

The Illness, Stigma, Culture, or Immigration? Burdens on Chinese American Caregivers of Patients With Schizophrenia

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Abstract

In this study, the author investigates the burden of 30 Chinese American caregivers of patients with schizophrenia using both quantitative and qualitative data. The relatives experienced enormous burden because of being intensely involved in patient care. Burdens were strongly positively related to family conflicts. In the literature, conflicts among caregivers have rarely been examined, but these conflicts seem particularly important to Chinese families because of the intense involvement of more than 1 member in caregiving. The significant relationship between length of stay in the United States and burden is perhaps related to caregivers' sense of mastery in language and knowledge of community resources in coping with stress.

THE ENORMOUS BURDEN involved in taking care of a family member suffering from a severe and persistent mental illness such as schizophrenia has been well documented (Cook, 1988; Greenberg, Greenley, McKee, Brown, & Griffin-Francell, 1993; Hatfield, 1978; Lefley, 1996, 1998; Thompson & Doll, 1982; Winefield & Harvey, 1994). The stigma attached to mental illness and the practical strains involved in caring for a patient are significant sources of stress. Minority families with a mentally ill relative experience double stigma: from both the illness and their minority status (Guarnaccia, Parra, Deschamps, Milstein, & Argiles, 1992). In addition to social stigma, cultural and immigration factors influence minority families' caregiving experience through their perception of the illness, the availability of family support, coping resources and strategies, and their involvement in caregiving. All of these factors affect their sense of burden (Guarnaccia et

al., 1992; Guarnaccia & Parra, 1996; Kung, 2001; Solomon, 1998). In the United States, few researchers have reported on the unique burdens and coping strategies of minority families caring for a mentally ill member (Biegel, Johnsen, & Shafran, 1997; Guarnaccia & Parra, 1996; Horwitz & Reinhard, 1995; Lefley, 1990). Even fewer investigations have focused on Asian Americans. Because Asian Americans are a growing population with an increase of 72% in the past decade (U.S. Census Bureau, 2002), their experience deserves attention. In this study, I examine the burdens experienced by caregivers of schizophrenic patients of Chinese descent, the largest ethnic group within the Asian American population (U.S. Census Bureau, 2002). The investigation of a specific ethnic group is in response to the increasing recognition of variations in culture and premigration experience within a given race (Neighbors, 1990; Uba, 1994).

Literature Review

Literature on caregivers of mentally ill patients generally distinguishes between objective and subjective burden. *Objective burden* is defined as readily verifiable behavioral phenomena such as patients' disruptive behaviors and negative symptoms, as well as disrupted lives of caregivers and families in terms of domestic routine, social and leisure activities, social isolation, and financial and employment difficulties (Bulger, Wandersman, & Goldman, 1993; Greenberg et al., 1993; Kuipers, 1993). *Subjective burden*, in contrast, refers to the emotional reactions of caregiving such as worry, anxiety, sadness, resentment, difficulty sleeping, guilt, shame, stigma, fear, grief, loss, anger, and rejection (Bulger et al., 1993; Greenberg et al., 1993; Kuipers, 1993).

A culture's definition, attribution, and expected treatment of mental illness can exacerbate or reduce a caregiver's experience of burden (Kennedy, 1973; Kleinman, 1980; Lefley, 1998; Tseng, 2001). These values can influence caregivers' perceptions of patients' neediness, and thus the amount of help given; the cause of illness and controllability of symptoms, and thus the level of sympathy or tolerance; and the stigma attached, and thus their relation to the outside world.

Involvement of Caregivers

Given the sociocentric values and centrality of family in traditional Chinese culture, caregivers are likely to be very involved in helping a mentally ill family member (Kung 2001; Lin & Kleinman, 1988; Pearson, 1993). It has been empirically shown that caregivers of Asian Americans are very involved in patients' treatment process, including escorting patients to clinic visits (Lin, Miller, Poland, Nuccia, & Yamaguchi, 1991). Studies in China also demonstrate the close involvement of families who were expected by the service providers to stay in the hospital to help care for their mentally ill members (Pearson, 1993). This expectation partly reflects the inadequate Chinese health care system and partly the assumed family responsibility in patient care. The intense involvement could aggregate caregivers' objective burden. Yet, because taking care of one's own family is such a natural responsibility in the culture, the social expectation might also reduce feelings of resentment (Miller, 1994). It has been suggested that caregiving is so integral to the role of minorities and women that it is not experienced as burden, not even an objective burden (Guarnaccia et al., 1992). However, for immigrant families who have limited support and resources, caregiving can be very trying. Given Chinese caregivers' strong sense of obligation toward their ill relatives, they may feel trapped, helpless, and frustrated (Kung, 2001).

Family Conflict

Because Chinese families are likely to be intensely involved with patient care, conflicts may arise between patients and caregivers as a result of differences in opinion

about what is best for the patient and the rest of the family. In China, allocation of family resources to help the patient has been found to cause strain among family members (Phillips, 1993). Because of Chinese culture's emphasis on interpersonal harmony (Gabrenya & Hwang, 1996), such conflicts may cause extra subjective burden to caregivers. Cheung (1986) noted that Chinese families in Hong Kong were distressed by behaviors displayed by schizophrenic patients that disrupted harmony.

Social Stigma and Social Support

The social stigma related to mental illness is widely recognized as a source of burden to caregivers (Greenberg et al., 1993; Link & Cullen, 1990). Not only does stigma directly increase the subjective burden, it also lowers access to social support, resources, and opportunities, leading to social isolation and thus greater objective burden (Corrigan & Penn, 1999; Penn & Martin, 1998). The sociocentric shame-based Chinese culture, which emphasizes family honor and dreads the "loss of face," is particularly sensitive to such stigma (Sue, 1994; Uba, 1994). In addition, the notions of "genetic taint" (Pearson, 1993) and "bad seed" (Sue & Morishima, 1982) raise concern over the marriageability of patients and their family members, which may lead to careful guarding of the illness as a family secret, thus reducing social support. For immigrant families with an already curtailed social network, this could further limit their resources. A study of caregivers in Singapore revealed that Chinese, compared with the native Malays, have less and often insufficient social support (Bentelspacher, Chitran, & Rahman, 1994).

Caregivers' Sense of Mastery

Caregivers' sense of mastery or personal control over the mentally ill patients' condition was found to be highly predictive of their distress, because such secondary appraisal overrode the effects of objective burdens imposed by the illness in primary appraisal (Perlick et al., 1999). This means that caregivers' perception of coping resources is important in affecting their burden. Most immigrant families, compared with natives, have less social support, knowledge of community resources, and financial resources. When further restricted by language barriers and a mistrust of officials, they may feel more helpless and burdened by caregiving (Guarnaccia et al., 1992; Lam, Chan, & Leff, 1995). The cultural tendency of Chinese to refrain from seeking help outside the family (Leong, 1986; Sue, 1994) may further limit their coping alternatives, thereby increasing caregiver burden.

Perception of Patients' Control

Caregivers' perception of patients' control over their symptoms can affect a household's climate (Hooley, 1987), and thus subjective burden. Families tend to be more

critical and hostile in responding to schizophrenic patients' symptomatic behaviors, especially negative symptoms, when they seem to be within patients' volitional control. Such behaviors are perceived as deliberate attempts to irritate caregivers and the responsibility or blame is placed on the patients (Lopez, Nelson, Snyder, & Mintz, 1999; Provencher & Fincham, 2000; Weisman, Nuechterlein, Goldstein, & Snyder, 1998). Caregivers' belief that patients could control their symptoms aggravates the caregivers' burden, which springs from their sense of helplessness and rage (Perlick et al., 1999). Given the high level of involvement, strong sense of obligation, and the intense objective burden among Chinese caregivers, the belief that patients are in control of their symptoms is likely to cause even greater subjective burden.

Expectations of Patients' Role Performance

It has been suggested that lower expectations of individuals' performance in some minority groups leads to less disappointment when there is an aborted academic and career aspiration because of an illness (Angel & Angel, 1993; Horwitz & Reinhard, 1995). This, however, may not apply to Chinese families. Academic and occupational achievements are perceived as channels to elevate individual and family status in the Asian culture, and failure can be perceived as bringing shame to the whole family (Uba, 1994). Thus, Chinese families are likely to have a greater sense of shame or chronic sorrow over the permanent loss of patients' capacities, such as holding a job. In fact, a study of caregivers in Singapore revealed that patients' lack of steady employment is a chronic source of frustration and tension to Chinese families (Bentelspacher et al., 1994).

Aims of the Study

In this explorative study of Chinese American caregivers of patients suffering from schizophrenia, I investigate the source and extent of burden in caregiving as well as factors that affect the burdens. The modulating effects of Chinese cultural values and immigration will be closely examined. I aim to provide some hints to mental health professionals to help them attain a better understanding of and thus alliance with caregivers and offer some directions for researchers on future investigations of their experience.

Research Method

Recruitment of Respondents

This study was conducted between 1998 and 1999; participants were 30 Chinese Americans who had relatives with schizophrenia. Using convenience sampling, I recruited 23 respondents through three mental health agencies serving mainly Asian clients, 3 respondents from two private

Chinese psychiatrists, and 4 respondents from the National Alliance of the Mentally Ill. For each patient, the referrer invited 1 caregiver closely involved in patients' care in daily living (though not necessarily living with them) to participate. All were asked to provide information on their beliefs, stress, and coping in relation to caregiving with an aim to develop culturally sensitive services. Informed consents were obtained from the respondents. All patients and respondents were over 18 years old.

Data Collection Procedures

Respondents were given the option of being interviewed at their homes, mental health agencies, or public places such as restaurants or parks. In addition to me, five trained interviewers were involved, all of whom were proficient in Chinese (Mandarin or Cantonese) and English and were either master's social work students or had a graduate degree in humanities. The interviewers received over 24 hr of training, including lectures, discussion, role-playing, and trial interviews with nonrespondents. The scales and open-ended questions were administered in about 2 hr in the respondents' choice of language and dialect; 14 chose Cantonese, 9 used Mandarin, and 7 used English.

Instruments

The following standardized scales were used:

1. *Burden Assessment Scale* (BAS; Reinhard et al., 1994). This 19-item scale assesses both objective and subjective burdens of caregiving experienced in the past 12 months. The 10 objective burden items include financial problems, limitations on personal activities and social interactions, and household disruption. Subjective burdens include shame, stigma, guilt, resentment, grief, and worry. Higher scores indicate greater burden. Reliability alpha reported elsewhere ranged from .89 to .91 (Reinhard, Gubman, Horwitz, & Minsky, 1994). Alpha for the whole scale was similar in this study ($\alpha = .89$), but alphas were lower separately for objective and subjective burden ($\alpha = .84$ and $.68$, respectively). Mean scores of the whole scale and subscales were used in the analyses.
2. *Perceived Social Support for Caregiving and Social Conflict Scales* (Goodman, 1991). This 9-item scale reflects caregivers' perception of availability and use of social support from nonprofessionals. The types of support include understanding, information, advice, insight, emotional control, universality, expression, modeling, and support satisfaction. The 3-item social conflict scale reflects quarrels, conflict, and lack of approval in caregiving. Higher scores indicate lower social support, but higher social conflict. Previously reported reliability alphas for social support and conflict were $.84$ and $.72$, respectively (Goodman, 1991), and alphas for this study were $.80$ and $.78$, respectively.

3. *Family Coping Index* (McCubbin, Thompson, & Elver, 1996). This 24-item scale was originally divided into three subscales: family's tendency to seek professional help and spiritual guidance, help from relatives and friends, and use of self-affirmation on family's confidence. Because of the different tendencies among Chinese people in using professional and spiritual help as reflected in the nonsignificant correlation between the means of the two sets of items ($r = .16$, $p = .40$), they were separated into two subscales. Sources of professional help include community agencies and programs, family doctors, and professional counseling. Spiritual coping includes going to a church service, Buddhist or Taoist temples, and so forth; participating in religious activities; and seeking advice from religious leaders. Seeking help from relatives, friends, and neighbors includes sharing difficulties and concerns; seeking information, advice, and encouragement; receiving favors and assistance; and getting together with them. Affirming family's confidence includes reassuring its own strength and power to solve problems, facing problems "head-on," accepting difficulties, redefining problems positively, and having faith in a higher power. Higher scores indicate greater tendency to use the coping strategy. The original test-retest reliability ranged from .41 to .57 (McCubbin et al., 1996).
4. *Suinn-Lew Asian Self-Identity and Acculturation Scale* (SL-Asia; Suinn, Ahuna, & Khoo, 1992). The shortened version of this scale consists of 10 items tapping the respondents' language use, acquaintances, generational status, place where they grew up, food, festival celebration, values, and self-identification. Higher scores indicate higher acculturation. The alpha of the original scale was .91 (Suinn et al., 1992), and for the shortened version here, it is .75. The mean score was used in the analyses.
5. *Perceived Causes of Mental Illness Scale* (Krauss, 1988). This 23-item scale captures the respondents' attribution of mental illness to biological, stress-related, psychodynamic, moral, and supernatural causes. The subscale used in this discussion pertains to moral causes, which consist of four items attributing patients' problematic behaviors to their laziness, current or past use of street drugs or alcohol, manipulation of others, and volitional control over symptoms. Higher scores indicate greater tendencies to subscribe to such beliefs. This scale was administered among Chinese caregivers in Taiwan and had a reliability alpha of .79 (Yang, Hsieh, Wu, Yeh, & Chen, 1999). Alpha in this study was .80 for the whole scale and .60 for the moral attribution subscale. The mean subscale score was used in the analyses.

Patients' use of various types of social services in the past 12 months was also examined; these services included

pharmacological treatment, individual and family counseling, social skills training, job training, day treatment, social club for recovering mental patients, and referral for social services.

All the scales and checklists were available or developed in English and then translated into Chinese by two bilingual translators using back translation. It has been documented that individuals from immigrant and minority groups may not be familiar with the scaling format of instruments (Land & Hudson, 1997; Takeuchi & Young, 1994). All the instruments used a 4-point Likert-type scale (1–4) except the SL-Asia Scale, for which 5-point scales were retained because of the specific wording of the responses. The standardized gradation across instruments aimed at making it easier to choose a response. In addition, large laminated charts that indicated the different levels of choices were presented to respondents to help them pick a response.

Narrative data were also collected on open-ended questions inquiring into caregivers' concerns about the patients' problems, major problems the illness caused for the family, and the description of patients' problems to others. To avoid respondents' potential discomfort with audiotaping, their responses were summarized in writing by the interviewers during the interview. Actual wordings of respondents were used as far as possible, and translations, when applicable, were done by me.

Data Analysis

For the quantitative data, the dependent variable was caregivers' burden as captured by the mean objective, subjective, and total scores of the BAS. Descriptive statistics were calculated. Pearson's correlations and t tests were computed to examine the relationships between burden and patients' gender, chronicity of illness, employment status, respondents' socioeconomic variables, relationship with patient, involvement in caregiving, residence with patients, social support and conflicts in caregiving, acculturation, length of stay in the United States, moral attribution of the illness, coping patterns, and services used. Because clear directions of the relationships were hypothesized, one-tailed tests were used. Given the small sample size, stepwise regressions were employed to detect significant predictors of the various burdens, and trend significance at the .10 level was also reported. It must be pointed out that because of the convenience sampling method used and the small sample size, the statistical analyses employed could only explore relationships among variables within the sample instead of for inference to the population.

Narrative data from the open-ended questions were tabulated, categories were devised, and responses were coded and counted. In coding the responses, I considered the total context of each respondent's narrative information. In addition to me, a master's student in social work helped derive the categories. I alone categorized the responses.

Results

Characteristics of the Respondents and Patients

Of the 30 respondents, 18 (60.0%) were patients' parents (11 fathers), 6 (20.0%) were siblings (5 brothers), 2 were spouses (6.7%, of both genders), and 2 were sons (6.7%). The mean age of the sample was 57.4 ($SD = 15.7$). Two thirds of the respondents were male. Twenty-two respondents (73.3%) lived with the patient, and 26 patients (86.7%) lived with immediate (25) or extended families (1).

Close to half (43.0%) of the respondents were retired, and about a quarter (23.0%) worked full-time. Overall, the annual family income was relatively low, with 56.7% reporting an income of less than \$35,000. Although these families might live on savings not accounted for here, the low income and low education level (half had no more than a high school education) placed the majority of respondents in the lower socioeconomic stratum. Only 3 were born in the United States (10%); the rest were immigrants born in Mainland China (53.3%), Taiwan (6.7%), Hong Kong (3.3%), or Southeast Asia (20%).

More than half (56.7%) of the patients were female. The average age was 40, with a range of 26 to 80. The mean age at the onset of illness was 24, and the average illness history was 16 years ($SD = 9.6$). None of the patients was in full-time employment, though 2 worked part-time and 2 were full-time students; thus the sample consisted of caregivers of relatively disabled patients.

Caregivers' Burdens

On the basis of the 4-point scale of the BAS, the mean composite score for subjective burden was slightly higher than the same score for objective burden: 2.25 ($SD = 0.56$) and 2.11 ($SD = 0.66$), respectively. The mean total burden was 2.18 ($SD = 0.55$). Half of the respondents had an average objective burden score above 2, indicating burdens beyond "a little;" for subjective burden, 70.0% had scores greater than 2, and for total burden, 56.7% had scores greater than 2. Among the subscale items, the highest three mean scores for subjective burden were "worry about patients' future" (3.30, $SD = 0.95$), "upset about patients' change" (2.83, $SD = 1.20$), and "feel trapped by care-giving role" (2.63, $SD = 1.20$). The highest mean scores for objective burden were "upset of household routine" (2.40, $SD = 1.16$), "cut down on leisure time" (2.34, $SD = 1.14$), and "change of personal plans" (2.32, $SD = 1.19$). Subjective and objective burdens were significantly correlated ($r = .62, p < .001$).

The narrative data on burden were based on responses to three open-ended questions: "What are your concerns about (patient)'s problem?" "What are the major problems that (patient)'s mental illness has caused for your family?" and "How would you describe (patient)'s problem to others?" The types of burdens reported are categorized and

summarized in Table 1. The responses validated some of the quantitative findings. For subjective burden, worries about patients' future care stood out distinctly, being stated by two thirds of the respondents. Parents, in particular, were most concerned about where their ill children would reside and who would care for them when the parents were gone.

Table 1. Caregivers' Burdens Based on Narrative Data ($N = 30$)

Type of burden	Number	%
Subjective burden		
Worries: patients' future care	20	66.7
Patients getting into trouble outside of home	8	26.7
Condition of patients' illness	8	26.7
Effects of medication	6	20.0
Genetic implications on relatives	3	10.0
Distress, frustration, and resentment	14	46.7
Family conflicts	11	36.7
Stigma and shame	6	20.0
Sadness and disappointment	4	13.3
Helplessness	4	13.3
Guilt	2	6.7
Objective burden		
Patients' disturbing and bizarre behaviors	16	53.3
Patients' dependence requiring constant care	15	50.0
Practical strains (e.g., financial, social, temporal, and legal)	8	26.7
Patients' negative symptoms	4	13.3

Note. Percentages total more than 100 because of the multiple burdens respondents reported.

Over one quarter of the respondents (27%) were worried that patients might get into trouble outside the home. This concern caused both subjective and objective burdens. The relatives tried to keep the patients accompanied at all times. Some designated a family member to keep a close watch, which thus reduced family income through loss of gainful employment and seriously curtailed the caregivers' social life. Caregivers also worried about the condition of patients' illness, such as when a relapse might occur and whether the illness had deteriorated when patients' behaviors became increasingly disruptive. These worries also affected their ability to concentrate at work. Six caregivers (20%) had concerns about patients' medication, such as long-term side effects, addictiveness, and impact on patients' reproductive functions. Three (10%) worried about genetic implications of the illness on siblings and children.

The strongest objective burden, expressed by more than half (53.5%) of the caregivers, was patients' disturbing and bizarre behaviors. Half of the respondents also perceived patients as very dependent, demanding, and constantly needy. This is reflected by the following statements: "We have to take care of him all the time," "He can't take care

of himself on his day-to-day needs,” “Bothers the family on big and small issues,” “Demands to be listened to,” and “Stops whatever the family is doing if it bothers her.” A few mentioned that the patient easily threw tantrums and “nag[ged] like a child.” Relatives also felt the need to closely supervise patients at home lest they harm themselves or others, such as by carelessly causing a fire. Over half of the caregivers mentioned being bothered by patients’ positive symptoms such as delusions and hallucination, four (13.3%) involving threats of violence. Four were bothered by the patients’ negative symptoms, such as poor hygiene and low motivation to help out at home and to acquire a skill to earn a living.

Given the intensity of familial involvement, it was no surprise that close to half (46.7%) of the respondents reported feeling distressed, frustrated, and resentful. This corresponds to the quantitative finding that the “feeling trapped” item had the third highest average score on subjective burden. A father recalled an experience in which the family went on a 3-week vacation with the patient: “We never had a meal with all of us being together throughout the trip because when she wanted something all of a sudden, someone in the family had to go with her; our whole plan was disrupted.” Another father mentioned feeling trapped: “It is painful and difficult to live with him, but we can’t get rid of him. We have to be with him and accept his abnormal behaviors.”

Family conflicts in caregiving were another important source of stress and had implications for both objective and subjective burdens. More than one third of caregivers mentioned such conflicts. When conflicts arose between patients and certain family members, others felt trapped, such as parents feeling torn between children. Other conflicts resulted from different opinions over how to handle patients. Some respondents complained that other family members lacked understanding of patients’ uncontrollable behaviors, thus aggravating patients’ problems by their reactions. Some lamented that there was “no peace and harmony in the house,” and “the mood of the family was much changed.”

The subjective burden of stigma and shame was indicated by 6 (20.0%) respondents. They feared “rejection from relatives and society” and tended to hide the illness. In response to the question regarding how they would describe the patients’ problems to others, 17 (56.7%) employed minimizing statements such as the patients being “in unstable mood,” “not in good spirit,” “lacking sleep,” “under too much pressure,” “depressed, dependent, having low self-esteem,” “having confused and distorted thoughts, thinking too much,” and “lacking self control.” Four (13.3%) respondents candidly admitted that they would not reveal the illness to others, especially distant relatives and friends, because “they can’t help,” and “it’s personal.” The fear of stigma led to social isolation

as families refrained from inviting friends home or from going out to avoid public embarrassment over the patients’ bizarre behaviors.

Sadness and disappointment about patients’ illness were expressed by 4 respondents (13.3%). Four respondents reported a sense of helplessness over not knowing how to accommodate and deal with patients’ symptoms, interact with them effectively, and help.

Despite the fact that the open-ended questions focused on the burdens and difficulties of caregiving, 3 respondents (10%) showed a very accepting attitude toward the patients and indicated some gratification in giving care. Some remarks included, “Because of love, I don’t see taking care of my brother as difficult,” “It doesn’t bother me much, because I have responsibilities to my uncle. If I can do something for him, I’m happy,” and “I don’t feel bothered at all, just a little sad. He is our own.”

Bivariate Relationships With Burden

Results of *t* tests and Pearson’s correlations between burden and other variables are reported in Tables 2 and 3. Giving care to male patients caused a greater burden than giving care to female patients. This difference is significant for objective and total burden, whereas only trend significance was noted for subjective burden. Higher objective burden (at the trend level) was experienced by female versus male caregivers and parents versus relatives, but no difference was found for subjective burden. Caregivers living with patients showed higher subjective burden (at trend level) but not objective burden. Involvement of patients in school or work did not significantly reduce caregiver burden, which was an unexpected result.

As expected, respondents’ involvement in caregiving based on residence with patients, frequency of contacts, and provision of day-to-day care was positively related to both objective and subjective burden. As hypothesized, conflict in caregiving positively correlated with burden, but counterintuitively, the relationship was much stronger with objective ($r = .53, p < .01$) than with subjective burden ($r = .23, p < .10$). Caregivers’ perceived peer support, number of services used in the past 12 months, and coping patterns in using help from various sources (including self-affirmation) were not significantly related to either objective or subjective burden. Unlike acculturation level, the number of years caregivers had stayed in the United States were significantly related to both objective and subjective burden.

The chronicity of the illness was negatively related to objective and subjective burden. That is, longer illness was associated with less burden. Greater belief in patients’ responsibility for the symptoms and illness (moral attributions) was positively related to objective burden at the trend level, but not to subjective burden. Finally, higher household income was negatively related to both objective and subjective burden.

Table 2. Results of *t* Tests on Burden

Characteristics of Respondents and Patients	<i>M</i> objective burden	<i>t</i>	<i>M</i> subjective burden	<i>t</i>	Total BAS	<i>t</i>
Respondent's sex		-1.50 [†]		-1.01		-1.46 [†]
Male	1.99		2.18		2.08	
Female	2.36		2.40		2.39	
Relationship		-1.66 [†]		-1.00		-1.42 [†]
Parents	2.25		2.33		2.30	
Others	1.91		2.12		2.01	
Residence		-0.57		-1.4 [†]		-1.1
With patients	2.15		2.34		2.25	
Not with patients	2.00		2.01		2.00	
Patient's sex		2.05*		1.61 [†]		2.09*
Male	2.38		2.43		2.41	
Female	1.91		2.11		2.01	
Patient's employment		-0.37		0.35		-0.02
Employed	2.17		2.20		2.19	
Not employed	2.08		2.28		2.18	

Note. BAS = Burden Assessment Scale. All *p* values are one-tailed.
[†]*p* < .10. **p* < .05.

Table 3. Pearson's Correlations With Burden

Characteristics of Respondents	Objective burden	Subjective burden	Total BAS
Respondent's involvement	.37*	.38*	.42**
Social support	-.15	.16	-.01
Number of service used	-.19	-.16	-.19
Social conflict	.53**	.23 [†]	.45**
Chronicity of patients' illness	-.43**	-.25 [†]	-.39*
Years in United States	-.47**	-.45**	-.52**
Acculturation	-.16	-.18	-.19
Household income	-.42**	-.30 [†]	-.41*
Years of education	.25 [†]	.05	.18
Moral attribution of symptom/illness	.26 [†]	.15	.23 [†]
Use of relatives' and friends' help	-.02	-.14	-.09
Use of professional help	-.11	.05	-.04
Use of spiritual help	.05	-.25	-.10
Self-affirmation	.02	.02	.02

Note. BAS = Burden Assessment Scale. All *p* values are one-tailed.
[†]*p* ≤ .10. **p* ≤ .05. ***p* ≤ .01.

Explanatory Models of Burdens

The results of stepwise regressions in predicting burdens are reported in Table 4. For objective burden, four variables emerged as significant, $F(4, 20) = 7.34$, $p = .001$. They were social conflict, accounting for the greatest variance (28%), followed by household income (13%), number of services used (11%), and relatives' and friends' help (6%). Together, they explained as much as 58% of the variance. The length

of stay in the United States stood out as the only significant predictor of subjective burden, $F(1, 23) = 6.16$, $p = .02$, explaining 20% of the variance.

For total burden, significant predictors in the model again included length of stay in the United States, which explained 24% of the variance, followed by parents versus others as caregivers, explaining another 11%, and a further 6% by years of education. The whole model explained 41% of the variance, $F(3, 21) = 6.67$, $p = .002$. Somewhat unexpectedly, more educated caregivers experienced greater total burden, though it accounted for a small variance.

Discussion

As expected, culture shaped the caregiving experiences of this sample of Chinese American relatives of schizophrenic patients. The high involvement of families in caregiving and the important impact of family conflict strongly affected burden. Immigration status also seemed to exacerbate the burden experienced.

Involvement of Caregivers and Culture

This study indicates that the caregivers experienced intense objective and subjective burdens. Their intense involvement in caregiving, especially close supervision of the patients, is impressive. The 86.7% of patients in this sample residing with families is comparable to the 79.0% and 90.0% reported in studies in China (Phillips, 1993; Phillips, Li, Stroup, & Xin, 2000), though it is in contrast to the 23.7% (Greenberg, Greenley, & Benedict, 1994) or 60% (Bulger et al., 1993) noted in other studies in the United States. This

Table 4. Stepwise Regressions on Objective Burden, Subjective Burden, and Total Burden

Predictors	Objective burden			Subjective burden			Total BAS		
	Standardized β	Model summary	R^2 change	Standardized β	Model summary	R^2 change	Standardized β	Model summary	R^2 change
Social conflict	.59***		.28						
Household income	-.47**		.13						
Number of services used	-.45*		.11						
Use of relatives' and friends' help	.28		.06						
Years in United States				-.45*		.20	-.61***		.24
Parents as caregivers							.36*		.11
Years of education							.38*		.06
<i>F</i> value		7.34			6.16			6.67	
<i>p</i> value		.001			.02			.002	
Degrees of freedom		20			23			21	
Model R^2		.58			.20			.41	

Note. BAS = Burden Assessment Scale.

Only significant betas are included in the regression models.

† $p \leq .10$. * $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

difference reflects the centrality of family and familial obligations in Chinese culture (Miller, 1994).

The tenacity of Chinese American families in providing care for the patients despite immense subjective and objective burden was striking. This should be considered a merit of the culture because family involvement in caregiving is noted to correlate with positive patient outcome (Lin et al., 1991). However, the literature on expressed emotions has indicated that overinvolvement of caregivers predicts patient relapse (e.g., Kavanagh, 1992; Leff & Vaughn, 1985). The extent to which family participation is considered overinvolvement has to be considered within a sociocultural context as expectations of autonomy and independence differ between cultures. In the general population in China, it is not unusual for unmarried adults to live with their parents. For ill children, even unmarried adults, Chinese parents are expected to act as a buffer against the outside world, and parents' self sacrificing and devoted behaviors are considered part of their responsibilities (Phillips, 1993). In addition to the subjective preference of families, the lack of adequate residential facilities in China also explains patients' high coresidence rate with families. This may be similar for Chinese American patients because of a lack of bilingual and culturally sensitive residential facilities. This service gap is reflected in parents' great concern over patients' future residence and care when they pass on. Although one should withhold judgment on caregivers' overinvolvement, these findings should alert practitioners regarding families' involvement that hampers the well-being of both patients and caregivers.

The higher proportion of male caregivers (66.7%) in the sample was contrary to what has been reported in the literature (e.g., Bulger et al., 1993; Guarnaccia & Parra, 1996).

This may be related to a cultural norm of Chinese families, where men interact with the outside world, such as meeting with interviewers, while women take care of domestic affairs, including caregiving (Honig & Hershatter, 1988). In fact, over half (56.7%) of the primary caregivers in this study were women. Nevertheless, though some of these male respondents were not primary caregivers, they had to be very involved in patients' day-to-day care to meet the inclusion criteria. Their involvement was made easier with their availability because 55% of them were retired. The presence of nonprimary caregivers who were closely involved in caregiving points to the likelihood that in Chinese American families more than one relative is intensely involved in caregiving.

Women and parents experienced higher objective burden at the trend level than other caregivers; this finding is likely due to their greater involvement in both psychological and practical patient care (Cook, 1988; Horwitz & Reinhard, 1995). The finding that caregiving to male patients is related to greater objective and subjective burden than female patients is perhaps due to the greater threat of violence in men and thus the need for closer supervision.

Family Conflict and Burden

The need to rally around the immediate family in the intensive care of the patient seems to cause great family conflict. The difficulty is likely to be exacerbated for a few reasons: (a) The social stigma of mental illness in Chinese culture restricts familial social support as do severed ties resulting from migration; (b) Chinese families prefer to seek help within a selected inner circle because of fear of "loss of face" (Kung, 2001); (c) the varying degree of understanding and acceptance of schizophrenia among family members

causes conflicts in dealing with patients; (d) Chinese immigrants mistrust officials (Lam et al., 1995); and (e) the shortage of bilingual and culturally sensitive programs reduces the use of social services (Guarnaccia et al., 1992), thus intensifying family strain.

The high family conflicts coincided with findings from studies in China, where families with a schizophrenic patient indicated higher conflict, lower cohesion, and poorer adaptability compared with control families (Phillips, West, Shen, & Zheng, 1998). Given the Confucian value that emphasizes social cohesion and family harmony (Gabrenya & Hwang, 1996), these conflicts may cause great subjective burden to caregivers. However, this was not evidenced in the findings. Instead, objective burden was exacerbated with increase in family conflict. This was perhaps due to the practical difficulty in coordinating helping efforts, especially in supervising patients, when family conflicts were high.

Although some Chinese caregivers chose to become emotionally disengaged from the patient (Phillips et al., 1998), this coping strategy does not seem desirable because they may still feel trapped by caregiving obligations. Moreover, studies have shown that high emotional intimacy with patients is related to low burden and high gratification in caregiving (Bulger et al., 1993). This finding is reflected in the few positive comments in this study.

From the significant findings of the explanatory model for objective burdens, it seems that familial resources, be they tangible (income) or intangible (family harmony or low family conflict), are important in alleviating objective burden. External support from friends, relatives, and social services, which were nonsignificant in bivariate analyses, became significant in reducing burden when effects of internal resources were controlled.

Burden and Immigrant Status

The immigrant status of Chinese American caregivers seems to have intensified their sense of obligation to protect ill family members. Their great fear of the patient getting into trouble outside the home may reflect a sense of insecurity in a foreign land. Indeed, some caregivers reported that hostile encounters patients experienced outside of their homes exacerbated their symptoms, and for some, had legal ramifications. Thus, families felt the need to keep close watch over the patient, thereby draining their physical, temporal, financial, and emotional resources. In this study, more respondents reported concerns over patients' positive psychotic symptoms than negative withdrawn symptoms, which contrasted with findings elsewhere (e.g. Bentelspacher et al., 1994). This may be partly explained by fear of consequences from uncontrollable positive symptoms.

The finding that caregivers' length of stay in the United States reduced subjective and total burden is likely to be related to better language skills and knowledge of social sys-

tems and resources. This speaks to the importance of secondary appraisal of the perceived sense of mastery and control in coping with stress (Perlick et al., 1999). A lower sense of mastery often leads to the fear of what might happen next (Eakes, 1995). Language barriers and unfamiliarity with the social system would make it harder for caregivers to negotiate with the environment on behalf of their ill relatives, thus exacerbating their fears and worries. The significant negative relationship between the chronicity of patients' illness and objective burden is contrary to findings in the literature (e.g., Noh & Turner, 1987). This may be explained by caregivers' greater sense of control and familiarity with social resources. In fact, the chronicity of illness was significantly positively correlated with respondents' length of stay in the U.S. ($r = .46, p = .006$, one-tailed). However, the nonsignificant prediction of burden by acculturation indicated that integration into the American lifestyle and values may not be necessary to reduce the burden of care.

Strengths and Limitations of the Study

This is one of the first few reported studies of the burdens of caregivers of schizophrenic patients from one ethnic group instead of a race in the United States. It highlights the impact of idiosyncratic cultural values and the immigrant experience of Chinese Americans on caregiving. Because finding respondents in Asian mental health research is often difficult (S. Sue & N. Zane, personal communication, July 2002), this study is an effortful attempt to reach out to this sensitive clientele. Because of the small sample size and the use of convenience sampling, the findings are only expected to shed light on some possible directions for future research and give hints for practitioners; generalization to the Chinese American population is limited. Although the inclusion criteria restricted respondents to only those who were closely involved in patients' day-to-day care, the varying relationships of respondents with patients was a concern. The inclusion of the variable distinguishing between parents and nonparents as a predictor in the explanatory model was an attempt to address this limitation. Because respondents were recruited as volunteers, those who participated in the study were likely to be biased toward greater involvement in caregiving.

Narrative data gathered from open-ended questions helped to enrich the quantitative data by giving a fuller picture of caregivers' experience. In this study, I attempted to reduce the unfamiliarity of minority respondents with Likert-type scale measurements by using visual aids and standardizing responses to 4-point gradations (except for the SL-Asia Scale), making it easier for respondents to choose accurately. However, because two of the original measures used 5-point scales, the comparability of the findings with other studies was reduced.

Implications of Findings

Implications for Research

It is important to note that the issue of conflicts among caregivers is rarely addressed in Western literature of schizophrenia studies, including those in the United States and Britain. It is more often examined in studies of more traditional cultures, for example, China (Phillips, 1993) and Turkey (Karanci, 1995). It seems that more family members are involved in caregiving in more traditional cultures. Because the family instead of the individual is the unit of caregiving in Chinese culture, future studies of these caregivers should attend to the family as the unit of study. Furthermore, although the narrative data gave some hints on the causes of conflicts among family members over the patients, further examination of how the conflicts arise and their impact on family and patient functioning is necessary. Studies on expressed emotions among families with schizophrenic patients have been focused on the extent to which critical comments and overinvolvement affect patients' treatment outcome (e.g., Kavanagh, 1992; Leff & Vaughn, 1985). Given the emphasis on family harmony and cohesion in Chinese culture, it is worth examining how family conflicts affect patient functioning. Finally, because Chinese culture demands intense care from relatives of their ill members, it is important to examine what factors lead to higher gratification and reward in the caregiving process. These factors have been fruitfully examined in studies with other populations (e.g., Bulger et al., 1993; Greenberg et al., 1994; Winefield & Harvey, 1994).

Implications for Practice

The finding that family conflicts cause enormous burdens on caregivers suggests that these tensions need to be addressed in family interventions with Chinese Americans. It seems that family psychoeducation on the causes and course of schizophrenia and effective ways to interact with patients not only helps to dispel caregivers' sense of helplessness but also reduces their misconceptions and conflicts. Because the unit of caregiving is likely to be the family, involvement in the treatment process of other family members besides the primary caregivers is important. Given the significant impact of family conflict on caregivers' burden, the provision of clinical intervention in addition to psychoeducation is important. Families also need to be coached to maintain appropriate levels of involvement with patients in order to reduce their stress and to prevent overindulging patients, causing their overdependence. This could lead to a vicious cycle of strain and frustration for the caregivers.

Bilingual and culturally sensitive treatment programs, including day treatment and shelter workshops, may help alleviate the constant care that family members feel they have to provide. In addition, bilingual assisted-living

facilities are helpful to ease caregivers' worries about long-term future care for patients.

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