Experiences of Family Burden in Caring for the Severely Mentally Ill in a Foreign Land: A Qualitative Study of Chinese Immigrant Families in Toronto, Canada

Samuel Law[1,2] (iD), Lisa Andermann[1,2], Wendy Chow[1,2], Xing Wei Luo[3] and Xiang Wang[3]

Abstract
There is a relative dearth of qualitative studies on the actual experiences of families caring for members suffering from serious mental illness, and even less is known about disadvantaged ethnic minority immigrant families. This explorative qualitative study examines the burden experienced by 15 family members of Chinese immigrant background in Toronto, Canada. Six common themes emerged from the study: 1) significant worries about not being able to take care of ill members in the future; 2) on-going strain and changed family life; 3) pervasive social stigma, discrimination and lack of resources; 4) general appreciation of Canadian health and welfare systems and opportunities; 5) cultural factors and beliefs uniquely shape families' support and caring commitment; and 6) families find various ways to cope and help themselves. Opportunities for improved care delivery based on these understandings are discussed.

Introduction

In North America, family caregiver burden is on the rise, influenced by increasing life spans, smaller family sizes, decreases in long-term care availability, and increases in the complexity of responsibilities arising from technology and health system changes (Sales, 2003; Wirsén et al., 2017). Despite the reputation of "downward social spiral" with relationships, 83% of patients in North America with serious mental illness (SMI) such as schizophrenia have families living close by, maintain regular contact (80%), and many live with one or more family members (30–65%) (Lehman et al., 1998; Lehman & Steinwachs, 1998; Guarnaccia, 1998). In a large scale quantitative US study, Perlick et al., (2006) described four prominent components of burden found in family members caring for those with SMI: 1) difficult experience of patient problem behaviors; 2) patient impairment in activities of daily living; 3) perception of patient not being helpful; and 4) resource demands and disruptions in the caregiver's personal routine. Their further analyses showed that ethno-racial background of

being African American, when compared to Whites, was one of the strongest predictors of family burden, along with intensity of psychotic symptoms, presence of substance abuse, anti-social behavior, duration of illness, income, and education.

There is a limited number of studies on family burden that include factors such as ethnicity and immigration status. The National Alliance on Mental Illness (NAMI) Family-to-Family Education Program study found African Americans had higher levels of burden and negative caregiving experiences, and less knowledge of mental illness than their White counterparts

[1]Community Mental Health Services, Mount Sinai Hospital, Canada
[2]Department of Psychiatry, University of Toronto, Canada
[3]Medical Psychological Institute, Second Xiangya Hospital of Central South University, P.R. China

Corresponding author:
Samuel Law, University of Toronto, 30 Bond Street, Toronto, Ontario M5B 1W8, Canada.
Email: laws@smh.ca

(Smith et al., 2014). With mixed methods, Rosenfarb and colleagues (2006) found that families' perceived burden of care affected rejecting attitudes towards their ill family members, and were more common among White caregivers than their Black counterparts. Magaña et al. (2007) found that Latino families in the US experienced comparatively higher level of burden than the general population, with significantly higher depressive symptoms, which were associated with caregivers' young age, lower levels of education, and higher levels of the patients' mental illness symptoms. In general, studies found that immigrants, for a variety of reasons including a lack of access to resources, financial and language barriers, and culturally based beliefs, etc., are comparatively more involved in the caring of family members with SMI than the general population, with comparatively heightened personal costs (Awad & Voruganti, 2008; Breitborde, Lopez, Chang, Kopelowicz, & Zarate, 2009; Gater et al., 2014; Martens & Addington, 2001). Immigrant caretakers' quality of life, financial stability, increased levels of stress, anxiety, and sense of stigmatization are negatively impacted (Carretero, Garces, Rodenas, & Sanjose, 2009; Papastavrou, Charalambous Tsangari & Karayiannis, 2010), while these groups were found to be at greater risk for mental illness and substance abuse disorders themselves (DeVylder & Lukens, 2013).

Among Chinese immigrants in North America, limited studies have also shown significant concerns. In their country of origin, with kinship-centred relational structures and limited community mental health services, over 90% of patients with schizophrenia live with their families, who are often the only source of support and care (Phillips, Pearson, Li, Xu, & Yang, 2002; Tang, Leung, & Lam, 2008). Immigrants to North America from this backdrop carry with them dramatically different caretaking understandings and caretaker identities. Compared to the general population, Chinese immigrants in North America are more likely to be involved in the routine caring of ill members, have delayed help-seeking, utilize fewer services, have more involuntary admissions and longer hospitalization stays, poorer adherence with treatment, higher relapse of illness, and lower rates of follow-up (Lin & Lin, 1981; Chiu, Lebenbaum Newman Zaheer & Kurdyak, 2016; Ziguras, Klimidis, Lewis, & Stuart, 2003; Klimidis, Hsiao, & Minas, 2007). Typical explanatory hypotheses include language barriers, shortage of culturally appropriate services, poor understanding and knowledge concerning mental illness, and stigma. (Blignault, Ponzio, Rong, & Eisenbruch, 2008; Chiu et al., 2016). In depth qualitative studies on Chinese immigrants' caretaker burden are limited. A mixed methods study found cultural and immigration-related factors such as financial restraint, limited social interactions, stigma and shame related to illness, and various forms of household disruptions interacted with caregiver burden (Kung, 2003). One qualitative study of Chinese Canadian immigrant families coping with first episode psychosis found the families were more likely to hold more negative conceptions of mental illness, keep it secret from others, and blame the ill person for their illness relative to their Euro-Canadian counterparts (Ryder et al., 2000). In turn, these issues translated to reluctance and delay in seeking psychiatric treatment, more direct family care, and a higher level of family burden.

To broaden the understanding, this qualitative research aims to explore, in-depth, the lived experiences of families who care for family members with SMI, with particular attention to their prior experiences, narratives, values, expectations, and coping mechanisms. In turn, we hope to learn how to improve services for this growing, typically marginalized population.

Methods

Study overview

The main research question was: How do Chinese immigrant families understand and experience care giving when faced with socio-cultural and linguistic barriers in a new country? The development of the qualitative interview guide and data analysis were informed by constructivist grounded theory (Charmaz, 2014). In particular, the methodology helps to guide our research to explore the situations, actions, social psychological processes, and the social and cultural determinants related to the immigrant caretaking experience.

Setting

This study was conducted at the Mount Sinai Hospital Assertive Community Treatment (ACT) team, located in downtown Toronto, Ontario. Chinese immigrants constitute about 11.1% of Canadian immigrants, and patients with schizophrenia tend to live with their family, with challenges of limited education, poor English skills, and high levels of stigma (Census, 2016; Chow et al, 2010; Chiu et al, 2016). This ACT team is unique as it serves specifically ethnic minorities with SMI (Yang, et al., 2005). About 40 of the 100 ACT patients are of Chinese background. Of these, about half have close family members involved in their care.

Participants and recruitment

The inclusion criteria for family members were: 1) over 18 years of age; 2) having lived with the patient for

more than a year; 3) patient has been part of the ACT team for six months or more; 4) suffering from no active mental illness; 5) of Chinese immigrant background (i.e. those born in another country and have become citizens or permanent residents; and 6) able to provide meaningful consent. The participants were recruited using a multi-stage process involving staff identifying the participants and Research Coordinator (RC) following up. Fifteen of the 18 family members approached agreed to participate. No obvious clinical and demographic (age, gender, income level) differences were noted between the participants and those who declined. Written consent was obtained from each patient and family member. Recruitment and interviews took place between 2013 and 2015. This study was approved by the Research Ethics Board at Mount Sinai Hospital.

Data collection

Guided by literature review and input from the research team, a semi-structured qualitative interview guide was developed based on the validated Chinese version of the Family Burden Interview Schedule (FBIS) (Chien & Norman, 2004), originally developed by Pai and Kapur (1981). A semi-structured interviewing format allows an in-person, informal and open approach, yet guides the interview for known key areas of inquiry based on literature review and the main research question.

Family burden is a multifaceted subject often conceptually divided into subjective and objective dimensions (Hoenig & Hamilton, 1966; Braithwait, 1992; Schene, 1990). Subjective burden refers to a caregiver's own perceptions of distress, stigma, worrying, shame, and guilt (Maurin & Boyd, 1990), alongside burden from grief and loss, chronic strain, and empathic pain (Marsh & Johnson, 1997). Objective burden includes more external and measurable dimensions of intensity of the illness, actual tasks of care, daily living and managing problems, changes of family routine, loss of leisure and employment, and impact on finances, time, and overall qualities of health and family life (Hjarthag, Helldin, Karilampi, & Norlander, 2010; Flyckt, Lothman, Jorgensen, Rylander, & Koernig, 2013, Maurin & Boyd, 1990).

The semi-structured interview aimed to capture both dimensions. A Master's level RC, fluent in Mandarin and Cantonese conducted the interviews. All 15 interviews were concluded in a single session, either in a private setting in the community or at the ACT team office, in either Mandarin or Cantonese by the interviewee's preference, on average lasting 60 minutes. The interviews began with open-ended questions to foster rapport building and reflection. The questions were designed to be broad enough to allow a wide range of experiences to be reported beyond the basic "sensitizing" dimensions, and emphasized learning the interviewees' meanings and experiences. All interviews were audiotaped and transcribed in Chinese verbatim by the RC who carried out the interviews. We also collected sociodemographic data of the participants in person and related patient demographic and diagnostic information from a chart review.

Data analysis

The RC checked for accuracy of the transcripts and then independently and sequentially open coded and wrote memos for the transcripts. To enhance cultural and linguistic interpretations of the information, a second analyst (SL) also reviewed the transcripts and made codes and memos. These codes and memos were then reviewed and discussed together to enhance the completeness and credibility of the analyses. Notes on the discussions were also taken to inform the ongoing coding process. The coding process was concurrent with the data collection as analyses performed during this time period were helpful to inform "sensitizing concepts" in later interviews. As analyses continued, analytic memos were generated to capture the key issues relevant to each code, and earlier transcripts were re-read and re-coded as necessary to capture newly emerging themes and concepts. The basic "sensitizing" concepts (e.g. financial impact, quality of life) found in the interview questions were used to inform initial thematic coding structure, while broader and novel concepts and themes were actively pursued. Frequent and salient codes were identified; thematically linked codes were clustered to aid the development of distinct and informative thematic categories. Data saturation was determined by the research team when no more new codes or categories emerged. In general, the two analysts were complementing each other and achieved the desired goals for completeness and gaining depth in the analyses. Disagreements were generally minor; when they occurred, consensus was reached through ongoing review and discussion. Quotations were selected to represent themes in the data, aiming to illustrate the thematic points beyond their specific content. The team met roughly every two to three months. All research team members except one are bilingual with fluency in English and Chinese.

Results

Participant demographic data

The participants (n = 15) included six mothers, four fathers, three husbands, one wife, and one daughter;

Table 1. Clinical and demographic characteristics of study participants and family patient member.

Family member #; Manuscript ID	Family member relationship to patient; Age	Family member occupation	Family member education; English proficiency	Family years in Canada	Family Chinese regional origin	Family member immigration status	Patient age; Gender (M/F)	Patient diagnosis	Patient years with team
1; [M1]	Mother; 56	Homemaker	Middle school; Low	30	Southeast China (Fujian)	Permanent resident	30; Male	Schizoaffective disorder	4
2; [W1]	Wife; 30	Cashier	High school; Low	15	Southeast China (Fujian)	Permanent resident	30; Male	Schizoaffective disorder	4
3; [F1]	Father; 65	Factory labourer	High school; Low	13	Southeast China (Fujian)	Citizen	32; Male	Schizoaffective disorder	5
4; [M2]	Mother; 65	Factory labourer	High school; Low	13	Southeast China (Fujian)	Citizen	32; Male	Schizoaffective disorder	5
5; [B1]	Brother; 56	Real estate agent	University; High	20	Taiwan	Citizen	51; Female	Schizophrenia	6
6; [M3]	Mother; 68	Homemaker	Elementary school; Low	21	South China (Guangdong)	Citizen	37; Male	Schizophrenia	9
7; [M4]	Mother; 76	Small business owner	High school; Middle	25	South China (Guangdong)	Citizen	42; Female	Schizophrenia	10
8; [M5]	Mother; 60	High school teacher	University; Middle	11	East China (Shanghai)	Citizen	28; Male	Schizophrenia	5
9; [H1]	Husband; 48	Chinese medicine practitioner	University; Middle	6	East China(Jiangsu)	Citizen	42; Female	Schizophrenia	3
10; [M6]	Mother; 52	Homemaker	Elementary school; Low	20	South China (Guangdong)	Citizen	28; Male	OCD	6
11; [F2]	Father; 56	Factory labourer	High school; Low	20	South China (Guangdong)	Citizen	28; Male	OCD	6
12; [H2]	Husband; 35	Factory Labourer	Technical College; Low	12	Central China (unknown province)	Permanent resident	29; Female	Schizophrenia	2
13; [H3]	Husband; 38	Chinese medicine practitioner	University; Middle	13	East China (Shanghai)	Permanent resident	33; Female	Schizoaffective	4
14; [H4]	Husband; 49	Truck driver	Middle school; Low	13	South China (Guangdong)	Citizen	43; Female	Schizophrenia	7
15; [D1]	Daughter; 23	Office administrator	University; High	13	South China (Guangdong)	Citizen	43; Female	Schizophrenia	7

their age ranged from 23–76. The patients (n = 11) were between the ages of 28–51 (M = 35.9; SD 7.3); they mainly suffered from schizophrenia and schizoaffective disorders (10/11, 90.9%); one person had severe Obsessive Compulsive Disorder. The length of time the patients have been on the ACT team ranged from 2–10 years (M = 5.5; SD = 2.3) (see Table 1).

Qualitative findings

Theme 1) Significant worries about not being able to take care of ill members in the future

Parent generation's unrelenting concern. One mother [M2] put it simply when talking about her daughter: "*She is quite good right now. Stable. Only regret is no family. We are not going to be around for long. That's a problem.*" Another parent [M3], worried about her own frailty, said: "*We two old ones cannot fall sick, if we fall sick, the child is finished, too.*" Another parent [F1] was also to the point: "*We are worried until we die. If we die, we won't know how he is, then it is just that. We live. We worry. We just have to take care of him as long as we live. He is our son!*" Another mother [M1] captured the sentiments as follows: "*What I am most worried is how to take care of him in the future, when we are not around anymore!*"

Worry about lack of care is prevalent. Similarly, younger generation family members looking after their parents or siblings felt dread. One daughter [D1] of a patient said: "*Now I am worried about my youngest brother. When mom got sick, he was* very *young, he never got the good care; he is struggling now. How are we going to keep taking care of mom now?*"

Theme 2) Family caregivers experience on-going strain and changed family life

Burden of loss of hope. One parent [M1] summarized her experience as: "*When he was diagnosed it was the most difficult. It is incurable! That is the hardest. We cried every day for three years. Doctors said there is no cure. He was home for 10 years. People told us that we saved the government a lot of money by him staying at home.*" A husband who has been caring for his wife for over 20 years said: "*The illness has been so long, there is no more hope to recover.*"

Frequent worries of violence and stability. Along with hopelessness, parents worry about what their ill children's behaviour. A mother [M3] lamented: "*No hope, if he can come quietly down for dinner, that's already good and our best hope for peace..., I never know what he is up-to upstairs, I cannot sleep, I am worried.*" A father [F1] had a different kind of worry, with far reaching impact: "*We cannot leave him alone, when we come home the tables would be upside down and the home a mess. I go out to work and all I can think of is him staying at home, I cannot think of anything else. How can we feel at ease going out to work?*" And he [F1] added: "*He hits his mother, that's the worst part about him, sometimes every two to four days... she is very afraid of him. Terrible.*"

Ongoing financial burden and worries. Financial worries are a prominent part of caregivers' 'unending' worries. One parent [M3] said: "*Other parents are resting now, retired, but we have to keep working and care for him..., I am way over 60. I wish I can relax like other parents, go travel.*" Another parent [F2] echoed this: "*Because of him, we could not truly work for three years. Right now it is ok, we can borrow here and there. One day we may need to sell the house, but what can we do?*" One husband had to stay home: "*We are affected a lot, the biggest thing is our son is not finishing school. She has no way to care or help him when she herself is so sick..., I eventually stopped working driving long distance trucks to be at home.*" Other financial burden came from unexpected places. A husband recounted the stress when his wife lost the ability to care for their children: "*Children's Aid came over. They would not allow the kids to be alone with her, so we had to use daycare. That cost so much, but Children's Aid did not care how and where we send the kids, just not with her. We got into a lot of debt.*"

Relational and family life sacrifices and changes. Families also found it hard to manage their own relationships. One mother [M3] complained: "*I ask [patient] to come to church with me but [my husband] really went against that. He says don't go. He takes him to casino and play cards and gamble..., and we fight over this.*" Another mother [M3] had very strong words about her marriage: "*If it wasn't for our son, I would have left him tens of years ago. I don't know how long I will last. We never help or console each other, he is a bastard.*" Home life was also trying for some. A daughter [D1] recalled: "*If I have to bring friends home. I usually don't... I rarely did anyways..., my mom can be hostile for no reasons. I wanted to move out.*" Another mother [M2] recalled her home life changed quickly when her daughter needed help: "*When her husband left her, we just made a room for her in our house. We spend more time on Saturdays and Sundays with her. We looked after their daughter more. That's what we did to make it work. That's life.*" Another father [F2] echoed: "*We are always worried. He calls us anytime, saying this is not working, that is going wrong. Then we have to go and help him. We cannot be away. We used to go away here and there, but now we just stay around. We just stopped doing things for*

ourselves." As well, a husband captured their restricted life as: "*We had no social life, can't leave children alone too long. Can't go to work party, can't visit friends. That was what became of us. In ten years, I only went back to China to see my parent once.*" The same husband also found the impact on their young children troubling: "*Kids used to ask, how come my mommy didn't come to pick me up like the other kids moms? The kids felt bad. Now they understand more.*" Strikingly, a mother [M6] made big life decisions based on her worry: "*I have this tumor and it's been around four years. They recommended surgery and I said I could not. I have my son to care for. I cannot fall sick. The tumor is a little smaller now, I am watching it…*"

Theme 3) Pervasive social stigma, discrimination and lack of resources experienced as immigrants

Negative experiences of social judgments and discrimination. One mother [M5] recounted hardship dealing with her neighbours and family: "*My neighbours and relatives knew he has this illness, so they poke fun and laugh at him, and look down on us. They tell people that he is sick and no good, so we don't have him come home to visit us much. They are really mean. We hardly interact now.*" A father [F2] recounted their dwindling social network: "*There are people who don't understand mental illness, no idea about the medical part. They stopped coming to our house or being friends. They used to come when nothing is happening, now something has happened and they don't come anymore.*"

Rejections by family and relatives. One mother [M4] reported her experiences of rejection: "*My son's mother-in-law was so against the relationship before they got married. It is about the schizophrenia, of course.*" A wife [W1] admitted that: "*When I learned that he has schizophrenia, I really thought about splitting up with him, but I stayed on, to stay in Canada, and he made my heart soft for him…*" She added: "*My parents really were against it. I was soft. Worried about genetics. Passing down to the kids' generation. But we stuck it through.*" Stigma also impacted on social life. The same [W1] family member recalled her social isolation: "*I cannot talk to his mother or sister, they keep busy. I cannot even talk to my good friends because I don't know what they will think of me… I just keep it to myself, keep it simple. It's our business. No point broadcasting things… I do wish he had more friends.*" Another parent [F2] sorrowfully said: "*The illness is embarrassing to us. Some relatives know. Some we just avoid. Many of them just stopped asking. Maybe they look down on us.*"

Trying to manage stigma and discrimination in various difficult forms. Some families tried to rationalize. One father [F1] said: "*To be honest, and it does not sound good, but if he had cancer, he either lives or dies, but this kind of illness, what can we do? If it was cancer, we could detect early and save him, we could spend money and save him; with this illness, the whole family is game over. Cancer death is at least clear, this illness is life long and forever…what can you do, the entire family is dragged down, what can you do?*" Another parent [M5] invoked fate and fortune: "*No matter how you put it, it is very bad fortune to have this problem [of mental illness]. We are doomed as a family.*" One other parent [M1] told her story of avoidance and isolation: "*I cannot, and I am afraid of telling other people or relatives. Other people don't know and don't understand this illness. If we did he will never have a girlfriend. We were all alone.*"

Lack of resources. Getting psychiatric help was very difficult for many, one mother [M6] described the ordeal: "*They had meetings and interviews and then meetings to decide. I was so stressed, not certain whether they will take my son. I had so much hope for some good help. He has been to so many doctors. … I could not sleep well and my health took a hit. I fainted four times.*"

Theme 4) General appreciation of Canadian health and welfare systems and opportunities

Thankful for disability welfare and public psychiatric care. Without any prompt, one mother [M4] said: "*The Canadian medical system is very good here, really. We could not have afforded the medications and hospitalizations in China. He was beat up by co-patients there a lot. I had to live in the hospital to accompany him. Here there are single rooms and good nursing protection. We would have been bankrupted if we were still in China…*" One mother [M2] also said: "*The government assistance is so helpful; it relieved our burden. Our lives changed for the better as otherwise we would not be able to pay for her [treatment]. Canada has such good social benefits.*" Another family member echoed: "*She takes medications that are so expensive. If the government steps away, we will not be able to make do. Too much burden.*" One husband [H2] put things in perspective despite adversity: "*The society does a pretty good job supporting and coordinating for us. You cannot do it alone. Even the Children's Aid helped our kids a lot, and the ODSP [Ontario Disability Support Program]… there is good social structure and welfare, just not many friends and family.*"

Appreciation for Canadian culture of acceptance and immigration opportunities. One mother [M4] said: "*It's different in China. The village people would laugh at us*

for this kind of illness, even close family relatives... here the social workers, big shots in the community, the doctors, they care and take care of him. People are respectful. No looking down on us. So lucky we are here." Also finding relief in Canada, a family member [W1] recounted: "*In China people like to talk. This one talks to that one, rumors abound. We don't want to go back, what for? People like to talk and lots of prejudice against his mental illness. An uncle of mine sent his daughter-in-law home [terminating an arranged marriage] after she had a mental breakdown. They are like that.*" Similar sentiments were coming from a husband: "*In Canada the government is attentive to her. Poor people's lives are not bad... In China mental health patients are more discriminated [against], that happens. They think you are always a patient. In Canada they think this is a brain illness. In China they think you are off your mind. They see you coming and they walk far away to avoid you.*" Speaking in appreciation of his immigrant opportunity, one father [F1] said: "*We came with nothing, but now we all own houses, but [the patient] will never, though.*"

Theme 5) Cultural beliefs and immigration factors uniquely shape families' support and caring commitment

Strong notions of obligation, loyalty and sense of responsibility. A father [F1] talked of parental obligation: "*You cannot count on siblings or others to look after [the patient], only parents can, or a wife. If no wife, he will be not cared for, and [we parents] can only be with him as long as we live, but it is not forever for him.*" One parent [M3] talked about the importance of progeny: "*He had a wife who left after four years and unable to bear a child... there was no life security without kids..., we don't blame her for leaving.*" Another parent [M4] added: "*Siblings can help, but they have their families, their mortgages, their car loans, their kids. We don't blame his sister. We had no choice because we were his parents, we had to protect him on our own.*" One mother [M1] put it simply: "*We all feel we need and should help him. It makes a big difference having a family around.*" Another mother [M5] summarized her traditional cultural views: "*He likes me to visit every week, I cannot go away much. I take care of him until someday when I cannot do it anymore. I don't know what that day is. I am getting old, I worry. I wish he had someone in his life to help him. I think like a traditional Chinese.*"

Cultural notions of filial piety and gender role stereotyping. A family member used a Chinese idiom to describe a parent's resentment of a child with SMI: "*There is a Chinese saying that children with long term illness are not going to be filial kids because they cannot take care of their parents. …. The parents get tired and exhausted over time. 'We have spent so much heart and energy, why are you still not normal?'*"[1] On the other hand, children struggle to fulfill their filial duties and other cultural traditions, as a daughter [D1] complained: "*My four siblings are talking [about] how to split the work. May be even send mom to an institution. But we cannot agree on this. The logic of thinking is, 'you are the daughter, you are supposed to be cooking and cleaning'... My grandmother kind of trained me to take on the responsibility. You know. I guess being the second and being a girl. It's more like it's just my responsibility. The son is always pampered. She [grandmother] didn't put any burden on my older brother. She put all the responsibility on me.*" This respondent did not only shoulder extraordinary caring duties from a young age, but also felt she could not refuse the demands and expectations of the family due to a sense of filial duty and culturally based practices cultivated by her family because she was female.

Lament on loss of cultural support and resources. Coming from a close knit, traditional cultural background, one family tried to secure support through matrimonial match-making for their son, and the father [F1] reported: "*We borrowed a lot of money to try to find him a wife in China. Still owe a lot. Still no wife. Things are very expensive, but what can we do, this must be done.*" Living in urban Canada is often a challenge, the same father [F1] also said: "*It's just bad luck when a family is hit with an illness like this. Family connections are watered down, just less here than in the village in China where we came from – we lived close to each other, all relatives lived in the same village; here maybe one lives in Scarborough, one in Mississauga [suburbs of Toronto], way too far; our village was 600 square metres, 8,000 people, I could walk the entire place in half an hour.*" Another family member [M3] recalled: "*In my old village the women typically did not work, they come and go and visit a lot... Here women all work, same as the men. They live far apart, no one to help. I regret immigrating here.*" One husband summarized succinctly: "*The good thing about China is you have lots of friends and relatives, they can chip in and help. Here you have no one; that is a big advantage back home.*"

Theme 6) Families find various ways to cope and help themselves

Drawing strengths from within and being an ally and advocate in treatment. One mother [M2] credited her own family strength: "*We had no problem with her illness. We all knew this is a serious illness. Our family all supported each other. When she is well, we are well. When she is sick, we feel sick, lots of worries.*" One family member [D1] found her own principles in life

helpful ("*If life is hard, then you need to try harder. That's the only way out.*") while maintaining hope through finishing school: "*Education helped me growing up, having my own job, and trying to cope with this situation. It's still hard to get that education with troubles that we have. It kind of provides me that sense of security…, it opens doors where you can get a job.*" A mother [M5] echoed: "*I always think studying more and getting more education helped me, it gives me a sense of security, so I can be a better care-taker.*" One family member simply cherished his role as a supporter of treatment after a protracted time of medication refusal in his wife: "*I keep telling her, if you take your medication, you are just normal like the rest of us. We can manage that…*"

Strengths through spirituality and acculturation. Others drew support from outside and through acculturation, as one mother [M3] recounted: "*Let me tell you, my biggest fortune is that I joined a church, it has given me the most strength – the strength to handle his illness; otherwise I would have collapsed long time ago. You follow the local culture and see what helps you. He likes going to church, people are nice to him there; no one bullies or takes advantage of him there.*" Another mother [M5] echoed: "*He could not tell who is nice and who is bad, but he became a Christian and the pastor is very kind and nice to him. He really trusts him and enjoys going to church for some activities when he could. When the pastor is busy, he told my son to visit him still. My life is given to me by God.*"

Strengths in pride as caretaker. Being proud of their care and commitment towards their ill members was also a source of strength. One parent [M3] said: "*Other people may look down on him, but we are family, we cannot do that. If there is no one sick, then there will be no need for hospitals. Sickness is normal. We look after him like family should, we need to protect him.*" Another mother [M5] reported with pride: "*I have brought him up from a tiny baby. Don't mind me saying so, if other families have a sick child, they won't care for him as much as I do; I spoil him too much.*"

Strengths in acceptance and understanding of mental illness. One family member [W1] found acceptance helpful: "*I treat him like a normal person, chat with him, argue a bit; if I always think he is ill and need special treatment I will be very tired. I don't put too much in my mind, and don't hold grudges for long. If I do, I will be exhausted. No one wants to have someone who is ill. You have to deal with it and move on, don't put it in my mind forever.*" Others have found strength simply through better understanding, as one husband said: "*In the beginning we had no understanding, now

understanding can help. The only hope is she continues treatment. Now understanding is the best help for her treatment.*"

Strengths in seeking community of mutual support and pride of independence. Some also found encouragement in each other. One mother [M1] recalled: "*When I went to a family support meeting for the first time, I saw a lot of unhappy people, but I was feeling relieved. I started to know I was not alone.*" In a different domain, one family [M4] adapted in somewhat unusual ways: "*We don't want government support. We didn't have much money because he is sick, so we picked beer bottles, making 30 or 40 dollars a day that would be enough to live on.*" Another family member ventured on how they manage financially: "*Some people here in Canada will spend all their check and live nicely for the first half of the month. Then money is all gone. We are fine. We never let money run out. Less money, you just spend less. Simple.*"

Discussion

This qualitative study of Chinese immigrant families' experiences in caring for family members with SMI identified a number of themes. To start, participants studied here share many similarities with other immigrants in terms of experiencing lower social economic status, language barriers, social isolation, and a lack of understanding of and access to social resources (Kokanovic, Petersen, & Klimidis, 2006; Kirmayer, 1989).

One strong theme found in the study is the culturally shaped extraordinary commitment in the caretaking of their family members. Chinese cultural heritage generally places enormous value on the family and sees it as the building block of a healthy society, and families are expected to take on the responsibility of caring for its members. In turn, the family's caring ability reflects the health and respectability of the family (Poon & Harvey, 2013; Hong & Domokos-Cheng Ham, 2000; Wong, Tsui, Pearson, Chen, & Chiu, 2004). These ideals may be generally perceived as positive, but can also negatively affect both the patient, in their feeling of having failed to achieve normalcy, and the care giver, in their feeling of having inadequately cared for the ill (Hsiao, Klimidis, Minas, & Tan, 2006; Sun, 2014).

Socio-economic reasons may also play a role. Historically and currently in China, there have been very low levels of formal, government-run community based support for families, and the cost of psychiatric care in hospitals is increasingly prohibitive, reinforcing the need for self-reliance in family caring (Zhou et al., 2016; Zhai, Guo, Chen, Zhao, & Su, 2013). When Chinese immigrate abroad, these cultural aspects

most likely continue to shape the way they manage family members with mental illnesses. Wu and Tseng (1985) identified several important cultural continuation elements integral to Chinese communities worldwide, among them: family based collective responsibility, emphasis on the parent-child relationship and bond, value of social interaction, preference for emotional control and morality-based reasoning, and valuation of education and achievement are most prominent. From this perspective, severe psychotic mental illness disrupts all the valued cultural aspects and the family is often left with a desperate sense that it needs to take the primary responsibility to cope and restore the lost bonds, social interactions, and respectable achievements. Burden is more likely to take root when compared to a more Western model where mental illness is perceived as requiring medical or psychiatric attention, not something to be resolved by the family (Ryder et al., 2000).

More specifically, immigrant parents of elderly age are particularly noted in the current study to bear a high level of worry and uncertainty about how to take care of their ill children in the future. This may partly reflect a context in which accessing adequate and appropriate care is still perceived to be difficult, and comfort level with the current services is limited. These sentiments from the immigrants are notably similar to the findings in Asia where public services are less robust. For example, researchers in Taiwan (Hou, Ke, Su, Lung, & Huang, 2008) have reported similar worries regarding patients' illness, dependency, and concerns about their safety and illness relapses. As well, researchers in Hong Kong (Chien, Chan, & Morrissey, 2007) and China (Li, Lambert, & Lambert, 2007; Yang, Bryne, & Chiu, 2016) have found older parents prominently worried about the future, compounded by perceived lack of social support, low income, poorer quality of life, and low number of family members living with patients. There are also research findings that show older caregivers tend to have higher burden levels than younger ones (Vella & Pai, 2012), possibly related to their health conditions and looming financial precarity (Grover, Avasthi, Chakrabarti, Bhansali, & Kulhara, 2005). It is also likely a reflection of traditional Chinese culture where the elderly in a family are to be respected as the 'heads of household' with responsibility to take care of all family members. Failure to meet this responsibility, particularly when immigration related loss or lowering of employment, loss or lowered availability and control of resources (and therefore respectability) is often associated with a sense of guilt and shame, and it may shape the expressions of worry about the future of loved ones (Wong et al., 2004; Lin & Lin, 1981).

The current study's findings on the plight of burden also echoes research on role captivity and role overload, when caretakers are facing inordinate responsibilities and feeling trapped within (Pearlin, 1983). Echoing similar studies, many participants in our sample felt their lives were inescapably altered or diminished as they had to resign to putting their ill family members' needs before their own (Ostman & Kjellin, 2002; Van Der Voort, Goossens, & Van Der Bij, 2009; Suro & Weisman de Maman, 2013). Relatedly, one should be aware that when immigrant families like the ones studied here are highly committed to assisting their ill family members, it may easily lead to an underestimation of the resources needed in the community, or the need to inform them of available resources. As well, care services may need to pay attention to immigrant patients' level of dependence, and ability to be independent as part of assessments and recovery goal setting.

A few participants have put extraordinary effort into securing their ill family members with a life partner through marriage. This effort likely reflects a strong cultural expectation for marriage as a form of domestic support and continuation of family. It also gives context to the extended worry and grief found in families' beliefs that the ill member will be less capable of caring for themselves in the long run (Richardson, Cobham, Murray, & McDermott, 2011). An appreciation of this culturally based imperative is helpful for health care providers to understand the clients' priority in familial goals, hope, and attendant sense of fulfillment or burden. International research finds this also common in Latino and Indian cultures (Hernandez & Barrio, 2015; Chakrabarti, 2010).

The current study also found a high level of disruption of the participants' normal lives and social activities. A recent large family burden study in an acute in-patient setting in China found social isolation and disruption of caregiver routines very problematic (He, Zhou, Sun, Guo, & Rosenheck, 2015; Zhou et al., 2016). As immigrants, in a setting where social networks and support are already diminished, this is likely even more impactful. Designing and developing care to provide relief, respite, and social support for immigrant families appears highly worthwhile.

Furthermore, the current study found that the effects of stigma on mental illness is pernicious on many levels. Stigma led some families to shun social activities, isolate themselves, hide the illness, and avoid seeking help. Notably, stigma acts as a wedge for these families who celebrate close knit social network of support and family interdependence, yet face shame and reluctance to communicate or obtain support for mental illness from their extended families. This retreat and high reliance on the nuclear family likely have contributed to their caretaker burden over

time (Phillips et al., 2002; Poon, & Harvey, 2013). These findings echo other research on impact of stigma in Chinese communities such as delayed help seeking, and less adherence with treatment (Poon & Harvey, 2013; Ryder et al., 2000; Hsu, 1985; Chiu, Poon, Fong, & Tsoh, 2000; Mak & Cheung, 2008).

Beyond discrimination and social stigma, family participants in the current study also described an internalized sense of shame, guilt and regret that carried deep invisible scars (Kung, 2003; Larson & Corrigan 2008). This is particularly impactful for those who hold the belief that their neglect caused or worsened the development of mental illness in their family members, a not uncommon explanatory model for the cause of schizophrenia in the Chinese community (Phillips, Li, Stroup, & Xin, 2000; Furnham & Chan, 2004; Hsiao et al., 2006). Service providers would do well in gaining understanding of the illness explanatory models from both patients and their families, so psychoeducation and culturally meaningful care could be better targeted. Furthermore, practices and policies could focus more on relieving such internalized blame (Chiu, Wei, & Lee, 2006).

The current study also identified a mixed experiences of lacking understanding of, access to, and perceived satisfaction with mental health services. Immigrant families are typically under-served by the general mental health system (e.g. Kokanovic et al., 2006). It is worth noting that evidence shows ethno-cultural services that target marginalized ethnic minorities do significantly improve clinical outcomes, ranging from children (Yeh, Takeuchi, & Su, 1994), to the chronically mentally ill (Yang et al., 2005). Proper and adequate services are essential to ameliorate delayed help seeking, poor attendance for follow up and low adherence with treatment (Ryder et al., 2000).

On a different note, there is a very clear appreciation of the welfare system from the current study's participants. This is an honest and grateful positive recognition that is not typically reported by other research. The Canadian system should take some pride and note that a well-funded welfare and health system should not go unrecognized, and its continuation and improvement as part of a basic social safety net is essential to reach those who are the hardest to reach.

Lastly, the current study found a strong theme in that family caretakers have developed various ways to cope with their worries and burden. Drawing strength and solace from religious beliefs and spiritual support seemed very helpful to a number of participants. Acceptance of the illness helped with coping for a number of others. Chinese culture may have some predisposition to appreciating that some major life events happen due to larger than life forces that are beyond one's control, and one can only accept

and cope with the outcome (Wong et al., 2004). This cultural aspect may be very helpful in considering newer psychological counselling models such as Acceptance and Commitment Therapy where a focus on acceptance is emphasized, and promotes finding new meaning and purpose in the caring journey for the family members (Öst, 2014). Whether the coping is through spirituality, acceptance, humour, or taking pride in their care, the participants have arrived at these gains in a manner reflective of a path of recovery, where they have learned to maintain hope, accept their challenges, empower themselves over time, and find new meaning in what they have achieved – parallel to the recovery journey of the patients themselves (Anthony, Cohen, Farkas, & Gagne, 2002; Myers, 2010; Slade, Phelan, & Thornicroft, 1998). More could be done. A recent meta-analysis on interventions to improve caretaker experiences found psychoeducation, family support groups, and problem-solving bibliotherapy to be positive, though the quality of the evidence was low (Yesufu-Udechuku, Harrison, & Mayo-Wilson, 2015). More effort to include these components to support any family, not the least marginalized immigrant families, is an area demanding more active support (Dixon et al., 2014).

Limitations

The current study has a number of limitations. The sample size is relatively small, the age range wide, and comes from one service program. We recognize that Chinese immigrants are diverse in socioeconomic and geographic and ethnic origins, and our sample's representativeness is limited. It is hoped that the current findings reflect some of the general experiences of immigrants who have struggled with similar burdens. There may also be some selection bias as not all families approached agreed to participate. The general impression of those who participated and declined were not remarkably different. We also did not have enough sample size for sub-analyses, such as how different relationships to patients may influence the sense of burden. Other limitations may also be related to the sensitive topic itself. Some participants may not be open to talk about burden as it may seem they are complaining about something they should be doing and therefore risk losing face (Hsiao et al., 2006). Additional limitations may be related to potential biases as the participants were introduced by team workers and participants may be predisposed to talking about more positive aspects of their experiences.

Finally, despite basing our semi-structured interview on a validated Chinese instrument on caretaker burden, the participants reflected experiences that are not all

captured by the notion of burden, as they included unreserved commitment, hope and adaptation, acceptance, and pride in their work. The notion of "burden" may not be the best fit for everyone. It may have implied some negative connotation, an aversive label, suggesting something unwanted, negative, invariably imposed upon, when some family members may not consider giving care a burden, but rather an obligation that is willingly honoured as part of a cherished family role (Sales, 2003), and something positive and rewarding that helped to add purpose and positive meaning in life (Chen & Greenberg, 2004).

Implications for practice

Our study has identified several important caretaker burdens and issues for the Chinese immigrant families. Having service providers paying particular attention to parent or elderly caretakers' worries would be a strong recommendation for all service providers. Determining and understanding the special coping strategies of the family caretakers and helping to strengthen these and their social and support network in general would also be synergistically productive and rewarding for both caretakers and service providers. The need to combat illness stigma at the patient, family and societal levels are again highlighted. Last but not the least, on-going collaboration with the family system and assessing their needs and experiences should be part of the standard of care working with chronic and marginalized populations.

ORCID iD

Samuel Law ⓘD https://orcid.org/0000-0002-1918-8782

Note

1. The idiom, "jiŭ bìng wú xiào zǐ" (久病无孝子), describes parents who have chronic illness tend to have unfilial children because of the long-term burden and deprivation exacted on the children, causing them to be less filial over time. The participant here used it in a reversed sense.

References

Anthony, W. A., Cohen, M., Farkas, M., & Gagne, C. (2002). *Psychiatric rehabilitation*. 2nd edition. Boston: Boston University Center for Psychiatric Rehabilitation.

Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers. *Pharmacoeconomics*, *26*(2), 149–162.

Blignault, I., Ponzio, V., Rong, Y., & Eisenbruch, M. (2008). A qualitative study of barriers to mental health services utilisation among migrants from mainland China in South-East Sydney. *International Journal of Social Psychiatry*, *54*(2), 180–190.

Braithwait, V. (1992). Caregiving burden: Making the concept scientifically useful and policy relevant. *Research on Aging*, *14*, 3–37.

Breitborde, N. J. K., Lopez, S. R., Chang, C., Kopelowicz, A., & Zarate, R. (2009). Emotional over-involvement can be deleterious for caregivers' health. *Social Psychiatry and Psychiatric Epidemiology*, *44*, 716–723.

Chakrabarti, S. (2010). Impact of schizophrenia on caregivers: The Indian perspective. In Kulhara P., Avasthi A. & Grover S. (Eds.), *Schizophrenia: The Indian scene*, 2nd ed (pp. 215–262). Chandigarh: PsyPROM, PGIMER.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: SAGE.

Carretero, S., Garces, J., Rodenas, F., & Sanjose, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*, *49*, 74–9.

Census. (2016). Census Profile, 2016 Census: Toronto, Ontario, Canada. https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/details/Page.cfm?Lang = E&Geo1 = CSD&Code1 = 3520005&Geo2 = PR&Data = Count&B1 = All

Chen, F., & Greenberg, J.S. (2004). A positive aspect of caregiving: The influence of social support on caregiving gains for family members of relatives with schizophrenia. *Community Mental Health Journal*, *40*(5), 423–435.

Chien, W., Chan, S. W. C., & Morrissey, J. (2007). The perceived burden among Chinese family caregivers of people with schizophrenia. *Journal of Clinical Nursing*, *16*(6), 1151–1161.

Chien, W. T., & Norman, I. (2004). The validity and reliability of a Chinese version of the family burden interview schedule. *Nursing Research*, *53*, 314–322.

Chiu, S. N., Poon, T. K., Fong, S. Y. Y., & Tsoh, M. Y. (2000). A review of 354 outreach patients of Kwai Chung hospital community psychiatric team. *Hong Kong Journal of Psychiatry*, *10*(3), 6–13.

Chiu, M., Lebenbaum, M., Newman, A. M., Zaheer, J., & Kurdyak, P. (2016). Ethnic differences in mental illness

severity: A population-based study of Chinese and South Asian patients in Ontario, *Canada. The Journal of Clinical Psychiatry*, 77(9):1108–1116.

Chiu, M. Y. L., Wei, G. F. W., & Lee, S. (2006) Personal tragedy or system failure – a qualitative analysis of narratives of caregivers of people with severe mental illness in Hong Kong and Taiwan. *International Journal of Social Psychiatry*, 52, 413–423.

Chow, W., Law, S., Andermann, L., Yang, J., Leszcz, M., Wong, J., & Sadavoy, J. (2010). Multi-family psychoeducation group for assertive community treatment clients and families of culturally diverse background: A pilot study. *Community Mental Health Journal*, 46(4), 364–371.

DeVylder, J. E., & Lukens, E. P. (2013). Family history of schizophrenia as a risk factor for axis I psychiatric conditions. *Journal of Psychiatric Research*, 47, 181–187.

Dixon, L., McFarlane, W. R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., ... Sondheimer, D. (2014). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services*, 52, 903–910.

Flyckt, L., Lothman, A., Jorgensen, L., Rylander, A., & Koernig, T. (2013) Burden of informal care giving to patients with psychoses: A descriptive and methodological study. *International Journal of Social Psychiatry*, 59(2), 137–146.

Furnham, A., & Chan, E. (2004). Lay theories of schizophrenia: A cross-cultural comparison of British and Hong Kong Chinese attitudes, attributions and beliefs. *Social Psychiatry and Psychiatric Epidemiology*, 39(7), 543–552.

Gater, A., Rofail, D., Tolley, C., Marshall, C., Abetz-Webb, L., Zarit, S. H., & Berardo, C. G. (2014). "Sometimes it's difficult to have a normal life": Results from a qualitative study exploring caregiver burden in schizophrenia. *Schizophrenia Research and Treatment*, 2014, 368215. doi:10.1155/2014/368215.

Grover, S., Avasthi, A., Chakrabarti, S., Bhansali, A., & Kulhara, P. (2005). Cost of care of schizophrenia: A study of Indian outpatient attenders. *Acta Psychiatrica Scandinavica*, 112, 54–63.

Guarnaccia, P. J. (1998). Multicultural experiences of family caregiving: A study of African American, European American, and Hispanic American families. *New Directions for Mental Health Services*, 77, 45–61.

He, H., Zhou, Y., Sun, B., Guo, Y., & Rosenheck, R. A. (2015). Brief Chinese version of the family experience interview schedule to assess caregiver burden of family members of individuals with mental disorders. *Shanghai Archives of Psychiatry*, 27, 55–61.

Hernandez, M., & Barrio, C. (2015). Perceptions of subjective burden among Latino families caring for a loved one with schizophrenia. *Community Mental Health Journal*, 51, 939–948.

Hjarthag, F., Helldin, L., Karilampi, U., & Norlander, T. (2010). Illness-related components for the family burden of relatives to patients with psychotic illness. *Social Psychiatry and Epidemiology*, 45, 275–283.

Hoenig, J., & Hamilton, M. W. (1966). The schizophrenia patient in the community and his effect on the household. *International Journal of Social Psychiatry*, 12, 165–176.

Hong, G. K., & Domokos-Cheng Ham, M. (2000). Psychotherapy and counseling with Asian American clients: A practical guide. *Multicultural aspects of counseling series* (Vol. 16). Thousand Oaks, CA: SAGE Publications.

Hou, S., Ke, C. K., Su, Y., Lung, F., & Huang, C. (2008). Exploring the burden of the primary family caregivers of schizophrenia patients in Taiwan. *Psychiatry and Clinical Neurosciences*, 62(5), 508–514.

Hsiao, F. H., Klimidis, S., Minas, H., & Tan, E. S. (2006). Cultural attribution of mental health suffering in Chinese societies: The views of Chinese patients with mental illness and their caregivers. *Journal of Clinical Nursing*, 15(8), 998–1006.

Hsu, J. (1985). The Chinese family: Relations, problems, and therapy. In Tseng W. S. & Wu D. Y. H. (Eds.), *Chinese culture and mental health* (p. 96). London: Academic Press.

Kirmayer, L. J. (1989). Cultural variations in the response to psychiatric disorders and emotional distress. *Social Science & Medicine*, 29, 327–339.

Klimidis, S., Hsiao, F. H., & Minas, I. H. (2007). Chinese-Australians' knowledge of depression and schizophrenia in the context of their under-utilization of mental health care: An analysis of labelling. *International Journal of Social Psychiatry*, 53(5), 464–479.

Kokanovic, R., Petersen, A., & Klimidis, S. (2006). "Nobody can help me ... I am living through it alone": Experiences of caring for people diagnosed with mental illness in ethno-cultural and linguistic minority communities. *Journal of Immigrant and Minority Health*, 8(2), 125–135.

Kung, W. W. (2003). The illness, stigma, culture, or immigration? Burdens on Chinese American caregivers of patients with Schizophrenia. *Families in Society. The Journal of Contemporary Human Services*, 84(4), 547–557.

Larson, J. E., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry*, 32, 87–91.

Lehman, A. F., & Steinwachs, D. M. (1998). Translating research into practice: The Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations. *Schizophrenia Bulletin*, 24(1), 1–10.

Lehman, A. F., Steinwachs, D. M., Dixon, L. B., Postrado, L., Scott, J. E., Fahey, M., Fischer, P., Hoch, J., Kasper, J. A., Lyles, A., Shore, A., & Skinner, E. A. (1998). Patterns of usual care for schizophrenia: Initial results from the Schizophrenia Patient Outcomes Research Team (PORT) Client Survey. *Schizophrenia Bulletin*, 24(1), 11–20.

Li, J., Lambert, C. E., & Lambert, V. A. (2007). Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. *Nursing & Health Sciences*, 9(3), 192–198.

Lin, T. Y., & Lin, M. C. (1981). Love, denial and rejection: Responses of Chinese families to mental illness. In Kleinman A. & Lin T. Y. (Eds.), *Normal and abnormal behavior in Chinese culture* (pp. 387–401). Dordrecht, the Netherlands: Reidel.

Magaña, S. M., Ramírez García, J. I., Hernández, M. G., & Cortez, R. (2007). Psychological distress among latino

family caregivers of adults with schizophrenia: The roles of burden and stigma. *Psychiatric Services*, 58(3), 378–384.

Mak, W. W., & Cheung, R. Y. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, 21(6), 532–545.

Marsh, D., & Johnson, D. (1997). The family experience of mental illness: Implications for intervention. *Professional Psychology: Research and Practice*, 28(3), 229–237.

Martens, L., & Addington, J. (2001). The psychological well-being of family members of individuals with schizophrenia. *Social Psychiatry & Psychiatric Epidemiology*, 36, 128–133.

Maurin, J., & Boyd, B. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, 4, 99–107.

Myers, N. L. (2010) Culture, stress and recovery from schizophrenia: Lessons from the field for global mental health. *Culture, Medicine and Psychiatry*, 34(3), 500–528.

Öst, L. G., (2014). The efficacy of acceptance and commitment therapy: An updated systematic review and meta-analysis. *Behaviour Research and Therapy*, 61, 105–121.

Ostman, M., & Kjellin, L. (2002). Stigma by association: Psychological factors in relatives of people with mental illness. *British Journal of Psychiatry*, 181, 494–498.

Pai, S., & Kapur, R. L. (1981). The burden on the family of a psychiatric patient: Development of an interview schedule. *British Journal of Psychiatry*, 138, 332–335.

Papastavrou, E., Charalambous, A., Tsangari, H., & Karayiannis, G. (2010). The cost of caring: The relative with schizophrenia. *Scandinavian Journal of Caring Sciences*, 24, 817–823.

Pearlin, L. (1983). Role strains and personal stress. In: Kaplan, H. (Ed.), *Psychosocial stress: Trends in theory and research (pp. 3–32)*, NY: Academic Press.

Perlick, D. A., Rosenheck, R. A., Kaczynski, R., Swartz, M. S., Cañive, J. M., & Lieberman, J. A. (2006). Components and correlates of family burden in schizophrenia. *Psychiatric Services*, 57(8), 1117–1125.

Phillips, M. R., Li, Y., Stroup, T. S., & Xin, L. (2000). Causes of schizophrenia reported by patients' family members in China. *The British Journal of Psychiatry*, 177(1), 20–25.

Phillips, M. R., Pearson, V., Li, F., Xu, M., & Yang, L. (2002). Stigma and expressed emotion: A study of people with schizophrenia and their family members in China. *The British Journal of Psychiatry*, 181(6), 488–493.

Poon, W. C., & Harvey, L. J. C. (2013). Experiences of Chinese migrants caring for family members with schizophrenia in Australia. *Social Work in Health Care*, 52, 144–165.

Richardson, M., Cobham, V., Murray, J., & McDermott, B. (2011). Parents' grief in the context of adult child mental illness: A qualitative review. *Clinical Child and Family Psychology Review*, 14, 28–43.

Rosenfarb, I. S., Bellack, A. S., & Aziz, N. (2006). A sociocultural stress, appraisal, and coping model of subjective burden and family attitudes toward patients with schizophrenia. *Journal of Abnormal Psychology*, 115(1), 157–165.

Ryder, A. G., Bean, G., & Dion, G. (2000). Caregiver responses to symptoms of first onset psychosis: A comparison study of Chinese and Euro-Canadian families. *Transcultural Psychiatry*, 37, 225–235.

Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12 (Suppl. 1), 33–41.

Schene, A. H. (1990). Objective and subjective dimensions of family burden: Towards an integrative framework for research. *Social Psychiatry & Psychiatric Epidemiology*, 25, 289–297.

Slade, M., Phelan, M., & Thornicroft, G. (1998). A comparison of needs assessed by staff and by an epidemiologically representative sample of patients with psychosis. *Psychological Medicine*, 28, 543–550.

Smith, M. E., Lindsey, M. A., Williams, C. D., Medoff, D. R., Lucksted, A., Fang, L. J., & Dixon, L. B. (2014). Race-related differences in the experiences of family members of persons with mental illness participating in the NAMI Family to Family education program. *American Journal of Community Psychology*, 54, 316–327.

Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia. *Dementia*, 13(6), 803–818.

Suro, G., & Weisman de Mamani, A. G. (2013). Burden, interdependence, ethnicity, and mental health in caregivers of patients with schizophrenia. *Community Mental Health Journal*, 51, 939–948.

Tang, V. W., Leung, S. K., & Lam, L. C. (2008). Clinical correlates of the caregiving experience for Chinese caregivers of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 43, 720–726.

Vella, S.-L., Pai, N. (2012). The measurement of burden of care in serious mental illness: A qualitative review. *Australian & New Zealand Journal of Psychiatry*, 47(3), 222–234.

Van Der Voort, T. Y. G., Goossens, P. J., & Van Der Bijl, J. J. (2009). Alone together: A grounded theory study of experienced burden, coping, and support needs of spouses of persons with a bipolar disorder. *International Journal of Mental Health Nursing*, 18, 434–443.

Wagner, C., Tanmoy D., Bigatti S., & Storniolo, A. M. (2011). Characterising burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. *Cancer Nursing*, 34, E21–E30.

Wirsén, E., Åkerlund, S., Ingvarsdotter, K., Hjärthag, F., Östman, M., & Persson, K. (2017). Burdens experienced and perceived needs of relatives of persons with SMI – a systematic meta-synthesis. *Journal of Mental Health*, 29(6), 712–721.

Wong, D. F., Tsui, H. K., Pearson, V., Chen, E. Y., & Chiu, S. N. (2004). Family burdens, Chinese health beliefs, and the mental health of Chinese caregivers in Hong Kong. *Transcultural Psychiatry*, 41, 497–513.

Wu, D. Y. H., & Tseng, W. S. (1985). Introduction: The characteristics of Chinese culture. In Tseng W. S. & Wu D.Y. H. (Eds.), *Chinese culture and mental health* (pp. 3–13). Orlando, FL: Academic.

Yang, J., Law, S., Chow, W., Andermann, L., Steinberg, R., & Sadavoy, J. (2005). Best practices: Assertive community treatment for persons with severe and persistent mental illness in ethnic minority groups. *Psychiatric Services*, 56(9), 1053–1055.

Yang, X., Bryne, V., & Chiu, M. Y. L. (2016). Caregiving experience for children with intellectual disabilities among parents in a developing area in China. *Journal of Applied Research in Intellectual Disabilities*, 29(1), 46–57.

Yeh, M., Takeuchi, D. T., & Sue, S. (1994). Chinese-American children treated in the mental health system: A comparison of parallel and mainstream outpatient service centers. *Journal of Clinical Child Psychology*, 23, 5–12.

Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., ... Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-analysis. *Bristish Journal of Psychiatry*, 206, 268–274.

Zhai, J., Guo, X., Chen, M., Zhao, J., & Su, Z. (2013). An investigation of economic costs of schizophrenia in two areas of China. *International Journal of Mental Health Systems*, 3, 7–26.

Zhou, Y. L., Rosenheck, R., Mohamed, S., Ou, Y. F., Ning, Y. P., & He, H. B. (2016). Comparison of burden among family members of patients diagnosed with schizophrenia and bipolar disorder in a large acute psychiatric hospital in China. *BMC Psychiatry*, 16, 283.

Ziguras, S., Klimidis, S., Lewis, J., & Stuart, G. (2003). Ethnic matching of clients and clinicians and use of mental health services by ethnic minority clients. *Psychiatric Services*, 54(4), 535–541.

Samuel Law, MDCM, MPH, FRCPC is the Clinical Director of Mount Sinai Hospital Assertive Community Treatment Team, Toronto; an Associate Scientist at the Li Ka Shing Knowledge Institute at St. Michael's Hospital, Toronto; and an Associate Professor, and Lead of the China Initiative at the Department of Psychiatry, University of Toronto. Dr. Law works, teaches, researches and publishes on immigrant mental health, cross-cultural mental health services and international adaptation, and community-based assertive psychiatric care with severely mentally ill populations.

Lisa Andermann, MPhil, MDCM, FRCPC is an Associate Professor and Co-Chair, Equity and Inclusion Council, in the Department of Psychiatry at the University of Toronto, and psychiatrist at Mount Sinai Hospital, where she works in the Psychological Trauma Clinic and Ethnocultural Assertive Community Treatment Team. Her main areas of interest in research and teaching focus on cultural psychiatry, refugee mental health, and community psychiatry.

She has been part of the Toronto-Addis Ababa Psychiatry Program (TAAPP) since its inception in 2003, assisting in the development of the first psychiatry residency training program in Ethiopia. She has an undergraduate degree in Anthropology from McGill University, where she completed her medical studies, and a graduate degree in Social Anthropology from Cambridge University.

Wendy Chow, MSW, RSW is the Program Manager of Mount Sinai Hospital Assertive Community Treatment Team, Toronto; an Assistant Professor at the Department of Psychiatry, University of Toronto; and Global Health Associate at The Peter A. Silverman Centre for International Health. She is also a training consultant for mental health professionals in Japan, and Shenzhen and Changsha (Xiangya), China. She has worked and published a Cultural Competency Training Manual for Law and Mental Health Professionals, and peer reviewed articles regarding community-based assertive community treatment with severely mentally ill populations.

XingWei Luo, MD, is an Attending Physician and researcher at the Medical Psychological Institute, Second Xiangya Hospital of Central South University, China. He is also a trainee teacher in mindfulness-based cognitive therapy (MBCT). Dr. Luo researches and publishes on depression, suicidality, Assertive Community Treatment in severely mentally ill populations, and MBCT for preventing recurrence of depression.

Xiang Wang, PhD, MD, is a professor of clinical psychology and psychiatry in the Medical Psychological Center, Second Xiangya Hospital of Central South University, China. Dr. Wang's research is focuses on the underlying psychological and neurophysiological mechanism of reward-related motivation and decision-making processing dysfunction in patients with mental disorder; and the comprehensive psychosocial intervention for patients with severe mental illness. She is currently a committee member of Medical Psychological Board in Chinese Psychological Society and Cognitive Behavior Therapy Board in the Chinese Association for Mental Health. Dr. Wang is the primary investigator of 11 national, ministry, and provincial research grants, and has published more than 130 peer-reviewed research papers.