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Chinese Families and Mental Illness: The Experiences of Immigrant Chinese Women Who Provide Care to a Family Member with a Mental Illness in New York City

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Author
An, Linh My

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Chinese Families and Mental Illness: The Experiences of Immigrant Chinese Women Who Provide Care to a Family Member with a Mental Illness in New York City

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Anthropology

by

Linh My An

2014
ABSTRACT OF THE DISSERTATION

Chinese Families and Mental Illness: The Experiences of Immigrant Chinese Women Who Provide Care to a Family Member with a Mental Illness in New York City

by

Linh My An

Doctor of Philosophy in Anthropology

University of California, Los Angeles, 2014

Professor Douglas W. Hollan, Chair

This dissertation is an intimate ethnography of immigrant Chinese women’s experiences as caregivers to family members with mental illness in New York City. It examines how cultural ideals, the individual particularities of respondents and their ill relatives, and their interactions with institutions affect the construction and enactment of caregiving in everyday life.

Previous research on families and mental illness has predominantly been based on quantitative studies of Euro-American participants and tends to highlight the negative aspects of caregiving. Thus, this dissertation contributes to the limited qualitative research on minority caregivers. Utilizing ethnographic observations and interviews over a three-year period, the study finds that there is a strong cultural ethos of providing care to mentally ill family members, and that caregiving is often framed as a duty that is expressed through instrumental support. The enactment of these obligations and the extent of respondents’ involvement in care, however, are
mediated by other factors, including the willingness of the care recipient to accept help, the caregiver’s competing family responsibilities, and the manageability of illness symptoms. In particular, respondents’ limited English proficiency and unfamiliarity with the mental health system creates difficulties in coping and advocating that are distinct from the ones faced by Euro-American caregivers. However, using a Chinese family support group as social capital, respondents are able to meet their needs for information on etiology and treatment of mental illness; obtain practical advice on how to respond and manage difficult symptoms and situations; acquire information on community resources; and receive assistance with advocacy and emotional support.

While past anthropological inquiries of mental illness have emphasized context and how individuals interpret their experiences, these studies have prioritized the subjective experience of the ill individual. As such, they have underemphasized and underexplored how mental illness can impact family members’ lives and how families co-construct shared perspectives of mental illness, normalcy, and recovery. In shifting the unit of analysis away from mentally ill individuals to their family members, this dissertation illuminates the more social aspects of mental illness, and advances methodological and theoretical conceptualizations of this topic in anthropology.
The dissertation of Linh My An is approved.

Thomas S. Weisner

Yunxiang Yan

Min Zhou

Douglas W. Hollan, Committee Chair

University of California, Los Angeles

2014
This dissertation is dedicated to the families who had so generously shared their stories with me.
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VITA

2004  Bachelor of Arts (B.A.) in Anthropology
      City University of New York, Queens College
      Flushing, New York

2008  Master of Arts (M.A.) in Anthropology
      University of California, Los Angeles (UCLA)
      Los Angeles, California

2006-2012  Teaching Assistant, Teaching Associate, Teaching Fellow, Lecturer
           University of California, Los Angeles, Department of Anthropology
           Los Angeles, California

2012-present  Writing Consultant
               Columbia University, Writing Center
               New York, New York
Chapter One: Introduction

* * * * *

Interlude

Paula’s car pulled up to the curb in front of a red brick building on a quiet side street in New York City’s Manhattan Valley neighborhood, nested in the middle of the posh Upper West Side and Morningside Heights where Columbia University is located. To the west is the Hudson River and to the east is Central Park. It is a short subway ride on the C train to the Museum of Natural History and the bustling restaurants on Columbus Avenue in the Upper West Side. The building looks like any other brick apartment building on the tree-lined street.

I moved to the front seat while Paula got Joyce’s backpack and a plastic bag with Chinese buns (sweet or savory breads typically eaten for breakfast or as a snack) out of her trunk and handed it over to Joyce. I saw the mother and daughter hug and exchange good byes from the rearview mirror. I had spent the day with them both at Columbia University’s annual schizophrenia conference. I had met Paula a few years earlier when she spoke of her experiences as a caregiver at a support group for immigrant Chinese families who provide care to a relative with a mental illness. This was my first time meeting Joyce. She looked like a completely different person from the one I had seen in photographs, taken before she was diagnosed with schizophrenia. She had gained a lot of weight and her long black hair was cut short, permed, and dyed a coppery red color, possibly to hide her thinning hair. She wore glasses and bright red lipstick that stood out against her porcelain skin. Over coffee, Joyce shared with me her plans to
return to school to be a nutritionist, and possibly to move in with her boyfriend, who also has schizophrenia but is high functioning enough to work full time as a social worker. It didn’t seem likely that she could accomplish this. Paula later told me that Joyce’s cognitive function has decreased over the years, resulting in difficulties with focusing and learning new things. My meeting with Joyce left me with a profound sense of sadness and loss. Perhaps, because she had attended UCLA and we are close in age, I identified with Joyce more so than the other ill family members of my respondents. My sadness intensified when I realized the things I often take for granted are not available to her, such as finishing my dissertation, pursuing a fulfilling career, marriage, and caring for children and elderly parents. Whether Joyce actually wants these things is irrelevant; it is more that these options and possibilities are generally off the table from the start.

I can’t imagine how Paula felt when a psychiatrist at UCLA called her and told her Joyce was very sick and needed to come home. Or when she realized Joyce’s condition could be “clinically stabilized,” but that she could not be cured. After that meeting, I secretly hoped that Joyce might be able to return to school and become a nutritionist. However, when I met the mother and daughter for coffee a few months later, Joyce’s mental condition seemed to have deteriorated. I then understood one of my respondent’s cautious approach when she said, ‘With mental illness, the patient goes up and down. You never know.’ Joyce did not mention anything about being a nutritionist, but instead talked about moving to Seattle and how the slower pace of life was a better fit for her. Paula opposed the idea, because Joyce ‘will have to apply for disability and public health insurance again. She can’t do this on her own. She will be off her meds and on the streets. I won’t pick up and change my entire life again to move to Seattle.’ I asked Joyce what would happen with her relationship (she had moved in with her boyfriend
against her mother’s wishes) if she did move. She explained that she suspects her boyfriend had cheated on her with another girl, and also told me that her sister had slept with her boyfriend behind her husband’s back. Joyce is adamant that she heard them having sex. I sensed Paula’s embarrassment when Joyce called her sister a slut and immoral, and she quickly interjected, explaining to me that it was simply not true. Paula later clarified that Joyce has auditory hallucinations and sometimes has difficulty distinguishing what is real. Joyce’s memory has also worsened in the last few years, and she has been telling people her mother locked her out of the house and that is why she has a mental illness. In actuality, Joyce was already diagnosed with schizophrenia when Paula took the house keys away from her because she was bringing homeless people back to the house.

This dissertation is about immigrant Chinese women like Paula, whose lives are thrown into disarray when a family member is diagnosed with a mental illness, and they assume the role of a caregiver. More broadly, it examines how individuals “try to grasp what and who they are, (and) could be” (Parish 2008:ix) when they encounter disruptive events that fall outside of their experiences and expectations of life. It is in this reflective process that they rework their understandings of the past, present, and future, and learn to cope with or to exist in their circumstances.

* * * * *

Research Objectives

Since the US deinstitutionalization movement in the 1950s, the responsibility of caring for mentally ill patients has shifted from professionals and psychiatric institutions to community
treatment centers and families (Jenkins 1988, Tessler and Gamache 2000). There were a number
of factors that contributed to this transformation in the delivery of mental health services. First,
historically, most psychologists and psychiatrists worked in state mental hospitals, but during
WW II many began practicing in military hospitals (Lefley 1996). There was an urgent need for
clinicians to psychologically screen military candidates, and to treat war-related psychiatric
illness in soldiers and return them to combat as soon as possible. What these practitioners
discovered was that many individuals were able to get better with short-term inpatient care,
which prompted them to question whether long-term institutionalization was necessary or even the best treatment option. Second, social criticism increased in response to revelations of
deplorable conditions in asylums, inpatient abuse, and admission criteria that were often arbitrary
and inhumane (Lefley 1996). Mental health advocates and scientists argued that
institutionalization, rather than being therapeutic, could increase dependency and dysfunction in patients. Furthermore, the introduction of a new generation of anti-psychotic medications
successfully stabilized many inpatients who had been unresponsive to the earlier anti-psychotics.
This enabled individuals to reside in the community while they continued to be treated in
outpatient centers (Lefley 1996). Third, mental health advocates found support from fiscal
conservatives in the federal government who were searching for a low cost alternative to long-
term custodial care (Lefley 1996). The shift to community treatment was reinforced with the
passage of the Community Mental Health Act of 1963, which spurred large-scale reductions in
institutional beds and the closing of psychiatric hospitals (Lefley 1996).

Finally, the deinstitutionalization period marked the beginning of a trend in seeing families not as causal agents of mental illness, but as potential allies in providing treatment
(Marsh and Johnson 1997, Solomon 1998). In the previous era of asylums, families were
initially seen as incompetent in protecting the patient from societal stress, and then later on, as a contributing factor to mental illness (Terkelsen 1990, Lefley 1996). Therefore, putting individuals in asylums to separate them from their families was a routine part of treatment, and families were often ignored or not informed of their relatives’ conditions by clinical staff (Terkelsen 1990). When mental health services shifted to community settings, many families were not prepared to take on their new roles as caregivers, which often came with various stressors and burdens. Fortunately, as families gradually became the de facto caregivers of relatives who were discharged into the community, mental health professionals began to establish more collaborative relationship with them.

Despite this change in professional attitude, many families were increasingly dissatisfied with how their relatives were being treated, the lack of communication between themselves and clinicians, and the enduring bias shared among many mental health professionals that the family environment contributed to the mental illness (Shetler 1986). This led to the emergence of family advocacy and support groups that provided support as well as opportunities to share experiences. In 1979, these grassroots support groups met in Madison, Wisconsin, and formed a national coalition of independent groups, the National Alliance for the Mentally Ill (NAMI) (Shelter1986). NAMI, which remains influential today, has contributed to the massive expansion of local support groups, and spearheaded many of the legislative changes in mental health through its advocacy efforts (Solomon 1998).

In the last few decades, there has been a plethora of scholarly work that examines families’ experiences as caregivers to relatives with a severe and persistent mental illness. The term “mental illness” itself is used to describe a wide range of diagnoses and conditions. Many people who have received a diagnosis of mental illness and may have even been hospitalized at
various times, are nevertheless able to function in daily life because they are mostly asymptomatic. My respondents’ family members, on the other hand, have severe and persistent mental illness that requires regular help from caregivers. Harriet Lefley, one of the pioneers in family caregiving and mental illness research, describes adults with severe and persistent mental illness as:

a population of functionally impaired adults with periodic needs for crisis stabilization and hospitalization and with ongoing needs for outpatient care and long-term rehabilitation…These individuals have been ill for over a year—most have been ill for many years—and they are disabled in major areas of living. They are typically unable to fulfill societal roles normally expected of persons their age, physical intactness, and intellectual capacity. This is the population most likely to be involved with family caregiving. (1996:4)

Building on these earlier works, my dissertation project explores the experiences of middle-aged and elderly immigrant Chinese women in New York City who are caregivers to relatives diagnosed with severe and persistent mental illness. The majority of my respondents also attend a monthly support group for Chinese families who have a relative with a mental illness. With few exceptions, most of these women are in the lower socio-economic strata, speak limited English, and receive some kind of public assistance, such as food vouchers and Medicaid. The sample consists mostly of mothers and some sisters.

The dissertation examines how cultural ideals, the individual particularities of respondents and their relatives, and their interactions with institutions affect family caregiver roles. In doing so, my dissertation addresses several more specific research questions, providing a clearer picture of immigrant Chinese women’s experiences with mental illness. What salient cultural ideas affect their interpretations and responses to their relatives’ mental illness? How do mothers and sisters differ in their level of involvement? How does English fluency and
participation in a family support group affect respondents’ abilities to cope? What are the experiences of these women’s interactions with the mental health system and other government bureaucracies? How do gender and aspects of severe and persistent mental illness create similarities and differences in caregiving experiences cross-culturally? Given my small convenience sample of women who chose to stay and provide care to their ill relatives, the generalizability of my findings is limited. However, it is a significant first step to understanding the intimate lives of immigrant Chinese families who have a relative with a mental illness.

Below, I situate my research in two bodies of scholarly work to clarify how my work speaks to them. Then I present a brief historical overview of Chinese immigrants in the US to show how macro-processes affect the composition of families and the resources they have available to cope with stressful situations. Since most of my research participants are working class immigrant women, I also discuss how the need for economic survival increased their status within their families, but also resulted in a negotiation of gender roles and less family time between parents and children. This discussion clarifies how my respondents differ from their predecessors and contemporaries, and provides the context to understanding their lives. Finally, I briefly outline the following dissertation chapters.

**Studies on Families and Mental Illness**

There is an abundance of research that consistently shows the caregiver role is associated with various stressors and burdens. However, most studies on mental illness and families focus on Westerners (Aschbrenner et al. 2009, Møller et al. 2009, Van Der Voort et al. 2007, Karp 2001, Smith and Greenberg 2008). They have also been predominantly quantitative (Ryder et al. 2000), in that specific variables are identified and measured with research tools, such as surveys
and questionnaires, with minimal attention to participants’ perspectives and actual experiences. Moreover, these studies often highlight only the negative aspects of caregiving (Kung 2003, Wong et al. 2004; for positives aspects of caregiving see Schwartz et al. 2002, Onwumere et al. 2008, Veltman et al. 2002) and the primary caregiver is usually the only relative recruited (Kung 2003, Ryder et al. 2000). The impact of the illness on various domains of the caregiver’s life is rarely examined.

It is surprising that there is so little research on immigrant Chinese families and mental illness in the US, considering how central families are to the prevention and management of stressful situations. Families are often involved in defining the disorder, outpatient consultation, record keeping, discharge and continuing care (Phillips and Pearson 1996). In addition, other family members usually contribute to the care of the patient besides the primary caregiver (Kung 2003). Similar to other minority families in the US, Chinese patients tend to reside with kin before and after hospitalization for mental illness (Jenkins 1991, Guarnaccia and Parra 1996, Milstein et al. 1995, Birchwood et al. 1992, Snowden 2007). Even individuals who are not the primary caregiver, generally feel obligated to provide housing for relatives with mental illness or to put their family’s needs for help with caregiving before their own needs (Chen 2001).

Despite common reports of experiencing embarrassment, shame, frustration, and anger many Chinese caregivers reported they would still continue with their caregiving role (Chang and Horrock 2006). This resolve to provide care may be connected to notions of wellbeing. Research in cultural psychology has shown that wellbeing in Chinese individuals is tied to their ability to fulfill societal obligations and to maintain harmonious relations with others and their surroundings (Christopher 1999, Lu and Gilmour 2004, Hsiao et al. 2006). Similarly, studies have found that in cases where individuals fail to fulfill obligations, especially family
obligations, they often exhibit symptoms of depression and anxiety (Mak et al. 2011, Chen et al. 2009, Chen et al. 2006, Hsiao et al. 2006).

Preliminary evidence also indicates social disruption within the family is a prime motivator for families to seek mental health services (Abe-Kim et al. 2002, Kung and Lu 2008), suggesting families may play a critical role in pathways to treatment seeking. It seems that the most stressful patient behaviors are those that prevent the patient from performing their familial and work roles (Hsiao et al. 2006). Therefore, symptoms of psychosis are less tolerated than ones related to depression or anxiety disorders, which may be more culturally acceptable (Okazaki 2003, Althsuler et al. 1988, Parker et al. 2001). In addition, lack of success in school or work is particularly upsetting because these achievements elevate individual and family status in Asian societies (Uba 1994). The value of education is also emphasized, because many Chinese immigrants see it as a major route to self-reliance and success in the US (Chao 1995). Hsiao et al. (2006) found that when patients failed in achieving success and bringing honor to the family, they saw themselves as unfilial children. Acculturation seems to be another mediating factor in help seeking. More acculturated Asian Americans are more likely than less acculturated ones to seek help, to tolerate the stigma of seeking professional psychological help, and more willing to discuss personal problems with a psychologist (Atkinson and Gim 1989, Kung 2003). However, a limitation with many studies that detected a connection between acculturation and mental health utilization is that they often use standardized acculturation scales, which don’t tell us much about meaning and intent, and what individuals actually do in their lives.

et al. 2008, Huang et al. 2003, Li et al. 2007, Ran et al. 2003, Sung et al. 2004, Wong et al. 2004, Yen and Lundeen 2006). However, like the studies with Western research participants, this body of work also tends to use quantitative approaches. My research contributes to this area of work, because it uses qualitative and longitudinal approaches to obtain insights to the meanings behind individuals’ actions. In doing so, it uses previously identified categories to guide the research, while still providing flexibility to discover new themes that emerged in process.

**Mental Illness in Anthropology**

An anthropological approach with an emphasis on experience and meaning can complement these quantitative studies on families of the mentally ill. Early in the history of anthropology, there were researchers who used family life to understand the social dimension of mental illness (i.e., Bateson et al. 1956, R.D. Laing 1969, Henry 1965). They shifted the emphasis away from intrapsychic conflict to interpersonal dynamics. However, since then, the majority of anthropological work on mental illness has centered on patients’ experiences (for exceptions see Scheper-Hughes 2001, Jenkins 1991). Previous research examined how social structures and cultural notions of illness and abnormality affect the everyday lived experiences of patients and the way they respond to these externalities (Estroff 1981, Obeyesekere 1981, Kleinman 1988, Kleinman and Good 1985, Jenkins and Carpenter-Song 2008, Jenkins and Carpenter-Song 2009, Luhrmann 2007, Luhrmann 2008, Desjarlais 1997, Desjarlais 1999). There has also been a rise in cross-cultural psychiatric research that examines the cultural basis of mental disorders (Guarnaccia 1997, Kirmayer et al. 1995, Neal and Turner 1991, Weisman 1997, Brown et al. 1972, Vaughn and Leff 1976, Jenkins and Karno 1992, Lopez et al. 1999, Jenkins and Barrett 2004, Kirmayer et al. 2007).
My research builds on these earlier works by expanding anthropological inquiries to the psychological and social world of family members of individuals with mental illness. It is not only the identified patient but also “the suffering community that surrounds the patient—those intimate others like parents, siblings, and close friends who also suffer and whose lives are unutterably altered by the fate of the illness” (Mattingly 2010:166). For example, one mother in my study was forced to move out of the bedroom that she shared with her schizophrenic son. He was afraid to leave the room because of his paranoid delusions, so he urinated in a pail, defecated on his clothes and then discarded the soiled clothing in the trash. This mother removed all her clothing from the closet in the bedroom, and had to sleep on the couch in the living room.

My dissertation also draws from anthropological research on individuals’ experience of kinship and intimate household life (Hollan and Wellenkamp 1994, Yan 2003, Schneider and Waite 2005, Arnold and Lang 2007), and families coping with chronic illness, developmental disabilities, and behavior problems (Mattingly 2010, Raghavan et al. 1999, Skinner and Weisner 2007, Weisner 2009). These studies employ an experiential and holistic framework in their understanding of families’ beliefs and adaptations within sociopolitical worlds. The research on illness and disability, in particular, places emphasis on how families coproduce meaning and practices, their responses and adaptation to disabilities, and examine how larger institutions and inequities shape families’ understandings and experiences (Skinner and Weisner 2007:302). More importantly, this framework helps me shift the research focus away from stress and coping models that look for responses to challenges or threats to the everyday lived experience of my respondents.

**Background**

11
An ethnography about immigrant Chinese families is also a story about their migration and settlement in the US. Geographical relocation is associated with a host of changes, including the composition and structure of families that shape kin relations. Essentially, this section sets the stage and background that fleshes out my characters. There is great heterogeneity in Chinese communities all over the world. Anthropologists have long questioned the idea of culture as an “an organized set of symbols, resting on distinctive underlying principles and constituting a global reality for those raised in a particular cultural tradition” (Ewing 1990:257-258). Most would also agree that culture does not just exist “in territorially fixed communities and stable, localized cultures,” but is influenced by an “interconnected world in which people, objects and ideas are rapidly shifting, and refuse to stay in place” (Gupta and Ferguson 1997:4).

Despite the heterogeneity of Chinese culture around the world, I employ the “traditional” label as a heuristic device to illuminate the cultural continuities and transformations present in my respondents’ families. This is because there seems to be enduring features of Chinese culture and child-rearing practices found across Chinese societies around the world. Wu and Tseng (1985) identified five common characteristics of Chinese societies: family and collective responsibility; the prominence of the parent-child bond; art of social interactions and importance of social networks; emotional control and moral cultivation; and the value of education and achievement. Bond’s (1991) review of studies that examine how acculturation impacts Chinese immigrants in the US is consistent with Wu and Tseng’s (1985) claim. In addition, Chung (2006) indicates that Chinese immigrant parents often perceive their children’s academic achievement by their children as a family goal and as a way of achieving honor and status. Sue and Sue (2003—as cited in Chung 2006:369) claim Chinese parents and children express love and affection through the former performing caregiving tasks, and the latter submitting to
parental wishes and achieving academic success. I will elaborate more on some of these characteristics, as they arise in later chapters.

Migration History

The 1850s marked the first major wave of Chinese migration to the US with young healthy, working class Chinese men (the coolies) coming to work in the gold mines (Sung 1987, Lee and Mock 2005). Disillusioned with the political and social unrest in China and motivated by an intense desire to migrate these men ignored the imperial decree against immigration and boldly came to the US. They were mainly sojourners from the Pearl River Delta regions who had planned to quickly make money and return home to their families (Sung 1987).

After the gold mining and railroad building was completed there were not many jobs left in the US. The white American working class saw the Chinese as major competitors for jobs and pressured Congress to pass the Chinese Exclusion Act in 1882, which severely curtailed immigration into the US (Sung 1987). Since Chinese immigrants could not return to the US once they leave the country, many of these men chose to stay in the US. The demographics of that time consisted primarily of bachelors. In response to the institutional racism, Chinese men congregated at Chinatowns where they formed fraternal and family associations based on the clan system (Sung 1987). Although these organizations were often based on fictive kinship, they provided unrelated people a way to unite against a hostile society, which can be overwhelming for the unsupported individual (Baker 1979:171).

In 1930, a revision in immigration law allowed wives of Chinese merchants and individuals of Chinese ancestry to join their husbands in the US (Lee and Mock 2005). As a result, the number of single households decreased and family units, consisting of both immigrant
and American-born relatives, increased. These families often owned small businesses, such as Laundromats, and functioned as a productive unit (Chang 2003—as cited in Lee and Mock 2005:303). From 1943-1964, women made up the majority of Chinese immigrants who came to the US (Lee and Mock 2005). The Repeal Act of 1943 and the War Brides Act of 1946 allowed many Chinese men to reunite with immediate family members and bring foreign-born wives and fiancés to the US. However, because husbands were often separated from their families for years, if not decades, they often felt like strangers to their wives and children who had developed very strong bonds in their absence. This period also marked the emergence of trans-Pacific marriages where Chinese men, with the help of matchmakers and relatives, would go to Hong Kong to find wives, who were typically 10-20 years younger than them (Lee and Mock 2005).

Later temporary relief laws further increased the annual quota of Chinese immigrants, but entry was still restricted to a few thousand people because of political and legislative barriers. Beginning in 1949, socialist China closed its doors to the outside world, allowing people neither to come in or out. Chinese students who were not permitted to return to China and Nationalist officials seeking political refugee status came to the US (Sung 1987).

The 1965 Immigration and Nationality Act played a major role in creating the demographic makeup of the current US Chinese population (Sung 1987). The new law significantly lowered the barriers to immigration by increasing the quota from 105 to 20,000 individuals (Loo and Mar 1982:97), emphasizing the reunification of family members and recruiting individuals with special skills or education needed by the US labor force. Therefore, from 1965-1977, most Chinese immigrated to the US as a family unit (Lee and Mock 2005). These families tended to settle in metropolitan areas and resided in Chinatowns or nearby communities. In working class families, both husbands and wives had to work in labor-intensive
and low paying jobs, such as garment factories and restaurants. Since the priority was often economic survival of the family, parents did not spend much time with their children. The majority of my respondents were immigrants who arrived during this period.

Beginning in 1978, the influx of immigrants of Chinese descent came from China, Hong Kong, Taiwan, and countries in Southeast Asia (Lee and Mock 2005). When China and the US resumed a diplomatic relationship, students and professionals came to study in the US and many ended up settling here. Many individuals from Hong Kong, concerned about the 1997 transfer from a British colony to a territory of China, elected to immigrate. Taiwanese parents brought their families over to the US, both because of the political climate and a desire to provide their children with a better education. Refugees of Chinese ancestry from Vietnam, Laos, and Cambodian were also part of this wave of immigration. Adding to this diverse group of immigrants are “astronaut” families (families in which children stay in the US while adults work in their home country) and tech professionals working in Silicon Valley (Lee and Mock 2005). Community-based organizations replaced the role of family associations in helping new immigrants settle. This is because the traditional organizations, which were established in the late 1800s and early 1900s and were often based on fictive kinship, did not have the capabilities to manage the large numbers of newcomers (Sung 1987). And, unlike their predecessors, many new immigrants settled in areas outside of Chinatown (Zhou 1992).

Lee and Mock (2005:306) summarize some of the major shifts in contemporary Chinese families in the US. The number of nuclear families increased while extended families decreased. In addition, the prominence of the patriarchal family system waned, giving way to one where husbands and wives share decision-making. Fathers are no longer expected to be the sole contributor to household income, but share the responsibility with other adults in the home. This
transformation in gender dynamics is reflected in childrearing practices. There is a decrease in the favoring of sons, while daughters, who now receive comparable parental investment as their brothers, are also expected to provide care to elderly parents. The diminished importance of the parent-child relationship is mirrored by a shift from arranged marriages to marriages based on romantic love, reflecting the prominence of the conjugal relationship. Finally, adult children are more likely to leave their natal homes, and children’s academic and professional achievements are a measure of successful childrearing.

Status and Gender in the Working Class

Since my dissertation project focuses mainly on working class Chinese immigrant women who came to the US with their families, I feel it is important for the reader to understand the economic role immigrant women from this social class play in their families. Therefore, in this section I discuss these women’s motivations to join the labor economy, and how their participation changes their self-perceptions and consequently their role in the family. This in turn provides a context of for how my respondents cope with mental illness and the demands of providing care.

In general, traditional Chinese families were patriarchal and the individual existed as a representation of the family who would continue the family line (Baker 1979). Sons were responsible for providing care to elderly parents, producing male heirs, and ancestral worshiping. Although sons enjoyed more privileges than daughters, both were responsible for the production of sons. Daughters were also expected to provide support through paid and unpaid labor, to their natal family and their husband’s family, and were responsible for all domestic work (Zhou 2009). They stayed in their natal homes until they got married and were transferred to their
husbands’ households. Essentially, a woman’s “life is tied to the family to which she belongs, and her own identity is buried in her family” (Zhou 2009:177). The laws and the religious sphere worked to support a Generation-Age-Sex hierarchy that held families together (Baker 1979). In return for their submission to their families, individuals gained economic and political security. Under the traditional inheritance system, sons got equal shares of the estate, and if the sons work together their profits will be more than if they left with their own share. Not only could families pool their labor together, but they could also diversify the type of economic activities they engage in. With economic power came political power. In certain areas of China where lineages and clans were common, these groups employed a similar strategy, uniting through real or fictive kinship to compete with other groups (Baker 1979).

While in modern times, the extreme patriarchal system described above has been rejected. However, there is still a cultural expectation that immigrant Chinese women, specifically from the working class, put their families before themselves (Zhou 2009). They are expected to help their families adjust to life in the US, to send remittances home, petition for their relatives to come over and to help them adjust once they arrive. For most of these women, such goals and obligations are fulfilled by working outside the home (Zhou 2009). They are also more willing to take lower status jobs than their husbands (Sung 1987) and often work as nannies or in garment factories. Even though immigrant Chinese women participate in the wage economy and often contribute significantly to the household income, they are still responsible for the majority of the domestic work and childcare. This is why garment factory jobs were once especially attractive for these women—the flexible nature of the work allowed them to continue performing their domestic duties (Zhou 2009). For example, a woman could take one hour off to pick her children up from school and then return to work. Some bosses even allowed female
laborers to bring their children to work (Zhou 2009). The children would do their homework at the factories while they waited for their mothers, and were kept out of trouble and watched over by the other female garment workers. According to US standards, these women’s low wages and work environment may seem exploitative, but they do not see it that way. This is because they compared their current job and wages to previous jobs and salaries in their motherland, where they made a lot less money for the same amount of work. Furthermore, like the pooling of labor in traditional Chinese society, Chinese immigrant women’s garment work has to be seen as “part of a collective effort to fulfill family obligations, helping the family move ahead in the U.S. society…a crucial part of the family struggle for upward mobility,” and not simply as an “individualistic drive for social mobility” (Zhou 2009:183). When the garment factories started closing down in the mid-1990s, many of these displaced female laborers became home aid attendants. After undergoing training, the women were placed in homes to help Chinese clients (usually elderly individuals) with housework, cooking, food shopping, and daily self-care tasks (combing hair, showering, etc.). Although they were not paid a lot, their job was unionized and they received health insurance and other benefits for their husbands, children, and themselves. One of my respondents, a retired nursing aid, receives health insurance for her husband and herself through her union.

As Zhou (2009) has noted, the income that these immigrant Chinese women contributed to their household was essential for the survival of their families, especially in the early period after immigration. As a result of their monetary contribution, these women experienced an increase in their status within the family, had more say in family decisions, and developed “a sense of confidence and self-fulfillment that they might never have experienced in traditional Chinese society” (Zhou 2009:178). She (2009:178) provides quotes illustrative of this self
confidence: “My husband dares not look down on me; he knows he can’t provide for the family by himself.’ ‘I do not have to ask my husband for money, I can make my own.’ ‘I help pay for the house.”

Although their salary and the benefits associated with their jobs improved their self-confidence and their family’s economic wellbeing, it also complicated cultural ideals of gender roles, because it directly challenged the cultural expectation that men are the breadwinners of the family (Sung 1987). This can put a strain on the conjugal relationship at a time when the husband’s self esteem is low and the family is still making adjustments. The distress may be higher for husbands who were wealthy or educated in their home country, but are unable to find commensurate employment after immigrating to the US. I remember when my roommate’s nanny haughtily commented how her husband does not have much say in family decisions because he does not have a stable job. Though her husband had been a successful mechanic in China, he had difficulty finding stable employment in the US. Throughout their fifteen years in the US, he has worked in only a handful of jobs and it was mainly her income as a nanny that supported the family. The following incident also highlights the connection between money, power, and female status in families. I mentioned to a family friend what a great husband she had, because he mopped the floor on his day off. This was her response: ‘Of course he should do that. He’s not making tons of money and supporting me. I still have to go to work every day.’

I believed immigrant Chinese women’s status in their natal families also improved, because of their economic contributions to their family of origin. Oxfeld (2010) has observed an increase in status among daughters in a village in Guangdong, China. These women found employment outside towns and cities, and used their salaries to supplement the livelihood of their parents, who more often than not, lacked significant savings or pensions. Even though they
are married, they still have a major say in family decisions and their parents feel obligated to help them in nonmonetary ways, such as providing childcare. Since current immigration laws gives priority to reuniting immediate family members, immigrant Chinese women who marry men in the US, not only provide monetary support to their families of origin, but also act as a link to the chain of trans-Pacific migration. This is what a few of my respondents and friends’ parents did. They were trans-Pacific brides who were introduced to their husbands through family and friends. Once settled, these women started the process to sponsor other relatives—one friend’s mother petitioned for her parents and eight siblings to come to the US. Although it is illegal, some paid legal residents of the US to marry their family members, which reduces the processing time. Once the family member gets naturalized to become an American citizen, he or she can begin the divorce process and start petitioning for other family members to immigrate to the US. I know one woman who convinced her son to marry (it was a fake marriage) his maternal cousin, so that the girl could come to the US. This woman was not particularly fond of her niece’s father, because he was selfish and did not take very good care of their elderly mother, even though this woman would send monthly remittances back to them. However, she still felt obligated to help her brother, as her following comment illustrates: ‘That was the least I can do for him. Once my niece gets her green card, she can petition to have her parents come to America on her own.’

Despite the improved status of Chinese immigrant women, there are negative impacts that immigration has on the parent-child bond. Chinese families generally immigrate to the US as a unit, but when separation occurs it is most likely because the father comes to the US first to settle in, and then the rest of the family joins him (Suárez-Orozco et al. 2002). During this time the wife takes on both parental roles, acting as the head of the household while she develops
deep emotional bonds with the children. Therefore, by the time the wife and children come to the US, the father often feels like a stranger to his own family (Sung 1987). In most societies, the process of socialization is from parent to child, but in the US, many Chinese immigrants rely extensively on their bilingual children to guide them through the interactions with the dominant culture, so there is a reversal of hierarchies (Lee and Mock 2005). Furthermore, parents work long hours so they do not see their children very often. If the family is not fortunate enough to have a grandparent around, the children are usually left alone at home.

There are class differences in the development of alienation between immigrant parents and their children. Qin (2006) uses two family case studies (one working class and one upper class) to demonstrate the host of developmental, immigration-related, and cultural factors that lead to growing alienation between parents and children of different class backgrounds. Children in all societies separate from their parents and shift their focus from family life to peers during adolescence. This was true for both families in her study. However, immigration-induced factors seem to have a bigger impact on working class families and consist of 1) separation (usually one parent comes to the US and rest of the family comes over at a later time); 2) lack of time together (parents usually have to work long hours); and 3) language barriers (children are losing their native language much faster than their predecessors). Cultural factors, which are more of an issue for the upper class family, include 1) parallel dual frame of reference; and 2) high academic pressure. The conflicts stem from a dissonance in acculturation rates, because parents compared their children’s behaviors to what is expected in China and children compared their parents’ behavior with the parents of their American peers. Qin (2006) asserts that, while pressure from parents to excel in school may motivate children in upper class families, it also causes a lot of tension and decreases emotional closeness. While this is relationship between
pressure and tension may be true, I believe high academic pressure is not restricted to upper class Chinese families, and can also be prevalent in other classes.

**Chapter Outlines**

In chapter 2, I reflect on being a native ethnographer, focusing on how that has affected my access to research participants, and the nature of my relationships with key respondents. These reflections are woven into a discussion of the strengths and weakness of my methods to give a context for how the data was collected. At the end of the chapter, I provide brief bios of key informants to whom I refer to throughout the dissertation.

In chapter 3, using Karp’s (2001) qualitative study of Euro-American family caregivers as a comparison group, I examine Chinese ideals of family obligations, and clarify variables that affect the enactment of these obligations. Both groups of respondents were similar in that they reported burdens and stressors related to caregiving, and female relatives tended to be more involved. In addition, Euro-American and Chinese respondents tend to delay labeling erratic behaviors as manifestations of a mental illness. Since the onset of their family members’ psychiatric disorders is generally during adolescence and young adulthood, many respondents attributed the behavior to the stress and confusion of maturing into an adult. The delays in the Chinese cases also seem to reflect caregivers’ unfamiliarity with a biomedical model of mental illness and efforts to protect an ill family member from stigma. It is in the recognition of the illness’ chronicity, and the necessity of long—term care that we start to see differences in both groups. The Euro-Americans expressed concerns of letting their relative’s illness consume their lives, because they felt that would be indicative of a pathological relationship of codependency. Consistent with the literature, the Chinese narratives had fewer words that convey emotions, and
they tend to express care in more practical ways, in particular with food. Chinese respondents seem to have a higher tolerance for disruptions in their lives and did not pathologize their involvement with a family member. This is most likely because positive appraisals of the self are tied to fulfilling obligations to an ill family member. However, the enactment of obligations is constrained by other factors, such as symptomology that is difficult to manage, and the availability of social and financial resources.

In chapter 4, I illustrate how caregiving is a contextually based practice. Financial resources, severity of illness, competing family responsibilities, and different acculturation rates among family members impact how respondents understand and enact caregiving. Caregiving also evolves with changes in family and individual life cycles, and with the progression of the illness. In general, Chinese siblings, compared to Western siblings, are more likely to replace parental caregiving after parents have passed away, and when there is an absence of a spouse or children to assume the caregiver role. Since most of their family members have been ill for years, many respondents have accepted that they will never accomplish things that persons of their age, gender, and physical intactness are able to do. Using the literature on the socialization of Chinese children, I argue that because their ill relatives often cannot achieve milestones that mark their passage into adulthood, such as marriage, children, and stable employment, the interactions between my respondents and their ill family members resemble a parent and a small child, especially in the correction of behaviors in public.

In chapter 5, I identify challenges my respondents encounter while they help their relatives obtain or continue treatment, such as the horrible side effects of some medications, laws that make involuntary treatment difficult, premature discharge of patients, and clinical staff’s refusal to include them in treatment planning and implementation. While these conflicts also
affect families in other racial and ethnic groups, my respondents’ lack of English fluency and unfamiliarity with the mental health system makes coping more difficult, especially in light of the lack of standardization and quality control in mental health translation services. I conclude the chapter with a discussion on the strategies respondents use to work the “system.”

In chapter 6, I focus on the Chinese family support group as a source of social and practical support for my respondents. Like other support groups, participants learn about the causes and treatment of mental illness, the availability of community resources, how to cope with difficult symptoms, and to have their personal experiences validated from hearing stories similar to their own. This is done in a linguistically and culturally sensitive environment. More importantly, the group is a source of social capital to help participants navigate the mental health system, while also acting as leverage in advocating for services. However, there seems to be a discrepancy in how volunteers and family participants see each other’s roles. Using a more professional gaze, volunteers view family participants as clients. In addition, adopting NAMI’s peer model, they encourage participants to lean on each other for support and to play a larger role in leading the group. On the other hand, employing a Confucian model of teacher and student, family participants see volunteers as authority figures who are exemplary models because of their intellectual and moral superiority. The volunteers’ moral authority is further reinforced by their choice to work in the mental health field and their willingness to volunteer time from their busy lives for a charitable cause.

Finally, in chapter 7, I summarize the major findings and discuss directions for future research.
Chapter Two: Personal Relationships and Fieldwork

You will probably look for academic jobs after you graduate. But if you’re interested in mental health, you really should maintain community contacts, or you won’t really know what’s going on out there. You don’t want to be an “armchair anthropologist.”

(Thomas, a support group volunteer and a clinician)

My dissertation project is designed to allow for adjustments in the research questions and methodologies as I learned more about my respondents’ own stated concerns. My purpose is to tell a story that is not based on my own theoretical priorities, but rather, on my respondents’ views, concerns, and dilemmas. In this chapter, I explain my methodology and also reflect on how being a native anthropologist affected my relationships with respondents, in order to contextualize how the data was collected, analyzed, and reported.

The term “native” implies an intimate and privileged perspective that results in a more authentic understanding of a culture (Narayan 1993). A “regular” anthropologist, on the other hand, is a “foreigner,” studying and learning about an alien culture, which often requires an immersion into a world that is drastically different from what the anthropologist had previously known. In a sense, this dichotomy between “native” and “regular” is problematic, and scholars have questioned whether anyone can be considered an authentic insider (Narayan 1993, Aguilar 1981, Messerschmidt 1981). This is because of the inherent heterogeneity in any culture, and the multiple ways we define ourselves—class, education, gender, sexual orientation—that are constantly in shift. Rather than getting into the details of this debate, I focus on my personal experience studying my own culture and how that has affected my relationships with respondents.
Like many of my respondents, I grew up in New York City, speak Cantonese fluently, and come from a working class immigrant family. There was a slight discomfort in the initial stages of fieldwork, but nowhere near the cultural shock experienced by anthropologists studying a completely foreign culture. I did not have to learn a new language or how to navigate the NYC subway and bus system. I already knew many of my respondents’ cultural idioms, traditions, and customs from attending Chinese school\(^1\), and because growing up, my family spoke Cantonese at home and continued to practice many of these traditions. The downside of being an “insider” is that it is easy to take things for granted. I felt, at times, less likely to ask for clarification, because I assumed I knew what my respondents were talking about, since we have a shared cultural identity. This can result in misinterpretations or missed opportunities to explore certain themes. In addition, being an “outsider” provides a comparison group (i.e., Euro-American culture) that helps one identify cultural traits particular to Chinese families.

However, some amount of distance was possible, because all my respondents were from East Asia (Hong Kong, China, Taiwan). Although ethnically Chinese, my parents and their siblings were born and raised in Saigon, and had lived through the Vietnam War. Several of my aunts and uncles were part of the second wave of boat people to leave that country after the war. In addition to the unique political circumstances that my family came from, the anthropological gaze created further distance between my respondents and me. Reviewing the literature on family caregiving also helped to develop an analytical perspective. First, I used the studies about Euro-American families, particularly qualitative ones, to establish a comparison group. Second,

\(^1\) Many Chinese parents in the US send their children to Chinese school, so they can learn about Chinese culture and maintain their heritage language. The schools are usually on the weekends and last between 3 to 4 hours.
I used two bodies of existing literature—how mental illness is viewed in Chinese culture and studies on kin relations in Chinese families—to corroborate my findings.

Despite these potential problems in being a native anthropologist, I do not think I would have gained as much access to my respondents’ lives if I did not look like, speak like, and act like them. As a Chinese-American psychologist, who works on bereavement in the Chinese elderly population in NYC, shared: ‘When I work with clients that have just experienced a lost, I don’t say, “Sorry for your loss.” Instead I say a Chinese phrase, which kind of means cut off your feelings and smooth sailing. I don’t ask them how they are feeling. I communicate support through asking about their day, how they are sleeping, and their diet. I gain credibility with clients by acting in culturally appropriate ways.’

“Credibility” can also be established by speaking a common language. A few months after I started observing the support group, a prominent Chinese-American academic came to recruit participants for his study on Chinese families and mental illness. This researcher, who is more fluent in English, generally has Chinese-speaking research assistants to recruit, conduct interviews, and transcribe for him. On that night, his student was running late, so without a prepared script or time to practice, the researcher explained the goals of his study, the nature of the participation, and the eligibility requirements in very broken Mandarin. I heard some family members chuckle at his poor language skills. As well, a man with whom I had been chatting with prior to the start of the meeting turned to me and expressed his amusement that the researcher is Chinese but cannot speak the language.

The laughter was harmless, reflecting Chinese immigrants’ stereotypes of ABCs (American-born Chinese) as people who are naïve and unfamiliar with their heritage culture and language. However, things can quickly get confrontational in higher stake situations. At the end
of one support group meeting, a veteran volunteer, Wendy\(^2\), introduced a new volunteer, Nikki, who was completing her MFA in non-fiction writing. Wendy asked her to tell the group something about herself, but Nikki turned down the request, probably because she was embarrassed she could not speak Chinese fluently. However, her refusal to talk made some family members upset and raised suspicion regarding her motivations for being a volunteer. One of my respondents raised her hand and asked Nikki in English: ‘I don’t mean to be rude, but if you don’t speak Chinese, what can you do as a volunteer? The things we talk about in the meeting are very sensitive and personal. How do we know you won’t use it for your own writing?’ At this point, Wendy stepped in and explained that Nikki is editing the English translations of the group’s quarterly newsletter, so it did not matter whether she spoke Chinese or not.

I later spoke with this respondent and she commented, ‘She can’t even speak Chinese! How can she help us if she can’t even communicate with us? You know, what really pissed me off was that she did not want to introduce herself. It’s okay if she introduces herself in broken Chinese, she can even speak English and have someone translate for her. She just seems shady. It’s okay if she wants to use our group for her Masters thesis, but she should be up front about it.’ Another participant at the support group echoed this respondent’s concerns when she reached out to a different volunteer, Ling, to find out more about Nikki’s background. Later, when Ling realized Nikki majored in non-fiction writing, she too seemed a little uncomfortable with her being a volunteer, and suggested protocol to ensure that the privacy and confidentiality of family members are protected.

\(^2\) All names of volunteers and research participants are pseudonyms.
Through the above anecdotes, I want to open up the conversation to the importance of establishing credibility as a researcher and developing bonds of reciprocity with Chinese respondents. It is very difficult to recruit minorities, in particular immigrant women (Neufeld et al. 2001), to be study participants in mental health research. In her speech at the New York Coalition for Asian American Mental Health’s 2013 conference, Irene Chung, a Chinese-American, who is an associate professor at Hunter CUNY and a practicing clinical social worker, points out that Western models of therapy may be incompatible with specific Chinese cultural traits. She suggests Western-trained clinicians consider a more relational approach when working with Chinese patients. A few points she mentioned that I feel are the most relevant for developing rapport with my respondents are: 1) intuition about others’ needs and concerns; 2) mutuality and reciprocity; 3) discretion about disclosing family information to strangers until they are incorporated into the kinship network; and 4) emphasis on practical help.

I believe my ability to understand and enact this cultural knowledge helped my respondents feel comfortable enough to share their lives with me. Essentially, my respondents saw me as an “insider.” At first, conversations with my respondents were awkward because they were trying to size me up, but as they saw me more and more at the family support group meetings they realized I was harmless. I was also able to develop close relationships with my respondents because I was a bilingual volunteer at the family support group. Being a volunteer projected a public image of me as a “good” person. In general, attendees of the family support group perceive individuals that enter the mental health field as kind and compassionate people, because they chose to do it. Volunteers in mental health were also associated with these positive characteristics, because not only did they choose this type of work, they don’t receive monetary
compensation. Furthermore, the veteran volunteers, with whom the respondents already have established strong relations, vouched for me and endorsed my research.

Since I was a bilingual volunteer and my job was to help them, family members felt comfortable asking me for practical help (more so with non-English speakers), such as translating for them at government offices or explaining the content of English letters. My parents don’t speak English and growing up my siblings and I often had to be language translators and cultural brokers; therefore I understood firsthand the frustration and anxiety immigrants often feel when they cannot communicate with staff at government agencies, and easily assumed this interpreter role. Because I was a student, I was also more available to help than other volunteers who worked full time. It is through this practical assistance and the moral debts incurred to me that foster bonds of reciprocity. As I became part of their personal networks, so they became increasingly comfortable sharing their experiences, some of which were shameful and heartbreaking. Again, I am not suggesting that an anthropologist of a different race or background cannot gain these respondents’ trust, I merely want to point out how I was able to capitalize on being Chinese.

I cannot emphasize enough how important personal connections have been in my study, particularly in the recruitment of research participants in phase one. When I asked one respondent how she heard about my study, she explained that I had given a brief description of my research project at her sister’s day treatment program. One of the staff members, who her sister really likes, encouraged her to participate in the research, and so her sister called and asked this respondent to join. This respondent had reached out to me twice before. The first time her message got cut off, so I did not get her contact information and could not return her call. Fortunately, she called back a week or two later. About half of my other participants in phase
one were recruited with the help of Mary, a veteran volunteer at the family support group. As a
director of a day treatment program in Chinatown, Mary facilitated a support group for the
families of her clients, who suffer from severe and persistent psychiatric disorders. One day
Mary called, asking for clarification of my recruitment criteria, research procedures, and my
target sample size. Knowing that it is very difficult to recruit Chinese subjects for mental health
research, I said I would take anyone who matches the criteria and is willing to participate. She,
again pressed for a concrete number, and I blurted out a figure that was roughly half of my target
sample size. While I was perplexed by her request at the time, I later realized Mary asked for a
number because she knew she could deliver; the female caregivers at her support group trusted
her deeply and Mary knew she could convince a good number of them to get involved in the
study. Although these women did not personally know me, they wanted to help Mary, who
undoubtedly has been a great help to them.

I had similar experiences with respondents in phase two. By the time, I had asked them
to join my study, we had moved beyond mere acquaintances and had established a certain level
of trust. Everyone signed the informed consent form without reading it through (all respondents
were given copies of the consent forms to take home, in case they decided to review it later). On
one occasion, I asked one mother why she did not even look over the form before she signed it,
and she replied that she knows I am a good person, and I would not do anything to hurt her.

**Research Design**

*Field Site*

Research was conducted for three consecutive years in New York City, which was
chosen as the field site for two reasons. First, there is a large population of Chinese and Chinese-
Americans there; indeed, over half of the Chinese residing in the US live in three cities: NYC, Los Angeles, and San Francisco (as cited by Zhou 2009:47). The Chinese communities in NYC share similar patterns of ethnic business development, immigration, and middle class suburbanization with these other cities. (Zhou and Kim 2003). Therefore, the findings in this study may also be applicable to Los Angeles and San Francisco. Second, the family support group I mentioned earlier is one of the few groups in the US that is not affiliated with a treatment center and is carried out in Chinese (mostly in Mandarin, but accommodations are made for Cantonese speakers who do not comprehend or speak Mandarin), which allowed me to investigate how community-based organizations (CBOs) affect immigrant caregivers’ ability to cope.

Research Population

Most of the participants, in both phases, are in the lower socio-economic strata and receive some kind of public assistance, such as food vouchers, housing subsidies, and Medicaid. They are predominately mono-lingual speakers of Cantonese. The sample consists of mostly mothers and some sisters that provide care to an adult child or sibling, as they represented the majority of care relationships I encountered in the field. Most of my respondents live in New York City, concentrating in three boroughs, Queens, Manhattan, and Brooklyn. Two live in Staten Island and one lives in New Jersey. As I have noted earlier, there are a few individuals that are outliers in that they are either middle class, or they are middle class and speak English fluently. These outliers own their own homes, but they are similar to my less affluent respondents in that they read, write and speak Chinese proficiently, because most of their formal education was in Asia. These women frequent ethnic businesses in Chinatown, such as
restaurants, supermarkets, and doctors. For example, after moving to New Jersey, one respondent would make a three to four hour round-trip drive to get a haircut in Flushing, Queens. They celebrate Chinese holidays, understand many of the traditions and customs, and have a large network of Chinese family members and friends. Essentially, they are still very connected to the Chinese community.

*Phase One—Six Months*

The first six months was the easing-in phase. I recruited eight women, each of whom had a relative diagnosed with a mental illness, for a semi-structured interview. Most of the respondents were primarily from the family support group and four community clinics that provide services to working class Asian American clients. I received permission to post flyers, and to give brief presentations of about my project at staff meetings in clinics and day treatment programs for patients. An interview schedule adapted from Daley and Weisner (2003) was used to collect information on demographics, family composition, life histories, effects of the illness on one’s life, and explanatory models for the onset, treatment, and management of the illness. Exploratory questions about daily routines and accommodations were also included. The responses helped me get a sense of general concerns, and to identify preliminary themes to further explore in the second phase. The interviews were about one hour long and were recorded, unless the respondent requested it not be, in which case notes were taken during the session. Participants were paid $30 for their participation in the interview.

I also began attending the family support group meetings, and continued to do so for the rest of the fieldwork period. Even though I received permission from volunteers and family members to collect data at the meetings, I was asked to not use a recorder or to take any pictures.
Therefore, I mostly took notes. I also participated as a volunteer at all of the group’s outreach events, and I attended volunteer meetings. I was granted access to the support group’s past minutes, newsletters, financial records and some email exchanges between the volunteers. Through informal conversations with family participants and volunteers, and observations at the meetings, I learned how family caregivers perceive mental illness, familial roles, coping strategies, and interpret their experiences. Although there was no systematic effort to follow all the attendees of the support group, I highlight some of their experiences in later chapters to strengthen my claims. Throughout the whole data collection period, I attended events related to mental health issues in NYC, and kept on top of changes to healthcare policy and Medicaid.

Phase Two—Thirty Months

In the second phase, I asked seven participants for permission to observe and interview them over time to understand how having a mentally ill relative has affected their lives. Through examining their lives in depth, I attempt to understand how these women personalize cultural notions and use them to give meaning to their experiences. These key informants also shed light on how socio-economic factors mediate families’ responses and coping abilities. Five of the women are mothers and two are sisters. All the women have been living in the US for at least ten years and their family members have been ill for ten years or more. Therefore, these women have experience dealing with the mental health system in NYC and have some bio-medical understanding of their relative’s illness. All patients were diagnosed with a schizophrenia spectrum disorder, except one individual, who was diagnosed with bipolar and obsessive compulsive disorder (OCD). The caregivers’ ages range from 45 to 80 years old (mothers of patients tend to be older). The women were recruited at different times during the research
period. However, all of them have been involved in the study for at least two years. I contacted the women monthly, either by phone or at the support group meetings, to get updates on their lives. If their schedules permitted or if they needed my help, we saw each other more frequently. For example, when one of my respondents left her job, we would see each other a couple of times a month. With two of my respondents, we also communicated through email and Facebook. All of the women, except one who had moved to New Jersey, live in one of the five boroughs of NYC—on average it took about 1 ½ to 2 hours to get to their homes on public transportation. It was easier to visit the respondents who lived in Manhattan’s Chinatown, because I did not have to transfer to a bus after getting off the subway. It was very difficult to visit my respondent who lived in Staten Island, because I had to take the subway to downtown Manhattan to catch the Staten Island ferry, which ran every half an hour or every hour, depending on the time of day and whether it was a weekday or weekend. Once I got off the ferry, I had to take another 30-minute subway ride, and then walk about ten minutes to her house. At the end of this chapter, I provide short biographical sketches of these women, with more details of their lives in latter chapters.

The research study consists of a small convenience sample, and does not include a diverse range of female caregivers (i.e., wives, aunts, cousins, sisters, etc.). In addition, the research project only includes the perspectives of women who chose to provide care to an ill family member. Therefore, the findings do not capture a full range of experiences and cannot be generalized to all Chinese families in the US. It does, however, further our understanding of caregiving processes through its fine-grained analysis of how culture interacts with economical, political, and personal factors to produce specific contexts and subjective experiences of
caregiving. Furthermore, because I was a volunteer, I can also address the differences in how respondents and volunteers conceptualize the mission of the support group.

Data collected from respondents were mainly from informal conversations and observations. I was interested in cultural ideas of normalcy, family, and illness; how these ideals are communicated and reinforced in everyday family life (i.e., who escorts the patient to the clinic, who does the cooking); how multiple social roles were embodied by individuals; verbal and non-verbal practices of affect communication; and interactions with the mental health system. Observations were conducted at support groups, doctor visits, family ritual and holiday gatherings, and in respondents’ homes. I also observed interactions between my respondents and other support group participants, social workers, psychiatrists, and staff at social welfare agencies.

I translated key parts of recorded interviews into English, and field notes for both research phases were also written in English. I took notes as each individual spoke if the conversation was over the phone, or if it was someone speaking at the family support group. In face-to-face conversations and other situations where note taking would be distracting for the parties involved, I wrote notes afterwards, usually within an hour, paying attention to key terms and phrases. For example, one female patient was very paranoid of others talking about her, so when visiting her and her mother at their apartment, I never took notes.

Ideally, for the sake of accuracy, conversations and notes should be recorded with a digital recorder or by hand as the conversations and observations are taking place. However, I made the decision not to do that, because given the stigmatizing nature of the topic and the personal matters discussed, I felt respondents might be reluctant to participate or be less forthcoming in discussing their lives. As the above example with the volunteer, Nikki, suggests,
there seems to be general suspicion and mistrust of others among this research population.

Reconstructed conversations, therefore, are in single quotation marks, and exact words or phrases are in double quotation marks. Given the time I spent with my most of my respondents, I feel confident with my translations and interpretations of their narratives and actions. This is also one of the reasons why one dissertation chapter was devoted to methods. As the tool of data collection, I feel it is important to disclose my potential biases, motivations, research goals and compromises, and the nature of my research relationships, in order to be a trustworthy storyteller for my audience.

*Data Analysis*

Data analysis was done in parallel with data collection and consisted of examining notes for common narrative structures and coding the data for recurrent themes (Ochs and Capps 2001). The analysis focused on: 1) ideas about normalcy, causes of psychiatric illness, and treatment; 2) cultural ideas of family obligations and factors that affect respondents’ capacities to enact them; 3) caregivers’ degree and type of involvement with their ill family member; 4) how movement through life stages, English proficiency, and socio-economic status impacts caregiving; 5) engagement with the mental health system and ways of advocating; and 6) using the family support group as social capital. After transcribing all the data onto index cards, I sorted them by themes. The findings are reported as they arise throughout the chapters to best show how the themes interrelate, and in doing so, to clarify how social, cultural, personal, and economic variables intersect in producing both commonalities and differences in experiences.

**Biographical Sketches of My Primary Respondents**
Mrs. Lau

Mrs. Lau is an eighty-year-old retired nursing home aid. She has a middle-aged son, Kevin, who suffers from schizoaffective disorder and has been institutionalized for the last two decades. Mrs. Lau was born in Guangzhou, a city in Guangdong province in Southern China. She currently lives in Chinatown with her husband and speaks limited English. When I first met her, I felt she looked like the prototypical Chinese elderly lady. Her hair was gray, cut short and permed. She worn orthopedic shoes with Velcro, and around her neck she had a lanyard strap connected to a badge holder, where she kept her reduced fare metro card and IDs. She had her LeSportsac side bag across her shoulder, and a book bag with a retractable handle and wheels that she can roll. Mrs. Lau seems to have two main life objectives. First, to get Kevin discharged from the psychiatric hospital, and second, to advocate for treatment and services (long-term residency, finding employment) after his release that will help him have a full and meaningful life, despite his illness. She carries a small photo album with family pictures in her purse and I have observed her showing others these photos as she tells stories about Kevin.

Carol

Carol is a single mother of two children. Her daughter, Jessica has been diagnosed with bipolar disorder and obsessive-compulsive disorder. Carol came from a large family of eleven children in China. Her parents favored sons over daughters and since they had so many mouths to feed, they decided to give her away. In her early thirties, Carol married a Chinese-American man, who had returned to China to find a bride. Although he was more than 20 years older than Carol, she agreed to marry him. When their daughter, Jessica, was about six years-old, he died from a heart attack, leaving Carol all alone to take care of their young daughter. The husband had bought life insurance policy with Jessica as the sole beneficiary, because he was afraid that after he passed away, Carol would remarry someone else and give the money to her new
husband. As his dependent, Jessica received payments from her father’s social security and when she turned 18, she was able to collect the insurance money. According to the mother and daughter, Jessica was later denied disability for her mental illness, because she could not prove that she had actually spent this money. With limited English proficiency and no one to explain the bureaucracy and complex regulations of health policy and systems, Carol has a difficult time comprehending Jessica’s diagnosis and treatment, and therefore advocating for her daughter.

One central and persisting conflict in the family is that Jessica’s stepfather, who is the biological father of her half brother, Sean, had sexually abused her. The whole family lives in a one-bedroom apartment in Chinatown.

Ms. Ng

Ms. Ng is a petite woman who wears glasses and has a face lined with shallow wrinkles. She has a short bob, often with gray roots showing on the top of her head. She has a son, David, who has been diagnosed with schizophrenia in college. She is a single mother working as a home aid attendant. She shared that her husband did not want to come to America, so they divorced and she came to the US with her son. The husband was later diagnosed with cancer and died in China. As is typical for many immigrants, things were hard at first. She and David lived in a basement apartment that was dark and humid. Ms. Ng worked long hours as a waitress in a Chinese restaurant, and did not spend much time with David. Back then, her main concern was their livelihood. Things improved after she became a home aid attendant and they moved into a one-bedroom apartment in Brooklyn. She still feels guilty about not taking David to the doctor earlier, and wonders if his prognosis would have been better if she had. I detail in later chapters how she used ethnic resources, such as Chinese media and community-based organizations, to find appropriate mental health treatment for her son.
The following four women are more affluent, but only Stacy and Paula are college educated and speak English fluently.

_Cindy_

Although she is in her early 60s, Cindy looks significantly younger. She was 18 years old when she immigrated to the US to join her late husband, who was 14 years her senior. At our first encounter, in her newly built two-level townhouse in Staten Island, she told me her husband was a great husband, father, and employee. When he retired several years ago, Cindy said, ‘he bought this house for me.’ After her husband passed away two years ago, Cindy reached out to the family support group because she did not know what to do with her youngest son, Dan. For the last ten years, Dan had difficulty finding employment. He stayed home all the time and became more and more isolated. All his friends got married, had children, and got on with their lives. Things became worse after his father passed away. He started hearing voices from the air vents, and wanted their downstairs tenants to move out because ‘it was not safe for them to stay there anymore.’ Dan insists there is nothing wrong with him and refuses to see a doctor.

Cindy’s older son, Jerry, lives a couple of houses down the block with his wife and two children. At first, Jerry was very judgmental of Dan’s life choices and inability to find a job. Jerry and his family used to have dinner at his parents’ house every night and the two brothers would get into very heated arguments. Dan often became quite upset after these fights, so the father asked Jerry to take the cooked food back to his house, instead of eating at their home. Jerry seems to now understand that Dan is ill and has been less critical of him. He attends the support group with his mother.

_Hanna_
Hanna is in her early 70s, but does not look it. She is married with two sons, who live in New Jersey. She is the eldest of seven siblings. She emigrated from Hong Kong with her family in the 1980s, but she frequently travels back to visit. From what I gathered during our conversations, she helps manage a family business (she was reluctant to disclose the details). Every time I see her, she is always well put together, and has a beehive hairdo. Her sister, Laura, has been sick for the last twenty years, but does not believe it and refuses to see a doctor or take medication. Since Laura believes that Hanna collaborated with a previous social worker to get her hospitalized, she refuses to see her. She also has delusions that Hanna killed their parents and took away her son. Hanna told me that she tries to be a kid at heart, which helps her be light hearted about life.

Stacy

Stacy is a heavy-set middle-aged woman, about 5’3”. She wears glasses and has short hair with a few strands of gray in the front. I met Stacy at the family support group, where she was both a family participant and a volunteer (she is no longer a volunteer). She grew up in Hong Kong with her paternal grandmother, mother and younger brother. Her father illegally entered the US when she was a young child, so both her and her brother did not live in the same house with him until they were young adults. Stacy has a brother, Cory, with mild mental retardation and schizophrenia. He lives in a group home, and is able to perform daily self-care tasks. Although Stacy works long hours at her company she manages to find time to see Cory on the weekends and holidays, and accompanies him to most of his doctors’ appointments. Stacy had one condition for participating in my study, that her brother would not be involved at all. However, as our friendship developed she allowed me access to her brother’s life, inviting me to
visit him at the hospital, at his group home, and to their weekly dinners. She carries a digital camera to take pictures of anything that piques her interest, usually food.

**Paula**

Paula is one of my more affluent and acculturated respondents, and the most fluent in English. She was born in Taiwan and she, along with her two sisters, was raised Buddhist and Christian. She attended one of the top high schools in Taiwan, and then received an engineering degree at an American university. She dropped out of college and eloped with her husband because her family did not approve of her being with a “White man.” She later divorced her husband because he had another woman, and obtained custody of their two daughters, Bella and Joyce. Her youngest daughter, Joyce, was diagnosed with schizophrenia in her early twenties. At that time, Paula was working at an investment firm in San Francisco and Joyce was in her last quarter in college. Paula currently lives in Princeton, NJ, while Joyce resides and receives treatment in NYC. Paula attends a Chinese family support group that is an affiliate of NAMI NJ, not the one in NYC that I discuss in chapter six. She is very active in the group and has developed close friendships with several other Chinese mothers who also participate in the support group. As of 2014, she has turned her attention to advocacy, focusing on policy and legislative issues related to mental health. Obviously, Paula is very different from my other respondents, but in comparing them, we see how socio-economic resources affect the caregiving experience and begin to identify universal family processes.

**Concluding Remarks**

The central goal of this chapter is explain my methodologies, which involves a discussion on the nature of my relationship with key informants. As a native ethnographer, who speaks
Chinese and understand many aspects of the culture, I gained creditability with respondents. In addition, as a bilingual and bicultural volunteer at the family support group, I was able to help my respondents in very practical ways (I elaborate on how family participants at the support group view volunteers in chapter six). My respondents, in turn, felt compelled to reciprocate through participating in my research project. I cringe thinking of how IRB would disapprove of the pragmatism in these relationships. However, most anthropologists can understand the moral economy involved in working with other cultural groups. I remember reading an ethnography about a Nepalese village as an undergraduate. The author struggled to grasp how her foster mother could capitalize on their relationship, but also love her. I remember thinking that just because someone is useful to me, it does not mean I can’t love him or her as well. In a similar way, just because my respondents and I are instrumental to each other, it does not detract from the genuineness of our relationship.

Mayfair Yang eloquently describes the importance of *gaunxi* (social relations) in Chinese culture. She (1994:8) asserts, “Guanxixu or ‘the art of guanxi’ places an emphasis on the binding power and emotional and ethical qualities of personal relationships.” She draws on the analogy of a gift economy to further clarify its salient features and underlying logic: “That is, in guanxixue can be found the elements of the ‘obligation to give, to receive, and to repay,’ a mixture of disinterested and instrumental generosity, of voluntary and coerced reciprocity. The term ‘gift economy’ also suggests that whatever material benefit can be gained in this economy can only be won by the enactment of ritualized forms of such relationships” (1994:8). Working in the early 1980s in China, Yang (1994:23) felt, in that particular social order, it was better to “conduct fieldwork through fluid social networks and relationships, than at any fixed and contained factory site.” At that time, individuals were still wary of the government and
concerned with personal security, so people were reluctant to be seen talking to her, an American researcher. Yang also faced bureaucratic barriers to gaining access to factories. Similarly, I used guanxi, specifically the trust produced from personal relationships, to recruit subjects for mental health research, a topic that is still highly stigmatized in the Chinese community. This chapter should give a sense of how the data was collected. We now turn to the first data chapter, which examines how obligations are framed and enacted.
Chapter Three: Constructing and Enacting Family Obligations

Brother: When mom and dad die, she’s going to have a nervous breakdown. She’s going to realize that there is no one to take care of her.
Sister: You can take her in with you?
Brother: You see how I live. I can barely take care of myself. She has to go with you or John (eldest brother). I think John will take her.

In this chapter, I examine Chinese notions of familial obligations and how my respondents attempt to honor these commitments. I draw on Karp’s (2001) study of Euro-American caregivers of relatives who have a mental illness to highlight salient themes in my sample. Although the caregiver’s relationship to the care recipient affects the nature of the bond, in this chapter, I do not differentiate between the different roles because I want to paint a broad picture of themes prominent to both the Euro-Americans and the Chinese. Cross-culturally, parents, especially mothers, tend to take on the role as the primary caregiver. Siblings are generally not involved in caregiving and when they are, they tend to be involved in different ways than the parental caregivers. In the next chapter, I explain under what circumstances Chinese siblings assume the caregiver role and elaborate on the qualitative differences between their involvement and Euro-American siblings.

The main objective of the chapter is not only to identify Chinese cultural ideals of familial obligations, but also to explicate the factors, including severity of illness and available resources, that affect the extent of my respondents’ involvement. It seems that, in the beginning, both the Euro-American and the Chinese caregivers don’t assume mental illness is the cause of their family member’s erratic behavior, but once the label is applied, respondents feel relief. With the diagnosis, caregivers also have a renewed sense of hope, that is, until they recognize the chronicity of the illness. It is in long-term sustained caregiving that we start seeing differences
between the two groups—Chinese respondents seem to tolerate more stressors before they
decrease their involvement. This difference in threshold, I argue, is tied to a Chinese
interdependent sense of self that grounds one’s identity to the family. Therefore, stressors and
burdens associated with caregiving are normalized in that respondents see the caregiving tasks as
part of what they do for their families. However, the manageability of a family member’s illness
symptoms, and the caregiver’s financial and social resources are critical factors that mediate my
respondents’ level of involvement.

Because I use Karp’s (2001) respondents as a comparison group, it is important to first
give a detailed account of his sample, which provides the contexts for thinking through the
similarities and differences between the two groups. Karp and I are both interested in how
family caregivers frame obligations, and so we focus primarily on individuals who chose to stay
and provide care. His study (2001:267) is also one of the few that uses qualitative methods,
including in-depth interviews, and observations of a support group. He used his observations of
a support group, between December 1996 and May 1997, and six pilot interviews, to identify
topics and domains for the later in-depth interviews, which ran from two to three hours.
Between May 1997 and July 1998, he conducted 54 additional interviews—twenty—24 of these
interviews were with participants at the family support group; nineteen answered ads that Karp
posted in a local newspaper; and the remaining fifteen were referees. His book is based on
these 60 interviews (2001:267), whereas I focus on a smaller number of respondents who I
observed in different social domains over time.

There are also major differences between the demographics of our respondents. Most of
his participants are Euro-Americans—58 of his respondents are white, one is African American,
and one is Filipino (2001:267). Approximately 60 percent of his respondents are professionals,
white-collar workers, and clerical workers. The rest are blue-collar workers (8 percent), students (13 percent), and unemployed or retired (18 percent). Women were significantly overrepresented in both our samples, but I focused exclusively on mothers and sisters, while Karp recruited people from a range of caregiving relationships (2001:267). Of the 40 women Karp interviewed, fourteen are parents, eight are spouses/partners, nine are children, eight are siblings, and one is a friend. Of the 20 men interviewed, there are six parents, six spouses/partners, five children, one sibling, and two friends (2001:267).

**Signs of Trouble**

I begin my analysis with the story of Leslie, one of the mothers in Karp’s (2001) study. Since her narrative touches upon several themes that are representative of other Euro-American caregivers, I use her as a springboard into a discussion of how Euro-American and Chinese respondents are similar and different in their caregiving experience. Leslie is married with three children. Her eldest son, Mike, in his mid-20s at the time of the interview, had been diagnosed with schizophrenia. There were hints of a problem when Mike was in sixth grade. He was skinny, wore glasses, and loved to read. He hated sports and didn’t really fit in with the other children. He was teased a lot which was unsettling for Leslie and her husband, but what was especially disturbing to them “was a call from Mike’s sixth grade teacher who felt obligated to tell Leslie that ‘Mike looks at me like he wants to kill me’” (Karp 2001:4). Since Mike was a “‘kind child…an excellent student (and) was a good kid at home,’” Leslie just “‘thought the teacher was crazy’” (Karp 2001:4). However, Mike’s ninth grade teacher made a similar comment. According to Leslie, this was the beginning of “‘a crescendoing…an escalation of signs of trouble’” (Karp 2001:4). As Mike got older, Leslie could no longer attribute Mike’s
strange, irresponsible, and violent behaviors to adolescent confusion, or hope that it would resolve itself.

Mrs. Lau, a Chinese mother in my study, reported a similar experience. When she immigrated to the US with her family, her son Kevin was in his early teens. Both she and her husband had high aspirations for him, because unlike his older sister and brother, he had the opportunity to benefit from an American education. Mrs. Lau described Kevin as an ‘obedient son who often helped her with the cleaning.’ They expected him to graduate from college, find a good job, get married, have children, and maintain close contact with them. These aspirations reflect both the hopes of working class Chinese immigrants, who use education for social mobility, and more broadly, Chinese parents’ general expectations that their children will provide support for them, if not practical, then at least emotional (Wu and Tseng 1985).

However, things changed when Kevin started attending college. Mrs. Lau reported that Kevin was out all the time, became short tempered and had extreme fluctuations in his moods. Kevin and his father fought so much that eventually his father kicked him out. Mrs. Lau secretly rented a room for him to stay in until things blew over at home. After moving out, Kevin’s erratic behavior continued. One day, while reading the newspaper, Mrs. Lau received a call from Kevin explaining that he had gotten arrested and been charged with physical and sexual assault. Her nephew, who spoke English, helped her find out where Kevin was being detained. During the legal proceedings, Mrs. Lau met Kevin’s wife for the first time. They had met online and Kevin had flown to Beijing to marry her. It seems this girl scammed Kevin, because after she arrived in America she moved in with her boyfriend who was already living in New York City. The girl may have felt guilty because she did accompany Mrs. Lau to visit Kevin several times before they stopped hearing from her. Kevin was eventually convicted and sent to a prison.
upstate. At least once a month, Mrs. Lau would spend a couple of hours riding the bus to visit him at the prison in upstate New York. Later on, the doctors discovered Kevin was suffering from a mental illness and transferred him to a psychiatric hospital, and for the last 18 years he has been shipped back and forth between prisons and psychiatric hospitals.

There are several key similarities between Leslie’s and Mrs. Lau’s early experiences. They saw the destructive and strange behaviors of their sons as adolescent issues that would eventually resolve on their own, which in some ways normalized the behavior. Similarly, another Chinese mother, Ms. Ng, first thought her son David was just unhappy because he saw everyone else with a girlfriend and he did not have one. These women’s assumptions made sense, because the onset of severe and chronic psychiatric illness is generally during adolescence and early adulthood. Other Chinese respondents reported they initially thought their family member was going through a stressful period (school, finding a job, etc.). Some attributed it to a character flaw, such as laziness, shyness, or lack of motivation. Likewise, Hanna told me that for years everyone attributed her sister’s behavior to a stubborn personality. In general, mental illness was not the first thing my respondents thought of.

Given the stigma associated with psychiatric illness, it is understandable why both groups of caregivers may want to delay a label of mental illness. With Chinese families, in particular, an admission of mental illness also reflects poorly on the family name because it implies the family is incapable of resolving its own problems (Lam et al. 1995). In addition, stigma resulting from mental illness is shared by the entire family and diminishes the economic and marriage value of patients and their families (Ng 1997). Therefore, Chinese families are motivated to protect their ill relative’s moral status as a participant of the community. Yang et al. (2010) found that the Chinese families in their study often use the cultural idiom of xiang tai
duo (excessive thinking) to interpret psychotic symptoms in kin, which delays a diagnosis of mental illness.

My Chinese research participants may also be unfamiliar with or have difficulty comprehending a biomedical definition of mental illness, specifically as a “brain disease” or a “broken brain.” Carol shared that, ‘no one in the family has mental illness. In China, people just call individuals with mental illness crazy. We don’t have money to take them for treatment.’ Then she told me how her village handled one woman who was not normal: ‘Her family married her off, but she ended up returning to her natal family. After she put something in our village well, her father took her to the forest and left her there.’

Mrs. Lau and Hanna’s cases, on the other hand, suggest that a biomedical understanding may not be relevant for Chinese families. When I first met Mrs. Lau, she pulled out a blue book that resembled the examination booklets college students use, pointed to the word “schizoaffective disorder” in her booklet, and then asked me to explain what this illness is. It struck me as odd that she did not know what schizoaffective disorder is, even though her son has been diagnosed over a decade ago and she has extensive experience with the mental health system. In later meetings, Mrs. Lau mentioned that Kevin’s behaviors were a result of his “illness,” but she rarely stated his diagnosis of schizoaffective disorder. In the three years that I have known her, she has only once alluded that there was something wrong with his brain, but that was in the context of convincing another mother, Cindy, to take her son to a psychiatrist. While Mrs. Lau understands the brain model, it doesn’t seem salient for her since it is not one of the causal factors that she consistently cites. Similarly, Hanna has read extensively about schizophrenia, but she doesn’t talk about her sister’s illness as a brain disease. In later sections
of this chapter, I elaborate on how my respondents’ limited use of the broken brain model may be tied to an interdependent construct of the self.

Most of the Euro-American and Chinese caregivers hope for the best as long as they can, but then accept that something is very wrong. In Leslie’s case, the family realized that Mike had to be removed from the house after he attacked his younger brother, Josh, and threatened Leslie. Mrs. Lau’s son, Henry, was arrested and afterwards was diagnosed with schizoaffective disorder. For Hanna, it was when she got a call about her sister’s involuntary psychiatric hospitalization. There is usually a sense of relief when a family member receives a diagnosis because it explains the previous incoherent behaviors. Karp quoted one mother, “I loved getting the diagnosis. That was the best day of my life” (2001:50). One wife stated, “…one of the best days of my life was when I got a phone call from the hospital telling me what they decided was wrong with him (husband) and they couldn’t understand why I was so excited or happy” (Karp 2001:51). Consistent with Lin and Lin’s (1981) findings in Chinese families, Mrs. Lau was also relieved when Henry received a diagnosis. She shared at a family support group meeting that, before Kevin was diagnosed, her friends and relatives often blamed her for spoiling him and contributing to his bad behavior. When Kevin received his diagnosis, Mrs. Lau felt vindicated because her critics could now see that the illness, not her parenting, was the underlying cause of his bad behavior,. She told the support group that these people ‘learned their lesson.’ Although she may have felt partly responsible for Kevin’s illness, she did not want to be publicly criticized as an incompetent mother in front of others.

So far, the general pattern of family response found in Euro-Americans and Chinese caregivers is similar to the initial stages of family response identified by Tessler et al. (1987:12): “initial awareness of a problem, denial of mental illness, labeling, faith in mental health
professionals, recurrent crisis, recognition of chronicity, loss of faith in mental health professionals, belief in the family’s expertise, and worrying about the future.” In both groups of respondents, there is an initial awareness of a problem, but caregivers do not automatically assume their family members are mentally ill, and they are not sure how to handle it. After a diagnosis of mental illness has been applied, there is a sense of relief and a hope for a cure, but repeated hospitalizations leads to the recognition of chronicity. Paula thought her daughter would recover just by going to the doctor. She did not expect schizophrenia to be a life-long illness. While my respondents’ perceptions of self-efficacy as caregivers improved over time, and they learned to question clinical judgment, they didn’t lose faith in mental health professionals, probably because there is a cultural emphasis on respecting experts and people of authority (Moy 1992, Sue and Sue 1999, Lin 2002). Furthermore, given the older ages of my respondents, there is definitely the concern of who would take care of their ill family member after they pass away. I expand on these last two points in a later chapter. The next section focuses on what happens after family caregivers recognize the chronicity of their family member’s mental illness.

**Long Term Care: Negotiated Choice or Duty**

In this section, I discuss how Euro-American and Chinese caregivers differ in how they perceive their role as long-term caregivers. Karp (2001) shows, like the other mothers he has interviewed, that Leslie finds it difficult to distance herself from her child’s illness. She also recognizes that her involvement with Mike is hurting her husband, her other children, and her own wellbeing. Her ambivalence is reflected in the following excerpts from her interview.
‘Sometimes, I think it would be easier if he had cancer. His disease is so dreadful.’ ‘Not to sound melodramatic, but it’s worse than a movie. I mean, I can’t believe it’s my life, my son’s life.’ ‘We don’t have a life. We don’t have a life.’ ‘I just look at him and my heart breaks all the time.’ ‘It’s always on my mind. It’s my existence. I am obsessed with my son’s illness. His illness is my life.’ (Karp 2001:9)

‘I honestly don’t think there is a minute of the day that I am not thinking about…my son…It’s my existence. He’s my child.’ (Karp 2001:12)

‘I am failing my other children and failing my husband.’ … ‘I am stuck in this little world of my son and me.’ (Karp 2001:12)

During his lengthy hospitalizations, Leslie visited her son nearly every day, but did not expect anything approaching such an involvement from her children. Josh is ‘away at school and he really can’t get back here.’ ‘Andrea,’ she explained, ‘is very sympathetic, I mean, she loves him (Mike), but she finds it very difficult to go there (the hospital) and visit him. So, she’s gone a few times, but she doesn’t go and I understand. She just finds it too hard. She needs that space.’ When our conversation turned to her relationship with Bob (her husband), she was willing to say, ‘If I were my husband, I’d want to leave me at this point.’ (Karp 2001:12-13)

She admitted to me with some hesitation that her own depression had grown to the point where (she) ‘actually felt suicidal.’ Although she has suffered from bouts of depression in the past, Leslie understands that her current debilitating insomnia is intimately connected with Mike’s plight. When I asked about her capacity to distance herself from Mike’s illness, she told me, ‘Oh, I have a very long way to go, a very long way, …(Right now) I feel like I will drown…if I don’t get a little more (distant)…(But) I’m his mother. It’s very, very difficult for me not to be there.’ (Karp 2001:14)

Karp explains:

Intellectually, Leslie may understand the wisdom of gaining distance from her son’s problems. However, the prescription to withdraw from a child’s trouble is emotionally counterintuitive. Leslie cannot easily accept that profound empathy for her child’s pain might be an obstacle to greater wellness. Numerous interviews affirm that it is an exceedingly hard lesson for any mother to learn. (2001:14)

What is evident from Leslie’s statements is that she feels she is a bad mother and wife for being so occupied with Mike’s problems. Like other mothers, she understands her other children’s need for distance from their ill sibling, but finds her husband’s detachment frustrating. Later in
her interview, she continued to tell Karp how her psychological health has suffered, and her
statements suggest that she perceives her over-involvement with Mike as unhealthy.

Consistent with other narratives in Karp’s (2001) study, Leslie’s narrative exhibits a clear
concern of being engulfed by a family member’s illness, and consequently, a preoccupation with
preserving one’s sense of self, including physical and mental health. Karp argues that Euro-
American caregivers protect their sense of self by continuously redefining boundaries, and
balancing involvement with distance. Other studies have also identified an accordion-like
pattern of interaction, where caregivers and their ill relative oscillate between periods of
closeness and separation (Tessler and Gamache 2000, Stoneall 1983). Caregivers who become
too enmeshed in the lives of their ill relative are considered by others and by themselves as
pathological, and are associated with terms, such as “enabling” and “codependence.”
Codependency is viewed as a disease because Americans have a deep ambivalence about
extensive social ties (Karp 2001). While personal fulfillment and realization is prized, there is
also the equally compelling but contradictory cultural prescription to care for one’s family at
whatever cost. The following quotes from two daughters reinforce this connection between
over-involvement and pathology. The first one, in particular, suggests the constant evaluation of
how much assistance to provide can be more stressful than the ultimate decision to discontinue
contact.

‘...But having to always say, “Now what should I be doing for this person, and what
should I not be doing? You know, they’re disrupting my life. How much should I give?”
It’s a constant struggle. That’s the one that’s the toughest, and it just really gets wearing
and very difficult...And I’ll tell you, the few times that I have walked away, I get just an
incredible feeling. When you’ve drawn the line and you’re not doing this reevaluating,
and you’re not having any contact, and you’re living a normal life, it’s just incredible.
It’s a wonderful feeling...you go out with friends. I mean, you don’t think about it. It’s
just great…But it’s always constantly reevaluation. That’s the most difficult thing.’ (Karp 2001:47-48)

‘I know… my limit is reached (when) all I think about is getting her (mother) in the car and driving off a cliff because I can’t stand to be with her and I feel she can’t do this to people anymore… In a way my identity disappeared because I was just sucked into blackness and weirdness.’ (Karp 2001:35)

The burdens and stressors of caregiving have been associated with negative mental and physical health in caregivers (Francell et al. 1988, Cook 1988, Greenberg et al. 1997). Although caregiving has similar negative effects on my respondents, they do not see their presence in their ill relative’s life as over-involvement or unhealthy. As Guarnaccia and Parra (1996) have pointed out, perceptions of burden vary cross-culturally, because in some groups caring for an ill family member is seen as something they ordinarily do, and therefore is not perceived as extraordinary sacrifices or responsibilities. It is also because of this normalization that respondents don’t see their lives pathologically enmeshed with their ill relative. As such, my respondents rarely frame their caregiving role as a choice that is based on “love.” The Chinese women I interviewed may sometimes use the world “care” and “concern,” but it is extremely rare for the word “love” to come up. In general, their narratives used few adjectives—such as excited, enthusiastic, awful, terrible, furious—that denote strong emotions. Instead, they emphasized obligation and responsibility as motivators for caregiving. I illustrate my point with some quotes below.

Mother: It’s my daughter. She is my responsibility.

Paula: …it is my responsibility to take care to Joyce. I don’t want to use the word “burden,” but it is a burden. (laughing)

Carol: What can I do? She is my daughter. I have to take care of her.

Hanna: I’m not an altruistic person. It is my responsible to take care of her (sister).
Two respondents also cited feeling sorry for their family members.

Mother: When she acts out, she hits me and yells at me. I continue to care for her because she is my responsibility. Sometimes when I look at her, she seems so pitiful.

Stacy: I am really angry at my mother. She left me with the burden of taking care of my brother. I’m not angry with him because he’s a victim. He’s the way he is because she refused to accept that he has a mental illness and get him the treatment and the rehabilitation services he needed.

Karp’s (2001) respondents, on the other hand, often claim love as being the primary motivator to provide care to an ill family member.

Leslie: ‘…and I mean, I still love him.’ (Karp 2001:12)

Son: ‘…What the hell are you supposed to do if you have a sick parent in the house…and you’re part of the family? … What are you supposed to do, throw them by the wayside? … I mean, I love my parents… I did it out of love and…’ (Karp 2001:35).

Mother: ‘I wanted to kill myself, David...It wasn’t just because I was depressed. It was because I felt responsible and helpless to do anything and no one loved him but me in the whole wide world and my love was not enough.’ (Karp 2001:42)

In addition, my respondents don’t necessarily see their involvements as pathological or co-dependent.

Hanna

Hanna shared:

My sister does not think she is sick. She refuses to take her medication and insists on living alone. It takes me about 3 hours, round trip, to go to her apartment to drop off her monthly disability check. If she were home, she would curse me out, tell me to go to hell, and refuse to open the door. I usually just slip her check underneath the door…I have asked her neighbors to keep an eye on her for me. My sister is very kind and she doesn’t want people to kill living things, so she goes down 8th Ave (a smaller Chinatown in Brooklyn, NY) and tells restaurants and food stores not to kill animals. I have spoken to all the staff and owners at these establishments and explained my sister’s situation to
them, because I know she is disrupting their business. Most of them are very understanding, and some have called me to tell me about her whereabouts in the past…I will never give up on my sister. I have hope.

*Paula*

Paula recognizes that she plays a greater role in Joyce’s life than other parents, because, as she proudly told me: ‘The past director at Joyce’s day treatment program said I was the most involved mother. Most parents are here in the beginning but then are gone. I know I am outspoken and have stepped on people’s toes.’ Caregiving has affected many aspects of Paula’s life. About 10 years ago, she bought an apartment in Shanghai, because she had originally planned to retire at 47 years old and move there with her girlfriends. However, her dream of early retirement was put on hold when Joyce was diagnosed with schizophrenia. For the last ten years, the apartment has been left empty with white cloths draped over the furniture. Paula had torn through her savings when she took time off to care of Joyce. She can’t imagine living too far away from Joyce, at least not any time in the near future. Her role as a caregiver has also impacted her health. She shared:

I was heading back to New Jersey from New York. I was stuck in traffic for 45 minutes and was really upset over Joyce’s condition. I had a big headache. As I entered the Lincoln Tunnel, my headache got worse; I became numb on my head and on one side of my body. My vision went blurry. I did not get into an accident because traffic was moving so slow. The two dogs were in the back seat. As I exited the tunnel, I was trying to figure out the closest hospital to go to, but then I remembered I had two dogs in my backseat. (both of us laughing) The next day I went to the doctor and he told me I had a stroke. The MRI showed dead gray matter in the front part of my brain. I think that is why I am not really good at learning new dance moves and my memory is not as good as it used to be…I also have high blood pressure. Many family members don’t realize they have depression or anxiety until they come to our support group.

*Mrs. Lau*
Although many Euro-Americans may perceive Mrs. Lau’s relationship with her son, Kevin, as codependent, her actions are typical of the other Chinese women I interviewed. Since her son’s incarceration 18 years ago, Mrs. Lau has tried to help him live a meaningful life, despite the limitations of his mental illness. I believe it is also by helping him create a new life that she achieves her ideals of a “good” and competent mother. From the time I have known Mrs. Lau, she has been preoccupied with two main goals: to get Kevin discharged from the inpatient psychiatric ward, and to advocate for his treatment and services after his discharge that will enable him to have a life as close to normal as possible (i.e., long term residency, finding employment, recreation activities, etc.). When he was at the upstate prison, Mrs. Lau would ride a bus for a couple of hours to visit him there at least once a month. In her late 70s, when I met her, she traveled more than an hour each way to visit Kevin a few times a month at a NYC psychiatric hospital where he was an inpatient. A book bag with a retractable handle and rolling wheels always accompanied her when she made the trip. The bag held a variety of Chinese dishes, including chow fun, rice congee, small dishes of dim sum and homemade soup (made by her husband) for Kevin. Mrs. Lau always brings Kevin Chinese food when she visits him. She explained, ‘He doesn’t like the American food at the hospital. He misses Chinese food. It’s something that he looks forward to.’ It is common in Chinese culture to show love and concern through food. Stacy and Paula take their ill family members out for dinner, usually Asian cuisine, almost every time they see them. When I met with respondents in Chinatown, it was very common for respondents to get calls from their ill relatives, requesting they bring home specific food items.

I will discuss how Mrs. Lau navigates the mental health system and performs the role of the “cooperative mother” in the chapter on the mental health care system. Here, I will focus on
how Mrs. Lau creates opportunities for Kevin to socialize and get job experience. As an inpatient, Kevin’s day is structured into blocks of time for meals, therapy groups, free periods, chores, and recreation; he has no choice but to socialize with other people and to keep busy. As an outpatient, however, Kevin sees other consumers of mental health services at his day treatment program, but there is no motivation for him to socialize with them. Besides mental stimulation, Mrs. Lau feels Kevin also needs physical activity to help him lower his weight and keep his diabetes in check. She also hopes that he will be able to find some type of employment, because most of his disability check goes to paying for his food and board at his residential facility. This leaves him with limited spending money for Chinese food and public transit, which are the two main things he spends money on.

Mrs. Lau finds various ways to address these areas that are important for his physical and mental wellbeing. She first asks Kevin’s social worker if there are activities at the day treatment program that are more educational, but the answer is no. She values the stimulation of the body and mind because she believes it gives a person a purpose. She told me, ‘Kevin is happy when he plays mahjong because he is using his brain.’ She has offered to organize small parities at her house so that family participants at the support group can come over with their family members and socialize with Kevin. In particular, she hopes that Kevin can become good friends with George, another family member’s son. George is a soft-spoken young man who helps her carry groceries and does chores around her house. Mrs. Lau believes the men may be compatible because they are close in age, have a similar diagnosis and speak both Chinese and English. Most importantly, George’s condition has been stable for years, and therefore he is a good role model for her son. Mrs. Lau also takes Kevin to free fitness classes offered by different community agencies in Chinatown, to field trips organized by her senior citizen center and to
family celebrations. Mrs. Lau wants Kevin to participate in these field trips to familiarize himself with the staff at her senior citizen center, so if a job position comes up he can be apply for it. The physical and emotional stress of worrying and planning Kevin’s life takes a toll on Mrs. Lau. She sees a therapist and also takes anti-anxiety medication, and about a year ago she had a pacemaker put in. But this is something that she has accepted as part of her life.

The discussions at the support group that Karp (2001) observed centered on gaining control of one’s life. For example, caregivers often express difficulty in taking vacations because they fear what may happen with their relative when they are away. When an elderly couple who have struggled with these feelings was finally able to go on a vacation, everyone applauded them. This is not something that is of concern for the participants at the Chinese support group. One Chinese mother sums up how normal it is for Chinese families to be heavily involved in the lives of their relatives: ‘This Chinese mental health professional told me that I should not get too involved with my daughter’s life (her daughter is in her 30s). I can’t believe she said that. Doesn’t she understand Chinese culture?’ Her disbelief is intensified because she expected someone who is Chinese to understand kinship relations, especially more so than a Westerner. However, heavy involvement may not always be a good thing. One volunteer shared, ‘many family members think they are right, and the decisions they make for their ill relative is right and it is in their best interest. They also try to do everything for them because they are ill, but this just reinforces their dependency.’

Stacy

Since caregiving is inherently stressful, there are times when leaving is tempting, but Stacy does not feel she has a choice and continues to endure. Being a caregiver to her brother,
Cory, has been very stressful for Stacy and she has gone to a doctor for emotional issues related to the stress of being a caregiver. She explained, ‘at that time, I will start crying all of a sudden; my mind would just go blank. I crossed the street while the light was red twice and almost got hit by a car. I was on a low dosage of anxiety medication for a short while.’ During one of Cory’s hospitalizations, Stacy felt very overwhelmed and hopeless. Two of her close friends gave her contradictory advice: ‘Both of them had good intentions. One told me not to pick him up from the hospital. She felt I was in too much stress and will break down. The other friend said, he is your brother, you have to take care of him.’ This dilemma resembles the one faced by many of Karp’s (2001) participants, but while Stacy acknowledges the stress of being a caregiver, she doesn’t see her involvement as codependency, let alone that she could actually turn her back to her brother. She shared, ‘What can I do? I either die or continue living.’ In Stacy’s mind, she does not have a choice.

**Caregiving and Notions of Self**

Chinese families’ strong sense of duty and active involvement with a mentally ill family member has been attributed to an interdependent construct of the self (Markus and Kitayama 1991, Miller 1994, Snowden 2007). People with this understanding of the self construct their identity in relation to others and according to their social circumstances. The ability to exercise self-restraint and adjust one’s own behaviors to the social setting in order to maintain harmonious social interactions holds primary significance. Therefore, individuals with an interdependent orientation are obliged to be aware of others and focus on their needs, but this attentiveness is only selectively given to in-group members, such as kin. More recently, scholars have been moving away from these all or nothing dichotomous categories of independent vs.
interdependent selves. Lu (2003- as cited in Lu 2010:338) offers the construct of a composite self, which allows room for both independent and interdependent features to coexist and is, according to him, a way to express two universal needs in humans, uniqueness and relatedness. He has also found that the Taiwanese value independence and interdependence equally (Lu 2009). Similarly, others have documented the presence of a bicultural self in both Mainland Chinese and Taiwanese (Lu et al. 2008).

Although categorizing ethnic groups as either independent or interdependent is reductionistic and gives the illusion of in-group homogeneity (Hollan 1992), this dichotomy can be useful in conceptualizing cultural proclivities in specific domains of social life. Rhee et al. (1996) found that Koreans were only more collectivistic than Euro-Americans in relation to their families, and not with non-kin or general others. Similarly, Oyserman et al. (2002) found no significant differences in measures of collectivism between Euro-Americans, African-Americans, Asian Americans, and Latinos, except in the domain of perceived sense of duty to in-group members, such as kin. Therefore, discussions of independence and interdependence need to clarify who the in-group reference is and other contextual factors.

Chao (1995) offers insight regarding how Chinese-American children are socialized into an interdependent sense of self. Using Markus’ and Kitayama’s (1991) distinction between the independent and interdependent self, Chao (1995) persuasively argues that Euro-American mothers and immigrant Chinese mothers have different notions of the self that impact their child rearing practices. The two groups of mothers stressed making their children feel loved, but for very different reasons. The Euro-American mothers believe they can help their children be independent by building up their self-esteem; this way they will feel confident about exploring the outside world. To foster self-esteem, these mothers always tried to be positive, looked for
opportunities to praise and encourage, and avoided criticizing their children. When they punished the child for misbehaving, the bad behavior is always separated from the child, so that he or she knows they are loved and accepted no matter what. The mothers encouraged their children to identify and express their inner feelings, so that their needs can be met, but they did not stress learning to understand and listen to others’ feelings and needs.

While the immigrant Chinese mothers also believe it is important for a child to feel loved, it is for the purpose of fostering a close mother-child relationship and ensuring the continuity of the relationship as the child matures. These mothers emphasized the sacrifices they make for their children, specifically defining their role as a caretaker—“...a role that especially emphasizes devotion and self-sacrifice...” (Chao 1995:342). Overall, the immigrant Chinese mothers promoted characteristics and skills that foster harmonious relationship within the family and with others in the community. Past research with youth has confirmed this emphasis on family obligations and interdependency. Chinese adolescents in China and in the US reported expectations to fulfill family obligations through tasks, such as doing housework and providing care to parents as they age (Fuligni et al. 1999, Fuligni et al. 2002, Fuligni and Zhang 2004). The Chinese mothers’ concept of independence is also distinct from the Euro-American mothers in that it focuses on self-reliance, which involves the ability to take care of oneself and to become successful (Chao 1995). Therefore, the immigrant Chinese mothers stressed teaching their children general life skills (i.e., grooming, cooking, cleaning, etc.) and making sure their children excel in school so that they can find good jobs as adults. The emphasis on self-reliance reflects a cultural value of interdependency, because “in Chinese society, individuals are expected to know how to take care of themselves and to have the life skills to become successful
and useful persons…so they may grow up to be contributing members of the family and society…” (Chao 1995:345).

The deep sense of commitment and loyalty that Chinese immigrants have for their families is “a duty, not a choice and is engrained in the core of Chinese identity” (Ward and Lin 2010:669). Therefore, in the management of illness, Chinese individuals have what Miller (1994) calls a duty based interpersonal moral code, in which individuals’ sense of self is intimately tied to their duty to care for a sick family member (Miller 1994). Although their role is an obligation rather than a choice, their motivation and caring affect is enhanced, because they are attempting to enact a cultural ideal. Miller’s idea stresses that fulfilling one’s obligations through providing care can be extremely rewarding. My findings also suggest that the positive self-identities of my respondents’ hinges on their ability to meet culturally expected caregiving obligations, which are dictated by their relationship to their family members.

Miller (1994) contrasts the interpersonal moral code to the individually oriented one found in Western culture, which emphasizes free choice and self-actualization. Individuals in this second group weigh the responsibility to an ill relative with their own desires and needs, and therefore see their caregiving role as a negotiated commitment, rather than an obligation. Similarly, Karp (2001) found that the decision to stop providing care is often motivated by a feeling of losing oneself and being engulfed by a family member’s mental illness. He argues that Euro-Americans use expressive individualism (i.e., the lost of self), an ethic code, to minimize their felt obligations to family members. This is a response to the ambivalence that arises from two powerful but contradictory cultural values: love and care for your family regardless of personal costs and the right to pursue personal happiness.

The difference in self-construct is also reflected in the prevalence of the “broken brain”
explanatory model used by many of Karp’s (2001) research participants to reify and separate the illness from the patient. Although my respondents noted that their relatives acted differently when symptomatic, they did not actively distinguish the person from the illness. However, the Euro-American respondents saw the illness and abnormal behavior as separate from their relative’s core self. This distinction is evident in Leslie’s quote:

‘Mike has the potential for violence. And…because I know this is being recorded, it’s really important to me for you to know that he is innately a very, very sweet and kind person. But (because of) his disease he gets very paranoid. His disease has made him a danger to others…I mean, he wouldn’t even step on a bug, you know? But this illness is so (awful) and he has attacked his brother, attacked his sister.’ Leslie repeatedly sought assurance that I (Karp) would not confuse Mike with his disease. (Karp 2001:4)

The broken brain theory utilizes a disease model to relieve both the caregiver and the ill relative from the majority of the responsibility in causing and controlling the illness (Karp 2001). Karp often hears family members draw the analogy of taking insulin for a hormonal imbalance with taking psychotropic drugs for chemical imbalances in the brain. He (2001:153) reported that in every support group meeting the Four Cs are recited in unison: “I didn’t cause it. I can’t cure it. I can’t control it. All I can do is cope with it.” He explained that the predominant etiological explanation among his research participants is the broken brain theory, which traces the cause of mental illness to a physiological defect in the brain. Many family advocates, in particular NAMI, have also promoted this theory, in response to an enduring perspective among mental health professional and the public that families are the cause of mental illness.

While my sample is small and the generalizability of my findings is limited, I think it is significant that none of my respondents adopted the broken brain theory as their dominant explanatory model. Consistent with Lin and Lin (1981:388), my respondents reported
religious/cosmological, physiological, psychological, social and genetic explanatory models. They generally recounted a mixture of these factors, but a psychosocial explanation was the most prevalent. In general, there was an identifiable causal agent or event, and multiple treatment options were used simultaneously. For example, they may go to a Chinese shaman, a traditional Chinese medicine practitioner, and a psychiatrist. Below, I provide examples of some of my respondents’ explanatory models.

Mrs. Lau:

During the Cultural Revolution, the students at my school held the teachers as prisoners, and destroyed and vandalized the school. I was lying on the floor, using my hands to shield my head, while students kicked and punched me. I was pregnant with Kevin at the time. I feel the trauma and violence that I encountered contributed to his illness. This is “womb education.” I also feel guilty for giving him the Chinese name ling, which means zero, because it is such an inauspicious name and did not bode well for his life. My elder son added to the bad luck with his constant teasing of Kevin, calling him crazy ling. Kevin’s relationship with his father and wife were also significant factors; they pushed a normally quiet and compliant Kevin to flip. Kevin told me he hates all the women in this world.

Paula:

Well, Joyce’s father was very paranoid in his 40s. He also had two family members who committed suicide. Joyce used marijuana and was into extreme sports. It was also a very stressful time in her life when she got sick. She was 22 years old, in her last year of college, and was trying to maintain a long distance relationship.

Beliefs evolved as we encounter new experiences. After attending Columbia’s annual conference on schizophrenia, Paula, Joyce, and I went to a café and started discussing one of the presentations on the risk factors of schizophrenia. In this example, Paula makes a direct connection between these risk factors and Joyce’s mental illness. She used this new knowledge
to reinterpret her past and emerged with two novel etiological theories for Joyce’s illness, maternal stress and head trauma.

P: I was four months pregnant with Joyce, and I fell down the stairs.

L: Did you go to the emergency room?

P: No. I did not want to leave my one-year-old daughter by herself, so I just tried to climb back up the stairs. I never told anyone about this. That’s one factor, a stressful event for the mother. Also, Joyce used to smoke marijuana and had head injuries from playing sports, which are all risk factors for schizophrenia.

The lack of exposure to the broken brain theory does not adequately explain why my respondents rarely mention this idea. Even though it was not explicitly referred to as the broken brain theory, I know this idea has been presented at the family support group. Even Stacy and Paula, who speak English fluently, identify as family advocates, and have been involved in NAMI (who are big supporters of this disease model of mental illness), have never cited this explanatory model in our conversations of etiological theories. Paula has also taught NAMI’s family-to-family classes, a twelve-week course for family caregivers of individuals with severe and persistent mental illness. The course is taught by a trained family member and provides family caregivers with information on different diagnoses, medications, research on the biology of brain disorders, treatments, communication with patients, self-care and coping strategies, community resources, and advocacy initiatives (http://www.naminycmetro.org/education/namisignaturecourses/tabid/75/default.aspx).

The broken brain explanatory model, I believe, is more appealing to Karp’s research participants, because it is consistent with a Euro-American independent construct of the self. People who embody this concept of the self believe individuals have core attributes that remain
stable through time and context (Markus and Kitayama 1991). A traumatic event, in this case mental illness, divides an individual’s life into two distinct sections, one before the illness occurred and one after. The broken brain theory is compatible with an independent self-construct because it allows Euro-American families to reconcile bizarre or frustrating actions of a relative that had been normal until their illness hit. Similar to how Euro-American mothers separate the bad behavior of their children from the individual child (Chao 1995), Euro-American family caregivers separate manifestations of mental illness from their relative’s core identity. In addition, the disease model provides Euro-American caregivers with a rationale for terminating caregiving obligations when they feel the illness is taking over their identity. Since they “can’t cure it” and “can’t control it,” they cannot change the situation.

My claim is not that Euro-Americans are motivated by love, whereas my respondents are motivated by duty—both emotional attachment and devotion are significant in how both groups justify their actions. I am also not suggesting that these Chinese women are morally superior to Euro-American caregivers, because they have a higher tolerance for disruptions and stressors in their lives. Their persistence comes at a high price. It is obvious that, at times, the illness takes up their whole lives, and they struggle to balance caregiving with their other social roles and personal needs. There were times when some of these women have thought about turning their back to their sick family members, and some do. A staff at NAMI shared the experience of a Chinese mother:

In 2008, this woman’s husband passed away. Afterwards, her daughter got sick and was hospitalized for 11 months. She was later discharged to a group home because her family could not provide 24-hour supervision. This woman was so stressed out that she became very depressed. Someone from her church criticized her for putting her daughter in a home. Similarly, other friends and family members felt she should take responsibility for
her daughter. This woman felt really guilty, but she realized that she could not provide the type of care her daughter needs at home.

This mother’s distress stems from her failure to live up to a model of a self-sacrificing mother who will always take care of her daughter. This is what she and others expected of her. Both choosing to stay and to leave can be extremely painful for my respondents.

However, my respondents’ distress may be slightly mitigated because the cultural emphasis on interdependence and family obligations provide relatively clear directives on what to do when a family member becomes ill. As a result, they don’t view their involvement with their ill family member as excessive or unhealthy, and it alleviates some of the distress that comes from the continuous negotiation of how much care to provide, as seen in Karp’s (2001) respondents. When caregiving is a choice it allows room for ruminations about one’s role, and that in itself can be stressful.

**Time to Let Go**

While cultural ideals of family obligations are important, there are other significant variables that affect the degree of my respondents’ involvement. Two main ones are disruptive symptoms that are difficult to manage, and the availability of resources to help one cope (Edgerton 1969).

**Symptoms**

Difficult symptoms, especially violence, seem to be one of the main motivators for help seeking for the Euro-American and Chinese respondents. Karp describes one incident:

Leslie’s daughter (17 years old) was ‘barricading her door at night, piling stuff up against it, and hung bells on her door so that if the door moved the bells would jingle.’ Her son
(14 years old) was ‘using one of those bars advertised on TV…He was locking himself in with that at night.’ (Karp 2001:9)

Few studies examine the violence against family caregivers by their adult relatives with mental illness, because of fear that this population would be further stigmatized (Solomon et al. 2005). However, as Leslie’s case shows, violence does occur. There is increasing evidence of a link between specific symptoms of mental illness and violence (Link and Stueve 1995, Link et al. 1992, Torrey 1994, Silver et al. 2008), with family members being the most likely victims (Gubman and Tessler 1987, Straznickas et al. 1993, Estroff et al. 1994, Chan 2008). Solomon et al. (2005:40) estimated the prevalence rate of violence within families of the mentally ill to be between 10 percent and 40 percent which is significantly higher than for the general population.

Although none of my respondents reported being hurt by their ill family members, some received threats of physical harm or had feared for their personal safety. These factors significantly affect family members’ level of involvement and their decision to continue providing care. Carol struggles with whether to have her daughter, Jessica, live with her and her son, Sean. Her two children are always quarreling and on several occasions the neighbors have called the police. She told me, ‘My two children are always fighting. The neighbors have called the police several times. Taking care of Jessica is psychologically taxing. I worry that she will kill herself or that she will hurt me or my son.’ Carol mentioned her son is seeing a social worker at school because of his situation at home. On the one hand, she worries about her and Sean’s safety and emotional wellbeing, because Jessica has threatened them numerous times. On the other hand, Carol feels, ‘I am Jessica’s mother, I have to take care of her…I don’t care what others think of Jessica’s illness.’ Carol was forced to grapple with what kind of mother she is and wants to be when Jessica pleaded with her: ‘Don’t make me move out. I am afraid to be by
myself. I will take the medication. I would rather die than go back to the hospital.’ Carol also worries that people will take advantage of Jessica because she is ‘ naïve and not very bright.’ She told me ‘Jessica is not that smart. She is also very immature, more so than her younger brother.’ As we can see with Carol’s case, even if a relative has never been violent, their threats can be just as stressful.

The dynamics may also differ depending on the gender of the individuals. One husband at the support group shared that when his wife gets aggressive he calls the police. However, by the time the police arrive she has calmed down significantly and what they see is a distressed woman crying. The police get a very distorted image of the situation, and the husband is fearful that they might think he is abusing his wife and arrest him. Similarly, the dynamics may differ if the aggressor is a man and the caregiver is a woman. Since men are typically stronger than women, there may be a higher probability of physical harm or more distress in anticipation of violence. Symptoms and behaviors do not have to be violent to be disruptive, as we will see in later examples, but violence is more difficult for families to manage and cope with.

Access to Resources and Treatment

Availability of resources seems to be another major element that influences respondents’ willingness and ability to provide care. Cindy initially joined the support group because she did not know what to do with her youngest son, Dan. For the last ten years, Dan had a hard time finding employment. He did not have to worry about paying for rent and food, because he lived at home with his parents. As time went on, he became more and more isolated, while all his friends got married, had children, and got on with their lives. He became fixated on racial discrimination, believing that the Department of Drug Enforcement turned him down for a job.
because he is Chinese. Cindy shared that Dan is very rigid and is easily upset over minor daily nuisances, such as a car turning without signaling first. Since he did not have much going on, his parents offered to send him to China to learn Mandarin. Dan really enjoyed his time in China, so when he again failed to secure employment in the US, he returned for another visit.

Dan’s condition worsened after his father passed away from cancer two years ago. He started hearing voices from the air vents and demanded that their downstairs tenants move out because ‘it was not safe for them to stay here anymore.’ He believed an ‘overweight White women and a Chinese man’ put surveillance devices inside the air vents of the house to spy on him (these devices also allowed him to hear what they were saying). Dan told me they lived in the neighborhood and he had overheard them saying he is retarded. He has called the utilities companies in the past to tell them about the surveillance devices and warned them that he might pursue legal actions if they did not remove these items for him. His brother Jerry, who lives a few doors down with his wife and two children, has told him he did not hear any voices. Dan responded that he has hearing problems (Jerry wears a hearing aid in one ear) so of course he can’t hear, and requested that Jerry buy him a recording device, so that he can record the voices. Since that conversation, Jerry has installed the recording device for Dan, and has told him if he hears anything, both Jerry and one of his friends will come over to check the vents and the recording device.

Although Dan’s family recognizes his behavior is odd, and that he probably has a psychiatric disorder, they are able and willing to accommodate him. The house that Dan lives in with his mother does not have a mortgage and his father had also put aside money so his family will be taken care of after his death. Cindy does not incur much financial cost with Dan living with her, except for food. I also think she feels lonely since her husband passed away, and
appreciates Dan’s company. Although he does not work or like to leave the house, he is high functioning in many areas of his life. Cindy claimed that he cooks, cleans, exercises, fixes things around the house, plays with his nephews, and is able to drive. Jerry explained he ‘never felt Dan would hurt his children or anyone else. He’s kind of like everyone else, except he hears voices.’ Because Dan had not been disruptive of family routines, there was no real sense of urgency to get him to treatment, even when he started hearing voices. When Cindy told her story to the support group, some participants were very surprised that Dan had been unemployed for so long. They were working class Chinese immigrants who assumed that every adult family member would work and contribute to the household.

Ms. Ng, a Chinese immigrant and single mother, has a very different story than Cindy’s. She shared with me how she first became aware of her son, David’s, illness:

Someone from church had told me something was wrong with my son. At that time, my son was in his second year of college. I was working at a Chinese restaurant so I was only off on the weekdays when he was at school. I always have to work on the weekends. I couldn’t take him to the doctor. Besides, we also did didn’t have health insurance back then…When I saw him at home, he seemed fine. It didn’t really hit me that there was something wrong with him until that night when he got up at 2 in the morning and was opening and closing the bedroom door forcefully. He woke me up. I asked him what was wrong, but he didn’t say anything. He just looked really mad; the vein on his neck was popping out. When he finally got tired, he pushed our dresser against the door. I was very worry because I have never seen him like that before.

Money is a very real concern for many of my immigrant working class respondents, and can play a role in whether mental health services are utilized. The difference in income is clear when we examine the homes of both mothers. Cindy lives in a two-floor townhouse, with one master suite, two smaller bedrooms, 2.5 bathrooms, a furnished basement and a manicured backyard. Ms. Ng lives in a small rental property where she shares the one bedroom with David.
The two main reasons Ms. Ng cited for not taking David to see a doctor earlier was difficulty in getting time off from work and no health insurance—both financial reasons. In addition, like many immigrants, Ms. Ng worked long hours, which may have prevented her from seeing and understanding the severity of her son’s illness. She told me, ‘I will talk to him at night, but did not get into long conversations with him. I had to work the next day, so I would rush to go to bed…When I saw my son at home he seemed fine. If I had listened to others earlier and had taken him to a doctor maybe he would not have gotten so sick.’

Since Ms. Ng did not speak English, she relied on Chinese community-based organizations for information and mental health services.

I learned that patients do best with both medication and psychotherapy. Since my son’s psychiatrist does not offer therapy I had to find another treatment center that did, but I did not know where to find it. I went to XXXX Community Center for help to apply for benefits for my son and that’s where I learned about the family support group. Through the support group I learned about XXXX XXXX House and that they provide both therapy and medication management. My son also attends their day treatment program now.

She also used ethnic media to seek treatment for her own emotional distress.

I also got sick. I couldn’t sleep, eat or drink water. I couldn’t go to work and had to take a leave of absence (by this time Ms. Ng was working as a home aid attendant). I kept thinking when will I get better? If I don’t get better I can’t get to work, and then what? I went around asking people for help, telling them about my situation. I found doctors in the Chinese newspapers. I tried Chinese doctors that practiced traditional Chinese medicine, and doctors that practice Western medicine. My life was consumed by visiting doctors. I probably went to all the doctors in Chinatown.

Although being in the lower socio-economic strata meant Mrs. Ng was disadvantaged in ways Cindy is not, she also benefited in less obvious ways. Her inability to supplement David’s livelihood made the debilitating effects of his mental illness more apparent and increased his
chance of receiving government disability payments. Once an individual is officially recognized as disabled, it opens a lot of doors for other services, such as supportive housing. Since they are in the lower income bracket, David also easily qualified for Medicaid, which provides equal coverage for physical and mental health treatment. Interestingly, unlike respondents that Tessler and Gamache (2000) interviewed in Ohio, my respondents did not view the public system negatively. This may reflect a difference in mental health services across states as some of my respondents have noted. For example, Stacy has pointed out to me, ‘NYC is pretty good in providing services and benefits to patients.’

While Ms. Ng focused on navigating government bureaucracies to get her son into the “system,” which has its own accompanying stressors, Cindy stressed over how to get health insurance for Dan. Although Dan insists he is not sick and refuses to see a doctor, Cindy anticipates a day when he deteriorates so much that they will have to take him to the emergency room. Cindy expressed concern about the cost of his future treatment: ‘I had kidney stones removed. It costs $12,000, but luckily my insurance covered most of it. I can’t imagine how much it would cost if Dan has to pay for medical treatment.’ Although he doesn’t work, and therefore cannot get health insurance through his employer, Cindy worries that he will not qualify for Medicaid or other low cost insurance from New York City, because he received an inheritance from his father.

This is a very legitimate concern for Cindy. Some of my respondents are more affluent than others, but they still are not wealthy enough to pay for their relative’s treatment, psychiatric medications, and rehabilitative services. A friend of my sister told me she prefers to work full time, but she does not because she may lose Medicaid and then won’t be able to pay for her psychiatric medication. Furthermore, most housing facilities and some programs require
participants to have a recognized disability by the Social Security Administration. On one occasion, Paula asked me if I knew of any estate attorney. She is concerned that the inheritance she leaves Joyce will affect services and payments she receives for her illness. Right now she has willed everything to her eldest daughter, Bella, while she tries to figure out how to set up a special needs trust for Joyce that clearly stipulates what the funds can be used for. These socioeconomic differences are less apparent in Karp’s (2001) study, probably because his respondents were predominantly from the middle class.

Cindy’s insurance problem eventually did get resolved because of recent changes in health care policy. Cindy was successful in convincing Dan that whether he plans to see the doctor or not, the recent healthcare reform laws requires that he has health insurance or he will get fined. He was also able to get Medicaid, because a recent change in the qualification criteria uses only income and not assets to determine eligibility.

Having a supportive partner is also an important resource. Previous literature (Cook 1988, Greenberg et al. 1999, Sin et al. 2008) has documented that females tend to be more involved in caregiving, and therefore more emotionally affected by their relative’s illness. Another source of frustration can emerge from husbands’ unwillingness and inability to provide the type of care or involvement that female caregivers expect or desire. Therefore, the stress and unhappiness that these women experience partly reflects a difference in how men and women relate to a child with a mental illness.

Like the other mothers that Karp (2001) interviewed, Leslie was upset that her husband was able to remove himself from the situation and compartmentalize his feelings:

…she also expressed frustration that Bob did not understand her feelings as a mother. Leslie spoke for most of the mothers in this study when she lamented that her husband
‘puts things in compartments. He can go to work and he puts it out of his mind. But with me…it colors everything I do and he doesn’t understand this…What I hoped for all my children (was) for them just to be happy…(Karp 2001:12-13)

Karp further supports his claim with excerpts from an interview with an elderly couple, Nancy and Frank. Calling her husband an escape artist, Nancy complained that he is better able to “compartmentalize” different aspects of his life, referring to his ability to distance himself from their daughter’s illness (Karp 2001:44). Frank concurred with Nancy’s assessment. Another husband commented:

‘My opinion (is that) this (mental illness) is something guys handle better than women…Guys are better at rationalizing…(and) saying, Yuh, I did do as good a job as I can. It wasn’t a great experience, but there wasn’t anything else I could do about it and I learned from it and then moved on.’ (Karp 2001:43-44)

My sample seems to have a gender difference similar to Karp’s (2001). Most of the participants at the support group are females. The average number of attendees at the monthly support group meetings is about 15-20, and there are usually only one or two males present. More importantly, instead of focusing on their husbands’ ability to separate themselves from the situation, my respondents complained about the way their husbands interacted with a mentally ill child. Similar to other wives at the Chinese family support group, Mrs. Lau described her husband as stubborn, bad tempered, authoritative and, like many Chinese fathers, lacking in warmth. These mothers tend to have closer relationships with their children than their husbands, and they act as buffers when conflicts arise between the father and child. As Mrs. Lau explained, her husband does not understand that ‘you can’t use force these days with children, you have to talk to them so you can understand them and show them that you care.’

This appears to be a common problem among mothers at the support group. In the past,
other mothers have expressed difficulties in getting their spouses to change their parenting approach. Two mothers complained that their husbands used physical punishment on their children and that their actions have negatively impacted their children. One mother feels her husband’s frequent beatings of their son when he was young affected his personality and made him more vulnerable to mental illness. Another mother believes her ABC (American-born Chinese) daughter became sick when her father threw a spoon at her. After the father passed away, this daughter told her mother that she feared her father would ‘beat her (mother) to death’ (the mother never indicated that there was domestic violence that went beyond the normative degree of corporal punishment in families). This insensitivity extended to how fathers provide care to their children with mental illness. When Paula’s mother was diagnosed with cancer, she sent her daughter to live with her ex-husband, so she could concentrate on taking care of her mother. However, Paula regrets that decision. Her ex-husband lacked perceptiveness and could not tell when Joyce was decompressing until she had a full relapse. By the time Joyce moved back in with Paula, her condition had deteriorated significantly. More recently, Paula became upset with her ex-husband, because he told Joyce that he wants to move to Seattle and also encouraged her to move there as well. Paula feels that while he just idly threw these words around, she is the one who has to put the pieces back together. I provide more examples in later chapters of how the lack of social support motivates my respondents to seek assistance in the community and in the support group.

Spouses also have to negotiate between themselves on how much support they want to give a child who is mentally ill. In 2006, Mr. and Mrs. Lau were notified that Kevin could be discharged as long as he has a home to return to (one of the criteria to be discharged from a state psychiatric hospital). Since his parents refused to let him stay with them, Kevin had to remain in
the hospital and wait for the social worker to find him alternate housing. In her first telling of this story, Mrs. Lau framed the decision to not let Kevin come home as a joint one between her and her husband. She explained that she lived in subsidized housing and because the lease did not include Kevin’s name, he could not move in with them. Since the Laus were retired and did not have much money, they did not want to jeopardize their housing by letting Kevin stay with them. Later on, for reasons that Mrs. Lau does not know, Kevin was transferred to a different psychiatric center in Manhattan. The doctors at the new hospital had a different clinical judgment and did not think he was ready for discharge. Mrs. Lau believed Kevin was upset with his parent’s decision because he did not send them a Christmas card and was quiet and distant for a long period of time after the incident. In another retelling of the story, Mrs. Lau shifted the blame more towards her husband. She complained that it was her husband who was too worried about the housing board finding out, and implied she was willing to take the risk.

My respondents’ criticism of their husbands has to be understood within the different but complementary roles of mothers and fathers in Chinese culture (Wolf 1970). The role of the father is generally more prestigious and crucial as reflected in the Chinese saying, *yi jia, yi ju*, which means master of the family (Shek 2001). They are primarily responsible for the discipline of children while mothers are responsible for providing nurturance and protection (Ho 1987, Shek 2007). The difference in parental responsibilities is “succinctly captured in the popular expression, ‘Strict father, kind mother’ (cf. Wilson, 1974, p. 73). The father was typically characterized as a stern disciplinarian, more concerned with the demands of propriety and necessity than with feelings, who was to be feared by the child; and the mother as affectionate, kind, protective, lenient, and even indulgent” (Ho 1987:230-231). While mothers may also educate or discipline their children, the role of the nurturer was solely women’s work.
Chinese parents believe loving a child too much could interfere with discipline and lead to a spoiled child, hence the Chinese expression *niai*, which means “drowning love” (Ho 1987:232). Ho (1987) explains how distinct parental roles enable parents to love a child but not too much. Since the father was typically the disciplinarian he was responsible for monitoring and ensuring that his, and especially the mother’s, behavior, did not overindulge the child. Therefore, Chinese fathers tend not to display affection toward their children publicly. In contrast, mothers were responsible for providing “a secure and loving environment within the home” (Jankowiak 1992:347). Given the primary role of mothers as nurturers, they often are accused of spoiling a child as evident in the popular saying, “A kind (soft-hearted) mother brings up mostly rotten sons” (Ho 1987:232).

Although parental roles are not as extreme in contemporary Chinese communities, I believe fragments of this ideal are still entrenched in the culture. Chinese adolescents saw fathers as more restrictive and expressing less concern than mothers (Shek 2000). Holroyd (2003) found that mothers in Hong Kong were often blamed for a child’s mental illness. My respondents used gender ideals to interpret their husband’s response to a mentally ill child and it is also evoked by others in their social circle to explain why a child misbehaves. Her relatives had blamed Mrs. Lau for spoiling her son. Even now, her husband and daughter criticize her for not managing Kevin’s diet and the amount of sleep he gets. Cindy also shared, ‘my daughter-in-law is not a kind person and would say hurtful things. She thinks Dan is the way he is because I spoil him. One time in front of Dan, she told me to kick him out of the house. I turned to her and reminded her that I am his mother and this is my house, and no one is throwing Dan out. Even if I die, this house belongs to Dan.’
Despite being embedded in Chinese culture, the contemporary adherence and enactment of these parental roles is complicated by immigration-related factors, such as long work hours, migration patterns, and different rates of acculturation. In most societies, the process of socialization is from parent to child, but Chinese immigrants in the US rely extensively on their children to guide them through interactions with the dominant culture. This reversal of hierarchies can be stressful for parents (Lee and Mock 2005). Furthermore, parents and children tend to have different levels of acculturation, which can lead to conflicts because of a parallel dual frame of reference (Qin 2006). Parents compare their children’s behaviors to what is expected in China and children compare their parents’ behavior with the parents of their American peers. Parental pressure to excel in school, loss of native language in children, and long working hours that prevent parents from spending time with children, further increases tension and decreases emotional closeness. One girl shared, ‘I know my parents love me, but they don’t really understand what mental illness is. They will ask me why am I depressed, or they will point out that so many people are worse off then me but they are not depressed. I try explaining to them what depression is, but my Chinese is limited.’

Fathers may experience more difficulty connecting with their children, because mothers are often responsible for childcare (Zhou 2009), and therefore they tend to have more intimate relationships with children. In addition, it is often the husband that comes to the US first to settle in, before the rest of the family joins him (Suárez-Orozco et al. 2002). During this time the wife takes on both parental roles; she acts as the head of the household while she develops deep emotional bonds with the children. Therefore, when the wife and children arrive in the US, the father often feels like a stranger with his own family (Sung 1987). While previous work has
examined parental authority and control in immigrant Chinese mothers (Chao 1995, Gorman 1998), more research is needed on Chinese fathers (Chao and Tseng 2002).

**Concluding Remarks**

The goal of this chapter is to use some of Karp’s (2001) findings with Euro-American caregivers to examine Chinese ideals of family obligations, and to clarify variables that affect the enactment of these obligations. It seems that in both groups, respondents tend to delay attributing the erratic behaviors to mental illness, with female relatives, usually more involved. Since the onset of their family members’ psychiatric disorders tends to be around adolescence and young adulthood, many respondents may have attributed the erratic behavior to the stress and confusion of maturing into an adult. With the Chinese cases, the delay in labeling may also reflect individuals’ unfamiliarity with a biomedical model of mental illness and efforts to protect an ill family member from stigma. It is in the recognition of the illness’ chronicity and that long-term care would be needed, that we start to see differences in both groups. Chinese respondents seem to have a higher tolerance for disruptions in their lives and did not pathologize their involvement with a family member. This is most likely because their sense of self is tied to fulfilling obligations to an ill family member. However, the enactment of obligations is constrained by other factors, such as symptomology that is difficult to manage, and the availability of social and financial resources. While this chapter examines obligation in a very general way, the next chapter focuses on how factors, such as age, class, and family position, affect my respondents’ interactions with their ill family member.
Chapter Four: Caregiving and the Family Life Cycle

Father: Why did you ask Dr. Leung to refer your mother to a psychiatrist?
Daughter: You really don’t think there is something wrong with her?

In the previous chapter, I offered a broad view of my respondents’ understanding of family obligations, highlighting the normative Chinese expectations of high involvement that is framed as a duty. Here, I will focus more on the particularities of my respondents’ individual situations that affect their perception and performance of care. In the first section, I examine the contexts in which Chinese sisters assume the primary caregiver role. Although sisters may feel obligated to help their ill sibling, other aspects such as disease symptoms, financial resources, and competing family responsibilities can greatly impact their ability and willingness to help. Furthermore, Chinese mothers also express ambivalences on how involved they want their healthy children to be. Previous research on mental illness and sibling caregiving has been limited, so my findings will contribute case material and identify issues that may be specific to immigrant Chinese families.

In the second section, I shift my unit of analysis to Chinese mothers and sisters who are primary caregivers, focusing on how life cycles and the illness trajectories (including the associated disabilities) create a similar dynamic between caregiver and care recipient, with the former assuming a role of authority and the latter taking on a child-like dependent status. When appropriate, I will explain the role of socioeconomic status in both sections. The primary goal of this chapter is to demonstrate that caregiving is a process that is situated in everyday life and evolves as the life cycles of families and individuals change.
Sisters and Mothers

Since deinstitutionalization, most research focused on mothers, because they are typically the main caregivers and the ones blamed for causing the illness by clinicians (Smith et al. 2007). However, as many of these mothers approach the end of their lives, their other children may have to assume the caregiver role. In normative sibling relationships, siblings turn to each other for support when other bonds terminate as a result of death, divorce, or relocation (Bedford 1998, Ciorelli 1995). The importance of sibling support is magnified in individuals with mental illness, because they generally have few intimate relationships. Within the diagnosis of schizophrenia, men tend to remain single, while women are more likely to get married (Lefley 1996). There is also a difference in diagnosis in that individuals with affective disorders are more likely to be married than individuals with schizophrenia (Lefley 1996). In general, persons with severe and persistent psychiatric disorders rarely get married or have children (Kramer 1983, Tsuang and Faracone 1997, Smith et al. 2007), and therefore tend to experience the illness as a single person within their family of origin, rather than a married one within a conjugal family (Lefley 1996).

Tessler and Gamache (2000) found that compared to other familial relationships, parents experienced the most gratification in their caregiving role. In addition, the parent-child bond may be the strongest of all family bonds, and therefore the least tenuous in persistent dependence (Tessler and Gamache 2000, Cook and Cohler 1986). Since parents are a strong source of support in all ethnic groups (Horwitz and Reinhard 1995), cultural differences in family obligations will more likely be present in other family relationships, which is why we need to examine sibling caregiving. Despite being one of the most enduring relationships for persons with psychiatric illness, there are few studies examining how mental illness affects healthy
siblings and their role as intended and actual caregivers (Horwitz 1993, Horwitz 1994, Seltzer et al. 1997, Hatfield and Lefley 2005). Below, I outline some of the major findings in this body of literature on Euro-Americans siblings and then discuss how my research contributes to it.

Sin et al. (2008) argue that early family interventions for children with mental illness center on helping parents cope, while the needs of other family members, in particular healthy siblings, are overlooked. They identified both similarities and differences between the healthy adolescent siblings in their study with healthy adult siblings in the previous research. The adolescents were less involved in everyday caregiving tasks, and less aware of the genetic inheritability of mental illness, but they played a larger role in providing opportunities for ill siblings to socialize and participate in normalizing activities (Birchwood 2003, Stein and Wemmerus 2001). Similar to findings in the adult siblings literature, Sin et al. (2008) detected a gender distinction in that females were more involved in caregiving, and received more assistance as care recipients. This may reflect the socialization of females to nurturing roles and the caregivers’ view that female patients have less challenging behavior (Greenberg et al. 1999, Lohrer et al. 2007).

In general, it seems that the quality of sibling relationships, particularly during adolescence, predict future involvement in caregiving (Smith et al. 2007, Greenberg et al. 1999, Jewel and Stein 2002). Healthy siblings are also more willing to provide assistance to ill siblings when they viewed the relationship as reciprocal (ill relatives reciprocate through affection, gifts, chores, etc.) and when they are able to identify gains and gratifications from their caregiving role (Horwitz 1994, Smith et al. 2007). However, the nature of their assistance emphasizes emotional and social support (inviting ill family members to family events, support during crisis, social visits), rather than instrumental (providing housing, monitoring medication, helping with

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Judge (1994) determined that when support was more practical there tended to be feelings of tension and conflict. It seems siblings are not substitutes for parental care because the former prefers to offer support that is emotional, periodic and does not required daily contact (Horwitz 1993). The research, therefore, suggests siblings will most likely assume a more secondary role in future caregiving, and rely on the mental health system to provide more practical assistance to their ill siblings (Smith et al. 2007).

In addition, siblings seem more ambivalent than parents in regards to their presence in their ill brother’s or sister’s life. One sister in Karp’s (2001) research project, Angie, commented, “…I do feel like your family comes first. But by the same token, how much…is realistic for a sibling to give up? Are you supposed to give up your life? And (give up) your career? I mean, (do you give up) your hopes?” (2001:130). Angie still struggles with her role in her brother’s life, even after he committed suicide, as seen in the following comment, “Should I give up having a life, like my parents did, to help my brother who was getting progressively worse? You go back and forth. There is no clear answer.” (2001:131). While her father understands Angie has to live her own life, her mother’s expectation that she does everything she can for her brother amplifies her guilt. Angie stated, “I guess my mother and I are just different…Maybe she’s more unselfish than I am. She would do whatever had to be done, (whereas) I think sometimes you have to be a bit logical.” (2001:132). I want to note here that what is “logical” is culturally grounded in the notion that caregiving is a choice. For Angie, it doesn’t make sense for her aging parents to continue proving home care to their son, whose illness is progressively getting worse. If she remarries, it is also unfair for one person (her brother) to disrupt the lives of her children and her husband.
In the following paragraphs, I discuss how my research speaks to the above findings. I spoke extensively with five sisters (not counting brief conversations with other sisters and observations at the family support group); two of these women are my key informants and are the primary caregivers to their ill relative. This low number of sisters may reflect the secondary role that siblings tend to play cross-culturally when parents are alive and capable of caring for a mentally ill child. Hanna, who is her sister’s main caregiver, also noticed the low number of sibling caregivers and shared: ‘We Chinese people…it is usually the parents that take care of children. Rarely do you have siblings providing caregiving. Stacy is different, because her parents have passed away, and she only has her brother. It’s the two of them for the rest of their lives, so she has to care for him. If you look at our support group, it is mostly parents…that provide care to patients.’

While there is a cultural expectation to help an ill relative, there are also external factors that encourage siblings’ willingness and mediate their ability to provide care. Like Stacy, Hanna’s parents have passed away, and both women’s ill siblings do not have spouses or children to provide assistance. Stacy’s brother, Cory, never got married. Hanna’s sister, Laura, was married and has a son, but she and her husband divorced early on and her son left. Her paranoia was so disruptive to her son’s professional and personal life that he felt the need to discontinue all contact with his mother and all his maternal relatives. Currently, Laura does not know where her son is and has no way of contacting him. The other three sisters I interviewed provide minimum emotional and instrumental support to their siblings because their siblings live with their parents or family of procreation. One woman’s brother lives with his parents and the other two women have sisters who are married and reside with their husbands and children. Since most persons with severe and persistent psychiatric illness don’t get married, the general
order of involvement, like previous research, is first with parents and then siblings.

However, unlike siblings from the literature cited above, the siblings in my study seem to take over parental care in that they provide both social and practical support when they become the primary caregiver. Tessler and Gamache (2000) pointed out that caring for and caring about may not necessarily be linked, because family members may refuse to perform tasks, such as cooking, cleaning, helping with personal hygiene, but still care deeply about their ill relative. And conversely, family members may be involved in daily mundane tasks, but not care about their ill relative. Hatfield and Lefley (2005) also found that Euro-American siblings emphasized emotional support more, because unlike practical support, you can’t buy it or obtain it from the public system. My findings, on the other hand, indicate that many Chinese family caregivers stress both practical and social support. In an informal survey of service changes they would like to see in the mental health system, participants at the Chinese family support group stated two main items: 1) getting paid as home aid attendants for the practical caregiving tasks they perform for their ill relative (family members are prohibited from being paid caregivers to their relatives); and 2) more day treatment programs, club houses, and recreational activities for patient socializing. Often times, caring about and caring for cannot be teased apart, because love is shown through very practical ways in Chinese families.

There are two main points I want to convey with the following sibling case studies. First, as argued in the last chapter, Chinese siblings have a more interdependent orientation than Euro-American siblings, which is manifested in a higher level of involvement expressed in more pragmatic and culturally appropriate ways. Second, despite a cultural value to support one’s family, there are a multitude of factors, including severity of symptoms, family members’
openness to receiving help, financial resources, and competing family responsibilities that influence siblings’ decision to provide care.

Stacy and Hanna

Although Stacy does not live with her brother, Cory, she still has to do a lot of things for him. After his parents passed away, Cory continued to live in the low-income housing complex that he had shared with them. Stacy came over to check on him frequently. Each week she prepared all his psychiatric medications into a pill case and reminded Cory’s home aid attendants to watch him swallow the pills. Stacy also handled all the correspondence with the apartment building’s managing office, submitted maintenance requests, and waited for them to come in. She tries her best to accompany Cory to all his doctors’ visits and checks in regularly with his social worker. Stacy always spends the holidays with Cory and takes him out to dinner every weekend. Because she does not cook, she pays a family friend to make him home cooked soup and then brings it over to her brother. Home cooked soup, in particular for Cantonese people, is tied to general wellbeing and conveys care and concern. When he was hospitalized the last two times, I observed that she would visit him almost every day and bring him Chinese food that had been purchased at restaurants. One time she asked me to get take-out in Chinatown for him, requesting that I get a dish with a particular Chinese green that is Cory’s favorite.

After Cory moved into group housing for individuals with developmental disabilities, his routine changed and Stacy had to make some adjustments in her life as well. He stopped attending his day treatment program, and thus he rarely went out, except to see the doctor. As a result, Stacy made more effort to see him on the weekends; she worried he would feel too isolated living in the group home. She also explained, ‘the residents have a kitchen where they
prepare meals and eat communally. They post the menu on the fridge, and it is mostly American food. He gets tired of eating that food. That’s why I take him out to get Asian food in Chinatown on the weekends’. Here we see that Stacy stresses social and practical support.

Stacy also has to manage Cory’s relationships with his housemates. When she visits him she stays out of the bedroom that he shares with another resident. Stacy liked her brother’s first roommate and often invited him to come to dinner with them on the weekends. After he moved out, Cory got a new roommate of whom Stacy was not too fond of. This new roommate kept drinking Cory’s Gatorade without asking him. (They originally attached labels with Cory’s name on beverages and left them in the communal refrigerator. However, other residents ended up taking them.) Initially, Stacy told Cory to put his drinks away, so they are not be in plain view. Stacy cannot understand this roommate’s behavior, because ‘his father works at Trader Joe’s so why can’t he afford to buy drinks.’ If hiding the Gatorades does not work, Stacy plans to speak to the father or to the staff at the group home.

Hanna is much less involved with her sister, Laura, than Stacy is with her brother. This is because Laura does not think she is ill and refuses to take medication. Because of her paranoia, she believes Hanna killed their parents and refuses to see her. Hanna explained, ‘My sister has a lot of yang (the complementary life force to yin and is associated with masculinity) in her, so she is feisty...curses me out all the time, and won’t listen to others.’ A couple of times in the past when Laura was involuntarily committed into a psychiatric wards, Hanna was able to convince her to go back on her medication and move back home, but Laura would always stop taking the medication and then disappear. She currently lives alone in Brooklyn and refuses to see her family, unless she is the one who initiates contact. Laura’s rejection of assistance from her natal family forces Hanna to help her behind the scenes without her knowing.
Laura believes in socialist ideals, so she doesn’t think she should have to pay for her landline phone bill or her rent. Consequently, in the past her phone line had been disconnected, and she owed her landlord several thousand dollars in back rent and was at risk of getting evicted. Hanna was not comfortable that Laura couldn’t be reached or call for help in emergencies, so she set up an automated payment by linking Laura’s phone account to her checking account. After paying for Laura’s rent for several months, Hanna and her other siblings decided this was not a feasible option in the long run. They worked out with the landlord that they would deduct rent from Laura’s month disability check before giving her the rest of the money. The landlord would then tell Laura that the rent deduction is a new legal requirement.

On another occasion, Laura caused a racket in her neighborhood when she started banging on the radiator. Hanna believed Laura may have been hearing voices and was making noise to drown them out. Some of her neighbors yelled at her outside her building and threw rocks at her window, but she didn’t stop. Hanna went around apologizing and explaining her behavior to the neighbors. I inquired why she does not call the police and get her involuntarily committed. She explained, ‘I did one time, but it was so traumatic for her. The police busted open her door, pushed her down and handcuffed her. Laura was very scared. I don’t want to do that to her again.’

Besides a cultural expectation for Stacy and Hanna to provide care and support to their siblings in both emotional and practical ways, there are other factors that enable them to take on this role. In many ways, Cory’s illness is easier to manage than Laura’s. First, he is relatively stable and his residual symptoms are not disruptive. Second, he is also open to receiving help and has given Stacy the power of attorney to make treatment decisions on his behalf and access his
medical records. Third, Cory lives in a group home that is staffed 24 hours with clinical staff, so Stacy can work and not have to supervise him. Fourth, since Stacy is not married and does not have children, she has limited competing family responsibilities.

It doesn’t seem likely that Stacy will have many competing responsibilities in the future either. Her experiences of taking care of her parents and mentally ill brother have significantly impacted her decisions regarding romantic relationships and starting a family. Stacy shared:

I dated a man with multiple sclerosis and my friend said to me you have to care for your brother, do you also want to care for your partner as well? If I did not have my brother, I would have continued my relationship with this man. Another friend told me you would need to find someone who wouldn’t mind your family problems. I have dated some men briefly in the past. With most of them, I never talked about the future and only some of them have ever met my brother. The few that have, did not mention anything afterwards. Cory and I are opposites, he is really dependent and I am really independent. I am okay without having a partner.

Witnessing the relationship between Cory and her parents, Stacy is certain that she does not want to have children. ‘Parenting is very hard…What you do can affect your children for the rest of their lives. My mother was overprotective of my brother, and therefore he is so dependent…he’s a mama’s boy…During a very difficult period, I almost collapsed taking care of my brother. I don’t want the pressure and anxiety of taking care of a child.’ It is very common for healthy siblings to struggle over when and how to tell a partner about having a mentally ill brother or sister, and be anxious over how a partner will react (Karp 2001, Sin et al. 2008). There are also concerns about the genetic vulnerability of future generations. However, it seems Stacy has come to terms with not being romantically involved with another person, and has ruled out being a mother.
Her brother’s illness and her parent’s denial of it have also influenced her career choices. She told me, ‘I was deciding if I want to return to my old job. I have two co-workers who suffer from depression. One keeps to herself, and I just stay away from the other one when she gets emotional. If I go back I will have one at home and two at work.’ Part of the reason Stacy decided not to return to the newspaper company, despite having difficulties finding a job, is that she does not want to be surrounded by people with psychological problems. She has also ruled out any job that is related to the mental health field.

Laura’s belief that she does not have a psychiatric illness and her refusal to take medication makes it difficult for her family to provide her with assistance. Despite her sister’s resistance, Hanna develops strategies to help Laura without her knowing. Her current physical health, economic, and family situation enable her to extend herself to Laura in a way that other family caregivers may not. Although she is 70 years old, Laura has few health problems and no issues commuting and walking. She also has the time and few competing family responsibilities, since she is retired, her two sons are grown up and out of the house, and her parents have passed away. Since her husband and younger siblings work, Hanna spends most of her day alone, giving her time to manage family affairs. Hanna explained, ‘All my siblings work in American companies, some of them are in pretty high positions. I am the only useless one that doesn’t know English. I try to help out in other ways. I watch out for Laura and do things like, keep an eye on the contractors when they do renovations at my siblings’ houses.’ She seems to genuinely enjoy helping her family out. Currently, one of her nephew lives with her, because it is more convenient to commute to his university from Hanna’s house than from his parents. Acting like a surrogate parent, Hanna cooks and cleans for her nephew, and keeps tabs on his whereabouts. Not all families are able to provide the amount of assistance that Hanna can. While
many scholars have argued that the Chinese emphasize loyalty and duty to one’s family, things become complicated when fulfilling your obligation to one family member may hurt another. I will elaborate more on one sister’s story in the next chapter, but for now I just want to point out that this sister felt very guilty when she could not let her brother stay with her and her family. At that time, her brother refused to take medication and had violent tendencies, so she and her husband decided they couldn’t risk having him in their home with their two young children.

Maternal Expectations of Sibling Involvement

Pruchno et al. (1996) concluded that while parents hope healthy siblings would be considerably involved in their ill brother or sister’s life, they don’t expect it because they assume their children would be busy with their own lives. Similarly, out of 210 elderly parents, Hatfield and Lefley (2000) found that 63 percent turned to patients’ siblings for help planning the future, while the remaining one-third were considered not helpful. The mothers in my study also recognize the external factors that prevent their healthy children from assuming the caregiving role. Paula has no doubt that her eldest daughter, Bella, will take care of Joyce when she passes away; however she does not want this to consume Bella’s life. A year ago, Bella and her family moved to Kuwait so that her husband could take over his family’s business. Although Paula misses her daughter and granddaughters, she feels it is best that Bella is far away:

When Bella was living in New York City, Joyce will drop by unannounced several times a week. Bella has asked Joyce to call before she comes over; just because she is home does not mean she is free. When Joyce drops by, Bella will have to stop whatever she’s doing to entertain her sister. This annoyed Bella’s husband. Although he never said anything to Joyce, these visits were a source of conflict between him and Bella… Bella will always want to take care of Joyce, but she also has to live her own live. It also doesn’t help that Bella’s husband thinks mental illness is just stress and you can
overcome it. He has not told his family about Joyce’s mental illness. They are too old school.

Mrs. Lau’s eldest daughter, Karen, is married with two sons, and is the most stable and reliable out of all her children. However, being a mother and wife herself, she knows she can’t expect her daughter to be too involved with Kevin’s care, because ‘she has her own family to care for. Besides they live out in New Jersey and she is so busy at work.’ While she understands her daughter’s circumstances Mrs. Lau does not always approve of her actions. She described her elder daughter as a caring sister. In the early days of his incarceration she would visit Kevin often, but then she got married, had children, and moved to New Jersey with her family. Between her full time job and childcare, she did not have much time for Kevin and her visits became less frequent. She also did not tell her sons about Kevin, so even as teenagers, they were not aware that they had another uncle. Compared to other respondents and their families, the sister was very concerned with the stigma of mental illness, and took rather extreme measures to hide it from her sons. She justified the omission as a way to protect the life and educational opportunities of her sons, but Mrs. Lau feels her daughter is being overly cautious. She brought up another incident that annoyed her. They were finalizing plans for her daughter to come to NYC for a family celebration. ‘She was complaining that she’s so busy and implying that it was a hassle to drop off Kevin at his housing unit. You know, if she doesn’t have time he can just take public transportation home by himself. I know she’s stressed lately…I’d rather her take her frustration out on me than on Kevin.’ While Mrs. Lau does not expect her daughter to be actively involved, she should not be a source of stress for Kevin. Mrs. Lau and Paula demonstrate how priorities shift as families evolve.
Conflicts between parents and siblings may also emerge due to different interpretation of caregiving and doing the best thing for the ill relative. One sister shared:

I know that once my parents pass away, I will have to take care of my sister and we will probably live together. I don’t think my parents expect me to replace their role as my sister’s caregiver, but I feel obligated and also want to do it. However, she’s not going to have a free ride and throw her little tantrums the way she did when she was living with our parents. I expect her to help out around the house and to start seeing a therapist and a psychiatrist. My brothers may contribute in monetary ways, but they are not attentive and nurturing people. I half jokingly tell my boyfriend that my sister will live in our basement. I want to test his reaction and prepare him for what life will be like if we get married.

This sister’s narrative reveals some of the recurrent themes previously noted, including positive affect related to fulfilling obligations and the nurturing role often assumed by females.

Sometimes siblings may assume caregiving responsibilities, even while parents are still alive and physically capable. During a conversation with a young couple, Bob and Sue, who were attending the family support group for the first time, I learned of their story. Sue explained:

My brother-in-law, James, has a developmental disability and has schizophrenia. But we are not really here for ourselves. We want my husband’s parents to come. They are very old school and don’t want to accept that James has a mental illness. They got James to marry this woman in China, but once she came to the US, James’s condition rapidly deteriorated. They argue a lot, even though they can’t really understand each other. James speaks very little Mandarin and his wife cannot speak English. The wife also feels she was cheated, because my parents-in-law never alluded to James’s illness. It wasn’t even like they told her he is kind of slow. James moved in with us, we found him a psychiatrist and a therapist, and we are in the process of helping him apply for disability. My parents-in-law still don’t understand and they will say things that upsets James like, “you’re fine now. You don’t have to continue seeing the doctor. Doctors just want your money.” They want him to move back home, but we don’t think it is a good idea. My husband and his older brother have a hard time explaining the situation to their parents, because they cannot speak Mandarin too well. As a daughter-in-law, I don’t want to say too much and tell them how to take care of their son.
Sue’s narrative reveals the myriad of complexities that emerges in family relations when there are generational differences in acculturation levels and fluency in the heritage language. Although Bob’s parents have lived in the US for several decades, they chose to stay within their ethnic community and remained fairly closed off to mainstream American culture. Since psychiatric illness and developmental disabilities are still extremely stigmatizing and shameful in the overseas Chinese communities (Kung 2003), the parents have difficulty accepting that their son has both. In their attempt to create a visage of James as a “normal” adult male, they pushed him to marry a woman from China. The parents refused to look at the Chinese language resources on mental illness that Bob and Sue would leave around the house. They not only wanted James, but also Bob and Sue, to move back in with them. James says he wants to go home, but Sue explained, ‘When he says he wants to go home, I think what he means is that he wants things to go back to the way they were, before his wife came, before he had to take medication.’ The conflict between the parents and their children is complicated because both groups lack a shared language to communicate in. Sue often has to be the translator for her husband and her in-laws, but she feels she is too much of an outsider to get into a private discussion with her in-laws about managing James’ condition. Currently, an aunt is the main mediator between the two generations. Bob and Sue’s situation validates numerous previous findings on mental illness in Chinese culture, including the highly stigmatizing nature of psychiatric illness, the importance of a trusted family member or friend in accessing treatment, and the role acculturation plays in accepting a diagnosis and seeking treatment (Atkinson and Gim 1989, Kung 2003).

While some Chinese siblings may not mind taking on more caregiving responsibilities, they may have to negotiate with parents on the type of assistance to provide and what is the best
thing for their brother or sister. It is in these negotiations that the ideals of motherhood and tensions in family relationships become apparent. Although it is a lot of work being her brother’s caregiver, Stacy’s anger and frustration is directed towards her mother, who in her opinion was not a good mother. Ever since they were children, her mother had different standards for Stacy and Cory, which Stacy felt contributed to the sibling rivalry between her and her brother. Stacy always had to get good grades but not Cory. After they immigrated to the US, Stacy’s mother expected her to take care of all the tasks requiring English, such as communicating with the management company of their apartment. She also wanted her daughter to pay for everything, and Stacy, to a certain extent, wants to be able to do that for her parents. Stacy shared, ‘If I can pay for it, I will. But I’m not making a lot of money and also have a mortgage to pay.’

Stacy believes the only way her mother knew how to protect her children was by sheltering them, rather than teaching them to be independent and to stand up for themselves. ‘Growing up, my mother did not like us going out because she thinks we will learn to do bad things from our friends. My brother listened to her, so he never had any friends. I grew less and less compliant as I got older. The first time I went to the movies with my friends was when I was a senior in high school’. The most obvious sign of her mother’s failure is her response to Stacy’s abuse. Below is an excerpt of Stacy’s recount of her sexual abuse:

I can still vividly remember it like it was yesterday. I was about 7. We were living in Hong Kong in a walk up building. I wanted to go out outside, I don’t remember why. My mother did not want me to, but I did not listen to her. As I walked down the stairs, there was a man standing in the stairwell. He stopped me, put his hands into my pants, and then he ran away. I ran back upstairs and told my mother, but she did not do anything. Shouldn’t she have called the police?
Stacy then traces her mother’s bad parent philosophy and practices to her maternal family in her description of a second incident of sexual harassment:

I was in my teens this time. I was on the bus with my maternal grandfather. There was a fat guy sitting next to me. He rubbed his erect penis against my thigh. My grandfather saw this, but did not do anything. When that man touched my arm, I yelled and told him if he did not stop I will call the police. He got off the next stop. I started crying. My grandfather did not do anything. My family does not know how to protect us. The only way they know is to tell us to stay at home.

Stacy’s mother was always babying Cory, doing everything for him, but her worst disservice to him was refusing to recognize his problems. ‘Even in her death bed she would not admit that he has problems.’ Although she knew that her son was slower than other children in his class, she let him stay in regular classes rather than putting him in a special school for more individual attention to his specific learning needs. When her brother was diagnosed with schizophrenia and mild retardation in the US, her mother lied to other family members and friends that he was working and doing fine. Stacy’s mother wanted to find her son a wife from China or Hong Kong, because she thought it would make him better. It was only after her mother passed away that Stacy could enroll her brother in a program for individuals with mental retardation.

I want to point out here that Stacy’s model of a competent mother represents just one ideal out of numerous cultural models and is interpreted through her own personal experiences. I witnessed a conversation between Cindy and another father from the family support group. This father commented that Cindy should feel grateful that her older son helps out with Dan. In response to his remark, Cindy stated, ‘Do you know how much my husband has helped him (older son)?’ The subtext of this statement is that Cindy and her husband have raised him, put

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him through school, and has helped him financially, and therefore he has the obligation to repay them through supporting Dan emotionally. This father, in turn, offered a different perspective of parenthood, ‘We as parents just give. We don’t expect to get something back.’ These two parents provide different interpretations of the obligations between parents and children. My respondents often have to contend with competing virtues of what it means to live a good life and to be a good person, which is much harder than simply choosing right from wrong.

**Caregiver and Care Recipient Relationship**

In this section, I examine why cross-culturally, caregivers and their relatives with severe and persistent mental illness often have a parental/authority-child/dependent type of relationship. Then I discuss how my respondents react to their ill relative’s inability to meet adult milestones, such as marriage and finishing school, and assume a parental role. Although there seems to be a level of acceptance of their family members’ limited life opportunities, respondents attempt to manage their behavior. Through identifying similarities in the strategies my respondents use to teach their ill relatives with the childrearing practices Chinese mothers use with young children, I argue my respondents are attempting to communicate how to be a “good and proper” person in Chinese culture.

Individuals go through normative life stages that are marked by specific milestones with a general timeline for reaching them. Severe and persistent mental illness that impairs functioning and causes enduring disabilities disrupts the life cycles of patients, caregivers, and more broadly the family life cycle. Patients are unable to fulfill societal roles normally expected of persons of their age, physical intactness, and intellectual capacity, and the caregivers often
have to modify their lives to help their sick family member (i.e., parents delay retirement, so they can help a mentally ill child financially).

Carter and McGoldrick (1989—as cited in Lefley 1996:82-83) identified six basic stages in the family life cycle of middle class nuclear families in the US:

1) Single young adults leaving home; accepting emotional and financial responsibility for the self.
2) The joining of families through marriage; the new couple, with commitment to a new system.
3) Families with young children; accepting new members into the system.
4) Families with adolescents; increasing flexibility of family boundaries to include children’s independence and grandparents’ frailties.
5) Launching children and moving on; accepting a multitude of exits from and entries into the family system.
6) Families in later life; accepting the shifting of generational roles.

While the stages are based on a Western nuclear family system, and therefore may not reflect childrearing patterns, kinship roles, and fluidity of boundaries in other cultures, most of these developmental stages are essentially universal (Lefley 1996). Generally, there are milestones that mark the shift to young adulthood, with marriage being the hallmark of the transition from adult child to the spousal role. Furthermore, there is commonly a reversal in generational roles; as children grow older, parents’ obligations to them decrease, and children take more responsibility in ensuring their aging parents receive adequate care.

I contend here that patients’ failure to pass through culturally normative life stages, in a specific sequence and at appropriate ages, creates a parental/authority-child/dependent relationship. Landy (1977—as cited in Tessler and Gamache 2000) asserts that, with a physical illness, acceptance of the sick role by the caregiver and care recipient requires the adoption of a dependent childlike status. Tessler and Gamache (2000) argue that this relationship is applicable
to cases of mental illness. Parents and siblings, particularly older siblings, routinely act as
guardians and provide behavior management to minor children and siblings. This power
dynamic tends to be reproduced in caregiving relationships with persons who have psychiatric
disorders. Lefley (1996) compares this dependency-independency conflict to the one typically
found between adolescents and parental figures.

The Chinese concept of *yang* and *laiwang* offer an indigenous framework to understand
how ill relatives’ transition to adulthood is interrupted by their illness. Parents *yang* (to care for),
their children and in their old age their children are obligated to return the care (Stafford 2000).
This notion is closely related to patriliny and the Chinese emphasis on *xiao* (filial obedience), but
it does not require actual blood relations or vertical decent. Therefore, obligations of *yang* can
be between foster parents and children, a sister who has raised and cared for her younger
siblings; while the failure to return *yang* could result in termination of “natural” descent ties (i.e.,
a father disowns a son who fails to provide for him). *Laiwang* describes the reciprocal
movement back and forth between people who have a relationship of mutual assistance, and can
be seen as an extension of *yang* (Stafford 2000). Both *laiwang* and *yang* are based on a cycle of
mutual support that is built on small actions and transactions and involves commensality,
transfers of money, and the sharing of responsibility. For example, a man gets loans and gifts
from friends, kin, and neighbors to build a new house. If the son of one of these individuals is to
get married, the man is obligated to attend the ceremony and help pay for the banquet (money is
taken in lieu of gifts at Chinese weddings). These minor transactions are crucial to building up
relatedness between people who are not related by blood. Given the emphasis Chinese societies
place on personal networks and how individuals’ social roles and duties are defined by their
relationship with others (Yang 1994, Bond and Hwang 1986), I contend that it is an ill relative’s
inability to participate in these cycles of reciprocity, in particular caring for their elderly parents, that marks him or her as a child.

The age of onset of a psychiatric illness is a significant factor in determining whether an ill relative can participate and fulfill obligations to others in their social network. Since independence is contingent on individuals’ education and skill levels, and social competences, Lefley (1996) asserts the age of onset, rather than the diagnosis, determines the likelihood of independent living. The earlier in life people become ill, which is often the case with severe psychiatric illness, the less likely they would have acquired these capabilities. Furthermore, because severe and persistent mental illness oscillates from acute to more manageable symptoms it is unlikely that affected individuals can remain stable enough to acquire competences, particularly at institutions outside of the family, such as schools and places of employment.

While patients’ dependency on caregivers may be common across societies, the way caregivers and their ill family members interpret and enact kinship roles, and respond to each other is shaped by cultural norms, and their personal experiences and circumstances. For example, assuming a parental role may be more difficult for some caregivers. One Euro-American wife reported that she wants to “…still be a wife and not a mother—because when he is really sick I would describe my behavior (toward him) as mother-like.” (Karp 2001:139).

Below, I discuss how my respondents’ older age and the length of time their relative has been sick influence their response to their family member’s inability to accomplish culturally-valued goals of getting married, and excelling in school and professionally. Although there is sadness regarding the loss of a potential life a family member could have had, there also appears to be a sense of overall acceptance of their family member’s limitations. Respondents, however, continue to stress the cultivation of a moral self (I use moral, in the sense of what is culturally
valued) in everyday interactions by reminding and demonstrating to their relatives with mental illness how to be sensitive to others’ feelings and to be a contributing member in the family and in society.

Marriage

Marriage is an important milestone for individuals cross-culturally, but it is especially significant in Chinese culture, because it is through marriage and childbirth that individuals fulfill their duty to continue the family lineage and realize two of the milestones to personhood (Yan 2003, Stafford 2006). Therefore, many Chinese families attempt to find a spouse for their family member with a mental illness (Pearson 1993, Pearson 1995, Lin and Lin 1981). However, I found that many of my respondents actually prefer their ill relative to remain single. They also did not appear overly concerned about the genetic disposition of mental illness in future generations as I had expected. Instead, most of the women expressed fear that their sick family member may get emotionally traumatized, that they lack the maturity to manage a marital relationship, or they saw marriage as a potential stressor. Some expressed fear their family members’ martial conflicts may spill over to their lives, increasing their caregiving burden. To illustrate these concerns, I present three caregivers’ thoughts about marriage below.

One time over tea, Mrs. Lau told me, ‘Kevin talked about finding a girlfriend, I told him he needs to focus on himself and not to think about these things.’ Given his history of violence toward women, she fears Kevin will get into trouble if he gets involved with women. She knows he will be locked up for a long time if he commits another felony. Despite her reservations, she is sad that Kevin and his brother will probably never get married. In a conversation about Kevin’s future care, she lamented, ‘If my sons had wives I would not be so worried about them.’
This statement suggests Mrs. Lau sees a clear distinction in gender roles, with women being the nurturers and essential to men’s wellbeing. She also struggles with getting older and worries that no one will be around to help take care of Kevin after she passes away.

One night over dinner, I asked Stacy about marriage. Below is an excerpt of our conversation.

S: One of my mother’s greatest regret is that my brother and I did not get married and have children. You know when my brother first got sick, my mother considered finding him a wife because she thought it would make him better. I think it will just exacerbate his symptoms. I’m so glad it didn’t happen. (Smiling) You know he has a girlfriend right now at his day treatment program.

L: Oh, really?

S: It’s not what you think. They are more like platonic friends. They only hold hands and see each other at the activity center and sometimes talk on the phone. She is cute, so she has many other boyfriends besides him.

L: Do you think Cory can get married one day?

S: I know he wants to, but I don’t want him to get married.

L: Because the children might have a genetic vulnerability for mental illness?

S: There is that, but my main concern is that he does not have the emotional maturity to be married. Also, he can’t take care of any children he has. This will only increase my burden. For instance, I can imagine having to go over and mediate every time he gets into an argument with his wife.

Stacy explained that marriage and children, for her mother, are natural stages in one’s lives and related to the continuation of the family line. Stacy was glad that it never happened, because she can imagine being pulled into managing her brother’s marriage.

Below is a part of a reconstructed conversation with Paula about marriage.
L: Do you want Joyce to get married?

P: No, I don’t want her to. I don’t really know her boyfriend, Andy, that well. Also, when Joyce first got sick, she was making progress in her recovery until her boyfriend at that time broke off the engagement. The young man was older than Joyce, very accomplished and came from a wealthy family. After Joyce got sick, he came to me to ask for Joyce’s hand in marriage, and I told him to think this through clearly, it’s a big responsibility. I asked him if he was sure he is ready for this type of commitment. I eventually gave him my blessings. He later broke off the engagement because of pressure from his family; they want him to marry someone accomplished and who does not have a mental illness. Joyce was devastated. I don’t want Joyce to get hurt again.

While Stacy’s parents saw marriage as essential to personhood and the continuation of the family line, the range of responses indicate respondents have different priorities, and vary in how much they adopt this view of marriage. Unlike her parents, Stacy does not think having a spouse and children is what defines a person. With her brother, in particular, what concerns Stacy is that his being married would create still more stress and problems for her. Mrs. Lau is sad that Kevin won’t have someone to share his life with and to take care of him, but given his past sexual assault charges, his imprisonment for almost two decades, and the legal consequences of being convicted of any future crimes, she prefers that he remains single. Paula, on the other hand, is worried that Joyce will get hurt in a romantic relationship, and that this trauma will lead to a relapse. For Mrs. Lau and Paula, keeping their child safe, physically and emotionally, is their priority.

Education

Under the Confucian model of personhood, education is an essential part of obtaining personhood (Stafford 2006). Academic and professional success also elevates individual and family status in Asian societies (Uba 1994), so the failure to realize these achievements because of mental illness can be very distressing for patients and their families. Asian parents often use
academic success as a measure of successful parenting (Chao 1995, Wu and Tseng 1985). Moreover, Chinese children who do poorly in school are viewed as expressing abnormal, deviant, and anti-social behavior (Wu and Tseng 1985). Hsiao et al. (2006) have also found that when Chinese psychiatric patients failed in achieving success and bringing honor to their families, they saw themselves as unfilial children. Given the emphasis on education, it surprised me that many of the women in my study did not push their ill relative to continue with school, even though they alluded to the importance of education for success. In one conversation, describing why she wanted to reenroll her son in college, Mrs. Ng stated, ‘I wanted my son to be successful one day.’ Mrs. Lau believed Kevin, being her youngest child, would have minimal difficulty learning English, and would attend college in the US, opportunities that his older siblings did not have.

As the illness progresses, respondents and their ill family members’ hopes to return to school gradually fades. Many of the patients were college undergraduates when they first got sick, and most were not able to complete their education. Joyce tried attending a local college when she moved home to live with Paula. However, she would keep relapsing because of the stress from school. She eventually finished her degree after enrolling in one course per semester in an online program. Another mother shared that both her sons got their college degrees in the same manner. Joyce has mentioned to me her plans to attend graduate school to be a nutritionist, and I asked Paula about it afterwards, to which she replied, ‘She has cognitive deficiencies related to her illness. She process things slower and takes longer to learn new things. She should first go part time, because she cannot handle a full load of classes. She always tries to do too much.’
Sometimes it is the ill relative who decides to quit school. After Mrs. Ng’s son was discharged from his first hospitalization, his social worker helped him apply to a community college, and Mrs. Ng even accompanied him to register for classes. However, after one week of attending classes, he decided to drop out because he felt the course material was too difficult. His illness and medication also impeded his ability to concentrate on his studies. One sister reported, ‘My sister won’t be able to go back to school. It’s just too stressful. It’s a shame because she was so close to finishing her degree, just a few more classes.’ Most of my respondents recognize the difficulties of going back to school and the connection between academic stresses and relapse, so they don’t push their family member to return. In addition, since most patients have been ill for over a decade, caregivers have come to terms with their family members probably not finishing school; therefore this topic does not come up often in our conversations.

The sense of loss and sorrow for an ill relative’s inability to complete his or her education may be more pronounced early on after receiving a diagnosis. A staff member at the New York City Department of Health and Mental Hygiene Family Resource Center supports this hypothesis. This agency hires individuals that have experience accessing mental health services for their own children to be family advocates, who provide support through information, referrals, workshops and groups to families with children under the age of 24 with emotional and/or behavioral challenges. The staff member I spoke with works specifically with Chinese-American families on Manhattan’s Lower East Side. She told me that for these families ‘it’s all about education, education, education,’ because they desperately want their children to succeed academically. The children in these families have recently been diagnosed, so the families may not have had as much time to adjust their expectations.
Time changes people’s expectations of themselves and others, and what they see as possible for the future. Although Mrs. Ng has a glimmer of hope that her son could return to school, she knows it is not realistic: ‘He has been out of school for so long (about 10 years). I can’t imagine where he would start. I know he feels that way as well.’ Paula described how she has changed:

I have learned to let go, because I can’t control everything. I don’t take so much responsibility for Joyce and I have learned to compromise. I think God has a plan for each of us, like the dogs coming into my life and Bella moving away. He’s laughing at me now. I used to be very competitive, caring about status and wealth. Type A personality, always wants to be the best. Now, all I care about is that my children are happy and healthy. I try not to make assumptions about others and I refrain from judging others too quickly.

Paula sees her change as positive because she has evolved from a superficial person to someone with more substance and depth. However, not everyone shares her values in life: ‘Joyce is actually the best grandchild. She is always visiting her grandma and taking her to the movies, but my mom does not recognize these things she does. She’s into success and riches, so she’s more impressed with her other grandchildren’.

Wu and Tseng (1985) assert that education is one of the most enduring characteristics of Chinese culture. Although my respondents have come to terms with their ill family member’s truncated education, learning is still a vital part of their lives. Studies have shown that Chinese caregivers are better able to cope when they are offered information about mental illness and taught strategies to interact with their relatives with mental illness (Ran et al. 2003, Chien and Wong 2007). Therefore the cultural emphasis on learning may be a protective factor. Karp (2001) claims that, after a diagnosis is received, family members go through a phase of actively seeking out information about mental illness, through activities such as talking to mental health
professionals or reading extensively about the illness. Unlike Karp’s (2001) respondents, my respondents’ desires to learn more about mental health, particularly services available to patients, continue through the course of their family members’ mental illness. Hanna described the different books and articles on mental illness that she had accumulated over the years. She shares her collection with new members at the family support group, who usually have a relative who has just been diagnosed with a psychiatric disorder. Like other caregivers at the support group, Hanna asks for handouts with key ideas of a presentation before it begins, and takes notes during the presentation. Mrs. Lau regularly refers to attending the family support group as “learning,” and brings in fliers about wellness talks and recreational activities families can attend with their ill relative.

English proficiency allows for access to a wider range of literature and resources. Stacy routinely forwards me information on presentations, conferences, and events related to mental illness in NYC. When her daughter, Joyce, moved to New York City to live with her, Paula spent about two years ‘visiting Joyce at the hospital and going to lectures and workshops on mental illness.’ These workshops helped her realize how much she did not know about mental illness and how widely states differ in the type and range of mental health services they offered. She also became very involved with the NAMI metro chapter in Manhattan, and credits them for helping her learn ‘so many new things,’ and ‘meeting people in the same boat.’ Paula actively searches for new information and resources related to mental illness to improve her knowledge. Below is an email she sent out to guest speakers at the Chinese family support group’s 10th anniversary celebration and fundraiser. These individuals work in government offices and nonprofits in mental health and caregiving:
Hi everyone,

It was an honor and a pleasure to meet or reconnect with all of you wonderful and caring professionals in the mental health field at last night's event. As a family member, I am reassured about the care and future for my daughter Joyce who suffers from schizophrenia.

At the mean time, I hope we can all keep in touch so that I may, selfishly, gain new knowledge about mental illnesses, medication discovery, treatment options, resources available as well as advocacy opportunities.

Have a wonderful summer and see you at the next event...perhaps a CAMHOP event? :-)

Training: Obedience with Love

Although it is apparent to my respondents that their family members will probably never achieve the development stages Carter and McGoldrick (1998- as cited in Lefley 1996:82-83) have identified, the mothers and sisters expect their family members to act appropriately and have basic life skills, and they reinforce these values in everyday interactions. Drawing from the literature on Chinese childrearing, I contend many of my participants’ actions to manage their ill relative’s behavior are strategies similar to the ones Chinese mothers utilize to socialize their young children.

Chao (1995) demonstrates how Euro-American and immigrant Chinese mothers’ desires to foster an independent and interdependent orientation in their children, respectively, influences their child rearing practices. Although forming an identity separate from one’s parents is generally a universal process, the two groups of mothers interpreted independence very differently. The Euro-American mothers advocate individuality and believe they can help their children be independent by building up their self-esteem. Children are encouraged to see themselves as individuals, and to identify their inner feelings so that they can communicate it to others and have their needs be met. Chao (1995) argues that Chinese mothers encourage a close maternal-child relationship that continues beyond adulthood, with the child considering parental
wishes in his or her pursuit of life goals. This group of mothers interprets independence to mean the ability to take care of oneself and the acquisition of life skills to become successful and useful members to the family and to society (i.e., education, financial stability, cooking, cleaning, etc.). For many of these mothers, making sure their children are doing well in school and finding good jobs afterwards is the primary way to acquire self-reliance and success. The mothers also want their children to have harmonious interactions with family members and others outside the kin group. They accomplish this goal through teaching their children to be awareness of and concern for others, and fostering good personality traits, such as adaptability and good morals.

The socialization of shame is central in teaching Chinese children to be aware of how others view them (Schoenhals 1993) and to actually care, because their misdeeds not only reflect their inferior morality, but also shame their family. Miller et al. (1996) examined two types of storytelling in Euro-American and Chinese families: the mothers and children’s co-narration of past events and the stories the mothers told in the presence of the children. They found that both types of narrations in the Chinese group focused on rule violations and the child as the transgressor. They conclude that shame and face is socialized in children through public evaluation and criticism, and it is through this process that children learn appropriate conduct at an early age. Similarly, Schoenhals (1991) has identified evaluations, criticism, face, and shame as key constructs in middle school children in China. Teachers and parents openly criticize the children up until puberty (Schoenhals 1991), and parents are considered incompetent if they raise their children to not know shame (Miller et al. 1996).

The parenting goals and practices of Chinese parents are often portrayed as restrictive and controlling (Chao and Sue 1996) and some of the events that I describe below may seem harsh to
Euro-American readers. However, Chao (1994) argues that the concept of “authoritarian” parenting does not accurately capture Chinese childrearing, because the former developed under a long tradition of evangelical and Puritan religious movements that held ambivalent views of children (Smuts and Hagen 1985). Since the historical root of the concept is so culture-specific it cannot be applied to Chinese families (Chao 1994). Moreover Euro-American and Chinese children may differ in how they interpret their parents’ restrictiveness. Among Euro-Americans, strictness is often associated with parental hostility, aggression, mistrust, and dominance (Rohner and Pettengill 1985) and involves parents applying a standard of conduct without explaining, listening or providing emotional support (Baumrind 1971).

Strictness in Chinese families, on the other hand, is perceived as a requirement for organizing and maintaining harmonious familial relations (Lau and Cheung 1987). Chinese families see control and governance as an expression of parental care, concern, and involvement (Chao 1994). In the Chinese language, the word guan means to govern but is also associated with “to care for” and “to love” (Tobin et al. 1989). Chao (1994) offers “child training” as an alternative and more accurate term for Chinese child rearing practices. A central part of this training is teaching children societal values and goals while maintaining a close and supportive mother-child relationship. Underlying this idea of training is the belief that children are inherently good and shaped by the environment they are raised in (Chao 1994). In Confucius thought, individuals’ social roles are defined by their relationships with others, which tend to be hierarchically structured (Bond and Hwang 1986). Therefore, as elders to their children and students, control and governance are often seen as the responsibility of parents and teachers. It is within this cultural concept of training that we should interpret the interactions between respondents and their ill relatives.
Stacy and Mrs. Tam—Teaching Self-Reliance and Concern for Others

Stacy feels Cory is unable to manage daily tasks and social relationships. One time, she asked Cory not to leave his apartment until she arrived, because she wanted to make sure that someone is there to let the maintenance staff in to fix the toilet. Cory did not listen to her, because he was worried he might be late for his day treatment program. Stacy told me, ‘I was upset that he did not listen, but he’s a patient, what can I expect.’ Note that the word “patient” could easily have been replaced with the word “child,” which then becomes a remark mothers commonly make when their children do not listen to them.

Although Stacy recognizes she can’t depend on Cory in high-stakes situations or have overly high expectations for him, she wants him to be independent, in the sense that he should do things that are within his limits. Shortly after he relapsed one time and was admitted to the inpatient psychiatric ward, I visited him at the hospital and offered to help him peel an orange, but Stacy said, in front of both of us, ‘let him do it on his own, he can do it.’ I have observed Stacy giving Cory detailed instructions when she wants him to do something. For example, she brought over a stepladder and asked him to ‘clean the dust off the ladder with Clorox and then put it in your closet, so it’s out of the way.’ When he needs to wash his hair, she arranges his bathroom, putting the shampoo and towels within hand’s reach, and often reminds him to change into fresh clothes.

Stacy also stresses the importance of being self-reliant, as a way to be considerate of others. When she visits him at the group home, rather than ringing the doorbell, she calls his cell phone so that he can come down to open the door for her, because Stacy does not want to bother the other residents. She also expects Cory to contribute, so when they go out to eat he pays the
gratuity. She feels that when families do too much for patients they are really doing them a disservice. She commented on Cindy’s struggle to get her son, Dan, to find a job: ‘Cindy told me she feels helpless. I don’t think she should be too nice to Dan. You know what they say, a kind mother brings up mostly rotten sons. They are going to Hong Kong and Taiwan in the summer and Cindy is paying for the trip. If Dan does not need a job, he won’t get one. Cindy is his backup plan. You know, she told me she does not know how to donate money to NAMI online. I told her to ask Dan to do it for her, that will give him something to do.’

Stacy believes patients can be manipulative and petty, and therefore caregivers should not baby them too much. She explained, with a smile on her face, why she never tells her brother when she goes away for a vacation: ‘He always relapses when I tell him. John (one of the volunteers) says that patients purposely do that because they are jealous and want attention.’ Other respondents have reported similar pettiness in their ill relatives. During an interview, one sister told me that her brother does not like seeing her daughter when she comes home from college to visit, because her success is a reminder of his own failures. On the Staten Island ferry, one mother, Mrs. Tam, explained why her younger daughter is jealous of her elder sister:

My younger daughter is 45 years old and lives at home with me. She first got sick in China and couldn’t finish college and her romantic relationship ended. She does not like her older sister, because she feels her sister is not nice to her. I think she is just jealous. My older daughter went to college, married another Shanghainese, had kids, and moved to Toronto. These are things that my younger daughter wants and I am saddened that she will never have the opportunity to experience them. I think she resents her sister for having everything…When I told her I plan to visit Shanghai with her older sister and her children, my younger daughter was not happy. I explained to her that her sister has not been back for so long and now that her kids are older she wants to bring them back. After that, she was okay.
It is not uncommon for psychiatric patients to feel ambivalent and frustrated with their dependency on others, and their poor life prospects (Lefley 1996). Bornstein and O’Neill (1992) determined that their sample of adult children with psychiatric illness, compared to the control group, felt more ambivalence towards their parents, and focused on their own feelings of gratification and frustrations. Unfortunately, many psychosocial rehabilitative programs provide inadequate self-esteem and social skills training to help patients manage their resentment toward relatives and friends who have more fulfilling lives than them (Hatfield and Lefley 2005). These negative feelings can potentially be dangerous, because it may be incorporated into delusions and projected onto the caregiver, or, the displaced anger may generate violence toward the caregiver (Lefley 1996).

Stacy assumes a parental role similar to Chao’s (1995) immigrant mothers in stressing appropriate behavior, self-reliance, and consideration for others. By setting the bathroom up and reminding Cory to wash his hair and change his clothes, Stacy teaches basic life skills (where to put the shampoo) and reinforces social norms of personal hygiene. Stacy also encourages Cory to be considerate of others in requesting that he opens the door for her and to also be a contributing member to his family by chipping in for a restaurant bill. Similarly, in her attempt to appease her younger daughter, Mrs. Tam demonstrates how to be empathetic in her explanation of why her sister wants to go visit China. Through dramatizing other peoples’ emotions and thoughts and how to relate to them, Stacy and Mrs. Tam illustrate how to maintain harmonious relations.

Paula—Correcting Behavior

Paula used to do a lot for Joyce, but she has learned to let to go and let her daughter be accountable for her behavior. Paula offered an example of how she has changed: ‘I was paying
for her credit cards and bills. I stopped because I want Joyce to learn to be responsible and to budget her money. Her father was upset that she would ask him for money. I don’t want to be an enabler. Joyce should not be excused for doing or not doing certain things because she has a mental illness. She does not have any credit cards now.’ Paula and Joyce have also decided to live separately, because of their personality and lifestyle differences. Joyce doesn’t want to follow Paula’s rules and thinks her mother is too invasive because she asks too many questions. Paula thinks Joyce is too messy and that they don’t see eye to eye on many things. When Joyce visits her, Paula asks that she keeps the guest bedroom door closed so that she does not have to see the mess. She goes in to clean the room once Joyce leaves.

I would say that Paula is the most acculturated to Western parenting ideals and practices, because she is less restrictive compared to the other women in the study. However, during my first meeting with Joyce, Paula acted very uncharacteristically. At a conference on schizophrenia with her and Joyce, I noticed that Paula would correct Joyce’s behavior. In a rather critical and authoritative tone Paula made comments that included: ‘wait until the speaker is done before you ask questions;’ ‘don’t drink the soda in the conference room;’ ‘cough into a tissue and turn your head to the other side. Germs fly six feet. I don’t want to get what you have;’ ‘slow down when you speak;’ ‘write down things you need to tell your therapist, so that you don’t forget.’ This is similar to how Mrs. Lau would bring up Kevin’s past transgressions in front of others. Before Kevin was discharged from the psychiatric hospital, Hanna and I accompanied Mrs. Lau to visit him. Prior to visiting Kevin, we spoke with his psychiatrist and learned that Kevin’s discharge was delayed until the hospital could find a day treatment program and a living facility to accept him. They were experiencing difficulty because most housing programs did not want to accept a
person with felony convictions. Afterwards, Mrs. Lau shared this information with Kevin and criticized him in front of us.

Paula’s and Mrs. Lau’s commentaries echoed how Chinese mothers teach their young children culturally-appropriate behaviors by bringing up their transgressions (Miller et al. 1996). Chao (1995) found that compared to immigrant Chinese mothers, Euro-American mothers were more concerned with building a positive self-identity in their children, which they accomplish through praising, encouraging, and avoiding criticism. Children’s bad behavior is always separated from their core identity, in order to communicate to children that they are always loved and accepted.

Later in the conversation, Paula was trying to convince Joyce to first get a job and an apartment through her treatment program (she currently has her own bedroom, but shares the apartment with other roommates), before returning to school.

J: I don’t want to talk about my plans. Why don’t we talk about your plans?

P: My plan is to retire in a few years. My plan is for you to be independent. What is going to happen to you after I die? I don’t want you to be a liability for Bella and for society…You want to go to graduate school, but your first priority is to get a job and your own place. You’re getting lazy and need a schedule. You have to consistently go to the treatment program and follow the rules, like keeping your room clean. If you are dedicated and responsible, they will award you a scholarship for school and give you your own apartment. (Turning to me) Joyce does not want to go to her day treatment program because people there are not as high functioning as she is. (Turning to Joyce) You have to help these other people.

Paula explained that most employees at the treatment program have a mental illness as well. She compared Joyce to other people that are not as stable or high functioning but were able to get hired. Like teachers in China, Paula evaluated Joyce and her peers’ behaviors and then publicly compared these appraisals to highlight what Joyce was doing wrong (Tobin et al. 1989).
Paula consistently struggles with how much she should intervene in Joyce’s life. Although she doesn’t agree with many of Joyce’s life choices she does not want to be overly critical and impose her views on her daughter. Paula shared that Joyce wants to give up her room and move in with her boyfriend, David, who lives in the Bronx. This is something that Paula is against:

(Speaking to Joyce) Why do you want to live in a roach infested apartment? When you get a job and your own apartment you can be independent, your friends from California can come visit and you can go back to school. The job and apartment will teach you how to budget your money. When you begin school, you need to set aside money for lunches, textbooks, and travel.

Knowing that Joyce supports women’s liberation and gender equality, I pointed out that by giving up her room and living with her boyfriend, she puts herself in a vulnerable position. If he ever wanted to end their relationship, she would have nowhere to go. I think Joyce sees my point, because she begins to tell us negative things about David, such as: ‘He doesn’t like it when I hang out with my friends…I think I caught him cheating on me once.’

After we dropped Joyce off at her place, I had some time to speak to Paula before she went to visit her mother. Without Joyce there, Paula was able to speak more openly:

P: Joyce won’t listen to me. She won’t tell me anything bad about David. I never knew he doesn’t like her having friends and that he cheated on her.

L: Joyce talks about going to graduate school to be a nutritionist, do you think she can?

P: She has cognitive deficiencies related to her illness, so she should first go part time. She cannot take a full load of classes. She always tries to do too much.

Aging Caregivers
In this section, following the thread of caregiving as a practice that evolves with changes in the life cycle, I briefly discuss the implications of being an aging caregiver. Most my respondents are over 50 years of age, and therefore have different concerns than people in their 20s or 30s. The main thing that these women grapple with is what will happen to their family member after they pass away. The age factor also adds urgency to teaching their ill relative to be self-reliant, and finding supportive resources. Family caregivers varied in how they prepare for the future.

Unlike her eldest daughter, Bella, who is married and is a stay-at-home mother, Paula does not feel Joyce has the same life opportunities available to her. Paula wants to set up a trust that will stipulate what the money she leaves to Joyce can be used for, so she can continue to receive her healthcare coverage and disability payments through the government. She plans to give Joyce her condo because Bella already owns a house with her husband, and Joyce has always wanted to own a home but does not have the financial means to buy one. As of right now, Paula has everything willed to Bella, because she trusts Bella to do the right thing and split the inheritance equitably.

At 80 years old, Mrs. Lau is realistic about her own mortality, which is why she does whatever she can to give Kevin a solid foundation in the present. She also wants to be fair to her two other children; they should not have to bear the burden of providing care for Kevin after she is gone. She hopes that Kevin’s condition will continue to be stable, but does not say much about the future except, ‘I am old. There is not much I can do for Kevin. He has to depend on the government.’ She does have one hope. Currently, the lease to her apartment has two names on it, her name and her husband’s. She explained to me, ‘When one of us is gone, we can add another person to the lease, so I want to add Kevin’s name to it. The apartment is rent stabilized,
which means he will be able to pay for it with his disability check. This way he will always have a place to live. If I go first, at least my husband will have Kevin there to help him.’ Mrs. Lau later discovers that this plan will not work if Mr. Lau passes away first, because the building does not allow two opposite sex tenants in a one-bedroom apartment, even if it’s a mother and her son.

Unlike Mrs. Lau and Paula, Stacy has a nonchalant approach to planning for the future, because she does not feel she has control over it. I asked her about her hopes for the future. She responded, ‘I don’t know. You know mental illness wavers. Sometimes patients are fine and then they’re not doing so good. They go up and down. There’s no point for me to think of the future.’ Stacy does know that she will not name Cory as the beneficiary to her co-op, because, in her words, ‘it’s a waste because any money he gets will go towards paying his medical bills. I left the apartment to my aunt and uncle.’

Uncertainties about their relative’s future care stems from an inadequate formal mental health system, and a lack of informal support available to my respondents. One mother shared, ‘I have no family in the US and my daughter is the only child, so she does not have any siblings to help her. When I pass away I don’t know who will take care of my daughter. My daughter does not speak English and there are no long-term residential facilities for monolingual Chinese speakers.’ Similarly, both Mrs. Ng and Carol do not know what will happen to their children once they pass away. Mrs. Ng and her late husband divorced before she immigrated from China, so it is basically her and her son. She tries to prepare her son psychologically for her death. She told him:

about running into a female patient at his day treatment program and learning that this women’s mother has passed away. I wanted to see his reaction. Then I told him he has
to learn to take care of himself. I asked him to move out but he refuses, so I said I will move and then he got nervous (laughing). I was just messing with him, but I want him to really start thinking about how he is going to take care of himself after I die. Now I make him watch me cook.

Although Carol maintains some contact with her daughter’s paternal relatives, she does not receive any support from them and is raising her two children on her own. When I asked about her hopes for the future, she lowered her eyes and said, ‘I don’t know.’ As seen with Mrs. Ng’s son, it is often scary and stressful for patients to imagine life without their main caregiver. Jessica expressed distress when her mother started having panic attacks and would not take psychiatric medications to manage her anxiety: ‘I don’t know what I would do if something happens to my mother.’

Finally, even if my respondents are able and willing to help their relative, it also depends on their family member being open to receiving their assistance. Many of the things Hanna does for her sister are in the background. During a phone conversation, Hanna expressed her concern about her sister’s living situation:

Right now, I step in to smooth out her conflicts and arguments with her neighbors. What will happen when I pass away? My siblings and I have talked about this. One idea was to buy her a condo or co-op and letting her stay there, but then what will happen when she is disruptive? They will kick her out…(I asked about housing for the mentally ill) The problem with that is my sister does not think she has a mental illness, so she won’t take medication, see a doctor, or apply for services for the mentally ill. You need medical documentation and the patient’s signature on the application in order to qualify for housing and these other services.

Concluding Remarks

In this chapter, through capturing moments in my respondents’ lives, I hope to reinforce my claim that while Chinese cultural ideals stress providing care to an ill family member, other
issues such as such financial ability, family composition, and competing family responsibilities, can be just as critical in determining the type and extent of the involvement. In my study, sisters tend to assume the primary caregiving role when no other kin is available, and they have limited family and work responsibilities. It also seems that Chinese siblings, compared to Euro-American ones, are more willing to provide instrumental support, which I argue is grounded in a cultural proclivity to express love in practical ways.

Once siblings become the main caretaker, they assume a parental/authority role, like the mothers in my study, and ill family members assume a child/dependent role, because they are not able to perform tasks and fulfill responsibilities associated with being an adult. Although this dynamic may be inherent in caregivers and their ill relative cross-culturally, cultural models of personhood and particularities of their situations mediate caregivers’ responses to their family members’ limitations. According to the Confucian model, marriage and education are essential in the process of obtaining full personhood in Chinese culture; however other personal variables, such as trying to protect a family member, moderate the embodiment of this value in my respondents.

This chapter focuses on illustrating how caregiving is a process that evolves over time and is situated in the particularities of both the caregiver and care recipient’s life. In the next chapter, I examine how the mental health system affects my respondents’ experience of caregiving. I explore the sources of my respondents’ conflicts with the system, and discuss their ideas of what makes a doctor “good,” how they “work the system,” and learn to be lay clinicians themselves.
Chapter Five: “Working” the Mental Health System

Father: Will the psychiatrist lock your mother up in the hospital?
Daughter: No!

There is an extensive body of research that consistently demonstrates being a caregiver to a relative with a mental illness is associated with subjective and objective burdens that adversely affect caregivers’ physical and mental health (Lefley 1996, Francell et al. 1988, Cook 1988, Greenberg et al. 1997, Noh and Turner 1987, Oldridge and Hughes 1992, Reinhard and Horwitz 1995, Rungeangkulkij and Gilliss 2000, Liu et al. 2007). The mental health system, following Karp’s definition (2001:196), consists of the local police, community crisis teams, the court system, psychiatric hospitals, bureaucrats, doctors, various sorts of therapists, and outpatient services (day treatment programs, vocational programs, social club houses, etc.), and is often a major stressor for families. In 1998, Solomon (1998:78) reported that families identified several major stressors, including 1) reluctant, ambiguous, and contradictory communication with providers; 2) failure to train or involve families in treatment planning; 3) financial drain; 4) inadequate community services; 5) stressors in dealing with the legal and criminal system (police are not trained in recognizing and dealing with psychotic disorders, legal constrains on involuntary hospitalization, etc.).

In this chapter, I discuss research that demonstrates these issues still persist, almost two decades after Solomon published her work. Then I compare these findings, which are largely based on Euro-American participants, with the Chinese women in my study. I argue that my respondents also encounter professional and institutional barriers that prevent their inclusion in their ill relative’s treatment planning and implementation, and often have to endure inadequate,
inappropriate, and unprofessional services. However, their limited English proficiency creates a different set of problems in advocating for care, in particular relying on lay interpreters, or interpreting services that are not standardized and have limited oversight on quality. My study addresses the lack of research on the needs of ethnic minorities and low-income families in studies of families and mental illness (Rose et al. 2004). In addition, through documenting my respondents’ strategies to “work” the system, it attempts to shift the intellectual conversation away from simply documenting how the mental health system affects caregivers, to one that explores the ways individuals engage with and contest institutions of care and structural inequalities.

**Existing Research on Family Inclusion in Treatment**

Based on previous research (i.e., Bernheim and Switalski, Hanson and Rapp 1992, Marshall and Solomon 2000, Smith 2003), Kim and Salyers identified services that families need, including “information about the etiology of mental illness and its treatment, practical advice on how to respond to difficult symptoms and situations, emotional support, information on community resources, respite care, and advocacy” (2007:337-338). As a result of the growing awareness of families as treatment partners, many standards of care recommend family involvement in psychiatric treatment and encourage the sharing of patient information with families (Marshall and Solomon 2000, Dixon and Lehman 1995, American Psychiatric Association 1997). Family involvement in treatment has been linked to positive outcomes for patients and families, including improved social functioning, decreased hospitalization time, improved social and vocational functioning, reduced family conflict and burden, and improved

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3 I discuss how the support group meets these needs in the next chapter.

Families of psychiatric patients also need more support because the stigma of mental illness alienates them from traditional family and social support networks (Veltman et al. 2002). Conflict often arises between family members because of divergent views on mental illness and how to handle it (Rose 1997). One mother at the support group expressed how isolated she feels because her husband and daughters don’t believe her son is mentally ill; they just think he is lazy. Another mother reported that some of her relatives stopped visiting her when they learned her son had been discharged, even though he does not live with her. Family caregivers are also reluctant to share with friends and co-workers, because they fear being misunderstood or having their privacy violated (Chafetz and Barnes 1989, Rose 1997). Some of my respondents have also reported that they avoid disclosure, because they do not want to ‘make people feel uncomfortable’ and want to ‘respect the privacy’ of their ill relative.

Despite the positive implications for including families in the care process, Perreault et al. (2012) claim families are routinely left out in actual practice. Many times, when families are involved, it is in the context of what kind of support (housing, emotional, financial, etc.) they can provide to their ill relative (Solomon 1998). Families are excluded from treatment planning, and mental health providers don’t actively encourage family involvement (Biegel et al. 1995, Jensen 2004, Levine and Ligenza 2006). In their study, Kim and Sayler (2008) have found that mental

4 These studies are different from the Expressed Emotion (EE) research. EE is a clinical construct that measures the emotional atmosphere of families and its connection to the prognosis of a mental illness (for a review of EE studies see Hashemi and Cochrane 1999, Bhugra and McKenie 2003, Hooley 2007). There has been an increase in research that examines the cross-cultural validity of the EE construct when applied to Chinese groups (Healey et al.2006, Phillips and Xiong 1995, Ran et al. 2003, Yang et al. 2004, Phillips et al. 2002).
health professionals have limited contact with family caregivers and offered very few services, which is consistent with past findings (Biegel et al. 1995, Marshall and Solomon 2004, Rose 1998). Families are dissatisfied with mental health services when there is lack of contact, communication, and partnership with providers (Downs et al. 2006, Gigantesco et al. 2002, Ruggeri et al. 2003, Perreault et al. 2005, Hanson and Rapp 1992). In addition, caregivers have reported frustration with the lack of support for their own anxieties and little guidance on how to manage illness symptoms of their family members (Rose 1997, Rose 1998). Perreault et al. (2012) identified collaboration with providers as one of the most significant variables in caregiver satisfaction with mental health services. They detected a positive correlation between satisfaction and perceived collaboration, and between satisfaction and the number of patients’ needs met. All this research suggests a complementary relationship between the formal and informal systems of care can be beneficial. Providers help families cope, and families help providers carry out long-term community based treatment (Nicholls and Pernice 2009).

Barriers to collaboration come from a number of sources, including families/patients, providers, and institutions. Some obstacles identified by Nicholls and Pernice (2009) are high turnover rates of psychiatrists, limited sharing of information between the different mental health personnel that treat the same patient, issues of patient confidentiality, lack of continuity of care, heavy case loads, and lack of training to work with families. This is consistent with Rose et al. (2004), who found patient confidentiality, lack of resources (inadequate staff, lack of space), short hospitalizations, and an emphasis on crisis care as significant barriers to involving families. Many clinicians in inpatient settings admit that all they can do is “deal with the crisis, stabilize the patient, and send them home” (2004:42). Furthermore, providers believe their primary responsibility is to treat and support patients, and not to help families (Rose et al. 2004, Nicholls
and Pernice 2009). Therefore, while they acknowledge families require support, providers feel family needs are secondary and do not warrant equal attention. Few mental health professionals also receive training to work with families and to involve them in the care process, even though research shows providers are more competent and positive about working with families when they have received training (Rose et al. 2004, Jensen 2004, Mohr 2000, Wright 1997). Providers and families also seem to differ in the type of support they feel is important. The former prioritizes education, and while the latter would agree, they also value assistance with practical matters, such as finances, obtaining post-hospitalization community care, and individualized advice in managing the symptoms (Rose et al. 2004).

Confidentiality is also a major concern for providers. Many feel it is difficult to maintain confidentiality and also be supportive to families (Nicholls and Pernice 2009, Zipple et al. 1990, Rapaport et al. 2006). The fear of getting sued has also made some providers overly cautious in sharing with family members. While confidentiality is important for the therapeutic relationship—patients have to trust that their therapist will not disclose their information without their prior consent—some providers refuse to share information because they hold on to outdated etiological theories that blame families for mental illness (Lefley 1996). Marshall and Solomon (2000) explained sharing information is also difficult because there is currently no formal consent forms or clear procedures for handling patient confidentiality, and therefore it largely depends on providers’ interpretation of confidentiality laws. They reported that some clinicians refused to release general information that can be disclosed legally and some correctly (based on privacy laws) denied information on specific diagnosis, medication, and treatment plans. This inconsistency in information sharing confuses families, who don’t know if a clinician is hiding behind a veil of confidentiality. Consistent with past research (Perreault et al. 1999, Perreault et
al. 2005), Marshall and Solomon (2000) have found that most patients feel it is important to involve their families in their treatment. Interestingly, the authors detected that patients’ attitudes toward their family and family involvement were significantly associated with whether they were encouraged by providers to include their family. However, only 36 percent of research participants were asked by their clinicians if they wanted to include their family. Nicholls and Pernice (2009) recommend providers encourage patients who will return home or will be taken care of by their family, to sign consent forms to share information and to do periodic reviews of these forms, in case changes have to be made.

**Chinese Caregivers**

Below, I present examples of how respondents deal with a variety of issues, which had been identified in past research as common in the process of advocating for care. The purpose is to illustrate the resources and skills respondents employed to resolve differences in opinions regarding treatment and rehabilitation, and in many cases, to challenge the “expert.” (I elaborate more on how the family support group acts as social capital in the next chapter.)

*Getting Clinicians to Listen*

Similar to what has been reported by other caregivers in the literature, my respondents believe they can offer valuable clinical information, thus they are frustrated when providers disregard or refuse to listen to what they have to say. Since family caregivers spend more time with patients they are afforded a more “accurate” perspective of their relative’s clinical condition (Rose et al. 2004). They are more likely to detect early signs of relapse (Muhlbauer 2002, Dournbous 2002, Ferriter and Hubannd 2003, Nicholls and Pernice 2009). The frustration of
being ignored or discounted may be magnified in my respondents. The existing medical system emphasizes patient privacy because they see adult patients as independent individuals who can make informed decisions about their health. However, aspects of Western biomedical ethics may be incompatible with Chinese culture, which stresses family interdependence. Lack of information and inclusion by providers, therefore, is distressing for my respondents and their ill relatives, because families are expected to play an integral role in the treatment, discharge, and aftercare of their mentally ill relatives. Many participants at the support group have complained that their relative’s clinician won’t talk to them. One mother, who speaks for many respondents, commented, ‘families are a valuable resource to clinicians, because they are around patients all the time. We know if they are not taking medication or are acting differently.’ For example, Ms. Ng felt her son was acting strange, so she confronted him about taking his medication. It turns out that he had stopped taking one of his medications.

Respondents have developed strategies to work around patient confidentiality. Some respondents, like Stacy, have asked their ill relative, in moments of lucidity, to give them the power of attorney, so they can have access to their health records and make treatment choices on their behalf. One volunteer at the support group suggested that family members provide clinically relevant information to providers, because privacy laws do not prevent clinicians from listening to patients’ families. Furthermore, it is not only the content, but also how the information is presented to a professional that is important. Another volunteer, who is also a provider, recommends family members, ‘write down what you want to say before you meet with the doctors. Sometimes family members get nervous and forget what they want to say. As a clinician, I do value the information I get from families, if it is delivered in a concise manner.’
One mother concurred that being polite is very important, and Stacy added that families should only set up meetings when it is necessary.

The ability of providers to listen, if not resolve, respondents’ concerns is a major variable in whether collaborative relationship can be established. Families’ concerns and perceived needs, in turn, are determined by their relative’s clinical condition. An individual who has just been told that their family member has a mental illness may need emotional support, and information on mental illness and psychiatric medication, and how to apply for disability benefits. On the other hand, if a relative had a relapse and was hospitalized, families may be more focused on reevaluating the medication and discharge plan. For an individual who has a relative that has been in treatment for some time and is relatively stable, periodic updates on treatment progress from providers may be enough. Families judge providers more favorably if they take the time to talk and address patients and family caregivers’ current needs. Below are some quotes that illustrate this point.

Mother: When my daughter was hospitalized, the doctor called twice a day to check on her. She offered to translate for me if I cannot find someone in the hospital to do it. She is very nice.

Stacy: The only positive thing to come out of this hospitalization is meeting Dana. She was my brother’s social worker at the hospital and she followed up on his case even after his discharge.

Paula: I loved Joyce’s first social worker. She was so helpful. She showed me how to apply for benefits for Joyce.

Paula: Joyce has a new social worker. Not sure how she is, but if I have to be there to tell her what to do, then what is the point…I love her primary care physician. He sat down and talked to us for half an hour to find out what’s going on in Joyce’s life. He is so kind…he’s like a grandfather.
The above comments from Paula suggest that needs evolve. As a novice to the mental health system, Paula was grateful that the social worker helped her apply for disability benefits. Now as a more experienced family advocate, she understands the roles and responsibilities of a social worker and what services are available for Joyce. This also makes her a better judge of providers’ professionalism and competency.

Mrs. Lau: Kevin’s current psychiatrist is pretty good. She is polite and tries to address my concerns.

Carol: The caseworker would set up meetings with us, but then she would not show up. She doesn’t call to cancel or reschedule.

After doing a tour of a very reputable day treatment program with other participants at the family support group, Ms. Ng was impressed with the different types of social and rehabilitation activities they offered. She wanted her son, David, who spends most of his time at home sleeping, to give it a try, so she contacted his social worker. The social worker did not think David was ready to make that step yet. There was nothing Ms. Ng could really do, because she needs the social worker to write a clinical evaluation for David in order to apply. She did complained to me that, ‘you can’t really tell if David is ready, unless you let him try it. Besides, he’s doesn’t have to attend the program everyday. He can start slow at first; no one says he has to start by going five days a week.’

Similar to what has been reported in the literature, respondents’ interactions with their ill relative suggest their loved one is capable of more, and therefore they feel mental health professionals should do more to help their relative set and achieve concrete goals (Hanson and Rapp 1992). In Ms. Ng’s case, she lives with her son, so she has an intimate understanding of him, allowing her to read the subtext in his words and actions. For example, recently David has
gotten into the routine of sleeping during the day and staying up all night to watch television. Ms. Ng keeps hearing, on the Chinese radio station, an advertisement for a school that is right off the train in Chinatown, and offers day and night classes. She brought up the idea of enrolling in classes with David: ‘I told him about the school. It’s right by the subway station, so he doesn’t have to travel very far. David’s lazy and doesn’t like commuting, especially walking. Since he’s up all night, I said he could enroll in the night classes. He responded, “I don’t want to go at night.” (laughing) That means he’s not against enrolling in classes, just not night class.’

It is not only knowing the likes and dislikes of an ill relative, but also being creative in coming up with strategies to get them to do things that foster independent living. For example, Chinese-American children are generally expected to bring their bowls to the sink and soak them in water after a meal (mothers typically wash all the serving bowls and utensils after everyone has finished eating). This is because, when the residual rice dries on the bowl, it is very difficult to clean. David always forgets to do this, so Ms. Ng came up with the idea of having David do bicep curls with free weights every time he forgets to soak his bowl in water. Since he doesn’t like to exercise and had been gaining weight, she figures this punishment is a win-win situation. Not surprisingly, because there are actual consequences for forgetting to bring his bowl to the sink, David has been more diligent in remembering to do the task. In another example, Ms. Ng has used what some may consider unorthodox ways to get David to take his psychiatric medication. He used to have a psychiatrist, Dr. Chen, who was a tall man with a solid build and a stern demeanor. Aware that David saw Dr. Chen as an authoritarian father figure and feared him, she would threaten to tell Dr. Chen if David did not take his psychiatric medication. And her tactic did work. Someone from outside the culture may question the ethics of manipulating an individual to act in a certain way, but Ms. Ng’s actions are not out of the norm. For example,
some respondents have reported mixing psychiatric medication into their family member’s food or “sweet talking” them into seeing the doctor. These family caregivers see their deceptions and manipulations as actions done for the good of the patient, and their logic reflects a Chinese bioethics, which is generally more paternalistic than a Western one (Bowman and Hui 2000). In short, while Ms. Ng is not a clinician, she has an intimate understanding of her son from interacting with him in everyday life. Unfortunately, this type of knowledge is rarely taken into account or if it is, it is not given equal weight to the clinical knowledge of mental health professionals.

_Nancy—Continuity of Care_

Rose et al. (2004) reported frequent turnover rate of therapists as one of the defects with the mental health system. Clinicians and patients spend time forming rapport and developing a trusting relationship and when a new clinician takes over the case, this process has to start all over again. The lack of continuity disrupts treatment, which ultimately influences the quality of care. To further illustrate how frequent turnover rates can impede on the quality of care, I describe Nancy’s attempt to advocate on behalf of her son, Ken, below. After being discharged in December 2011 for depression and anxiety, Ken continued to take medication and see a therapist at the hospital’s outpatient service. In June of 2012, Ken told his mother, that he would not continue attending his therapy sessions because the hospital kept changing his therapist every 3-4 months. Each new therapist would always ask him the same questions, typical of a first diagnostic session, such as when did you first get sick, what kind of things worried or bothered you, how long has it been since you stop attending school. After this awkward initial period, the clinician and Ken would begin to build rapport, but the end result was always the same, they
would switch Ken to another clinician. This situation annoyed Ken and it had greatly impacted his motivation to continue therapy. His mother, Nancy, contacted the hospital and with great difficulty got the name and number of his most recent therapist. She called the therapist and asked for help in convincing her son to return for treatment.

Nancy described this clinician as someone with ‘a good heart, who patiently talked to my son several times and finally my son agreed to go see him.’ However, the thing that she fears most happened again—this therapist left in October of 2012. Since then, Ken has discontinued therapy because he feels it does not help him. Nancy has contacted the hospital to address this issue and was told that the previous therapists were interns who only stay in their positions for a few months. She requested the hospital assign a resident therapist to her son but her request was turned down. Nancy was frustrated with the hospital’s response, so she wanted to find other hospitals or clinics to continue providing care to her son, but this hospital told her that Ken could only go to certain hospitals for treatment because he has Medicaid. They added that if she insists on going to a different hospital then she would have to pay a lot of money out of pocket. One of the volunteers pointed out this hospital was not being totally honest because, since Ken speaks English, he actually has more options than the hospital administrators have led the family to believe. The support group wrote a letter, on Nancy’s behalf, to the Consumer Affairs division at the NYC Department of Health and Mental Hygiene. They also gave the letter to the Assistant Director, when he came to speak at the group’s 10th anniversary celebration and fundraising banquet.

*Carol—Lack of Professionalism*
Families are usually stuck with the tasks of seeking housing, treatment options, and trying to navigate the system of entitlement (Hanson and Rapp 1992). Although mental health professionals are supposed to help their clients identify the services they need and connect them accordingly, in reality this is not the case. With the global recession, mental health services are compromised with cut-backs in governmental funding and agency downsizing. Clinical staff are assigned more cases, which means more paper work, and less time for patients and professional development. Providers lacking in professionalism further compromise the quality of care. In 2013, Carol and Jessica decided to pursue legal action against the man (father of Jessica’s half-brother) who had sexually abused Jessica. Jessica told her caseworker, Susan, about her intentions, and Susan told her to call the sexual abuse hotline to find out more about the legal process. Many of the volunteers at the support group felt this was an unrealistic expectation of Jessica. She has difficulties expressing herself clearly, especially when she gets nervous, so how can she tell a stranger on the phone about her abuse and inquire about legal options? The volunteers were especially concerned that Jessica would have to describe her abuse multiple times to different people during the legal proceedings, and feared she would not be able to mentally handle a trial, let alone a not-guilty verdict. Everyone felt Jessica’s psychiatrist would also need to be informed of Jessica’s intentions to pursue legal actions, so she can closely monitor her mental condition. It is best if Jessica’s psychiatrist, caseworker, and vocational counselor at her day treatment program had a meeting or a phone conference to discuss how they can work together to support her. However, as often is the case, there is a lack of communication between the different clinical staff that works with one patient (Rose et al. 2004).

Carol went to different community-based organizations to learn about different legal resources. She also called the support group for help. The initial plan was to have Stacy, Mary
(a volunteer at the support group), and me accompany Carol and Jessica to a meeting with her caseworker, in order to apply some pressure on her to stay on top of Jessica’s case. On the day of the meeting, Susan did not show up, and did not contact Jessica to cancel or reschedule. The five of us stood outside in the cold and snow, ringing the doorbell to her office. Jessica called Susan’s cellphone and learned that she was sick and could not attend the meeting. Susan explained she did not realize this was going to be a group meeting. Mary, Stacy and I were appalled because, whether it was a group meeting or not, she should have let Jessica know that she could not attend. Jessica and Carol were less surprised because she has done this before. It is incidents like this that contribute to families’ perceptions of mental health providers as unreliable and uncaring (Rose et al. 2004).

Mrs. Tam—Lack of Community Programs and Medication

A common complaint families have is the lack of community programs that help patients structure their time on a daily basis (Hanson and Rapp 1992, Jenson 2004), and the fact that, with increasing cutbacks, this problem will probably worsen. Mrs. Tam, a mother from the support group, complained that the staff at her daughter’s day treatment program asked her daughter to leave. The daughter, Lucy, who is clinically stable and has been attending the center for a long time, was asked to give up her spot, because, faced with budget cuts, the administration wanted to make room for patients who need the service more. Mrs. Tam felt very distressed over this. She stated, ‘the center has doctors, nurses, and social workers and they organize various activities and events for their clients. When my daughter is there, I feel secure and can go about my day without worrying about her.’ One volunteer, who is also a mental health provider, was
upset when he heard this story. He could not believe the center had asked the daughter to leave without giving her a referral to another agency. He felt that Mrs. Tam should file a complaint.

Stacy volunteered to investigate this case for Mrs. Tam, because this same organization has ‘tried multiple times to kick my brother out. I have fought to keep him in.’ She warns Mrs. Tam that the center’s staff can refuse to talk to her about her daughter because of patient privacy. However, the social worker was able to give her some information. She called me afterwards to fill me in. ‘They did not force Mrs. Tam’s daughter to leave, they asked her and she agreed. The daughter has to urinate every 15 minutes, which makes it hard to leave the house. One time she had to go so badly, she went in a corner in the subway station. Lucy doesn’t want to go and there’s nothing we can do. Unless Mrs. Tam has power of attorney, she can’t intervene in her treatment. It’s not totally the staff’s fault. Sometimes we can’t just listen to the family’s side of the story.’ In short, patients are adults with their own goals and desires that may be incongruent with what their family wants for them. Issues that at first seem to be the result of shortcomings in the health system, may actually be the product of conflicts between family caregivers and their ill relatives. Therefore, to understand a conflict over acquiring adequate and appropriate services requires an examination of the dynamics between all the parties involved. Interestingly, most of the literature on barriers to collaborations focuses on the perspectives of providers and families, leaving patients’ voices out (Rose et al. 2004).

As we see from the above case, what initially seemed like a treatment center disregarding the patient’s best interests, turns out to be about a caregiver and her daughter wanting different things. Mrs. Tam likes that Lucy goes to her day program, because it provides her some respite and she knows her daughter is safe. Lucy, on the other hand, has expressed her dislike of the program, because most of activities offered are recreational and she prefers educational ones. It
was also difficult for her to commute because she needed to use the restrooms so often. When her mother was visiting China, she was asked by the clinical staff to “graduate” from the program, and Lucy conveniently took this opportunity to stop attending the program without consulting her mother. Often times, caregivers forget that even though their family members are mentally ill, they still (like anyone else) have their likes, dislikes, goals, and hopes.

Ultimately, respondents cannot control what their ill relative chooses to do with their lives. Stacy does not want her brother to get married, but admits ‘if he insists, there’s nothing I can do.’ In the last chapter, I mentioned Paula was concerned Joyce will give up her room at the housing program to move in with her boyfriend, Andy. A couple of months after she expressed these concerns to me, over coffee, she told me Joyce did move in. By giving up her housing, Joyce lost the clinical support associated with the housing program and has become dependent on her boyfriend. It is clear that she is a “guest” at his place, because she cannot make changes to the apartment or let people come in without his permission. Her new living arrangements have also been detrimental to her physical health, because the apartment is so dirty. Joyce’s cancer came back and she had to have a second operation to remove the tumor from her neck. The sutures from her first surgery healed so well that there was practically no scar on her neck. However, for her second surgery, she was recovering at her boyfriend’s place and her surgical wound kept getting infected, prompting Paula to attribute her difficult healing period to the fifthly living conditions. In fact, the visiting nurse refused to enter the apartment at all and called Joyce’s doctor, stating her concerns about changing bandages in such an unsanitary place.

According to Paula, Joyce and Andy have brought roaches when they visited her house. After that, Paula refuses to have them over again, explaining, ‘I know not letting Joyce come over to my house makes me look like a horrible mother, but I don’t care. I don’t want roaches in
my place. All they have to do is to let the cleaning lady come in (Andy is reluctant to give permission), but Joyce doesn’t want to bring up the issue of cleaning the apartment with Andy. Maybe she is afraid Andy will break up with her. I’ve talked to Bella about this and we agreed—it’s okay that Joyce wants to live in filth, but it’s also okay that I don’t want her to come over.’ Paula is not happy that Joyce and Andy have recently gotten engaged. She feels Andy is very controlling; something that is okay if he is making choices for Joyce that have her best interest in mind, but this does not seem to be the case. Since Joyce has confided to me that Andy has cheated on her, I suspect she knows some aspects of his character are questionable, however, she is able to ignore his past transgressions because their relationship allows her to feel like a “normal” woman. I have never met Andy, but from pictures he looks very handsome. Although suffering from schizophrenia, he completed his master’s degree in social work at a prestigious university and is currently a social worker, so he is very high functioning. One Friday afternoon, Joyce called while I was visiting Paula at her house. Over the speakerphone, Joyce shared that Andy was driving home from work, and they were going out to dinner later that evening. In that particular moment, Joyce resembled a normal woman in her mid 30s telling her mother about dinner plans with her live-in boyfriend. While Lucy’s decision to leave her treatment program and Joyce’s move to her boyfriend’s apartment may not be the best thing for their illnesses, it reveals their humanity, bringing to light their interests and desires. What I feel is missing in the research on families’ interactions with the mental health system is a sense of people’s motivations for doing the things they do. In short, what is at stake for people and how do conflicting interests get resolved. I believe there are fruitful ways to integrate quantitative methods that identify relationships between variables with ethnographic methods that capture the richness of meaning and daily life.
After leaving her day treatment program, Lucy switched to another psychiatrist in Chinatown. After he changed her medication, she relapsed and was admitted to a hospital in Brooklyn. Since Lucy did not speak English and the hospital did not have a bilingual clinician, it was difficult to provide care. Shortly after Lucy was discharged, she was readmitted again, but this time to a hospital that had an Asian psychiatric unit. Mary, one of the volunteers at the support, shared her thoughts about this case. Her comments reveal how families evaluate providers based on the medication they prescribe, and in having an honest, caring, and pleasant attitude in their interactions with patients and families (Jensen 2004):

The psychiatrist Lucy switched to is not a good doctor. He wants to keeps new patients by showing that he is effective, so he switches all his patients to clozapine. This is a very aggressive medicine that lowers the white blood cells count, and is usually the last resort when all the other standard medication doesn’t work. One of my clients started seeing him and got really sick. It’s been a year, and she is still recovering…I asked Mrs. Tam which social worker at the hospital is now in charge of Lucy’s case, and it is Dana (the same one that Stacy like and felt was competent). Lucy is in good hands. Dana is a very dedicated social worker. She contacted eight or nine agencies to find an adult housing program for one of my clients. Although, at the end, she could not find one that will accept him, she was able to get him a home aid attendant. Mrs. Tam just needs to tell Dana what her needs are.

Medication controls many of the psychotic behaviors, such as hallucinations, delusions, thought disorders, and movement disorders, and therefore enables a higher degree of independent living. Unfortunately, these anti-psychotics are associated with a plethora of side effects that may potentially lead to other physical health problems, such as diabetes from the extensive weight gain. The side effects are often very distressing for respondents, because they are embarrassing, violate expectations of a healthy body, and are obstacles that impede patients’ integration back into the community. Therefore, the topic of medication often comes up with
clinicians. As one clinician mentioned, ‘medication is one of the most important parts of treatment for patients with chronic and severe mental illness. The goal is find the right combination that reduces the symptoms while having the least side effects. We must find the most appropriate one for each person.’

Respondents’ evaluations of the competency and the professionalism of a clinician are intimately connected to a provider’s ability to correctly diagnosis and prescribe effective medication, and their response to family concerns regarding medication. Jensen (2004:37) reported higher satisfaction in caregivers when providers saw the patient as a whole person, offered advice on healthy living, and had a positive demeanor while they searched for an effective medication. On the other hand, caregivers reported negative experiences when providers confused side effects as illness symptoms, refused to run diagnostic tests that identified medical problems and injuries that may be causing psychotic symptoms, and preferred one diagnosis or one medication (especially if it is an older one that causes miserable side effects). Below, I present some comments from respondents to illustrate how the side effects causes distress and the connection between competency and medication.

Paula: There are these embarrassing side effects, such as shaking hands, weight gain, and hair lost. Her hand handshaking is most obvious when she picks up a cup. Joyce used to be thin, alethic, and had really long beautiful hair. The medication changed her metabolism so she gained a lot of weight and got diabetes. She used to weigh around 110-115, but now she is 185 lbs. In the past, she would try to exercise to control her weight, but now, I think she feels defeated and doesn’t do anything. She also drools. During one of Joyce’s overnight visits, I noticed her pillow got all wet. I asked if she had spilled something on it. That’s when she told me the medication makes her drool. Now I put two pillowcases and a towel on her pillow. I also switch from down pillows to synthetic ones that can be washed.

Mrs. Lau: I want to talk to Kevin’s psychiatrist. I think the psychiatric medication he takes makes him very tired, hungry, and he has to urinate frequently. He is always sleeping and only gets up to eat. All that food makes him fat and he is always
constipated. There were several times when Kevin could not get to the bathroom quick enough and ended up urinating in his pants; this happened on the subway once. I am old, so I sometimes can’t hold my urine, sometimes when I cough a little, pee will come out. That’s why I wear adult diapers, but Kevin is still so young and should not have problems like this.

Both Mrs. Lau and her daughter showed Kevin how to use adult diapers and sanitary napkins. The side effects of his medication also makes it difficult to find employment, but he can never go off of his medication because they are essential to managing his illness.

Carol: ‘Every time Jessica’s medication gets changed, she gets anxious. She worries over the littlest things. It’s such a pain.’

Cindy: ‘I worry about the side effects of the medication. After taking psychiatry medication, my cousin is fat and seems mentally slow.’

Ms. Ng: I want to have off on the weekends so that I can watch David and not let him sleep all day. He goes to bed early, but does not get up until noon. I think it’s his meds that make him so tired. Because he sleeps so much he never really leaves the house… The clinic was getting a lot of monolingual Chinese speaking patients, so they asked David if he was okay with switching to a English speaking psychiatrist. He agreed. At the first session, the doctor changed David’s medicine, because he was all puffy and swollen from sleeping. Now he doesn’t sleep too much. The doctor also convinced David to get a physical check-up. Then he scheduled a meeting with me. I don’t speak English, but the receptionist translated.

Here, Ms. Ng is pleased with David’s new doctor because he switched his medications, which reduced some of his side effects. He also convinced David to take care of his physical health and was proactive in setting up a meeting with Ms. Ng to involve her in the care process.

Paula: I took Joyce to see this psychiatrist because he treats my friend’s son and she highly recommends him. Joyce’s a new patient, so he does not know much about her. Why did he change her medication? She was doing fine with her current dosage. The doctor should have talked to the family members first to get a better understanding of her condition. He changed her meds and then went on vacation. Only doctors can do that, ruin someone’s life and then go on vacation. I made an appointment for Joyce to meet
this particular psychiatrist because he was recommended by one of my best friends. I was not impressed with the quality of care that was provided. My friend probably has lower standards than me.

Bella (Paula’s older daughter): ‘It’s a problem, every time Joyce’s doctor changes, they change her medication.’

We see that Paula was upset when the doctor did not consult with her before changing Joyce’s medication. Her annoyance was probably intensified because unlike David, Joyce relapsed.

Respondents have rather complicated feelings about psychiatric medication. They know their relatives need to take psychiatric medication, and they monitor them to make sure they swallow the pills. Although most patients with schizophrenia see a decrease in positive symptoms—psychotic behaviors such as hallucinations, delusions, thought disorders, and movement disorders—many, like Joyce, still have residual symptoms. Paula pointed out that negative symptoms are harder to treat because the medications do not target those problems. She believes that is why Joyce has a hard time connecting with other people: ‘people can tell Joyce is different. That’s why she doesn’t really have friends and feels lonely.’ This view is echoed in the medical literature as well. The Harvard Medical School Family Health Guide states:

…psychotic or “positive” symptoms — exaggerations and distortions of normal perception and thinking — are not necessarily the most important or characteristic ones. Another set of symptoms is much more pervasive and persistent and has a much greater effect on a patient’s quality of life. These “negative” symptoms are so called because they are an absence as much as a presence: inexpressive faces, blank looks, monotone and monosyllabic speech, few gestures, seeming lack of interest in the world and other people, inability to feel pleasure or act spontaneously… Positive symptoms make treatment seem more urgent, and they can often be effectively treated with antipsychotic drugs. But negative symptoms are the main reason patients with schizophrenia cannot live independently, hold jobs, establish personal relationships, and manage everyday social situations. These symptoms are also the ones that trouble them most. Surveys find
that their chief concerns are difficulty in concentrating, thinking, socializing, and enjoying life. (http://www.health.harvard.edu/fhg/updates/update0706c.shtml)

Furthermore, even if a cocktail of psychotropic drugs is working well, a stressful event may throw the patient off. There are no guarantees. This is why any change in the patient’s behavior is taken seriously. For three weeks in the spring of 2013, Mrs. Lau noticed that Kevin did not want to spend the weekends at her apartment and this concerned her. He loved coming over to eat Chinese food, socialize with his family, and play mahjong. She shared, ‘We made sure he felt welcomed at our house. We gave him a set of keys and frequently went out to eat with him…also got him a laptop. Everything seemed fine and then all of a sudden he wants to do things without his family.’ She worried that he is lying to her. One night when she called his housing facility, another resident answered the phone and told her Kevin had gone out. When she called back, Kevin was already asleep. The next morning, Kevin told her he went out for a walk, but she was concerned that he was hiding something from her. ‘What was he doing walking by himself after dark, at 9, 10 in the evening. The housing facility is located on an island and the surrounding area does not have businesses or residential units, so it is pretty isolated out there.’

Mrs. Lau was worried that Kevin had stopped taking his medications because staff at the housing program do not check if residents actually swallow their pills. Kevin told her that he was hanging out with people, but she does not believe him because, ‘he doesn’t have friends! Who is he hanging out with? The bad people from his past?’ This is the type of information that may be important for clinicians to know, especially given Kevin’s situation at that time. Having lived in a prison or a psychiatric hospital for the last 18 years, Kevin had just been discharged from the hospital and was living in transitional housing in the back of the hospital until his social
worker could find a housing program to accept him. Unfortunately, when he left the hospital, he was switched to a different psychiatrist and social worker, neither of whom had ever worked with Kevin before. This is a situation where it would make sense for providers to hear what a family caregiver has to say, because how do not they know how a new patient generally acts and thinks? In addition, Kevin’s discharge may be more overwhelming and anxiety-provoking for his family and himself, because he has spent such an extended period of time in institutions, away from society. On the first day of his treatment program, Kevin had a staff member from the housing program accompany him to the center and show him how to take public transportation. Somehow, he got separated from the staff member, and could not figure out how to get back to his place, so he took a cab to his parent’s apartment in Chinatown. Mrs. Lau was so surprised to see Kevin at the door. She and her oldest son escorted Kevin back to his home.

Respondents understandably prefer not to take psychiatric drugs. Carol, who has been hospitalized twice for panic attacks, shared, ‘I don’t like how it makes me feel.’ In addition, her son’s father has been threatening to get custody of their son, and she is afraid he will use the medication to suggest she is crazy and unfit to be a mother. Stacy explained that she used to take a small dosage before, but has stopped. Like many immigrant Chinese, she feels Western drugs are fast acting, but very rough on the body (Kung 2001, Kuo and Kavanagh 1994). Instead, she prefers Traditional Chinese Medicine (TCM), because it is slow-acting and less harmful for the body. She sees a TCM practitioner for her dermatitis, returning weekly for treatment and to pick up herbal medicine (back in the day, you had to bring home the herbs and boiled them yourself, but now there are instant packs). I asked her why she does not apply cortisol cream to her rashes, and she explained, ‘the cream only deals with the symptoms, it doesn’t get the toxins out of the body which is the root of the problem.’ Stacy also brings her brother to the same
practitioner as well, to promote general wellness. She told me, ‘if Chinese medicine can cure his schizophrenia, I would definitely prefer that, but it can’t.’

It seems TCM health principles are relevant for many Chinese immigrants. One time, I ran into Ms. Ng and commented that her “face color is good” (Chinese idiom that means someone looks healthy and well rested). She laughed and told me, ‘When my son was sick, I did not take good care of myself. I couldn’t sleep or eat, and so my health suffered. Recently I was watching the Chinese channel and they were teaching viewers types of food that can improve their health and how to prepare it. I tried it, and I do feel a difference.’ Consistent to what Lin and Lin (1981) have found, respondents employed several treatment strategies simultaneously, including taking their ill relative to a TCM practitioner. Even fairly acculturated Chinese Americans use TCM. Two of my friends have tried TCM for fertility problems. One friend stated, ‘According to Western medicine I’m perfectly healthy and shouldn’t have problems conceiving, but sometimes they can’t see certain things. The TCM practitioner said my uterus is too cold and so an egg can’t attach itself to it.’

Mrs. Lau—“Shuffle and Jive”

Like the African American parents Mattingly (2010) worked with, my respondent “shuffle and jive” as they acquire the cultural competencies to work with mental health professionals. Mrs. Lau understands that she is more likely to get help if she is perceived as a concerned and cooperative parent by clinicians. In the beginning of one meeting with the treatment team, Mrs. Lau wanted me ask the team for her, ‘how she can work collaboratively with the team to help Kevin.’ She makes an effort to attend the hospital’s monthly support group meetings, even though she does not always have a translator and therefore does not understand or
contribute to the discussion. One time I suggested she stay home instead of attending the group, because it was very cold outside. Mrs. Lau responded, ‘no, I have to go. I missed the last two meetings.’ When she stopped receiving meeting reminders in the mail, she asked me to call to confirm that the hospital has her correct address. Mrs. Lau also attends every meeting with Kevin’s treatment team to discuss his progress, and she proactively schedules meetings with her son’s social worker if she has specific concerns. When she goes on vacation, she always lets Kevin’s social worker know where she is going and for how long, leaving her with a list of contacts, in case there is an emergency. She also apologizes for not being able to attend social events hosted by the hospital for families and inpatients.

Mrs. Lau tries to keep on top of things. Before every meeting, she writes down all her questions and concerns, in case she forgets, and spends about ten minutes reviewing this list with me. Last month, Kevin’s social worker was sick and out of office for a couple of days. Mrs. Lau was not sure when she would return and was worried that Kevin’s case would fall through the cracks. She asked me to call the director of social work to check if someone was following up on her cases. Although she knows the director is not in charge of Kevin’s case, Mrs. Lau routinely offers him updates on Kevin. As someone who is very conscious of the hierarchy in the hospital staff, she believes developing a good relationship with him is important, because he is the supervisor of her son’s social worker and can potentially intervene on her behalf if there is a disagreement.

Since differences in opinions over treatment decisions are inevitable, Mrs. Lau has created strategies to help the clinical staff see her point of view. I provide two different examples of this below. Mrs. Lau has attributed Kevin’s past behavior to his “illness,” but she rarely refers to his illness as schizoaffective disorder, or discusses any of his symptoms.
Although she has not adapted a biomedical understanding of mental illness, she does reference a Western discourse of freedom, redemption, individual rights and pursuit of happiness to justify why the hospital should discharge her son. Mrs. Lau certainly feels Kevin has already paid for his crimes with the loss of his freedom. Having spent most of his early adult life institutionalized in prisons and psychiatric hospitals, he lost a big part of his youth. And, although the hospital keeps telling Mrs. Lau that Kevin is doing well and should be discharged soon, she is tired of waiting. She pointed out the man who attempted to assassinate President Reagan had been released from prison, but Kevin is still locked up in the hospital.

I generally accompany Mrs. Lau and help her translate at meetings with Kevin’s treatment team, which includes his psychiatrist, psychologist, social worker, and about ten other professionals who provide different types of support and therapy. Through me, she tells the team Kevin is very depressed because his freedom has been taken away from him for so long. Mrs. Lau believes the team’s primary goal should be to help Kevin, now a reformed man, reintegrate into the community, and that the first step in this process is to have more faith in him and slowly give him more freedom. As Kevin proves himself in these “tests” and gains more of their trust, she argues they can make an accurate assessment of whether he is ready for discharge. Mrs. Lau knows that, in the past, some inpatients were allowed to have day trips outside the hospital, and she wants Kevin to have the same opportunity. She promised to pick him up, escort him back to the hospital, and to keep a close eye on him. This is something that Mrs. Lau has brought up numerous times in our conversations, at the Chinese family support group, and at the hospital’s support group for families of inpatients. She believes by letting Kevin leave the hospital, the treatment team is progressing in the right direction and moving towards the day he can leave the hospital. On numerous occasions, the treatment team has explained to her that the hospital
changed their policy and no longer allows inpatients to have day trips. It took a while before Mrs. Lau accepted that she would not be able to change hospital policy. That was the first and only time I saw a look of defeat in her; she became quiet, her eyes down, and shoulders slumped over.

After the meeting, on our bus ride home, Mrs. Lau complained how ironic it is that Kevin had more freedom and privileges in prison than in the hospital. She nostalgically described one time when she and her husband, and family members of other inmates, were invited to attend a lunch prepared by Kevin and the other inmates. She and her husband had a very pleasant time. Mrs. Lau also liked that Kevin was paid a small salary to work at the prison library, and exercised while doing landscaping in the prison yard. She felt the hospital’s environment lacked enrichment, because ‘besides attending therapy sessions, socializing with other inmates, all he does is eat and sleep…did you see how big his stomach is?’ Here we see a glimpse of what Mrs. Lau sees as central for Kevin’s wellbeing: physical and mental work, and contact with the outside world.

A couple of months later, I went with Mrs. Lau to another meeting with the treatment team. The purpose of this meeting was to help Mrs. Lau understand why they decided to keep Kevin in the hospital after they evaluated him for discharge. Kevin was in the STAIRS program, which works specifically with inpatients with a history of violence. The goal of the program is to reshape these individuals’ thinking processes, so they can address conflicts without violence. The treatment team needs to be confident that the likelihood of Kevin “getting into trouble” after he is discharged is pretty low, because as his social worker said, ‘if he is arrested again, he will be locked up for a long time.’ As part of his doctors’ assessment, they gave Kevin some hypothetical situations of conflict and asked him how he would handle it. In one particular
scenario, Kevin said he would seek revenge, which raised a red flag for his clinicians.

Through me, Mrs. Lau tried to explain to Kevin’s treatment team that he only talked about seeking justice through violence, because she recently gave him DVDs with movies about the Chinese mafia, which glorified revenge. Therefore, she does not feel they should take Kevin’s comments too seriously because personal vendettas are common themes in Chinese movies. The treatment team, however, still felt he was not ready to be discharged. Mrs. Lau was very upset that the clinicians were “testing” him (here, testing as in tricking and entrapment) and he fell for it. I don’t have a clinical background or know enough about how Kevin was evaluated, but I do think that Mrs. Lau raised an important point: were Kevin’s responses culturally contextualized? Part of the problem is that Kevin’s hospital has very few Asian-American mental health professionals and patients. For example, “I don’t want to live,” is a common Chinese idiom that expresses distress but does not necessarily suggest suicide ideation. This would be important information to help clinicians determine what follow-up questions they should ask and the actual risk of suicide, but how likely is it that a non-Chinese clinician would know this?

The above examples demonstrate how Mrs. Lau tries to bridge cultures by finding a shared discourse. Although she has not fully adopted a biomedical understanding of her son’s mental illness, she uses American ideas of freedom, justice, and happiness to convince doctors that Kevin deserves these things and therefore should be discharged back into the community. In the second example, Mrs. Lau attempts to help Kevin’s doctors understand the tendency of Chinese movies to glorify personal vendettas, and how this may have affected his responses to their hypothetical scenarios.
Limited English Proficiency

So far, most of the examples I presented above focus on respondents with limited English proficiency, who depend on a translator to advocate for patient services and care. Stacy explained, ‘Trying to work the system is hard. It took me two years to get Medicaid for bother. I know it is even harder for family members that don’t speak English. Li, a family caregiver at the support group, pays a translator $100 each time she helps her translate.’ Stacy also claims her ability to speak English helps her be a better caregiver, because it makes communication with health professionals easier: ‘If my brother is not taking medication or not attending a program the staff can contact me directly. They can leave me a message or email me. It’s not like that with other family members who can’t speak English. Most of them don’t know how to use the Internet, and some don’t even know how to check their voicemail.’

Although state facilities that provide direct public services are required to provide language interpreters (Governor Andrew M. Cuomo), and treatment centers generally do make an effort to accommodate non-English speaking family members, many respondents don’t get interpreters or are unsatisfied with the quality of the services. Mrs. Lau explained, ‘At meetings with Kevin’s treatment team, they ask Angela, a secretary in the upstairs office, to translate for me. The meetings are always at four in the afternoon, around the time Angela gets off work. She is always rushing so I never feel like all my concerns and questions are addressed.’ Often, treatment centers rely on staff to be lay interpreters, as seen with Ms. Ng and Mrs. Lau. However, Mrs. Lau feels rushed and has to communicate in a Chinese dialect that is her second language, Mandarin.

Even when professional interpreters are utilized, the quality of the interpretation is not guaranteed, because there is no standardized curriculum or national accreditation exam in
medical interpreting, particularly with mental health interpreting (Doris Chang personal communication). A staff at a community-based organization that helps parents who have their children taken by Child Services shared: ‘I understand Mandarin. When I accompany Chinese immigrant parents to family court hearings, I am appalled by the amount of mistranslation and information that gets omitted.’ A senior staff at an agency that monitors the quality of culturally competent mental health services in NYC recounted a story that offers another snapshot of the problem:

My mother had a stroke and was hospitalized. They assigned her an interpreter. The hospital wanted to use their own interpreter, but this woman was so bad that I had to take over. In another hospitalization, the doctor diagnosed my mother with schizophrenia. I’m in the mental health field and I know my mother does not have schizophrenia. It turns out when they asked her how many plates she saw in front of her and she said two, they decided she was schizophrenic. My mother is double sighted!

Furthermore, being bilingual does not mean an individual has knowledge of psychiatric terminology or basic mental health literacy. I recruited Paula to write a column in the support group’s quarterly newsletter, and gave her the option to write in English or Chinese. She laughed and told me, ‘It has to be in English. My entry into mental illness was in English. I don’t even know how to say certain things in Chinese. For example, I don’t know the Chinese terms for psychologists and psychiatrist.’ Similarly, a friend, who is a bilingual social worker, shared, ‘I’m looking for an English-Chinese medical dictionary for psychiatric terms, but it’s so hard to find. I have no idea how to say things like hallucination and mania.’ Knowledge of medical terms is important, but it also requires a level of clinical understanding to accurately explain the terms to immigrant Chinese families, who often have very low mental health literacy. Paula shared, ‘In a room of 20-25 family members at the support group, only about five people,
and these are individuals that have been long time participants at the group, know the difference between psychiatrist and psychologist.’

Part of the problem is that there is no reliable source of information in Chinese. Many governmental sites that provide information on mental illness give users the option to translate the site into Chinese. However, most of my respondents who don’t speak English, also don’t know how to access the Internet, something that is true regardless of socioeconomic status. There is a need for mental health education among the immigrant Chinese population. Recently, the United Health Care office in Flushing (a satellite Chinatown in the borough of Queens that offers monthly lectures and workshops on wellness to the Chinese-American community), asked the support group if they could do a presentation on mental illness. The manager of the store explained, ‘Chinese people don’t really understand what is mental illness and there is not a lot of information out there. I think the topic is still highly stigmatized, so people are afraid to talk about it, even if they are curious or need help.’ In the past, the NAMI chapter in Manhattan, one of the biggest in New York City, had attempted to organize a support group for Chinese families, but was not able to find suitable partners.

Given the difficulties with accessing information and quality interpreter services, family members often times have to rely on an ill relative to translate, which they feel is not ideal. At one support group meeting, one mother asked, ‘Are there translators available? Right now my daughter translates for me, but I don’t trust her to tell me the complete truth.’ Stacy concurs, ‘How can you ask a mentally ill patient to translate?’

The lack of professionalism exhibited by staff at social service agencies doesn’t make things easier. Below, Stacy narrates one incident where she accompanied her aunt to one such agency:
We walked up to the front window. The lady was speaking on the phone and after she got off, she told us she was going to lunch. Can you believe that? I went back to the front desk to ask for the name of this woman. The receptionist got defensive and wanted to know why I wanted this staff’s name. If I had not spoken English, things would have been worse.

Unfortunately, these experiences are not isolated incidents. Once, I accompanied a friend’s cousin and her fiancé to apply for their marriage license, because they did not speak English. On that day, the clerk behind the window had an intern next to her. The clerk asked if the wife wanted to take the husband’s last name and, after checking with my friend’s cousin, I told her no. The clerk then turned to the intern and announced, ‘Chinese women don’t take their husband’s last name,’ as if the three of us were invisible. Her comment, was not only incorrect (most Chinese women do take their husband’s last name), but also identified us as the “other.” Furthermore, as a senior staff member who trains junior colleagues, she is reinforcing stereotypes and modeling culturally insensitive behaviors.

In my final case study, I focus on Stacy’s experiences over a period of several months after her brother relapsed and was hospitalized. Being a caregiver and an advocate is a big part of Stacy’s identity. In our early email exchanges, she would sign off with her name and, just below it, “caregiver and advocate.” I have also seen her include these two descriptions of herself when she exchanged contact information with other people in the mental health field, such as clinicians, consumers, and other family caregivers. Stacy saw the system as sort of a game with complicated rules and regulations that family caregivers need to learn in order to “work it” to their advantage. Let me note here, Stacy is different from my other respondents; she is educated, speaks English, and has an astute understanding of how bureaucracies work due to her experiences of taking care of her parents and brother. Most of my respondents depend on a translator to speak for them—it is their norm. Stacy, on the hand, does not have to, so when she
does recruit people to help her advocate it’s definitely out of the ordinary for her and suggests she does not feel confident handling a particular situation on her own. Although Stacy is not a typical respondent, I discuss her ordeal in detail, because her story reveals common problems with bureaucracies and the difficulty of navigating the mental health system, even for someone with her skills and resources. Furthermore, Stacy tends to be very vocal about her experiences with health professionals at the support group, offering advice and cautionary tales. Many family members respect and look up to Stacy, so she is almost like a mentor, showing other caregivers how to work the system.

Stacy- “You have to play the system, or it will play you”

I called Stacy one day to see if she wanted to catch up over dinner. She answered the phone and quickly said, ‘I’m in the emergency room with my brother. I’ll call you back.’ She later filled me in that her brother had relapsed and had to be sent to the emergency room. He was admitted to the psychiatric ward at Pinewood Medical Center (names of all institutions in this case study have been changed). Prior to being hospitalized, Cory showed signs of memory loss, had high sugar levels, and experienced problems sleeping. His doctor thinks he stopped taking his medication, but Stacy believes two stressful events contributed to the relapse.

First, the company that the government contracts to provide home aid attendants sent a representative to Cory’s apartment for a home visit and an interview. The purpose of the interview was to determine if Cory still needed a home attendant (at that time he had one for the daytime and one that stayed overnight) and if he did, the number of hours he would need. Second, the management office at his low-income apartment informed Cory that another tenant complained that he was being too loud. Stacy thought this was “bullshit” because she knows her
brother is a very quiet person. She has been annoyed with the staff member who is the main contact person between Cory and the management office, because this woman ‘is rude, and never returned her calls.’ Therefore, Stacy goes over her head and only corresponds with this woman’s supervisor. She feels that the housing board ‘takes advantage of nice tenants, but not the ones that are nasty.’ When I accompanied Stacy to the management office to return the apartment keys, she told the manager his staff was not friendly to her brother, and he apologized for that.

Like my other respondents, Stacy visited Cory every day after work when he was hospitalized to check on his progress, and to sit with him. She can’t cook, but she will buy Chinese food and bring it to Cory. Sometimes she will buy the ingredients and ask her friends or aunt to make Chinese soup for him. Although Stacy is not actively doing anything, her visits are a way to express her love and care. As Paula said, ‘I went to see my daughter at the hospital every day. It doesn’t do anything, but I feel like I should. I guess it’s a Chinese thing to do (laughing).’ Stacy also feels it is important to show her face because, ‘the hospital will be more careful if they know family members are watching.’ As we all know, the more family and friends who are around to monitor the quality of care in an institutional setting, the lower the possibility of medical mistakes and patient abuse.

However, despite her vigilance, two things happened to Cory while he was at Pinewood that negatively affected Stacy’s confidence in the administration and clinicians there. First, as a nurse was helping him up, Cory fell out of his bed. Stacy pulled out a picture of Cory’s face taken about five days after the fall, to show it was still very bruised and swollen. I remembered wondering how did he get so badly hurt from just falling off his bed? Second, the hospital gave him the wrong medication and that caused an adverse physiological reaction, resulting in Cory going into the intensive care unit. Stacy worries that the medication will have permanent effects
on his cognitive function. She was also upset with how flimsy the patient ID bracelets are. The patient’s info was written in ink on a piece of paper that was easily smudged when wet. She showed me a photo of the smudged writing on Cory’s ID. The final straw for Stacy was when Pinewood wanted to discharge Cory before he was ready. She had the staff from the NAMI office in Manhattan, who are experienced family advocates, accompany her to the meeting with the treatment team to challenge their decision to discharge Cory. However, the doctors’ final decision was to discharge Cory.

Less than a month after he was discharged from Pinewood, Cory was again showing signs of relapse. This time Stacy called a cab and took him to the emergency room herself. She did not want to call an ambulance because the EMT decides where to take him, probably back to Pinewood. Again, we see Stacy playing the game here when she personally takes her brother to the ER. Stacy specifically brought Cory to Maple Grove Medical Center in another part of Manhattan, because she had heard good things about them (I have also heard other family members praise this hospital). After he was admitted to Maple Grove’s psychiatric ward, Stacy waited for the hospital’s social worker to contact her. She wanted to give the person some time to ‘catch up on the paperwork… if the social worker does not follow up with me, then I will contact her.’ Respondents who have gone through multiple hospitalizations with their relatives have a general idea of the process, from admission to discharge.

Overall, Stacy was happy with how Maple Grove operated. She felt they were generous. Pointing to a small table against a wall in their inpatient psychiatric ward, she explained, ‘they always have coffee, tea and hot chocolate for family members. They have generous food portions and if there is an extra tray of hospital food they give it to family members.’ Stacy also claims she has certain privileges that go against hospital regulations. She can stay past hospital
visiting hours and, although family members cannot enter patient’s rooms, Stacy sometimes goes into Cory’s room and sets up his bathroom so that he can shower. She shared, ‘the staff treat my brother well. There are certain things they forget to do occasionally, like change the bed sheets or help him shower. But when I politely ask them, they always do it. I buy them little gifts, like chocolate, to thank them.’ For Stacy, their generosity and flexibility suggests the hospital wants families to feel welcomed and involved in patients’ care.

Stacy also thought they were very patient centered. Cory had to be interviewed for an opening in a group home for people with developmental disabilities (he currently lives there). Although Maple Grove could not let Cory leave the hospital to do a trial sleepover at the group home, they arranged transportation for his interview. He has a dual diagnosis of schizophrenia and a developmental disability, but Stacy prefers finding services and activities for individuals with developmental disabilities, because she believes these individuals, like her brother, generally do not have violent tendencies. In addition, she feels organizations associated with developmental disabilities are better advocates and receive more funding, partly because the diagnosis is less stigmatizing than a psychiatric disorder. Bob and Sue are also in the process of trying to get Bob’s brother-in-law into the same system. Sue explained, ‘He may not qualify because his IQ is slightly above the cut-off point, so we are trying to find some loopholes right now.’

While Pinewood eliminated neurological causes without doing a CAT scan or an MRI, the doctors at Maple Grove were cautious in making a diagnosis. When I visited Cory at the hospital I saw that he was very quiet, and occasionally smiled to himself. Stacy was concerned that he babbled to himself and had problems with short-term memory. His psychiatrist at Maple Grove had several hypotheses as to why Cory was in his current state: 1) overmedicated at
Pinewood, 2) exhibiting early signs of Parkinson’s disease, or 3) in the psychotic state of schizophrenia. She will slowly wean him off of all his medications to rule out the different possibilities.

Maple Grove represents a quality treatment center. While Pinewood wanted to discharge Cory even though he clearly was not stable enough, Maple Grove was thorough with running diagnostic tests to rule out various diagnoses. They took good care of their patients and made accommodations, such as arranging transportation for Cory’s interview at the group home. Maple Grove had been generous, not only with patients, but to family caregivers in regards to food and being lenient with hospital rules. In short, these are things other caregivers have associated with competent care (Jensen 2004).

Regrettably, after all the accolades Stacy had given Maple Grove, she was disappointed at the end. She called me one day to tell me that the hospital gave Cory a double dose of his prescription. She expressed her concerns and frustrations: ‘these medications are dangerous. They affect his blood pressure and can make his white blood cells extremely low….The incident happened at 10AM, but the hospital did not contact me until 4PM. When I saw my brother, his face and hands were swollen. They told me he’s all swollen because of the IV. I don’t believe them. It took three days for the swelling to go down. This is a reputable hospital, but I have lost confidence in them.’ Nurses at Maple Grove always check the patients’ ID bracelets before administering medicine to ensure they are giving the right medication to the patients. However, this time, one nurse had given the medication to Cory, but forgotten to indicate it in the logbook, and so another nurse gave him a second dose. Pinewood and Maple Grove both sent Stacy a letter after each incident. Although she is still upset with both hospitals, she felt Maple Grove was more professional because they admitted it was their mistake.
The medical system is supposed to help patients, but what Stacy has learned from sad experience is that financial constraints, bureaucratic logic, and liability issues often take priority over the care of patients. Therefore, Stacy believes “you have to play the system, or it will play you.” Like my other respondents, she has developed a set of tools that help her navigate the health care system, and advocate for her brother. However, Stacy has an easier time doing these tasks because she speaks, reads, and writes English.

First, since mental health institutions often serve many clients and have to manage all the paperwork associated with these individuals, there are bound to be mistakes and things can easily fall through the cracks. Family caregivers have to be organized and prepared to follow up. For Stacy, this means keeping copies of all documents, such as her brother’s lease agreement, which was signed more than 15 years ago, and getting written documentation for everything. While Cory was hospitalized in Maple Grove, they were notified that he was accepted to the group home he had interviewed for. Stacy was very happy because she does not think her brother can live by himself anymore, even with home aid attendants. However, she is still cautious, because the acceptance was only verbal, and verbal promises can be retracted or miscommunicated. She told me, ‘I am waiting for written notice before I can really relax,’ because written documents are more tangible than words and can be used in future disputes. As you can imagine, keeping track of documents may be more difficult for respondents who do not speak, read or write English. Furthermore, phone conversations with program administrators require making arrangements to have a translator present or giving the contact information of someone who can speak English and later relay the information.

Besides double-checking and confirming information, Stacy thinks of creative ways to get people’s attention. She has the power of attorney for her brother, so the SSI office sends her a
copy of everything they send him. Recently, Stacy faxed them her new mailing address, but she never got confirmation that they received it, so she wanted to double-check. As we waited for her ticket number to be called, she showed me a copy of the fax she sent. It had a very eye-catching border around the text and I commented on how nice it was. Stacy explained why she included the border, ‘most faxes are very plain. I want to make mine more interesting so the office staff will be more likely to pay attention to it.’ When Stacy was called to come to the window, her suspicion was confirmed, the office never received her fax. Again, the ability to perform these tasks is something that we take for granted. Many respondents don’t know how to operate a fax machine or send emails, and trips to the Social Security office require finding someone who speaks English.

A second one of Stacy’s adages is, know when to “make some noise.” Although Stacy realizes it is best to be perceived as a polite and patient family caregiver, she believes sometimes you have to make some noise. She shared, ‘if my brother did not get accepted to this group home, I will complain and make a big deal about it. I actually got this advice from a higher up from this agency. She works for this agency but is sympathetic to patients.’ Similarly, when she was not getting the type of service she expected from the staff at the housing office, she decided to correspond directly to this woman’s manager and made sure to let the manager know she was unsatisfied with the service. Administrators and clinical staff often have different motives and interests than patients and their families, so one has to “play the game,” knowing when to be compliant and when to “make some noise.” Paula similarly echoes this sentiment: ‘The past director at Joyce’s day treatment program told me that I am one of the most involved mothers. Most parents are here in the beginning but then are gone…I know some people in Joyce’s
treatment team find me very vocal, aggressive, and I’m sure I have stepped on people’s toes in the past. However, I have to speak up and advocate for Joyce.’

Third, Stacy advocates recruiting people in high places who can help with patients. She had the NAMI staff accompany her to the meeting with Cory’s doctors at Pinewood, because she believes they have more experience as family advocates. The way Stacy sees it, ‘there are some professionals that are really good and others that are really bad. Some are compassionate and want to help, but they lack experience or have no power. Then, there are those that have the power, but lack empathy. Thomas (one of the volunteers at the support group) is great with handling public relations, but he lacks empathy, maybe it’s because he does not have a family member with a mental illness. He actually thought my brother’s flimsy hospital ID bracelet was acceptable! Ling (another volunteer) is a supervisor and has been in the mental health field for a long time. She’s just putting in hours and not up to date with changes in mental health services and policy. We have to develop relationship with health professionals that have the desire and the power to help.’ Being bilingual, Stacy has more opportunities than other respondents to foster relationships with professionals, because she can communicate with English-speakers.

Her perceptive awareness of the distinction between willingness and ability to help is reinforced by past engagements with hospital administrations. A year before Stacy and I met, Cory was taken to the emergency room at Willow Oak Hospital, which did not have a psychiatric ward. The hospital did not have a resident psychiatrist, only one who came by once or twice every week. Since the hospital was providing Cory with limited psychiatric care, they could not bill Medicaid for his entire stay, and therefore Willow Oak was losing money. The following is an excerpt from our conversation:
L: Why don’t they move Cory to another hospital?

S: Well, they can’t do that. They don’t want to be accused of dumping their patients on other hospitals. They were losing money because they could not charge Medicaid. That’s why they wanted to discharge him to me, but I refused. If I take him, I am responsible for him. I can’t control what happens on the way to the hospital. What if he runs out when the cab stops at a red light? I went to the Director of Patient Services for help, but he was useless. He thinks that I am Lulu (slang that describes someone as a fool or ignorant), that I don’t know anything. The funny thing is that I ran into him a few years later. By that time he was promoted to Vice President of Patient Services. A friend of mine invited me to dim sum and when I got to the restaurant I saw him sitting there, so it seems like we have a mutual friend. He tried to explain that he was just following hospital protocol in the way he handled my brother’s case. Of course, I was polite and I said I understand. But, in reality, I don’t think he is a good patient advocate. You know later on, that hospital fired a translator that spoke several Chinese dialects, but kept one that only speaks Mandarin. The one they kept is younger, more attractive and knows how to kiss ass. Even if this man was not directly involved in making decisions regarding lay offs, he could have intervened. It’s more cost efficient for Willow Oaks, and better for patients and their families if the hospital keeps a translator who can speak several Chinese dialects. He should have thought about how this personnel decision will affect patient care.

Fourth, Stacy encourages being a lay expert in mental illness. Although Stacy does not have any clinical training, through the years she has learned what Cory’s stressors are and how to read his mental condition. During one hospitalization, when the doctors wanted to discharge Cory, Stacy argued that he was not stable enough. From the first day that he was admitted, Stacy asked Cory to sign his name every day, to gauge his cognitive functioning. She pulled out this paper and showed the doctors that his penmanship did not improve at all, which suggested his mental condition had not improved at all. Not only was Stacy’s idea ingenious, it demonstrated her astute understanding as what counts as “evidence,” to challenge the expert knowledge of a clinician.

Fifth, “playing the system” may require families to be less than completely honest. After our meeting with the management office of Cory’s old apartment, Stacy told me about duplicate keys that she did not return. I was surprised because the action seemed uncharacteristic of her,
and I commented that she was very cunning. She laughed and explained, ‘the housing office is not on top of things. The housing manager wrote the wrong zip code. His writing is unclear and he did not even put the apartment number on the forms.’ Stacy’s past experience has reinforced the idea that bureaucracies are disorganized and treat clients differently (they are nice to the mean ones), so keeping the keys is a way for Stacy to protect herself. Having the keys in her possession does not give her with any real power, because most likely the management will change the apartment’s locks and Stacy is not the type to do anything illegal, such as trespassing. However, she feels empowered by pulling a fast one over the management, and in some ways justified because they are so disorganized.

Similarly, Stacy believes it is okay to omit certain information when applying for services for one’s family member. After Carol’s husband passed away, the money from his life insurance policy went to Jessica who was then eight years old. When Jessica turned 18, she received the money, about $80,000. The family spent it and, when Jessica applied for SSI, she was denied because the Social Security office wanted to see proof that the money was spent. Stacy feels the family was ‘too honest and should not have disclosed information about the insurance policy. The fact is, the money was spent and ‘Jessica needs the SSI money so she can have more access to mental health services, such as housing.’ Stacy does not think her advice is unethical, because they did spend the insurance money ($80,000 for a family of three doesn’t go very far in NYC), and Jessica does need SSI. Although what Stacy is espousing Carol and Jessica do is technically against the rules, it is understandable given the more than often incomprehensible logic of bureaucracies. From Stacy’s perspective, Carol and Jessica are not trying to commit fraud, nor are they trying to abuse the system.
Involuntary Psychiatric Hospitalization

Interestingly, there are few studies that discuss families’ difficulties in getting their relatives involuntarily committed for psychiatric care (Karp 2001, Lefley 1996, see Earley 2006 and Pierce-Baker 2012 for personal accounts) in the literature on caregivers’ interactions with the mental health system. I have included accounts of this, because it is one of the most frustrating and distressing experiences for respondents. Ling, one of the volunteers at the support group and a social worker, told me, ‘When a patient refuses to take medication, there is little the family or clinicians can do.’ This is because, under New York State law, you cannot force an adult to receive treatment, unless they are a danger to themselves or others. If a clinician petitions a judge for permission to force treatment, a patient is assigned a public defender to protect his right to refuse treatment.

More attention should be given to this phenomenon, because this is an emotionally taxing and arduous process for caregivers to go through, as seen in one sister’s attempt to help her brother. In the last chapter, I discussed a sister who could not let her psychotic brother stay with her family, because she has small children. This woman’s name is Jane and her neighbor, who happens to be a long-time participant of the support group, referred Jane to the group. Jane did not know what to do with her brother, Todd. He wrote graffiti all over the house, put chains around the family dog, and forced him to drink coffee, tea, or whatever he was drinking. Jane took pictures of the house and went to the police. The police took him to the hospital, but Todd refused to take medication. The judge ordered psychiatric evaluations, but by that time, Todd had calmed down significantly and was able to answer the clinician’s questions. He was ruled to be stable and released.
Later on, Todd was again hospitalized and they had to repeat the whole legal process. Although the judge released him again, he warned Todd that if he appeared at court a third time, he would be admitted. After Todd was released, he did not want to return home, because ‘he felt there was something in the house.’ Jane and her family were trying to find him a place to stay. At that time, he was going to Internet cafes at night and coming over to Jane’s house in the daytime. Jane and her husband did not want him to stay overnight at their home, because, as indicated previously, they have small children. Ling helped the family find shelters in Queens, but since most of the residents there are African Americans, the family did not want Todd to stay there, either. Regardless of the family’s preference, Ling pointed out that it might take a while before a spot opened in these shelters. In the end, Jane was able to convince Todd to return home.

Hanna and her sister Laura, offer a different angle on the problem. Although Laura is not violent, her eccentric behavior makes independent living difficult. Hanna, at 70 years of age, has to constantly manage Laura’s relationships with her landlord and neighbors, but won’t be able to do this forever. She hopes her sister will apply for services available through the mental health system, such as housing programs. However, Laura does not believe she is ill and refuses to apply for services. Hanna can’t do it on her behalf either. There was some discussion with the other siblings about buying an apartment, either a co-op or a condo, for Laura, but then there is no guarantee that she would want to live there. Even if she agrees to live there, she will be thrown out by the housing board if she starts makes a lot of noise or does things that disrupt her neighbors.

Hanna has tried many ways to get Laura into treatment. She has sent a community crisis team to talk to her, but Laura refused to let the team come in. After the third failed attempt, the
crisis team told Hanna, ‘they can’t take her case.’ In the past, Hanna has called the police, but it was a very traumatic experience for both sisters. Hanna watched as the police broke down the door and forced Laura down and handcuffed her. The mental health system, operating under bureaucratic logic, tends to normalize routine, and rationalize events that are experienced by caregivers as “horrifying crises” (Karp 2001:199). While in hindsight, Hanna can understand the “bureaucratization” of her personal problems and turmoil, it was still a very frightening scene to watch the police, who were supposed to help her sister, handcuffed her instead. The effect on the patient is also something that mental health practitioners consider. One senior level social worker shared an experience early on in his career: ‘I had a patient that needed to be hospitalized. I called 911 and the police arrived. I knew the police would handcuff him, but I also knew that would not be good for the patient. This is not part of the routine, but I offered to ride in the police car with the officers, if they wouldn’t handcuff the patient. This is not normally part of the protocol, but I felt, in this situation, it was the right thing to do. My supervisor also backed up my decision.’

Jane and Hanna’s cases offer insight into the link between family involvement and mental health disparities. As noted by Parcesepe et al. (2011), numerous studies (i.e., Department of Health 2003, Kung 2004, Alegria et al. 2008, Harris et al. 2005) have documented mental health disparities in access and quality of care in minorities. Snowden (2007) and Ryder et al. (2000) suggest Asian Americans’ high involvement in patients’ lives is associated with lower rates of professional treatment. However, the causal relation is unclear (Snowden 2007). On the one hand, the cost of divulging the secret can be socially disastrous, so Chinese families tend to shield their mentally ill family member from the rest of the community, which leads to treatment delays (Ryder et al. 2000). An admission of mental illness, however, reflects poorly
on the family name because it implies the family is incapable of resolving its own problems. Ultimately stigma resulting from mental illness is shared by the entire family and diminishes the economic and marriage value of patients and their families (Ng 1997). As a result, many people who would benefit from mental health services opt to decline or withdraw from available services (Corrigan 2004). On the other hand, lower rates of service use may indicate patients who are more integrated into their family may suffer fewer symptoms, function at a higher level, and therefore require less treatment (Snowden 2007). There needs to be more research that examines how cultural differences in family involvement and support are related to mental health treatment disparities (Snowden 2007).

Jane and Hanna’s experiences, I believe, are cautionary reminders to not overemphasize cultural explanations, in particular Chinese families delaying treatments because of stigma. These women demonstrate it is not the stigma of mental illness that acts as a barrier to seeking mental health treatment, but rather patients’ refusals, suggesting legal constraints on getting individuals’ treated involuntarily, which affects all families, may be more pertinent. Intra-familial coping is more likely in milder cases of mental illness (Lin and Lin 1981), whereas psychosis that involves violent or acting out behaviors are more difficult for Chinese families to manage and are less tolerated, which would encourage help seeking (Okazaki 2003, Althsuler et al. 1988, Parker et al. 2001).

In addition, Parcesepe et al. (2011) points out that national studies of mental health disparities may also not accurately reflect the health services in different US cities. According to their 2011 New York State Office of Mental Health Assessment Report on Unmet Needs, there is limited knowledge on disparities in accessing services in NYS. However, Parcesepe et al. (2011) found that once individuals enter the mental health system, there is little difference in service
utilization and psychotropic use across racial and ethnic groups. In general, it may be easier to access to quality services in cities than in rural areas (Jensen 2004), which have fewer treatment centers and a less developed public transit system. More importantly, the lack of difference in service utilization in NYS may be the result of a more culturally competent health system that encourages minorities to stay in treatment. Despite the limitations I have noted above, NYS seems to have a pretty decent mental health system, in comparison to other states. In 2010, NYS had the second highest mental health expenditures nationwide (National Association of State Mental Health Program Directors Research Institute, Inc., 2012). The Adult Consumer Assessment of Care in New York State, 2012 Statewide Final Report (New York State Office of Mental Health, 2012) also indicates patients were fairly happy with their services. Furthermore, the state also works with two centers, the Nathan Kline Institute (NKI) Center of Excellence in Culturally Competent Mental Health, and the New York State Psychiatric Institute Center of Excellence for Cultural Competence, to ensure culturally competent services for mental health consumers. The above findings suggest health policy directed at minimizing mental health service disparities in NYC Chinese immigrants should focus more on encouraging access than on retention.

Hanna’s case, in particular, also suggests caregivers’ reluctance to seek treatment is tied to their past negative interactions with the mental health system, and to the horror stories they hear from other families. Although Cindy recognizes that her son, Dan, is getting more mentally unstable and needs to see a doctor, she is reluctant to call 911, because she fears having the police come and take him to the hospital, which will make his condition worse. The above examples involve police who know they are dealing with an individual with a mental illness, but what about when they don’t know? At the support group, Carol reported that Jessica was injured
after being tackled by three police officers. It is not uncommon for undercover New York City police officers to linger around subway turnstiles to catch people selling swipes on their metro-card or someone using a reduced fare metro-card that was assigned to an elderly or disabled individual. The police officers thought it was suspicious that Carol’s daughter, Jessica, swiped her reduced fare card. Since they were wearing street clothes, Jessica had no idea they were police officers, and when they tried to stop her, she ignored them and kept walking. Three officers then proceeded to tackle Jessica, who is about 5’3 and 110lbs, to the floor. They took her to the station where they determined that the metro-card did belong to Jessica (her picture was on the back of the card) and that she did not break the law. Carol took her daughter, who was covered in bruises and scrapes, to the doctor. As Carol told the story, I saw a few other family members shaking their heads. Mrs. Lau noted, ‘these are the things we worry about when our family members are out without us’ and another mother added, ‘bad things can happen when police officers don’t know they are dealing with a mentally ill person.’ It is stories like this that contribute to respondents’ mistrust and reluctance to seek help from officials and professionals in the mental health system.

Concluding Remarks

Consistent with findings from earlier research with Euro-Americans, my respondents encounter professional and institutional barriers that prevent their inclusion in their ill relative’s treatment planning and implementation, and they often have to endure inadequate, inappropriate, and unprofessional services. Furthermore, their limited English proficiency and unfamiliarity with the bureaucratic logic of the mental health system creates distinctive challenges that further impede their ability to effectively advocate on their family member’s behalf. Most notable, is
that they have to rely on another individual to translate and interpret everything they say and is said to them. Furthermore, these women have to depend on interpreters or interpreting services that are not standardized, and have limited oversight on the quality of the translation. Stacy’s experiences highlight just how difficult navigating the system is, even for someone who speaks English and is an experienced patient advocate.

Through discussing different cases of conflicts with the mental health system and patients, I examine the creative strategies respondents employ to maneuver around patient confidentiality policies, manage symptoms, question clinical decisions, and recruit professionals to help with advocacy. It is also in these situations that we can see how respondents grapple with their ambivalence toward psychiatric medication and understand how they evaluate mental health professionals. The strength of ethnography comes through clearly in this chapter—in revealing the motivations of the different parties involved, it opens up the possibility for conflict resolution. In Mrs. Tam’s case, what seemed to be a deficiency in the mental health system was really about a mother and daughter wanting different things. In addition, Jane and Hanna’s situation suggest that with psychotic psychiatric disorders, legal constraints for involuntary commitment and past negative encounters with the mental health system may be more important than fear of stigma in determining whether Chinese families pursue treatment.

Through the stories in this chapter, I hope to show that not only can clinicians and family caregivers have complementary relationships, but also that integrating quantitative and qualitative approaches can be just as productive. In the next chapter, I shift my focus to how the family support group provides practical and emotional support, and how volunteers and respondents conceptualize their relationships with each other.
Chapter Six: Chinese Caregivers and Family Support Groups

Sister: I head from dad that you asked our family doctor to refer mom to a psychiatrist. Why did you ask for a referral? You know mom won’t talk to a psychiatrist.

Many Immigrants experience difficulty adjusting to their new environment (Williams and Berry 1991) because of social isolation, language barriers and unfamiliarity with the new socio-political system (Dion and Dion 1996). This acculturation stress has been connected to poor physical and mental health, especially among more recent immigrants (Vega and Rumbaut 1991, Oh et al. 2002). The trauma and stress involved in adjusting to a new country, therefore, makes it more difficult for immigrant families to cope with a mentally ill relative. Chinese families’ ability to cope is mediated by cultural factors such as illness beliefs, stigma, and culturally prescribed coping mechanisms (Kung 2001, Kung 2003, Kung 2004). In addition, pre- and post-immigration factors, including education status, linguistic ability, refugee status, residence in ethnic neighborhoods, and the availability of social networks are significant (Williams and Berry 1991). In particular for recent, immigrants, help seeking is discouraged due to lack of knowledge of community resources, limited financial resources, and general mistrust of government officials (Kung 2003).

Ethnic support groups can be a major source of practical and emotional aid for immigrant Chinese families coping with mental illness (Kung 2001). This chapter contributes to the limited literature on minority caregivers’ involvement with support groups by examining my respondents’ experiences as participants in a NYC support group for Chinese-speaking caregivers. My research offers a unique opportunity to explore the effectiveness of support groups and the actual therapeutic processes for minorities, who often are reluctant to participate
in mental health research in the US (Solomon 1998, Chan and O’Connor 2008). The support
group, acting as social capital, helps respondents meet needs that have been identified as
important in previous research on families and mental illness, such as information on etiology
and treatment of mental illness; practical advice on how to respond and manage difficult
symptoms and situations; emotional support; information on community resources; and advocacy
However, the most significant support is the practical assistance from the group facilitators, who
are bilingual and bicultural Chinese mental health professionals, especially during times of crisis.

While the Chinese support group offers assistance typical of support groups, it differs
from more mainstream ones that are family- and professional-led, in that it caters to limited
English proficiency caregivers who have not fully acculturated. The relationship between
volunteers and family members, in turn, reflects a fusion of different relational frameworks,
including clinical and mentorship. Adopting NAMI’s peer group approach (family to family)
and attempting to maintain professional boundaries, volunteers encourage family participants to
support each other and to advocate for themselves, hoping that one day they can lead the group.
Family participants, on the other hand, place emphasis on their relationship with volunteers,
which they view as one between a teacher and student. These relationships are imbued with
moral undertones, because learning, and by association teachers, is tied to moral cultivation.
Furthermore, according to Chinese ideals, to be a “good person,” family participants should
remember and try to repay others for their kindness (Oxfeld 2010), in this case the volunteers.

While volunteers encourage family participants to develop and foster relationships with
each other outside of group meetings, this has proven to be difficult. Most people are busy with
work, caregiving, and other domestic duties, so they lack the time and energy to develop
friendships. It is also difficult for some of the retired family members to travel, especially during the winter months when it snows and temperatures drop to single digits. Beyond the logistic and practical barriers to developing friendships, there seem to be subtle divides based on class, education, dialect, and nationality.

In the following sections, I discuss the positive outcomes associated with support group participation, and explain in what ways support groups are congruent with the coping styles of immigrant Chinese families. Afterwards, I provide some background information on the Chinese support group in my study, and describe how it differs from more traditional groups that are either family- or profession-led in the US. Despite these differences, the Chinese group offers benefits—such as emotional support, coping strategies, education, and advocacy—similar to these more traditional models, but tailored to immigrant Chinese caregivers. Finally, I discuss how the teacher-student relationship develops and how this process, along with family participants’ obligations to remember and reciprocate the assistance they received, promotes a moral understanding of their relationships to volunteers. Furthermore, because volunteers are the ones who can provide practical assistance in times of crisis, a critical type of support for families who lack the resources and knowledge about the health care system, it is unlikely that family participants will assume leadership roles in the support group.

**Support Groups and Chinese Families**

The emergence of support groups and other family interventions reflects a shift in clinicians viewing families as the cause of mental illness to treatment partners who can be a supportive resource for patients (Solomon 1998, Marsh and Johnson 1997). Solomon defines family intervention as “any strategy or program, clinical or nonclinical. Designed to help and
empower these families to cope with these devastating disorders through such means as the provision of support, education, and skill training” (1998:7). This includes programs such as psychoeducation, supportive family counseling, and family support and advocacy groups. Previous research has shown that Euro-American caregivers receive positive benefits from participating in support groups, including increased knowledge about mental illness, improved relationships with patients, increased family and peer support, and lower caregiver burden (Lefley 1996, Saunders 2003, Norton et al. 1993, Abramowitz and Coursey 1989, Citron et al. 1999, Pickett-Schenk et al. 2000, Winefield and Harvey 1995). Similar positive family and patient outcomes have been documented in Chinese family support groups in Asia (Chien et al. 2008, Chien et al. 2004, Chien et al. 2006, Chou et al. 2002).

However the generalizability of the findings from these two sets of literature is limited to immigrant Chinese families in the US. Support groups in the US generally consist of participants that are White, female, middle class, and educated (Gidron, et al. 1990, Karloff and Friesen 1991, Norton et al. 1993). In general, individuals are more likely to participate and benefit from attending groups with participants who have similar demographics and personal attributes (Maton 1989, Maton 1993). Therefore, since cultural and professional backgrounds of group facilitators and participants significantly determine the structure, dynamics, and goals of the group, a group with predominantly Euro-American family caregivers may not be as beneficial or attractive to minority caregivers. Instead, minority caregivers may prefer groups that endorse their social and cultural norms, such as the use of alternative health systems or praying (Guarnaccia and Parra 1996).

The motivation and meanings attached to participation, and the actual benefits may also differ based on class. Gidron et al. (1990) have found that support group participants have more
psychosocial stressors, whereas non-participants tend to struggle with financial difficulties and other issues related to daily survival. The authors attributed the difference in participation to the fact that caregivers in higher socioeconomic status (SES) groups are less occupied with issues of daily survival, and therefore are able to attend support group meetings to focus on psychosocial distress. Interestingly, my respondents don’t fit the general characteristics of support group participants. While participants in the Chinese group are females, they differ demographically from the majority of support group attendees nationwide in that they are in lower SES groups and cannot speak English. Although I have never systematically measured their psychosocial functioning, using the physical and mental health issues faced by respondents as proxy, I would argue their stress levels are very high.

This divergence from the pattern identified by Gidron et al. (1990) suggests other mechanisms may be motivating Chinese caregivers to participate in support groups. Perhaps Chinese caregivers are driven to attend a support group, despite ongoing financial struggles, because their lack of English proficiency and knowledge of the mental health system severely impedes their ability to find adequate services for their ill relative and for themselves. Furthermore, many of my respondents reported feeling overwhelmed and frustrated, because they are receiving little assistance from other family members or they lack the support of a significant other. Of my seven key informants, five are single (divorced, widowed, etc.) and the last two’s husbands are not involved. The need for support in these families may also be more urgent, because unlike many NAMI members, all of my respondents’ ill relatives are unemployed and most cannot speak English. Therefore, these women have limited support and more caregiving burdens, which may be their primary motivators for joining a support group.
Although the second body of literature focuses on Chinese caregivers’ experiences with support groups, they were conducted in Asian countries, where most of the population speaks Chinese and individuals tend to have a larger familial network. All these factors can make it easier to access services and social support. In addition, since providers are probably Chinese, they may be more sympathetic and understanding of family dynamics and concerns. For example, when I carried out exploratory research at a psychiatric hospital in China, I observed family members staying inside the ward with their ill relative, where they were involved in various caregiving tasks, from washing patients’ clothing, helping them bathe, to peeling an orange for them. More importantly, the clinical staff expected family members to carry out these tasks. Furthermore, there was no sense of patient privacy because doctors openly discussed patients’ conditions and treatment with their families. Essentially, studies in Asia may not accurately capture why Chinese family caregivers in the US attend support groups.

Despite the limits generalizing the above findings to immigrant Chinese families in the US, support groups seem to be a promising resource, because they provide a type of social capital that help families with limited social and financial support to adapt to life in a new country. Lau (1981) has found that Chinese families build instrumental networks outside the family in order to adapt to local ecological conditions, and as a way to cope with a diminished familial network (Lau 1981). Similarly, Wong (2008) demonstrates how a community-based organization (CBO) provides low-income immigrant Chinese families with the information, skills, and advocacy they need to understand and navigate the US public schools and other institutions (i.e., tutoring, ESL classes, and test-prep classes). For these families, the CBO acts as a critical bridge to the dominant society (Zhou 1992). Similarly, ethnic support groups not only provide a space for families to share and learn from others who have similar experiences
(Lefley 1996), but also the social capital to adapt to an unfamiliar health care and public entitlements system.

Although Chinese families generally are less receptive to discussing problems with outsiders because of the fear of “losing face” (Lam et al. 1995, Kung 2001), Han and Li (2008-as cited in Hwang and Han 2010:484) suggests they will open up in situations where the benefits of disclosure outweigh the costs. They found that in cases where the possibility of losing face is low, individuals seek support first from family members, then friends, and finally strangers. On the other hand, in cases where face is threatened, such as with mental illness, the sequential order is reversed, with the most distantly related group coming first. Pragmatically, it makes sense for my respondents to turn to strangers who are in the mental health field or are caregivers to a mentally ill relative. To encourage participation in ethnic support groups, like culturally competent mental health treatments, groups should be structured in a way that appeals to a group’s norms of interpersonal relationships and dynamics. For example, Pickett-Schenk (2002) suggests that church-based support groups may be appealing to African American families coping with mental illness. Similarly, models that promote seeing group members as pseudo-kin or one’s “own people” may be important in creating a sense of belonging, and encourage sharing in Chinese families (Hsiao et al. 2004).

The Chinese Support Group in NYC

The Chinese family support group is a volunteer-led community organization, founded in 2002 through the collaborative efforts of Chinese-American mental health professionals. The volunteers are bilingual and bicultural social workers, intensive case managers, psychologists, and graduate students of social work. While conducting research on immigrant Chinese
caregivers of mental health consumers for his dissertation, one of the founding members learned that caregivers often face stigmatization and isolation, with few community resources to help them cope with their burdens and stressors. He and several other mental health professionals started organizing informal monthly support group meetings. The first few family participants were the family members of these professionals’ patients or referred by other mental health providers to the group.

The vision of the volunteers is to promote self-empowerment among Chinese-American caregivers of mentally ill individuals through education and the facilitation of monthly support group meetings. Because most family members have limited English proficiency, meetings are in Mandarin. The group meets every fourth Tuesday of the month in the evenings, and light refreshments, consisting of hot tea and Chinese pastries, are served. At the beginning of each meeting, volunteers or guest speakers present on topics that promote mental health literacy, such as the availability of Chinese-speaking mental health agencies, policy changes that will affect the delivery of services to mental health consumers, and ways to cope with the burdens of being a caregiver. At the end, family members have time to share their concerns and feelings, update each other on what has been going on in their lives, and provide personal advice on issues, such as working collaboratively with the consumer’s psychiatrist and therapist. One volunteer believes the group offers a ‘safe space that helps family members cope with feelings of stigma, shame, and isolation.’ In the past ten years, the group has organized several community outreach events, held two fundraisers, and obtained non-profit status. In addition, the group maintains a website and publishes a quarterly newsletter written in Chinese that provides updates on the organization, articles on mental health, and personal stories. One of the group’s major annual
events is their Thanksgiving party for family members and their mentally ill relatives to celebrate their accomplishments.

Most of the family participants are middle aged and elderly working class females who are parents or siblings of adult individuals with a schizophrenia spectrum disorder, and have been attending for one year or more. On average, there are about 15-20 family caregivers in attendance at each meeting. Some family members come when they have a crisis and then stop attending when their situation has been resolved. Other family members attend intermittently through the years, but there is a core group of family caregivers that consistently come. Lefley has similarly identified this pattern of participation in other support groups (1996). Attendance is also influenced by weather conditions. Many family members are older, so they have a harder time traveling during the NYC winters, especially when it is icy and windy outside.

Since the group support relies solely on volunteers and donations, there is difficulty securing financial resources to expand the group. While there is a core group of volunteers that have stayed through the years, with period of absences because of family and work conflicts, the turnover rate of volunteers is very high. Part of the problem is veteran volunteers have full-time jobs and can only provide limited supervision and management of new volunteers. Similarly, the group lacks the human and monetary resources to engage new family members and motivate them to continue coming to meetings. First time attendees are usually individuals who have just learned their relative has a mental illness, or they are in some crisis situation, which means they have very different needs and concerns than participants who are providing care to a clinically stable family member. Veteran volunteers have attempted to address this issue by being more attentive to new participants and allowing them more time to speak about their issues.
Volunteers currently lead the group, but their ultimate goal is to hand over the majority of leadership and administrative duties to family participants. Essentially, the volunteers aspire towards the NAMI model, which they interpret to mean empowering families through education and support, so that they in turn can provide support to each other. At one support group meeting, a veteran volunteer shared with everyone, ‘NAMI is a very powerful organization. They help advocate for family members and patients. We wish to be like them one day.’

Therefore, the support group does not fit in with existing professional- and family-led support group models. Also, thus far, very few studies have examined the differences in group dynamics and outcomes between these two types of groups (see Pickett et. al 1998 for exception). Most research has focused on differences between participants and non-participants (Pickett et. al 1998). What we do know is that professional- and family-led groups often work from very different paradigms (Solomon 1996).

Professional-led groups are usually based on psychoeducational models that are offered in conjunction with mental health treatment for an ill family member. Psychoeducational models educate families on the causes and treatment of mental illness, problem solving, and strategies to improve communication and manage behavior (Solomon 1996). The primary goal is to reduce patient relapse by reducing family distress. Therefore, these support groups are often run by professionals in agencies that provide treatment to the participants’ ill family members, such as hospitals or day treatment programs. While family-led groups also teach problem solving and coping strategies, and educate families on etiological theories, they focus exclusively on families’ needs, using education and supportive relationships to increase coping skills and feelings of self-efficacy. Family-led groups are generally affiliated with organizations such as NAMI or NDMIDA that prioritize advocacy.
The needs of families are so diverse that one single group format cannot satisfy everyone (Solomon 1996). An individual’s relationship to the ill relative or the time elapsed since diagnosed, among many other variables, are factors that influence needs, and motivations to participate in a support group. Needs also evolved with length of tenure, because new members attend support groups for information and support, whereas long-time participants of support groups place more emphasis on advocacy (Solomon 1998). Therefore, when a new family caregiver comes to a group that focuses on advocacy, they do not continuing attending after the first few meetings (Citron et al. 1999). In addition, since most participants at support groups are parents, spouses may feel less connection, and therefore don’t continue attending long enough to meet other spousal members or get involved in the group (Mannion et al 1994, Mannion 1996). Pickett et al. (1998) have found professional-led groups also attract more participants that are minorities than family-led ones, which suggest this organization may appeal to minorities more. Given the emphasis on education and hierarchy, it would make sense that Chinese caregivers are attracted to professional-led groups. The question, then, is not which types of groups are better, but what each group format can offer. Although we know that family support groups should be fairly homogenous to be the most beneficial, it is unclear what characteristics should be used to sort caregivers (Hatfield 1997).

The Chinese family support group fits in neither model. Although the group is led by mental health providers, these volunteers are not affiliated with a particular treatment agency and do not treat the family participants’ ill relatives. This means they are not compensated for the therapeutic work they do with families, and thus, they focus on improving caregiver coping and feelings of mastery, rather than patient outcomes. Volunteers prefer ill family members not come, so that family caregivers can feel free to share their feelings and concerns. They also
make it clear that the support group belongs to family members, encouraging participants to take on more tasks and advocacy efforts. Despite this difference, the Chinese support group offers family participants similar benefits, but tailored to their cultural norms. The following sections will discuss these aspects.

*Emotional Support*

Respondents reported feeling safe and understood when they expressed their feelings and concerns. Mrs. Lau does not feel comfortable discussing her son’s illness with others, because she believes most people have misconceptions about mental illness that are reinforced in movies and news reports of mentally ill individuals who commit suicide or other violent acts. However, she is comfortable talking about these matters at the support group because the other participants have an ill relative and can empathize with her. She calls the group her ‘family.’ Stacy echoed similar feelings. She explained, ‘I can talk to my friends about the difficulties of being a caregiver to my brother, but they cannot truly understand since they don’t have a family member with a mental illness.’ She also pointed out that most people have many misunderstandings about mental illness, and as a result they fear patients. Stacy wants to share her ‘feelings with someone who has similar experiences and understands where I am coming from. This is one of the main reasons I attend the support group.’

Mrs. Lau and Stacy’s comments suggest it is not just support, but support from someone who has gone through similar trials (Lefley 1996). Hearing others people’s similar experiences validate one’s own experiences and feelings, and helps respondents come to terms with emotionally difficult decisions. In an earlier chapter, I mentioned a woman who was castigated by family and friends for sending her daughter to live at a housing facility. However, she was
treated with compassion by family participants at the support group, who reminded her she could not give her daughter the 24-hour care she needed. Hearing other participants’ stories also helps individuals put their situation in perspective. For example, the grief and stress of having a son with a mental illness, who is clinically stable, may not seem so bad when you hear another mother’s story about her child’s violent acts and refusal to accept treatment.

This sense of connectedness with other support group participants is crucial, I argue, because emotional support within the family may be limited for several reasons. Mrs. Lau and Helen are my only two married key respondents, and even then, their spouses are not involved in providing care. After Kevin’s discharge, many of Mrs. Lau’s relatives have stopped visiting her, because they were scared of her son. My other respondents are either divorced, widowed, or in Stacy’s case, single. Furthermore, relatives may not be as patient or supportive in the long term. As Ms. Ng shared: ‘eventually family and friends will get tired of me unloading my problems and feelings on them.’ Also, as the family cycle progresses, families lose members through death. Stacy’s parents had passed away, so she is her brother’s only living immediate relative. Her extended family lives in another town and as Stacy explained, ‘they are busy with their own lives.’

Cindy is a good example of how loss of support through natural changes in the family promotes help seeking. Cindy spoke lovingly about her late husband: ‘I am a woman that does not know anything. I came to the US when I was 18 to marry my husband who was 32 years old. He was a good man. I never had to work; he only asked that I take care of the house and our sons. He even helped me with the domestic chores.’ When her husband passed away she lost her pillar of support and could not cope with her son’s illness. Furthermore, her son’s psychotic symptoms worsened after his father passed away.
It was under these stressful circumstances that Cindy reached out to the group and requested they come to her home and assess the situation. Every two to three months, one of the volunteers, Ling, will organize a visit to a family caregiver’s home, or their ill relative’s place of residency. Typically, Ling and another volunteer will accompany two or three family participants on these home visits. The family visits are a culturally appropriate and practical way to demonstrate support, and they tend to be for families that are going through some crisis or tough times. Just as family caregivers visit their ill relatives at the hospital, family participants visit each other as a show of support.

When we arrived at Cindy’s house, she quickly filled us in on Dan’s condition. Just that morning, he was yelling into the air vents, and swore he would never play the piano again. Although it was Cindy’s birthday and the family usually goes out to dinner to celebrate, they decided to stay in because, as Cindy explained, ‘Dan did not think it was safe to leave the house.’ Cindy wasn’t even sure if her son would come downstairs to greet us, but he did when she requested he greet some of her friends who came to wish her a happy birthday. Dan was chatty with us and seemed to enjoy our company. He gave us a tour and of the house and even played the piano for us.

Cindy was very happy that we came for a social visit. She shared, ‘When my husband was around, his friends would visit and we would have these small karaoke parties. Since he left us, our house has been very quiet.’ Cindy was also touched that Mrs. Tam also came along. Mrs. Tam typically does not go to these family visits, because she has a neurological disorder that causes her feet to constantly twitch and makes walking difficult. Despite her physical ailments, Mrs. Tam insisted on visiting Cindy and Dan, because Cindy reminded her of her own
despair and struggles as a mother with a mentally ill child. Therefore, she felt a need to connect with Cindy and show her she is not alone.

Getting to Cindy’s house was no easy task. Mrs. Tam had to take a 40-minute train ride from her house to the Staten Island ferry terminal, and then board a 20-minute boat ride. Once she arrived, she had to wait for Ling to pick her up at the parking lot and then it was another 30-minute drive to Cindy’s house. Mrs. Tam’s home aid attendant took the train and ferry with her, but since she gets off at 4 PM, Mrs. Tam will have to get home on her own. She speaks very little English and is not familiar with areas outside her neighborhood and Chinatown, but nevertheless insisted on making this visit. Her efforts demonstrate she has *xin*, in other words, “someone with *xin* acts with consideration and thoughtfulness about others” (Oxfeld 2010:56). Of course, stating that someone has *xin* can just be a polite expression to greet visitors; however, in this particular case, the amount of effort Mrs. Tam put in demonstrates her good character.

While the social visits do not actually change the lives of family caregivers, they provide some relief from the social isolation mentally ill individuals and their families often face. It seems “caregivers’ satisfaction with their supportive resources and the perceived availability of those resources were often more critical than the actual amount of help received” (Hsiao and Van Riper 2010:87). In addition, as Ling asserted, ‘the support group is addressing a crack in the mental health system. Sometimes the ill relative may not want to get treated, and families have nowhere to turn, or they may not trust the health care providers. The support group is a non-threatening way to obtain information about mental illness and treatment, and a source of emotional support for families.’ Furthermore, in observing family interactions in a naturalistic environment, volunteers have access to insights that is not normally available to professionals who see their clients strictly in the office. For example, during one family visit, one volunteer,
Mary, did an informal family consulting session with Carol and her two children. Although Jessica and her brother had gone to individual therapy appointments, they never met with their therapist as a family to learn strategies to diffuse family tension and conflicts. For 15 minutes, I watched Mary worked her magic, giving the family concrete steps to ‘love and take care of each other.’ The plan she drew up for them is still hanging in Carol’s refrigerator.

Family visits also provide the rare opportunity to see family members interact with patients and diffuse the critical stance caregivers often have. As I mentioned in the last chapter, family caregivers take on a parental role with ill relatives in directly criticizing or pointing out their transgressions. While these are culturally normative, not pathological, family processes, they can negatively affect mentally ill family members (Lefley 1996). Expressed Emotion (EE) is a clinical construct that measures the emotional atmosphere of families and its connection to the prognosis of a mental illness. There is increasing evidence that high EE in Chinese families is associated with patient relapse (Phillips and Xiong 1995, Ran et al. 2003, Phillips et al. 2002), in particular, Yang et al. (2004) has found a link between critical comments and relapses.

The support group discusses how to communicate with patients in productive ways, and family caregivers, through time and personal experiences, learn to identify triggers for their ill relative. However, sometimes, in the heat of the moment it is difficult to put this knowledge to practice. Visitors from the support group act as friendly reminders to do so. Stacy described accompanying Mrs. Lau to visit Kevin in the hospital: ‘Mrs. Lau was giving Kevin pressure to get discharged. I took her aside aside and pointed out that he will be discharged once the doctors feel he is ready. Pressuring him will not hasten the process, but can actually make him regress.’ Visitors can also diffuse a tense situation. During a visit with Hanna, Mrs. Lau told Kevin his doctors couldn’t discharge him until they found a day treatment program and a living facility that
will accept him. The process is taking an extremely long time because most housing programs are reluctant to accept him, due to his conviction on felony charges. Mrs. Lau’s voice expressed disappointment and resentment, as she lamented why he had to get in trouble with the law. Hanna jumped in and explained to Kevin, ‘his doctors are taking their time to plan his living arrangements because they really care about him and want the best for him.’ When Kevin got up to use the restroom, Helen advised Mrs. Lau not to bring up the past. Helen also tried to build up Kevin’s self esteem with comments, such as ‘you’re very handsome…you have a good face so you will have good fortune,’ and encourage him to be patient because ‘beautiful things require time, like the growth of a flower or the transformation of a caterpillar to a butterfly.’

Stacy and Hanna’s actions are significant in light of Kevin’s attempts to detach himself from his past. I asked Mrs. Lau why Kevin does not attend a day treatment program in Chinatown, which would make visiting her and getting Chinese food easier. She responded, ‘I know, but he does not want to run into those people from his past, the ones he went around and did bad things with, so he doesn’t want to spend too much time in Chinatown.’ Kevin may be ashamed of what he did. His caseworker explained, ‘One of the reasons it is taking him so long to find a residential facility is that he keeps failing the housing interview. The staff would ask him about his past criminal convictions, and he doesn’t want to talk about it. I guess he thinks those things happened in the past and it’s really no one’s business. But people take it as a bad sign. I told Kevin they have his full report in front of them and they would have already known of his past convictions.’

*Education and Practical Advice*
The support group is a place where family members can get reliable information. Past presentations focused on topics that are typical of other support groups, such as housing facilities, communication with patients, and changes in Medicaid policy that will impact mental health services (Pickett et al. 1998). Previous studies found that psychoeducation programs for Chinese caregivers led to increased feelings of self efficacy, improvement in caregiver burden and family functioning (Cheng and Chan 2005, Chien and Wong 2007). In particular, family caregivers who participated in a professional-led support group reported lower degrees of depressive symptoms and caregiver burden than the control group (Chou et al. 2002). Rachel, who has a daughter diagnosed with mental retardation and schizophrenia, models how an individual’s change in perspective can transform the way they approach problems. She shared with the group, ‘since coming here (the group) I am more optimistic and proactive. I find ways to help my daughter and plan for future problems, instead of feeling hopeless.’ Volunteers’ professional expertise and experiences offer clinical and administrative insight to family members’ situations. This is reflected in the advice they provide to family caregivers, as seen in the following excerpts:

One volunteer shared that family members should have a summary of family members’ clinical history and medication written out in English, in case they have to bring them to the emergency room.

Another volunteer recommended a day treatment program. He pointed out that the organization ‘has a lot of political power. Clients learn different life and work skills gradually. They slowly learn to be independent.’

One volunteer informed the group: ‘state hospitals can discharge patients as long as the patient is clinically stable. City hospitals want to make sure the patient has a home to return to first.’
Family participants also share their own experiences and give each other advice on how to communicate with the clinicians and other professionals in the mental health system. As Mrs. Lau pointed out, ‘each family is different, so when we share our experiences we can learn from each other.’ The exchange of information and advice is very relevant, because families encounter similar personnel and agencies. Since there is a limited number of bilingual outpatient treatment centers, patients often go to the same clinic for services and may actually have the same therapist and psychiatrist. I often overhear respondents evaluate mental health professionals, treatment centers, and different rehabilitation and vocational programs. Families also interact with the same government agencies, such the Social Security and Medicaid offices. Furthermore, through helping others, family participants who offer advice feel a sense of mastery and competence. Below are examples of information and advice that are exchanged in meetings between family participants.

Rachel: I don’t know English or understand the effects of each medication, but I write down the name and dosage of each medicine. When the doctor adjusts the medication, I make note of the changes and closely observe my daughter for any side effect and symptoms of relapse.’

One family member suggested, ‘your daughter may qualify for a home attendant,’ as a way to lessen the caregiving burden of another participant.

One support group participant offered advice when another family member expressed frustration with communicating with her daughter’s treatment team: ‘You will have better luck if you speak politely to them. Sometimes that’s hard to do. You also have to set up meeting with the doctors when it is necessary. The doctors will be more flexible if you do these things.’

Stacy shared her brother’s experiences at two hospitals (discussed in the previous chapter) with other family members so they can be aware that medical mistakes do happen. Stories like Stacy’s encourage family members to ask questions regarding patients’ care and advocate for services. This is important because Chinese culture places value on hierarchy and authority, which means family members may be reluctant to
question people who hold official titles and are deemed to be experts (Moy 1992, Sue and Sue 1999, Lin 2002).

Addressing Deficiencies in the Mental Health System

In an informal poll conducted by an outside researcher to determine what mental health services are lacking, family participants reported they wanted more treatment programs and activities for patients to socialize. In a different survey, administered by the volunteers who evaluated family participants’ satisfaction with the support group, a quarter of the participants reported wanting more social activities that included their ill family member. It seems family participants want to use the support group to address current deficiencies in the mental health system, in particular they want to create more opportunities for their ill relatives to socialize. It perplexed volunteers that family caregivers would want to include their ill relative in group activities, especially since the support group is supposed to be a space for them to talk about their feelings among others who share similar experiences. At first, I also thought it was odd, but then I realized that it is equally incomprehensible from my respondents’ point of view that clinicians do not include family members in treatment planning and implementation. To my respondents, it doesn’t make sense not to use their connections to improve the lives of their ill relatives. For these family participants who choose to continue their caregiver role, their wellbeing is connected to the health and happiness of their ill relatives.

There are several ways in which participants utilized the support group to lessen the social isolation of family members diagnosed with mental illness. Some family participants suggested forming a peer group for ill family members to discuss their thoughts and concerns. Elaine supports this suggestion. Her daughter has only one friend, so she hopes she can meet more people, especially others who, like her daughter, are in their 30s and are educated. Ms. Ng
faces a similar problem with her son, David, who only leaves the house when he has an appointment with his social worker or psychiatrist. Mostly likely because of his medication, David generally sleeps until she gets home from work in the afternoon. He’ll be up for a few hours, but then go back to bed after dinner. Joy wants him to make friends and to have activities outside the house, because she thinks it will improve his quality of life. Getting their ill relatives to use their time constructively is a preoccupation many family participants seem to have.

Understanding the isolation many health consumers face, both Cindy and Mrs. Lau have offered up their houses for small parties. Furthermore, family participants will try to reach out to ill relatives of other caregivers. For example, Elaine is the family participant currently responsible for making calls to remind other family caregivers to attend the monthly meetings. In one of her calls to Cindy, she took some time to talk to Jerry, who rarely interacts with anyone outside the family. Cindy was very appreciative of this small act of kindness. Similarly, after a social event hosted by the support group, a father and mother went up to me and thanked me profusely for chatting with their son. I had only spent a few minutes asking how he was doing, but they were so appreciative. In trying to work out a time for me to visit and stay over on a weekend, Paula has requested we schedule it so that Joyce can join us as well. Paula explained, ‘she does not have many friends. It would be nice if she can spend some time with you. You’re kind of like her big sister.’

*Moral Lives*

Using a more professional gaze, volunteers view family participants as clients. On the other hand, employing a Confucian model of teacher and student, family participants see volunteers as authority figures who are exemplary models because of their intellectual and moral
superiority. This discrepancy in how volunteers and family participants see each other has concrete consequences in their actions and requires a constant negotiation of roles. Few studies examine the views of professionals who run support groups (Pickett et al. 1998), but as a volunteer, I had the unique opportunity to observe how volunteers’ perceptions influence their relationships with family caregivers.

Volunteers see their current roles as facilitators and mentors who “educate” and “empower” family caregivers, and anticipate handing over leadership to family caregivers in the future. While they refer family caregivers to community services, they are adamant about not being a direct service organization that offers concrete assistance, such as help with applying for public entitlements. Volunteers also encourage family members to turn to each other for emotional support and share knowledge about the mental health system, because caregivers are the real “experts.” In addition, as practicing professionals or graduate students in social work, volunteers are trained to establish clear boundaries between themselves and their clients, and to be cautious of over-involvement. The volunteers carry this professional training over to their work with family participants. As one volunteer stated, ‘we are not their friends, at most we are their mentors.’ Another volunteer shared, ‘I was her (a mother from the support group) daughter’s psychologist a long time ago. She asked me why I don’t call them anymore. I mean, why would I call them? Her daughter is no longer my patient.’ This mother’s expectation of contact with an ill relative’s clinician, even after the clinical relationship has ended, is not that uncommon. During the holidays, Stacy will send gifts, such as chocolate and cookies, to one of her brother’s past social workers. Another way volunteers draw boundaries is that they purposely don’t pick up calls from family participants after 10 PM. They do this to reinforce the
idea that calling after a certain time in the evenings is inappropriate, as that is the time reserved for resting and spending time with family.

The following example illustrates these concerns about boundaries. In 2013, in response to a low attendance rate of family members, Ling, the chair of the family relations committee assigned each volunteer 4-5 family members to call once a month and check in on. During a volunteer meeting, a discussion of how to implement this new program ensued, revealing the power dynamics between volunteers and family caregivers. Some volunteers had concerns over family participants seeing their phone numbers in the caller ID, so one volunteer suggested using the *67 function to block the calls. One particularly astute graduate student in social work pointed out, ‘We are asking them to trust us, but we do not give them our numbers. Isn’t that bad?’

Ling was also concerned that these monthly calls will turn into therapy sessions. The support group does not have liability insurance, and the liability insurance volunteers receive through their employers does not cover the work they do with the support group, so technically, family caregivers can sue volunteers as individuals. It is unlikely that any lawsuits will be filed, but this apprehension suggests how ingrained volunteers’ professional training is. I once suggested to a mother she might want to consider moving her son out to prevent future conflicts between him and his father. Ling explained that I should refrain from dispensing advice like that: ‘you don’t know what will happen after the son moves out of the house. The family might blame us in the future.’ The following quoted excerpt from an email a veteran volunteer sent out to the volunteer listserv succinctly captures many of the concerns discussed above:

However, we need to set some limits, otherwise, everybody will be burned out. We also need to educate family members that we really can not offer to provide "direct" services
at the present time (unless we can recruit those volunteers who are retired or who do not have full time job). I know that they will get very upset and frustrated but this is the reality. Our role is to provide education, emotional support, and transfer case to community agency…

Given the colossal amount of paper work and high rates of burnout in the psychiatric field, it is understandable why volunteers are protective of their time. However, the unequal power to establish boundaries undermines volunteers’ attempts to show family members that they are the real “experts,” capable of advocating for themselves, and thus not dependent on the volunteers. In addition, underlying family participants’ resistance to such efforts is their perception of their relationships with volunteers as being identical to that between a teacher and a student. As I have noted earlier, the importance of education is an enduring feature in Chinese culture. Stafford (2006:61) affirms that learning and being a proper person are inseparable, and therefore, teachers are one of the most respected members of society. This reflects the cultural notion of learning “as a process of direct personalized transmission” in which teachers are viewed as the “transmitters and living examples of morality” (Stafford 2006:61). This is the reason why students of calligraphy “trace and imitate the calligraphy of a master, down to every stroke and nuance, in order to achieve mastery” (Stafford 2006:61). As one young man explained to Stafford (2006:61-62) what it means to be a virtuous and morally upright teacher:

‘They don’t make much money, but they have a lot of virtue!’ He specifically said that teachers should be the kind of people who refuse “red envelopes” (hongbao), i.e., bribes. Then everyone would zun shi zhong dao, “respect the teacher and respect his way” (i.e., respect his teachings).

In this sense, volunteers share similar traits to teachers. They educate families about mental illness. They also exhibit moral virtues in choosing to be health professionals, in
particular mental health providers. Several respondents have commented that *choosing* to work in mental health suggests that a person is compassionate. This belief is reinforced by the fact that, despite their busy schedules, volunteers take the time to help families. In expressing her gratitude to the volunteers, one family caregiver shared at a support meeting: ‘Ling called me at three in the afternoon. She was so busy at work that she did not even have time to eat lunch yet. We, as family members, need to be grateful for everything that the volunteers do for us.’

In addition, volunteers are not paid and do not ask family participants to contribute financially to the group. In the past, Mrs. Lau has tried to present me with ‘red envelopes,’ as a token of gratitude for my help and to compensate me for my time and travel costs, but I have refused her. At one meeting, volunteers asked family participants to describe something that they are grateful for and their hopes for the future. These reflections would be included in the group’s program for their fundraiser. Mrs. Lau shared that she is very touched by the volunteers’ compassion, making an explicit reference to the fact that we refuse to take her “red envelopes.”

Red envelopes are used in various social practices, ranging from activities that are seen as corrupt and unethical (i.e., bribery) to ones that involve fulfilling an obligation of reciprocity that can be instrumental and moral (Oxfeld 2010). Because volunteers are morally upright, they serve as examples for others, in particular for patients. Mrs. Lau requested that volunteers from the support group visit her son, Kevin, when he was still an inpatient at the psychiatric hospital. She wanted Kevin to see that there are people who care for him. She had also requested a male volunteer so that Kevin can identify with a positive male figure. Mrs. Lau saw the visit as an opportunity for others to “teach” and encourage Kevin to continue his progress. Here, we see how volunteers are used to instruct and to demonstrate positive characteristics.
The model of teacher and student also implies a hierarchy with volunteers as authority figures and family participants as subordinates. Confucius defines five major dyadic relationships (Hwang and Han 2010): sovereign-subordinate, father-son, husband-wife, older brother-younger brother, and friend-friend. Although it is not one of the five cardinal relationships, the teacher-student relationship operates in a similar fashion because it is based on a vertical differentiation of power that shapes the behavior of both parties. The subordinate is expected to respect, obey, and follow the enlightened superior, and the superior in turn is expected to treat the subordinate with kindness, gentleness, righteousness and benevolence (Moy 1992, Sue and Sue 1999, Lin 2002). Their subordinate role is reinforced by the reality of family participants’ marginalization in society—most are working class and cannot speak English, so they depend on volunteers for help in translating and other concrete assistance.

Whether consciously or not, volunteers reinforce this model because they see themselves as educators, teaching family members how to deal with patients, relatives, clinicians and other professionals and officials in the mental health system. These roles are also spatially replicated in the seating arrangements at support group meetings. Meetings take place in a conference room that has a long rectangular table with chairs all around it. The audio/visual equipment and a large screen are in the front of the room. The presenter is usually in the front, especially if he or she is doing a PowerPoint presentation, and volunteers typically sit together toward the front of the room. The seating arrangement not only physically separates the volunteers from family participants, but confers a sense of importance to volunteers, since they will be in view when everyone directs their gaze to the presenter at the front. Volunteers are also the only ones who stand up and make announcements in the front. I was not conscious of how space differentiated volunteers from family participants until Mrs. Lau pointed it out. One day, as I was walking into
the conference room, Mrs. Lau stopped me at the door and asked that I help her call her son’s psychiatrist. I directed her over to a seat where her coat and hang bag were, and said we can discuss the details over there. Her response and tone suggested family participants are conscious of the divide between volunteers and family participants: ‘No, no, you should sit in the front with the rest of the volunteers. Put your stuff down and I’ll come over to speak to you.’

The relationship between volunteers and family participants is moralized in another way. The concrete assistance, such as providing translations and helping family caregivers advocate in times of crisis creates obligations to remember and reciprocate. Below, I provide examples of how respondents use the support group to legitimatize their position as a family advocate and increase their leverage with mental health professionals. When Kevin was still an inpatient at a psychiatric hospital, I would accompany Mrs. Lau to a monthly support group for family members of inpatients at the hospital. Mrs. Lau mentioned how happy she was that I came along to help her understand the discussion and to express her opinions. A hospital staff member is usually there to provide Spanish translations, if needed. Although Mrs. Lau is the only Chinese-speaking family member, she is aware that the hospital can make the same arrangements for her as well, having seen them use a hospital staff member as a translator in past meetings with Kevin’s clinicians. However, she does not make this request and prefers to have me accompany her. She explained, ‘they have their own Spanish translator there. We can bring our own Chinese translator.’ In her statement, she clearly distinguished “us” versus “them,” in this case, the in-group being she and I, and the out-group being the hospital staff. More accurately, the in-group represents the idea of an organized institution.

Mrs. Lau strategically makes her affiliation with the support group known. When she introduced me to Kevin’s social worker for the first time, she asked me to tell her that I am a
doctoral student and that we belonged to a family support group. She also brought along a flyer that advertised the group. This process was repeated each time Kevin switched social workers, doctors, or moved to a different housing program. The use of the support group as social capital is most apparent when I saw Mrs. Lau at a meeting in early 2014, right after the Lunar New Year. She asked me to come with her to Kevin’s new housing facility to translate and also to meet the staff, because ‘it is always better to have someone from a formal organization.’ She has also shared with other family participants that when she brings me to help her translate she ‘sees a major difference in the attitudes of mental health professionals and the type of service I (Mrs. Lau) receive.’

Hanna provides another example of how family members use volunteers as social capital. Hanna’s sister, Laura, showed up unexpectedly in front of her house and started yelling obscenities at her. A concerned neighbor called the police, who then brought Laura to the psychiatric unit at the ER. Hanna was hopeful that her sister would receive treatment at the hospital. Unfortunately, her sister refused to take her medication and there was nothing the doctor could do.

Hanna differs from most support group participants in her financial and social resources. She is from a solid middle class background, and although she does not speak English, her younger siblings and two sons were educated at American universities and are in white-collar professions. Despite these resources, Hanna asked one of the volunteers, Ling, to help her communicate to the doctors her sister’s clinical history and her tendency to stop taking her psychiatric medicine. Ling, a psychiatric intensive case manager, made phone calls on behalf of Hanna and showed her how to document the seriousness of Laura’s condition and her history of refusing treatment. She also accompanied Hanna to a meeting with Laura’s psychiatrist to
challenge his clinical judgment that she was stable enough to be discharged. Ling went beyond being a mere translator and showed Hanna what is considered “evidence” that can be used to contest clinical decisions. Ling later told me ‘the hospital backed down because we represented an organization that advocated for family members.’

There is another incident where the volunteers’ professional experiences are seen as an asset. Stacy and I had planned to accompany Carol and Jessica to a meeting with Jessica’s caseworker. We had concerns that the caseworker was not doing all she could to get Jessica the services she needed, specifically in obtaining assistance to pursue legal action against the man who had sexually abused her. According to Carol and Jessica, the caseworker told Jessica to try calling the sexual abuse hotline on her own, which was unrealistic. When Jessica gets nervous she stutters and has a hard time communicating her thoughts. It took her a really long time to explain the abuse to me, partly because she did not have the vocabulary to describe what this man did to her. Therefore, it did not make sense for the case manager to ask Jessica to make the call on her own. Stacy had insisted, Mary, a volunteer at the support group, come along because, ‘Mary is in the mental health field. She will know if the case worker is bullshitting us and how to respond.’ Mary also knew how to coach the mother and daughter. Prior to the meeting, Mary spoke briefly with Carol and Jessica, helping them identify their needs, and reminding them that though volunteers would be joining the meeting to provide moral support, they themselves would have to tell the caseworker what they needed.

A close analysis of family participants’ narratives and actions reveals a moral discourse on remembering past acts of kindness, even if they cannot be fully repaid. As Oxfeld (2010:4) asserts, “Acting upon one’s memory of past help is a central element of the notion of what it means to be a good or ‘moral’ person in many domains. The connection between memory and
morality is summed up by a commonly quoted maxim,…It (the maxim) refers to the necessity of remembering who helped you, and it is a principle that is deeply rooted; it is both consciously articulated and unconsciously assumed.” Volunteers thus offer much more than instrumental support to family caregivers; their relationship with family participants demonstrates how “many long lived concepts such as reciprocity (bao) and making use of one’s social network (guanxi) have been reinvigorated” (Oxfeld 2010:25). Below, I provide examples of how respondents frame their participation in the support group in moral terms.

Stacy showed me the speech she gave at the support group’s 2009 fundraiser and shared, ‘I did not want to give a speech, because I felt like I was violating my brother’s privacy, but I felt I should help the group. When my brother was stuck in the hospital without adequate psychiatric care, many of the volunteers gave me advice and actually went with me to different mental health agencies to explore what other options I had. I am very grateful for their help, so I don’t want to disappear after the problem has been resolved. I know people that are like that and that is wrong.’

Stacy, again, connects memory, morality, and reciprocity in her critique of another family participant’s actions:

Mrs. Chen has only one son. After a car accident, he lost his ability to walk and has problems with his motor skills in his upper body. Because of this, Mr. Chen became very depressed and refused to leave the house. Her husband and son stay home, unless they really have to go out, for instance, to the doctors. A home care attendant comes everyday to help take care of them while Mrs. Chen is at work. Mr. Chen has a very sad story. I used to feel very sorry for her, but then as I helped them advocate for services through their social worker, I realized they are trying to take advantage of the system. They want all the services to be brought to their house. The social worker told me that the son wanted a motorized wheelchair that is controlled with the hand, but he has limited mobility in his hands so it’s actually very dangerous. They complained that the social worker doesn’t help them, but if she did not care she would not have spent more than twenty minutes talking to me. The son also used different names so that he can request
duplicate services and benefits. After we (the support group) helped the family last time, they stopped coming to the monthly support group meetings. I am not going out of my way to help this family anymore.

While Stacy questioned Mrs. Chen’s character, because she accused the social worker of not helping her, in actuality the social worker was looking out for the son’s best interest. The social worker even spent twenty minutes explaining the situation to Stacy, time that her job will probably not compensate her for. From Stacy’s point of view, the Chens are demanding, wanting to receive all the services at their home, and greedy in requesting duplicate services and benefits. When they cheat the “system,” they are taking resources away from people who really do need them. Finally, after getting help from the support group, Mrs. Chen stopped attending, which demonstrates her failure to remember acts of kindness, and therefore to be a moral person.

It is through continued attendance that family participants show their support and gratitude to the group. A potential family participant came to check out a monthly support group meeting for the first time on a day with low family member attendance. Stacy called George, who consistently attended the meetings with his mother and asked why he was not there. He explained that his mother did not want him going out because it was raining so hard. Stacy spoke to his mother afterwards, and reported that there were ‘more volunteers than family members at the meeting. She continued to explain that as family members ‘we have to show our support,’ and the low attendance reflects badly on the group, the group ‘loses face.’ She did not feel that rain showers should not prevent George from coming to the meetings. Stacy believes the success of the support group depends on the work of both the family members and the volunteers.

Mrs. Lau is an example of how a family member expresses gratitude in more concrete ways by taking on more responsibilities in running the group. When volunteers requested that
family members assume more leadership roles in the group, she responded, ‘I am old, but I will try to do whatever you guys ask me to.’ During the monthly meetings, she goes around with the sign-in sheet and makes sure everyone puts down his or her name and contact info. As a nonprofit, the support group is required to keep these records. More importantly, the attendance list makes it easier for volunteers to update existing contact information and add new family participants to the roster. Mrs. Lau recognizes the significance of having the most updated list, because for the last two years she has assumed responsibility for calling family members to remind them to attend the meetings. In these phone calls, she spends a lot of time and energy telling family members how important it is that they come and support the group. She has also referred other family caregivers to the group, and more recently has recruited two social work graduate students to be volunteers.

Despite being 80 years old, Mrs. Lau does not let her age stop her from supporting the group. During the 2012 NYC NAMI charity walk, Mrs. Lau was having difficulty keeping up with the other group members, so a volunteer, who was concerned about her well-being, told her to go home. She was sitting on a park bench as we continued on without her. When the group stopped at the halfway point to admire the view from the Brooklyn Bridge, we saw Mrs. Lau approaching. A young Caucasian man, who was also a walk participant, albeit from a different organization, was helping her along. Her dedication was also exemplified in another situation. In March 2013, she went to see her doctor for shortness of breath. Her doctor felt her heart was beating too slowly and insisted on calling an ambulance to take her to the emergency room. The ER doctor suggested she needed a pacemaker. Mrs. Lau did not want the pacemaker, but she felt her quality of life would significantly decrease if she did not get one, fearing that she would not be able to fly on airplanes, go swimming, or do other types of exercise. Although she was at the
emergency room debating whether to go ahead with surgery, she still made sure to call a volunteer to let him know that she would not be able to make the reminder calls to family members for the upcoming meeting.

While I spoke of the support group in general terms above, Stacy and Mrs. Lau had expressed gratitude to the volunteers for past acts of kindness, even though their actions benefit the group as a whole. The following examples clarify this connection. When family participants thank volunteers, volunteers are quick to remind them that they should thank the group as a whole. Family participants also try to include volunteers in activities they will typically engage in with people in their guanxi, making volunteers, who prefer to maintain a professional relationship, uncomfortable. Even though volunteers have politely turned down their invitations, Cindy and Elaine continue to invite volunteers to have dinner with them, making it clear that they will treat. When a volunteer’s mother passed away, Mrs. Lau bought a card and went around to get family members to sign it and collect “white gold”—money to help the family with the funeral expenses. Mrs. Lau was also the one to spearhead the idea that family members should contribute money to the annual Thanksgiving dinner, as a way to thank volunteers. Normally the support group pays for the party with donations collected throughout the year, but in 2011, following Mrs. Lau’s suggestion, several family participants insisted they contribute money to the party as a way to express their gratitude. One volunteer, who was touched by this gesture, shared: ‘I am surprised they offered to pay. It seems that family members feel connected to us, which is nice, but the support group is really about them. They need to lean on each other for support.’

Volunteers also model this moral ideal for family participants in their own remembrances and actions. For example, when the support group first started and did not have much in funds,
The Chinese Church Association allowed the group to use their space for free. Although the group no longer uses that space, volunteers used their own money to buy tickets to the organization’s annual fundraiser and then donate tickets to family participants who wanted to attend. They also explicitly stated that the tickets were a show of support to The Chinese Church Association for its past help. Similarly, when the president of the Asian American Mental Health Providers Association wanted to take an informal poll of service utilization among family participants for her research, volunteers reminded the group that the association had donated money to the group, which had paid for dinners at the monthly meetings for a year.

Acts of kindness create moral obligations to reciprocate, but payment is not tick for tac (some acts can never be repaid), and the relationship does not terminate after repayment. In other words, there “is never closure to” some relationships (Oxfeld 2012:3). When others violate expectations of reciprocity, it creates confusion and discomfort. For the 2013 fundraiser, volunteers were reaching out to their social and professional networks to sell banquet tickets. Thomas, a volunteer, shared with me: ‘I am surprised that the Asian American Mental Health Providers Association did not buy any tickets. They have always supported us. I’m not sure if they are upset that I have not been attending their monthly meeting, and so maybe they are not supporting us with this fundraiser.’

In another incident, Thomas made a comment about a prominent researcher who has recruited research subjects from the support group: ‘I emailed him about the fundraiser, but he never emailed me back. That’s really strange.’ While in the first example, Thomas questioned if he had violated an expectation to show support, which in turn prompted the association to withdraw their support, in the second example, Thomas did not understand why this researcher, who had benefited from the generosity of the support group, did not reciprocate. Since access to
this population is very difficult, the assistance received by this researcher is significant and therefore his failure to remember is a bigger transgression. Thomas explained, ‘it is very difficult to recruit Chinese subjects for mental health research. Just last week, I turned down three people who want to recruit subjects from my agency. I didn’t even bother emailing them back. I don’t want to waste their time or mine.’ This researcher’s failure to remember is further highlighted when another researcher, who had also recruited subjects from the group, could not attend the event but purchased two tickets to donate to family participants.

In the previous example, we see that the extent of the moral debt incurred is based on the assistance received, as perceived by the recipient. For example, when Mrs. Lau referred to me as her enren, which roughly translates as “savior” in English, I felt slightly embarrassed because I did not feel I deserved such an exalted term. I had served as her main interpreter with Kevin’s clinicians, but that was a small inconvenience, considering she was gracious enough to share her stories with me. Later, I realized, regardless of how I perceived our exchange, it meant a lot to Mrs. Lau that I took time to help her translate, especially since I would not take her red envelopes. My mother still talks about a Chinese clerk at the food stamps office she met many years ago, when our family had just arrived in the US and was still struggling financially. Every few months my mother, who does not speak any English, had to travel to the food stamps office to renew the application for our household. The Chinese clerk would move her to the front of the line, and help her with the renewal process. He was so kind to her that some of his colleagues thought she was his relative. One day, the clerk was gone, and my mother never knew what happened to him. However, to this day, she speaks fondly of him. Just as it was not costly for me to help Mrs. Lau, it was the same for the clerk; but for my mother, who had just
moved to a new country and did not speak an ounce of English, she very much appreciated that help.

**Concluding Remarks**

The Chinese support group offers similar benefits to support groups for Euro-American families with a relative who has a mental illness. The group meets respondents’ needs for emotional support, education about illness and treatment, and practical advice on communicating with patients and clinical staff. The support, however, is tailored to caregivers with limited English proficiency, who are unfamiliar with the mental health system, and in many cases lack financial resources. Accordingly, the support group serves as social capital, helping family participants understand, integrate, and at times contest the mental health system.

Family participants, in turn, view their relationships with volunteers as one based on moral obligation. As their “teachers,” volunteers are moral examples for family participants, who turn to them for guidance. Furthermore, the volunteers’ expertise and the marginalized position of most family participants in society, creates opportunities for volunteers to help them navigate the mental health system. This assistance, in turn, creates moral obligations for family participants to remember and attempt to repay. These moral obligations, understood through the “general principles of reciprocity, hierarchy, and moral modeling” (Oxfeld 2010:47), explain why family members feel more connected to volunteers, rather than with each other.

While all the family caretakers get along, there are factors, such as dialect and social class, that create subtle divisions and impede identifications with other family caregivers. Meetings are in Mandarin, because it is assumed most Cantonese family participants and volunteers can speak and understand Mandarin. Although this is generally true, the Cantonese
family members vary in their fluency of Mandarin. It seems many Cantonese speakers have a harder time speaking Mandarin than understanding it. The Cantonese speakers also seem to gather together, which makes sense because language plays a major part in creating rapport and intimacy in any type of group work. Mary, who directs a day treatment program for Cantonese-speaking adults with mental illness, explained, ‘We only accept Cantonese clients, because we do a lot of group work that focuses on receiving support from your peers. The clients need a shared language to communicate their feelings and concern.’ This is the same reason that Mrs. Lau prefers to do informal gatherings with only Cantonese family participants.

Family participants also have preconceptions of each other based on education and place of origin. Being a teacher in China, Mrs. Lau expressed difficulty connecting with other family members who have little formal education. Stacy, who is from Hong Kong, pointed out cultural differences between her and family members from mainland China: ‘Sometimes I can’t blame Americans for discriminating against Chinese, in particular people from the mainland. I went with Rachel to visit one of our family participant’s sons at a nursing home, and she kept spitting on the street. Or, last time when I went with Mrs. Lau to visit her son at the psychiatric hospital, Mrs. Lau poured a little bit of water into a bowl to rinse it. Instead of pouring that water out into the sink that was located a couple of feet away; she poured it onto the floor.’ Paula echoed similar sentiments when she spoke of family caregivers from mainland China in her New Jersey support group: ‘There are a lot of mainlanders in the group, but the most active members are from Taiwan. When the mainlanders want help they are nice, but they do not have this idea of service, of giving back. It’s just not part of their culture…They are so rude. A lot of mainlanders go to Taiwan now. I was at a museum and they just pushed me out of the way.’
When the group first started out, most families were from the working class, but there are one or two more affluent families now. Although it is not explicitly discussed, family participants are aware of this class difference. When Cindy explained that her son has not worked for the last ten years, but still drives his car to run errands, Mrs. Lau and Elaine chuckled and made comments about privilege. Stacy caught their response and later shared with me that ‘it wasn’t nice of them to do that. Having money just means you have one less thing to worry about.’ Volunteers also struggle with this shift in group membership. Some felt family participants should contribute to the group, even with small donations, because then they will learn to give back. However, some felt uncomfortable with this. When Mrs. Lau suggested that family participants pay for the holiday party, one volunteer stated, ‘I don’t want family members that cannot contribute money to feel bad.’

Family participants also judged each other based on clinical and demographical characteristics of their ill relatives and of themselves. Rachel and Hanna got into a little tiff over who suffers the most: a mother taking care of mentally ill child who also has mental retardation or a sister who is desperately trying to help a sister who does not think she is mentally ill and refuses any help from her family. Family participants also embody common misconceptions regarding mental health consumers that are reproduced in mainstream society. Hanna shared with me that ‘Mrs. Lau’s son does seem like he is mentally ill,’ and Elaine expressed surprise that ‘Cindy’s son is very intelligent.’ Unfortunately, the stigmatization of mental illness is also replicated. One mother shared she does not want her son interacting with Cindy’s son, because her son’s clinical condition is not as serious; ‘he doesn’t hear voices.’ Ironically, Cindy shared with me that this mother’s son is more serious than Dan, because ‘he had to be hospitalized for inflicting harm on his body by scratching himself.’
The main goal of this chapter is to explore the group processes at work in a Chinese support group, and while it clarified the similarities and differences between this group and Euro-American support groups, it also raises questions about the framework and viability of this ethnic support group. Can family participants assume leadership roles in the future? According to Stacy, ‘most can’t even speak English, how much can they do?’ Will splitting family participants into discussion cohorts based on language or care relationships (parents, siblings, etc.) for parts of the meeting increase identification with other caregivers? Will hosting events or scheduling activities that create opportunities for family participants to cultivate relationships based on reciprocity help bridge the personal differences discussed above? Should the support group become more of a direct service agency? How can we get family participants to rely less on volunteers and to recognize their own expertise in negotiating with the mental health system?

Thomas shared, ‘When I started the group, I just want to provide a space for family members to share their feelings and know that they are not alone. I am happy as long as we can continue to do this, but it seems family members have different expectations.’ The ‘different expectations’ refer to family requests for instrumental help, such as providing translations in meetings with clinician staff. In light of the socioeconomic status and language fluency of most family participants, it is understandable that these caregivers prioritize practical support. The support group has great potential to help family caregivers in the immigrant Chinese community, but as a non-profit with limited resources, it has to be creative in developing strategies to meet caregivers’ practical needs and increase its community impact. The questions I posed above will, I believe, help volunteers and family participants approach this task. In the next and final chapter, I summarize the major findings of my dissertation research and discuss their implications.
Chapter Seven: Conclusion

...the market has an important role in health-care financing and health systems reform, but it should not reach into those quintessentials of caregiving that speak to what is most deeply human in medicine and in living. This is the moral limit of an economic paradigm. Or at least it should be. (Kleinman 2012:1550)

For Arthur Kleinman, a physician, medical anthropologist and a caregiver to his late wife, caregiving is central to being human. His words suggest that meanings and practices attached to caregiving are similar cross-culturally, if not universally. Kleinman asserts, “Caregivers protect the vulnerable and dependent. …caregiving is also a defining moral practice. It is a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human” (Kleinman 2009:293). Drawing from ancient Chinese philosophy, he goes on to say that caregiving is not only a self-cultivation practice that makes us more human, but also humanizes the world—“our ethical cultivation at the very least fosters that of others and holds the potential, through those relationships, of deepening meaning, beauty, and happiness in our experience of the world” (Kleinman 2009:293).

Although Kleinman claims that he is “not a naive moralist,” because he has “had far too much experience of the demands, tensions, and downright failures of caregiving to fall into the sentimentality and utopianism,” (Kleinman 2009:293) his descriptions are rather idealistic. Reading his work, I am reminded of the cultural psychology literature that discusses Chinese notions of filial piety, face, family obligations, and mental illness in very abstract and formulaic ways. What is missing in this body of literature and Kleinman’s ideas is an account of how real people interpret and put into practice cultural models of care. Caregiving is an interesting topic of inquiry; it is something we often take for granted, because we see it as natural and therefore
have expectations of what it entails. I think most people’s perception of caregiving is similar to Kleinman’s descriptions—it is difficult but you naturally want to take care of your loved ones. It is in the actual practice of providing care when individuals are faced with feelings of resentment, anger, grief, loss, and ambivalence that these ideals are challenged. For example, a good friend confided in me she was very sleep deprived a few months after her daughter was born. On one occasion, my friend became very frustrated, because the baby would not stop crying. She had this sudden urge to throw the baby on the floor, so she quickly handed the baby to her husband. Afterwards, my friend felt very ashamed that she felt this way, because for her, mothers are suppose to provide unconditional love to their children.

In reality, many factors, such as health insurance, class, cultural ideals of familial obligations, severity of the illness, competing family responsibilities, and conflicts among family members on how to manage illness, complicate ideals and affect how care is enacted. Caring for someone with a mental illness poses a different set of ambiguities, confusion, and complexities than caring for someone with a physical illness (Karp 2001). Individuals diagnosed with a serious physical illness, such as cancer or heart disease, rarely, question their diagnoses. On the other hand, individuals diagnosed with a mental illness often will deny or contest the label. In addition, respondents also question patients’ ability to turn symptoms on and off as a way to use their illness to manipulate others. This is a reasonable assumption when they see that their ill relative has calmed down when the police arrive, or that their family member “forgets” to take medication whenever they go on vacation. Just as my respondents learn to navigate the mental health system, patients also learn how to present themselves to clinicians. Because there is no actual medical test to detect mental illness, the illness does not have the concreteness of an aliment that caregivers can see in a blood test or x-ray. It is also difficult to be empathic, kind,
and remain hopeful when patients, because of their psychosis, treat caregivers as the enemy or resent their efforts to help. Mental illness also prompts caregivers (especially parents) to contend with the possibility that they contributed to the illness (Karp 2001).

My dissertation project examines how macro-processes and institutions interact with cultural and personal factors to influence how caregiving is conceptualized and enacted in the everyday lives of immigrant Chinese women. I see caregiving as a practice that is situated in everyday life, and as I have shown in the previous chapters, these perspectives and practices are redefined through the course of the illness, and the caregiver’s and care-receiver’s life cycle. As an anthropological work, the dissertation places emphasis on the acceptance, negation, and modification of cultural ideals in constructing experience. However, it does not privilege culture, but sees it as only one of the many variables that affect caregiving. Culture, particularly the idea of habitus, is often used to iron out the difference between people and their experiences, in some cases to presume similar behavior to mean similar thoughts, feelings, and imaginings (Hollan 2012). Individuals, however, do not experience culture in a similar fashion (Spiro 1951), because experience and behavior are not just mediated by common habitus, routines or practices, but by dispositions, memories, desires, past interpersonal engagements, imaginings of the future, and other significant experiences.

Below, I summarize the major findings from each chapter. When appropriate, I will bring in my experiences of growing up with a mother and sister with a mental illness. I concur with Jackson’s (2010) assertion that our personal experience can inform our understanding of our respondents’ lives and more broadly the human condition. Reflexivity, however, should be not driven by a confessional impulse. Instead, personal stories, I believe, should help clarify concepts and processes and contribute to a better understanding of the study. In my case, as
someone who lived with a mentally ill mother and sister for most of my life, I hope my reflections underscore how caregiving is subject and context based, and that concerns and needs of caregivers evolve with the progression of the illness and changes in the family cycle. In comparing my experiences with my respondents’, I also show how resources and accommodations are employed when there is someone mentally ill in the family, and how that can affect help seeking. In the last section, I end with a discussion of the significance of my research.

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In chapter three, I illustrate how, in the early stages of psychosis, both Euro-American and Chinese caregivers delay labeling family members as mentally ill. Families, across ethnic groups, are reluctant to use the term because mental illness is very stigmatizing (Lefley 1996). Furthermore, since psychiatric illness tends to occur around adolescence and young adulthood, families can easily dismiss it as unruly teenage behavior that would eventually resolve itself as the child matures. Chinese families, in particular, may not be familiar with a biomedical understanding of mental illness.

Once the label is applied and accepted, Euro-American and Chinese families alike have a sense of hope and relief that diminishes as families recognize the chronicity of mental illness. As I argue, it is in long-term care that we begin to see differences in the levels of involvement in both sets of caregivers. Reflecting an interdependent self that motivates individuals to fulfill family obligations, the Chinese caregivers normalize the caregiving tasks they perform, which results in a higher threshold for stress before caregivers’ commitment starts to retract. It seems
the severity of the illness and the resources families have determine Chinese caregivers’ level of involvement.

The onset of my mother’s illness was later in life. In many ways, she lived a very normal life—she had friends, worked, got married, and had children. However, by the time she immigrated to the US, one of her brothers had drowned, she’d lost a son in childbirth, and had lived through the Vietnam War and endured long periods of waiting to see if her siblings who’d left the country had arrived safely at refugee camps. When she came to the US, her social support network diminished, and because she stayed at home to care for my grandparents and her four children, she did not have many opportunities to make friends. She was also afraid to go too far from the house, because she did not speak any English.

I don’t remember how things started, if it was gradual or abrupt, but my mother developed these fears of contamination along with cleansing rituals. She did not like walking past homeless people or dogs. She prefers not to have to cook after doing needlework, because of concerns that the needle would drop into the food. When she washed greens, she examined each leaf, cutting out parts that were slightly yellow or had holes in it, probably from insects nibbling on them. If she did find a bug in the greens, she would throw all the vegetables in the trash. Then she would put the bug in a zip lock bag, place the bag next to the garbage can, and show my father when he got off from work. Even to this day, when my father takes out the trash, he checks with her to be sure she does not need to show him anything.

Karp (2001) asserts that children who grow up with one or two parents with mental illness, often don’t recognize the dysfunction in their home life. However, my siblings and I clearly recognized there was something wrong with our mother. We knew leaving the house was stressful for her, so our aunts usually did the grocery shopping. I always went over to my
friends’ houses to play, because it was a given that friends could not come over. Growing up, we never had pets. I remember my mother was prescribed medication, but she stopped taking it because it made her so drowsy that she spent the day in bed. Mary explained to me that many psychiatrists tend to prescribe too high of a dosage too quickly, which is why many patients stop taking medication.

A big part of why my mother was never hospitalized, and why there was no urgency to get her treated, was because her illness was manageable with the family resources we had. The distress from her obsessions and compulsions were bearable for my mother as long as she stayed in a controlled and predictable environment, in this case our house. She also had help from my grandparents, my father, and his unmarried siblings. As my siblings and I got older and were able to walk to school on our own, she left the house less and less. Even now, my mother rarely leaves the house, and when she does she needs to be accompanied by a family member. Unlike many of my respondents who immigrated to the US with their nuclear family under the 1965 Immigration Act, we arrived as an extended family with my father’s parents and siblings. Since most of my father’s siblings were not married, we all lived in a two-family house. Essentially, we had a larger support network that allowed us to spread out the accommodations among various family members. In addition, an ethos of family loyalty and caring for the sick, the elderly, and our ancestors was reinforced in everyday family life and in religious worship. I watched how my family took care of both my grandparents to the very end, and one of my uncles who was disabled from polio. In the living room, we have an altar with Buddhist and Chinese folklore paraphernalia, and ancestor plaques, where my mother will make food offerings. We continue to observe Ching Ming, which is a day families commemorate their ancestors by visiting their family tombs to clean the surrounding area and offer sacrifices.
Being single mothers, Ms. Ng and Carol had a more difficult time coping with their children’s illness than did my family. Because of her son’s illness, Ms. Ng could not sleep or eat, and had to take time off from work. As the sole bread-winner, she realized if she did not take care of her emotional state first, she wouldn’t be able to return to work and both she and her son would be on the streets. While Carol also had financial hardships, her daughter’s violent outbursts and threats to her and her son’s life, demanded her attention. Although Paula is also a single mother, she is educated and has more financial resources. When doctors diagnosed Paula’s daughter, Joyce, with cancer the second time, Paula quit her job to focus on taking care of Joyce. She was unemployed for several months, but did not rush to find a job after Joyce recovered from surgery and was cancer free. She was mainly looking for consulting jobs, because contracting work gave her flexibility to leave when problems with Joyce’s health emerged. She also prefers working in New Jersey, but is willing to commute to New York City if the job is healthcare related. She also toyed with the idea of just retiring, but decided she wanted to work for another six months for ‘Joyce’s sake’—she wants to save a little more money to leave behind for her. As a computer programmer, Paula has a highly sought-after skill, and therefore has more leverage with her employers, and at times, is able to put her daughter first.

In contrast, Carol does not have the same bargaining power as Paula, because she neither speaks English nor has a specific set of skills. Since 1995, Carol has also been on disability due to severe dermatitis in her hands, making them dry, cracked, and prone to bleeding. As a result, she could not work in many of the professions typical of immigrant Chinese women that involve manual labor with the hands, such as garment factory worker, cashier, or home aid attendant. Carol’s socioeconomic status created a different set of concerns and priorities for her. She was criticized for her acceptance of a “bribe” from her ex-boyfriend in exchange for not going
forward with legal proceedings in regards to her daughter’s abuse. She explained ‘I did not show up to court. I also asked Jessica to write a note to the judge stating that we do not want to sue him anymore. Jessica lost her father, so I did not want my son to lose his father as well. That man also promised to give me $30,000, and for a short period of time, he gave me $600 each month but then he stopped. We had a written agreement, but then he asked his uncle to come talk to me. I showed the uncle the paper and then he just took it and left.’ Carol was castigated by friends and family in her decision to take the money, but her actions are understandable, even if they are contrary to our ideals regarding motherhood—she can’t change the past, but the money will help her family move forward. Furthermore, Carol feared having to tell her son, Sean, why his father was in jail. On one occasion, Sean asked if he and Jessica had the same father. Carol did not answer him, but took him to a therapist instead.

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Chapter four explores the contextual nature of family obligations and caregiving. I assert that caregiving is a process that evolves over time and is situated in the particularities of both the caregiver’s and care recipient’s lives. The level of involvement reflects a negotiation of various factors, such as age at onset of the illness, caregiver’s relationship to care recipient, severity of illness, coping resources, and family members with different acculturation levels and views on how to approach treatment and care for the patient. Although Euro-American and Chinese siblings generally have limited involvement in their siblings’ lives, the latter places more emphasis on instrumental support than the former. It seems that when parents have passed away and children or a spouse of a patient is not available, Chinese siblings will assume more
Caretaking responsibilities, replicating parental support. In general, Chinese parents and siblings (ones that become the primary caregiver) treat their ill relatives like children, because they are often unable to achieve the typical adult milestones. The similarities are most apparent in the ways the caregivers critique transgressions and instill values that encourages harmonious interactions.

As noted above, my mother did not get ill until later on in her life, after she had gotten married and had children. She had acquired many of the skills and competencies to be a stay-at-home mother, and with the help of my father and his family she was able to be somewhat productive in this role. The onset of my sister’s illness, however, was much earlier, in her late adolescence and early adulthood, before she developed many of the life skills and competencies necessary for adulthood. Our family resources and ethos of taking care of family members who are ill allowed my mother to function in daily life without treatment, and created a stable home environment that enabled my brothers and I to succeed academically and professionally, and to be independent. However, it also reinforced my sister’s tendency to rely on others to do things for her, and further impeded her development as adult. Being an anxious person who is very sensitive to stress, it is extremely difficult for my sister to do even the most basic things, such as writing a check, boiling water, or washing a dish. She can only work part time as an English tutor. We could no longer share a bedroom, because she was hoarding piles and piles of newspapers. When she leaves the house she spends an extraordinary amount of time checking the zipper on her book bag and making sure the front door is closed behind her. Without my family, she would have to be on disability.

As with many immigrant families, education was highly valued—it was expected that all of us would go to college—and our sole responsibility was to do well in school. Most of the
children had summer jobs, but we were never asked to do chores and were expected to stay at home to study after school and on the weekends. I did not learn how to cook and clean until I moved out. My sister enjoyed the sheltered life and was never interested in establishing her independence, so in some ways, she naturally transitioned to the sick role. Her mental illness deteriorated when she returned from UC Santa Barbara. She had been accepted to doctoral programs at several top tier universities, but decided on Santa Barbara. It wasn’t long after she moved into graduate housing that living on her own with a recent diagnosis of diabetes became too overwhelming. I remember her calling my parents and asking them to mail her socks and lotion, things she easily could have bought from the school bookstore. She had to withdraw from school and my aunt flew to California to take her back home. A year later, she applied and was accepted to another doctoral program in New York City, but after two semesters she became really depressed. She told a school counselor that she thought about suicide, and was sent to the ER.

The difference between my sister and the rest of her siblings demonstrates how family environments can have very different effects on children within the same household. Gladstone et al. (2005) point out that the literature on parental mental illness and its effects on children have been dominated by a discourse about “at risk” versus “extraordinarily resilient” children, a model that presumes children will be adversely affected by a parent’s mental illness. If children are not thus affected, then it is presumed they must be extraordinarily resilient in some way. This framework reinforces the “hegemonic image of children as passive, developing, ‘unfinished’ persons,” without acknowledging children as competent contributors to social life (2005:2542). In addition, it assumes caring for an ill parent involves a role reversal that forces a child to prematurely assume an adult role (Chase 1999, Jurkovic 1997). Although there are positive
effects in this process as well, most studies focus on the negative aspect of children sacrificing their needs for those of their parents (Chase 1999). This paradigm, I believe, privileges a Euro-American middle class understanding of child development, and does not actively consider class and cultural differences (in some groups it is a given that children’s needs are secondary to adults or to the family more broadly), and the unique processes and routines within each family.

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Chapter 5 engages with the literature on how the mental health system affects families with a relative with a mental illness. Problems reported by Euro-American families, such as immature discharge, inadequate services, and clinical staff’s resistance to including families in treatment planning and implementation, were also identified in my sample. However, my respondents’ limited English proficiency and unfamiliarity with the bureaucratic logic of the mental health system impedes their ability to advocate for their ill family member and for themselves. In response, they develop creative strategies to maneuver around patient confidentiality policies, manage symptoms, question clinical decisions, and recruit professionals to help with advocacy. This chapter also highlights ethnography’s strength in studying local worlds and eliciting subjects’ motivations to further understanding of how health decisions are made. My respondents’ experiences suggest laws regarding involuntary commitment and the police (who are not trained to deal with the mentally ill) may be bigger obstacles to help seeking than stigma in Chinese culture, especially for psychotic behaviors that are difficult to manage. It also illustrates how caregivers’ treatment goals for their ill family member can be very different from what their relative actually wants.
Unlike many of my respondents, my family did not prioritize seeking treatment for my mother and sister. I was back from my first quarter at UCLA for the winter break, when my sister called home and told my mother that the school counselor was sending her to the emergency room. My mother told me to go to the school and find out more. When I got there, my aunt, who had left work earlier, was trying to convince the counselor that we will watch over my sister and that there was no need to take her to the emergency room. The counselor refused and would only allow the ambulance to take her to the hospital. I don’t remember much of the details of that day, except that I sat with my sister at the emergency room in the New York City Presbyterian Hospital for a long time before she was transferred to a psychiatric hospital in Westchester County.

We went to visit her the next day. The hospital reception area was actually very warm and inviting, quite contrary to what I had expected. There were cushiony seats and the room was decorated in rich browns and reds with soft lighting and artwork on the walls. Since her condition had been deteriorating for a while, I felt the hospitalization was a good thing, but this opinion was not shared by the older generation in my family. Two of my uncles were trying to convince the social worker to discharge my sister. My sense was that there was a fear of stigma, but it was less about the loss of “face” of the family and more about how the hospitalization would affect my sister’s academic and professional opportunities. Because she is a young college-educated woman, family members experience a greater sense of loss and grief that her illness will prevent her from achieving things that someone with her intellect and overall physical health would otherwise be able to do.

Although my parents did not speak English, I translated for them and helped them understand the situation, to spare them the frustration of trying to communicate with English-
speaking clinicians at the hospital. However, they did not understand why the hospital could not discharge my sister after a day or two. At that time, my sister’s depression was more acute than her obsessive-compulsive disorder (OCD), so her illness did not seem as severe to my parents. My sister was discharged in about a week, though she continued getting psychiatric medication management and seeing an outpatient therapist. I was busy with graduate course work and getting situated in Los Angeles, so I did not really follow up on her progress. From the pieces of information I gathered during phone calls or short trips home, I learned my sister was on medication for a short period of time (about one to three months), which is very short, considering our family history and the chronicity and severity of her illness. Although medication would improve her quality of life, as an adult my sister decided not to take it—a decision supported by my family, who also doubted the medication’s efficacy and had concerns about the side effects.

I know that my sister’s therapist had suggested she move out, because she was getting into arguments with our parents, especially my father. Being a Chinese-American, the therapist knew that Chinese children rarely discontinue relationships with parents and daughters generally do not move out of their natal homes until they get married. Furthermore, my sister did not have a full time job and lacked the skills and competencies to live independently. I am not sure if the therapist referred my sister to a treatment program or a social clubhouse to work on her social skills or suggested family therapy. However, I do know that my parents felt judged, as if they were causing the problems and they were the enemy.

I was able to play a larger role in my sister’s treatment than in my mother’s. First, being older and educated granted me legitimacy and authority with my sister and family. Since I was her only sister and we were close in age, my sister identified with me and trusted me and allowed
me to access her medical information. When a social worker at the psychiatric center asked if my sister wanted a family member to be included in her initial intake, she requested that I sit in. I was asked to contact her professors to let them know she would need to take an incomplete, and to follow up with her social workers and clinicians. As previous research has noted, Chinese-American families are less patriarchal and daughters receive comparable parental investment as sons, and are expected to provide support to elderly parents. Although my family exemplifies this shift in many ways, treatment decisions were largely still a negotiated process between members of the older generations (i.e., my parents, aunts, and uncles), and it seemed the general consensus was that outpatient treatment was not a priority, especially if my sister did not want to do it.

Like many patients, my sister is ambivalent and frustrated with her dependency on others, and with her poor life prospects. As she grows older, her emotional maturity remains undeveloped. Even though there are plenty of leftovers in the refrigerator that she can microwave, she gets nervous about getting fed when my mother leaves the house to go to a doctor’s appointment or to go shopping with my father. When my younger brother, who has moved out, visits our parent’s home, my sister is resentful of the attention and food that my parents and aunts shower on him. On one occasion, she overheard a phone conversation I had with a friend where I was giving her advice to housetrain her new puppy. When I got off the phone, she made some inquiries about the dog, and then asked me: ‘When Lucky (our family dog) gets old and ugly, will you still want him? Of course you will. I am neurotic, but I am not stupid. I know I am selfish. When mom and dad get old and useless to me, I would not want them. I know you will still care for Lucky because you are a sensitive person.’
My sister seems especially ambivalent towards me, because while she identified with me, I also reminded her of her failures. She was always the scholarly one who enjoyed studying. As a teenager, I skipped both American and Chinese school and was out at all hours of the night. My grandfather had predicted that I would run away from home by the age of 15. As an adult, however, I got along with our parents and brothers, and had a circle of close friends. I was awarded the same fellowships as my sister in undergraduate and graduate school, and was finishing my doctoral degree. As my life was progressing, hers was static.

One day, a friend asked my brother why the family dog does not like my sister (she is the only person that he growls at), and my brother explained, ‘all the past family pets don’t like her. Animals are smart and intuitive. They can sense she is not a nice person.’ This is true—my sister can be a very selfish, mean, and petty person. There were times when it was clear to my brothers and me that the police should be called or that my sister needed to be taken to the emergency room and hospitalized. However, the same emphasis on family loyalty that provided us stability also paralyzed us in making the call. This is because we knew other family members would see our actions as a betrayal—in contacting mental health professionals or the police we were hurting our sister because she would then be “locked up,” with a permanent record of her hospitalization. Essentially, family support is a double edged sword for both ill and healthy members. For the ill family member, it can be a source of assistance or an enabler of maladaptive behavior, as seen in my mother and sister. My siblings and I benefited from the stability and support, but we were also expected to be loyal to our family and contribute to caregiving. Because our family played such a significant role in our lives, fear of ostracism and abandonment discouraged subversion; hence my brothers’ and my reluctance to call 911.
The potential of the family to be both a source of support and burden (sometimes even to the point of overbearing), is an enduring dilemma that respondents grapple with. Dan is able to delay treatment, because his mother, Cindy, has the resources to provide him with a safe and controlled home environment. She even stopped renting out the first floor of her house, losing significant rental income, because she felt tenants would increase Dan’s stress and exacerbate his illness. Her eldest son, Jerry and his wife, feel that Cindy is making too many accommodations for Dan, and this has been an ongoing contentious issue among them. Cindy criticizes Jerry for not providing adequate emotional support to Dan, ‘his only brother.’ For Cindy, she and her husband had raised Jerry, put him through school, and helped him financially, and therefore he has the obligation to repay them through emotionally supporting Dan. Stacy represents a more extreme case. After they immigrated to the US, Stacy’s mother expected her to take care of all tasks that require speaking English, such as communicating with the management company of their apartment. She also wanted her daughter to pay for everything, and Stacy, to a certain extent, wants to be able to do that for her parents. Stacy shared, ‘If I can pay for it, I will. But I’m not making a lot of money and also have a mortgage to pay.’ Stacy was relieved that her parents did not follow through with the plan to find her brother a wife, because she knew she would be left to manage the consequences of the marriage after her parents passed away.

Not all families expect other kin to be heavily involved in providing care to a mentally ill relative. Paula’s eldest daughter, Bella, and her family moved to Kuwait so that her son-in-law could take over his family business. Although Paula misses her daughter and granddaughters, she feels it is best that Bella lives far away. This is because Joyce’s unannounced home visits to Bella were adversely affecting her marriage—Bella’s husband did not like his wife dropping everything she was doing to entertain and cater to Joyce. Paula knows Bella loves her sister and
will always want to take care of her, but she wants Bella to live her own life because Joyce is not her burden to bear. Similarly, Mrs. Lau would like her daughter, Karen, who is married with two sons and is the most stable and reliable one out of all her children, to play a larger role in Kevin’s care. However, being a mother and wife herself, Mrs. Lau understands she cannot expect her daughter to be too involved when she has her own family to care for. In addition, involvement is also difficult because Karen lives in New Jersey and works full time.

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Chapter six compares the similarities and differences between Euro-American family support groups with the Chinese one most of my respondents attended. Similar to support groups for Euro-American, the Chinese family support group meets respondents’ needs for emotional support, education about illness and treatment, and practical advice on communicating with patients and clinical staff. The support group, however, is tailored to caregivers that have limited English proficiency, are unfamiliar with the mental health system, and in many cases lack financial resources. In doing that, the support group serves as social capital, helping family participants understand, integrate, and at times contest the mental health system.

The relationship between volunteers and family members reflects a fusion of different relational frameworks, including clinical and mentorship. Adopting NAMI’s peer group approach (family to family) and attempting to maintain professional boundaries, volunteers encourage family participants to support each other and advocate for themselves, hoping that one day they can lead the group. Family participants, on the other hand, place emphasis on their relationship with volunteers, which they view as one between a teacher and student. These
relationships are imbued with moral undertones, because learning, and by association teachers, is tied to moral cultivation. Furthermore, according to Chinese ideals, to be a “good person,” family participants should remember and try to repay others for their kindness (Oxfeld 2010), in this case the volunteers. Despite these positive outcomes, there are divisions between respondents based on dialect, place of origin, class, and caregiver’s relationship.

My family will probably never attend a family support group, because they are able to manage and accommodate my mother’s and sister’s illnesses. When my sister found out I had asked our family doctor to refer my mother to a psychiatrist she laughed and said, ‘You know no one in our family will get help.’ However, support groups can be a valuable resource for families in the lower socio-economic strata who also have limited social support. The groups are a non-threatening way to obtain information about mental illness and treatment, and a source of emotional support for families, especially ones that distrust mental health practitioners. As a way to improve its community impact, the support group may want to explore how to use Chinese media (i.e., newspapers, magazines, radio, etc.) to increase mental health literacy, because ethnic media has been shown to facilitate immigrant Chinese’s assimilation to mainstream American culture (Zhou and Cai 2002).

Intellectual Significance and Broader Impacts

In providing rich ethnographic data, my dissertation seeks to complement the quantitative research on families and mental illness. It contributes specifically to anthropological theory in three main ways. First, as noted in earlier chapters, the anthropological literature on mental illness has focused primarily on the experience of the patient. Using the family as the unit of analysis can illuminate the more social aspects of mental illness and advance methodological and
theoretical conceptualization of the topic. Second, the research contributes to studies of families. It speaks directly to scholars interested in the individual’s experience of kinship and intimate household life (Hollan and Wellenkamp 1994, Yan 2003), and to scholars working on families and chronic illness (Raghavan et al. 1999, Bernheimer and Weisner 2007, Gallimore et al. 1996, Skinner and Weisner 2007, Weisner et al. 1991, Weisner et al. 2005). This project examines how the illness impacts the psychological and social world of family members. In doing so, it shifts intellectual conversation to family-level changes and successes, rather than patient-level outcomes. Finally, the study contributes to anthropology’s longstanding interest in culture and notions of self. Analyzing families’ obligations to a mentally ill kin not only furthers our understanding of how moral selves are constructed and enacted in daily life by different generations and gender, but also demonstrates how individuals accept, reject, or modify resources in their behavioral environment to affect the development and reproduction of cultural notions of the self (Hollan 2003).

While the generalizability of my findings is limited, being based on a small group of women, it suggests themes and connections that need to be corroborated and further explored, in both future qualitative and quantitative studies. For example, how does intra-familial and extra-familial coping differ based on the chronicity and severity of an illness? How do contemporary immigrant Chinese interpret stigma and face? What social and demographic variables should be used to create family support groups so that they are the most beneficial? More large scale studies that focus on a particular caregiver and care recipient relationship (parents, siblings, spouses) are also needed. Another area that needs further exploration is the experiences of male caregivers. The dominant rationale for focusing on female caregivers is that they tend to be more involved and therefore more negatively affected by caregiving. However, there may be
qualitative differences between how Chinese male and female caregivers interpret their situation and learn to cope.

In addition to my dissertation’s intellectual contribution, the broader significance of the project is its potential to be applied in clinical practice and health policy. I recognize my work can be very applied, but it was two encounters that prompted me to think concretely about how to accomplish this. First, Stacy once shared, ‘academics are always bullshitting, all they talk about is theory…They don’t understand our lives.’ On a different occasion, I met a Chinese-American woman who has two siblings living successfully with mental illness. After I gave her a brief overview of my research, she asked why I was doing research on Chinese families and mental illness. Not satisfied with my response detailing the lack of qualitative research in this area, she pressed on with the following questions: ‘What is your motivation? What do you get out of it? Do you expect your work to make it better for the people you study? Will you continue to volunteer?’ I was taken aback by her questions, as they were very direct.

After some reflection, I realized Weisner and Hay’s (forthcoming) partnership model offers a framework for integrating my findings with practice to improve the lives of families and patients. As Weisner and Hay note, the use of evidence-based practices (EBP), which are informed by research findings, is increasingly being mandated by health insurance companies, hospital administrators, and governmental agencies, because EBP have been shown to improve patient care. Less is known about the effectiveness of cultural competency training programs, but there is evidence that when tailored to local contexts, these programs can be effective (Kirmayer 2013). As a way to merge cultural competency programs and evidence-based practices, Weisner and Hay advocate using ethnographic methods that examine culture and context to inform evidence-based practices. Furthermore, while sharing her experience in
conducting research that affects health policy, anthropologist Tamara Daley noted that organizations and agencies are mostly interested in stories and narratives, not quantitative measures.

The partnership model can also be utilized to increase access to Asian American respondents, who are often reluctant to participate in mental health research. From my experience, there is a lack of dialogue between researchers and practitioners, who are often the gatekeepers. At the quarterly breakfast forum hosted by the New York City Department of Health and Mental Hygiene, one of the conversations focused on how practitioners who work with mental health issues in the Chinese community could be better informed on innovative strategies for increasing culturally competent services for immigrant Chinese. Since I have been involved in some of this research, I know it is out there, but for some reason researchers and practitioners are not connecting. I found Thomas’ comment about turning down several offers for research collaborations in one week intriguing, because it suggests some practitioners are reluctant to work with researchers. The partnership model, which incorporates the views from all relevant parties (practitioners, researchers, patients, families, etc.) in establishing research goals and design, enables us to understand practitioner’s reservations, and provide opportunities to foster mutual understanding and increase collaboration.

In the last few years, there seems to be a move toward making anthropological findings more accessible to individuals in other disciplines and outside of academia. For example, several anthropological journals are now open access. Wenner Gren has an Engaged Anthropology Grant that funds past grantees of their Dissertation Fellowships to return to their fieldsites to share their findings with the community. These efforts are mirrored by the UCLA Social Science Division’s efforts to build partnerships between the social sciences with the professional
world, government agencies, and community organizations. In particular, their Dissertation Launch Program teaches graduate students to make their “thesis more relevant to understanding and solving problems of interest to a broad audience” and in doing so, it demonstrates that social science research can contribute to public good. While these large institutional efforts are great, the degree of their success is contingent on how scholars disseminate their research findings. It was only recently that I realized if I did not understand an anthropological text, it was not because the topic itself was obtuse, or that I did not have enough background, or that I was not intelligent enough. Instead, it says more about authors’ lack of reflection in thinking through the best prose to effectively communicate their ideas to an intelligent audience. After all, what is the value of a scholar’s research if people cannot apply the findings or engage with the ideas, because they cannot be comprehended?
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