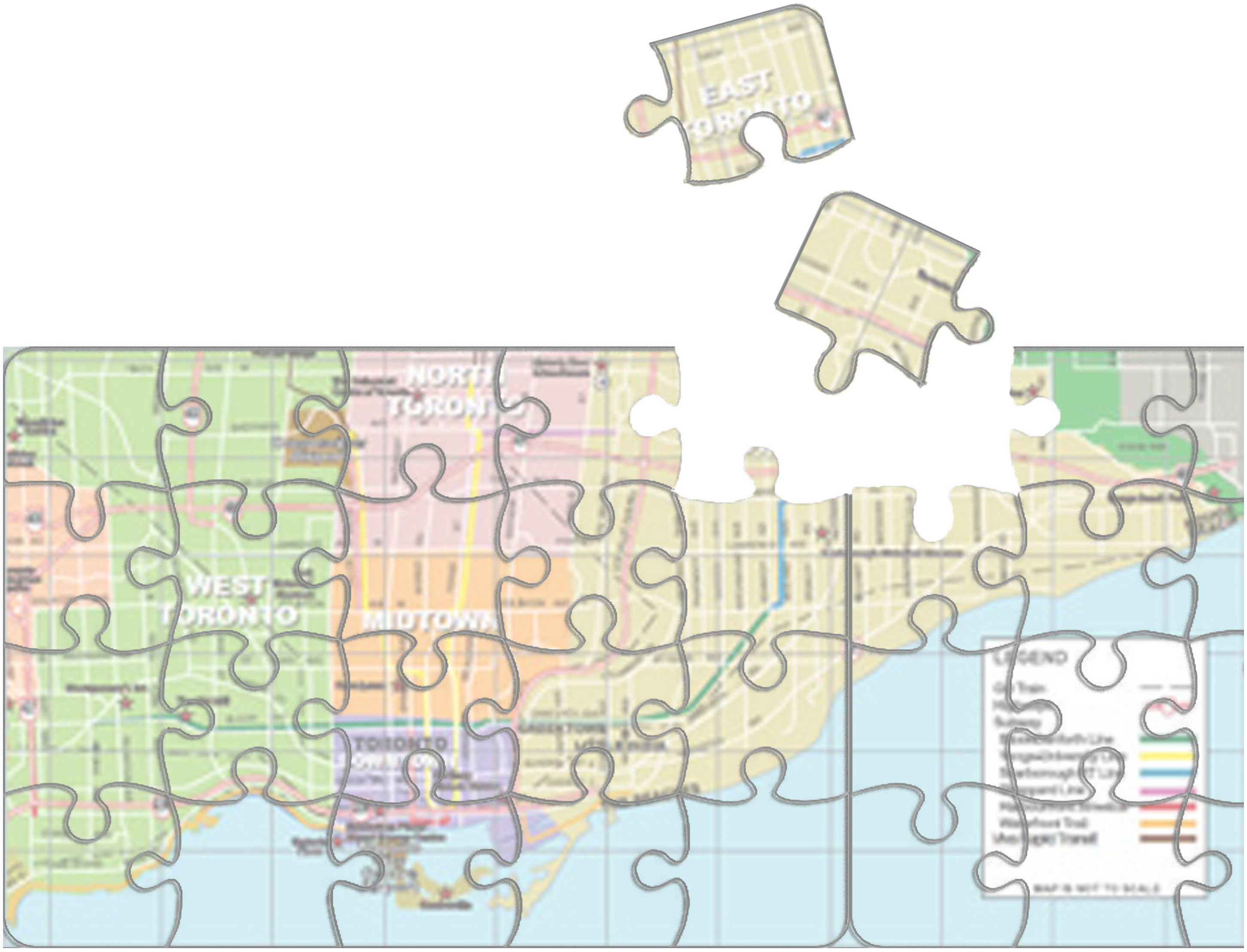
Mapping Ourselves:

Current Services and Resources for Chinese Caregivers
&
Caregiver Barriers and Needs



Chinese Caregiver Network

Alzheimer Society Toronto
Canadian Diabetes Association
Carefirst
Heart & Stroke Foundation
Hong Fook Mental Health Association
Osteoporosis Canada / Ostéoporose Canada
St. Paul's Community Services and Housing
The Kidney Foundation of Canada
Wellness Centre 恆康中心
Yee Hong Centre For Geriatric Care 頤康中心

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Acknowledgements

The Chinese Caregiver Network would like to thank the Heart and Stroke Foundation for its generosity to fund this project. We would also like to acknowledge Deborah Konecny of the Catalyst Centre for her expertise and guidance during this project, as well as Bernice Chan, Master of Social Work candidate at the University of Toronto, for her efforts in completing the interviews and presentation.

We would like to recognize the caregivers who participated in the focus groups. Their insights and feedback are necessary for the Network to better understand the needs of Chinese caregivers.

We thank the following participating agencies for their contributions to the completion of the project and report: Alzheimer Society of Toronto, Canadian Diabetes Association, Carefirst Seniors & Community Services Association, Heart and Stroke Foundation, Hong Fook Mental Health Association, Osteoporosis Canada, St. Paul's L'Amoreaux Centre, the Kidney Foundation of Canada, Wellness Centre, and Yee Hong Centre for Geriatric Care.

Last but not least, we would like to thank the committee members for their time and effort in developing our Network: Barbara Beauchamp, K.C. Chan, Phillip Chan, Sarafina Hui, Anne Le-Quang, Leqin Lu, Bonnie Wong, Julie Wong, Doris Yang, Rachel Zeng and our co-chairs, Maria Chu and Leon Lau. We also thank Bonnie Hao Yan Wong, writer of this report, and Barbara Yang, editor and translator, for their contributions.

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 want 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?

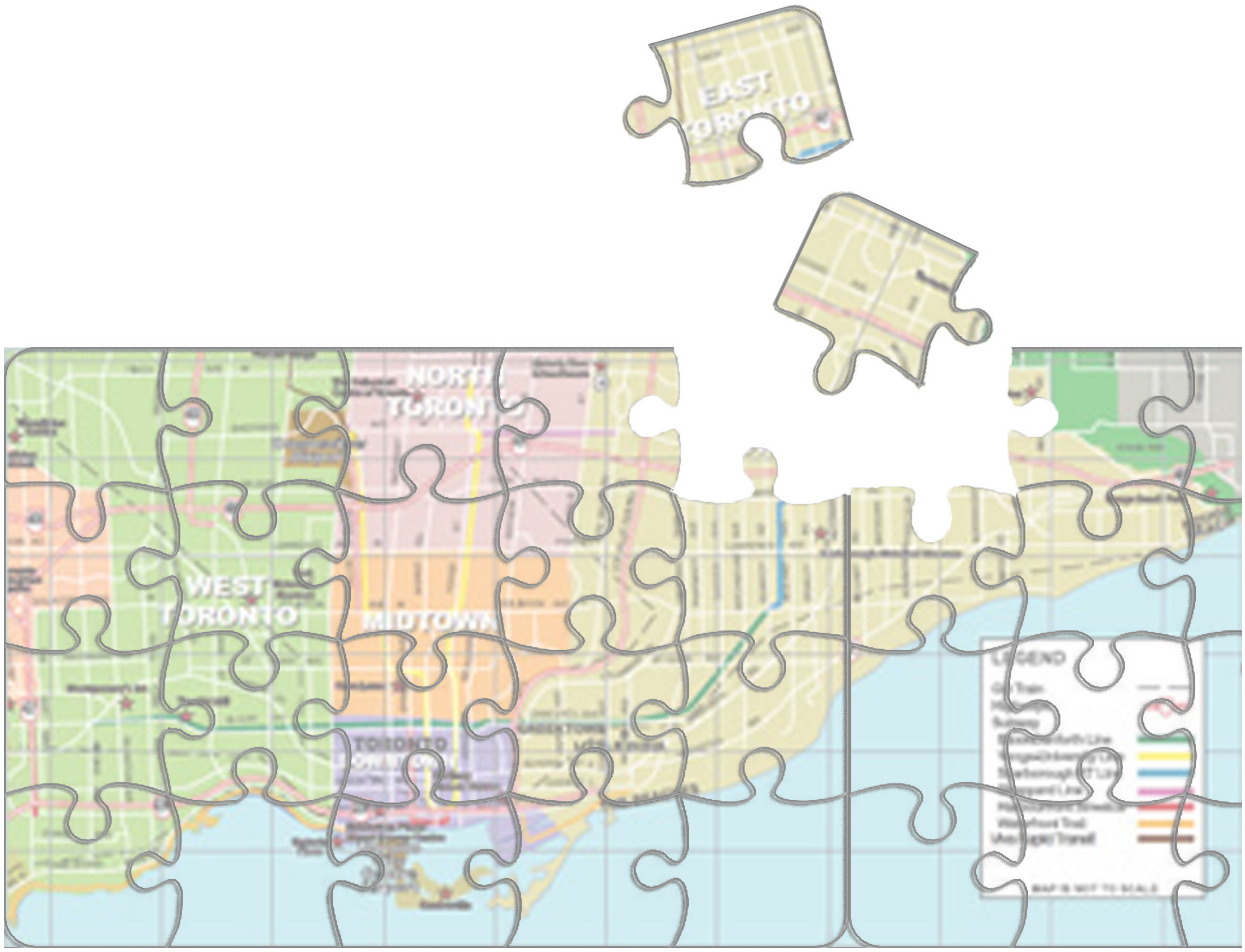
5) **What are the strengths that you bring to or have developed in coping day to day in your situation?**
   Sometimes I can be surprised at where I find solutions or strength. What has surprised you about your ability to cope?
   Finish this sentence: My day would be worse if I did not remember to....
   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?

華人關顧者現有服務及需要研究



華人關顧者網絡

Alzheimer Society Toronto

Canadian Diabetes Association

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Heart & Stroke Foundation

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Osteoporosis Canada
Ostéoporose Canada

St. Paul's Community Services and Housing

The Kidney Foundation of Canada
The foundation of kidney care.

Wellness Centre
恆康中心

Yee Hong Centre For Geriatric Care
頤康中心

鳴謝

華人關顧者網絡感謝心臟及中風基金會慷慨資助這個研究項目，Catalyst Centre 顧問 Deborah Konecny 提供意見及指導，以及多倫多大學社會工作碩士研究生 Bernice Chan 完成訪問及簡報。

我們表揚參與焦點小組的關顧者。他們的意見和反饋十分重要，讓本網絡對華人關顧者的需要有更深入的瞭解。

感謝以下機構的參與，為這個項目及報告的完成作出貢獻：多倫多認知障礙症協會、加拿大糖尿病協會、耆暉會、心臟及中風基金會、康福心理健康協會、加拿大骨質疏鬆症協會、聖保羅中心、加拿大腎臟基金會、恆康中心及頤康中心。

最後，我們感謝華人關顧者網絡所有委員為網絡的發展付出寶貴的時間和努力：Barbara Beauchamp、K.C. Chan、Phillip Chan、Sarafina Hui、Anne Le-Quang、Leqin Lu、Bonnie Wong、Julie Wong、Doris Yang、Rachel Zeng，以及我們的共同主席 Maria Chu 和 Leon Lau。我們也感激這個報告的作者 Bonnie Hao Yan Wong 以及編輯和翻譯 Barbara Yang。

目錄

摘要

爲家人提供無償照顧的關顧者所付出的貢獻和犧牲往往得不到承認和表揚。在士嘉堡及鄰近地區，有不少資源為粵語社區裡的關顧者提供支援。在 2012 年，華人關顧者網絡通過訪問和關顧者焦點小組，向參與機構和關顧者蒐集意見，以便對現有服務作出評估。這份報告縱覽華人關顧者網絡的成員機構現有的關顧者服務，並且凸顯關顧者的需要和能力。

主要的調查結果包括：

- 需要更多切合語言文化需要的服務和資源，包括暫顧服務以及身體和實質上的輔助。
- 需要更切實的支持系統，包括社會、經濟以及心理社會上的支持，以彌補關顧者爲了照顧長期病患者以及支持長者在社區內過著獨立和融合的生活而作出的貢獻和犧牲。
- 需要改善服務導航以及更全面地推廣現有的服務提供者，例如社區醫療護理服務中心（CCAC）和社區健康中心。

華人關顧者網絡建議政府與參與機構合作，積極回應關顧者人口的需要。根據這些調查結果，本網絡的成員機構可以探索更好的合作方式，協助關顧者使用不同的服務，不僅是在本網絡之內的服務，也包括其他現有的服務提供者。華人關顧者網絡可以作爲一個平台，讓關顧者表達他們的關注，並且可以作爲倡導的渠道。

一、研究項目描述

基本原理

華人關顧者網絡由十個衛生及社會服務機構組成，目的是在安省的華人社區之中倡導及推廣華人關顧者的聯繫、教育、資訊共享及訓練。本網絡的成員機構希望探索最有效的合作途徑，為社區內的關顧者提供必需的支援和服務。本報告的附錄一列出十個參與機構的名單。這些機構被劃分為社區教育機構和直接服務機構。

目的

華人社區對於家庭關顧者可以使用的服務和資源缺乏記錄和一致的理解。本專案目的是蒐集成員機構現有服務的資訊以及確認關顧者的需要和能力，並且根據調查結果提出建議，作爲華人關顧者網絡未來工作計劃的指引。

蒐集數據方法

調查所得的資料直接來自兩個源頭：伙伴機構以及可能使用其服務的家庭關顧者。我們採用伙伴調查或訪問的方式，確定參與機構目前向關顧者提供的服務和資源。此外，個別直接服務機構組織和主持關顧者焦點小組，瞭解關顧者的需要。

所有數據都在 2012 年 6 月及 7 月通過調查和焦點小組蒐集。

二、調查結果

調查方法

（一）招募參加者

華人關顧者網絡全部十個成員機構獲通知進行資源共享訪問；每個機構指派一位最熟悉機構資源的職員回答問題。

（二）程序

一位社會工作碩士研究生接受顧問的訓練，對參與機構進行訪問。所有機構均直接與研究生聯繫。在四個社區教育機構之中，有三個通過電子問卷調查回答問題；第四個社區教育機構則完成電話訪問。在直接服務機構之中，五個機構完成面談，餘下的機構則完成電子

問卷調查以及電話跟進訪問。電話訪問約為 30 分鐘，面談則平均約達一小時。在訪問期間，調查員記錄詳盡的筆記，並且在訪問結束不久之後總結已蒐集的資料。

（三） 調查問題

調查問題目的是瞭解參與機構目前向社區裡的關顧者提供的資源，以及確定參與機構是否願意與其他參與機構共享資源。要詳盡地列出所有可用的資源並不可能；因此，我們請參與機構凸顯它們可以與伙伴機構共享的關顧者資源。華人關顧者網絡的共同主席在顧問的協助下設計了一套問題，用以確定參與機構在調查期間的資源和能力。附錄二列出所有調查問題，其中第 6-9 條問題只須由直接服務機構回答。

主要訪問結果

（一） 資源共享

(1) 社區教育機構

參與調查的社區教育機構為加拿大糖尿病協會、心臟及中風基金會、加拿大腎臟基金會及加拿大骨質疏鬆症協會。這些機構都願意每年為關顧者和倡導者提供特定病症的工作坊，並且為直接服務機構提供培訓和教育。它們也願意共享與特定病症相關的印刷品資源。

(2) 直接服務機構

參與調查的直接服務機構為多倫多認知障礙症協會、耆暉會、康福心理健康協會、聖保羅中心、恆康中心及頤康中心。這些機構都願意為關顧者及其倡導者提供多種工作坊，題材包括失智症/老年痴呆症、關顧者壓力及情緒管理、糖尿病、預防跌倒及骨骼健康、喪親支援，以及有關不同精神健康議題的資訊。為直接服務機構提供的培訓或教育與關顧者工作坊類同，然而在題材上也包括了長期病患自我管理課程、虐老、長者心理諮詢和訓練、同輩學習和倡導工作坊、認識中國文化，以及幽默治療。

（二） 轉介程序

在十個機構中，有九個機構設有轉介程序。通常由一位接收個案工作者蒐集客戶的資料，填寫接收表格，並以電話或面談方式完成跟進評估。然後，接收個案工作者便會根據客戶的需要作出內部或對外的轉介。有六個機構不認爲華人關顧者網絡應該創立一個由成員機構一致採用的轉介程序；而有兩個機構則表示希望有這樣的程序。

（三） 直接服務機構或關顧者感興趣的活動

這些活動包括關顧者互助小組、探討華人長者需要的靜修會，以及不同機構合辦的多種健康展覽。

（四）為華人關顧者提供的服務

這個調查所蒐集的機構服務範圍有限。有五個機構把教育工作坊和互助小組列入它們為華人關顧者提供的最重要的服務。有三個機構列舉個別輔導；至於中文資訊材料、家居護理服務、長者日間服務和康樂活動則只各列舉一次。應注意實際數字可能更多，以上調查結果是根據個別機構認爲它們為關顧者提供的三項最重要的服務。

（五）華人關顧者普遍和未能滿足的需要

華人關顧者的普遍需要可以分爲兩類：情緒上的需要以及身體和實質上的需要。直接服務機構認爲目前缺乏照顧這些需要的資源和服務。切合語言和文化需要的實質服務能紓解關顧者的壓力，然而，受訪機構特別多次提及長者日間服務、家居支援服務和長期護理院的輪候人數極多。其他未能滿足的需要包括經濟上的支援和就業福利、照護方面的知識和技能教育、個人或小組輔導的支援，以及倡導關顧者權益所需的支援。

（六）向華人關顧者外展

所有受訪機構都使用大衆媒體與華人關顧者接觸。幾乎所有機構都使用某種形式的轉介：部分機構使用“口碑”；其他機構也使用網上資源向華人關顧者外展，例如機構網站。

（七）參與華人關顧者網絡的原因及機構可以作出的貢獻

參與機構凸顯華人關顧者的服務不足，通過合作，華人關顧者網絡可以致力找出成員機構的共同興趣，達成短期和長期目標。參與機構願意共享資源，彼此提供專業知識和資訊。這將會增加成員機構可使用的資源，將來可能發展更多中文材料以及這方面的總目或一個關顧者網站。整體來説，華人關顧者網絡可以建立集體倡導能力，在政策層面推動改變。

討論

調查結果顯示：伙伴機構大力支持華人關顧者網絡，成員之間有更大的合作空間。部分服務有所重疊，而一些服務和資源可以共享。此外，這個調查也凸顯了即使服務重疊，例如長者日間服務，輪候的人數仍然很多。是次服務調查讓華人關顧者網絡的成員機構有機會攜手合作，確保關顧者有知識和能力使用不同機構的服務。

華人關顧者網絡已討論共享資源的重要，包括發展網上資源數據庫，把不同機構的網站連繫起來。這可以讓關顧者一站式瀏覽成員機構提供的所有服務。華人關顧者網絡也將會探索建立一個包羅不同機構的服務總目，這個發展可以幫助社會工作者和個案接收工作者適當地把客戶轉介到不同的參與機構。

三、關顧者焦點小組

在六個直接服務機構之中，有四個機構完成焦點小組。這四個直接服務機構都為華人關顧者提供相關服務。

調查方法

（一）招募參加者

參與機構各自與它們的關顧者聯繫，告知他們舉行焦點小組，並且在過程中向他們介紹華人關顧者網絡。所有參加焦點小組的人當時都是關顧者，正在使用參與調查的直接服務機構所提供的服務。參與機構以華人關顧者為招募對象，但是並不以語言的要求限制他們參與焦點小組。

（二）焦點小組程序

焦點小組協調員接受“培訓導師”方式的訓練，由一位焦點小組專家顧問帶領。每個機構派出至少一位職員接受培訓，學習有效地主持焦點小組的必需技巧。職員受訓之後回到他們的機構協調他們的焦點小組。

顧問也準備了一個講稿，幫助協調員向參加者解釋焦點小組的目的和推進焦點小組的流程。協調員也跟組員仔細審閱焦點小組的議程。其中包括：

- 歡迎和簽署同意書
- 參加焦點小組指引
- 情景/處境問題
- 挑戰和力量議題
- 下一步

協調員向小組組員保證小組的保密性，並請所有組員填妥同意書。協調員及/或抄寫員在大會提供的記錄紙張上，把參加者的答案全部記錄下來；在討論期間，協調員也在掛紙白板上記錄所有答案。參加者可以確認他們的意見是否已被協調員恰當地記錄下來。在討論過程中，沒有記錄任何識別身份的資料。

（三）焦點小組使用的問題

焦點小組使用的問題起初由顧問根據不同的焦點小組報告草擬，然後再根據焦點小組協調員培訓課程中受訓者的反饋進行微調。焦點小組的問題集中於關顧者服務及支援方面的缺

口，用六個主要問題引出關顧者對以下事項的觀感：他們如何獲取資訊和支援、他們的應付能力，以及他們希望如何改善作爲關顧者的能力。每個問題都有預設的跟進問題，如果協調員認爲有必要，就可以使用跟進問題（附錄三列出所有問題）。這六個主要問題就是：

- 有時候，我們突然成爲了關顧者。當您接到一個電話，說：“爸爸中風了”，您會聯絡誰去取得資訊/支援呢？您需要哪一類的資訊/支援呢？
- 在別的時候，我們會逐漸成爲家人的關顧者。例如剛開始的時候，您幫忙做一些簡單的家務；然後，您要帶媽媽去看醫生；然後，要做的越來越多。您在哪個階段會說：“我需要幫助”？您會聯絡誰去取得資訊/支援呢？您需要哪一類的資訊/支援呢？
- 是什麼阻止您向外尋求資訊/支援？
- 您每天應付關顧者的角色時，經歷什麼個人問題？
- 您每天應付您的處境時，帶來什麼力量或培養了什麼力量？
- 如果我們能夠給您幾個願望，有什麼可以幫助您改善您作爲關顧者的生活？

（四） 數據分析

所有焦點小組協調員或代表聚首一堂，根據焦點小組抄寫員提供的書面資料，把焦點小組的調查結果結合起來。協調員並非獨立地研究每個問題，而是一起討論參加者提出的不尋常或出人意表的陳述、最能引起參加者回應的陳述或問題、經常重複的答案，以及服務機構及/或資助機構需要知道的任何資訊。協調員根據參加者的回應定出主題，並且用抄寫員的筆記來核實。

焦點小組結果

（一） 參加者

在 2012 年 6 月和 7 月期間，約八十位人士參加了九個焦點小組。其中八個小組以粵語進行。第九個小組則以英語進行，組內只有部分組員是華裔。這些關顧者所照顧的親友有不同的健康問題，包括長期病患、心理健康問題和失智症。

(1) 調查結果

焦點小組的主要問題引出參加者多項議題、障礙、關注和力量。協調員從這九個焦點小組的討論中，共同識別了下列主題：

1) 參加者對於他們作爲關顧者的角色產生負面情緒，包括灰心、壓力、倦怠、失控、無望。

    - a) 關顧者主要的負面情緒是憂慮；有些關顧者擔憂不已，往往影響他們不能入睡。
    - b) 部分關顧者覺得照顧家人是一種負擔，導致他們失去了自我價值，因爲不少關顧者爲了這個角色犧牲了他們的家庭和社交生活。
2) 需要更多暫顧服務以及身體和實質上的輔助或服務：
    - a) 多位關顧者覺得缺乏社區醫療護理服務中心（CCAC）的支援，他們的需要大多集中於身體上的護理和暫顧服務；部分焦點小組凸顯心理健康方面的需要，而現有服務不能滿足或漠視了這方面的需要。
    - b) 關顧者也指出 CCAC 的服務時間不足或不一致。
    - c) 並非所有關顧者都知道 CCAC 是什麼，也不認識 CCAC 的服務。
3) 所有焦點小組都表達語言障礙的問題：
    - a) 以中文提供的資源有限，包括長期護理和社區服務方面。
    - b) 以英語提供的服務也許存在，但是仍然需要傳譯服務以及與文化相關的服務。
4) 關顧者教育：
    - a) 關顧者需要知識和必須學習照護的技能。
    - b) 部分關顧者不知道外面的資源，當家人出院之後，感到缺乏社區的支援。
    - c) 關顧者必須學習自我管理。重視自我照顧十分重要。
    - d) 部分關顧者認爲照護家人是一個責任：“如果我不做，還有誰來做？”
5) 被關顧者的教育在兩個層面上很重要：
    - a) 被關顧者需要學習接受幫助。
    - b) 被關顧者也必須知道他們的態度可以影響關顧者；他們必須學習、明白和接受照護工作對關顧者所造成的壓力。
6) 通過教育加強社區的肯定和參與：
    - a) 所有焦點小組都指出關顧者的工作缺乏肯定，許多關顧者都覺得他們的工作沒有充分獲得家人和政府的欣賞和感激；關顧者相信通過社區教育，他們的工作將會在社區層面獲得更多支持。
    - b) 同時，關顧者希望通過更多教育，可以減少社會對於身體和心理健康有問題的人及其關顧者的成見和歧視。
    - c) 照護的責任應該由社區分擔，並且需要更多第三方的參與，包括通過社會工作者、個案工作者和醫護人員獲得更大的支援。
7) 為關顧者提供更全面的支援：
    - a) 關顧者希望有一條由醫療專業人士回答的中文危機熱線，而非一個自動化的“下拉式”選單。
    - b) 經濟援助和補助金：關顧者指出照護工作是 “無償工作”或“責任” ，缺乏支援關顧者的資源。

    c) 由受過培訓的義工與被關顧者溝通，提供支援及/或刺激，或提供暫顧服務，讓關顧者得以稍事歇息。
    d) 更多符合特定文化（不僅限於粵語小組）和特定病患的互助小組。
    - 關顧者指出當他們出席互助小組時，必須有照顧被關顧者的服務。
    e) 更多地方服務：現有服務通常集中在士嘉堡地區；這對於住在服務地區以外的關顧者不公平，因爲他們較不可能獲得切合語言文化需要的服務。
    f) 不同機構之間的聯繫需要改善。
    g) 需要倡導，包括一個爭取更多關顧者權益、更多服務和更多政府支援的平台。
8) 由關顧者確認的關顧者力量：
    a) 同理心。
    b) 壓力管理和自我意識；明白自我照顧的需要和保持輕鬆、冷靜的能力。
    c) 積極思想。
    d) 在信仰中尋求支持和仁愛，從而更有效地管理作爲關顧者的壓力。
    e) 願意尋求幫助。

討論

焦點小組的結果顯示：關顧者認爲現有服務不能滿足他們的需要。對關顧者的支援需要有更多實質上的輔助，而更重要的是情緒上和心靈上的支持，幫助他們應付作爲關顧者多方面的挑戰。多層面的教育可以有效地幫助關顧者應付照護家人的擔子，加強或培養他們的力量，以及藉著改善被關顧者、社區和政府的支持，改善關顧者的角色。因此，為這群備受壓力的關顧者人口進行倡導是必需的。

四、總結及結論

這個調查和焦點小組的結果讓我們稍微瞥見在安大略省內華人關顧者目前可以使用的服務。我們必須強調這些結果主要是來自大多倫多地區的粵語人口；這份報告並不涵蓋或代表安省所有華人關顧者的意見。伙伴調查和焦點小組的結果反映了現有服務對於華人關顧者來説是欠奉、不足或不適合的。參與機構和關顧者都表示需要更多切合語言文化需要的支援。這些服務必須包括實質上和情緒上的支援。同時，服務導航也需要改善，而現有的服務也需要更全面的推廣。更重要的是，政府需要承認關顧者日復一日所作出的犧牲和貢獻。華人關顧者網絡可以成爲一個平台，讓社區機構以及華人關顧者攜手合作和倡導更多關顧者權益。服務機構需要更多撥款，而關顧者也需要更多經濟上的支援，使他們在繼續照顧長者和其他長期病患者的旅途上，能保持身心健康。

附錄一、華人關顧者網絡成員機構

直接服務機構

多倫多認知障礙症協會
耆暉會
康福心理健康協會
聖保羅中心
恆康中心
頤康中心

社區教育機構

加拿大糖尿病協會
心臟及中風基金會
加拿大骨質疏鬆症協會
加拿大腎臟基金會

附錄二、資源共享訪問問題

1) 您和貴機構每年想為關顧者和倡導者提供哪種工作坊？
2) 您和貴機構每年想為直接服務機構提供什麼培訓或教育？
3) 您可以讓其他機構使用哪三種資源？
4) 當您收到關顧者或他們的倡導者直接來電時，是否有一個轉介程序？華人關顧者網絡是否應該設立一個所有成員機構都可以一致採用的轉介程序？
5) 在貴機構主辦的活動之中，有哪些是直接服務機構或關顧者可能感興趣的？
6) 您為華人關顧者提供的三項最主要的活動/服務是什麼？
7) 華人關顧者最常見的三種需要是什麼？
8) 華人關顧者最缺乏的三種資源/活動/服務是什麼？
9) 向華人關顧者外展的三種最主要的方法是什麼？
10) 是什麼推動您參與華人關顧者網絡？您需要什麼使您繼續參與？
11) 您有什麼可以提供給其他機構？

附錄三、焦點小組問題

1) **有時候，我們突然成爲了關顧者。當您接到一個電話，說：“爸爸中風了”，您會聯絡誰去取得資訊/支援呢？您需要哪一類的資訊/支援呢？**
   您獲知您的爸爸明天出院。您需要什麼支援？
   您會致電誰？您會怎樣做？
   您的爸爸第二次中風。您會/應致電誰？
   您曾否有類似的經歷？請詳細一點告訴我。
   在類似的情況下，您找到什麼支援？
   醫院的職員做了什麼去支援您？親友又怎麼樣？
   您現在已經成爲了關顧者，當時如果您知道什麼樣的資訊，可能會對您有幫助？
   在這種情況下，您感覺怎麼樣？（心理上、身體上、情緒上）

2) **在別的時候，我們會逐漸成爲家人的關顧者。例如剛開始的時候，您幫忙做一些簡單的家務；然後，您要帶媽媽去看醫生；然後，要做的越來越多。您在哪個階段會說：“我需要幫助”？您會聯絡誰去取得資訊/支援呢？您需要哪一類的資訊/支援呢？**
   您曾否有類似的經歷？請詳細一點告訴我。
   在類似的情況下，您找到什麼支援？
   職員做了什麼去支援您？親友又怎麼樣？
   您現在已經成爲了關顧者，當時如果您知道什麼樣的資訊，可能會對您有幫助？
   在這種情況下，您感覺怎麼樣？（心理上、身體上、情緒上）

3) **是什麼阻止您向外尋求資訊/支援？**
   有什麼可以幫助您克服這個問題？
   在您認識的人當中，您可以致電誰談談您的問題或壓力？
   爲何您可以很容易致電這些人？
   當您需要資訊或支援時，您會到哪裡尋找？
   您使用哪些非正式的支援？您使用哪些正式的資源？

4) **您每天應付關顧者的角色時，經歷什麼個人問題？**

是否有其他人經歷過類似的問題？您怎樣做？

一天裡某些時候，或一個星期裡某些日子是否比其他時候或日子較難應付？

請詳細一點告訴我們爲何有這種情況。

有時候，我們找到一些像魔法一樣神奇的資源。您曾否找到任何真正能幫助您處理關顧者角色的資源？那是什麼？

5) **您每天應付您的處境時，帶來什麼力量或培養了什麼力量？**

我從何找到解決辦法或力量，有時候讓我感到驚奇。您應付問題的能力有哪方面讓您感到驚奇？

完成這一句：如果我忘記了......，我的日子可能會更糟。

幫助我一個星期過得比較順利的一件事情就是......

6) **如果我們能夠給您幾個願望，有什麼可以幫助您改善您作爲關顧者的生活？**

時間許可才討論的問題：

您經歷過最不能幫助您的支援是什麼？

您有沒有其他意見或建議？