

# Assessment of Caregiver Experiences and Psychoeducational Needs of Chinese Families for Patients with Chronic Mental Illnesses: A Pilot Study

Harleen Bedi MD, Resident Physician, Faculty of Medicine, University of Toronto

Lisa Andermann MD, FRCP(C), Department of Psychiatry, University of Toronto and Assertive Community Treatment Team, Mount Sinai Hospital

Wendy Chow MSW, Program Manager, Assertive Community Treatment Team, Mount Sinai Hospital, Toronto and Assistant Professor, Department of Psychiatry, University of Toronto

Samuel Law MD, FRCP(C), Department of Psychiatry, University of Toronto and Assertive Community Treatment Team, Mount Sinai Hospital

### Abstract

Social support networks and family relationships have a profound impact on patients' self-esteem, attitude towards illness and level of functioning. Family-based interventions have been shown to improve illness outcomes by strengthening family relationships, breaking the social stigma associated with mental illnesses and reducing caregiver burden by building a strong social support network. This project aimed to learn the experiences of families from Chinese ethnicity in caring for their family members with mental illness, and the services they find most valuable in assisting them in their role as caregivers. Ten Chinese caregivers and nine clients with chronic mental illnesses participated in a two-hour-long focus group. A self-developed questionnaire was utilized to ask open-ended questions from participants on their experience and major concerns as a caregiver for a family member with chronic mental illness. Grounded theory methodology was used to conduct a thematic analysis of the collected descriptive data. Our results showed that: (1) caregivers experience a lack of available resources to learn about the medical illness of their family members; (2) linguistic and cultural barriers limit their access to health resources; and (3) more culturally informed approaches are needed to optimize rehabilitation and integration of psychiatric patients from ethnic minorities into the society. The particular Assertive Community Treatment Team (ACTT) service utilized by the participant caregivers in this study provided ethno-specific services, which were found to be a valuable resource by Chinese caregivers. The results from this study will argue the importance of community mental health services such as ACTT and others in developing family psychoeducation and assistance programs to meet the identified needs of ethnic minority caregivers at large.

### Introduction

Studies have shown that ethnic minority patients in North America with chronic mental illnesses are underserved, as evidenced by lesser access to mental health services and lower quality of care.<sup>1</sup> At the same time, the functional impairment of patients from minority groups is often compounded by stress related to migration, linguistic differences, socioeconomic disadvantages and discrimination.<sup>2</sup>

Social support networks have a significant impact on determining an individual's wellbeing. Family relationships and support affect patients' illness outcomes, self-esteem and critical measures of their level of functioning.<sup>3</sup> Moreover, cultural differences in family perceptions of mental illness, help-seeking behaviors and family dynamics have a significant impact on the clients' ability to cope and recover from mental illnesses.<sup>3,4</sup> For instance, some traditional Chinese families view mental illness as a punishment for misdeeds done by the individual or their family members. Issues of stigma force many families to keep mental illness of a family member a secret, which delays help-seeking behaviors in this ethnic group.<sup>4</sup>

To this end, family interventions have been shown to strengthen family relationships and reduce caregiver burden.<sup>5</sup> Family psychoeducation is an effective model that improves clients' outcomes and encourages positive involvement of caregivers in the clients' treatment plans. One example of such a model is the Multiple-Family Psychoeducation Groups (MFPG), which focuses on teaching caregivers coping and problem solving skills, increasing their knowledge of the mental illness and developing a support network.<sup>3</sup> These family focused services generally help to empower the caregiver in supporting their family member meet his or her personal recovery goal,<sup>3</sup> enhance patients' recovery, reduce caregiver stress and strengthen family relationships. Many studies have reported a decline in hospital use,<sup>6,7</sup> and reduction in relapse events by 15-25%<sup>8-10</sup> in patients who received family therapy. Additionally, patients who received comprehensive treatment that included family intervention showed improvements in mental status, treatment compliance, and social functioning.<sup>6,7</sup>

Overall, family support has a profound impact on the so-

cial functioning and rehabilitation of patients with persistent mental illnesses. Moreover, several studies have supported the cost-effectiveness of family therapy intervention, with lower cost of family management as compared to individual treatment.<sup>8</sup> In a multicultural society such as Toronto, linguistic and communication difficulties impose barriers to the access of mainstream mental health care programs by ethnic minorities. Cultural adaptation of family-based interventions can help address some of the barriers felt by individuals from minority groups to improve their management of mental illnesses. In this study, we qualitatively assessed the experiences of family members who are caregivers and psychoeducational needs of Chinese background. We explored the services that Chinese families find most useful in assisting them in their role as caregivers, as well as the barriers that they face in accessing those resources. Additionally, this study obtained feedback and suggestions regarding the desired psychoeducational needs.

## Methods

This study was carried out at the community office location of the Mount Sinai Hospital Assertive Community Treatment Team (MSH ACTT; Toronto, Ontario, Canada). ACTT is a well-established “gold standard” in community-based care serving chronic and severely ill patients with mental illness. The MSH ACTT is an innovation on the classic model by being the first ethno-specific community-based mental health program to be established in North America.<sup>11</sup> It aims to address disparity in service provision by providing ACT care tailored to the specific linguistic and cultural needs of ethnic minority persons.<sup>11</sup> The team includes bilingual staff and integrates cultural elements such as traditional Chinese medicinal interventions in clients’ rehabilitation plans.<sup>12</sup> The clientele is from a variety of ethnic minority populations – based on local resource and needs studies, largely Canadian immigrants of visible minorities, who do not have English as their first language. The agency currently serves close to 100 clients, of which 45.7% are Chinese, 15.7% Tamil, 15.7% Vietnamese, 14.3% Black, 7% Korean and 1.6% of other populations.<sup>11</sup>

A list of potential participants of Chinese ethnic background was generated by random selection from the ACTT database. Clients who had previously received family psychoeducation were excluded from the study. Individuals who met the inclusion criteria were initially invited by their caseworker to take part in the needs assessment study. They were asked to invite a caregiver to participate in the study. Potential participants were given orientation about the study purposes and procedures and signed a consent form. The study was approved by the Mount Sinai Hospital Research Ethics Board.

The first author (HB) and four staff clinicians facilitated interviews with clients and families. A qualitative assessment of the needs of Chinese caregivers and clients with persistent mental illnesses was conducted through a two-hour-long focus group interview.<sup>13, 14</sup> Since some of the families were not fluent in English, the focus group was conducted in Cantonese and Mandarin with the help of interpreters. The bilingual staff at MSH ACTT provided the translation services. The focus group discussion was audio recorded for analysis.

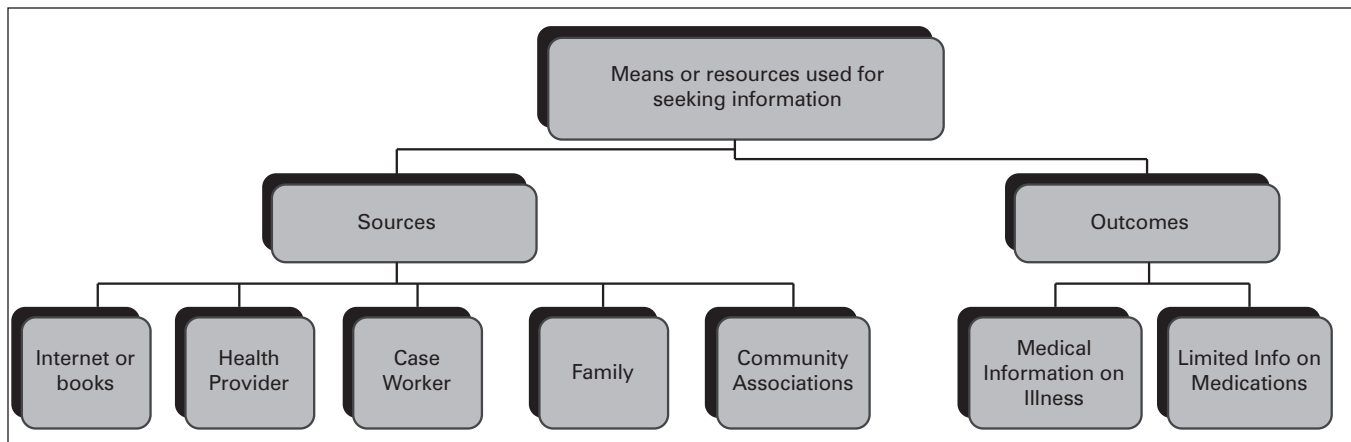
## Data Collection and Analysis

The descriptive data was collected through two focus group interviews over a period from January 2012 – March 2012. A self-developed questionnaire was utilized to ask open-ended questions from participants on their experience and major concerns as a caregiver for a family member with chronic mental illness (Table 1). The questionnaire specifically explored the resources that caregivers utilize to inform themselves of their family member’s condition as well as the barriers, if any, they face in accessing services or information to assist themselves. Questions were followed by specific probes to clarify the participants’ responses.

The audio-recorded data was transcribed, organized and indexed for ease of use. Grounded theory methodology was used to analyze the data.<sup>15</sup> After line-by-line examination of the material, the data was coded into concepts and organized into common themes, patterns, strongly held or frequently aired opinions. Constant comparative method was utilized to compare concepts and categories that emerged from inter-

**Table 1.** Questionnaire to assess needs of Chinese families in their role as a caregiver for patients with chronic mental illness

Interview Guide
1. What means/resources are you using to inform yourself of the medical condition of your family member?
2. What are the strengths of these materials?
3. What are the weaknesses of these materials?
4. What topics do the materials cover?
5. What additional resources/ information materials do you need in your role as a caregiver?
6. Identifying barriers to accessing resources: <ol style="list-style-type: none"> <li>Have you had difficulties understanding the needs of your family member?</li> <li>Have you had difficulties with accessing information on the medical condition of your family member?</li> <li>Have you had problems communicating with your healthcare provider?</li> <li>What difficulties have you faced in accessing services to take care of your family member?</li> </ol>
7. Previous experience with family therapy or psychoeducation: <ol style="list-style-type: none"> <li>Have you previously attended any family therapy or psychoeducation sessions?</li> <li>What did you find most useful in those sessions?</li> <li>What do you feel was not addressed adequately in those sessions?</li> </ol>
8. The ACT team at Mount Sinai Hospital might offer family psychoeducation groups to assist caregivers in supporting their family member with chronic mental illness in future. What information/services would you like to see added to such a program?
9. Preference on delivery of family psychoeducation sessions: <ol style="list-style-type: none"> <li>When would be the best time for you to attend those sessions?               <ol style="list-style-type: none"> <li>Morning/Afternoon/Evening?</li> <li>Weekday/ Weekend?</li> </ol> </li> <li>What would be the ideal number of sessions to offer?</li> </ol>
10. We have found from our experience that people find it helpful to hear first-hand from other families coping with similar problems. Would you find it helpful to hear directly from other families coping with similar illness?
11. Integrating services with alternative/ traditional Chinese medicine: <ol style="list-style-type: none"> <li>Have you had any consultation from traditional or alternative medicine practitioners?</li> <li>Would you find it useful if information on those services are integrated with the family psychoeducation sessions?</li> </ol>



**Figure 1.** Coding tree for means or resources utilized by caregivers to obtain information

view. Relationships between common themes were sought in order to identify needs specific to Chinese families. Analyst triangulation and peer review was used to further analyze and refine themes by reaching team consensus and combining the experience of two staff psychiatrists, a medical student and the MSH ACTT program manager.

## Results

A total of nine Chinese families (ten caregivers and nine clients), who were presently receiving treatment by MSH ACTT, participated in this study. A large majority of clients and families approached for the interview agreed to participate. While the interview was translated in Cantonese and Mandarin, some caregivers were fluent in English and were able to engage in conversation with the focus group facilitator directly.

Several key themes emerged from the content analysis of focus group transcripts: (1) means or resources utilized by caregivers to obtain information; (2) barriers that limit the access of Chinese caregivers and clients to health resources; (3) needs of Chinese families for rehabilitation and integration of clients into the society; (4) viewpoints on integration of ethnic therapies with western medicine in the management of clients with chronic mental illnesses. These themes are discussed in detail below:

### Means or Resources Utilized by Caregivers to Obtain Information

Caregivers often depend on the Internet or books to inform themselves of the medical condition of their family member. These resources were felt to be readily accessible, which helped family members in finding information at any time of the day. However, families pointed out the narrow scope of topics covered by these sources, as reflected by a caregiver's comment: "[The information I find on the Internet is] very general. Things like: medical condition, the disease, how the disease looks like. Not too much about symptoms. Generally it is very difficult to find any community resource or resource that I am trying to get." Additionally,

despite the easy availability of electronic resources, a client's sister challenged the validity of information available on the Internet: "For the Internet you got to be knowledgeable. And then there are so many [websites] and not everything is good. So the person should have some basic knowledge and better to have somebody to educate them." Moreover, families relied on their ACTT caseworker as a source of information on their family member's present medical condition. In the words of a client's brother, "[Caseworker] should be where [families] should be getting information, because we have no idea." In support of the previous comment, other families explained that they found their caseworker to be easily approachable and sought their assistance to connect with support services available in the community (Figure 1).

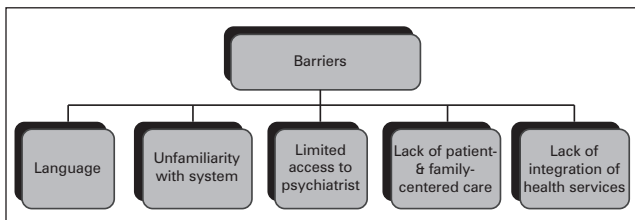
### Barriers that Limit the Access of Chinese Caregivers and Clients to Health Resources

Family members described several obstacles to gaining access to mental health services for their family member. Linguistic difference was felt to be the biggest hindrance in communicating with healthcare providers as well as accessing health-related services. Caregivers explained that the lack of proficiency in English language impeded them from collaborating with the healthcare team on medical decisions related to their family member. Given the language barrier, one family felt a strong need for an advocate to represent their values and viewpoints before the healthcare team. In addition, unfamiliarity with the Canadian mental health system imposed yet another challenge for immigrant families in navigating through the complex health system.

Secondly, caregivers felt a significant need for more frequent consultations with the psychiatrist to understand the needs of their family member better. For instance, a client's caregiver explained that, "I would like to learn more about schizophrenia and understand how it affects my brother. Maybe if we can have some more consultation with the psychiatrist. Maybe [provide] us some feedback on how we can be of assistance? [But] we don't get that kind of feedback as often." Additionally, another client's friend insisted on a preventative

approach in healthcare delivery. In her view, “sometimes [access to a healthcare worker] is very reaction based. You have a problem you go to ask the worker. Sometimes [it is better] to have more preventative knowledge, giving information on what [caregivers] should expect. Not just when things happen, [that families] have to find the case worker or scramble.”

Caregivers perceived a lack of patient-centered and family-oriented approach in care of patients with persistent mental illnesses. Some families advocated for a direct involvement in the decision making process in order to develop a better understanding of the medical condition and long-term prognosis for their family member. Moreover, some caregivers were distressed by the existence of a large communication gap among the various healthcare teams. For instance, a family shared their experience with the lack of continuity of care between hospital-based psychiatric services and the community. On the contrary, older clients of MSH ACTT found their case worker to be an excellent resource in coordinating the care of their family member: “It used to be very difficult to get information to help me in making decisions when she was in the hospital. The nurse would tell me something, but if I talk to doctor I may get more information. Specially, because I am not related to her, there used to be more convincing that I had to do to get useful information. But since we have been with the ACT team, it has become easier to communicate. And I actually need to know this kind of information” (Figure 2).



**Figure 2.** Coding tree for barriers that limit the access of Chinese caregivers and clients to health resources

### Needs of Chinese Families for Rehabilitation and Integration of Clients into the Society

As a group, caregivers were concerned about acquiring basic services needed for the wellbeing of their family member. Families emphasized the need to strengthen community resources that assist with clients’ integration into the community. A client’s sister pointed to the significance of daytime programs in providing support for individuals struggling with chronic mental illnesses during caregiver’s working hours. Another family explained their requiring assistance with acquisition of housing for their relative. Additionally, clients required assistance with managing finances, including obtaining entitled social benefits.

Thirdly, caregivers perceived a lack of adequate knowledge on the needs of their family member. For instance, a client’s friend asked, “What other things I can do to help her? Not just her disease, but how to get her better.” There was a general concern over the inability to understand the needs of a family

member coping with mental illness. For instance, a client’s mother stated, “I don’t understand what he needs. He doesn’t talk very much.” Moreover, some families were worried about loneliness experienced by clients. A client’s brother stated, “I get the feeling that because he lives alone he is very lonely. I don’t know how to solve that problem. I encourage him to go out, exercise, go to the library, but he doesn’t want to do that. So this is something that I don’t know how to solve or what to do about.” Lastly, families stressed the significance of teaching clients self-care skills in performing their activities of daily living. Caregivers felt a strong need to help their family member develop coping skills and learn self-care for better integration in the society (Figure 3).

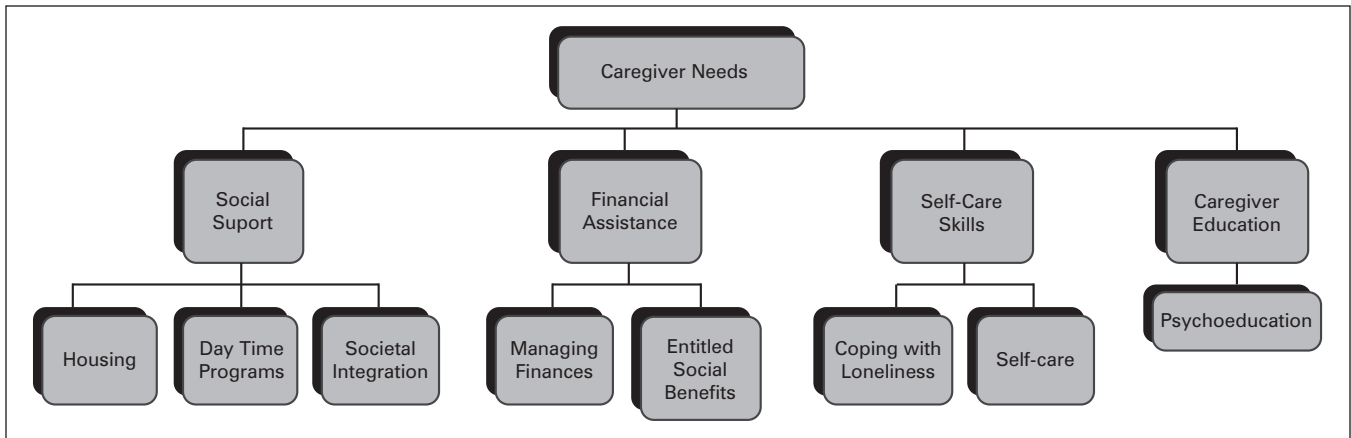
### Viewpoints on Integration of Ethnic Therapies with Western Medicine in the Management of Clients with Chronic Mental Illnesses

Through the focus group interview, we explored the viewpoints of families on integrating MSH ACTT services with traditional Chinese medicine by including consultation from alternative medicine practitioners. Most Chinese families were concerned that doing so might create confusion for clients. One caregiver suggested including evidence-based traditional drugs and therapies only to ensure patient safety. On the contrary, two families supported the integration of western and ethnic medicine, as that “doesn’t do any harm at least.” Similarly, a client’s daughter explained that her mother believed in traditional therapies and would therefore find the inclusion of information on those services useful (Figure 4).

### Discussion

In this pilot study, we explored the narrative experiences and everyday struggles of caregivers of individuals coping with chronic mental illnesses. From our focus group interviews, four major themes emerged. Firstly, our qualitative study revealed that caregivers often relied on the Internet or books to inform themselves of their family member’s medical condition. Through these sources, they were able to obtain information on the medical condition of their family member, associated symptoms as well as acquire basic knowledge of prescribed medications. Nevertheless, most families acknowledged that the sources probably contain outdated information, the validity and reliability of which was hard to determine. Additionally, a previous study by Khazaal and colleagues<sup>16</sup> noted that the knowledge of English language was an important predictor of user satisfaction in terms of accessibility and comprehension of the information found. Likewise, in our study we found that families pointed to a need for previous background on the particular research topic in order to effectively navigate themselves through the myriad of information available on these resources.

In contrast, caregivers who were connected to community associations and received support from their caseworker found their information network to be strong and trustworthy. The MSH ACTT caseworkers were felt to be a reliable source of information and families depended on them for direct information on the patient’s current medical status. However, many families recognized access to one-on-one time with



**Figure 3.** Coding tree for needs of Chinese families for rehabilitation and integration of clients into the society

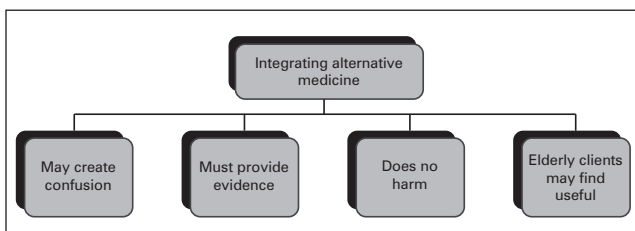
their caseworker as a limited resource. On the contrary, easy accessibility and immediate access to information through the Internet<sup>17</sup> inclined psychiatric patients and caregivers to use this resource frequently for seeking medical information.<sup>16</sup> Therefore, we recommend that psychoeducation programs provide families with health information resources as part of their education sessions. We suggest referring families to multilingual resources operated by the Multicultural Mental Health Resource Centre (website: [www.multiculturalmentalhealth.ca](http://www.multiculturalmentalhealth.ca)), the Centre for Addiction and Mental Health (website: [www.camh.ca](http://www.camh.ca)) as well as our community partner the Hong Fook Mental Health Association (website: [www.hongfook.ca](http://www.hongfook.ca)). This strategy will guide clients to reputable, medically validated and reliable sources of information thereby equipping them with the necessary tools to independently learn about their family members' mental health condition.

Coping with a chronic mental illness necessitates a longitudinal model of care that utilizes a comprehensive approach to rehabilitation. In their review of the randomized controlled literature on psychosocial treatments for schizophrenia, Bustillo and colleagues<sup>18</sup> advocated for the superior efficacy of integrated approaches that combine family therapy and social skills training over customary individual therapy in preventing psychotic relapse and hospitalization. Likewise, patients and their caregivers in our study identified four major domains that were felt to impact their family members' rehabilitation. Firstly, clients emphasized the need for support with social needs such as acquisition of housing and access to support networks in the community. Secondly, families were

concerned about meeting their financial needs as well as obtaining entitled social benefits for a family member struggling with a chronic mental illness. Thirdly, development of self-care skills such as coping with a mental illness, dealing with loneliness, fighting stigma were considered crucial in facilitating clients' long-term recovery. Finally, psychoeducation to empower families to manage the psychiatric illness and navigate the mental health system effectively was deemed significant. Moreover, ongoing support from caseworkers to assist with the financial, occupational and social needs of clients as well as social skills training were found to most benefit psychiatric patients. Therefore, effective outpatient management of individuals with chronic mental illness calls for a systematic approach with multimodal interventions and ongoing support.<sup>8</sup> In particular, patients with frequent relapse rates and high healthcare resource utilization might require a more intensive program with perhaps a greater role for more aggressive cognitive behavior therapy.<sup>8,19,20</sup>

A number of barriers made access to healthcare resources or health provider challenging for caregivers and clients from a culturally diverse population. Most families identified language as the biggest hindrance in communicating with the physician or from having greater involvement in the care plan for their family member. For that reason, some caregivers felt a strong need for an advocate to communicate their beliefs and wishes to the health providers at the hospital. To address this barrier in a multicultural society such as Toronto, culturally aware and linguistically sensitive mental health services need to be strengthened. To this end, the MSH ACTT model that provides ethno-specific mental health services by matching clients with providers who share the same language and ethnic background has shown to improve client outcomes.<sup>18</sup> Moreover, our study provides support for the utility of ACT services through the narrative experiences of older clients of MSH ACTT, who recognized their caseworkers as a valuable resource in coordinating the care of their family member as well as in easing the transition from hospital to care in the community setting.

Furthermore, through this study we explored certain cultural issues specific to families of Chinese ethnicity. We were interested in understanding the beliefs of Chinese families



**Figure 4.** Coding tree for caregiver viewpoints on integration of ethnic therapies into care plan for clients

on integrating ethnic therapies with western medicine by offering advice from alternative medicine practitioners in one of the MPFG sessions. Contrary to the commonly held belief, we found that most families did not favor the use of traditional therapies. A majority of participants had never consulted alternative medicine practitioners previously and among those who had used herbal remedies found them to be ineffective. While a few caregivers felt that herbal remedies did not do any harm and may generate greater compliance from elderly patients, most families were concerned that integrating these therapies in client care would create confusion. In sum, our study finds that immigrant families tend to prefer evidence-based western treatments to ethnic therapies. While it is essential to maintain open attitudes toward integrating traditional medicine with western medicine mental health services, allowing families to make the ultimate choice to seek out their own alternative practices may be a valid option. In this vein, our team offers ethno-specific supports by hiring culturally diverse staff that may be familiar with several alternative medicine practices as well as provide families support in cautious exploration of that option. However, our family psychoeducation program does not yet offer integrated care with alternative practitioners as a direct service.

This pilot study is unique in that it explores the experiences of everyday challenges and needs of caregivers from an ethnic minority by conducting in-depth focus group interviews with them. The interview was done in families' native language, which allowed for a greater level of comfort and open participation regardless of fluency in English language. However, to do so, this cross-cultural study required the services of an interpreter for an English-speaking researcher who facilitated the focus group. Therefore, some subtle but important points might have been lost in translation. Nevertheless, since the translators were also the caseworkers for these families and shared a great level of familiarity with the families, we tried to overcome this limitation by asking follow-up questions to elaborate on any responses as needed. Additionally, given the qualitative nature of the data, the study results are limited in their generalizability. Our study results should be confirmed in a larger population by future studies.

Overall, through qualitative, focus group interviews, this study explored the needs of Chinese families in their role as a caregiver for patients with chronic mental illnesses. The major themes that emerged from these discussions call for a shift away from the traditional, reaction based approach towards a preventative model of care focused on educating caregivers and clients as well as imparting skills essential for rehabilitation and recovery. Family involved services are also helpful in building a social network among families coping with similar challenges. Moreover, we see a tremendous potential for strengthening front line assessment of caregiver need(s) and family psychoeducation at the primary care and community health centre levels. These "gateway" providers often have the first contact with the clients and play a key role in the initial diagnosis and early management.<sup>21</sup> Even when the primary care providers cannot offer direct mental health services, their identification of caregiver and patient needs and actions in referral to a community psychoeducation program is indispen-

sible.<sup>21</sup> Therefore, we propose improving upstream service access by providing appropriate mental health needs assessment training and resource awareness to primary care clinicians as a worthwhile policy consideration for the future.

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