to make friends with X in the vignette

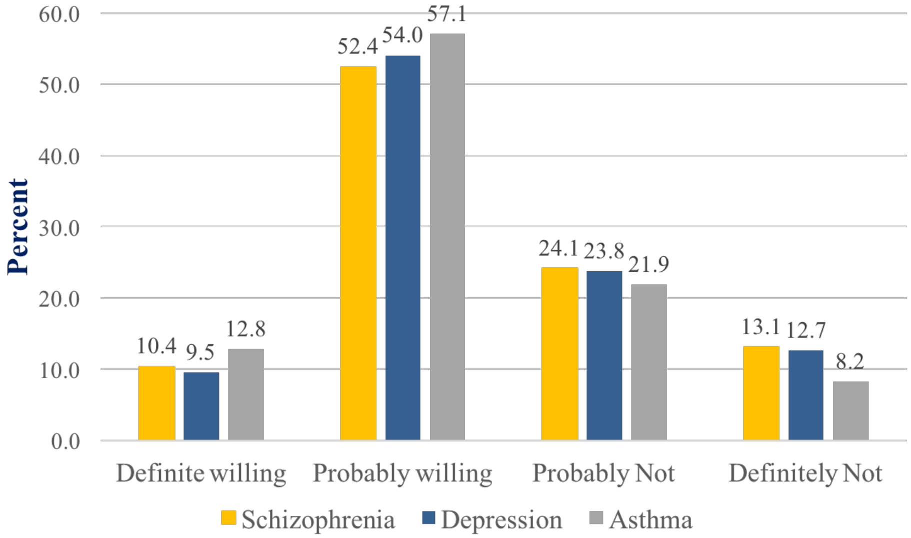


Figure 3.3 Willingness to have X in the vignette as your neighbor

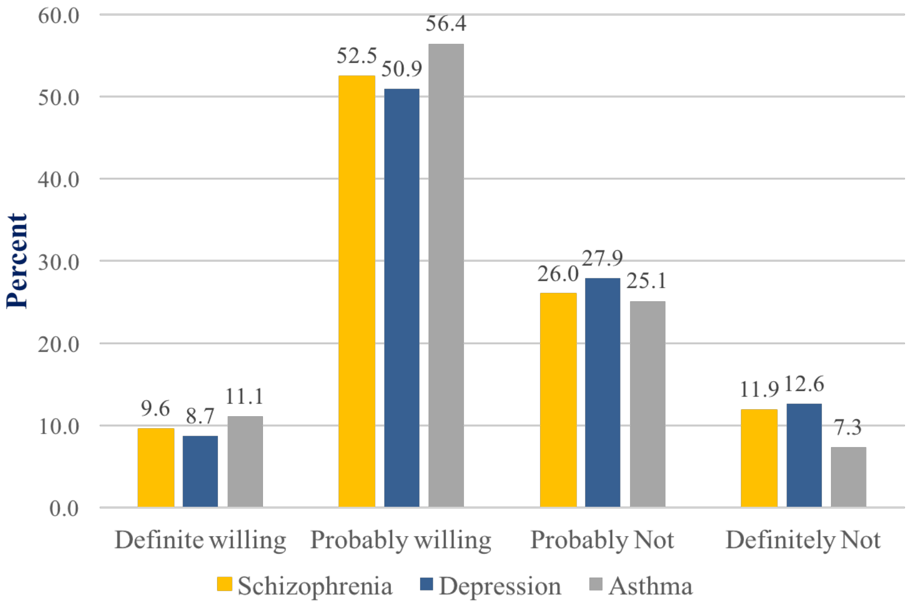


Figure 3.4 Willingness to socialize with X in the vignette

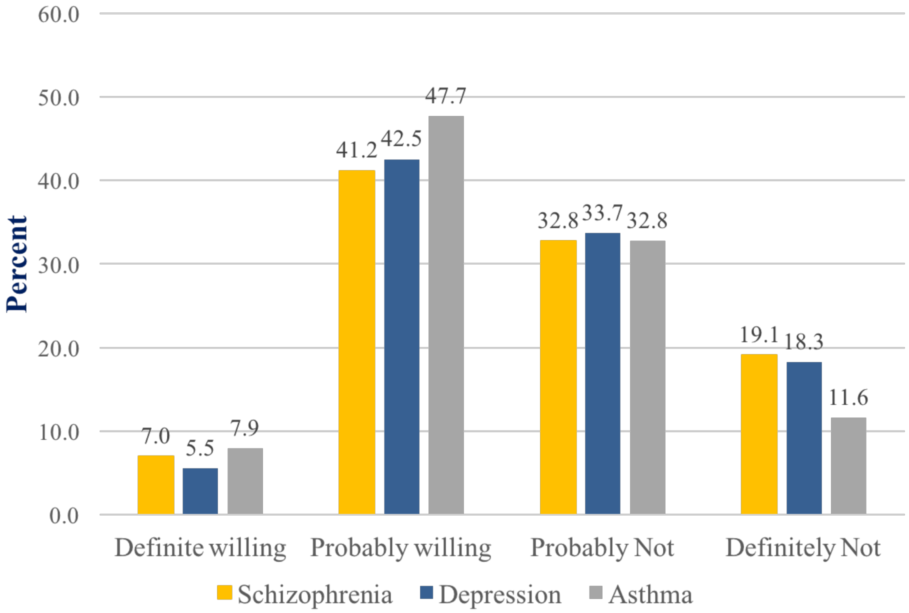


Figure 3.5 Willingness to work with X in the vignette

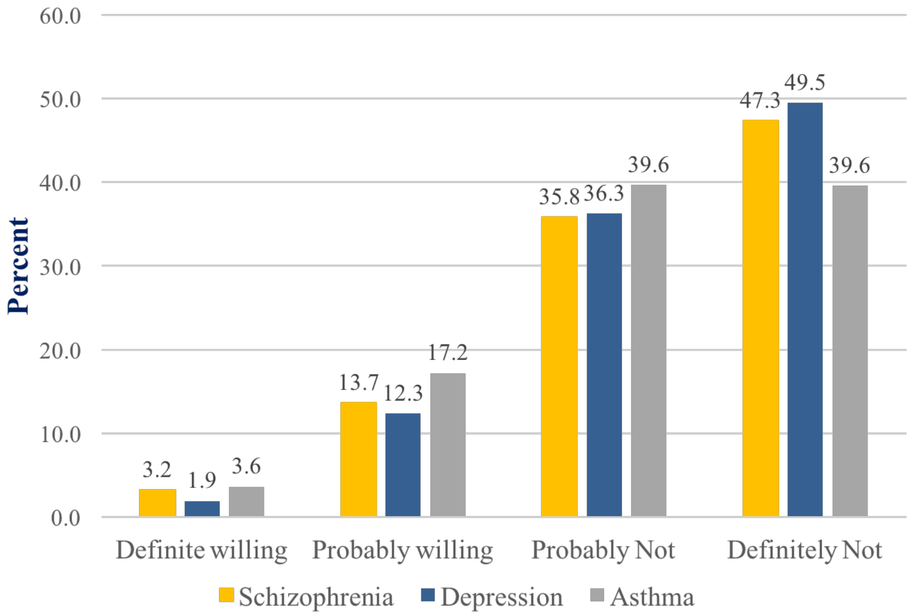


Figure 3.6 Willingness to let X in the vignette care for children

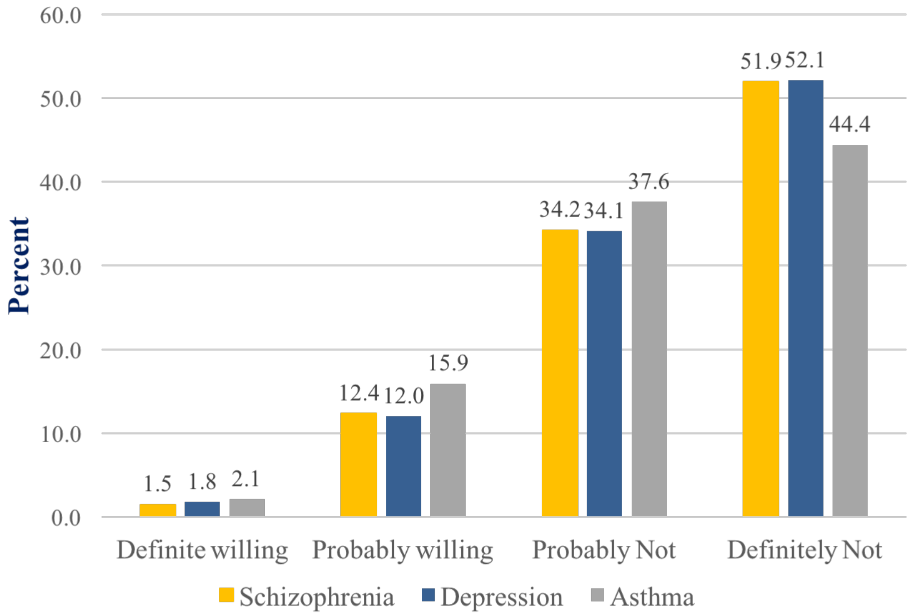


Figure 3.7 Willingness to let X in the vignette care for your children

Geographic variations in Social Distance

In Table 3.2, we examined geographic variation in social distance between provinces using a multilevel modeling approach. In this approach, provinces were treated as a random effect, that provincial variations were estimated in a response across 26 clustering groups of obervations. Results from the conditional multilevel random intercept models are shown in table 3.2. As shown from the table, in an initial random intercept null model, the between-province variance in mean social distace is statistically significant ($\sigma^2_{\mu 0}$ = 0.50, S.E=0.17), which indicates a significant provincial effect on social distance score. The results suggest that 3.5% (icc=0.035, S.E=0.01) of the variation in social distance can be attributed to the between-province effect. The provincial effects are all significant across other models in Table 3.2, after accounting for socio-demographic characteristics, causal attributes, labeling "mental illness" effect, perception of dangerousness, personal and interpersonal contact respectively in different models. Specifically, 5% of the variation in social distance can be attributed to the between-province effect after adjusting all possible covariates in model 5 (icc=0.05, S.E=0.015).

Different from the results in Paper II, we observed that of the five socio-demographic variables, only age and place of residence are found to be statistically associated with social distance score using multilevel approach. Education was no longer significant. Table 3.2 shows that people living in villages have a significantly lower social distance score than urban participants across model 2 to model 5. Desire for social distance was significantly greater as age increases; a unit increase in age was associated with a significant increase in social distance score in the multilevel models (β = 0.02, S.E = 0.004). Compared with linear regression models, multilvel models attenuate the coefficent of age from 0.03 to 0.02.

There is a gradient effect of the labeling of "mental illness" in Model 3. After accounting for the provincial effect, respondents who reported “somewhat likely” “not very likely” and “not at all” had decreasing coefficents on social distance scores compared with the reference group “very likely”. However, this pattern was altered after adding “ perception of dangerouness” in Model 4.

Both in Model 4 and Model 5, the perception of dangerousnes still remains robust in the multilevel model. The stepwide graident in the perception of dangerous also remains, where respondents who reported “somewhat likely” “not very likely” and “not at all” had decreasing coefficent on social distance scores compared with the reference group “very likely” to be dangerous. The direction of these relationships were consistent and statistically significant (P<0.01).

Table 3.2, Multilevel analysis for social distance

	Null Model	Model 1	Model 2		Model 3		Model 4		Model 5	
			Estimate	S.E	Estimate	S.E	Estimate	S.E	Estimate	S.E
Types of Vignettes										
Asthma (Reference)										
Depression		0.99***	0.99***	0.15	0.89***	0.15	0.80***	0.15	0.82***	0.15
Schizophrenia		0.82***	0.70***	0.15	0.59***	0.15	0.52**	0.15	0.54***	0.15
Social Demographics										
Rural			-0.37*	0.15	-0.33*	0.15	-0.37*	0.15	-0.37*	0.15
Religion			0.07	0.06	0.08	0.06	0.07	0.06	0.07	0.06
Age			0.02***	0.00	0.02***	0.00	0.02***	0.00	0.02***	0.00
Sex			0.12	0.13	0.09	0.12	0.10	0.12	0.09	0.13
Education										
Less than middle school										
Less than college			0.27	0.15	0.25	0.15	0.13	0.15	0.15	0.15
College and more			0.40	0.22	0.33	0.22	0.21	0.22	0.20	0.22
Causal Attributes										
• Bad character			1.27***	0.19	1.23***	0.18	1.06***	0.19	1.10***	0.19
• Brain disease			0.68***	0.13	0.44**	0.13	0.23	0.13	0.20	0.14
• Way of being raised			0.13	0.13	0.01	0.13	-0.06	0.13	-0.06	0.13
• Stress			0.65***	0.18	0.27	0.19	0.20	0.19	0.22	0.19
• Genetic			-0.37**	0.13	-0.21	0.13	-0.15	0.13	-0.12	0.13
• God's will			-0.14	0.24	-0.12	0.24	-0.18	0.24	-0.23	0.24
• Bad luck			0.25	0.18	0.24	0.18	0.28	0.18	0.31	0.18

Table 3.2(Continued)

	Null Model	Model 1	Model 2		Model 3		Model 4		Model 5	
			Estimate	S.E	Estimate	S.E	Estimate	S.E	Estimate	S.E
Labeling of the problem “Perceives as mental illness”										
Very likely (Reference)										
• Somewhat likely					-0.72***	0.14	-0.63***	0.14	-0.62***	0.14
• Not very likely					-1.73***	0.19	-1.44***	0.20	-1.44***	0.20
• Not at all					-1.83***	0.30	-1.32***	0.30	-1.33***	0.30
Perceive individual with Vignette problem as a danger to others										
• Very likely (Reference)										
• Somewhat likely							-0.64*	0.26	-0.62*	0.26
• Not very likely							-1.55***	0.25	-1.53***	0.25
• Not at all							-2.16***	0.29	-2.13***	0.29
Personal Contact									0.05	0.18
Impersonal Contact									0.04	0.07
Intercept	16.20 (0.15)	15.60 (0.17)	13.39	0.44	14.76	0.46	16.16	0.51	15.83	0.63
Between Region Variance	0.50 (0.17)	0.52 (0.18)	0.51	0.19	0.52	0.19	0.57	0.20	0.55	0.20
Within Region Variance	13.83 (0.32)	13.64 (0.31)	12.79	0.31	12.41	0.30	11.93	0.29	11.99	0.30
ICC	0.035	0.036	0.038	0.013	0.04	0.014	0.05	0.015	0.05	0.015

Notes: P=0.05, *p<.05, **p<.01,p<.001***

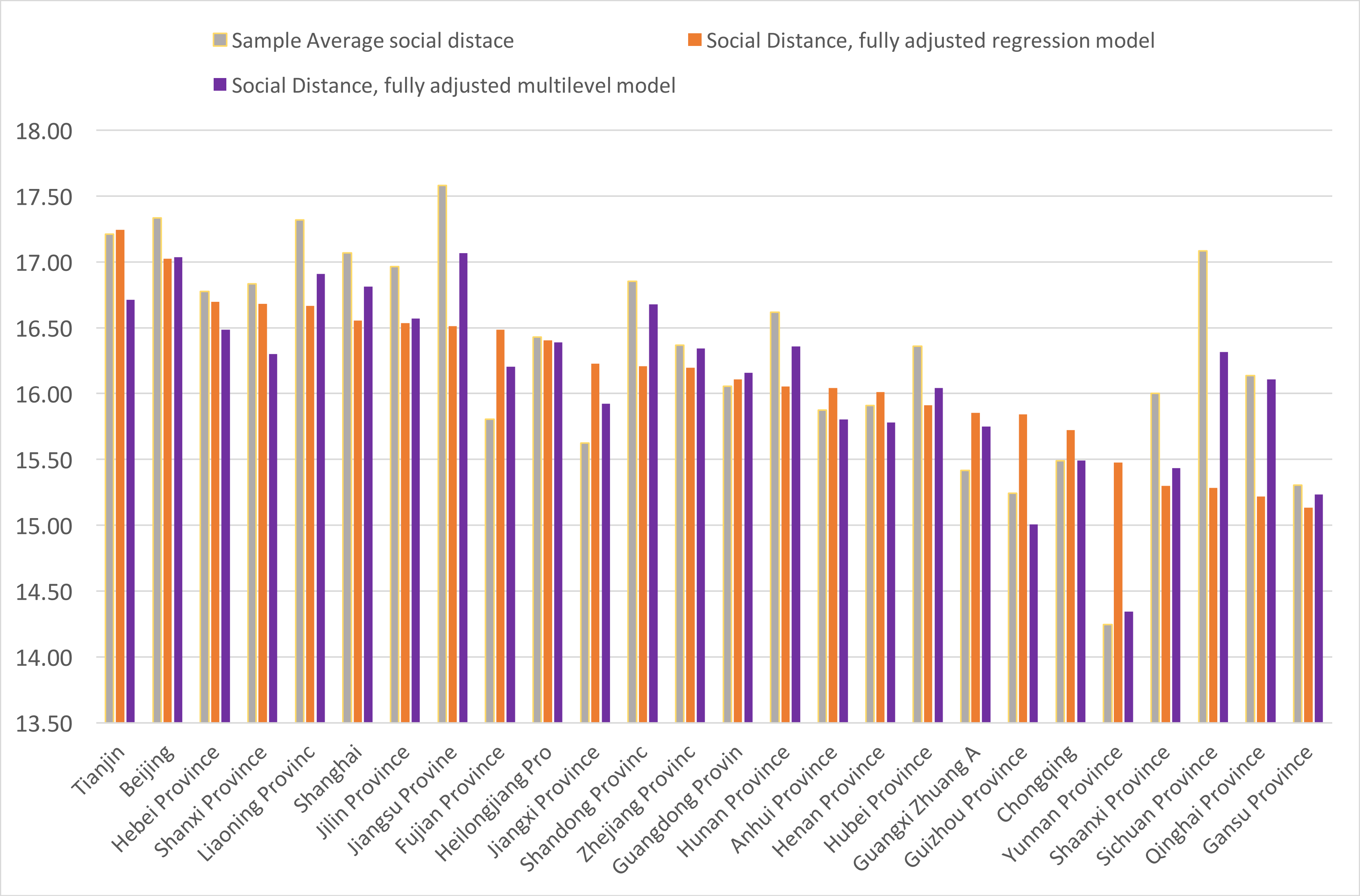


Figure 3.8 The average provincal estimation of the social distance score in China by different model approaches
Note: Adjusted by demographic, socialeconomic characteristics, causal attributes, label of mental illness, perceived dangerousness,and contact

A statistically significant difference in social distance score was observed between provinces in the linear regression model where provinces were treated as a fixed effect (p=0.000). In this model, social distance score was highest in Tianjing (average score = 17.25) and lowest in Gansu province (average socre = 15.13), which was equivalent to a difference of 2.12. (See Figure 3.8)

Compared to treating provinces as a fixed effect, the multilevel fully adjusted model yielded differnt provincial-level estimates. The social distance score was highest in Jangsu province (average score=17.07) and lowest in Yunnan province (average score=14.34), which was equivalent to a difference of 2.73. The differences between provinces were found to be 0.61 wider than the difference calcuated from fix effect estimates (2.73 vs 2.21). The ordering of provinces in multilevel estimate was generally similar to the fix effect approach. The fixed effects estimates for each province, compared to the multilevel model estimates are shown in Figure 3.8.

Discussion and limitations

The study shows several important findings. First, it provides quantitative evidence of the provincial effect on public stigma. Researchers in public stigma have been attempting to find evidence to address the critical question: "do larger cultural contexts of stigma differ significantly?" (Pescosolido, 2013). This study provides evidence and suggests that larger cultural contexts, defined as different geographical locations, do have a significant effect on individual attitudes towards people with mental illness. The statistical results show that geographic variations in social distance against people with mental illness remain after accounting for socio-demographic characteristics and individual variations in perceptions, suggesting the importance of place, at the level of provinces and regions in China.

This suggests that healthcare and public health are part of a reciprocal web of relationships among individuals, their social networks, and larger social structures. This perspective encourages researchers and policy makers to consider targeting stigma at different provinces and regions that might have long term, cascading effects across all levels.

Second, we noted strong gradients in social distance by levels of perception on “labeling mental illness” and “perceived dangerousness”, which were minimally changed after adjusting for potentially confounding variables. Differences remained in social distance scores between provinces after accounting for socio-demographic and attitudinal variables in both the fixed and random effects models. In the multilevel model, the estimated social distance scores were adjusted towards the national mean among provinces such as Hebei, Hunan, Sichuan, Shanxi, and the multilevel model tends to “shrink” over predicted provincial estimates, such as Yunnan, Guizhou, Chongqing, Guangxi. The multilevel model protects against the over-interpretation of extreme group-level differences which are potentially less reliable.

Third, one very important and interesting finding is that well-developed provinces and cities (Jiangsu province, Beijing, Shanghai) have the higest social distance scores, whereas less developed provinces (Yunan, Guizhou, etc) are at the bottom of the social distance scores, which means that less developed provinces are the least likely to reject people with mental illness. Based on the GDP data per person by province (see Figure 3.9a), Shanghai, Jiangsu, and Beijing are the richest regions, whereas Yunnan, GuiZhou, Gansu are the poorest regions (Figure 3.9b).

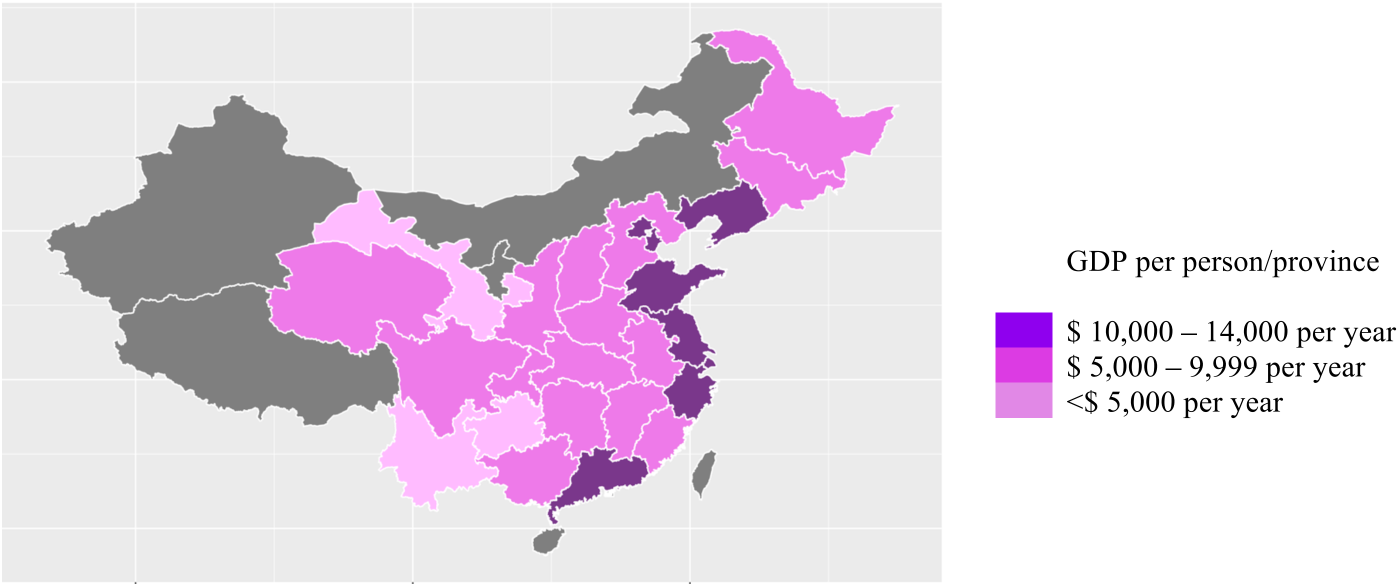


Figure 3.9a Chinese GDP per person by provinces
Source: (Comparing Chinese provinces with countries, 2011)

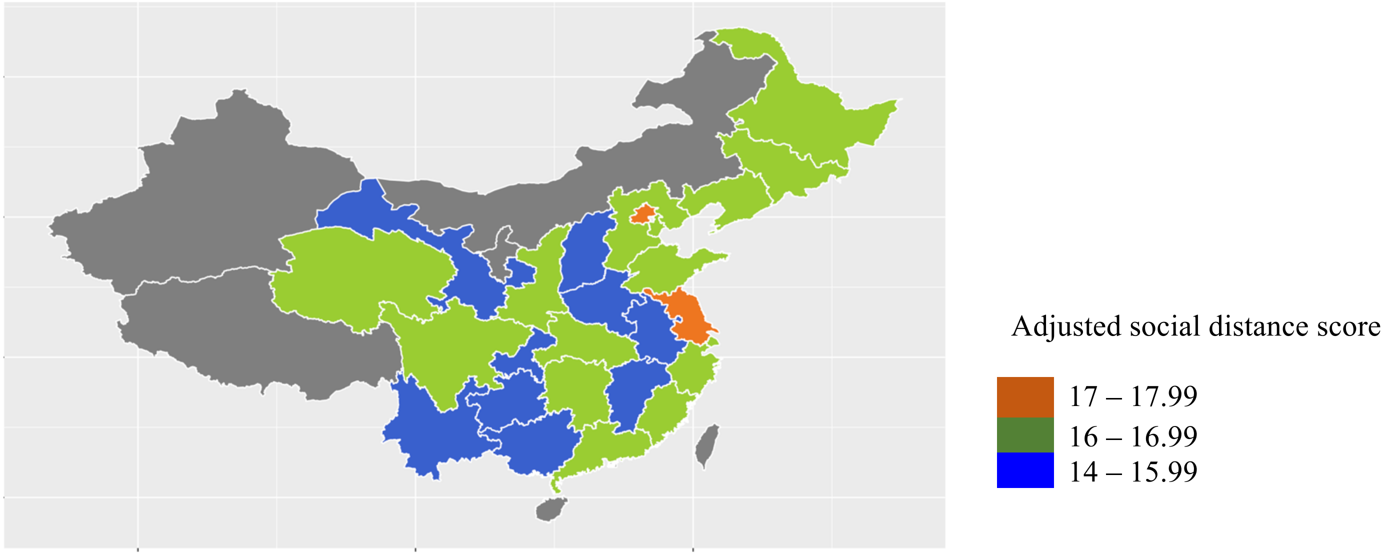


Figure 3.9b Multilevel model on social distance score by province, fully adjusted

It appears that provinces like Yunan, Guizhou have less stigma against people with mental illness. However, to what extent the social distance scale captures the constructs of stigma in certain cultural contexts is understudied and unknown. Among many negative characteristics that the public ascribes to people with mental illness, the belief that people with mental illness are dangerous is well studied as discussed earlier in this paper. However, beliefs such as weakness and incompetence have received much less attention. Other discriminatory attitudes and behaviors are less discussed, and current results on mental illness stigma are strongly in favor of context.

The social distance scale is based on the assumption that the people are afraid of those with mental illness due to their potentiality in violence and dangerous to towards others. Therefore, the corresponding reaction is to avoid them. However, in the Chinese context, public stigma may have different constructs and beliefs that are not reflected in the social distance scale. According to research by Chinese scholars, people with mental illness are more likely to suffer from physical abuse and sexual abuse. Among 266 mental illness patients in Shangdong province, 48.9 % of respondents reported to be a victim of physical violence and the violence occurred in working place (50.8%), community (43.8%), family (37.7%). Forty-nine percent of female patients reported experiencing physical abuse from family. Among male patients with schizophrenia, 52.9% had experienced physical abuse. Among female patients with schizophrenia, 33% had experienced sexual abuse. Patients from rural areas (52.5%) have significantly higher reports of abuse than patients from urban areas (47.3%) (Wang, 2007). Another anthropological study that looked into the stigma among people with mental illness in China suggested that stigma implies a strong emotion rather than an attitude resulting from risk perception and calculation; this emotion comes from its local moral meaning and daily practices. In this study, Guo (2008) found that people with mental illness are considered as non-human. People stigmatized mental illness patients because they thought they did not deserve to be treated as a normal person with social status and dignity. Seeing and treating somebody as weak, physically, mentally or socially is a form of discrimination, where in Chinese view, discrimination (qishi) often refers to behaving in an aggressive way, such as teasing, shouting, spitting at, or beating others (Guo, 2008). These studies may suggest that various aspects of mental illness stigma may be more prevalent in China than the aspect of “fear” in Western countries. It is therefore important to document the attributes of mental illness stigma in other cultural context.

The early dominant view of stigma from Western countries and its defined domains have reduced the general understanding of stigma to public attitudes toward risk, and hence, measuring and comparing that attitudinal variable quantitatively across countries may simplify our understanding of stigma with mental illness. Stigma is a moral statement about the relationship between an individual’s characteristic(s) and the social world (Yang, et al., 2007). Therefore, stigmatizing behaviors in China are dependent upon the relationship between the specific discrediting attribute of mental illness and the specific social context. As discussed in previously, Chinese lay beliefs of causes mental illness such as moral lapse (Geaney, 2004) and weak character (Parker, et al., 2001) do exist in China. However, they were less discussed and measured by Western scholars. Stigma, as a product of the social situation rather than any specific individual (Major & O'Brien, 2005b), should be measured in accordance with local beliefs.

The strength of this study is that it is based on the first population-based survey on attitudes and perceptions about mental illness. However, it has certain limitations. It is cross-sectional by design, and therefore the results of this study are not unable to address temporality and therefore we are unable to infer causation between social & cultural attributes and stigmatizing responses and behavior in different places. A multilevel analysis tends to disentangle the cultural attributes that are connected to individual stigma, but the cultural indicator in this study is “province.” This cultural variable does not necessarily capture the distinctive culture elements such as “face” or other constructs of stigma. However, it highlights the importance to develop more culturally relevant measures to investigate the mechanism.

In addition, all information is self-reported and therefore there is possible misclassification. Respondents may not feel comfortable providing answers that present themselves in an unfavorable manner or lead to unfriendly environment. Respondents may not be fully aware of their reasons for any given answer because of lack of knowledge, or memory on the subject. To some worse cases, respondents may lie. Chinese have very negative attitudes towards people with mental illness (Philips et al., 2000), but their attitudes or sociocultural elements may not be included in the survey. In addition, the extent to which we can draw inclusion from the social distance scale in the Chinese context is unclear. It seems that in Chinese culture, people living in more developed regions differ in level of reaction towards mental illness compared with people living in less developed regions.

We found significant differences against people with mental illness among 26 regions in China, and that the regional level represents around 5% of the variation of social distance in public stigma. This study indicates that group discrimination and segregation are embedded in a consistent social structure. We expect that this study can help inform policies that target structural discrimination and provide more direction to future community interventions. Further studies to determine the mediating factor at regional level are necessary, and more studies are needed to compare the regional cultural effect in China with that of other countries. This dissertation extends stigma research to non-Western contexts. It provides empirical evidence that may assist in mitigating the negative effects of stigma at the individual and structural levels.

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