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Heart and Stroke Foundation

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke:

Exploring Barriers and Service Gaps

**Carefirst Seniors and Community
Services Association**

Carefirst Research Team



October – 2012

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

The Heart and Stroke Foundation, a volunteer-based health charity, leads in eliminating heart disease and stroke and reducing their impact through:

- the advancement of research and its application,
- the promotion of healthy living,
- advocacy.

Carefirst Seniors and Community Services Association is committed to ensure that Chinese Seniors and where appropriate, others in need of services, in the Greater Toronto Area and the surrounding areas live a Quality & Enriched Life in the community. Specifically, we strive to promote and enhance their personal wellness through a range of Social, Health Care, and Supportive Services, planned and delivered on a holistic basis.

How to obtain this information

Specific inquiries about this report and request for copies of this report should be directed to:

Leqin Lu, Heart and Stroke Foundation

Telephone: 416-489-7111x437 Fax: 416-489-7141 Email: llu@hsf.on.ca

OR

Betty Duong, Carefirst Seniors and Community Services Association

Telephone: 416-502-2323x6306 Fax: 416-502-2382 Email: betty.duong@carefirstseniors.com

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

Table of Contents

Acknowledgements	1
Executive Summary	2
Introduction and Background	5
Age and Vascular Health: “Age is an axis along which inequities travel” Koehn et al., 2012	5
Populations at Risk	6
Cardiovascular Disease & Chinese Emigration	6
Research Aims	7
Study Objectives	7
Review of Pertinent Literatures	8
Literature on Health Care and Caregiving for Chinese Older Adults	8
Literature on Caregiving and Caregivers	10
Literature on Cardio-Vascular Diseases among Older Chinese Adults	10
Literature on Self-Management among Canadian-Chinese Older Adults with Heart Disease or Stroke	11
Summary of Literature Review	11
Research Questions	11
Research Design and Methodology	12
Sample	12
Semi Structured Interviews with Chinese Informants	13
Data Collection and Analysis	14
Recruitment of Participants	14
Recruitment Process	15
Formats	18
Data Analysis	18
Major Findings	21
Self-Medication	28
Significance of Identified Service Gaps, Unmet Needs, and Barriers	28
Limitations of the Study.....	33
Further Research	33
Recommendations	33
Macro Level.....	33
Micro Level.....	34
Conclusion	40
References	41

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

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Chinese Ontarians Living with Heart Disease or Stroke

October 2012

Executive Summary

Objectives

Generously funded by the Chinese Canadian Council of the Heart and Stroke Foundation, this study of Chinese Ontarians living with heart disease or stroke was conducted by Carefirst Seniors and Community Services Association. The purpose of the study was to examine the service gaps, unmet needs, and barriers faced by Chinese Ontarians living with heart disease or stroke from the perspectives of the survivors, their caregivers, and health care providers. In addition, self-management and self-care strategies used by Chinese Ontarian survivors and their caregivers were examined in order to develop recommendations for future initiatives, funding opportunities, and strategic directions for promoting vascular health of Chinese Ontarians.

Methods

A mixed research design utilizing both quantitative and qualitative data collection methods were used. This included a targeted literature review, focus groups and individual interviews with a sample of survivors, caregivers and health care providers from the Greater Toronto Area (GTA). In addition, individual interviews and open-ended surveys were completed with a non-random sample of survivors, caregivers, and health care providers from the non-GTA. Altogether, sixty-three informants were involved in the study: 26 survivors of heart disease or stroke, 19 caregivers, and 18 health care providers. The results reflect input from focus groups (n=9), individual face-to-face/phone interviews (n=8), and open-ended email surveys (n=9). Data analysis was guided by an awareness that informants' responses would reflect the social context of aging in Canadian society where gender, ethnicity, level of education, and length of residence in Canada are important social determinants of health.

Results

Major service gaps, unmet needs, and barriers were identified by survivors of heart disease or stroke, caregivers, and health care providers. Analysis of the findings generated four major themes:

1. **Equitable Accessibility** – language barriers, shortages of transportation and translation services, a shortage of Mandarin-speaking family physicians and specialists, lack of health information and knowledge of the Canadian health care system
2. **Affordability** – financial challenges involved in caregiving, a shortage of government subsidized culturally and linguistically appropriate community programs and supports for Chinese survivors living with heart disease or stroke and their caregivers, lack of affordable home care services to alleviate the burden of caregivers

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

3. **Integration and Coordination of Care** – long waiting times (due to insufficient Mandarin-speaking family doctors and specialists), as well as a general lack of information, led many survivors to seek health information and medical advice from “non-professionals” or from “unofficial” Chinese speaking sources
4. **Opportunities for Self-Management** – the concept of self-management among informants involved a mixture of self-care and self-medication, specifically among recent immigrants who used a mixed method of Chinese traditional medicine and prescribed Western medicine; the younger cohort of informants, however, favoured utilizing self-management knowledge and Western medicine; survivors of heart disease or stroke also practiced exercising on a daily basis, eating healthy food and maintaining a healthy lifestyle, actively seeking health information from various sources, and developing a positive/optimistic outlook; caregivers who play the dual role of patient and caregiver are often overburdened with their responsibilities, constraining their own opportunities for effective self-management

Recommendations

The recommendations from this research align with those of the Heart and Stroke Foundation, provincial health care strategies, and the recently released report, *Shaping the Future of Vascular Health: An Integrated Vascular Health Blueprint for Ontario* (Cardiac Care Network, Heart & Stroke Foundation & Ontario Stroke Network, 2012). Furthermore, these findings and recommendations are not limited to Chinese Ontarians. They are highly relevant to apply the findings to all areas of Ontario where diversity exists. To ensure quality and sustainable vascular health care for all Ontarians, service gaps, unmet needs and barriers associated with vulnerable and marginalized populations (e.g. Immigrant women, South Asian senior immigrant caregivers, older frail seniors), need to be identified and supported with integrated and coordinated systems.

Study recommendations parallel the above identified themes/issues related to service gaps, unmet needs, and barriers.

1. **Enhance Equitable Accessibility**

- Improve access to primary health care by expanding primary care and the role of physicians and other primary health care providers, e.g. the Family Health Team Model
- Invest in technology such as the *Ontario Telemedicine Network (OTN)* – “*Right Provider, Right Place & Right Time*” to increase access to diverse communities
- Develop culturally sensitive and linguistically aligned vascular health care practice models
- Develop a “One-Stop Information Portal / On-line Database” in the Chinese language which is user-friendly and easily accessible
- Develop a Mobile Primary Care Team including family physician, nurse, social worker, OT/PT and pharmacist which can provide timely medical/health consultation and intervention for high risk survivors

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

- Assist in providing to survivors/caregivers preferred language self-management and behavior modification support offered by health care professionals
2. ***Increase Affordability***
- Increase availability of subsidized home care programs and services
 - Offer financial subsidies to marginalized populations of survivors of heart disease or stroke, not only to support the survivors' basic activities of daily living, but also to prevent the costly alternative of premature institutionalization
3. ***Improve Integration and Coordination of Care***
- Formulate standardized clinical guidelines which can be communicated amongst health care providers and with patients in their preferred language
 - Disseminate tools, translated into preferred population languages, in order to optimize knowledge transfer especially at critical transition points
 - Develop intensive case management, care coordination and an inter-disciplinary team based approach that aims at promoting seamless care, accessibility and affordability for vascular health care which is culturally sensitive
 - Support the development of a Program of All Inclusive Care for the Elderly (PACE) Model which integrates coordinated vascular care with Family Health Teams and community support services which can maintain clients at home and prevent premature institutionalization
4. ***Support Utilization and Opportunities for Self-Management***
- Develop innovations in primary care practice and self-care models to help ensure timely, effective, and managed vascular care
 - Direct LHIN funding to develop and incorporate structured self-management programs for heart disease or stroke survivors and their caregivers especially in regions where there are high numbers of immigrant populations with increased incidence of heart disease or stroke
 - Adapt and expand the Stanford University Chronic Disease Self-management Program to the needs of Chinese Ontarian survivors of heart disease or stroke
 - Develop and integrate with existing chronic disease management centres (e.g. Complex Diabetes Care Centre) for care coordination and provision of disease specific structured health maintenance programs for heart disease or stroke survivors
 - Support further research to develop a new model that recognizes and integrates traditional health beliefs, medications and health/healing practices in modern health care for Chinese survivors from non-western cultures
 - Develop caregiver support groups with an emphasis on supporting those with a heavy burden of care and on senior women who often play a dual role of being caregiver to grandchildren and caregiver to a survivor, while themselves being a survivor of heart disease or stroke

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

I. Introduction and Background

The Heart and Stroke Foundation is in the midst of developing a national strategic plan to formulate key objectives and specific directions under which future policies and initiatives can align. With contributions made from the Chinese Canadian Council of the Heart and Stroke Foundation, this study was undertaken by Carefirst Seniors and Community Services Association to further explore the issues surrounding Chinese Ontarians living with heart disease or stroke, in order to produce recommendations for the 2014 provincial diversity strategy and beyond. The Carefirst Research Team includes: advisors, Sheila M. Neysmith (DSW, University of Toronto) and Judy Murray (MScPT, Mackenzie Richmond Hill Hospital), and members, Helen Leung (CEO, Carefirst), Alice Mui (Program Director, Carefirst), Betty Duong (Program Development Officer, Carefirst), Courtney Po (Research Assistant, Carefirst), Clare Cheng (Research Assistant, Carefirst), and Willa Liu (PhD, Ryerson University).

1. Age and Vascular Health: “Age is an axis along which inequities travel” Koehn et al., 2012

Canada is experiencing population aging due in large part to low fertility rates, longer life expectancy and the long range impact of the baby boom generation (Chow, 2011). Ontario’s senior population is projected to increase by 22% by the year 2031 (Heart & Stroke Foundation, 2010). Over the past decade, there has been significant discussion about the sustainability of the Ontario health care system due to the increasing demands of an aging population and the prevalence of chronic diseases. According to the Conference Board of Canada 2012, cardiovascular disease and the associated treatment of chronic diseases is estimated at costing Canada \$21 billion a year.

Vascular disease, despite reductions in the number of people who die each year, remains the number one threat to the health of Canadians. Specifically, vascular disease is considered to be the major cause of illness, disability, hospitalization and death in Canada. Co-morbidities such as diabetes and dementia for example account for sixty-five percent of deaths with vascular complications and twenty one percent with dementia in Ontario (An Integrated Vascular Health Blueprint for Ontario, 2012)

Now is a critical period for health care in Ontario to stem the “...growing tide of vascular ill health” (An Integrated Vascular Health Blueprint for Ontario, 2012 p. 10) and its associated costs. Research from the Heart & Stroke Foundation, the Cardiac Care Network of Ontario and others, unanimously conclude that navigating the health care system, and the intricate and complex continuum of care associated with managing vascular, health is:

- Fragmented especially at transition points due to poor coordination of care and treatment of multiple chronic conditions
- Inefficient due to duplication and logistics
- Provides limited support to translate and integrate knowledge on best practice and patient care

2. Populations at Risk

Persons at higher risk of developing vascular disease include: frail seniors, individuals with diabetes, reduced kidney function, heart disease, pre-existing history of a stroke, and peoples of First Nations, Metis, Aboriginals, and visible minorities.

With respect to frail seniors, frailty defined as "... when an individual has lost their resilience to bounce back, leaving them vulnerable to a downward spiral of decline" (Central East Local Health Integrated Network, 2012), predisposes people to multiple health risks all at once, including development of vascular disease. This emphasises the need for a highly coordinated system responsive to the specific and unique needs of the individual senior and their family and/or caregiver to enable them to live longer in their home and in their community.

Further examination of population health and ethnicity related to the risk of developing vascular disease recognizes that visible senior minorities are considered to be one of the greatest groups at risk due to the myriad of factors that already exist for marginalized and vulnerable groups. According to the Canadian National Advisory Council on Aging (2005), ethnically diverse senior's experience:

- Barriers to health care and social services stemming from cultural and linguistic differences
- Discrimination and racism
- Lack of access to income resources
- Age related barriers impacting access

3. Cardiovascular Disease & Chinese Emigration

In Canada, one of the largest visible minority groups is Chinese, with over 576,980 Chinese immigrants in Ontario (Statistics Canada, 2006). Chinese immigrants have experienced, during the last twenty years in China, significant economic progress which has exerted a great impact on everyday life, ranging from types of food and clothing consumed to changes in work, and living conditions. Despite the advantages associated with healthier lifestyles, new health problems have begun to emerge. Cardiovascular disease and hypertension, associated with lifestyle changes, urbanization, and longevity, are now considered to be the top health problems for Chinese residents. (Liu, 2007 and Yao et al, 1993).

Chinese emigration patterns to Canada have also changed during the past three decades. During the 1980s to 1990s most immigrants were Cantonese-speaking emigrating primarily from Hong Kong. Since the early 2000s, the majority of the Chinese immigrants are Mandarin speaking, having emigrated from Mainland China. Canadian immigration trends suggest immigration from Hong Kong is slowing while that from Mainland China is increasing exponentially (Chow, 2011). It is important to recognize these trends and their implications for service provision as there are significant variances amongst different immigrant groups around beliefs about health, understanding of health risks, and treatment modalities (e.g. Chinese traditional medicine).

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

4. Research Aims

This research aims to examine the range of service gaps, unmet needs and specific barriers encountered by Chinese Ontarians living with heart disease or stroke, their caregivers and the healthcare providers who are involved in supporting their health and well-being. Opportunities for survivors and caregivers to use self-care and disease management strategies will also be explored.

A mixed research design methodology which involves focus groups, individual face-to-face and phone interviews as well as an email/fax survey with open-ended questions were used to collect both quantitative and qualitative data. A gender-based approach to data analysis emphasises how the intersection of language, gender, age, ethnicity, level of education, and length of residence in Canada affects the quality of life of participants.

II. Study Objectives

The objectives of this research are:

1. To identify service gaps, unmet needs and specific barriers encountered by Chinese Ontarians living with heart disease or stroke including their respective caregivers
2. To identify from the perspective of the health care service providers, service gaps and unmet needs encountered by Chinese Ontarians living with heart disease or stroke
3. To illustrate the promising/best practices in living with heart disease or stroke for Chinese Ontarians to self-manage their disease and associated chronic diseases
4. To make recommendations for systematic, comprehensive approaches which align with the Integrated Vascular Blueprint for Ontario (August 2012) to:
 - Promote and protect the vascular health of Chinese Ontarians
 - Ensure culturally accessible, equitable, and effective vascular health diagnosis, treatment and recovery for Chinese Ontarians
 - Reduce avoidable vascular morbidity (illness and disability) and mortality (death) of Chinese Ontarians
5. To make recommendations for strategies to provide optimal patient care or self-care among family/community caregivers and health care providers (engagement in health promotion and disease prevention activities)
6. To understand population health patterns, health risks and associated health outcomes

III. Review of Pertinent Literatures

1. Literature on Health Care and Caregiving for Chinese Older Adults

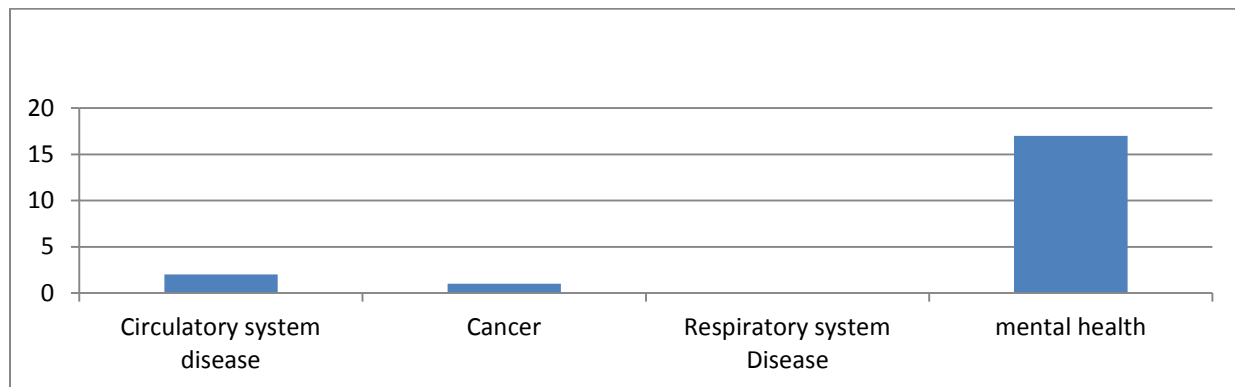
This literature review draws heavily on a recent scoping review on the health and health care of ethnocultural minority older adults done by Canadian researchers (Koehn et al., 2012). Approximately 3,300 abstracts in over 192 journals, books, book chapters, theses and dissertations from 1980-2010 were reviewed. Of the 816 abstracts that met the eligibility criteria, 70% were from peer-reviewed journal articles from a range of disciplines. The abstracts covered many countries, including those deemed most relevant to the Canadian situation, namely, the United States (52.8%), Canada (25.8%), UK (10.5%), Australia (3.2%), New Zealand (0.6%) and others (7%).

Of the 183 Canadian studies retrieved, Chinese and South Asian older adults—the two largest groups of immigrants to Canada since 1991—account for two-thirds of post-1980 publications. Research on older adults of Chinese origin accounted for almost 45% of the Canadian studies, which exceeds their share of the visible minority older adult population (35% of the total). According to Koehn et al. (2012) this is due, in part, to the productivity of researchers of Chinese Canadian origin interested in this population. South Asian ranked the second, accounting for almost a quarter (25%) of the Canadian studies, which is comparable to their share of the visible minority older adult population. Many groups were under-represented. Given the focus of this report on Chinese seniors, the following overview examines mainly research on health care for older adults of Chinese origin, both qualitative and quantitative from four sources: Canada, US, UK, Australia and New Zealand.

Koehn et al. (2012) found that Chinese older adults are also well represented in international abstracts. Of the 816 abstracts, 209 abstracts mentioned Chinese as the focus of their research, accounting for a quarter of the total number of abstracts on ethno-cultural group seniors. However, further analysis showed that coverage of issues and demographics was more partial than the figures implied. Many topics remained unexplored and the heterogeneity within populations was inadequately captured. For instance, very little research was found on respiratory system diseases, while a relatively large amount of literature existed on what might be categorized as mental health issues facing Chinese seniors (17%). On closer examination, however, mental health was seldom the main focus of these articles and/or was referenced only in general terms. Furthermore, there was no clear indication whether cultural factors played a role in mental health. Figure 1 illustrates the percentage of Canadian abstracts representing Chinese older adults.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

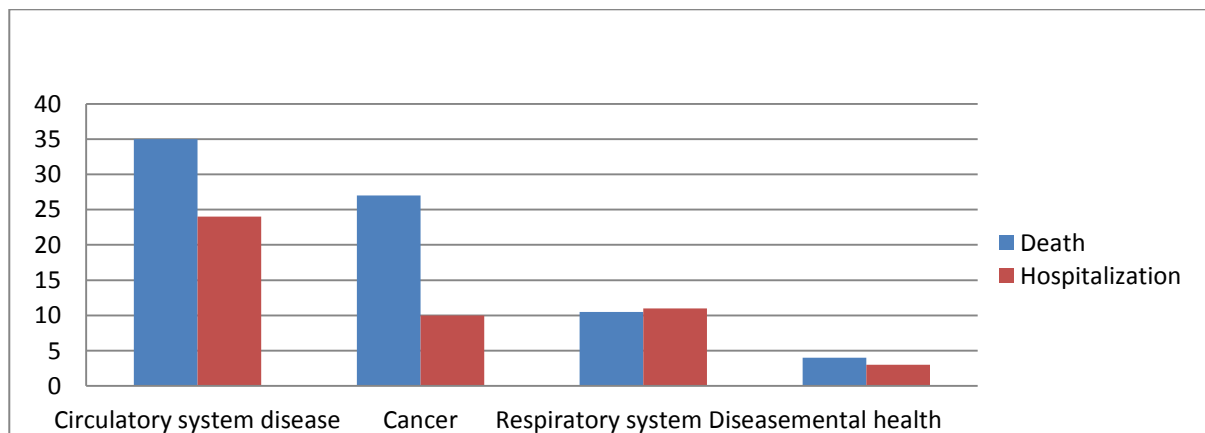
Figure 1: Percentage of Canadian Abstracts on Chinese Older Adults



Source: Koehn et al., 2012.

Koehn et al. (2012) also determined that, in the Canadian literature, there is little research on Chinese older adults that reports any of the leading causes of death or hospitalization. In contrast to the high percentage of death and hospitalization caused by circulatory diseases (35% and 24% respectively), only 2% of the Canadian abstracts on Chinese older adults is on circulatory system diseases, 1% on cancer-related death and hospitalization and practically no research is found on respiratory system diseases (0%). Instead, a large component of the literature on Chinese seniors focuses on mental health (17%). Figure 2 illustrates the percentage of the leading causes of death and hospitalization of visible minority seniors (aged 65+) in Canada.

Figure 2: Percentage of the Leading Causes of Death and Hospitalization of Visible Minority Seniors (aged 65+) in Canada



2. Literature on Caregiving and Caregivers

Koehn et al.'s (2012) also show that Chinese older adults in Canada are not adequately represented among users of services such as long-term care and home care facilities (see Table 1). Canadian studies on ethnic minority older adults, especially Chinese older adults, also show that there is a lack of linguistically and culturally appropriate services (such as food, language and communication styles) within the Canadian health care system that meet the needs of an ethno-culturally diverse ageing population.

Table 1: Number of Studies on Caregiving and Caregivers among Ethnic Minority Groups in International and Canadian Literature

Type	All sources	Canadian	Chinese in all sources	Chinese-Canadian
Long-Term Care (LTC): LTC facilities/nursing homes	47	20	15	5
Home Care: Medical and non-medical home services	23	7	9	4
Caregivers: Primarily informal care-givers	63	19	29	14
Cultural Competence/Culturally Sensitive Care	70	14	20	7

Source: 1. Koehn, S., Neysmith, S., Kobayashi, K., & Khamisa, H. (2012). 2. Khamisa, H. (2010).

Furthermore, the reviewers noted that "... there is even less research on the intersecting oppressions experienced by visible minority older adults, especially women, which influence their admission to and shape their quality of life in long-term care facilities" (Koehn et al., 2012, p. 18).

3. Literature on Cardio-Vascular Diseases among Older Chinese Adults

In the Koehn et al. study (2012) review there were all together nine abstracts that mentioned cardiovascular diseases among older Chinese adults, of which 7 were US-based, one was from the UK and one was Canadian. Three studies used heart problems or hypertension among Chinese older adults as one of the indicators to access their health care service utilization access indicators. Two studies examined the relationship between alcohol use and hypertension and between chronic cardiovascular diseases and mental health among Chinese older adults. Four studies examined the association of cardiovascular diseases with mortality rates and use of Western and non-Western medicine.

Despite a relatively large body of literature on health care patterns, barriers to healthcare services, as well as the health care of caregivers to elderly person with cancer and mental health, most of the literature is on medical care in formal and institutional care facilities. Only a few studies explored caregiving in an informal, home setting. Little or no research was found that examines family caregiving for Chinese seniors with heart disease or stroke.

4. Literature on Self-Management among Canadian-Chinese Older Adults with Heart Disease or Stroke

Our own literature review found only one research study of self-care or self-management among Canadian-Chinese older adults with heart disease or stroke. King et al. (2007), based their study on Chinese immigrants with heart disease in Calgary. King et al. (2007) found that Chinese informants, in comparison to other ethnic groups, were extremely diligent in seeking information and learning about their disease(s), as well as being motivated to seek and obtain care. The informants sought out physicians they had confidence in, connected with other health care service providers, and made use of other resources in their self-management process. Chinese informants in this study were strongly in favour of using Western medicines and used them exclusively in the management of their disease(s).

5. Summary of Literature Review

In this literature review, we have examined literatures from several sources: Canadian, US, UK, and Australia, mainly because these countries are similar in their composition of immigrants and health care delivery systems. Despite efforts to focus on Canadian literature, Koehn et al. (2012) found that the majority of abstracts were US-based. Out of the 209 research studies on Chinese older adults, no literature was found on self-care or self-management among Canadian-Chinese older adults with heart disease or stroke. However, a subsequent on-line search did find one Canadian-based study on Chinese immigrants with heart disease which was not included in the scoping review. Furthermore, although there is a relatively large body of literature on health care patterns, barriers to healthcare services, as well as information on the health care of, or caregivers for, elderly persons with cancer and mental health, most of the literature is on medical care in formal, institutional care facilities, only a few explored caregiving in an informal, home setting. Little or no research was found that focuses on family caregiving for seniors with heart disease or stroke.

IV. Research Questions

This research aims to explore the service gaps, unmet needs and opportunities for recovery of Chinese Ontarians living with heart disease or stroke. Secondly this research will assist in the development of recommendations for future provincial strategies and initiatives which align with providing quality integrated care along the health care continuum including the utilization of supports/resources of primary care, community care and self-care management.

Based on the above review of the literature, and proposal guidelines from the Heart and Stroke Foundation, the following questions were examined:

1. What gaps, unmet needs or barriers exist in the support of Chinese survivors of heart disease or stroke and relevant stakeholders (e.g. families, communities, etc.) face?

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

2. What gaps, unmet needs or barriers do Chinese survivors of heart disease or stroke face related to self-care management?
3. What gaps, unmet needs or barriers to optimal management of heart disease or stroke do health care providers who serve Chinese survivors of heart disease or stroke face?
4. What strategies do survivors of heart disease or stroke and their caregivers, use for self-care and self-management of their disease (s)?
5. What key opportunities exist for the Heart and Stroke Foundation do to better support families, stakeholders, and health care providers to ensure optimal management of Chinese survivors of heart disease or stroke?

V. Research Design and Methodology

1. Sample

Sampling began following receipt of approval from the Carefirst Seniors and Community Service Ethics Committee and an external Bioethicist Consultant. Written and informed consent was ascertained from all study participants. Translation was available. To strengthen the representativeness and validity of the research, participants were recruited according to the following principles and measures:

1. Different levels of connectedness with health care / social services providers – participants were referred / came from:
 - Health care providers such as hospitals, rehabilitation center, family health team,
 - Non-health care organizations such as social services organizations, settlement agencies
 - Individuals from the general public
2. Geographical areas having high concentration of Chinese – participants resided in:
 - Greater Toronto Areas (according to the 2006 census)
 - Toronto in particular Scarborough (19.5%), Downtown (11.4%), North York (13.2 %)
 - York region in particular including Markham (34.2%), Richmond Hill (15.4 %)
 - Mississauga (6.9 %)
 - Non GTA / Rural Areas (Using the Chinese population size of 5,000 as the threshold criteria, according to the 2006 census)
 - Windsor
 - London
 - Ottawa
 - Hamilton
 - Kitchener

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

3. Different dialects among the Chinese – participants spoke one of the two most common dialects among the Chinese population:
 - Cantonese
 - Mandarin

Sixty-three participants contributed to this research, which included twenty six survivors with heart disease or stroke, nineteen caregivers, and eighteen health care providers from across Ontario.

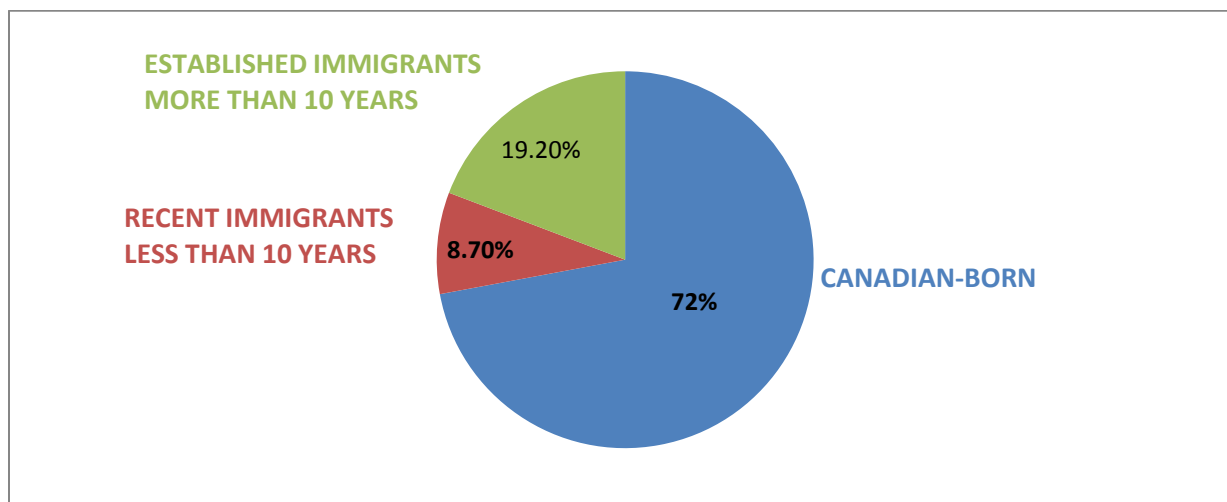
2. Semi Structured Interviews with Chinese Informants

Given the time parameters of this study, a mixed research design with both quantitative and qualitative data collection methods were used. This included a targeted literature review, focus groups and individual interviews with a sample of survivors, caregivers and health care service providers from the Greater Toronto Area (GTA), and individual interviews and open-ended survey questions with a sample of survivors, caregivers, and health care service providers from the non-GTA/rural area. Participants were selected to represent three categories of key informants: Chinese survivors of heart disease and/or stroke, caregivers and health care providers who supported the survivor. The overall intent of this sampling strategy was to be inclusive and to explore the key issues from different perspectives. In particular, the plan was to gather data that could reflect key dimensions of experiences that exist within the Chinese community as a whole. Thus participants of the research were selected to maximize opportunities to study diverse experiences (e.g. variation stemming from differences due to place of origin, length of residency in Canada, current living situation, age, how long a person had been living with heart disease or stroke).

Focus groups were created for survivors, caregivers, survivors and caregivers, and health care providers. Although the questions were similar across groups, each focus group included a unique phrasing that reflected who the participants were (e.g. survivor, caregiver or professional provider). This data collection approach, often referred to as triangulation, reflects an attempt to secure an in-depth understanding of a phenomenon. It recognizes diversity amongst perspectives and experiences; it adds breath, complexity, richness and depth (Denzin & Lincoln 2003, p.8). The aim was to do a gap assessment that will facilitate the ability of the Heart and Stroke Foundation to move forward in its decision-making for a provincial diversity strategy for Ontario.

The research is focused primarily in the GTA because it has the largest representation of the Chinese community in Ontario. With a population of 576,980 Chinese makes up 4.8% of the total Ontario population (Statistics Canada, 2006). Figure 3 depicts immigrant demographics in Toronto. Nearly half the population in Toronto reports belonging to a visible minority group: 12 % South Asian and 11.4 % Chinese. It is important to note that one half of all immigrants to the city have lived in Canada for less than 15 years. By 2031 it is expected that visible minorities will make up a projected 63% of the city's population.

Figure 3: Percentage of Representative Immigrant Populations in Toronto



Source: Census, 2006

VI. Data Collection and Analysis

1. Recruitment of Participants

Three distinct groups of informants were recruited for the research study: Chinese survivors of heart disease or stroke, family caregivers, and health care providers. The cultural diversity within the Chinese community was represented through the recruitment of informants who differed in age, gender, length of residency in Canada, language, and geography.

Rationale for Three Distinct Groups of Informants

The purpose of engaging three distinct groups was to obtain different perspectives and experiences on the same topics: the service gaps, unmet needs and barriers identified in accessing/providing health services, the healthcare system overall, and accessing community supports. Distinct groups also offered the opportunity to compare experiences and discover in what way/s their experiences might converge or differ.

Rationale for Two Dialect Groups: Cantonese and Mandarin

This distinction was necessary because dialect correlates with two major but very different groups of Chinese immigrants to Canada over the past three decades. In particular, the research study aimed to uncover diversities, such as country of origin and length of residence in Canada, which might be associated with variations in survivors' health-related experiences and health seeking behaviour.

Rationale for Recruitment of Equal Gender Representation

The literature reports significant differences between women and men who provide caregiving and experience heart disease or stroke. Specifically, literature on family caregiving indicates that caregivers are most often women (Hollander, Liu, & Chappell, 2009) and the majority of them are between the ages of 45-64 (Cranswick & Dosman, 2008). Although women already constitute the majority of heart failure patients, they have received, and continue to receive, very little attention in research. For example, elderly women with heart failure are at increased risk for adverse outcomes because of higher comorbidity, psychological distress and socioeconomic disadvantage. Yet, they are often left alone to deal with these problems, which can negatively affect their ability to carry out basic self-care tasks (Sabbadini, Travan & Toigo, 2012).

2. Recruitment Process

Participants were recruited in two waves for the period from June to August, 2012. The first wave consisted of recruiting survivors, caregivers and health care providers from the GTA. Carefirst, through its existing service users, network of community partnerships and close working relationships with relevant health care providers, was successful in recruiting the necessary participants for the study. The following strategies were used in this recruitment process:

- Posting and handing out recruitment posters internally and externally
 - Carefirst offices /services / volunteers at downtown Toronto, Scarborough, North York, Richmond Hill and Mississauga
 - Carefirst website
 - Carefirst Family Health Team and Carefirst Specialist Clinic
 - Public buildings such as libraries, community centres and churches
 - Businesses such as Chinese bakeries, Chinatown convenience stores, Chinese restaurants
 - Health care offices such as pharmacies and family physicians
- Sending emails and making phone calls to multiple community partners
 - Hospitals / Geriatric Assessment and Intervention Network Clinics / Stroke Clinics including The Scarborough Hospital, Rouge Valley Health Network, Mackenzie Richmond Hill Hospital, and Toronto Rehabilitation Centre
 - Settlement agencies, social services agencies and local community groups including Visiting Homemakers Association Home HealthCare, Community Care Access Centre, Centre for Information and Community Services, Welcome Centres, Woodgreen Community Services, St. Stephen's Community House, Yee Hong Centre for Geriatric Care
 - Chinese family physicians, cardiologists, physiotherapists and pharmacists

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

- Posting advertisements in Ming Pao Daily for two weeks to recruit participants in the community at large

The second wave consisted of recruiting participants and informants outside GTA. Five cities were selected: Ottawa, Hamilton, Windsor, Kitchener, and London, mainly because they have the largest Chinese populations (>5,000) in Ontario outside the GTA (2006 Census). Non-GTA survivors, caregivers, and health care providers were contacted through:

- Performing a thorough database search of health care service providers in those five cities (i.e. College of Physicians and Surgeons of Ontario), then emailing and faxing information packages consisting of a cover letter, information sheet and poster and following this up with phone calls
- Making phone calls and emailing to 36 organizations including social services and settlement agencies, health centres, Chinese churches and Chinese associations
- Emailing to different Chapters of the Heart and Stroke Foundation
- Connecting with colleagues, personal networks, pastors, settlement workers and members of the Needs Assessment Advisory Group

The process of non-GTA participant recruitment proved to be challenging particularly for doing with interviews. Some of the issues encountered were:

- **Limited numbers of Chinese-speaking physicians and specialists in non-GTA regions**

A comprehensive search of the database – *College of Physicians and Surgeons of Ontario* revealed a small number of Chinese-speaking physicians even in urban areas like Ottawa, Hamilton, London, Kitchener, and Windsor. For instance, there were only two Asian-speaking cardiologists for the entire Ottawa region.

- **The reluctance of health care receptionists to promote the study**

All health care providers meeting the sampling criteria were contacted twice via telephone and fax to solicit their participation. No physicians and specialists could be contacted directly, as health care receptionists declined on the health care providers' behalf, citing hectic schedules as the rationale.

- **Need to modify data collection tool and build relationships**

It was necessary to make numerous calls before successful communication was achieved and then apply the necessary resources to build the relationships with potential participants. Only then did they agree to partake in the study. Furthermore, most only agreed to provide written responses, not partake in phone interviews. To mitigate this challenge, the data collection method was modified. Using the questions from the GTA focus groups and interviews, a survey questionnaire was developed, thereby making it more convenient and less time consuming for health care providers. Utilization of a survey for data collection garnered nine responses out of 64 health care providers that were contacted.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

- **Limited referral opportunities to locate survivors and caregivers**

The limited number of Asian-speaking service providers outside the GTA, and their unwillingness to participate led to difficulty in meeting our desired sample size of non-GTA survivors and caregivers.

Table 2 and 3 summarize the final sample by type of participants, language spoken, and total number of participants per region (GTA and Non-GTA).

Table 2: Greater Toronto Area

	Types of Participant	Language Separation	Number
1.	Survivor	Mandarin	15 [from Toronto (downtown, North York, Scarborough), York Region (Richmond Hill, Newmarket, Markham), Mississauga]
		Cantonese	10 [from Toronto (downtown, North York, Scarborough), York Region (Richmond Hill, Newmarket, Markham), Mississauga]
2.	Caregiver	Mandarin	8 [from Toronto (downtown, North York, Scarborough), York Region (Richmond Hill, Newmarket, Markham), Mississauga]
		Cantonese	10 [from Toronto (downtown, North York, Scarborough), York Region (Richmond Hill, Newmarket, Markham), Mississauga]
3.	Dyads (Survivor + Caregiver) *included in the number of survivor and caregiver participants	Mixed	* 6 matched pairs [from Toronto (downtown, North York, Scarborough), York Region (Richmond Hill, Newmarket, Markham), Mississauga]
4.	Health Care Professional	Chinese-Speaking English-Speaking	11 from: <ul style="list-style-type: none"> • 2 Family Physicians • 1 Cardiologist • 1 Nurse (community based) • 1 Physiotherapist (hospital) • 2 Personal Support Workers (community based) • 1 Social Services Worker (settlement agency) • 1 Social Worker (rehabilitation) • 1 Pharmacist • 1 Placement Coordinator (CCAC)
Total			54

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

Table 3: Non-GTA/Rural Areas (Ottawa, London, Windsor, Hamilton, Kitchener)

	Types of Participant	Language Separation	Number
1.	Survivor	Mandarin	1 (Windsor)
2.	Caregiver	Mandarin	1 (Windsor)
3.	Health Care Professional	Chinese-speaking and English-speaking	7 (Ottawa, Hamilton, London, Kitchener)
	Total		9

3. Formats

Focus groups:

A total of nine focus groups with 47 participants were conducted.

- Focus groups with HS/Stroke survivors (n=2, 1 in Cantonese, and 1 in Mandarin)
- Focus groups with caregivers (n=2, Cantonese)
- Focus groups with both HS / Stroke survivors and caregivers (n=4, 2 in Cantonese, and 2 in Mandarin)
- Focus group with health care providers (n=1)

Face to face/phone Interviews:

Seven interviews were conducted with HS/Stroke survivors, caregivers and health care providers

- Interviews with caregivers and HS/Stroke survivors (n=2)
- Interviews with health care providers (n=5)

Open-ended Question Surveys:

Nine survey questionnaires were completed by health care and community service providers in Ontario.

4. Data Analysis

1. Sixty-three people participated in the study, twenty-nine men and thirty-four women from three distinct groups: survivors of heart disease or stroke (n=26), caregivers (n=19), and health care providers from across Ontario (n=18). Among the informants, the majority of HS / Stroke survivors were men (69%) and the majority of caregivers were women (84%), which is consistent with literature on heart disease or stroke. Specific details are illustrated in Table 4.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke:
Exploring Barriers and Service Gaps

Table 4: Number of Participants by Gender, Language and Category

	Survivor		Caregiver		Health Care Provider
	Cantonese	Mandarin	Cantonese	Mandarin	
Male	7	11	2	1	8
Female	3	5	8	8	10
Total	26		19		18

2. Two language groups of survivors and caregivers were recruited: Cantonese-speaking Chinese (n=20) and Mandarin-speaking Chinese (n=25). The majority of survivors (58%) and caregivers (63%) had obtained a college or university degree or higher. Most survivors were seniors aged 65 and above (92%) and suffered from more than one health problem. About 43 % of the survivors were recent immigrants who had been in Canada for less than 10 years. Details are presented in Tables 5, 6 and 7:

Table 5: Number of Survivors and Caregivers by Age group, Level of Education, and Years in Canada

Participants	Age Group			Education		Years in Canada			
	21 - 40	41 - 64	65+	College /University +	High School or Less	5 or less	6 – 10	11 – 20	21 +
Total Survivor	0	2	24	15	9	3	8	7	5
Cantonese	0	1	9	3	7	0	1	2	5
Mandarin	0	1	15	12	2	3	7	5	0
Total Caregiver	3	7	9	12	7	5	3	5	6
Cantonese	3	4	3	5	5	1	1	3	5
Mandarin	0	3	6	7	2	4	2	2	1

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke:
Exploring Barriers and Service Gaps

Table 6: Participants by Place of Residence

Participant	Place of Residence	Total
Survivor and Caregiver	GREATER TORONTO AREA	
	Toronto	24
	Scarborough	6
	Downtown	4
	North York	2
	Un-specify	12
	York Region	13
	Markham	1
	Richmond Hill	2
	Thornhill	2
	Un-specified	8
	Mississauga	6
	NON-GTA/RURAL AREA	
	Windsor	2
Healthcare Provider	GREATER TORONTO AREA	11
	Non-GTA/RURAL AREA	7
	London	1
	Ottawa	4
	Kitchener	1
	Hamilton	1

Table 7: Health Problems Reported by Survivors

Health Problem	Number of Survivor
Coronary Artery Disease	10
Hypertension	13
Angina	8
Myocardial Infarction	2
Transient Ischemic Attack	1
Stroke	13
Others: (Diabetes, hyperlipidemia, arthritis, Alzheimer's)	5

VII. Major Findings

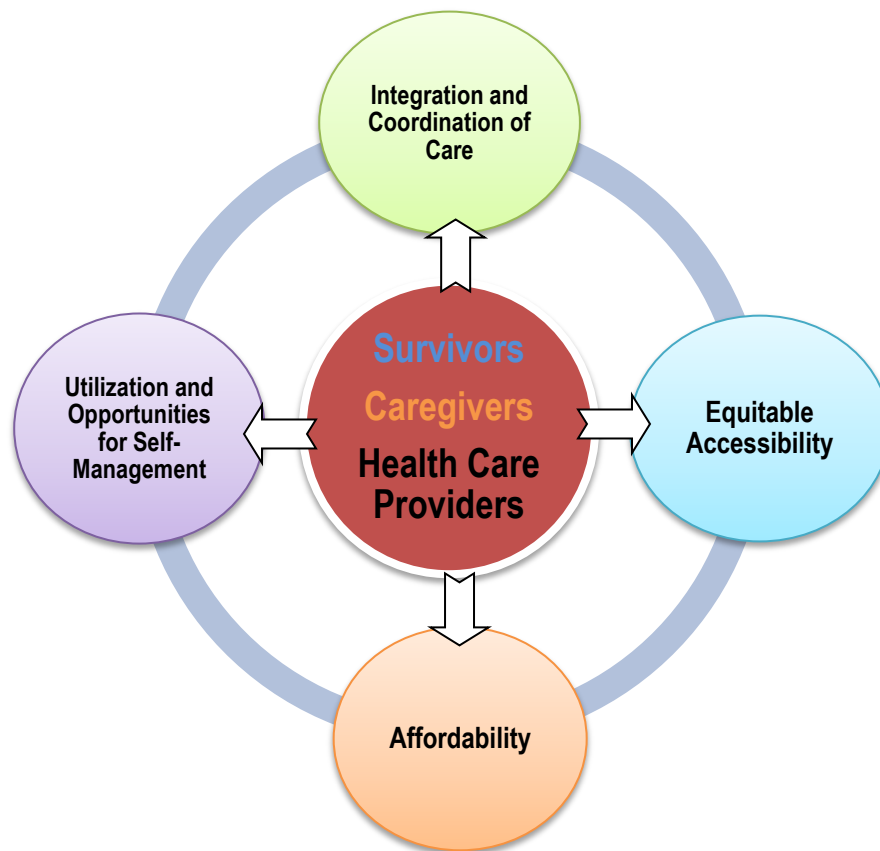
In analysing the data, four major themes were generated when exploring for service gaps, unmet needs, and barriers encountered by Chinese Ontarian survivors of heart disease or stroke, their caregivers, and health care providers. The themes which were identified included:

- **Gaps in the integration and coordination of care**
- **Inequitable accessibility and affordability**
- **Varying strategies which Chinese Ontarian survivors of heart disease or stroke and their caregivers utilized to maintain their health, opportunities for self-management and to care for themselves**
- **Future opportunities for initiative development**

It is important to note that in the process of our data analysis, distinctions were not made between service gaps, unmet needs and barriers. The non-distinction amongst these terms is intentional, as it was realized that these terms referred to the same issues, albeit they are used somewhat differently by different stakeholders. Thus, the findings have been organized to illustrate service gaps, unmet needs and barriers from three perspectives: survivors of heart disease or stroke, their caregivers, and health care providers. As depicted in Figure 4, survivors of heart disease or stroke, their caregivers, and health care providers experience similar themes of service gaps, unmet needs, and barriers, all of which overlap and interact with one another.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

Figure 4: Interaction of Service Gaps, Unmet Needs and Barriers from Three Perspectives: Survivors of Heart Disease or Stroke, Caregivers, and Health Care Providers



The first theme, which relates to gaps associated with the integration and coordination of care, is highlighted within the three distinct groups. Table 8 summarizes qualitative responses from the focus groups. When examining the two populations (Cantonese/Mandarin), it is interesting to note that there seems to be a greater risk of experiencing a lack of integration and coordination of care amongst new immigrants (10 years or less to Canada). Primarily Mandarin speaking, these participants reported linguistic barriers, a lack of awareness and understanding of the health care system and cultural reliance on Chinese traditional medicines. Such findings are consistent with information gleaned from available literature reviews. On the other hand, the caregiver focus groups identified the issue, not previously mentioned in the literature, of conflicts which arise and are associated with their dual roles and responsibilities. Many Chinese seniors immigrate to Ontario to provide support in caring for children or grandchildren. The conflict and resulting caregiver “burnout”, results from juggling multiple priorities with little time to care for the survivor or oneself, who may also be a survivor. Furthermore, although there is acknowledgement of the importance of respite care for caregiver burden, fiscal constraints limit the availability of support, resulting in an ongoing cycle of caregiver stress and fatigue.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke:
Exploring Barriers and Service Gaps

Table 8: Qualitative Summary of Service Gaps, Unmet Needs, and Barriers Related to Integration and Coordination of Care

Informants Theme	Survivors	Caregivers	Health Care Providers
Integration and Coordination of Care	<ul style="list-style-type: none"> ❖ Cantonese-speaking survivors: <ul style="list-style-type: none"> • 70% interviewed have resided in Canada for 20 years or more. • Relied heavily on family physicians as the integrators and care coordinators. • Majority of survivors were aware of the fragmented health care system and felt the need for improvement. ❖ Mandarin-speaking survivors: <ul style="list-style-type: none"> • 63% interviewed were recent immigrants (10 years or less). • Many survivors sought health information and medical advice from “non-professional” sources, such as friends, Chinese newspapers, Chinese websites, or doctors they knew in China. • Most survivors did not understand the Canadian health care system and had no knowledge of available resources, which lead to delayed treatment and unnecessary emergency room visits. 	<ul style="list-style-type: none"> • Caregivers often felt overwhelmed and burnout by the competing demands of caregiving for survivors, children, and grandchildren. • Caregivers had difficulty accessing homemaking services due to the insufficient hours and lack of coordination in the fragmented services. • Most felt more communication and information sharing was needed and crucial with health care providers. 	<ul style="list-style-type: none"> • Tension in the doctor-patient relationship was commonly felt when patients did not trust their doctors, which led to filed complaints and litigation of discrimination. • Stark differences in health care systems led to different expectations, medication, and disease management. • Majority of recent immigrant seniors lacked the knowledge of existing sources of health information (e.g. Home Care and TeleCare). • Centralized health information portal is greatly needed.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

The second theme emerging from the focus groups highlights issues of equitable accessibility. Table 9 summarizes the qualitative responses. According to the latest report from Health Quality Ontario, 93% of Ontarians have a primary care provider (Vascular Health Blueprint for Ontario, 2012). All three focus groups observed that, although the survivor may have a primary care provider, significant barriers exist to comprehending the provider, thus limiting access to treatment and increasing the risk of developing comorbidities. It is well known that early diagnosis and treatment, as well as modifying risk factors, can prevent up to 80% of cases of coronary artery disease and stroke. Unfortunately, one in seven Ontarians with high blood pressure is not adequately controlled and one in five is not receiving any treatment at all. It would be salient to know the Chinese Ontarian statistics for hypertensive control and treatment due to accessibility barriers.

Table 9: Qualitative Summary of Service Gaps, Unmet Needs, and Barriers Related to Equitable Accessibility

Informants Theme	Survivors	Caregivers	Health Care Providers
Equitable Accessibility	<ul style="list-style-type: none"> ❖ Cantonese-speaking survivors: <ul style="list-style-type: none"> • Most had a general understanding of the importance of medical treatment, disease education and the need to change lifestyle. • All were extremely motivated to seek out health information. • Survivors strongly expressed the need for ongoing, follow-up, and sustainment programs. Currently, they have access to rehab programs that are 3-6 months in length, but there are no on-going community maintenance programs. • Additional barriers that affect their accessibility include the severity of disease, age, and computer literacy. ❖ Mandarin-speaking survivors: <ul style="list-style-type: none"> • Survivors adamantly felt it was their responsibility to fulfill the role of caregiving to their families, therefore there was a 	<ul style="list-style-type: none"> • Recognized the existing language barrier and their knowledge deficit in understanding and accessing the Canadian health care system, and caregiving educational programs. • Emphasized on the lack of senior homes and nursing homes for survivors. These facilities were deemed important because they provide a space for survivors and caregivers to build on their social support network, and respite care services. 	<ul style="list-style-type: none"> • Language barrier made it difficult for doctors to communicate with their patients effectively, especially when it came to education on medication. • Widely recognized that there is a shortage of Chinese-speaking doctors. Survivors' longer wait time to see a doctor and for medical follow-ups were attributed to this factor. • An existing awareness that Chinese caregivers are often saddled with the cultural burdens of filial piety, which could lead to unwillingness

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

	<p>low incentive for them to seek help (“low felt” needs).</p> <ul style="list-style-type: none"> • Language barrier posed a big challenge, especially for recent immigrant seniors, in their communication with doctors, seeking medical treatment and mainstream sources of health information, and attending educational programs and community services. • Many survivors could not access services due to limited means of transportation. Often they depended on their children to drive them around. • Survivors all expressed feeling isolated from the mainstream society due to language and cultural barriers, and the lack of a social network. 		<p>to ask for help, creating further dependency and isolation for the survivors.</p>
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Snapshot on Shortage of Needed Program & Services – *Mei’s Story

Mei is a woman in her fifties. She has been in Canada for five years and has been taking care of her mother who had a stroke and became paralysed thirteen years ago. Even though a personal support worker comes to help with housework three times a week, Mei still finds it a challenge to bathe her mother by herself, to take her out in a wheelchair, and to cook special meals for her mother.

Currently, Mei is relying on her neighbours, friends, and relatives to come over for a day or two to take care of her mother if she needs to be away. Mei wishes for a daycare program with transportation services for Chinese seniors that her mother can attend and meet other Mandarin-speaking seniors. This will allow her to run errands or to have a few hours to herself.

The above snapshot highlights the needs of caregivers to access community supports and senior services. In Ontario, Community Care Access Centres (CCACs) offer eligible clients free services, up to a specified limit, based on need. The CCACs have been challenged to meet the growing demands of complex care seniors wishing to remain in the community. Community support services agencies offer senior programming and services (e.g. Adult Day Programs, Transportation etc.) for a fee. Many of the agencies have provisions to offer limited subsidies, often based upon a financial assessment, however affordability quickly becomes an issue when multiple services and programs must be used to meet the needs of the

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

senior. Table 10 is a summary of the qualitative data on service gaps, unmet needs and barriers experienced by the three focus group participants related to affordability.

Table 10: Qualitative Summary of Service Gaps, Unmet Needs, and Barriers Related to Affordability

Informants	Survivors	Caregivers	Health Care Providers
Theme			
Affordability	<ul style="list-style-type: none"> ❖ Cantonese-speaking survivors: <ul style="list-style-type: none"> • Expressed disappointment in the limited care services provided from the community (i.e. CCAC provide 2 hours of care per week). • Survivors with greater disease severity voiced their difficulties in hiring private care as they did not have the financial means. ❖ Mandarin-speaking survivors: <ul style="list-style-type: none"> • Many (80%) traveled back and forth from China to access care services as it is more affordable there, and they are able to seek support from a greater network of family members. • Majority of survivors continually use Chinese traditional medicine as a form of self- medication. • Financial challenges faced most senior survivors. Many lived with their children and grandchildren, and with inadequate space, survivors cannot continue their rehabilitation activities from home or access paid rehabilitation programs. 	<ul style="list-style-type: none"> • All caregivers felt a lack of social support and financial assistance for their unpaid care work. • Caregivers expressed difficulties in paying for rent, buying hospital beds, renovating their homes for wheelchair accessibility, and maintaining the upkeep of wheelchairs. • Female caregivers experienced a heavier burden of care, and mental and emotional stress. 	<ul style="list-style-type: none"> • Government's cut back on medical expense limited doctors' options on diagnostic examination (e.g. ECG), making it more challenging for doctors in their diagnosis and treatment of heart problems.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

According to the World Health Organization (WHO), an estimated 80% of heart disease, stroke and type 2 diabetes could be avoided if modifying risk factors (e.g. smoking, hypertension, unhealthy eating, and lack of exercise) were eliminated. There is significant potential to reduce the incidents and health care costs through improved secondary prevention and chronic disease management. Consider Table 11, which summarizes the qualitative data on service gaps, unmet needs and barriers experienced by the three focus group participants that relate to utilization and opportunities for self-care management.

Table 11: Qualitative Summary of Service Gaps, Unmet Needs, and Barriers Related to Utilization and Opportunities for Self-Management

Informants Theme	Survivors	Caregivers	Health Care Providers
Utilization and Opportunities for Self-Management	<ul style="list-style-type: none"> ❖ Cantonese-speaking survivors: <ul style="list-style-type: none"> • General “buy in” to Western medication and concept of self-management. • Female survivors often accessed and utilized self-management programs. • Male survivors preferred to self-medicate. Their inert behaviour in accessing and utilizing services is attributed to their loss sense of self-worth and pride. • Younger survivors and highly educated survivors were more resourceful in seeking out information for self-management • All expressed a desire for “structured health maintenance programs” much like the widespread diabetes education program. ❖ Mandarin-speaking survivors: <ul style="list-style-type: none"> • More likely to self-medicate and use traditional Chinese medicine rather than Western concept of self- 	<ul style="list-style-type: none"> • Many caregivers were seniors themselves and suffered from a multiple of health conditions, including cardiovascular diseases. • Numerous female caregivers reported deteriorated health, depression, frustration, and mental stress due to excessive burden of caregiving. • Lack of mutual understanding and support led to tension in relationships between caregivers and survivors. 	<ul style="list-style-type: none"> • The combined use of traditional Chinese medication with prescribed medicine could pose a potential health risk and in some cases, exacerbate patients’ health conditions. • Younger male survivors tended not to comply with medication for their hypertension. • More communication is needed with caregivers as many are not knowledgeable about self-management concepts, and therefore cannot assist survivors in their lifestyle changes. • A lack of supervision for doctors who practice Chinese traditional medicine.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

	<p>management (i.e. modification of lifestyle for health maintenance).</p> <ul style="list-style-type: none"> • New immigrant seniors showed particular concern for not knowing where and how to seek help in case of an emergency, such as a heart attack or stroke. 		
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Self-Medication

Due to language barriers and long waiting times to see a doctor/specialist, many heart disease or stroke survivors, and particularly recent immigrants from Mainland China, reported taking medicines, usually traditional herbal medicines, which they brought from China, when they feel unwell. Many chose not to inform their doctors about this practice for fear that the doctor may not understand or disapprove of the use of such medicines because they could not explain clearly what it was made of and how it works. Sometimes, the survivors reported using Chinese traditional medicine along with the medicine prescribed by their doctors without their doctors' knowledge. This practice of self-medication or mixed use of Chinese traditional medicine with Western medicine can be dangerous, as it can influence the effect of the prescribed medicine, mislead doctors in diagnosis and cause delay in treatment. The following is a snapshot from a survivor of stroke on his self-medication experience.

Snapshot on Self-Medication – *Mr. Leung's Story

"I had a stroke in 2010. I felt something was wrong. My left leg was stiff, and I had difficulty in speaking. I was living with my son. He called the ambulance and I was taken to the hospital. I stayed there for a few hours. I didn't use any medicine (at the hospital). I even prepared breakfast the next day, as usual. When I felt difficult to speak, I took some Chinese traditional medicine fufang danshen diwan¹. A year later, I took another medicine angong niuhuang wan². I went back to China for some time. When I came back, I brought some angong niuhuang wan with me. I am able to take care of myself, all the time."

Significance of Identified Service Gaps, Unmet Needs, and Barriers

Clearly, the key messages identified by participants focused on lack of integration and coordination of care, non-equitable access, lack of resources and affordability of purchased services/programs, and limited

* Pseudonyms are used in order to keep confidentiality of the informants' identities.

¹ A popular Chinese herbal medicine used in treating heart diseases, such as angina and difficulty in breathing.

² A popular Chinese herbal medicine used to treat coma and stroke in an emergency.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

opportunity and knowledge associated with self-care management of the disease (s). Significant barriers for ethnic populations revealed in this study are consistent with other research. For example, Lam et al. (1997) examined elderly Chinese immigrants in the United States and noted that this population was at greater risk for managing chronic diseases and tended to use fewer health care resources, reporting difficulties with access because of language abilities, lack of knowledge of available resources and other associated barriers.

1. Integration and Coordination of Care

Research participants consistently identified the strong need for integrated and coordinated care related to heart disease, stroke and secondary prevention such as diabetes. An example of this is depicted below as a caregiver speaks about her father.

“...I took my father to the emergency room because he hit his head and it was bleeding. I told the Doctor he used to have a heart condition and he hadn’t gotten his heart checked for over seven years. Just like that they found two arteries blocked. He also has diabetes, which according to the Doctor, masked all the heart disease symptoms”.

According to research from Heart & Stroke, Cardiac Care Network, and Ontario Stroke Network (2012), approaches to managing heart and stroke have been primarily treated as separate health care issues. In fact, many programs and services have been divided into “... disease-specific and even stage-specific (e.g. prevention vs. treatment) silos, even though they share many common risk factors and disease mechanisms” (Heart & Stroke, Cardiac Care Network & Ontario Stroke Network, 2012, p. 7). Little to no coordination of care across the healthcare continuum exists especially at transition points. For ethnically diverse populations, this imposes significant barriers and potential for fragmented care, inappropriate or lack of treatment and premature placement into Long Term Care Facilities (LTCF). Consider the following example from a caregiver:

“He has a stroke and now he is moody, staring at the four walls every day. He does not want to go out. I have asked the Doctor to send him to the psychiatrist. Nobody cares about his psychiatric care. I already booked it, but he can’t see the psychiatrist for six months. What do we do in the meantime?”

Paul Williams, a health care policy researcher at the University of Toronto, suggests that “everyone in the system is so overwhelmed that they don’t have time to think through what the possibilities are for providing care in the community, how to make connections out there.” Williams explains that the lack of integration amongst various providers leads to “long-term care being the default place” (Laupacis, Dhalla & Born, 2011).

2. Equitable Accessibility

The research identified the following as impacting on accessibility:

- Ability to speak English and lack of translation services
- Insufficient Mandarin-speaking family doctors and specialists
- Shortages of affordable/available transportation services
- Lack of health information and knowledge of the Canadian health care system

Below is an excerpt from a survivor of heart disease or stroke of his experience with access:

“It takes too long to see a doctor in an emergency case. Another issue is that I don’t know where to go if I have an emergency case, like a heart attack. So I went back to China for an examination.”

In exploring issues of access to health care, it was noted that the majority of Ontarians have a primary care physician (93%), however many do not. Research by POWER (Project for an Ontarian Women’s Health Evidence-Based Report – St. Mike’s Hospital, 2010), has identified alarming findings associated with marginalized and vulnerable groups and access to healthcare, such as:

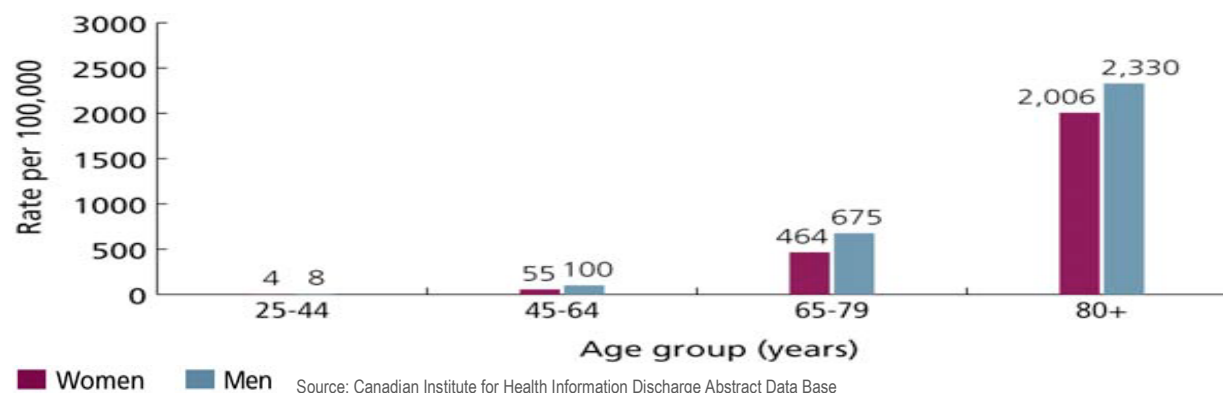
- Ontarians living in lower-income neighbourhoods were more likely than those living in higher income neighbourhoods to not have a primary care physician
- Immigrants who have been in Ontario less than ten years were the least likely to have a primary care physician; nearly one in six did not have one
- One in five Ontarians reported difficulty accessing care for urgent, non-emergent problems. Immigrants, specific ethnic groups, and Ontarians who did not speak either English or French at home were most likely to report these problems
- South and West Asian and Arab women often reported encountering more barriers to care than other ethnic groups
- One in four Ontarians reported difficulty seeing a specialist. Immigrants and specific ethnic groups were more likely to report challenges with access
- The majority of Ontarians (85%) who had sought care from a family doctor to monitor health problems reported no difficulties with access, however one in three South and West Asian or Arab women reported difficulties accessing care to monitor health problems as compared to less than one in five White women
- Many who had a primary care physician reported difficulties getting appointments for check-ups monitoring of health problems and urgent non-emergent care
- Women who had been in Canada for less than ten years reported more difficulties accessing care from a family doctor to monitor health problems than those who had been here longer or who were Canadian born
- Women who indicated that they did not usually speak English or French at home also reported more difficulties accessing care from a family doctor to monitor health problems than women who spoke English or French

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

Furthermore, POWER (2012) identified that gender influences access to care and women are particularly at risk for encountering certain barriers to care. Specifically, the research posits that women are much more likely to be poor and have greater caregiver responsibilities than men. Both factors present barriers to accessing health care services. Furthermore, women are more likely to have "...multiple chronic conditions and disabilities, the mismatch between the way health care is organized and women's health care needs creates a barrier to accessing effective care" (2012, p. 2).

Table 12 shows the percentage of adults aged twenty-five and older who reported no difficulties accessing specialist care for diagnosis or consultation, by sex and time since immigration, in Ontario, 2007. Note the gender and age variances in access.

Table 12: Percentage of Adults Aged 25 and Older Reporting No Difficulties Accessing Specialist Care for Diagnosis or Consultation



3. Affordability

Amongst participants considerable discussion occurred related to the significance of financial challenges and its impact for providing quality care and avoiding caregiver burnout. As well, shortages of government subsidized culturally and linguistically appropriate community programs and supports for Chinese survivors were also discussed. A caregiver in one focus group communicated the following:

"...I'm frustrated because I still need to go out and work. Like who's paying the bills? ...as long as you have money you can get services to help you."

"...you call CCAC to get help, and they tell you how many hours you get. They'll tell you, you get two hours, and you think, that's barely enough for them to come and help you bathe, that's enough for one shower...and they just keep cutting your hours down."

Home care services and caregiver burden have significant impact on the Ontario health care system. The Ontario Health Quality Council reported in 2010 that wait times for a long-term care bed in Ontario have tripled since 2005. What is significant is that a substantial number of people who are waiting for long-term

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

care – and some who are currently in long-term care – could be cared for at home or in “assisted living” facilities if they were provided with the right kind of support (Laupacis, Dhalla & Born, 2011).

4. Utilization and Opportunities for Self-Management

The concept of self-management among research participants involved a combination of self-care strategies (exercise, proper nutrition, smoking cessation etc.) and medication. In particular, (depending upon the age of the participant), elderly participants who were recent immigrants reported using a combined method of medication management including traditional Chinese herbal medicine and prescribed Western medicine. Younger participants favoured using self-management knowledge and Western medicine. Survivors and caregivers describe their perspectives below:

“I did not reveal to the doctor all the medicines I take. Doctors here forbid me to take medicines from China, like danshen pian, yinxing ye, shexiang baoxin wan, and shuxiao baoxinwan³. Whenever I feel not good, I put 2 or 3 pills/balls of shexiang baoxin wan in the mouth, and stay put. I try to avoid taking nitroglycerin, except in emergency cases. It should be taken three times, but I took it only at lunch and evening because I have to take the medication prescribed by the doctor here in the morning. Therefore, my health condition is fairly normal.”

“...so be it diabetes or high blood pressure, well if you don’t change your habits, well, so like my father in law, his condition went from minor to acute.”

“My father is afraid to exercise because he thinks that doing exercise will affect his heart, and he doesn’t know, well if he’s tried to go on a treadmill when they go to check his heart, or whatever, he will not do it...he is afraid he’ll die right after that. So he will not exercise at all.”

It was noted that younger cohorts and long-time settlers from Hong Kong and Taiwan preferred using educational resources related to self-management and Western medicine. Further analysis revealed that female survivors and caregivers were more likely to participate in community-based activities and programs, whereas male survivors or caregivers often preferred to manage on their own their own disease(s). It was interesting that the younger male survivors interviewed were less compliant with medications for high cholesterol and hypertension, were less concerned about their diseases, and admitted to being less likely to participate in community health promotion and education programs.

It is evident, as seen in this research, that there are many opportunities and strategies for future disease management programs. There is, however, a need to consider factors such as: gender, age, level of education, length of residency in Canada, and fluency in the English language, and survivors’ health

* Pseudonyms are used in order to keep confidentiality of the informants’ identities.

³ Popular Chinese herbal medicines used in treating and preventing heart diseases.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

seeking behaviours if the goal is to achieve successful behavior modification of individuals and develop strategies that will impact on the health system.

Limitations of the Study

The generalizability of this study finding beyond the GTA may be limited due to challenges with informant recruitment described earlier and the relatively small sample size associated with qualitative research. It is also recognized that reliance on self-reported data affect findings.

Further Research

More in depth research is needed to understand variations that are associated with main stream vascular health care practices and ethnic diversity. This study could only scratch the surface, even as it exposed issues related to integrated and coordinated care, access, affordability, and ongoing self-care management amongst Chinese Ontarians living with heart disease or stroke. Further examination of the complex relations that define how ethno-cultural groups and vascular health care interact are required if the four domains of innovation leading practice (Integrated Vascular Health Blueprint for Ontario, 2012):

- Population health and promoting healthy public policy
- Understand and support the individual and family
- Improve the quality and access to vascular services
- Developing system enablers and efficient use of resources and assets

are to be realized.

VIII. Recommendations

Macro Level

1. Inclusivity

The findings and recommendations from this research are not limited to Chinese Ontarians. They are relevant to all areas of Ontario where diversity exists. Addressing service gaps, unmet needs and barriers associated with vulnerable and marginalized populations (e.g. Immigrant women, South Asian senior immigrant caregivers, older frail seniors) are the basis of an equitable health care service. Identifying vascular health issues, supporting individuals and communities with integrated and coordinated navigation systems that focus on critical transition points along the continuum, and applying standardized enabling tools and guidelines, are fundamental to delivering quality and sustainable vascular health care for all Ontarians.

2. Experience –Based Co-Design (EBCD) - Client, Caregiver and Family Engagement

Involving clients, caregivers and family members in quality improvements is not a new process. It has played a key part in healthcare redesign over the last decade. However, to date, efforts have not necessarily focused on the client's or caregiver's experience, beyond asking what was good and what was not about a given service (e.g. client satisfaction sheets). The question asked with EBCD is, "what do you experience or wish to experience," recognizing knowledge from the client or caregiver is only experienced from one's unique perspective. Research carried out in the United Kingdom and Australia identified that "...the traditional view of the user as a passive recipient of a product or service has begun to give way to the new view of users as integral to the improvement and innovation process." (Bate & Robert, 2006, p.1). The result of using this methodology in re-designing health care systems has been remarkable; it truly demonstrates a client-centered approach by using resources and perspectives that usually go untapped. Who better to understand what they require than the clients and caregivers using the system. Applying this innovative quality design approach to vascular care in Ontario would align system change priorities with expressed needs and client /caregiver experiences.

3. Excellent Care for All Act 2010

Aligning with the provincial initiative, The Excellent Care for All Act 2010 will support the incentive for health care providers to develop an integrated approach to vascular care with all Ontarians. The prime objectives are to put clients first by improving quality care through the application of evidence-based health care and achieving client satisfaction which values, listens, and respects the client journey. Specifically, as described in the Integrated Vascular Health Blueprint for Ontario (2012, p.13-15), the focus will need to be directed at "... improving the quality of and access to a continuum of vascular services that understand and support the individual and family through the vascular health journey(s)." Ontarians expect: accessible (right service, right time, right place) healthcare to achieve best possible outcomes, effective coordinated and technologically advanced care, safe care which minimizes risks during care delivery (e.g. falls prevention, medication errors), client-centered services offered in a way that is culturally sensitive and respects dignity and privacy, equitable access ensuring that all Ontarians receive the same quality of care regardless of who they are and where they live, efficient provision approaches that are mindful of ways to reduce waste, and integrated systems that are organized, connected and working collaboratively along the health care continuum (Health Quality Ontario, 2011).

Micro Level

1. Develop Integrated and Coordinated System of Care

Examination of vascular disease in Ontario has shown that frequently there is a co-existence of multiple chronic conditions which are being treated in silos. "It is time to break down the artificial barriers between diseases and organizations and create a systematic, comprehensive approach (Cardiac Care Network, Heart and Stroke Foundation, & Ontario Stroke Network, 2012, p.8). As there are additional barriers

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

experienced by marginalized and immigrant populations which increase the risk of fragmented and poorly managed care, it is essential that system enablers are developed such as:

- Common and standardized clinical guidelines, in the preferred language of clients, which are communicated amongst and by health care providers in order to optimize knowledge transfer
- Dissemination of tools which are translated into the preferred language of clients to optimize knowledge transfer especially at critical transition points
- Assist in providing clients/caregivers with self-management and behavior modification support translated/offered by health care providers in the client's preferred language to optimize knowledge transfer and empower self-care activities
- Intensive case management and inter-disciplinary team based approaches that aim at promoting seamless care, accessibility and affordability to health care which is culturally sensitive

2. Enhance Equitable Accessibility

Accessibility is among the five principles that are fundamental to Canada's health care system. Health services, and barriers to accessing them, function as determinants of health. "When health systems fail to provide equitable care, or equitable access to care, they may worsen social disparities and be a factor in lowered health status" (Health Care System, Health Canada, 2004, p. 1).

3. Improve Access to Primary Health Care – Family Health Team Model by Expanding Primary Care and the Role of Physicians and other Primary Health Care Providers

Ontario's Family Health Team (FHT) model, implemented in 2005, may be North America's largest example of client-centered health care. Today, over two million Ontarians are served by over 170 FHTs (Rosser et al., 2011), with 1,500 physicians providing care. Primary Health Care is often the first point of contact a person has with the health system – the point where people receive care for most of their everyday health needs. In general, survivors of heart disease or stroke view family physicians or primary health care providers as their "health gatekeepers." In particular, the role is often seen as a "System Navigator" to access a diagnosis, treatment and follow-up of various health issues, disease prevention education, and referrals to specialists and diagnostic services such as laboratory tests or x-rays. The question for the future is, does Ontario have enough FHTs? Are they located in areas where underserved and marginalized populations live? Does the healthcare workforce with reflect the diversity found in the larger population so that it can address the cultural barriers that block access to effective care in Ontario's diverse communities?

4. Expand Usage of Technology: Ontario Telemedicine Network (OTN) – "Right Provider, Right Place & Right Time"

The OTN is one of the largest telemedicine networks in the world. Utilizing the free two-way videoconferencing capability for Ontarians, the relatively simple to use technology can provide:

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

- Access to care for clients in every hospital and hundreds of other health care locations across the province
- Facilitate the delivery of distance education and meetings for health care professionals and clients/caregivers which can address cultural and linguistic barriers to care
- Reduced wait times for accessing specialists from anywhere in Ontario in a timely manner
- Receive care closer to home with culturally competent health care providers
- Reduce the need to travel long distances to appointments, recognizing transportation has been reported as a major barrier to receiving care

Although more than 3,000 health care professionals in more than 1175 sites across the province use OTN to deliver care to their clients, greater awareness and funding is required for Ontarians and primary health care providers to utilize OTN. Access to the technology and health care providers eager to participate in the model which prescribes “connecting clients to care”, can be one of the solutions to meeting the needs of Chinese Ontarians and other vulnerable populations seeking treatment, education, and ongoing self-management of heart disease or stroke in the community where they live.

5. Adopt Program of All Inclusive Care for the Elderly (PACE) Model

The PACE Model of care began in the early 1970's, when the Chinatown-North Beach community of San Francisco saw the increasing needs of families whose elders had immigrated from Italy, China, and the Philippines and now needed long term care services. From these beginnings, the PACE Model has become a nationally known program that provides a full range of care to seniors with chronic care needs while allowing them to remain in their own homes for as long as possible, avoiding costly Long-Term Care placement. In the model, a “basket of services” which may include: a team of primary and secondary prevention health care providers (e.g. physicians, social workers, physical and occupational therapists and other specialists), acute care transportation, and meals are provided through an intensive and coordinated case management and interdisciplinary team approach for individual clients at home, at adult day care centers and in visits to specialists. Additional funding support is needed to integrate the PACE model into community based services and practice approaches here in Ontario. This is another potential solution to meeting the needs of Chinese Ontarians and other diverse populations living with heart disease or stroke. Many evaluations of PACE programs have shown that the model is cost effective, efficient, and promotes senior independence and thereby achieving the goal of healthy communities.

6. Support Culturally Sensitive and Linguistically Aligned Health Care

This study identified that accessibility to health care services and other programs for new immigrants (less than 10 years in Canada) was a major barrier. In particular, Mandarin survivors/caregivers who are more recent immigrants reported extensive barriers due to lack of health care knowledge and language comprehension. It is recommended to increase funding to providers of diverse community support services which serve newer immigrants in order to provide a comprehensive continuum of community care that is culturally and linguistically appropriate, which includes a basket of services such as: home care, respite

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

service, adult day program, transportation, interpretation, and emergency telephone contact services. These would support new immigrant Ontarians, and other diverse populations, through the complex and fragmented vascular health journey.

Also recommended is the development of linguistically and culturally appropriate health education materials that are easily accessible and build on existing information resources. An example the development of a **“One-Stop Information Portal / On-line Database”** in specific languages, which is user-friendly and easily accessible, would be a place where health care providers, community service providers, survivors and caregivers can find specific health-related information in their ethnic language.

Similarly, we encourage the development of mobile health education teams that would reach out to survivors/caregivers. To encourage health seeking behaviour, especially among the newcomers, a **Mobile Primary Care Team** including family physician, nurse, social worker, OT/PT and pharmacist could provide timely medical/health consultation and intervention for high risk survivors. This can also be a solution to the problem of reaching populations in non-GTA regions.

7. Increase Availability of Subsidized Home Care Programs and Services

There is a growing need to acknowledge issues of rapid changing demographics and risk associated with healthcare and marginalized populations within Ontario. Research, sponsored by United Way Toronto entitled Poverty by Postal Code (2004) illustrates and confirms the risk with the following:

- Between 1981 and 2001, the poverty rate among Canadian-born families increased from 12% to 14.7%. Among immigrant families, this rose from 14.8% to 24%
- Almost one half of the population of Toronto is born outside of Canada, and one third of all recent newcomers to Canada make Toronto their home. In 1996, over half of recent newcomers were living in poverty
- Between 1981 and 2001, the population of Scarborough grew by 33.8%, but low-income families grew by 136.6%
- In 1981, immigrants made up 48.5% of Toronto’s low-income population. By 2001, they made up 65% of this low-income population
- Statistics Canada (2005) data reports that by 2017, over 50% of the majority of people living in the Greater Toronto Area will be of Asian and South Asian origins

Newcomer Chinese Ontarian survivors of heart disease or stroke are among the growing marginalized population that is challenged to afford the appropriate home care to safely continue rehabilitation, manage independent activities of daily living (IADL and ADLs) and access appropriate treatment modalities that enable them to return to as independent and healthy state as possible. Currently, fiscal constraints have resulted in Community Care Access Centres (CCACs) providing services to moderate to high need clients, resulting in fewer available free community services. The alternative is fee for service/programs with not-for-profit community support service agencies who offer subsidies based on financial assessment. There is

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

a pressing need to increase the ability to offer financial subsidies to marginalized populations of survivors of heart disease or stroke. Provision of home care programs and services not only support survivors' basic activities of daily living, but they prevent the costly alternative of premature institutionalization.

Additional investment of funding is needed to offer affordable resources for survivors and their caregivers. There is a need to especially acknowledge diverse senior women who often play a dual role (caregiver of survivor/or survivor and caregiver of grandchildren). Consequently, they are often the least able to attend education sessions, seek regular health care monitoring, and lack the ability to reduce stress associated with the dual role. Expansion of health care services and programs to offer after hours and weekends programs may be one solution. Programs that offer affordable child care and transportation are also needed to enable attendance "without guilt".

Survivors with more complex health care needs require not just intensive medical services, but also adequate community support services, such as home care services, care coordination across multiple providers and transitions of care, as well as social supports in order to maintain good health and independence. Affordable respite care is essential to provide the caregivers temporary relief from emotional and physical demands, who are caring for heavy care survivors. Affordable in-home respite care programs and volunteer respite services are recommended to offer caregivers the opportunity to join in community activities which renew their energy, but equally important, address the quality of these individuals who continue to provide quality care that delay or avoid the personal and social costs of institutionalization.

8. Design Innovations in Primary Care Practice and Self-Care Models to Help Ensure Timely, Effective, and Managed Care

Client self-management education, as part of chronic disease management strategies, together with quality improvement interventions can improve client quality of life and reduce the need for urgent services. Thus, primary care innovation is key to assuring timely access to effective care. Working collaboratively with Local Health Integrated Networks (LHINs) and existing health service providers to spread existing community-based self-management education activities and programs is critical to achieve the desired outcomes. Currently, many of the fourteen Ontario LHINs have identified chronic disease management as a strategic priority. Directing LHIN funding to develop and incorporate structured self-management programs for heart disease or stroke survivors and their caregivers, especially in regions where there are high numbers of immigrant population with increased incidence of heart disease or stroke, is a priority. Emerging literature on chronic disease management suggests that successful programs rely heavily on client self-management skills, described as a set of skills that can be taught to clients in formal programs, without physicians. The Stanford University licensed Chronic Disease Self-Management Program is one model whereby a series of six - two and one half hour sessions facilitated by two trained leaders, one or both of whom are non-health professionals with chronic diseases themselves. Funding is needed to support the training of facilitators, coordinate and deliver and sustain the required programs at the

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

community level. As well, language translation of the program into Mandarin for example is time and resource intensive, a heavy burden on an already burdened community support service sector.

In order to specifically adapt the self-management program to Chinese Ontarian survivors of heart disease/stroke or any ethnic immigrant survivors, the following enhancement to the Stanford University model is recommended:

- Incorporate 3 to 6 months follow-up support into the program to monitor and sustain the participants' continued learning and self-management behaviour
- Encourage family members to attend the program as a source of support for the participants
- Expand program to eight sessions with two sessions focusing on specific illness/disease/materials due to:
 - Chinese or specific cultural community "information seeking behaviour"
 - Ability to reinforce and sustain participants' learning of self-management techniques
 - Consult with trained facilitators who are well respected by participants
 - Explore the issue of self-medication among survivors. Particular attention is required to understand and address the issue of self-medication among many recent Chinese immigrant survivors of heart disease or stroke - education on self-management versus self-medication

Secondly, develop and integrate with existing chronic disease management centres (e.g. Complex Diabetes Care Centre) for care coordination and provision of disease specific structured health maintenance programs for heart disease or stroke survivors. Resources and expertise from existing centres can be used to assist in the development of a structured care pathway for heart disease or stroke survivors. Effective navigation and management along transitions in the continuum of care (from acute hospital care to primary and tertiary care including home care, transportation, adult day program and in-home respite service) is recommended to ensure the client is not falling through the cracks.

Further research is needed to develop a new model that recognizes and integrates traditional health beliefs, medications and health/healing practices into modern health care for survivors from non-western cultures. Given the popularity and deep rooted belief in Chinese traditional medicine, it is suggested that professionals acquire a better understanding of how it works, and where and how Chinese traditional medicine and modern Western medicine can combine and complement each other. This would facilitate a more trusting physician-client relationship, promoting a client's fuller compliance with a medical regime.

Lastly, culturally appropriate caregiver support groups need to be developed. Participants in the study emphasized the need to express their stress and emotional frustration with difficulties coping from the burden of care. Easily accessible caregiver support groups and peer support programs that are culturally and linguistically appropriate for survivors and caregivers would provide the venue for much needed support. Benefits from establishing this service would range from members' participating in new research

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

to enhancing the service community's capacity for program and service planning that reflect the diverse richness found in Ontario communities.

IX. Conclusion

The results of this study align with recommendations in “*Shaping the Future of Vascular Health: An integrated Vascular Health Blueprint for Ontario 2012* – which focuses on developing an organized, integrated approach to the common and inter-related causes and prevalence of vascular diseases (Cardiac Care Network, Heart and Stroke Foundation, & Ontario Stroke Network, 2012).

In this research it was found that, despite differences in gender, age, level of education, length of residence in Chinese Ontarians, all Chinese Ontarians survivors of heart disease or stroke shared similar challenging experiences in coping with their disease and recovery. Many of the barriers faced by the participants arose from issues of integration and coordination of care, accessibility, affordability and self-care management opportunities. This study identified the challenges and issues faced by Chinese Ontarians living with heart diseases or stroke, caregivers and healthcare providers. It is hoped that this report will assist the Heart & Stroke Foundation to develop its 2014’s provincial diversity strategy and develop strategies to address the service gaps, unmet needs, and barriers encountered by the Chinese Ontarians in this report.

To specifically address the unique needs of Chinese Ontarians living with heart disease or stroke, we recommend that the Chinese Canadian Council of Heart and Stroke Foundation consider the following factors in developing their education programs and outreach to the Chinese community:

- Consider diversity within the Chinese heritage in Ontario (age, gender, immigration status etc.)
- Use Heart & Stroke Foundation’s leadership role and expertise in guiding the development of culturally sensitive health education resources. In particular, recognize and blend Chinese traditional health practices, and develop disease-specific, structured education programs
- Develop initiatives using technology such as OTN to reach out to Chinese Ontarian survivors who reside outside Greater Toronto Area

Lastly, the research findings and recommendations are not limited to Chinese Ontarians. They are highly relevant to all areas of Ontario where diversity exists. Pursuing these recommendations would go a long way toward addressing service gaps, unmet needs and barriers associated with vulnerable and marginalized ethnic immigrant communities. Programs where vascular health issues are identified, where clients are supported with integrated and coordinated system navigation, focused on critical transition points along the continuum, where standardized enabling tools and guidelines are applied, will ultimately lead to improved quality and sustainable vascular health care for all Ontarians.

Journey to Recovery of Chinese Ontarians Living with Heart Disease or Stroke: Exploring Barriers and Service Gaps

X. References

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