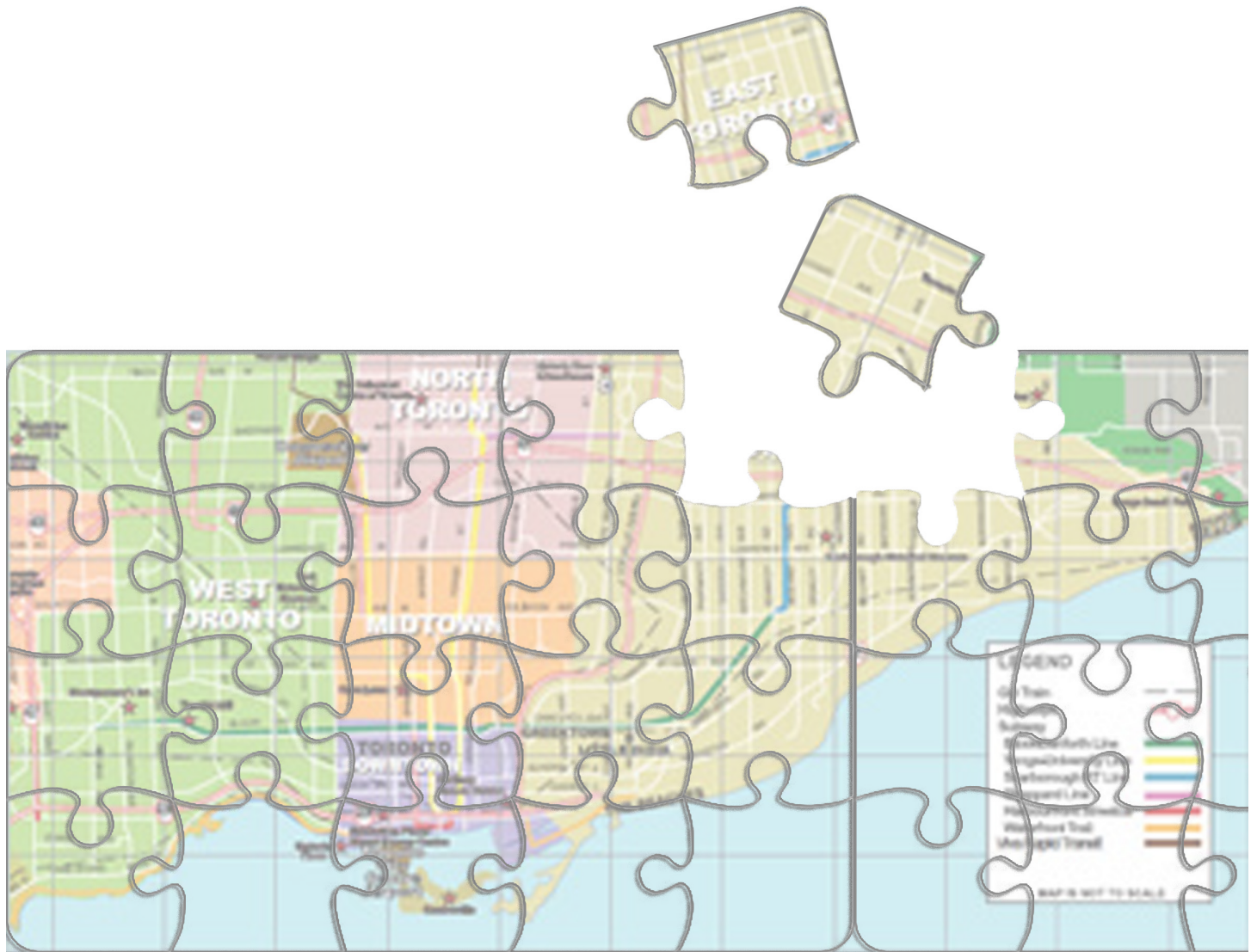


Mapping Ourselves: Current Services and Resources for Chinese Caregivers & Caregiver Barriers and Needs



Chinese Caregiver Network



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Executive Summary

Family members who provide unpaid care support for their loved ones are often not recognized for their contributions and sacrifices. Resources are available in the Cantonese community within Scarborough and the surrounding areas to help support caregivers in this endeavour. In 2012, the Chinese Caregiver Network obtained input from the participating agencies as well as caregivers through agency interviews and caregiver focus groups to assess current services. This report provides a general overview of the existing caregiver services available through the member agencies of the Chinese Caregiver Network, as well as highlighting caregiver needs and capacities.

The major findings include:

- Need for more linguistically and culturally appropriate services and resources including respite as well as physical and tangible aid.
- Need for a more substantiated system of support, including social, financial and psychosocial support, to compensate for the contributions and sacrifices caregivers make to support people with chronic health issues and seniors' independent and integrated living in the community.
- Need for improved service navigation and more comprehensive promotion of existing service providers such as the Community Care Access Centres and community health centres.

The Chinese Caregiver Network recommends that the government works with the participating agencies to address the needs of the caregiver population. Member agencies can use these findings to explore better ways of collaboration to assist caregivers in navigating services not only within the Network but also amongst other existing service providers. The Chinese Caregiver Network can serve as a platform for caregivers to voice their concerns as well as a route for advocacy.

Part I: Project Description

a) Rationale

The Chinese Caregiver Network (CCN) is a partnership among health and social service providers with a common goal to advocate and promote networking, education, information sharing and capacity building among caregivers in the Chinese community across Ontario. The members of the Network would like to explore the most effective ways in which they can work collaboratively to provide the necessary supports, services and programs to caregivers within the community. A list of the ten participating agencies has been included in Appendix A. These agencies are categorized as either community educators or direct service providers.

b) Purpose

Within the Chinese community, there is a lack of documentation and no unified understanding of what services and resources are available to informal caregivers. The purpose of this project was, therefore, to gather information on current services provided by the member agencies as well as to identify caregiver needs and capacities. Based on the findings, recommendations will be made to help guide the future CCN work plan.

c) Methods of Data Collection

Information was gathered directly from two different sources: agency partners and family caregivers that may access the providers' services. Partner surveying or interviewing was used to establish current services and resources available to caregivers through participating agencies. Caregiver focus groups were recruited and facilitated by individual direct service providers as a way to determine caregiver needs.

All data from the surveys as well as focus groups were gathered within June and July 2012.

Part II: Findings from Mapping Ourselves

a) Methodology

a. Participant Recruitment

All ten agencies of the Chinese Caregiver Network were notified of the resource sharing interview and each organization designated a staff member that would be the best at answering questions regarding the organization's resources.

b. Procedure

A Master of Social Work candidate was trained by a consultant to conduct the interviews with participating agencies. All agencies contacted the candidate directly. Three of the four community educators answered through electronic survey while one community educator completed a phone interview. For direct service providers, all but one agency completed an in-person interview with the remaining agency completed an electronic survey followed by a phone interview. Phone interviews were approximately 30 minutes long while in-person interviews averaged about an hour in length. Detailed notes were taken during the interview and the information gathered was summarized shortly after.

but these findings are based on what the particular agency believes are the top three programs or services it offers to caregivers.

e. Common and unmet needs of Chinese caregivers

The common needs of Chinese caregivers can be classified into two categories: emotional needs as well as physical and tangible needs. Direct service providers believe that resources and services are currently lacking to meet these needs. Tangible services that are linguistically and culturally appropriate provide relief for caregivers; in particular, services such as Adult Day Programs, home support services and long-term care homes were frequently mentioned as having extremely long waiting lists. Other unmet needs include financial support and employment benefits, education on knowledge and skills pertaining to caregiving, support through individual or group counselling and support in advocating for the needs of caregivers.

f. Reaching out to Chinese caregivers

All agencies stated using mass media as a way to connect with Chinese caregivers. Almost all of the agencies used some forms of referral: some used “word of mouth”; others also used online resources such as the agencies’ websites to reach out to Chinese caregivers.

g. Reasons for CCN participation and what agencies have to offer

The participating agencies highlighted that there is a lack of Chinese caregiver services and, through collaboration, CCN could strive to identify common interests and achieve short and long-term goals of the members. The agencies are willing to share their resources and provide one another with expertise knowledge and information. This would increase access to more resources and, in the future, this might lead to the development of more Chinese materials as well as an inventory or a caregivers’ website. As a collective, CCN could serve to build advocacy capacity to aim for making changes at the policy level.

c) Discussion

Based on the survey findings, it appears that the agency partners strongly support the CCN and that there is more room for collaboration amongst the agencies. There are some services that do overlap and some services and resources that can be shared amongst the agencies. In addition, this process has highlighted that despite overlap of services such as adult day programs, there are still long waiting lists. The service mapping provides CCN with an opportunity for the members to work together to ensure that caregivers have the knowledge and ability to access services across the agencies.

CCN has discussed the importance of sharing resources including the development of an online resource database to link the different organizations’ websites. This will allow caregivers to have a one-stop access to all of the services available across the CCN organizations. An inventory of the different agencies’ services will also be explored as its development can assist social workers and intake workers in making appropriate referrals to the different participating agencies.

c. Survey questions

The survey questions aimed to map the resources currently available through the participating agencies to caregivers within the community as well as to capture agencies' willingness to share these resources with the other agencies. It would be impossible to create an exhaustive list of all resources available; therefore, participating agencies were asked to highlight caregiver-related resources that can be shared amongst the partners. A set of questions were developed by a consultant in conjunction with the co-chairs of the Chinese Caregiver Network to capture the resources and capabilities of the organizations at the time of the surveys. For a complete list of survey questions, please see Appendix B. Questions #6-9 were only answered by direct service providers.

b) Key Interview Findings

a. Resource sharing

1) Community educators

The community educators, namely the Canadian Diabetes Association, Heart and Stroke Foundation, Kidney Foundation of Canada and Osteoporosis Canada, are all willing to provide disease-specific workshops annually to caregivers and advocates as well as training and education to direct service providers. They are also willing to share printed resources related to the specific illnesses.

2) Direct service providers

The direct service providers are the Alzheimer Society of Toronto, Carefirst Seniors & Community Services Association, Hong Fook Mental Health Association, St. Paul's L'Amoreaux Centre, Wellness Centre and Yee Hong Centre for Geriatric Care. They are willing to provide a variety of workshops for caregivers and their advocates on topics including dementia/Alzheimer's disease, caregiver stress and emotional management, diabetes, falls prevention and bone health, bereavement support and information regarding different mental health issues. Training or education for direct service providers is similar to the caregiver workshops, but also includes chronic disease self-management programs, elder abuse, psycho-geriatric consultation and training, peer learning and advocacy workshop, understanding Chinese culture and humour therapy.

b. Referral process

Nine out of the ten agencies stated having a referral process. The process often consists of an intake worker collecting client information and filling out an intake form with a follow-up assessment completed through a phone or face-to-face interview. Referrals are then made either internally or externally depending on the clients' needs. Six agencies stated that they do not think CCN should create a referral process to be used consistently across members, while two agencies would like to have such a process.

c. Activities and events of interest to direct service providers or caregivers

Events and activities ranged from caregiver support groups and retreats to research Chinese seniors' needs to multiple health fairs across the different agencies.

d. Services offered to Chinese caregivers

Only a limited scope of the agencies' services was gathered in this survey. Five agencies listed educational workshops and support groups as one of the top services they provide to Chinese caregivers. Three agencies listed individual counselling, while services such as Chinese information packages, home care services, adult day programs and recreational programs were only listed once. It should be noted that the actual numbers may be higher

Part III: Caregiver Focus Groups

Four of the six direct service providers completed focus groups. All four direct service providers provide caregiver related services to Chinese caregivers.

a) Methodology

a. Participant recruitment

Each participating agency contacted their caregivers to let them know about the focus groups and, in the process, introduced them to the Chinese Caregiver Network. All participants were caregivers at the time of the survey who were accessing the services at any of the direct service providers. The agencies targeted caregivers of Chinese descent but did not limit their participation by language.

b. Focus group procedures

Focus group facilitators were trained through a train-the-trainer method, where an expert consultant on focus groups led the training. Each agency sent at least one staff member to the training who was educated on the techniques necessary to effectively run a focus group. Staff members then returned to their agencies and facilitated their own groups.

A script was also created by the consultant to assist the facilitators to explain the purpose of the focus groups to the participants, as well as to assist the facilitators with the flow of the focus groups. The agenda of the focus group was reviewed with the members. These tasks included:

- Welcome and get forms signed
- Guidelines for participation
- Scenario/situation questions
- Challenges and strengths questions
- Next steps

Confidentiality of the group was assured and consent forms were completed by all participating caregivers. The facilitator and/or the scribe were provided with recording sheets to log all of the participants' answers, and facilitators also recorded all answers on flipcharts during the discussion. Participants were able to validate whether their concerns were recorded appropriately by the facilitator. No identifying information was recorded in the process.

c. Focus group questions

Focus group questions were originally developed by the consultant based on different focus group reports. These questions were further fine-tuned based on the feedback from the trainees at the focus group facilitator training session. The focus group questions centred on service and support gaps for caregivers. Six key questions were used to elicit caregiver perceptions of how they gather information and support, their strengths in coping as well as what they wish could happen to improve their ability as caregivers. Each question had pre-determined follow-up questions if they were deemed necessary by the facilitator (all questions are available in Appendix C). The six key questions were:

- Sometimes we become caregivers suddenly. A phone call that says, "Dad had a stroke." Who do you contact to get information/support? What type of information/support do you need?

- At other times, we become family caregivers over time. For instance, you begin by providing light housework, and then you're taking mom to the doctor's office and then more and more. At what point do you say, "I need help"? Who do you contact to get information/support? What types of information/support would you need?
- What stops you from reaching out for information/support?
- What are the personal issues that you experience in coping day to day in your caregiver role?
- What are the strengths that you bring to or have developed in coping day to day in your situation?
- If we were able to grant you several wishes, what would help to make your life better as a caregiver?

d. Data analysis

Based on the written information provided by the focus group scribes, all the focus group facilitators or representatives met to combine the findings of the focus groups. Instead of going through each question independently, the facilitators sat together to discuss unusual or surprising statements made by the participants, statements or questions that elicited the most responses from the participants, answers that were repeated often and any information that service providers and/or funders need to know. Themes were formed based on the responses and were validated by the notes taken by the scribes.

b) Focus Group Results

a. Participants

Approximately 80 individuals participated in nine focus groups between June and July 2012. Eight of the groups were conducted in Cantonese. The ninth focus group was conducted in English, of which only some of the participants were of Chinese descent. The caregivers varied on caring for someone with health issues including chronic diseases, mental health issues and dementia.

b. Findings

The key questions elicited a number of issues, barriers, concerns and strengths of the participants. The facilitators as a group were able to identify the following themes that were found across the nine focus groups:

- 1) Negative emotions arose regarding their role as caregivers, including frustration, stress, fatigue, loss of control and hopelessness
 - a) Worrying was a large part of the caregivers' negative emotions; for some it is non-stop and often affects their ability to sleep
 - b) Some caregivers felt that caregiving was a burden, and that caregiving has resulted in a loss of self-worth as many sacrifice their family and social life to assume the role of caregivers
- 2) Need for more respite as well as physical and tangible aid or services
 - a) Many of the caregivers felt that there was a lack of support from the Community Care Access Centres (CCAC), focussing mainly on physical and respite care; some of the focus groups highlighted that there are also mental health needs that are unmet and ignored by current services
 - b) Caregivers also found that CCAC service hours were not enough or were not consistent
 - c) Not all caregivers were aware of what the CCAC is, nor were they aware of its services

- 3) Language barriers resonated through all of the groups
 - a) There are limited resources in Chinese, including both long-term care and community services
 - b) Services may be available in English, but there is still a need for interpretation services and culturally relevant services
- 4) Education for caregivers
 - a) Caregivers require knowledge and must acquire skills for caregiving
 - b) Some caregivers were unaware of the resources out there, and found that there was a lack of community support after hospital discharge
 - c) Caregivers must learn to self-manage. A focus on self-care is important
 - d) Some caregivers believed that caregiving is a duty: "If I don't do it, who else will do it?"
- 5) Education for care recipients is important on two levels
 - a) Care recipients need to learn to accept help
 - b) Care recipients must also be made aware that their attitudes can affect caregivers; they must learn, understand and accept the stress caused by caregiving on their caregivers
- 6) Increase community acknowledgement and involvement through education
 - a) The lack of recognition for the work of caregivers resonated through the groups as many felt that their work is underappreciated by both family members as well as the government; caregivers believed that through community education, their work will lead to increased support at the community level
 - b) Also, through more education, caregivers hoped to lower stigma related to individuals with health and mental health issues as well as those that care for them
 - c) Caregiving should be a shared responsibility of the community, and there needs to be more third party involvement, including more support through social workers, case workers and general practitioners
- 7) More comprehensive support for caregivers
 - a) Caregivers would like to have a Chinese crisis line answered by health professionals and not by an automated "drop-down" menu
 - b) Financial aid and subsidy, with caregivers stating that caregiving is "an unpaid job" or "duty" that lacks caregiver support resources
 - c) Trained volunteers to communicate, support and/or to stimulate the care recipient or to serve as respite for the caregiver
 - d) More support groups that are culturally specific (beyond just Cantonese groups) and disease or illness specific:
 - Caregivers pointed out that services must be available to look after the care recipient while they are attending support groups
 - e) More local services as much of the services are often centred around the Scarborough area; it is unfair for caregivers that live outside of a service area because the services available to them are less likely to be culturally and linguistically appropriate
 - f) Linkages among institutions need to be improved
 - g) Need for advocacy, including a platform to advocate for more caregiver rights, more services and more government support
- 8) Caregiver strengths as identified by the caregivers
 - a) Empathy
 - b) Stress-management and self awareness, understanding the need for self-care and the ability to remain calm and relaxed
 - c) Positive thinking

- d) Turning to religions to find support and charity to better manage the stress of being a caregiver
- e) Willingness to find help

c) Discussion

Based on the focus group findings, caregivers appear to believe that current services are unable to meet their needs. Caregivers require more physical aid, but more importantly, emotional and spiritual support to help them cope with the multifaceted challenges of being a caregiver. Education at multiple levels could be effective in helping caregivers cope with caregiver burden, increase or develop their strengths as well as improve their roles by improving support from the care recipient, community and government. The need for advocacy for this vulnerable population is therefore necessary.

Part IV: Summary & Conclusion

The findings from both the surveys and focus groups only provide us with a very small snapshot of the current services available to Chinese caregivers within Ontario. It must be highlighted that the findings are based on the Cantonese population within the Greater Toronto Area; the report does not capture, nor represent, all the Chinese caregivers' opinions within Ontario. What the findings of both the partner surveys and focus groups portray is that current services are unavailable, inadequate or inappropriate for Chinese caregivers. Both the agencies and caregivers believe that more linguistically and culturally appropriate support is needed. These services must include tangible and emotional support. There is also a need for improved service navigation and more comprehensive promotion of existing services. More importantly, the government needs to recognize the sacrifices and contributions caregivers make on a day to day basis. CCN can become a platform in which community agencies as well as Chinese caregivers can come together to collaborate and advocate for more caregiver rights. More funding to agencies and more financial support for caregivers is needed to aid in maintaining the well-being of caregivers as they continue their journey to support seniors and other individuals with chronic health issues.

Appendix A. List of Chinese Caregiver Network Agencies

Direct Service Providers

Alzheimer Society of Toronto
Carefirst Seniors & Community Services Association
Hong Fook Mental Health Association
St. Paul's L'Amoreaux Centre
Wellness Centre
Yee Hong Centre for Geriatric Care

Community Educators

Canadian Diabetes Association
Heart and Stroke Foundation
Osteoporosis Canada
The Kidney Foundation of Canada

Appendix B. Resource Sharing Interview Questions

- 1) What workshop(s) would you and your agency like to offer annually to caregivers and advocates?
- 2) What training or education would you and your agency like to offer annually to direct service providers?
- 3) What three resources could you make available to others?
- 4) Do you have a referral process in place for when you receive phone calls directly from caregivers or their advocates? Should CCN collaboratively create a referral process that could be used consistently across members?
- 5) What events/activities does your agency host that might be of interest to direct service providers or caregivers?
- 6) What are the top three programs/services you offer to Chinese caregivers?
- 7) What are the top three most common needs of Chinese caregivers?
- 8) What are the top three resources/programs/services lacking for Chinese caregivers?
- 9) What are the top three methods used to reach out to Chinese caregivers?
- 10) What motivates you to participate in CCN? What do you need to continue?
- 11) What do you have to offer to others?

Appendix C. Focus Group Questions

- 1) Sometimes we become caregivers suddenly. A phone call that says, “Dad had a stroke.” Who do you contact to get information/support? What type of information/support do you need?**

You are told that your father comes out of the hospital tomorrow. What supports do you need? Who would you call? What would you do?
Your dad had a stroke for the second time. Who would/should you call?
Have you experienced anything similar to this? Tell me more.
What support have you found to help you in a similar situation?
What did the hospital staff do to support you? What about family and friends?
Now that you have been a caregiver, what information would have been helpful to have known then?
How did you feel in this situation? (Mentally, physically, emotionally)
- 2) At other times, we become family caregivers over time. For instance, you begin by providing light housework, and then you’re taking mom to the doctor’s office and then more and more. At what point do you say, “I need help”? Who do you contact to get information/support? What types of information/support would you need?**

Have you experienced anything similar to this? Tell me more.
What support have you found to help you in a similar situation?
What did the staff do to support you? What about family and friends?
Now that you have been a caregiver, what information would have been helpful to have known then?
How did you feel in this situation? (Mentally, physically, emotionally)
- 3) What stops you from reaching out for information/support?**

What could help to overcome that issue?
Who are the people in your life that you can call up about your problems or stresses?
What makes it easy to call these people?
When you need information or support, where do you look?
What informal supports do you use? What formal resources do you use?
- 4) What are the personal issues that you experience in coping day to day in your caregiver role?**

Has anyone else experienced a similar issue? What did you do?
Are there times of the day or days of the week that are more difficult to cope with than others?
Tell us more about why that is the case.
Sometimes we find resources that seem like magic. Have you found anything that really has helped you deal with your role as a caregiver? What is that?
- 5) What are the strengths that you bring to or have developed in coping day to day in your situation?**

Sometimes I can be surprised at where I find solutions or strength. What has surprised you about your ability to cope?
Finish this sentence: My day would be worse if I did not remember to....
The one thing that helps my week to go smoother is.....

6) If we were able to grant you several wishes, what would help to make your life better as a caregiver?

Time permitting questions:

What was the least helpful support you have experienced?
Do you have any other comments or suggestions?