GAP ANALYSIS

Availability of Educational Materials for the Public
On Primary Stroke Prevention that Incorporate
Self-Help, Empowerment, and/or Mutual-Aid Approaches

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directed towards newcomers and potentially marginalized populations

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I. EXECUTIVE SUMMARY

The mission of the Self-Help Resource Centre of Greater Toronto is to promote self-help/mutual aid. The goals of the Self-Help Resource Centre are to increase awareness about self-help/mutual aid in the community and among professionals, and to facilitate the growth and development of self-help/mutual aid groups, networks, and resources.

Self-help methodologies of consumer involvement and participation, validation of individual experience and small-scale community-based approaches to health issues have made self-help and self-care approaches one of the necessary components of any health promotion strategy, especially in dealing with chronic disease, including stroke.

In the past, it was thought that there was little that could be done to prevent or treat stroke, and therefore strokes tended not to be treated as a medical emergency that required urgent care, or rehabilitation resources. However, there is new evidence that suggests that strokes can be prevented, and there are many benefits that can be reaped from acute and rehabilitative care.

Beginning in 2000, the Ontario Ministry of Health and Long-Term Care (MOHLTC) began implementing a strategy to improve stroke care and primary prevention throughout the province. The Health Promotion and Wellness, Public Health Branch has recognized the need for staff within these centres to make connections to health promotion and to have access to resources for stroke prevention. The main focus for this work is to improve integration of health promotion and population health into the components of Ontario’s stroke care and treatment system.

It is the interest of the Self-Help Resource Centre to acquire funding from the MOHLTC through the Ontario Stroke Strategy to develop self-help/mutual aid (and related approaches) resources on primary stroke prevention. In order to acquire funding resources, the MOHLTC has requested that the SHRC review the availability of such resources.

The following report is a gap analysis, which assesses the extent to which self-help/mutual aid, empowerment and participatory approaches are being used by health promotion and disease prevention organizations, in the development and delivery of primary stroke prevention resources. Within this analysis, it is the interest of the Self-Help Resource Centre of Greater Toronto, to analyze the extent to which the materials are directed at readers who may experience barriers to health due to the following factors that are out of their control: people living on low incomes, people who are newcomers to Canada, and people with lower literacy or education levels. The analysis takes into consideration the extent to which primary stroke prevention resources are presented in such a way that persons experiencing the above barriers to health can see themselves or their reality reflected.

A comprehensive search was conducted to identify potential primary stroke prevention resources that incorporate self-help/mutual aid approaches. Originally, 5-7 organizations per risk factor were to be approached (i.e. 15-21 organizations). However, by the end of the process, 32 organizations had been approached.
The data collection methodology was comprised of key informant interviews (22), site visits (3), internet (4) and database searches (6), as well as scans and in-depth reviews of available resources (via the 32 organizations). In total, more than 300 resource descriptions were scanned to determine whether they were relevant to be analysed in-depth. From that list of more than 300 resources: 22 general stroke resources were analysed in-depth, 9 alcohol resources were analysed in-depth, 10 smoking cessation resources were reviewed in-depth, and 7 obesity resources were analysed reviewed in-depth.

A literature review pertaining to self-help, mutual aid, empowerment, adult education, and risk factors for stroke was also conducted - as a complement to the gap analysis. The SHRC was interested in identifying whether their hypothesis about the importance of audience specific support resources was substantiated in the literature. The results of the literature review indicate that self-help/mutual aid has applications and benefits that exist at many levels, including initiatives directed towards culturally specific, and lower socioeconomic groups, improved recovery, as well as in the area of cost containment. These results are discussed in greater detail in the report, and a complete copy of the literature review is available in Appendix 5.

The Discussion section knits together the findings from the gap analysis and the literature review. In spite of research and literature that demonstrates the strengths and benefits of self-help/mutual aid approaches, these kinds of strategies are being used inconsistently by health related organizations across the province. In particular, there are few resources available for newcomers, persons living on low incomes, and those with lower educational or literacy levels. The Discussion Section also notes inconsistencies in how self-help and mutual aid are defined, understood, and applied by health promotion practitioners.

Given the strengths and benefits of self-help, mutual aid, and empowerment approaches that are identified in the literature review, in conjunction with the finding that there is a dearth of self-help/mutual aid resources on stroke prevention, it is recommended that the SHRC be granted funding by the MOHLTC that would give them the capacity to develop new and/or refine existing primary prevention resources that are built on these approaches, and directed towards the target audience(s) identified in this gap analysis. More specifically, this work should include clients from high-risk communities in the development of new materials and/or the modification of currently existing stroke prevention materials to ensure that risk factor and lifestyle change information is contextualized in a framework of dialogue that validates the participants’ lived experience. Such strategies have been documented to encourage participant empowerment, ongoing self-help/mutual aid and health promotion benefits.
II. INTRODUCTION AND PROJECT DESCRIPTION

1. INTRODUCTION

The mission of the Self-Help Resource Centre of Greater Toronto is to promote self-help/mutual aid. The goals of the Self-Help Resource Centre are to increase awareness about self-help/mutual aid in the community and among professionals, and to facilitate the growth and development of self-help/mutual aid groups, networks, and resources.

Self-Help is a process of learning with and from each other. In this process the participants provide each other with support in dealing with a problem, issue, condition, or need. They learn to work together while acknowledging diversity of their personal situations within the similarities of their shared issue. Together, they investigate the existing solutions and discover alternative solutions, and are empowered by this process. Mutual Support (also referred to as mutual aid) is provided to members of self-help groups through their participation. It has been documented that participation in self-help groups is a contributory factor in improving the health of the individuals involved\(^1\). Group members develop collective knowledge based on their experience. Members are empowered to share their practical coping skills, resources and information and provide a positive role model. Duke University researchers who examined the value of social support to the life expectancy of cardiac patients concluded, “a support group may be as effective as costly medical treatment”\(^2\).

Self-help methodologies of consumer involvement and participation, validation of individual experience and small-scale community-based approaches to health issues have made self-help and self-care approaches one of the necessary components of any health promotion strategy, especially in dealing with chronic disease, including stroke\(^3\). Examples of SHRC self-help initiatives are provided in the Appendices section.

Health Promotion, as defined by the World Health Organization is “the process of enabling people to increase control over, and to improve their health”. Strategies of health promotion address the broader determinants of health\(^4\), supporting individuals, communities and populations, through an emphasis on holistic change at a personal, community, organizational and/or systems level. More specifically, health promotion is about:

- Increasing personal and community responsibility for health issues\(^5\).
- Creating a supportive environment and strengthening community action\(^6\).

\(^1\) (Riessman, 1965).
\(^2\) (Brody, 1992).
\(^3\) A stroke is a sudden loss of brain function. It is caused by the interruption of the flow of blood to the brain (an ischemic stroke) or the rupture of blood vessels in the brain (a hemorrhagic stroke). The interruption of the blood flow or the rupture of blood vessels causes brain cells (neurons) in the affected area to die. The effects of a stroke depend upon where the brain was injured. Heart and Stroke Foundation of Ontario. Accessed May 1, 2003. Available at: http://ww2.heartandstroke.ca/Page.asp?PageID=33&ArticleID=431&Src=stroke&From=SubCategory.
\(^4\) Examples of broad determinants of health include income, education, employment, and social and cultural factors.
\(^5\) Ontario Ministry of Health, Definition of Health Promotion, 1975.
- Developing personal skills\textsuperscript{7}.
- Responding to consumer demands for participation and public interest in pursuing healthy lifestyles\textsuperscript{8}.
- Providing opportunities for individuals to participate with professionals in making related choices\textsuperscript{9}.

Health promotion and self-help are interrelated and interdependent concepts, as is described below in Table 1.

<table>
<thead>
<tr>
<th>If Health Promotion</th>
<th>Then a self-help approach will</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is about increasing personal and community responsibility for health issues</td>
<td>Accomplish this by consumer involvement and participation</td>
</tr>
<tr>
<td>Is about creating a supportive environment and strengthening community action</td>
<td>Accomplish this by empowering people to support one another in making informed decisions, sustaining healthy lifestyles and advancing community education and action.</td>
</tr>
<tr>
<td>Is about developing personal skills</td>
<td>Accomplish this by validating individuals’ experiences and impediments and by identifying teachable moments for transfer of new skills.</td>
</tr>
<tr>
<td>Is in response to consumer demands for participation and public interest in pursuing healthy lifestyles</td>
<td>Accomplish this by building small-scale community-based arenas for public participation.</td>
</tr>
<tr>
<td>Is about providing opportunities for individuals to participate with professionals in making related choices</td>
<td>Accomplish this by relating the theoretical knowledge of professionals to the experiential knowledge of the clients.</td>
</tr>
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</table>

2. \textbf{PURPOSE}

Stroke is a leading cause of death and adult neurological disability (e.g. motor, sensory, cognitive, and communicative), affecting the lives of at least 90,000 Ontarians. It is also thought to be one of the primary causes of transfers of elderly persons to long-term care. The impact of stroke on the provincial economy is significant – almost a billion dollars annually\textsuperscript{10}.

In the past, it was thought that there was little that could be done to prevent or treat stroke, and therefore strokes tended not to be treated as a medical emergency that required urgent care, or rehabilitation resources. However, there is new evidence that suggests that strokes can be prevented, and there are many benefits that can be reaped from acute and rehabilitative care.

\textsuperscript{7} ibid.
\textsuperscript{8} ibid.
These developments have the potential to reduce the future human and economic burden of stroke\textsuperscript{11}.

Beginning in 2000, the Ontario Ministry of Health and Long-Term Care (MOHLTC) began implementing a strategy to improve stroke care and primary prevention throughout the province. They are also concerned that primary prevention activities be enhanced and more integrated with the care delivery system. The Health Promotion and Wellness, Public Health Branch has recognized the need for staff within these centres to make connections to health promotion and to have access to resources for stroke prevention. The main focus for this work is to improve integration of health promotion and population health into the components of Ontario’s stroke care and treatment system.

It is the interest of the Self-Help Resource Centre to acquire funding from MOHLTC through the Ontario Stroke Strategy to develop self-help/mutual aid (and related approaches) resources on primary stroke prevention (directed towards the adult population). In order to acquire funding resources, the Ministry has requested that the SHRC review the availability of such resources.

The following report is a gap analysis, which assesses the extent to which self-help/mutual aid, empowerment and participatory approaches are being used by health promotion and disease prevention organizations, in the development and delivery of primary stroke prevention resources\textsuperscript{12}. This gap analysis is based on the understanding of the link between health promotion and self-help (as described above in Table 1) in the primary prevention of stroke.

**Primary Stroke Prevention** includes educating people about risk factors and lifestyle changes to reduce risk, and identifying and altering risk factors to prevent the onset of cardiovascular disease leading to stroke\textsuperscript{13}. **Risk factors** follow the classification outlined by the American Stroke Council\textsuperscript{14} and include:

- **Non-modifiable risk factors**: age, race/ethnicity, sex and family history;
- **Modifiable risk factors**: hypertension, smoking, diabetes, hyperinsulemia, insulin resistance, asymptomatic carotid stenosis, atrial fibrillation, sickle cell disease, hyperlipidemia;
- **Potentially modifiable risk factors**: obesity, physical inactivity, poor diet/nutrition, drug and alcohol abuse, hypercoagulability, hormone replacement therapy, oral contraceptive use.

\textsuperscript{11} Ibid.
\textsuperscript{12} In this analysis, the term resources is used generically to represent a range of health promotion initiatives or activities including programs, self-help or mutual aid/support groups, or printed guides or manuals.
\textsuperscript{13} American Heart Association. Definition of Primary Prevention.  
For this gap analysis, the use of self-help/mutual aid approaches in primary stroke prevention are being explored, specific to three modifiable risk factors:

- **Alcohol consumption (i.e. “drinking”)** – “Alcohol use in excess of drinks per day is associated with increased risk of high blood pressure\(^{15}\), and heart disease. Alcohol abuse is also a risk factor for hemorrhagic stroke and subarachnoid hemorrhage\(^{16, 17}\).”

- **Obesity (i.e. overweight)** – “Being overweight, either excess weight (defined as a body mass index of 26 or 27) or obesity (body mass index >27) is one of the most common factors influencing the development of high blood pressure and diabetes. These conditions in turn are two important risk factors for heart disease and stroke. The greater the obesity, the greater the risk of heart disease and stroke\(^{18, 19}\).”

- **Tobacco use (i.e. “smoking”)** – “Cigarette smoking is the major cause of preventable death in Canada. Contrary to popular belief, smoking is responsible for more deaths due to heart disease and stroke than deaths to cancer. Smoking increases the incidence of all major forms of heart disease and stroke… In 1996/1997, a higher (63%) proportion of adults in the “lower” income group were either current or former smokers compared to “middle” (59%) or “highest” (55%) income groups.

“The behavioural risk factors for cardiovascular disease are well known: tobacco smoking, unhealthy diet, and inactivity. All of these behaviours are associated with lower income and social status. However, much of the cardiovascular literature assumes these behavioural patterns are adopted through voluntary lifestyle choices\(^{20}\).” Raphael suggests, “patterns of behaviours are strongly shaped by the social and economic environments in which people live. High levels of stress produce behaviours aimed at ameliorating tension such as high fat diets and poor nutrition, and tobacco use”\(^{21}\).

Within this analysis, it is the interest of the Self-Help Resource Centre of Greater Toronto, to analyze the extent to which the materials are directed at readers who may experience barriers to health due to the following factors that are out of their control:

- **Living on low income or unemployed** - “Individuals who suffer from material deprivation have greater exposures to negative events such as hunger and lack of quality food, poor quality housing, inadequate clothing, and poor environmental conditions at home and work.

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\(^{17}\) Heart and Stroke Foundation of Canada (1997). As above.


\(^{19}\) Heart and Stroke Foundation of Canada (1997). As above.


In addition, individuals suffering from material deprivation also have less exposures to positive resources such as education, books, newspapers, and other stimulating resources, attendance at cultural events, opportunities for recreation and other leisure activities, and involvement in other stimulating activities that contribute to human development over the life span.\textsuperscript{22}

- **Newcomers to Canada, and/or those whose first language is not English, and/or are experiencing cultural barriers** - “New Canadians are also more likely to be living with low incomes that other Canadians.\textsuperscript{23} This is the case is all major cities. The gap between immigrants and non-immigrants is especially great for West Asian, East Asian, and Southeast Asian, Polish, Arab, Jewish, Chinese, and Ukrainian residents. Such a gap is present for all groups except Spanish and Black/Caribbean, where the rates are very high for both immigrant and non-immigrant populations.

- **Lower literacy or educational level(s)** – “illiteracy is a public health concern. It contributes to a lack of comprehension regarding diagnosis and treatment plans and may impede participation in decision-making, and compliance with health care advice.\textsuperscript{24}"

Thus, the analysis takes into consideration the extent to which primary stroke prevention resources are presented in such a way that persons experiencing the above barriers to health can see themselves or their reality reflected in the strategy or resource. In other words, the level of analysis lies in whether the resources assist the reader with identifying ways in which they can modify their risk to stroke given the barriers that they face in their everyday living?

### 3. GAP ANALYSIS PROCESS

The original strategy for the gap analysis was to conduct telephone interviews or site visits with 5-7 representatives of organizations that produce, distribute and/or deliver resources relevant to primary stroke prevention relevant to each of the three aforementioned risk factors – for a total of approximately 15-21 interviews. However, in order to be thorough as possible, and to identify resources through venues that the general public would be most likely to use, this strategy was expanded to include a fourth category being “stroke” (in general) as well as a review internet sites or databases where they existed or where it was relevant to do so.

Therefore, the gap analysis was conducted using, key informant interviews, review of resources, database and internet searches, and site visits with a total of 32 organizations, some of which were relevant to more than one risk factor. Depending on the size of the organization, and their level of involvement in producing programs and/or resources related to stroke prevention, some

\textsuperscript{22} Ibid, p. 21.


or all of the data collection methods were used. These approaches, the process for collecting information, as well as the findings are described in greater detail below.

A broad range of health promotion, disease prevention, and treatment related organizations were contacted as a means for identifying primary stroke prevention resources for the gap analysis. A number of these organizations are members of the Ontario Health Promotion Resource System (OHPRS), of which the Ontario Self Help Network (of the Self-Help Resource Centre) is a member. The OHPRS provides support, in the form of training, consultation, print and electronic resources, network building, and referrals, to people and organizations working in the health promotion field to increase their capacity and effectively promote health. Additional key informants and organizations to be contacted for the gap analysis were identified through communications with OHPRS members.

The organizations that were approached were organized into four broad categories: stroke (general), alcohol use, obesity, and tobacco use (i.e. smoking), which are presented below in Table 2. The mandates of the organizations that were approached are described in the following section.

<table>
<thead>
<tr>
<th>Stroke (General)</th>
<th>Alcohol</th>
<th>Smoking</th>
<th>Obesity</th>
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<tbody>
<tr>
<td>b. Heart Health Resource Centre (database)</td>
<td>b. Alcohol Policy Network (and list-serve)</td>
<td>b. National Clearinghouse on Tobacco and Health Program (includes database)</td>
<td>b. Norfolk County Public Health Department – HUGS Program</td>
</tr>
<tr>
<td>c. Heart and Stroke Foundation</td>
<td>c. Centre for Addiction and Mental Health</td>
<td>c. Program Training and Consultation Centre (includes database)</td>
<td>c. Chatelaine/On the Move Walking Club</td>
</tr>
<tr>
<td>d. Ontario Stroke Recovery Association/Ontario March of Dimes</td>
<td>d. Hotel Dieu Hospital – Healthy Heart Program</td>
<td>d. Sudbury and District Health Unit – Smoking Buddies Program</td>
<td>d. Stonegate Community Health Centre – Healthy Heart Kit</td>
</tr>
<tr>
<td>e. Ottawa Stroke Association</td>
<td>e. Stonegate Community Health Centre</td>
<td>e. Oxford County Public Health – Smoking Cessation Program</td>
<td>e. Active Living Coalition for Older Adults</td>
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<td>g. Grey Bruce Heart Health</td>
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<td>h. AlgoMa Heart Health Coalition</td>
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<tr>
<td>i. Consumer Health Information Services – Toronto Reference Library</td>
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<td></td>
<td></td>
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<tr>
<td>j. Canadian Health Network</td>
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<td></td>
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<tr>
<td>k. Canadian Heart Health Initiatives (database)</td>
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<tr>
<td>l. Health Promotion Clearinghouse (Nova Scotia) database</td>
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<td>m. Health Canada</td>
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</table>

Key informants that were using and/or had produced materials for the public that were relevant to the gap analysis were asked to provide samples of materials that could reviewed to assess the extent to which self-help, empowerment, and mutual aid strategies were being incorporated. In some cases, resources (or descriptions of resources) were drawn from databases, internet sites, or
were reviewed or photocopied during site visits. The findings from the review of these materials are provided in the following section.

4. **CRITERIA FOR REVIEWING RESOURCES**

To assess the extent to which self-help, empowerment, and support strategies are being integrated into primary stroke prevention resources, the following list of questions were developed. These questions were used during key informant interviews, and as criteria for reviewing resources that were gathered or downloaded from the internet.

- What modifiable risk factors does the resource address?
- What is the history behind the resource? Was it developed based on a needs assessment, the findings of research, or dictates of prevailing theory?
- How is the material delivered – group format, media, poster, brochure, etc?
- Does the material deal with multiple risk factors?
- Does the material deal with modifiable risk factors in the context of the broad determinants of health (i.e. income, literacy, employment, social support, housing, other access barriers)
- To whom is the resource targeted (e.g. general vs. specific population).
- What has been the role of the target population in the development of the resource?
- Are the materials mostly geared towards giving information or prompting action based on the information?
- Does the material target affluent as well as less affluent or is it transferable?
- Are different peer support mutual aid/volunteer community mobilizers etc. models used in the delivery of the education?
- What kinds of materials are self-help groups choosing to use? What kinds of materials would they like to see produced?
- Do they promote a self-help approach as an educational strategy?
- Do they have any culturally specific stroke prevention materials?
III. REVIEW OF RESOURCES

1. STROKE GENERAL:

Provided below are the learnings and observations that were made having approached the following organizations about their primary stroke prevention activities.

- Ontario Prevention Clearinghouse (database)
- Heart Health Resource Centre (database)
- Heart and Stroke Foundation (printed and on-line resources)
- Ontario Stroke Recovery Association/Ontario March of Dimes
- Ottawa Stroke Association
- Women With Heart – London Middlesex Health Unit
- Grey Bruce Heart Health
- Algoma Heart Health Coalition
- Consumer Health Information Services – Toronto Reference Library
- Canadian Health Network (on-line database)
- Canadian Heart Health Initiatives (on-line database)
- Health Promotion Clearinghouse (Nova Scotia; on-line database)
- Health Canada

Organizations or programs that offer primary stroke prevention resources that incorporate self-help or related approaches are identified in **bold type**.

a. **Ontario Prevention Clearinghouse – Stroke Prevention Database Project**

The Ontario Prevention Clearinghouse (OPC) facilitates and empowers individuals, groups and communities to work towards the realization of their social, emotional, physical and environmental health and well-being. OPC provides information, support and advice to organizations and individuals who work in areas of primary prevention and health promotion. Training and education initiatives, together with the original networking component provide further linkages among people across the province. OPC also continues to link service providers across diverse disciplines that share similar community concerns. OPC does not develop, or coordinate programs for the public relevant to primary stroke prevention.

Beginning in 2000, the Ontario Ministry of Health and Long-Term Care (MOHLTC) began implementing a strategy to improve stroke care and primary prevention throughout the province. They are also concerned that primary prevention activities be enhanced and more integrated with the care delivery system. The Health Promotion and Wellness, Public Health Branch has recognized the need for staff within these centres to make connections to health promotion and to have access to resources for stroke prevention. The main focus for this work is to improve integration of health promotion and population health into the components of Ontario’s stroke care and treatment system.
One of the primary activities within this mandate was undertaken by OPC and involves the identification and compilation of a referral source list/network resource maps of health promotion programs and resources. These resource maps will be done regionally/locally and will be a practice tool to support client referrals and can link to patient care plans. Between eight and sixteen products will be developed and include francophone resources in bilingual communities (e.g. Windsor and Ottawa).

The SHRC Project Consultant requested a listing of primary stroke prevention related projects from the OPC Consultant for the Referral Source list/Network Resource Maps. Unfortunately, the mapping project was still in process and it was not possible to acquire this. However, the OPC Consultant did graciously attempt to do a key word search in their database, using “self-help and stroke” (given that the database was not yet complete). Of the 50 results pulled up, those results that were most relevant to the search included:

- 2 stroke support groups (i.e. for stroke patients, or families/caregivers of stroke patients). Because these groups are for stroke “survivors”, they are not primary stroke prevention initiatives.
- 2 professionally led smoking cessation groups (one through Rouge Valley Hospital, the second through the Centre for Addiction and Mental Health). Given that these are initiatives that are professionally led rather than peer-led, they are not examples of primary prevention self-help/mutual aid activities.
- 1 peer-led smoking cessation group (Easy Breathing, Toronto). This group is discussed below in the sub-section on Smoking.
- 1 smoking cessation guidebook produced by the Lung Association (Get on Track). This material is discussed below in the sub-section on Smoking.
- 1 non-profit self-help group for overweight people under doctor's guidance – Canadian Calorie Counters, Niagara Chapter. This group is discussed below in the sub-section on Obesity.

Because the OPC project was in process while this gap analysis was being conducted, it was not possible to acquire a more complete listing of primary stroke prevention initiatives that incorporate self-help and related approaches. Conflicting timelines meant that the SHRC Project Consultant conducted a search of sources of material independently.

b. Heart Health Resource Centre

The Heart Health Resource Centre (HHRC) is a project of the Ontario Public Health Association (OPHA) and is funded through the Public Health Branch, Health Promotion and Wellness of the Ontario Ministry of Health and Long-Term Care (MOHLTC). The mandate of the Heart Health Resource Centre (HHRC) is to enhance the capacity of public health agencies and their community partners to implement comprehensive, multi-risk factor, community-based heart health programs. The objectives of the HHRC include increasing the capacity of Ontario health promotion practitioners/intermediaries such that they can intervene effectively and, in turn, improve the health of Ontarians. In doing so, their services include resource development and
dissemination aimed at improving access to heart health (and stroke) resources and programming, including designated best practices.

Database Search

Through a key informant interview with the Coordinator of the Heart Health Resource Centre, it was learned that the HHRC has just very recently launched a searchable on-line database (on the HHRC web-site) ([http://dev.web.ca/home/hhrc/resources/browse.shtml](http://dev.web.ca/home/hhrc/resources/browse.shtml)). This database houses names and descriptions of stroke-related programs and resources from all across Ontario. An extensive keyword search was conducted to identify primary prevention programs that address the three aforementioned modifiable risk factors (smoking, alcohol use, and obesity). Two separate strategies were used for conducting the keyword search: 1) detailed search using a function provided by the database; and 2) manual search of the database. The results of each of these strategies are discussed in turn.

**Strategy 1 – Using Detailed Search Function Provided by Database**

Using the detailed search function, the Stroke database was searched by ‘audience’, ‘risk factor’, and health promotion ‘approach’. A detailed search of the Stroke database was also conducted, using a selection of keywords offered by the database. Keywords are organized into categories (e.g. audience, disease condition, setting etc.). Keywords selected for the database search are highlighted in **bold**.

- **Audience (by group type)** – Aboriginal/ethnic/faith/cultural, **community volunteers/partners**, family/parents/caregivers, **general community**, health professionals, **low income individuals**, politicians, recreation/fitness professionals, teachers and other.
- **Audience (by age)** – 0-12, 13-18, **19-64, 65 plus**
- **Audience (by gender)** – male, female or both
- **Risk factors addressed** – cancer, **excessive alcohol**, high blood pressure, high cholesterol, overweight, sedentary lifestyle, smoking, stress, unhealthy eating
- **Health promotion approach** – awareness, community mobilization, education/skill building, environmental support, and policy
- **Disease conditions addressed** – cancer, coronary heart disease, diabetes, stroke
- **Setting** – day care/nursery school, day camps, grocery stores, restaurants, health care settings, media, schools, work sites, or any.

For each combination of keywords entered into the database, only a very limited number of possible resources were identified. The specific resources identified for each combination of terms are described in Appendix 1. In summary, there were only a total of three sources that pertained to primary stroke prevention that warranted further exploration. These resources included:

- Smoking Cessation programs offered by North Lambton Community Health Centre. These programs are professionally led by a nurse however, and thus do not fit the description of “self-help”.
- **Low-Risk Drinking Guidelines** information, produced by the Centre for Addiction and Mental Health. These guidelines are reviewed in sub-section on Alcohol.
• *Stroke Card*, which is a wallet card designed to provide a quick reference for stroke risk factors and warning signs. It is produced by the Heart and Stroke Foundation of Alberta, Northwest Territories, and Nunavut, but is available by ordering on-line. While this resource is about primary stroke prevention, it is not a “self-help” or support resource that encourages individuals to take actions on reducing their risks. Rather it describes the signs of Stroke.

**Strategy 2 – Conducting “Manual” Search**

The Stroke database was searched manually using several risk factor related and approach related keywords. Examples of the keywords used included: tobacco, smoking, alcohol, drinking, obesity, overweight, nutrition, self-help, empower(ment), mutual aid, and peer (help). Provided below is a summary of the findings of the extensive key word search. The detailed analysis of how relevant sources were selected is presented in Appendix 2.

**Tobacco** - 18 programs and resources were identified and described. Of those 18 sources, there was 1 source that appeared relevant to pursue for more information (i.e. to see if it meets the identified criteria) – a smoking cessation program based on the “stages of change” theory, called *Step by Step*, which is being implemented by Stonegate Community Health Centre. This has been included in the review in sub-section on Smoking.

**Smoking** – 82 programs and resources were identified and described. Of those 82 sources, there was 1 source that appeared to be relevant to this gap analysis, warranting further review. This resource was the *3S Stop Smoking Support Program* offered by the Hotel Dieu Health Sciences Hospital, Niagara. This program is discussed in more detail in the sub-section on Smoking.

**Alcohol** – 61 sources were identified and described in the key word search. There were no alcohol specific programs that were identified. However, there were 2 sources cited that were about heart health in general that indicated including a component on alcohol. These sources included:

- A *Healthy Heart Kit* (that addressed stroke prevention) produced by Stonegate Community Health Centre
- A *Healthy Heart Program* offered via the Hotel Dieu Hospital in St. Catharines that discussed atrial fibrillation (which can be a precursor to stroke).

These items are discussed below in the Alcohol sub-section.

**Drinking** – When this key word was used, 5 sources were identified and described. All of these sources were repetitions of sources identified using the key word alcohol.

**Obesity** – only 1 source was cited when obesity was used as a keyword. The source identified was the *Chatelaine/On The Move Walking Club*, which is sponsored by the Canadian Association for the Advancement of Women in Sport and Physical Activity. This is discussed below in the sub-section on Obesity.

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25 The stages of change theory is a behaviour modification approach used in many health promotion and disease prevention programs. A number of the resources reviewed in this report are based on this theory. It is described in Appendix 3.
Overweight – 51 sources were cited and described using the keyword overweight. Of these 51 sources, 4 were deemed to be relevant for further review. Three of these sources are from the Heart and Stroke Foundation (their materials are discussed below). The remaining source was the same Healthy Heart Kit identified using the keyword alcohol (distributed by Stonegate Community Health Centre), and is discussed in greater detail in this report.

Nutrition – 36 sources were cited and described in the key word search. Of these 36 sources, none of the sources were specific to stroke prevention. They were more focused on general nutrition topics such as using the food guide (3 sources, one of which was specific to newcomers), making healthy food choices (3 sources), healthy food preparation (3 sources), reading food labels (2 sources), serving sizes (1 source), general nutrition (1 source) and living a healthy lifestyle (1 source).

Self-help – 3 sources were cited and described in the key word search. Of the 3 sources cited, there was 1 source that was relevant for further exploration – a program through the Nutrition Resource Centre called Food Steps. Refer to the sub-section on Obesity for more information.

Mutual aid – no sources were cited when the term “mutual aid” was used in the key word search.

Support – 42 sources were cited and described using the term support in the key word search. There were 9 sources that related to “support”, but they were not stroke specific initiatives. These sources addressed healthy lifestyle (2 sources), nutrition (1 source), smoking (cessation) (3 sources), an annual smoke free home contest (2 sources), and a Speaker’s Bureau of the Active Living Coalition for Older Adults (ALCOA) pertaining to active living for seniors (1 source). The Speaker’s Bureau is discussed in the section on obesity. Smoking cessation programs are discussed in the sub-section on smoking.

Empower – only 2 sources were cited and described in this keyword search. Both of the sources identified focused on secondary prevention, and were specific to diabetes education.

Peer (in the context of peer help or peer support) – 6 sources were cited and described in this keyword search. Of these sources, there was 1 that was relevant to the gap analysis – ALCOA’s Speaker’s Bureau that encouraged seniors to lead active lifestyles. This is the same source identified using the term “support” and is discussed in the sub-section on Obesity.

Site visit

The HHRC also houses an informal “library” of the resources that are identified on their on-line databases. A significant proportion of the materials on cardiovascular health and disease that are listed in their databases are included in this collection. The SHRC Consultant paid a visit to the HHRC to review the materials in the collection. After having reviewed more than 150 booklets and guides, more than 150 pamphlets and fact sheets, and approximately 40-50 manuals from programs across the province, it was observed that the majority of the resources pertained to heart health. (The HHRC staff did note in a telephone conversation that they are just in the
process of building their stroke collection). Given that heart disease and stroke share similar risk factors, these (heart health) materials were analysed re the extent to which self-help principles or determinants of health were incorporated. Interestingly, of the materials that were targeted towards adults and seniors, there were only 2 resources that appeared to fit the description of self-help (as it is defined by the SHRC). These materials are:


Both of these resources are discussed in greater detail in this sub-section.

c. **Ontario Heart and Stroke Foundation**

The Ontario Heart and Stroke Foundation (OHSF) is the provincial office of the Heart and Stroke Foundation of Canada. The OHSF is the primary producer of educational materials for the general public on heart and stroke prevention for Ontario. Materials are available from the OHSF through a number of vehicles: through their web-site; by calling or going to one of their offices; or, through staff that are involved in cardiovascular related programs and services (e.g. affiliated with hospitals).

Given that the OHSF is a primary producer of materials on stroke prevention, as well as the fact that many of the key informants approached during the gap analysis indicated that they OHSF materials for their (primary) stroke prevention activities, it was important to try to access their primary stroke resources in a variety of ways. These ways included: key informant interviews with the Provincial Office, as well as one of their regional offices, through their web-site, and by going to their head office. Presented below are the results of those activities.

**Provincial Office** – the SRHC Consultant made four attempts to connect with OHSF staff to discuss their educational materials specific to stroke prevention. These attempts were only moderately successful. Provided below are the learnings from brief conversations and exchanged voice mail messages:

- Resources developed by OHSF are broad based in the prevention area – for the “general” population and are not necessarily targeted towards groups that were marginalized such as those living on low-incomes. These materials generally do not address the determinants of health, such as low income, education, or housing (or their link to stroke). The topics include healthy living, and stroke signs and symptoms, and stroke risk factors. They also have wide range of materials that are directed towards stroke patients. Materials are produced in English and French, with a limited number of titles available in other languages (e.g. Chinese).
- The OHSF recently commissioned a special project to develop a guide for setting up support groups for families or caregivers of stroke, and stroke patients themselves. Refer the sub-section on the special project (below) for more details.

**Regional Office** – because the OHSF is a widely-recognized and reputable source of information on heart and stroke prevention and conditions across the province, a key informant interview was
also conducted with one of the regional offices. The OHSF has approximately 36 regional offices in Ontario. The Regional Office serving Hamilton was selected because Hamilton is a larger geographic area that attracts many newcomers, and also has wide income distribution, including a percentage of residents that are living on low-income. When the SHRC Consultant contacted this regional office, it was learned that the resources used by this office are the same as the ones that are produced by the Ontario office. They do not produce regionally specific resources and like the OHSF, there is nothing that is specifically targeted towards newcomers or those living on low-incomes.

Special Project – the OHSF recently implemented a special project to develop a guide\textsuperscript{26} for caregivers and families, as well as stroke survivors to set up social support groups. The development of this guide was part of a series of pilot projects funded by the Ministry of Health and Long-Term Care as a component of the Ontario Stroke Strategy. The Southeastern Ontario Stroke Network identified supports for stroke survivors in rural areas as a priority for action. The Ontario Community Support Association and the OHSF, working with other provincial organizations to enhance the resources available for stroke survivors in the community, agreed that the pilot project in the Southeastern Ontario Stroke Network should address the issue of social support.

Because this resource is specific to stroke survivors and their families and caregivers, and not primary stroke prevention, it was not included as a resource for review in the gap analysis. However, it is important to note that this resource exists, as it is an important use of self-help strategies in stroke recovery.

Site Visit

Given the challenges of reaching OHSF staff for more information about their stroke prevention strategies, the SHRC Consultant went to the OHSF head office (in Toronto) to pick up materials. There is a dedicated information area where the public can come to pick up educational materials on Heart and Stroke. In that visit, a series of materials were acquired. These are discussed below.

Summary of Materials Review

\textbf{Hard Copy Materials}

In the site visit to the OHSF, approximately 20 resources that appeared to be related to primary prevention were picked up. Of these materials, there were approximately 5 that appeared to be related to primary stroke prevention. The titles of those materials were:

- \textit{Are You At Risk Of A Heart Attack Or Stroke? You Tell Us.}
- \textit{Do You Know The Five Main Warning Signs Of A Stroke?}
- \textit{Get Stroke Smart}
- \textit{Healthy Habits Healthy Weight: A Practical Guide To Weight Management.}

\textsuperscript{26} Heart and Stroke Foundation of Ontario. (2003). \textit{A Guide to Starting a Self-Help Group for People who have had a Stroke and For Caregivers}. Prepared by Jenny Barretto. Copywright to OHSF.
• *Take Control: Actions To Lower Your Risk*

Of these 5 resources, the latter two most resembled a self-help tool.

• *The Healthy Habits Healthy Weight* is a 45-page guidebook that includes a wide variety of tips and suggestions for goal setting, healthy eating, meal planning, staying motivated, and living active. There is a good basis for shaping this resource into something that would be more appropriate to the SHRC’s desired target groups. There is an opportunity for a partnership with the Heart and Stroke Foundation to review and redevelop this resource in a number of ways so that it was culturally appropriate, linguistically specific, in clear language using less terminology, and adaptable to self-help or peer.

• In the same way as above, the booklet called *Take Control: Actions to Lower Your Risk* could be revised to make it more culturally appropriate, linguistically specific, in clear language using less terminology, and adaptable to self-help or peer support groups that wish to use it.

In addition to these resources, the HHRC database identified the *Stroke Card*, another HSF resource (produced by HSF of Alberta, Northwest Territories, and Nunavut). This is a wallet card designed to provide a quick reference for stroke risk factors and warning signs, and is not a tool for assisting someone in identifying strategies for modifying their risk factors.

**On-line Materials**

On the OHSF web-site users have the option of selecting from several choices on the main menu – one of which is an option on stroke. When “stroke” is chosen, the user then has a new series of options to choose from – being: (i) general information, (ii) risk factors, (iii) prevention, (iv) treatment and rehabilitation, (v) living with stroke, (vi) interactive tools, and (vii) support programs (for caregivers).

*When the ‘risk factors’ option was selected*, the user was presented with options to “understand the key risk factors for stroke and learn how to manage controllable factors and live a healthier lifestyle”. Of the 13 options presented, there were 3 that were relevant to the risk factors under consideration in this gap analysis – stroke risk factors, alcohol consumption, and smoking (the other topics listed included medical conditions such as diabetes, and amyloid angiopathy, drug use, and use of specific medications and street drugs). Upon reviewing the resources that were linked to these topics, the information that was presented included basic tips and strategies for minimizing risk, but were not sensitive to important considerations such as culture, literacy, or low-income. It was difficult to see how someone fitting such descriptions would be able to “see themselves” in these resources, and glean sufficient information that would help them to make modifications to the risk factors that they have control over.

*When the ‘stroke prevention’ option was selected*, the user was the presented with options to “learn to lead a healthier lifestyle by adopting some of our suggestions for improving your diet and following a few tips that can help reduce your risk for stroke”. Of 13 topics listed, there were 3 resources relevant to this gap analysis identified - *Controlling Your Risk Factors, Alcohol: Low Risk Drinking Guidelines*, and *Diet and Nutrition* (the other topics listed pertained to issues such as cholesterol, diabetes, alternative and herbal remedies, and secondary...
prevention). Upon review, these 3 resources were informational in nature, providing some basic tips and strategies but were not resources designed for self-help or mutual aid groups. However, they did not appear to take into consideration barriers experienced by newcomers such as low-income, or other determinants of health such as education or literacy level.

d. **Ontario Stroke Recovery Association/Ontario March of Dimes**

The Stroke Recovery Association (SRA) provides support and information to stroke survivors and their families. It exists to:

- Provide an environment in which stroke survivors and their families can meet, without being self-conscious, for social and educational programs. Peer support of both survivors and caregivers is the cornerstone of SRA philosophy.
- Further community awareness of stroke and its prevention, treatment, and effects, both short and long-term, on stroke survivors and their families.
- Promote continuing rehabilitation and education of stroke survivors as contributing and productive members of society.
- Ensure that there is adequate funding, both public and private, to further this mission.

There are 17 active chapters across Ontario providing services to more than 800 members and the community at large.

In an interview with one of the key members of the association, it was learned that the Ontario SRA, which is currently headed in Barrie, is becoming subsumed under the Ontario March of Dimes (OMD), which has been a long time supporter. The SHRC Consultant was directed to speak with the OMD for further information about stroke prevention activities.

The mission of the OMD, as it relates to the SRA is to maximize the independence, personal empowerment and community participation of people with physical disabilities. To this end, OMD is a leader in the provision of community-based services, advocacy and research. With the support of the OMD, the SRA provides:

- A stroke registry for survivors, caregivers and professionals,
- A province-wide network of peer-support chapters,
- Expanded services to meet the specific needs of stroke survivors and their families,
- Information services,
- Building community connections, and
- Funding of stroke recovery research.

Through an interview with the OMD, it was learned that at this time their collaborative work with the SRA is focused on secondary prevention, and rehabilitation. However, they are in the process of developing some educational materials, some of which *may* include primary stroke prevention education. Thus, there were not any programs or resources from OMD or the SRA identified for a more detailed review.
e. Ottawa Stroke Association

The Ottawa Stroke Association (OSA) aims to help stroke survivors and their families cope with life after a stroke. The objectives of the OSA are to bring encouragement and support to stroke survivors and enlightenment to their families and friends. It provides fellowship and understanding, opening the door to regaining self-confidence and independence.

A key informant interview was conducted with the Executive Secretary of the OSA, Susan Wright. The purpose of the interview was to clarify the mandate of the organization, and to clarify whether they are involved in any primary prevention activities. It was learned that their primary focus is on secondary prevention, and providing support to caregivers and stroke survivors. It was noted that if they received a call from an Ottawa resident that was interested in primary stroke prevention, that they would refer the caller on to OHSF.

The OSA did provide the SHRC Consultant with a booklet that is distributed to new members. This booklet, called *Stroke Dilemma*, contains information pertaining to what a stroke is, stroke rehabilitation and different types of therapies, and related personal and social issues. Because the organization is not involved in primary prevention, the booklet was not reviewed in greater detail.

f. Women with Heart Program, London-Middlesex Health Department

The mission of the Middlesex-London Health Unit (MLHU), a teaching health unit, is to promote wellness, prevent disease and injury, and protect the public's health through the delivery of public health programs, services and research. *Women with Heart* is a program that was developed by the MLHU out of a need to increase access to heart health information, particularly for newcomer women.

A telephone interview was conducted with the coordinator of the *Women With Heart* Program. Through that telephone interview it was learned that the MLHU had previously been using a heart health workshop model, which was not successful for the intended audience. A local partner agency, the London Community Resource Centre, who had recently participated in a SHRC peer-mentoring project (DSEF, refer to Appendix 6) was supportive of building a heart health program that built in elements of peer support and self-help.

The *Women with Heart* involves recruiting and training women in the community on topics related to heart health (e.g. smoking cessation, healthy eating). These women then go on to facilitate groups in their community, and provide the heart health information. The groups provide opportunities for participants to share information, concerns, and discuss strategies. It is also an opportunity for newcomers and persons living on low income to connect with others and discuss realistic means for building in heart healthy strategies. The program is in its final stages and is currently being evaluated. At the time of the interview, the evaluation results were not yet available.
Although program is not specific to stroke prevention, it was included in the gap analysis because it was a good example of the type of self-help, and peer support program that the SHRC was hoping to identify in this gap analysis.

g. Grey Bruce Health Unit

The Grey Bruce Health Unit articulates its mission as follows: “With the community as our partner, we provide leadership in health protection, health promotion and disease prevention”. Grey-Bruce counties have a community-based healthy living program run by people interested in promoting heart healthy lifestyles. This program takes a multi-risk factor approach to heart disease.

One of the resources of Grey Bruce’s heart healthy lifestyles strategy is a booklet called Walk Your Way – A Walking Program For All Ages. Through a key informant interview with the heart health coordinator for Grey Bruce, it was learned that this booklet is targeted towards individuals or groups who are interested in becoming involved in (a) walking (group). It is a 90-day walking program that is intended to reduce risk of heart disease, diabetes, obesity, osteoporosis, and some forms of stroke. It provides a system for tracking daily and weekly goals, by logging the amount of time and kilometers walked. It also provides information about healthy eating (51 Tips to Reduce Fat, Lower Calories, and Eat Right), and smoking cessation. This resource comes with a leader’s guide, which can be used by peer-led groups. Unfortunately we were unable to acquire a copy of the leader’s guide, so it was not reviewed.

This resource is generally aimed at adults, and does not target any specific sub-groups, such as people living on low incomes, or newcomers – although, in principle, it could be argued that a walking program would be something that almost anyone could participate in (for the exception of those with physical disabilities). If this walking program is completed in a group, then Walk Your Way provides a framework for individuals to incorporate affordable and achievable primary prevention strategies, and to provide and receive support from neighbours and friends on a shared issue.

The booklet does have a lot of text, which may be challenging for persons who have lower literacy skills, or do not read English well. Also, some of the nutrition tips used are appropriate to the “mainstream” population, but may be less relevant to people with diverse dietary practices or preferences. A public health nurse (i.e. the previous heart health coordinator) and a nurse affiliated with a local hospital developed this resource. Thus, Walk Your Way was created by professionals, rather than a (grass-roots) group out of an expressed need or interest for this kind of program (as is the case in self-help groups, as they are described by the SHRC).

In spite of how the program was developed, and concerns regarding literacy and examples used in this resource, the Walk Your Way provides a framework for being an effective self-help resource that individuals and groups interested in primary stroke prevention could use. In the event that resources were to be committed to shaping Walk Your Way, it is advised that the leader’s guide also be reviewed. It would also be important to validate this resource with the proposed target audience, to ensure its relevancy.
**h. Algoma Heart Health Project**

The Mandate of the Algoma Heart Health project is to promote heart healthy lifestyle choices and opportunities to prevent premature heart disease within the community of Algoma.

The *Take Heart – Heart Health for Algoma – Your Passport to Health* was identified for further review, in an initial scan of the resources during the site visit to the Heart Health Resource Centre. This scan prompted a key informant interview with the Heart Health Coordinator for Algoma. In that interview, it was learned that this resource is distributed through a worksite health promotion program. In this program, participants receive cholesterol, flexibility, carbon monoxide, and other health related tests and checks. Individuals who have high cholesterol receive a copy of the *Passport*. The passport is not designed to be a resource for self-help or mutual support groups.

The booklet focuses on individual level factors, such as blood pressure, healthy eating, waist-to-hip ratios, healthy weights (i.e. Body Mass Index), cholesterol levels, smoking, and active living. This information is presented in a visually pleasing way (larger print with diagrams). Some of the language used may be complex for those with lower literacy levels or educational levels, or for newcomers who are not proficient in English. While this resource does identify some active living strategies that are relevant to people living on low incomes (e.g. housework, going for a walk), this passport generally does not situate primary stroke prevention in the context of the broader determinants of health.

**i. Consumer Health Information Service (Toronto Reference Library)**

The Consumer Health Information Service (CHIS) helps people gain greater control over their own health through access to health information. The goals of CHIS are:

- To create and provide access to a reliable and up-to-date collection of consumer health materials;
- To provide the means for consumers to become more informed about their health; and,
- To support the provision of health information to public libraries.

Given the CHIS’s role in providing health information for the general public, the SRHC consultant paid a visit to the CHIS to review the collection on primary stroke prevention. In addition to books, the CHIS collection includes vertical files on a variety of subject areas, as well as a call-in service for Ontario residents who may have more detailed inquiries about health issues. These inquiries are responded to by qualified (medical) librarians who use the vertical files, the internet, and other vetted sources to respond to callers’ inquiries.

A review of the files on stroke revealed a significant amount of information pertaining to stroke prevention, signs, symptoms and treatment. It was observed that the vast majority of this information was drawn from medical journals, hospital or public health organization newsletters, medical magazines, and newspaper articles. Given the sources of this information, the materials
were relevant to higher literacy level audiences, and informational in nature. There did not appear to be any designed from a self-help, mutual aid, empowerment, or the like, as they are defined in the Introduction of this report. No materials that appeared to address broader determinants of health were found.

In addition, the CHIS designs Information Sheets called “Health Finders” which provide lists of (library) resources, web-sites and organizations that provide information on specific health topics. At the time of the site visit to the CHIS, the Health Finder on stroke was being revised and thus was not available for review in the gap analysis.

The CHIS provides an excellent health information service for the “general public”, and it is not the intent of this report to be critical of those services. However, for the purposes of this gap analysis, that the CHIS does not necessarily house self-help or empowerment related resources (as they are defined by the SHRC), or resources that would be targeted towards newcomers whose first language is not English.

j. Ontario Physical and Health Education Association (OPHEA)

Founded in 1921, the Ontario Physical and Health Education Association (OPHEA) exists to support Ontario’s school communities through advocacy, quality program supports and partnerships to enable children and youth to lead active, healthy lives – the latter being an important element in stroke prevention. It was decided that since the primary audience for the gap analysis was adults, that materials from the latter organization, OPHEA, would not be included in the materials review, as they are either directed at children and youth, or professionals who work with them.

k. Canadian Health Network web-site

The Canadian Health Network (CHN) is a national, non-profit, web-based health information centre. CHN’s goal is to help Canadians find the health information that they are looking for on how to stay healthy and prevent disease. The network is comprised of health information providers, including Health Canada, and national and provincial/territorial non-profit organizations, as well as universities, hospitals, libraries, and community organizations.

For this project, the web-site was searched in two different ways: 1) by key word combinations (i.e. Boolean search), using identified risk factor and health promotion approach key words, such as ‘alcohol and stroke’ and ‘self-help and stroke’; and 2) using the alphabetized index (called “A to Z Index”) looking under the key words alcohol, smoking, smoking cessation, obesity, self-help and stroke.

**Strategy 1: Boolean Search**

When the Boolean key word searches were completed, no resources were identified for the key words “alcohol and stroke” and “obesity and stroke”. When a search was completed on “smoking and stroke”, there was a total of 7 resources identified, 4 of which were British
Columbia provincial health planning reports. Two resources explained how cigarette smoking can lead to stroke and stroke statistics, but did not include any self-help information or strategies. The remaining resource was a 5-page (when printed) fact sheet that explained non-modifiable and modifiable risk factors for stroke. This resource also links the reader to other resources that provide basic tips and strategies for how to reduce risk (e.g. how to be more physically active). However, this resource is very wordy, targeted towards those reading at higher literacy levels (and obviously those quite proficient in English). Also, it does not appear to provide any clear strategies for people who may be living on a low income, or who are new to Canada.

When a key word search was completed using just the term “stroke”, 26 resources were identified. Of those 26 resources, there were several that discussed:

- Physical risk factors, such as atherosclerosis, transient ischemic attacks (TIA’s), and hypertension;
- Signs and symptoms of stroke;
- Organizations that do education and research related to stroke (e.g. Ontario Heart and Stroke Foundation); and
- Stroke statistics reports.

There were only 4 sources that appeared to be related to stroke prevention:

- One being related to healthy eating (produced by the Calgary Health Region),
- One about healthy lifestyles (produced by the Nova Scotia Provincial Health Council);
- A tip sheet for seniors about stroke (with limited information; by Health Canada); and
- A resource called “What Can I Do To Prevent A Stroke” (by the Canadian Health Network). None of these resources were written with newcomers or people with low literacy levels in mind, nor are they self-help resources as they are defined by the SHRC.

**Strategy 2: Search by A to Z Index**

A search of the CHN website was also conducted using the “A to Z Index”. From this index, information on each of the three risk factors was sought. No self-help resources pertaining to alcohol consumption and stroke prevention, or obesity and stroke prevention were identified. There were 3 resources relevant to smoking cessation identified, although they did not specifically address stroke prevention. Their relevance lies more in their potential utility(s) as individually oriented self-help tools to assist someone with quitting smoking.

- **I Want to Quit Smoking** – the Lung Association of Saskatchewan. This on-line resource provides some good tips and strategies for the reader on how to quit smoking, over a six-week period.
- **On the Road to Quitting** - Health Canada. This resource includes a lengthy on-line questionnaire for smokers, which asks about their smoking habits. It appears to be based on the stages of change model. The SHRC Consultant did a mock questionnaire (pretending to be an older female smoker). Following completion of the questionnaire, there was a choice between receiving an e-mailed individualized analysis of the responses, or to be linked with a web-page that provide the same analysis.
- **How Can I Quit Smoking** – Canadian Health Network (created by the Program Training and Consultation Centre). This resource is in smaller print (which may be challenging for those with reading difficulties), but it is in fairly clear language, and appears relatively easy to read.
And overall, each of the three tools appear useful from an information standpoint but they would not be considered comparable to a self-help or mutual support group.

The resources identified in the A to Z Index, under the heading called “self-help” were also reviewed. There were no sources cited that appeared to be relevant to primary stroke prevention, and the three risk factors under examination in this gap analysis. In summary, the CHN web-site is a comprehensive source of health information on a variety of topics, but does not appear to be a source of self-help/mutual aid related resource.

I. Health Promotion Clearinghouse (Nova Scotia) on-line database.

In 2001, the Nova Scotia Department of Health mandated the Unit for Population Health and Chronic Disease Prevention to coordinate the development of a provincial chronic disease strategy that built upon and enhanced existing health promotion efforts. The Unit also assumed the responsibility for providing the structure for the Health Promotion Clearinghouse (HPC).

The HPC assists organizations in building capacity for health promotion by supporting the work of volunteers and organizations through providing timely access to resources and expertise that exist in the community. One of their activities is a clearinghouse (i.e. database) of resources. This database was searched, by using keywords including stroke, alcohol, smoking and obesity. No relevant resources were identified for further review.

m. Canadian Heart Health Initiatives on-line database.

The Canadian Heart Health Initiative (CHHI) is a multi-level strategy that links national, provincial and local health departments, combining research with the implementation of community-based heart health initiatives. The CCHI is comprised of intersectoral partnerships and networks in order to develop and disseminate prevention knowledge. The 10 provincial departments of health, as well as the federal department co-fund the CCHI and the Heart and Stroke Foundation is a major partner. The CCHI utilizes a multifactorial approach – one that addresses the major risk factors that are preventable or controllable. Efforts are directed primary at the general population and concentrate on achieving environmental changes that support heart healthy habits and lifestyles.

The CCHI website is home to a database which houses a variety of heart health related resources (printed and digital) ad contacts (people, experts). The database is searchable using multiple criteria, such as resource type (e.g. reports, videos, promotional materials), determinants of health (e.g. income and social status, education, culture), risk factors (e.g. smoking excessive alcohol use, poor nutrition), chronic diseases (e.g. heart/stroke, diabetes, cancer), approaches/practices (e.g. education, skills building, community action), settings (e.g. community, workplaces, schools), and target populations (e.g. ethnic/faith/cultural groups, educators, public by age). Despite the wide range of options, and possible combinations of search terms that could be used to search for primary prevention resources on stroke, none were identified through this database.
n. Health Canada

Health Canada is the federal department responsible for helping people of Canada to maintain and improve their health. In partnership with provincial and territorial governments, Health Canada provides national leadership to develop health policy, enhance health regulations, promote disease prevention, and enhance healthy living for all.

Health Canada provides health information to the public in a handful of ways, including through the production and distribution of printed materials, and via their healthy information web-site called Health Canada Online. Both of these avenues were explored as means for identifying self-help and related resources on primary stroke prevention.

Strategy 1 – On-Line Resources

Health Canada Online can be found at http://www.hc-sc.gc.ca/english/index.html. When the internet user enters the site, they are presented with many different options. (For a savvy internet user, this front page is probably relatively simple to navigate through. But for a novice user, or for someone who does not read well, it could be quite overwhelming). The options of relevance to locating information about stroke prevention or the three risk factors of interest are located on the left side of the page. These options include:

- **Just For You** – which provides a range of options for specific sub-groups including Aboriginals, health professionals, immigrants, seniors, and women. When the immigrants sub-group was selected, there was a broad range of information relevant to newcomers presented, including employment, immunization, reports on new immigrants, and “other resources” (which included the Canada’s Food Guide, and the Physical Activity Guide). None of the material in this section appeared to meet the criteria set forth for the gap analysis.

- **Healthy Living** – which provides a range of publications that “help you to make informed choices” in areas including food and nutrition (e.g. body mass index, food advisories and recalls, folic acid, and the Canada Prenatal Nutrition Program), alcohol and drug use (which included a number of reports for professionals, as well as statistics specific to one cultural group), and smoking (which included some information on smoking cessation, including the Go Smoke Free program). None of the material in this section appeared to meet criteria set forth for the gap analysis.

- **Diseases and Conditions** – which lists surveillance and statistical information, most useful to health professionals and researchers. However, there was a sub-section on heart disease, through which the website user could acquire information on basic healthy heart tips (e.g. don’t smoke, eat a variety of foods, be active), as well as the Healthy Heart Kit (discussed in the alcohol and obesity sections). Like the other options (Just for You, and Healthy Living) this section did not appear to provide access to resources that meet the criteria for the gap analysis.
Overall, Health Canada On-line seems to be a resource that is most suitable for health professionals and savvy internet and information users. It does not provide information that is clearly defined as stroke prevention, nor do the resources appear to utilize self-help oriented approaches as they are defined by the SHRC in the Introduction of this report.

**Printed Resources**

A call was placed to the Federal Government’s information line “1-800-O-Canada”. This is an information line that informs callers to government programs and services. A request for information pertaining to smoking cessation was placed. The following materials were received in the mail: Tobacco – We Can Live Without It, Are Your Kids a Target?, and On the Road to Quitting – Understanding and Changing Your Relationship with Cigarettes.

The first resource, Tobacco – We Can Live Without It, is informational in nature. It provides some basic statistics on smoking, death rates related to smoking, and the risks associated with second-hand smoke. It also provides the reader with information about the federal tobacco control plan. It does not include information that could be used by a support group as a basis for working towards smoking cessation. The second resource, Are Your Kids a Target? is a fold up pamphlet that provides very basic information about the risks of smoking and second hand smoke, as well as “what you can do”. Although the information is presented in a clear, easy to read format (and language), there is simply not enough information in this resource for someone to use as a basis for a self-help strategy. This is the kind of resource that might encourage someone to seek more information.

The third resource that was sent was the On the Road to Quitting. It is also available on-line at www.gosmokefree.ca. Like other smoking cessation resources that have been reviewed in this report, On the Road to Quitting appears to have been based on the stages of change model. This resource does provide information in bite-sized formats, and moderately clear language. Some sections of the report are better than others in this regard. Also, readers are provided with a variety of strategies, which they can choose from – which is consistent with an adult education approach. Some concerns about this resource as a tool for persons living on low incomes include the suggestion of supports, which may be costly (e.g. use of nicotine patch). Similarly, the suggestion to choose a quit buddy or tell others about quitting may be less meaningful or realistic to a newcomer who may have few social supports. In conclusion, this resource does have an interesting framework and useful content. In partnership and collaboration with Health Canada, and if validated by the target audience, this resource could be adapted to be more suitable for people living on low incomes (i.e. include additional strategies for how to acquire patches while living on a low income), and to newcomers (e.g. identify opportunities for how newcomer support and smoking cessation support could be combined).

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27 The use of nicotine patches is a common and often successful smoking cessation approach, While the cost of patches may be more affordable in the long run than spending a similar amount of money on cigarettes, the cost of patches may be a barrier for people living on low incomes, as they are usually sold in quantities that require an initial outlay of resources.
2. **ALCOHOL USE:**

Provided below are the learnings and observations that were gleaned having approached the following organizations about their primary stroke prevention activities.

- Ontario Drug Awareness Program
- Alcohol Policy Network (and list-serve)
- Centre for Addiction and Mental Health
- Hotel Dieu Hospital – Healthy Heart Program
- Stonegate Community Health Centre

Organizations or programs that offer primary stroke prevention resources that incorporate self-help or related approaches are identified in **bold type**.

**a. Ontario Drug Awareness Program**

The mission of ODAP is to raise awareness of the effects of alcohol and other drugs by encouraging and supporting drug awareness initiatives throughout Ontario. Key activities of ODAP include setting the theme for the annual Drug Awareness Week Campaign, developing and distributing products to support this campaign, and coordinating communication between Drug Awareness Committees throughout Ontario through a quarterly newsletter, website and annual symposium.

In an effort to arrange a key informant interview with the Coordinator of ODAP, it was learned that there was a change of staff in that organization. Although the outgoing Coordinator was not able to participate in a telephone interview, she was able to report that the primary activities of ODAP centered on the coordination of Drug Awareness Week. The outgoing Coordinator also offered to pass along the gap analysis questions to colleagues during an upcoming teleconference. The SHRC Consultant requested that this happen. No follow-up information has been provided by ODAP to date. In addition, the outgoing Coordinator provided the name of a person to follow-up with for more information. Attempts were made to follow up with that contact, but there was no response.

**b. Alcohol Policy Network**

Alcohol Policy Network (of the Ontario Public Health Association) provides information on all views of alcohol policy and to profile prevention efforts of individuals and groups across Ontario - links to north American/international organizations dealing with alcohol issues. APN facilitates the development of policies that prevent problems associated with alcohol use and promote the health, safety and well being of individuals and communities across Ontario. APN monitors developments in alcohol policy and prevention research, disseminates timely information and best advice, promotes knowledge and skill development and facilitates networking and collaboration.
A key informant interview was conducted with the Coordinator of the APN. She commented that ‘to her knowledge’ there are very few self-help oriented resources related to alcohol use in general, and specifically stroke prevention. There was one resource that she noted, called Evaluate Your Drinking (discussed in the Centre for Addiction and Mental Health sub-section as they are the distributors of this resource), which did encourage people to consider their alcohol consumption. Otherwise, the only other resources that are related to self-help exist at the policy level, encouraging people to become involved in alcohol issues at the policy level (beyond the parameters of this gap analysis).

Another important element of the interview was the call for more self-help and support oriented resources related to alcohol use. Currently the APN and public health units do not receive any funding for the distribution of Evaluate Your Drinking, nor for the production of relevant materials. The APN Coordinator encouraged the SHRC, if they are successful in acquiring funding, to work with community partners to develop printed self-help resources (that address alcohol consumption and health issues) that people can easily integrate into their day-to-day living.

The APN Coordinator also recommended sending out a request to the APN’s list-serve (called Apolnet). Professionals working in the field of alcohol, including public health units across the province, and the Centre for Addiction and Mental Health access this list-serve. It was suggested that users of the list-serve might be able to identify other possible sources of primary stroke prevention materials that incorporate self-help and related approaches. The request to the list-serve is included in Appendix 4. Three responses to the Apolnet list-serve were received:

- One respondent, a public health nurse, stated that while the provincial stroke centres focus on secondary and tertiary care. “I don’t think that you are going to find much, if anything on primary prevention”.

- One respondent, affiliated with the Centre for Addiction and Mental Health, recommended “taking a long and careful look” at a document called Social Justice is Good for Our Hearts – Why Societal Factors, Not Lifestyles, Are a Major Cause of Heart Disease in Canada and Elsewhere by Dr. Dennis Raphael. This resource, and another research report by Raphael (cited in the Introduction) called Inequality is Bad for Our Hearts. Why Low Income and Social Exclusion are Major Causes of Heart Disease in Canada were reviewed, and are relevant background documents for exploring the links between the broad determinants of health, and cardiovascular disease. They provide research support for the necessity to identify and/or develop resources that are targeted towards people living on low incomes, newcomers to Canada, as well as persons with lower literacy or education levels.

- One respondent, a researcher in gerontology and alcohol at Simon Fraser University, replied, “I don’t think you are going to find much, if anything, in terms of stroke programs that even mention alcohol issues other than glossing over it”. The respondent was very encouraging of the work that SHRC is proposing to do, and indicated, “simply raising awareness of the connection between alcohol and stroke is an important step”.


c. Centre for Addiction and Mental Health

The Centre for Addiction and Mental Health (CAMH) is a public hospital providing direct patient care for people with mental health and addiction problems. The Centre is also a research facility, an education and training institute, and a community based organization providing health promotion and prevention services across the province of Ontario. CAMH produces and/or distributes books, pamphlets, videos and clinical tools for health care professionals, and clients and their families, who are dealing with addiction and mental health issues.

CAMH has an extensive web-site, which includes a subject listing of the publications that they have available for sale to professionals, families, and clients. Topics of materials that are offered include Drug and Alcohol Issues to Consider for the Gay, Lesbian and Bisexual Communities, Evaluating Drinking, Taking Action on Drinking, Women and Alcohol, Low-Risk Drinking Guidelines, Alcohol and Your Health (Low Risk Guidelines), Alcohol and Pregnancy, the Older Adult and Alcohol, Dealing with Drinking, Methadone Maintenance, Alcohol and Drug Treatment, and Having a Party

A selection of resources from this list were requested and received for further exploration. The titles under review (5 related to alcohol, and 1 related to tobacco) include:

- **Alcohol and Other Drug Problems – Your Family** – is a booklet that provides tips on how to prevent alcohol and other drug problem within the family, such as strategies for talking about concerns, providing support, being a good role model. It does not discuss (excessive) alcohol use as it relates to stroke.

- **Alcohol and Your Health** – is a pamphlet that discusses alcohol consumption, and highlights low-risk drinking guidelines for the general public, and for specific sub-groups. It does not discuss (excessive) alcohol use as it relates to stroke.

- **Dealing with Drinking – How to Quit or Cut Down** – is a pamphlet that defines moderate and problem drinking, and provides some basic strategies for cutting down alcohol use. It does not discuss (excessive) alcohol use as it relates to stroke.

- **Evaluate Your Drinking** – (Alcohol Policy Network) – is a pamphlet that assists the reader with determining their alcohol consumption for the week, comparing that with others, identifying potentially risky drinking behaviours, and making choices about drinking. It does not discuss (excessive) alcohol use as it relates to stroke.

- **Low Risk Drinking Guidelines – Maximize Life, Minimize Risk** – is a pamphlet that describes guidelines for alcohol consumption, when you should not drink, and tips for following the guidelines. It clarifies some of the messages on alcohol consumption as a preventive measure for heart disease. It does not discuss (excessive) alcohol use as it relates to stroke.

- **Do You Know... Tobacco** – is a pamphlet that discusses the risks of smoking (including stroke), the benefits of quitting, as well as some of the challenges and impacts of quitting.

Although all of these resources are useful in the information that they provide, for the exception of **Alcohol and Other Drug Problems – Your Family**, they generally do not fit the criteria for primary stroke prevention self-help/mutual support resources. For example, although some provide basic tips, they do not provide strategies that can be incorporated by someone living on low income. That is, the tips would need to be fleshed out and made relevant to someone who is living on a limited income. Also, for the exception of **Do You Know... Tobacco?**, none of the
resources relate alcohol consumption to stroke prevention. Further, for the exception of *Dealing with Drinking – How to Quit or Cut Down*, many would be challenging to read for those with lower literacy levels or who don’t have a strong command of the English language.

*Alcohol and Other Drug Problems – Your Family* is an interesting resource that does have some potential to be adapted to a self-help approach. It would appear to incorporate suggestions and strategies that could be used by diverse groups, although the cultural appropriateness of some strategies would need to be explored and/or adapted (i.e. some cultures may be more open or closed than others about talking about certain issues). Also, the examples would need to be made relevant from a cultural and socioeconomic perspective. Lastly, some work would need to be done to make the resource more readable (e.g. larger print) for those with lower literacy levels.

d. **Hotel Dieu Hospital – Healthy Heart Program**

The Hotel Dieu hospital, as part of the Niagara Health System, contributes to the overall health of Niagara's population through the delivery of community hospital services to residents. The Hotel Dieu hospital is home the *Healthy Heart* Program.

Although the Heart Health Resource Centre database identified the *Healthy Heart* program in a keyword search on alcohol, this program actually focuses on nutrition; specifically dyslipidemia (high blood cholesterol) and its relationship to cardiovascular disease. The *Healthy Heart* program was designed by a cardiac nurse, in collaboration with the Niagara Health Unit, in response to physicians being overwhelmed by the number of patients with high blood cholesterol. It is based on the stages of change model, and incorporates diet records, risk factor assessments, and counselling – all of which are the responsibility of the nurse that coordinates the program. Patients are also assessed on their passage beyond ‘precontemplation’ (in the stages of change).

The program is not specifically targeted towards a particular sub-group (e.g. newcomers, or people on lower incomes). It has been designed for the general population, and participants must be referred by their family doctor. Although this program is not a self-help resource as it is defined by the SHRC, it does incorporate two important elements of interest to this gap analysis. The first element is that it does discuss (albeit briefly) the link between (excessive) alcohol consumption and stroke. *This is one of the only resources identified through the entire gap analysis that does.* The second important element is the use of mutual support as one of the program delivery approaches. In addition to the counselling and various assessments, group sessions are held, where participants share their learning, experiences, tips, and strategies.

In summary, while this program has a number of strengths from a medical and lifestyle approach, it is not a primary stroke prevention program, it is professionally run, it does not

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28 It was learned in a key informant interview with the Nurse Coordinator, that this program will be ending in the summer of 2003. Despite its successes and strengths, the decision to close this program culminated out of hospital restructuring decisions for the Niagara Health System.
incorporate social determinants of health in its approach, and it does not meet the criteria set forth in this gap analysis.

e. Stonegate Community Health Centre

Stonegate Community Health Centre located in Etobicoke. Community health centres (CHCs) differ from most traditional health care facilities in that they take a holistic approach to health care, recognizing that many factors – financial, emotional, social, physical, and environmental – affect people's health. CHCs emphasize health promotion and illness prevention as complements to primary health care, and take special care to assist people who are at high risk of illness or are unable to access other facilities because of special needs or low income. A multi-disciplinary team of social and health care professionals delivers CHC services. Because staff are paid a salary, they are able to spend more time with clients than is possible with a traditional clinic's pay-per-visit approach.

Using the risk factor key words (e.g. alcohol, smoking), the Heart Health Resource Centre’s database indicated that Stonegate has been involved in developing and/or distributing a “Healthy Heart Kit” which includes a component on primary stroke prevention. This resource is available in hard-copy or on-line at http://www.hc-sc.gc.ca/pphb-dgspsp/ccdpc-cpcmc/hhk-tcs/english/index_e.htm. The on-line version of the resource was reviewed.

The Healthy Heart Kit is an interactive tool that allows the internet user to click on a range of choices related to heart health. Choices that relate to this gap analysis include “smoking and heart disease” and “weight control and heart disease”. When the user clicks on these options they are then presented with some clear language information related to that risk factor, important facts, and specific strategies for reducing your risk. The strengths of this resource include: at least some of the resource appears to be in clear language, especially the sections called ‘reduce your risk’; and some of the suggestions appear to be relevant across income or cultural groups.

However, there are some concerns about the resource: some of the suggestions are very basic, and not that instructive (e.g. eat 3 healthy meals a day; healthy meals are not defined) for someone who is trying to find low-cost alternatives; some of the strategies may not be very realistic for the SHRC’s proposed audience (e.g. keeping a smoking diary may not be realistic for someone with low literacy skills who cannot write; or taking your medication for smoking cessation may not be realistic for someone who is living on a low income); ironically, despite what was indicated in the Heart Health Resource Centre database, this resource does not actually discuss alcohol use, other than to say you should not consume more than 2 drinks per day; and while it is an informative piece, it is not a tool that was designed for self-help or mutual aid groups to use.
3. **TOBACCO USE:**

Provided below are the learnings and observations that were made having approached the following organizations about their primary stroke prevention activities.

- Focus Resource Centre
- National Clearinghouse on Tobacco and Health Program
- Program Training and Consultation Centre
- Sudbury and District Health Unit – Smoking Buddies Program
- Oxford County Public Health – Smoking Cessation Program
- Easy Breathing – Support Group
- Hotel Dieu Hospital – 3 S Smoking Cessation Program
- Haliburton Health Unit – Smoking Cessation Program
- The Lung Association of Ontario
- The Smoker’s Help-Line

Organizations or programs that offer primary stroke prevention resources that incorporate self-help or related approaches are identified in **bold type.**

a. **Focus Resource Centre**

The Focus Resource Centre (FRC) supports the training, consultation, networking, and information/dissemination needs of FOCUS Community Projects across Ontario which do alcohol and drug abuse prevention programming, including harm reduction, in their communities. Under the leadership of the Centre for Addiction and Mental Health, FRC builds on the resources and expertise of partner agencies to provide seamless service delivery to the 22 FOCUS sites in Ontario.

A key informant interview was held with the Coordinator of the FRC. In that discussion it was learned that the FRC is currently in the process of conducting a survey with its member programs. The focus of the survey includes (but is not limited to) a question about the resources that affiliated programs use for stroke prevention. The results of this survey will not be available at the end of May (at the earliest). The SRHC consultant requested to contact a couple of the affiliated sites in order to pose questions related to the gap analysis. However, due to significant time and resource constraints, the FRC Coordinator felt that it was most appropriate if the FRC shared the results of the survey when they become available.

Therefore, it is not known whether the FRC community projects coordinates, produces, and/or distributes primary stroke prevention self-help/mutual support resources related to tobacco.
b. National Clearinghouse on Tobacco and Health Program

The National Clearinghouse on Tobacco and Health Program (NCTHP) main services include a virtual library, reference services, and networking services. The virtual library offers a comprehensive inventory of critical information for health intermediaries and other professionals in the field of tobacco control.

A key informant interview was conducted with the Information Officer who handles general inquiries and research questions from health intermediaries. In that discussion it was learned that while the NCTHP does list some smoker’s hotline telephone numbers from across the country, they generally do not generate or distribute materials for the general public. It was advised that whatever materials they do have, which would be intended for use by intermediaries (with the public) would be documented in their on-line database. A scan of the database was conducted (http://www.cctc.ca/CCTCweb.nsf/MainFrameSet?OpenFrameSet). No materials pertaining to primary stroke prevention and smoking, targeted towards the general public were identified. Most of their materials appeared to be targeted towards professionals at a policy level.

c. Program Training and Consultation Centre

The Program Training and Consultation Centre (PTCC) provides training and consultation services to enhance the capacity of Ontario communities to implement effective community-based tobacco use reduction strategies. PTCC is a resource centre of the Ontario Tobacco Strategy. The PTCC maintains a roster of community consultants in Tobacco who are available for on-site consultation support in program planning and implementation. Training and consultation supports cover a variety of topics, including: program supports for the Ontario Tobacco Control Act, environmental tobacco smoke and bylaw development, strategic planning, smoking cessation and stages of change, implementing community awareness campaigns, reaching the hard to reach tobacco user, teen smoking cessation, women-centred smoking cessation, environmental tobacco smoke in home environments.

A key informant telephone interview was conducted with one of the consultants affiliated with the PTCC. In that conversation, the work of PTCC as a resource dissemination service was discussed. PTCC catalogues and print materials and make them available to intermediaries. The materials that they house pertain to topics such as smoke free homes information and city smoking policies, and materials such as youth advocacy guides (i.e. materials that are designed for young people to become active in tobacco control advocacy) – which would be useful to self-help groups working at the policy level29. PTCC is not involved in producing materials. If someone were interested in finding tobacco related materials they would refer them to the appropriate organization.

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29 This is beyond the parameters of this gap analysis.
d. Sudbury and District Health Unit Smoking Buddies Program

The Sudbury & District Health Unit (SDHU) is a non-profit agency, funded by local and provincial governments. Health Unit staff provide programs and services that strive to keep everyone in the districts of Sudbury and Manitoulin healthy and safe. The SDHU works with individuals, families and the community, providing programs and services to people of all ages in workplaces, nursery schools and day-care centres, schools, colleges, universities, homes, health care settings and neighbourhoods.

SDHU offers a smoking cessation program called “Smoke Free Buddies”, which was identified by the SHRC in a scan they were conducting to identify smoking cessation groups across the province. A telephone interview was conducted with the Public Health Nurse that has been involved in developing and coordinating the program. Smoke Free Buddies is a new initiative that engages and trains volunteers who have been smoke free for at least a year (ex-smokers) to offer telephone support to clients to people who are trying to quit or are in the act of quit phase. A nurse also provides participants with smoking cessation information.

Smoke Free Buddies comes out of a chronic disease prevention strategy, it is not specific stroke prevention (or prevention of any one specific disease). It has a more broad base approach to health and well-being. Participants come with different concerns, cancer, heart disease, needing bypass surgery etc. Smoking cessation and other health related materials from the Canadian Cancer Society, the Heart and Stroke Foundation, and the Lung Association are distributed to program participants as appropriate.

One of the strengths of Smoke Free Buddies is that it includes a peer support model. However, it was noted that while there is much work being done to get the program off the ground, one of the inherent challenges of the program’s model is that once participants have quit, or are in “maintenance” mode, their interest in the support element of the program tends to wane. The impact on the program is that there are fewer “buddies” to match up to individuals who are in the early stages of trying to quit.

Overall, Smoke Free Buddies is in part, professionally delivered. It also comes out of SDHU’s chronic disease prevention strategy, via Ministry of Health policy, and not directly through a needs assessment or grass roots interests. This is counterintuitive to a self-help approach.

e. Oxford Public Health – Smoking Cessation Group

The Mission of the Public Health Department (Oxford County Board of Health) is to strive for optimal health for the citizens of Oxford County by promoting and facilitating healthy behaviors in a healthy environment. They focus on service delivery, education and research and to a collaborative partnership with the community. Health Promotion programs aim to promote healthy lifestyles in order to reduce the incidence of preventable chronic diseases, cancers and injuries. The health of families is also promoted with an emphasis on supporting healthy pregnancies and healthy child development. This is achieved through activities targeted at the
community as a whole, group education and individual support, education and referral. Mandatory Health Programs and Services Guidelines require that the unit implement programs including smoke free living. It is through this requirement that Oxford Public Health runs a smoking cessation group.

A telephone interview was conducted with the Public Health Nurse that is involved in the planning and coordination of the smoking cessation program. In that interview it was learned that the group is professionally run, and addresses smoking cessation and health in general. Like the Smoke Free Buddies program in Sudbury, this program is not specific to stroke prevention, and emerges from their chronic disease strategy. The program does, however, attempt to reach persons who may have barriers to quitting smoking, such as lack of social support or living on low income. She also noted that she uses educational materials from the Canadian Cancer Society, the Heart and Stroke Foundation, and the Lung Association as appropriate or upon request.

This group was not reviewed in greater detail for a number of reasons: it is professionally run (thus is not a self-help approach as it is defined by the SHRC), and the program is not focused on primary stroke prevention, but rather smoking cessation in general.

f. Easy Breathing, Toronto

Information provided through the preliminary search of the Ontario Prevention Clearinghouse’s stroke database identified what appears to be a peer-led smoking cessation support group called “Easy Breathing”. The description of this group indicates that the group: shares “natural ways to cope with the cravings and withdrawal of quitting smoking”; discusses behaviour modification techniques; and, helps members to find quit buddies. Two attempts were made to reach the contact for this group, but to date there has not been a response.

Although the SHRC Consultant did not have the benefit of speaking with a group contact, based on the description of the group provided, Easy Breathing appears to be the kind of self-help initiative that the SHRC was hoping to identify through this gap analysis. More information would be required to confirm this deduction.

g. 3S Stop Smoking Support Program – Hotel Dieu Health Sciences Hospital, Niagara

The mandate of the Hotel Dieu Hospital is described above in the Stroke section.

Using the key word “smoking” the Heart Health Resource Centre database indicated that the Hotel Dieu Hospital offered a smoking cessation program called 3 S Smoking Cessation, which incorporates a component on stroke prevention. A key informant interview was conducted with the nurse that coordinates the program. In this interview, it was learned that, to have credibility
in the treatment of cardiovascular disease, the hospital should have a smoking cessation program.\(^{30}\)

In collaboration with the Niagara Public Health Unit, a program model was developed, based on the work of Dr. Douglas Wilson in Hamilton, Ontario. Dr. Wilson has expertise in smoking cessation, as well as training health professionals to lead smoking cessation programs. The Coordinator of the 3 S Smoking Cessation program received this training, and has incorporated Wilson’s program tools. These tools include a 10-12 page questionnaire that participants must fill out, to assess their smoking behaviour. The program itself includes individual counseling with the Nurse/Coordinator, physician supervision, as well as a support group component. The individual counselling has a motivational focus and also incorporates assessments of nicotine dependence, lifestyle factors, co-morbidities, and other strategies that the patient/participant has tried or could try. The Nurse Coordinator emphasized the importance of the group support element to the program. “Many people are in desperate need of support and often don’t have it”. The support group provides an outlet to share experiences and strategies.

While the group support is an important self-help element of the program, it would be inappropriate to suggest that 3 S Smoking Cessation fits the description of self-help/mutual support that is described in the Introduction section of this report. Although the program offers the nicotine patch at half-price to those living on low income, the program is targeted to a broad audience that is not culturally specific. Further, 3 S has been developed based on a professional model, and is professionally led, rather than being directed by a group of peers working together towards a common goal.

h. **Step by Step Program – Stonegate Community Health Centre**

A description of the mandate of Stonegate Community Health Centre is provided above, in the section on Alcohol.

Stonegate offers a smoking cessation program called Step by Step. It has two primary components: 1) individual (motivational) counselling provided by a Nurse Practitioner, and 2) a peer support group, also coordinated by the Nurse Practitioner. This program is run in partnership with Toronto Public Health, with the primary focus being on smoking cessation (versus stroke prevention, and/or the prevention of other chronic diseases). Instead, the intent of the program is that smoking related diseases and conditions (of which stroke is one) will be prevented or reduced. The target group for the program is “smokers” either in the process of quitting or who have already quit. The program is not targeted towards any particular sub-groups (i.e. low income, newcomers, or otherwise).

The support group element of Step by Step does incorporate elements of self-help (mutual aid and empowerment as it is defined by the SHRC). For example, the group sessions are (mostly) peer led, where members make decisions by consensus about the direction of the meetings. Group members provide support to one another and share strategies for quitting smoking.

\(^{30}\) It was also learned in the key informant interview that the 3 S Smoking Cessation program, like the Healthy Heart program is likely to be cut in August 2003, as a result of hospital restructuring activities.
However, the Nurse Practitioner plays a coordination role for the group, finding space and refreshments, as well as providing education and information about the Stages of Change (the theory upon which the program is based). Therefore, this program does not meet the criteria for self-help as it is defined by the SHRC in the Introduction section of this report.

i. The Lung Association

The mission of the Lung Association of Ontario is simply to improve lung health. This mission is implemented through a variety of lung-health related programs and initiatives related to asthma, chronic obstructive pulmonary disease, tobacco policy, smoking cessation, as well as home and environmental air quality.

The Lung Association offers a variety of resources related to tobacco, smoking and health, and smoking cessation. The following materials were acquired by contacting the Lung Association by telephone.

- Is there a Safe Tobacco?
- Stop Smoking, Stay Trim – Gain Your Freedom, Control Your Weight.
- Help a Friend Stop Smoking

The first three sources are largely informational in nature, explaining the health risks of smoking in detail, as well as some basic strategies for how to reduce or cut out nicotine consumption. While these resources do contain useful information, they are written at a relatively high literacy level, with many words on the pages. This may be overwhelming for someone who reads at a lower literacy level, or who is just learning English. Also, these materials do not discuss smoking cessation as it relates to stroke prevention. Lastly, these resources do not present the information in the context of the determinants of health, so persons who may have economic and/or social barriers and challenges, may not necessarily see themselves reflected in these pieces, or find the strategies to be relevant to their lives.

The final resource, Get on Track is a smoking cessation guide targeted towards individuals who are trying to quit. It presents some basic information about the risks of smoking (mentioning heart disease but not stroke specifically), as well as information about “thinking about quitting”, tips for trying to quit, and staying ‘on track’ after you have quit. It would appear that this guide is based on the stages of change model, although a key informant interview was not conducted with the Lung Association to confirm this.

In comparison to the aforementioned 3 resources, Get on Track is somewhat easier to read, at a lower literacy level, with less text, that is presented in an easy-to-use format. Yet, some modifications could be made to make the resource easier to read for someone who does not read well (e.g. larger font, smaller paragraphs, more simple word choices). The information presented seems to be relevant to most people regardless of income, or ethnic or cultural background. However, this guide does require the user to be able to write, which may be problematic. Overall, while this resource does contain useful information, and is based on a vetted behaviour
modification approach (consistent with a lifestyle approach), it is not reflective of the self-help
and related approach resources that the SHRC was aspiring to identify through this gap analysis.

j. The Smoker’s Hotline (Canadian Cancer Society)

The Canadian Cancer Society (CCS) is a national community-based organization of volunteers,
whose mission is the eradication of cancer, and the enhancement of the quality of life for people
living with cancer. The Smoker’s Hotline is a service of the CCS. It offers a confidential
telephone service, with trained “Quit Specialists” who: 1) assist with developing a structured
‘quit plan’; 2) can assist with questions; and 3) make referrals to community services.

The Smoker’s Hotline also offers a smoking cessation program for individuals called One Step at
a Time, which is based on the stages of change model. There are guides that assist the smoker
through the precontemplation and quit phases. The booklet on quitting is like a workbook that
encourages the smoker to write down their thoughts on particular topics and issues related to
their smoking. While the smoker can, theoretically, write their thoughts in any language, this
resource does assume a certain level of literacy.

Because the premise behind the Smoker’s Hotline and the One Step at a Time is cancer
prevention, and not stroke prevention, these resources do not meet the criteria for this gap
analysis. However, it was important to mention that they exist, because many of the key
informants (working in the area of cardiovascular prevention) that were interviewed, reported
directing their clients, and callers to this service, as they were not aware of other services that
had a cardiovascular disease prevention mandate. Also, the key informants felt that this was a
reliable service that provided good information.
4. OBESITY

Provided below are the learnings and observations that were made having approached the following organizations about their primary stroke prevention activities.

- Nutrition Resource Centre
- Norfolk County Health Unit – HUGS program
- Calorie Counters – Support Group
- Chatelaine/On the Move Walking Club
- Stonegate Community Health Centre – Healthy Heart Kit
- Active Living Coalition for Older Adults

Organizations or programs that offer primary stroke prevention resources that incorporate self-help or related approaches are identified in bold type.

a. Nutrition Resource Centre

The Nutrition Resource Centre increases the capacity of nutrition practitioners across Ontario to implement nutrition programs and strategies in a health promotion context by supporting implementation of provincial nutrition programs; facilitating networking and information sharing and providing updates about key developments in the field of community nutrition.

A key informant interview was conducted with the Coordinator of the Nutrition Resource Centre. In that interview, two programs were identified, the Food Steps Program, and the Healthy Eating program. Each are discussed in turn

*Food Steps Program*

Food Steps was described as a self-help, stage-based, correspondence program for healthy eating that emphasizes the reduction of dietary fat. The Food Steps Program focuses on reducing dietary fat. The message is in the context of a healthy diet based on Canada's Guidelines To Healthy Eating. Food Steps was written at a grade five to seven literacy level and was written for a healthy adult population. The program is based on the stages of change theory. Each booklet represents a program targeted to an individual's readiness to change and includes information and self-administered exercises to build skills and motivation. The first three booklets encourage participants to move at least, to the next stage of change and preferably, into the maintenance stage. The program is designed to be suitable for use in, and facilitated through:

- Community nutrition promotions through a health unit,
- Wellness programs at worksites,
- Healthy lifestyle counseling in physicians offices, and
- Nutrition and healthy lifestyle counseling in community health centers.

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The program does contain elements of self-help, by assisting people to identify strategies that they can integrate into their activities of daily living, for reducing their risk of stroke. However:

- The program is designed for the “mainstream”. In order to reach a newcomer or culturally specific audience, it would need to be adapted to include references and examples that are relevant to the target audience.
- While the guide has been written at a grade 6 literacy level, and some diagrams have been used, there are a lot of words on each page, which may be intimidating or overwhelming for someone who does not read well, whether as a result of low education level, or their first language not being in English.
- The program is meant to be facilitated by someone with a background in nutrition, such as a dietitian, and thereby does not comprise an element of participants providing each other with support in dealing with a problem, issue, condition, or need.

**Healthy Eating**

The *Healthy Eating Program* is an educational resource designed for individuals who have the opportunity to include healthy eating education in existing and developing programs in order to increase knowledge and skills on healthy eating. The Ontario Ministry of Health, Health Promotion Branch in conjunction with the Canadian Cancer Society, Ontario Division and the Heart and Stroke Foundation of Ontario, originally developed the Program in 1993. The responsibility for managing the Program was transferred to the Nutrition Resource Centre at the Ontario Public Health Association in 1999.

The Program can be used by anyone who delivers nutrition education. The individuals who have used this program the most in the past include: registered dietitians, public health nutritionists, public health nurses, occupational health nurses, fitness leaders, Community Food Advisors, and volunteers from health related organizations.

The *Healthy Eating Program* uses a small group education and skill-building approach. The mini-lessons are structured to provide information in an interactive way so that individuals learn new skills in understanding healthy eating.

Although this program uses a skills-building approach, it is a professionally led workshop, and thereby is technically not a self-help initiative. The program comes with a manual, which includes five interactive mini-lessons on topics such as fat, healthy eating out, and healthy weights. The manual has been “developed for leaders who have the opportunity and desire to incorporate healthy eating information into programs they are currently running or planning”\(^{32}\). The materials have been “developed for adults and their families who want to learn about healthy eating” and can be used in a variety of settings including “employees in worksites, as well as people in exercise, recreational, and religious programs”\(^{33}\).

The SHRC Consultant reviewed the manual. While it does present useful nutrition information in relatively generic ways (i.e. food components, such as starches, fibre etc.), a number of the examples are relevant to a mainstream audience, and may not be relevant to all ethnic or cultural

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\(^{33}\) Ibid.
groups. Also, there does not appear to be anything included in the curriculum about making healthy food choices while living on an income. (For many people living on low incomes, eating out is not an option, so information on making healthy food choices while eating out is not relevant).

b. **HUGS Program – Norfolk County Health Unit**

The mandate of the Norfolk County Health Unit (NCHU) is to strive for optimal health for the citizens of Oxford County by promoting and facilitating healthy behaviors in a healthy environment. It is committed to excellence in service delivery, education and research and to a collaborative partnership with the community. Health Promotion programs aim to promote healthy lifestyles in order to reduce the incidence of preventable chronic diseases, cancers and injuries. The health of families is also promoted with an emphasis on supporting healthy pregnancies and healthy child development.

Within the chronic disease prevention program, there is a new program being implemented, called HUGS. HUGS stands for Health focused, centered on Understanding lifestyle behaviours, Group supported, and Self esteem building. HUGS is a program that was developed by a Canadian dietitian consultant and purchased by Norfolk County Health Unit for approximately $600.

HUGS is not a stroke (prevention) specific initiative, but rather focuses on health - nourishing eating and activity patterns and self-acceptance rather than dieting and weight loss… by instilling new attitudes and knowledge about food and physical activity, the HUGS program enables participants to move from preoccupations around food, weight and behaviour (the vicious diet mentality) to a feeling of independence and self-reliance”.

HUGS program facilitators are “lifestyle professionals, which can include dietitians, nurses, health workers, therapists, fitness professionals, or other professionals with a health background”. The program also has a support group element, for participants. Support groups are lead by HUGS ‘graduates’, and provide an opportunity for participants to share their experiences. The support group leaders also have an on-line support forum, through which they can discuss concerns.

In a key informant interview with the public health dietitian at NCHU, it was learned that NCHU chose to purchase (and implement) HUGS after identifying a gap in nutrition and weight loss programs in the community. It is important to note that this program is not targeted to people on lower incomes. In fact, the program comes with a guide, video, cookbooks and other resources, which must be purchased, possibly creating barriers for people living on low incomes. Also, as described by the public health dietitian, these resources are “definitely not low literacy”.

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34 The HUGS program was identified in an environmental scan of Nutrition programs across the province, which was conducted by the Nutrition Resource Centre.
35 It was learned that the NCHU would be implementing the HUGS program with community members, pending a successful pilot testing of the program with NCHU staff.
In summary, although HUGS does include a support group element, there are many other program elements that are contradictory to the criteria laid out in this gap analysis, such as being professionally designed and led, and not affordable for participants living on low incomes, or accessible to people with lower literacy levels.

c. **Chatelaine/On the Move Walking Club**

The Canadian Association for the Advancement of Women in Sport (CAAWS) is a national not-for-profit organization founded in 1981. CAAWS works in partnership with Sport Canada and with Canada's sport and active living communities to achieve gender equity in the sport community. CAAWS operates with a strong base of volunteers and a small team of effective and efficient staff.

Chatelaine and CAAWS, have partnered to launch the 'On-the-Move Walking Clubs', a nationwide 'easy fitness' program to empower women to inspire women to enjoy fitness within a community of friends -- anywhere, any time. In a telephone interview with the CAAWS On the Move Walking Club representative it was learned that the purpose of the program is to encourage girls and women to become more involved in physical activity and fitness.

*On the Move* is not specifically a primary stroke prevention program. Rather the Coordinator indicated that there are benefits stemming from the program, which include decreased risk of diabetes, heart disease, stroke, cancer, as well as increased opportunities for socializing, social support, and exercise. The program is promoted through Chatelaine magazine (an English and French language magazine generally targeted towards older women), as well as by the program sponsors (the Running Room, Reebok, and Slim Fast). Women can also register for the program by going to the Chatelaine web-site ([http://sweatcentral.chatelaine.com/walkingclubs/index.htm](http://sweatcentral.chatelaine.com/walkingclubs/index.htm)) or the CAAWS web-site ([http://www.caaws.ca/english/index.htm](http://www.caaws.ca/english/index.htm); where there is a link to the Chatelaine web-site).

From a self-help and mutual support perspective, the strengths of this program include the opportunity for people, regardless of income, language, cultural background or education can walk. It also provides an opportunity for social support; program participants have the opportunity to meet others, discuss health issues, or provide social support. However, to the extent that program participants have to register for the program on-line and be able to maneuver through a fairly wordy web-site, presents barriers – especially for those whose primary language is not English, for those who may not read well or type, and in particular for those who do not have access to/cannot afford access to a computer.

d. **Active Living Coalition for Older Adults – Speaker’s Bureau**

The Active Living Coalition for Older Adults (ALCOA) is a non-profit association representing 26 partner organizations and agencies that have a commitment to active living for older adults. ALCOA’s vision is of an active society where all older Canadians are leading active lifestyles, thereby contributing to their physical health and overall well-being. ALCOA has active programs in communication, public education, creating supportive environments, and research.
ALCOA was identified through the Heart Health Resource Centre’s database. A key informant interview was conducted with their Toronto office. In that interview it was learned that the work of ALCOA generally happens at the policy level, with target audiences including organizations and health professionals. They do not generate (self-help or mutual aid) primary prevention resources on stroke.

That being said, the program that was specifically identified in the Heart Health Resource Centre’s database search was their Speaker’s Bureau. The interview with the ALCOA staff did not include the Speaker’s Bureau. However, printed materials about the Bureau were provided through a mailed package. Those materials indicated that the Speaker’s Bureau recruits, “active and articulate older adults to address groups and organizations in their communities… to spread the word about the importance of active living for older adults… the idea is to provide information about existing active living opportunities for older adults, Canada’s Physical Activity guide for Older Adults, and the Blueprint for Action”. A Blueprint for Action is a document targeted towards health professionals and policy-makers.

The recruiting strategy for the Speaker’s Bureau was not provided in the materials provided by ALCOA, so it is not known what their approach is. Generically speaking, a speaker’s bureau, as it is described above, has the potential to draw from a “mainstream” population that is well-educated or connected to community resources. This may not necessarily be the case for the target audience that the SHRC is interested in. It is reasonable to assume that persons who are new to Canada, or those with less education or literacy skills, may have more barriers to being able to participate in this kind of activity.

Generically speaking, a peer led speaker’s bureau could offer interesting (and empowering opportunities) for potential speakers to develop skills in a new area – in a “train the trainer” kind of format. For this resource to be a meaningful self-help/mutual aid resource that is relevant to the proposed target audience, the Speaker’s Bureau would need to recruit speakers from a diversity of backgrounds – ethnically and culturally, linguistically, socio-economically, and otherwise. The Speaker’s Bureau would also have to allow speakers to shape their presentations in response to the diverse and identified needs and interests of their potential target audiences.

In conclusion, it would be beneficial to learn more about the Speaker’s Bureau, including the potential to shape this resource into a train the trainer opportunity that allows speakers from diverse communities to share their wisdom with a diversity of audiences.

e. (Canadian) Calorie Counters – Niagara Chapter

Unfortunately it was not possible to identify mandate or organizational level information about (Canadian) Calorie Counters\textsuperscript{36}.

\textsuperscript{36} In a key informant interview with the area representative for the Niagara Chapter, the SHRC Consultant was directed to the Calorie Counter’s organizational website for this information. In spite of trying different search engines and key words, it was not possible to locate their web-site. A search of the telephone directory (Canada 411) was also unsuccessful.
In a key informant interview with the area representative for Niagara Falls, it was learned that *Calorie Counters* is a self-help weight loss group. The purpose of the program is to provide an avenue of support for persons who are trying to lose weight. *Calorie Counters* is a nation-wide program (in the same way that Weight Watchers is). There are specific tools and worksheets that are provided by the *Calorie Counters* head office to assist local chapters with recording weight and running support groups. There is a $40 annual fee for the first year. Subsequently, support group members pay $1.50 per session, which is applied to their following year’s fee.

While the group does utilize the worksheets (and a program) designed and distributed by a head office, it is important to note that this program is peer led, not professionally led. Group members identify their own leader, and determine the focus of group sessions. Sessions may be social or educational in nature, depending on the interests of the group. For example, the group may choose to bring in a dietitian, or another speaker of interest on a topic not related to weight loss. Other sessions are specifically designated as social times.

The target group for *Calorie Counters* is anyone who wants to lose weight. This is not a stroke prevention program specifically, although some members may share that they are losing weight for health reasons. *Calorie Counters* does not target particular sub-groups, such as persons who are living on low incomes or newcomers to Canada. The key informant indicated that income is an issue for a number of group participants, and that group members often discuss and share tips on how to find healthy and affordable foods.

Because we do not have additional organizational information about *Calorie Counters*, it is difficult to say conclusively what the program model is, and whether this is an organization that has grown through grass membership leadership and direction, or something that was professionally designed. In spite of this caveat, (*Canadian Calorie Counters*) does appear to have a number of important self-help and mutual aid elements, such as peer leadership and social support.

**f. Stonegate Community Health Centre**

The mandate of Stonegate CHC is described in the previous section. Using the risk factor key word obesity, the Heart Health Resource Centre’s database indicated that Stonegate has been involved in developing and/or distributing a “*Healthy Heart Kit*” which includes a component on primary stroke prevention. The Healthy Heart Kit was described above in the Alcohol section.

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37 The key informant reported that the group has access to educational materials from organizations including the Canadian Cancer Society, the Lung Association, and the Heart and Stroke Foundation.
IV. LITERATURE REVIEW

A literature review pertaining to self-help, mutual aid, empowerment, adult education, and risk factors for stroke was conducted as a complement to the gap analysis. The SHRC was interested in identifying whether their hypotheses about the importance of audience specific support programs was substantiated in the literature. A complete copy of the literature review is available in Appendix 5.

1. PROCESS

The literature review includes studies that speak to both of the following: self-help, mutual-aid, support, adult education, and empowerment; and one or more of the risk factors (as defined in the first section). Thirty-six search terms were used to search the literature, including alcohol abuse, diet, empowerment, lay help, lifestyle, mutual aid, obesity, peer support, self-help, social determinants of health, social support, and weight. Examples of search indices used in the search included CINAHL, ERIC, Healthstar, Medline, Sociofile, Social Work abstracts. Please refer to Appendix 5 for more detailed information regarding search terms and indices used.

2. FINDINGS OF THE LITERATURE REVIEW

There were several significant findings that emerged from the literature that are relevant to this gap analysis.

Culturally specific findings:
- Stroke risk factors, incidence and mortality are higher for non-whites, especially those who are African-American and Hispanic (Bradley et al. 2002, Claiborne Johnston et al. 2001, Din 2002).
- African Americans who have sickle-cell disease (a risk factor for stroke) and become highly involved in self-help groups report reduced emotional upset and decreased interference of the disease with their work and relationships (Nash & Kramer 1993 cited in Humphreys 1997).
- Risk reduction programs that incorporate culturally specific forms of social support and mutual aid (i.e. native healing circles, African American lay preachers) are generally more successful with ethnic communities than those that do not (Bates 2000, Kieffer et al. 2002, Napoli 2002, Resnicow 2000, Voorhees et al 1996, Yanek 2001).

Socioeconomically specific findings:
- Those with lower SES are also likely to be more at risk for stroke and will also receive poorer rehabilitative care (Kapral et al. 2000, Kunst et al. 1998, Redfern et al 2000, Sayler et al. 2001).

38 The literature review and gap analysis were completed independently by two different consultants, and were pulled together and compared following the completion of the gap analysis.
**Impact of Social Support**

- Perceived levels of social support seem to moderate the effect of work day stress on hypertension and risk for stroke (Steptoe 2000).
- Low levels of social support increase risk of stroke (Agewall 1998, Rozanski 1999).
- Individuals with lower levels of family support are more likely to participate in self-help groups (Kessler et al. 1997).
- Not only are strong supportive social systems vital for the well-being of seniors who have had a stroke, but in Canada they may also operate indirectly to reduce further strain on the healthcare system (Clarke et al. 2002).

**Findings on Cost Containment**

- Patient education programs directed at reduction of feelings of helplessness and improved empowerment may result in considerably greater cost containment and better outcomes in stroke (Pincus et al. 1998).
- Individuals treated in 12-step programs for alcohol abuse incur long-term health care costs up to 64% less than those treated in cognitive behavioural programs (Humphreys and Moos 2001).

**Examples of Benefits of Self-Help**

- The Trevose self-help group in Pennsylvania is one of the most successful obesity programs in the US with most members able to keep 15% of weight off for upwards of five years (Latner et al. 2002).
- Empowerment may significantly assist individuals with mental health problems not only with their diagnoses but also their obesity (Ekpe 2001).

**Applications for Self-Help**

- Self-help participation is highest for diseases viewed as stigmatizing (AIDS, alcoholism) and lowest for ‘less embarrassing’ issues (heart disease and stroke), individuals suffering from hypertension may attend groups such as Overeaters Anonymous (for obesity) rather than those that identify as stroke specific, they are also more likely to seek support after than before a stroke (Davison et al. 2000).
- Self-help/mutual aid/peer support is the core component of the national smoking cessation support service in the UK (Moore 2000).
- Caregivers of stroke patients are willing and able to use on-line support (Pierce 2002).
- Because of their knowledge and personal experience, support groups should be viewed as important partners in community stroke education (Weltermann et al. 2000).
- Adult education and self-help/mutual aid are valuable but neglected tools in stroke education, practitioners need to think more broadly in terms of tools and techniques (Hanger and Wilkinson 2001).
- Practitioners and policy makers need to recognize the importance of the public’s growing use of self-help in stroke prevention and care as well as the cultural realities of patients’ lives (Greenland 1996).
V. DISCUSSION

A comprehensive search was conducted to identify potential primary stroke prevention resources that incorporate self-help/mutual aid approaches. Originally, 5-7 organizations per risk factor were to be approached (i.e. 15-21 organizations). However, by the end of the process, 32 organizations had been approached.

The data collection methodology was comprised of key informant interviews (22), site visits (3), internet (4) and database searches (6), as well as scans and in-depth reviews of available resources (via the 32 organizations). In total, more than 300 resource descriptions were scanned to determine whether they were relevant to be analysed in-depth. From that list of more than 300 resources: 22 general stroke resources were analysed in-depth, 9 alcohol resources were analysed in-depth, 10 smoking cessation resources were reviewed in-depth, and 7 obesity resources were analysed reviewed in-depth. Presented below are the risk factor specific findings from the gap analysis, as well as a synthesis of findings related to the gap analysis “criteria”.

1. KEY FINDINGS ON STROKE (GENERAL)

- Searching for organizations that produce, distribute or offer “general stroke” resources was an add-on to the gap analysis search strategy. It was necessary to searching for organizations and programs using this generalized approach as, in the early days of the process, it appeared that there were a number of organizations that were producing, and/or distributing resources that were not risk factor specific, but were more general in nature (e.g. the Heart Health Resource Centre, the Heart and Stroke Foundation).
- Interestingly, the majority of stroke related resources were identified in this category (as compared with alcohol, tobacco, and obesity). This may be reflective of the trend that public health organizations are moving in, towards a generalized chronic disease prevention approach. It was in the Stroke (General) category that the most resources that incorporated self-help/mutual aid approaches were identified.
- 13 organizations were identified for key informant interviews, site visit, and/or internet or database review.
- Of the 22 resources analysed in greater detail:
  - There was 1 example of a self-help, train-the trainer program that uses peer support to educate women about heart health (Women With Heart, by London-Middlesex Health Unit). Although the program is about primary heart disease prevention rather than primary stroke prevention, it is a good example of the kind of program that the SHRC is trying to identify through this gap analysis.
  - There were 3 examples of self-help related literature that could be revised and adapted so that they are more relevant to the identified target audience, and incorporate determinants of health. Healthy Habits, Healthy Weights and Take Control: Actions to Lower Your Risk are produced by the Heart and Stroke Foundation of Ontario, and Walk Your Way by Grey Bruce.
2. KEY FINDINGS ON ALCOHOL RELATED RESOURCES

- Despite the best efforts to identify other organizations, only 5 were identified for key informant interviews, site visit, and/or internet or database review.
- The challenge of finding organizations doing work in this area was confirmed by the key informant at the Alcohol Policy Network, who indicated that there are very little financial resources in the province currently dedicated to the production or distribution of resources on alcohol (as it relates to stroke prevention, primary or otherwise). The dearth of resources linking (excessive) alcohol use and stroke was also identified through two other sources: by reviewing the Heart Health workshop (Hotel Dieu Hospital) and comments provided through the Apolnet list-serve responses.
- It was noted that the majority of work that is being done on alcohol as it relates to health is happening at the policy level. Also, a common topic across the resources (and providers) was low-risk drinking guidelines. It was not linked to primary stroke prevention (or other chronic diseases).
- The Alcohol Policy Network strongly encouraged the SHRC, if it is successfully in acquiring funding for the development of resources on primary stroke prevention and alcohol using self-help (or related) approaches. It was recommended that these resources be developed in partnership with organizations that have expertise in the area of alcohol policy and primary stroke prevention.
- Of the 9 resources analysed in greater detail, no self-help specific resources were identified. However, there was one resource, Alcohol and Other Drug Problems – Your Family that did incorporate some elements of self-help, and did provide a basic framework from which the SHRC could explore working with stakeholders to adapt.

3. FINDINGS ON TOBACCO RELATED RESOURCES

- 11 organizations were identified for key informant interviews, site visit, and/or internet or database review. Of these 11 organizations, there was one resource that was potentially identified as self-help/mutual aid – the Easy Breathing group. Because the SHRC Consultant was not able to connect with this group, more information is required about Easy Breathing before making any definitive conclusions.
- Many of the tobacco resources that were identified were either professionally led groups (which included individualized counseling) or printed booklets/programs that are based on prevailing health promotion theory (i.e. stages of change). As was noted in the literature review, tobacco cessation does lend itself well to self-help approaches.
- Many large health-related government and non-profit organizations (e.g. Health Canada, Canadian Cancer Society, the Heart and Stroke Foundation, and the Lung Association) are creating resources that are individually oriented (not group oriented).
- Many of the resources that were reviewed included information about the dangers and risks of smoking, both for the smoker, and those that are exposed to second-hand smoke.
4. FINDING ON OBESITY RELATED RESOURCES

- Despite efforts to identify other organizations, only 6 were identified for key informant interviews, site visit, and/or internet or database review.

- Of these 6 resources, there was 1 group that appeared to be incorporating a number of elements of self-help/mutual aid (Canadian Calorie Counters), which could be explored by the SHRC in greater detail. There was 1 other resource, ALCOA’s Speaker’s Bureau, which incorporated some elements of self-help. This latter resource could be adapted to meet the needs of the SHRC’s identified target population, but would need to be reviewed and validated by that group.

- There were few resources that were specifically based on obesity, and/or its link to stroke. The exception to this was the Canadian Calorie Counters. The vast majority of resources identified addressed obesity indirectly, through topics related to weight loss such as healthy eating, and active living.

5. SYNTHESIS OF FINDINGS RELATED TO GAP ANALYSIS CRITERIA

The criteria laid out in sub-section 4 of the Introduction of this report articulate the “screen” through which this gap analysis was conducted. Presented below is a synthesis of the findings that were identified through the key informant interviews, site visits, internet and database searches and materials review, as they relate to those criteria, as well as the research findings that were presented in the Literature Review.

A number of resources that were identified were not (primary) stroke prevention but were part of a broader chronic disease prevention strategy. These resources most commonly identified cancer, diabetes, and heart disease as the conditions that they were addressing through the resource. Stroke was identified less often, or was collapsed with the term cardiovascular disease. Thus, it was not made clear to the user of the resource that stroke is one of the chronic diseases that they may be at risk for, or the resource was addressing.

The majority of resources were targeted towards the “mainstream” or “general” population. Despite the facts that:

- Higher prevalence of stroke in the newcomer population39, and
- “Risk reduction programs that incorporate culturally specific forms of social support and mutual aid (i.e. native healing circles, African American lay preachers) are generally more successful with ethnic communities than those that do not”40,


there were very few resources that were targeted specifically to newcomers or persons whose first language was not English. Only one of the resources identified in this gap analysis (*Women With Heart*) specifically targeted this group.

Despite the fact that “those with lower socioeconomic status are also likely to be at more risk for stroke, and receive poorer rehabilitative care”\(^{41}\), there were few examples of resources that were either targeted towards people living on low incomes or that incorporated strategies that would benefit this group.

Many of the resources identified were developed by those professionals that were involved in delivering or distributing them, or were based on a prevailing health promotion theory (e.g. stages of change). Examples of these resources include the Hotel Dieu Hospital programs (*3 S Smoking Cessation, Healthy Heart Program*), materials developed by Health Canada (e.g. smoking cessation), and the smoking cessation program offered at Stonegate Community Health Centre. There was only one (e.g. *Women With Heart – London Middlesex Health Unit*) and possibly two others (*Easy Breathing, and Canadian Calorie Counters*) identified example(s) of a program that had been developed through a community process based on need and impetus.

The resources identified were generally delivered through professionally run programs/workshops, or were printed or on-line resources. This was the case despite research that indicates:

- Adult education and self-help/mutual aid are valuable but neglected tools in stroke education\(^{42}\),
- Individuals in peer-led 12-step support programs can incur long-term health care costs up to 64% less than those treated in cognitive behavioural programs\(^{43}\), and
- Self-help/mutual aid/peer support is the core component of national smoking cessation programs in the United Kingdom\(^{44}\).

There were only a handful of peer led or ‘train-the-trainer’ programs (e.g. *Women With Heart, Grey Bruce Heart Health, Easy Breathing – although not confirmed, and Canadian Calorie Counters*).

It has been found that patient education programs directed at reductions of feelings of helplessness and improved empowerment may result in considerable greater cost containment and better outcomes in stroke\(^{45}\). There were a handful of resources, particularly related to smoking cessation, which did incorporate some elements of support (e.g. *Smoking Buddies, 3 S Smoking Cessation, Step by Step*), in conjunction with professionally led counseling and education. Although these programs broadly would not be broadly defined as self-help/mutual aid, they should be noted for incorporating some of these approaches.

Most resources were informational in nature, including some basic (individually-oriented) tips and strategies for integrating risk reduction into daily activities. However, these tips and

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\(^{42}\) Hanger and Wilkinson, 2001. As cited in the Literature Review. Refer to Appendix 5.

\(^{43}\) As is demonstrated with 12-step alcohol abuse programs. Humphreys and Moos, 2001. Refer to Literature Review in Appendix 5.

\(^{44}\) Moore, 2000. Refer to Literature Review, Appendix 5.

\(^{45}\) Pincus et al 1998. As cited in the Literature Review. Refer to Appendix 5.
strategies tended to be simplistic and stated in general terms. They did not provide specific guidance or directions on how those tips or strategies would actually be carried out. In other words, there were few examples of how this information was made relevant to newcomers or persons living on low income. So, in many ways, these resources were not that useful to the SHRC’s audience of interest.

In interviews and reviews of printed/on-line resources, it was observed that many providers were identifying informational materials, as well as professionally mediated counseling or support groups as “self-help”. There appeared to be varying degrees of understanding of, and definitions for self-help and mutual aid. There is a clear discrepancy between the SHRC’s definition, and those of a number of the organizations that were approached in this gap analysis. This discrepancy is consistent with the finding noted above the self-help tools are oft neglected in stroke education, as well as the call for practitioners and policy makers to recognize the importance of the public’s growing use of self-help in stroke prevention (and care) as well as the cultural realities of patient’s lives.⁴⁶

⁴⁶ Greenland, 1996. As cited in Literature Review. Refer to Appendix 5.
VI. CONCLUSIONS AND RECOMMENDATIONS

In summary, of those resources reviewed and analysed, there were:

- 4 stroke (general) resources that were relevant in some way; 1 source (*Women with Heart* produced by London-Middlesex Health Unit) was a clear example of the type of resource the SHRC was seeking; 3 sources (*Walk Your Way* – Grey Bruce, and *Healthy Habits, Healthy Weights* and *Take Control: Actions to Lower Your Risk*) had some self-help elements that were incorporated would require some adaptation to be relevant to the target audience, or had the potential to be adapted into a self-help resource.

- 1 alcohol resource *Alcohol and Other Drug Problems – Your Family*) a booklet produced by the Centre for Addiction and Mental Health was “somewhat relevant”.

- 1 tobacco resource, the *Easy Breathing* smoking cessation group appeared to be “relevant”, although would have to be confirmed through a key informant interview with a group contact.

- 2 obesity resources that were “somewhat relevant”. One resource that has many self-help elements (*Canadian Calorie Counters*) has a number of characteristics that make it relevant to the target audience. The other resource, *ALCOA’s Speaker’s Bureau* would require adaptations to be relevant to the target audience, and to more fully integrated empowerment approaches.

There are significant gaps in the availability of resources – group-oriented, programmatic, printed, and electronic – on primary stroke prevention, which incorporate self-help/mutual aid approaches. This is particularly true in the tobacco and alcohol categories, as was validated by professionals working in alcohol policy and research. The category that had the most resources was “stroke general”. The latter is probably a reflection of the impetus on chronic disease prevention. There are a handful of resources, noted in the Discussion section of this report, where self-help elements are incorporated.

Given the strengths and benefits of self-help, mutual aid, and empowerment approaches that are identified in the literature review, in conjunction with the finding that there is a dearth of self-help/mutual aid resources on stroke prevention, it is recommended that the SHRC be granted funding by the Ministry that would give them the capacity to develop new and/or refine existing primary prevention resources that are built on these approaches, and directed towards the target audience(s) identified in this gap analysis.

More specifically, it is recommended that this work would include clients from high-risk communities in the development of new materials and/or the modification of currently existing stroke prevention materials to ensure that risk factor and lifestyle change information is contextualized in a framework of dialogue that validates the participants’ lived experience. Such

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47 The SHRC previously submitted a proposal to the Ontario Ministry of Health. The recommendations set forth in the current analysis reflect concepts set forth in the aforementioned proposal, but have largely been generated through the findings of the gap analysis taken in conjunction with self-help/mutual aid approaches.
strategies have been documented to encourage participant empowerment, ongoing self-help/mutual aid and health promotion benefits.48

Based on this concept, it is recommended that the SHRC base the work on the following premises:

- The socially, economically, and ethno-culturally diverse population are involved in the confirmation of relevant stroke prevention topics or resources such as the handful that were identified as “relevant” or “somewhat relevant” in this gap analysis. This work could be done through focus groups (in two different regions that have populations that are representative of Ontario’s overall population) whereby the participants are presented with the handful of self-help/mutual aid resources identified through this gap analysis, and asked to comment on their relevance and validity. With the help of these focus groups, volunteer community members from different cultures and socio-economic backgrounds would be recruited to tailor the generic materials to the cultural and socio-economic ecology of the participants. To be true to self-help and mutual aid, this process should be participatory in nature and establish a step-by-step blue print for engaging and involvement the community.
- Agencies such as Public Health Units, Community Health Centres, and Community-Based Organizations, and existing self-help/support groups should be involved (particularly those responsible for developing, implementing or distributing the resources identified as “relevant or somewhat relevant”, in order provide input in the development or refinement of resources. This could happen through the establishment of partnerships and collaborative initiatives.
- All of the activities will be connected and related to the overall Stroke Strategy.
- Evaluation is an important component of the work, allowing the SHRC to track the lessons learned, and importantly, the impacts and outcomes of the project. It is equally important that the results of the evaluation be shared with other providers who are doing work in the area of primary stroke prevention – to demonstrate the strengths and limitations of utilizing self-help/mutual aid approaches in primary prevention.

2 To name a few research studies related to behavioural changes: Cindy-Lee Dennis, Ellen Hodnett, Ruth Gallop, Beverly Chalmers (2002), “The effect of peer support on breast-feeding duration among primiparous women: a randomized controlled trial” Canadian Medical Association Journal, 166(1): 21-8 documents that significantly more mothers in the peer support group than in the control group continued to breast-feed at 3 months post partum (81.1% v. 66.9%); L.A. Jason, C.L. Gruder, et al. (1987). “Work Site Group Meetings and the Effectiveness of a Televised Smoking Cessation Intervention.” American Journal of Community Psychology 15: 57-77 documents that initial rates of quitting smoking were significantly higher for the 21 companies that supplemented the quit smoking program supplemented with 6 self-help group meetings (41% v. 21%) three months later these relative results were sustained (22% v. 12%); Spiegel, D., Bloom, J.R., Kraemer, H.C. and Gottheil, E. (1989), “Effect of psychosocial treatment on survival of patients with metastatic breast cancer.” The Lancet October 14: 888-891 documents that women whose oncologic care was supplemented by a weekly support group lived, on average, twice as long as control group members.
## APPENDICES

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Table 3 highlights the results of the database search. It is important to note that for each of the three health promotion approaches selected, the same sources (i.e. programs or printed resources) were identified. The numbers identified in the far right column correspond with the titles of materials or programs. These sources are described in greater detail below.

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1. *Heart and Stroke Information Catalogue*, Heart and Stroke Foundation of Ontario – is a catalogue of resources produced by the Heart and Stroke Foundation. As such it does not provide primary stroke prevention information, although some of the resources cited do. These resources have been analysed and are discussed in section called Stroke.

2. *Low-Risk Drinking Guidelines (i.e. Toolkit)* – Materials produced by the Centre for Addiction and Mental Health. It is designed for the general public, and provides some parameters for low-risk drinking (i.e. safe amounts). This piece is reviewed in sub-section on Alcohol.

3. *Speakers Bureau, Canadian Diabetes Association*, Sudbury Branch - While this is a primary prevention initiative, the goal of the Speaker’s Bureau is to increase awareness of diabetes. Volunteers are provided with training on the generalities of diabetes, management, and services, and then give presentation in the community. Because this program does not pertain to primary prevention of stroke, it was not included for further analysis.

4. *Urgent TIA and Stroke Prevention Program*, London Health Sciences Centre – the goal of this secondary prevention program is to provide rapid access to diagnosis to individuals who have suffered a TIA or stroke. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.

5. *Let’s Talk about Stroke*, Heart and Stroke Foundation of Ontario – This is a secondary stroke prevention resource that aims to provide information to TIA and stroke survivors about the disease
and recovery process. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.

6. Insulin: Things You Should Know, Canadian Diabetes Association, Sudbury Branch – the purpose of this secondary prevention resource is to increase awareness of the disease and provide reference resources for people affected by diabetes. It addresses specific conditions including coronary heart disease, diabetes, and previous stroke. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.

7. Kids with Diabetes in Schools, Canadian Diabetes Association, Sudbury Branch - the purpose of this secondary prevention resource is to increase awareness of the disease and provide reference resources for people affected by diabetes. It addresses specific conditions including coronary heart disease, diabetes, and previous stroke. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.

8. Living Healthy with Diabetes, Canadian Diabetes Association, Sudbury Branch – the purpose of this secondary prevention resource is to increase awareness of the disease and provide reference resources for people affected by diabetes. It addresses specific conditions including coronary heart disease, diabetes, and previous stroke. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.

9. Smoking Cessation Programs, North Lambton Community Health Centre – the goal of these programs are to encourage and support smokers to quit. They are facilitated periodically by the nurse practitioner to encourage and support smokers to quit. This program was not included in those selected for further review in the gap analysis because it is professionally led, and is thereby, by definition, not a self-help/peer support program.

10. Stroke Card, Heart and Stroke Foundation of Alberta, North West Territories, and Nunavut – this is a wallet card designed to provide a quick reference for stroke risk factors and warning signs. Given its size and intent for brevity, it does not include self-help or empowerment strategies. This material is discussed in greater detail in the section called Stroke – General Resources.

11. Take Control to Lower Your Risk, Heart and Stroke Foundation of Ontario – the goal of this resource is to provide information to general public about the warning signs of heart disease and stroke. This material is not specific to primary stroke prevention, but rather addresses coronary heart disease, diabetes, transient ischemic attack, and previous stroke.

12. Heart Healthy Recipes, Hand-outs, Quizzes and Videos, Stonegate Community Health Centre – these are secondary prevention initiatives, which address coronary heart disease, diabetes, and previous stroke. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.

13. Seniors Heart Smart Cooking, Stonegate Community Health Centre – the goal of this secondary prevention program is to teach principles of Heart Healthy Cooking and Canada's food guide. A registered dietician teaches heart healthy cooking to local seniors. The disease condition addressed in this program is diabetes. Because this program does not pertain to primary prevention of stroke it was not included for further analysis.
APPENDIX TWO
Heart Health Resource Centre Database Search
Criteria for Identifying Self-Help and Related Resources

**Tobacco – 18 sources cited** - Of those sources cited, those identified as not meeting the criteria included resources that were not primary prevention, resources that were targeted towards youth, resources that were targeted towards health professionals, resources that were telephone lines, and resources that addressed issues or topics not related to self-help/mutual aid and tobacco (e.g. environmental tobacco smoke). There was one source that fit the criteria for further review – a smoking cessation program based on the Stages of Change, delivered by Stonegate Community Health Centre.

**Smoking – 82 sources** – of those sources cited, those that were disregarded were included: those had been cited in the “tobacco” keyword search, those that were not primary prevention programs, those that were targeted towards health professionals, politicians or restaurants; those that were targeted towards youth or children; those that focused on conditions other than stroke (e.g. diabetes, cancer); those that were not accessible to Ontario residents; those that were of a time limited nature (e.g. a stop-smoking contest); those that focused solely on the signs and symptoms of having a stroke; those that were produced and distributed by the Heart and Stroke Foundation (because they would be discussed in another section of this report); those that were on topics other than smoking and stroke (e.g. nutrition); those that were professionally run programs. There was one resource that was identified as appropriate for further review – the Healthy Heart Kit distributed by Stonegate Community Health Centre (and produced by Health Canada).

**Alcohol – 61 sources cited** – of those sources cited, those that were identified as not meeting the criteria included: those that were not primary prevention resources; those that were targeted towards professionals, those that were targeted towards primary and secondary students; those that focused on health conditions other than stroke (e.g. diabetes, cancer); those that were not easily accessible to people living in Ontario; those that were organizations (and not resources, although these organizations were included in the gap analysis); those that were “off topic” (e.g. safe party hosting, drinking and driving, tobacco issues); those that were catalogues; those that were produced by an organization that was included in this gap analysis; those that were related to general health but not specific to primary stroke prevention (e.g. Canada’s Food Guide; those that were table-top displays. There were two sources cited for follow up, one being the Healthy Heart Kit distributed by Stonegate, and the other being the Healthy Heart Program, delivered by Hotel Dieu Hospital.

**Drinking – 5 sources** – These sources were repetitions of sources identified in the “alcohol” key word search, and focused on teen drinking, alcohol and general health, hosting safe parties (2), and binge drinking.

**Obesity – 1 source cited** - One source was identified, which was of interest – the Chatelaine/On The Move Walking Club, which is sponsored by the Canadian Association for the Advancement of Women in Sport and Physical Activity.

**Overweight – 51 sources were cited** – Of these sources cited, those that were identified as not meeting the criteria included: those that did not address primary prevention; those that were directed at professionals; those that were targeted towards children and/or youth; those that pertained to topics unrelated to weight and stroke (e.g. smoking); those that were available only through displays and presentations (and therefore not very available to the general public); those that addressed signs and symptoms of stroke and were not specific to prevention strategies; those that pertained to how the heart functions; those that related to weight but were not relevant to stroke prevention; those that were produced by an organization
already being reviewed in this gap analysis (e.g. Heart and Stroke Foundation). There was one source remaining, the Healthy Heart Kit distributed by Stonegate Community Health Centre, which also addresses weight.

Nutrition – 36 sources cited – Of these sources cited, those that were identified as not meeting the criteria included: those that did not address primary prevention; those that were organizations; those that were targeted towards children and youth; those that pertained to unrelated topics such as diabetes, cholesterol, and clean air. There were approximately 14 sources that were on general nutrition topics that were not specific to stroke prevention. They were on topics including using the food guide, healthy food preparation, reading food labels, and living a healthy lifestyle. There were no resources identified on nutrition and stroke prevention.

Self-help – 3 sources cited – of these sources cited, those that were identified as not meeting the criteria included: those that were telephone lines (i.e. to speak with a professional); and resources that highlighted healthy eating out in restaurants. While it can be argued that this may be a useful tool to support some individuals in reducing their risk, it is most accessible to persons living on middle and higher incomes, and not very accessible to people living on lower incomes. The remaining source, which was explored in this gap analysis was a program coordinated through the Nutrition Resource Centre (Ontario Public Health Association) called Food Steps. It is reviewed in the Obesity sub-section.

Mutual aid – no sources were cited.

Support – 42 sources cited – of these sources cited, those that were identified as not meeting the criteria included: those that were not primary prevention resources; those that were targeted towards children or youth; those that were directed towards professionals (e.g. teachers, administrators); those that were specific organizations (e.g. Canadian Cancer Society, OPHEA); those that addressed specific health issues other that stroke (e.g. diabetes, osteoporosis); those that were catalogues. This left 9 resources, all of which were “general”, and did not specifically address stroke. These sources addressed healthy lifestyle (2 sources), nutrition (1 source), smoking (cessation) (3 sources), and an annual smoke free home contest (2 sources), active living for seniors (1 source).

Empower – 2 sources cited. Both of the sources identified focused on secondary prevention, and were specific to diabetes education.

Peer (in the context of peer help or peer support) – 6 sources cited – of those sources cited, those that were identified as not meeting the criteria for further review included: those that were not primary prevention programs; those that were specific to student health or safe drinking for youth. The remaining source, which was reviewed, was the Speaker’s Bureau (ALCOA) that encourages seniors to lead active lifestyles. Although this resource was not stroke specific, it was reviewed anyway, and can be found in the sub-section on Obesity.
APPENDIX THREE

STAGES OF CHANGE THEORY

The "Stages of Change", also referred to as the Transtheoretical model, consist of different stages, which help identify where a person is regarding the change of behavior. It may relate to several different things such as smoking, exercise, etc. It consist of several different processes but it is divided into six main stages that are: precontemplation, contemplation, preparation, action, maintenance, and termination. Each one of these phases or "stages" describes an individual's attitude toward behavior change. Each individual may not be in the same stage for each behavior because the transtheoretical model is specific to each behavior.

Precontemplation - This stage represents those individuals who have no desire to change their behaviors in the immediate future. The immediate future usually refers to a six month time period. This is used because this is about as far in the future that most people plan a specific behavior change. It is also because most people are concerned with the present and don't plan far in the future so a six month time frame is used. Individuals in this stage usually have a lack of awareness about the specific behavior. Some individuals in this stage are very aware of the consequences of their behavior but may avoid getting involved in behavior change programs because of rationalizing their behavior to make sense to them. Individuals may also be tired of trying and failing at the desired behavior change.

It may be possible for the individual to move from precontemplation to the contemplation stage by increased awareness. Mass media on certain behaviors can influence awareness. Also, by setting goals that can easily be attained can ensure that the individual is successful and increase self-efficacy or the individual's confidence to make the desired behavior change.

Contemplation - This stage is where the individual has the intent to change his/her behavior within the next six months. Just as in the precontemplation stage, the six-month figure is used because this is about as far in the future that most people plan a specific behavior change. This individual is already aware of the benefits and barriers of the desired behavior and plans change their behavior based on their interpretation of the benefits and barriers.

While the benefits of specific behavior change maybe somewhat obvious, the barriers may be different for each individual. One person may not have the finances to perform a certain behavior change, while another may have family problems that prohibit the behavior change, and yet another may not make the desired behavior change because they don't have access to the necessary things.

The individual in this stage needs extra attention. Everything needs to be at his/her own pace and he/she doesn't need to be rushed into a behavior change that he/she is not ready for. Encouragement and motivational techniques can be used to persuade this individual to the next stage. This may be done by going beyond the awareness by using mass media but by using things that are "tailor-made" for the individual.

Preparation - Individuals in this stage intend to make a behavior change within the next month (30 days) and have made at least one previous attempt to make a behavior change. It is in this stage that the individual is most ready for a change. It is the job of the health promotion professional to help manipulate

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the environment in order to make it conducive to the desired behavior change, therefore promoting the change. This may involve some policy changes.

*Action* - The action stage is a period of time anywhere between 0 and 6 months that involves a sufficient change of behavior. This stage of change reflects a consistent behavior pattern, is usually the most visible, and receives the greatest external recognition. When measuring the pros and cons of the desired behavior change, the individual's perceived cons of the behavior should outweigh the perceived pros of the behavior if it is an attempt to abstain from certain behaviors such as drug abuse or smoking. The individual's perceived pros should outweigh the perceived cons if the individual is making an attempt at a positive behavior change such as exercise adherence. If the individual making the behavior change continues his/her pattern of behaviour, he/she will move into the fifth stage, called maintenance.

*Maintenance* - This stage is one that starts six months after the action stage and can last for several years. The behavior being changed is the key factor in determining how long this stage will last. It is in this stage that the self-efficacy (one’s confidence in oneself to make a behaviour change) of the individual is at its highest, especially when compared to the four preceding stages. Relapse prevention "is a self-control program designed to teach individuals who are trying to change their behavior how to anticipate and cope with the problem of relapse" and is probably the biggest concern of the health promotion professional in this stage. Since the Transtheoretical model is *cyclical*, the individual may relapse back several stages instead of just one. The individual needs to be prepared for relapse by knowing exactly what to do about it.

*Termination* - This phase is one in which the individual has permanently adopted a desirable behavior. This involves 100% self-efficacy (one's confidence in oneself to make a behavior change) and absolutely no temptation to relapse. In some behaviors, it may be a more realistic goal to obtain lifelong maintenance since acquiring 100% self-efficacy and no temptation to relapse may be too much to handle for some individuals.

References:


Dear Colleagues,

This is my first posting to Apolnet. Thanks to Paula Neves for pointing me in this direction.

I am a health promotion consultant doing a contract with the Self-Help Resource Centre (SHRC) of Greater Toronto. The project that I am working on for the SHRC is exploring the availability of primary stroke prevention materials and programs that incorporate self-help, empowerment, peer help, train-the-trainer types of strategies. We are examining the availability of materials and programs (available/produced in Ontario) that address any or all of the three risk factors - being alcohol use, tobacco use, and obesity. To date we have been successful in identifying a number of secondary prevention resources, or programs that are professionally led (e.g. professionally led smoking cessation programs). While these latter programs are important and valuable, they are not the focus of our analysis.

As a related question, we are also interested in identifying materials or programs (still primary stroke prevention) that assist people who may otherwise have access barriers to these kinds of resources due to low income, lower literacy levels, being a newcomer etc. Thus these would be materials or programs could use to develop strategies in their own lives for modifying the stroke risk factors that they may have the opportunity to control (as opposed to those that are beyond their control due to their access barriers).

I was wondering whether anyone is aware of programs, resources, etc. that fit these descriptions. I would appreciate any feedback or suggestions.

Thanks in advance for your consideration.

Sincerely,

Gillian MacKay
Project Consultant
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APPENDIX 5

Self-Help, Mutual Aid, Adult Education, Empowerment

And Risk Factors for Stroke:

A Review of the Literature 1995-2003

Submitted by: Jennifer Poole, MSW, PhD (candidate)
To: The Self-Help Resource Centre
For: MOHLTC

April 14, 2003
Introduction/Defining the Terms

What follows is an annotated bibliography of academic literature published after 1995 on *self-help, mutual aid, empowerment, adult education and risk factors for stroke*. Literature includes peer reviewed academic journal articles both in print and on-line published in Canada, the US, Europe as well as other international sources. Literature was limited to those sources printed in English and available through the Universities of Toronto and Ryerson library systems. A full listing of all 61 entries can be found at the end of the review.

For the purposes of this review, **self-help/mutual aid** was defined as;

> a process of learning with and from each other (similar to adult education). Participants provide each other with **mutual aid/support** in dealing with a problem, issue, condition or need. Participants learn to work together while acknowledging the diversity of their personal situation among the similarities of their shared issue. Together they investigate alternative solutions and are **empowered** by this process. (Rabbani 2002)

For the purposes of this review, **risk factors** follow the classification outlined by the American Stroke Council (Goldstein et al. 2001) and include:

- **nonmodifiable risk factors**: age, race/ethnicity, sex and family history
- **modifiable risk factors**: hypertension, smoking, diabetes, hyperinsulinemia\(^{50}\), insulin resistance, asymptomatic carotid stenosis, atrial fibrillation, sickle cell disease, hyperlipidemia
- **potentially modifiable risk factors**: obesity, physical inactivity, poor diet/nutrition, drug and alcohol abuse, hypercoagulability, hormone replacement therapy, oral contraceptive Use (deemed potentially modifiable risk factors)

This review includes those studies that speak to both 1. self-help, mutual aid, support, adult education and empowerment and 2. one or more of the risk factors listed above.

\(^{50}\) Please see the review of Goldstein et al. in this document for a explication of these and other risk factors.
The literature review has been divided up into sections. In each section, literature has been organized by date of publication with the most recent articles appearing first. The sections and their contents are explained as:

1. **Self-Help and Mutual Aid: Recent Developments**
   a. general information and statistics on self-help participation since 1995

2. **Risk Factors for Stroke: General**
   a. descriptions of what risk factors are for this condition and work on some of the current trends in the literature

3. **Risk Factors and Social Support**
   a. findings on the relationship between social support and risk prevention/reduction/response

4. **Risk Factors and Self-help, Mutual aid, Empowerment and Adult Education**
   a. studies on the use of self-help, mutual aid, empowerment and/or adult education models in response to/prevention of specific risk factors such as obesity, smoking, diabetes etc.

5. **Stroke Recovery and Secondary Prevention: Current Trends**
   a. findings on factors vital to the recovery process and prevention of (another) stroke

6. **Stroke Recovery and Social Support**
   a. research on the role of social support in the recovery/secondary prevention process

7. **Stroke Recovery and Self-Help, Mutual aid, Empowerment and Adult Ed.**
   a. studies on the use of self-help, mutual aid, empowerment and/or adult education models in response to/secondary prevention of stroke

8. **Family/Caregivers and Social Support**
   a. findings on the role of social support for caregivers of stroke survivors
   a. findings on the role of self-help, mutual aid, empowerment and/or adult education models in caregiving for individuals post-stroke

    a. articles advocating for the use of self-help, mutual aid, empowerment principles in stroke prevention and care

Search Terms

In searching the literature, the following terms were used:

- Addiction
- Adult education
- Ageing
- Alcohol abuse
- Chronic illness
- Diabetes
- Diet
- Disability
- Drug abuse
- Empowerment
- Group
- Habits
- Health
- Heart
- Hypertension
- Lay help
- Lifestyle
- Mental health
- Mutual aid
- Mutual help
- Mutual support
- Nutrition
- Obesity
- On-line support
- Peer support
- Physical inactivity
- Risk
- Risk factors
- Self-care
- Self-help*
Indexes

For this review, search indexes (or databases) used include:

- Ageline, CINAHL, Cochrane Collaboration, Embase, ERIC, Expanded Academic Index, HAPI, Healthstar, Medline, Psychinfo, Pubmed, Risk (abstracts), Sociofile, Sociological Abstracts, Social work Abstracts, Women’s Studies International

Other limits

Literature was limited to that published in English between 1995-2003 in Canada, the US and other International sources.

General Findings/Highlights

- In the US, 8 to 11 million people participate in self-help groups each year, average member is 43, male and white (Fetto 2000)
- Individuals over 65 are twice as unlikely to attend self-help groups (Wistler 1995).
- Stroke risk factors, incidence and mortality are higher for non-whites, especially those who are African-American and Hispanic (Bradley et al. 2002, Claiborne Johnston et al. 2001, Din 2002)
- Those with lower SES are also likely to be more at risk for stroke and will also receive poorer rehabilitative care (Kapral et al. 2000, Kunst et al. 1998, Redfern et al 2000, Sayler et al. 2001).
- Risk reduction programs that incorporate culturally specific forms of social support and mutual aid (i.e. native healing circles, African American lay preachers) are generally more successful with ethnic communities than

*Note: In the health literature, the term self-help was frequently associated with information or manuals rather than the sharing of mutual support.*

- Perceived levels of social support seem to moderate the effect of work day stress on hypertension and risk for stroke (Steptoe 2000)
- Low levels of social support increase risk of stroke (Agewall 1998, Rozanski 1999)
- Individuals with lower levels of family support are more likely to participate in self-help groups (Kessler et al. 1997)
- Not only are strong supportive social systems vital for the well-being of seniors who have had a stroke, but in Canada they may also operate indirectly to reduce further strain on the healthcare system (Clarke et al. 2002)
- Patient education programs directed at reduction of feelings of helplessness and improved empowerment may result in considerably greater cost containment and better outcomes in stroke (Pincus et al 1998)
- The Trevose self-help group in Pennsylvania is one of the most successful obesity programs in the US with most members able to keep 15% of weight off for upwards of five years (Latner et al. 2002)
- Empowerment may significantly assist individuals with mental health problems not only with their diagnoses but also their obesity (Ekpe 2001)
- Individuals treated in 12-step programs for alcohol abuse incur long-term health care costs up to 64% less than those treated in cognitive behavioural programs (Humphreys and Moos 2001)
- Self-help participation is highest for diseases viewed as stigmatizing (AIDS, alcoholism) and lowest for ‘less embarrassing’ issues (heart disease and stroke), individuals suffering from hypertension may attend groups such as Overeaters Anonymous (for obesity) rather than those that identify as stroke specific, they are also more likely to seek support after than before a stroke (Davison et al. 2000)
- Self-help/mutual aid/peer support is the core component of the national smoking cessation support service in the UK (Moore 2000)
- African Americans who have sickle-cell disease (a risk factor for stroke) and become highly involved in self-help groups report reduced emotional upset and decreased interference of the disease with their work and relationships (Nash & Kramer 1993 cited in Humphreys 1997).
- Because of their knowledge and personal experience, support groups should be viewed as important partners in community stroke education (Weltermann et al. 2000)
- Caregivers of stroke patients are willing and able to use on-line support (Pierce 2002)
- Adult education and self-help/mutual aid are valuable but neglected tools in stroke education, practitioners need to think more broadly in terms of tools and techniques (Hanger and Wilkinson 2001)
Practitioners and policy makers need to recognize the importance of the public’s growing use of self-help in stroke prevention and care as well as the cultural realities of patients’ lives (Greenland 1996).
Self-Help/Mutual Aid-Recent Development

The author notes that about 3 percent to 4 percent of the U.S. population, or between 8 million and 11 million people, participate in self-help groups each year. The average age of a self-help group member is 43 and is more likely to be male. 3.6 percent of men are attendees compared with 2.4 percent of women. White men and women are three times as likely to participate as African Americans.

**Key words:** self-help groups, recent statistics on participation in the US

Citing recent research, the author proposes that, despite reports to the contrary, self-help/mutual aid is flourishing in the US. He links this argument to the rise of small, community capital-creating (n=5-10) groups as opposed to larger self-help organizations.

**Key words:** self-help/mutual aid, rise of, size of group, social capital

Using data from the Survey of Ageing and Independence (1991), Wister explores why older adults do (or do not) attend self-help groups. He argues that those over 65 appear twice as unlikely to attend a self-help group. Persons who are working are also less likely to attend. Higher education increases the likelihood of attending. For those 65 and over, participation in self-help groups is more likely if the individual also seeks professional help, relies on informal mutual aid and uses self and spiritual care.

**Key words:** older adults, participation in self-help groups, reasons for
Risk Factors for Stroke-General


This article was included for its extensive review of all risk factors for stroke. A summary of these is listed below.

1. Nonmodifiable Risk Factors:

Age, Sex (stroke is more prevalent in men than in women, but mortality rates are higher in women than men), Race/Ethnicity (Blacks and some Hispanic Americans have high stroke incidence and mortality rates compared with whites due in part to higher prevalence of hypertension, obesity, and diabetes mellitus. Chinese and Japanese populations generally have high stroke incidence rates as well), Family History

2. Modifiable Risk Factors:

Hypertension (Incidence of stroke increases in proportion to both systolic and diastolic blood pressures. This relationship is “direct, continuous, and apparently independent.”), Smoking, Diabetes, Hyperinsulinemia, and Insulin Resistance (Insulin-dependent diabetics have both an increased susceptibility to atherosclerosis and an increased prevalence of atherogenic risk factors, notably hypertension, obesity, and abnormal blood lipids) Asymptomatic Carotid Stenosis, Atrial Fibrillation (common arrhythmia), Sickle Cell Disease, Hyperlipidemia (Abnormalities of serum lipids such as triglycerides, cholesterol, low-density lipoprotein [LDL], and HDL)

3. Potentially Modifiable Risk Factors:

Obesity (Defined as a body mass index 30 and over predisposes to cardiovascular disease in general and to stroke in particular) Physical Inactivity (Regular physical activity has well-established benefits for reducing the risk of premature death and cardiovascular disease. The beneficial effects of physical activity have also been documented for stroke)
**Poor Diet/Nutrition** (May be a protective relationship between stroke and consumption of fruits and vegetables especially green leafy vegetables and citrus fruit and juice)

**Drug Abuse** (Use of amphetamines, “crack” cocaine, and heroin is associated with increase in the risk of both ischemic and hemorrhagic stroke)

**Alcohol Abuse** (For hemorrhagic stroke, cohort studies have shown that alcohol consumption has a direct dose-dependent effect. For cerebral infarction, chronic heavy drinking and acute intoxication have been associated with an increased risk among young adults. In older adults, risk is increased among heavy-drinking men)

**Hypercoagulability, Hormone Replacement Therapy** (The Framingham Heart Study found a 2.60-fold increase in the relative risk of atherothrombotic stroke among women receiving hormone replacement therapy compared with nonusers), **Oral Contraceptive Use** (based on early studies with high-dose preparations and women who are cigarette smokers)

**Recent Trends in the Risk Literature for Stroke:**

**Diet and Ethnicity**
The authors identified all cases of first stroke in Northern Manhattan from 1993 to 1997 and calculated stroke rates for those 20 to 44 years of age. 74 cases of first stroke in young patients were discovered (47% women, 12% black, 80% Hispanic, 8% white). Case fatality rates at 30 days were higher in blacks (38%) and Hispanics (16%) compared with whites (0%). The authors conclude that blacks and Hispanics have greater stroke incidences than young whites.
**Key Words:** incidence, mortality, racial differences, stroke, young adults

The author reviews and comments on the article by Resnicow et al (see this review) urging further programming and study on culturally-specific food education and support, specifically those that partner with Black churches.
**Key words:** diet, risk factor, ethnicity, black churches

Because stroke has been the second leading cause of death in large cities in China since the 1980s, in 1987, a community-based intervention trial was initiated in 7 Chinese cities to reduce multiple risk factors for stroke. For each city, 2 geographically separated communities with a population of about 10,000 each were selected as either intervention or control communities. The intervention included weekly visits to community clinics, traditional and western pharmacology, health information as well as assistance with exercise, weight and alcohol control. Health education (leaflets and manuals distributed door to door) was also provided. After 3.5 years, 174 new stroke cases had occurred in the intervention cohort and 253 in the control cohort. The 3.5-year cumulative incidence of total stroke was significantly lower in the intervention cohort than the control cohort. The incidence rates of nonfatal and fatal stroke, as well as ischemic and hemorrhagic stroke, were significantly lower in the intervention cohort than the control cohort. **Key words: ethnicity, community prevention, multiple risk factors, population health interventions**

**Non-Prescription Drug Use**  
Nonsteroidal anti-inflammatory drugs (NSAIDs including ibuprofen but not aspirin) have been associated with bleeding complications and may affect the risk of hemorrhagic stroke. The authors performed a population-based case-control study to estimate the risk of the above in users of NSAIDs in Denmark. Identifying all patients with a first-ever stroke discharge diagnosis in the period of 1994 to 1999, 40,000 random individuals were selected. Results indicate that current exposure to NSAIDs is not a risk factor for hemorrhage, but offer no protection against first-ever ischemic stroke. **Key Words: anti-inflammatory agents, nonsteroidal, stroke, hemorrhagic**

**Previous Incidence of Stroke (and socioeconomic status)**  
The authors endeavoured to find out whether stroke survivors in London, UK changed their behavioural risk factors in any significant way after having a stroke. Although survivors had a 15-fold increased risk of recurrent stroke, at 1 year after stroke, 22% of patients still smoked, 36% of patients were obese, and 4% drank excessively. Younger patients, whites, and men were more likely to smoke, and younger whites were more likely to drink excessively. Women and nonwhites were more likely to be obese. The
authors argue that continued risk activity was associated with specific socio-demographic groups (SES, Race) indicating the need for targeted and community specific efforts to prevent stroke and its recurrence.

**Key Words:** lifestyle risk factors, SES, race, smoking, drinking, obesity, stroke prevention and recurrence


**Risk Factors and Social Support**


The authors report on a study of 256 randomly selected Mexican Americans between 35 and 70 years of age with type 2 diabetes. Over 3 months, participants received weekly education sessions on nutrition, blood glucose, exercise and 6 months of biweekly *support group* sessions to promote behavior changes. The approach was culturally competent in terms of language, diet, social emphasis, family participation, and incorporation of cultural health beliefs. Participants showed significantly lower levels blood glucose at 6 and 12 months and higher diabetes knowledge scores. **Key words:** diabetes, culture, support group


Obesity, impaired glucose tolerance (IGT), gestational diabetes mellitus (GDM), and Type 2 diabetes are prevalent among Latino women of childbearing age, particularly in low-income communities. This study brought together Latino women in three focus groups to find out 1. their knowledge of risk factors for diabetes and 2. their suggestions for a culturally-specific activity program. Few women identified activity as a risk factor, but most indicated a need for *social support*, as isolation, expressed as being *encerrado* (closed in the house) was perceived as a major barrier to physical activity. It was explained as the outcome of personal and family concerns about safety and ‘appropriate’ maternal behavior.

**Key words:** diabetes, pregnancy, Latino women, activity, social isolation and lack of social support as barriers to

The authors evaluated the effect of Choose to Move program designed by the American Heart Association for women across the United States. Participants received a welcome kit and manual with weekly information about how to manage cardiovascular disease risk factors and how to build a *support network* for lifestyle change. Ninety percent of the participants were white and 56% were aged between 35 and 54 years. Among the participants who completed the week 12 follow-up evaluation, the percentage who reported being active increased from 32% to 67% at the program's end. Those limiting excess calories or fat increased from 72% to 91% at week 10 follow-up. **Key words: diet and nutrition, obesity, exercise, self-help materials, social support networks**


The study explored the effect of stress on blood pressure during the ‘working day’ and whether it was buffered at all by perceived levels of *social support*. 104 school teachers (37 men and 67 women) had their blood pressure and heart rate measured every 20 min. Participants rated the degree of stress they were experiencing at the time of each measurement. They also completed support questionnaires, which placed them in high or low support categories. After controlling for body mass, high stress was associated with increased blood pressure and heart rate. However, the impact of stress was buffered by social support, with no significant increase in blood pressure or heart rate with stress in the high support group. **Key words: stress, blood pressure, effect of social support on**


The author reviews a plethora of recent studies with “clear and convincing evidence that psychosocial factors contribute significantly to coronary artery disease (CAD)” These factors include (1) depression, (2) anxiety, (3) personality factors and character traits, (4) social isolation, and (5) chronic life stress. The author also finds that they tend to cluster together. Citing Berkman et al who observed a nearly 3-fold increase in subsequent cardiac events for those reporting a low level of *emotional support*, he underscores the importance of programs targeted towards alleviating depression, anxiety and social isolation.
Key words: cardiovascular disease, link to mental health, social isolation and low levels of social support

This study compared the efficacy of a stroke prevention video with that of a video plus professionally-facilitated *support group* discussion for 657 older adults living in ‘independent living settings’. Results indicated that facilitation did not increase knowledge any more than using the video alone.
*Key Words: audiovisual aids, professionally-led support group, risk factors, stroke prevention, education*

412 Swedish men at risk for stroke or heart attack due to high cholesterol, smoking or diabetes were also assessed on their satisfaction with quality of life (*level of social support*, control, social activities etc). Authors argue patients with poor quality of life and low levels of social support are more likely to suffer from stroke. *Key words: stroke, quality of life, risk factors, social support*

The author explains the parameters of the national health education program in the States, reviewing the importance of a number of different interventions in the prevention of heart and lung disease including, but not limited to, formal and *informal support groups*. *Key words: multiple risk factors, heart and lung health, intervention and prevention, role of social support and support groups*

The authors question current thinking that access to primary care improves health and argue instead for investment in education, self-care, empowerment and social support. They state;
“Among persons younger than 65 years of age, arthritis and hypertension occur in about 25% of persons with less than 8 years of education. Similar patterns are evidenced for back pain, heart attack, peptic ulcer, diabetes, chronic bronchitis, renal disease, epilepsy, stroke, and tuberculosis.”

“social support and simple geographic differences may affect health more than recognized biomedical risk factors”

“Investment in education, improvement in social conditions, and research on self-management may improve health in persons of low socioeconomic status more than expanded access to medical care”.

“Patient education programs directed at reduction of feelings of helplessness and improved self-efficacy may result in considerably greater cost containment and better outcomes in chronic diseases than do current efforts to restrict medications and visits to specialists”.

Key words: risk factors, social determinants, importance of self-care, social support, empowerment and education in preventing disease

Risk factors and Self-Help, Mutual aid, Empowerment and Adult education

The authors explore the phenomenal success of the Trevose Behaviour Modification Program, a peer led self-help group for weight loss. The program boasts one central group in Trevose, Pennsylvannia and 63 satellite groups with approximately 10-40 members each. Average weight loss is approximately 15-17% of initial body weight, and is often maintained after 3, 4 and 5 years. The authors suggest that the success rate is tied to the group’s unique combination of rules, support, low cost, mandatory attendance and screening. Each prospective member must go through an unusual 5 week screening program during which they must keep and submit food records, attend all weekly meetings and lose 15% of their total assigned weight loss (unless this is over 80 pounds). If screened successfully, individuals may join as members, but this can only take place once and any violation of other rules results in ‘termination’. Key words: obesity, weight loss, physical activity, diet and nutrition, self-help group

Due to the severity of illness—in particular, diabetes, alcoholism, and arthritis, providing health care services to Native women has become a challenge. The author describes a successful health-promoting community-specific ‘circle’ for native grandmothers involving activity (walks, yoga), storytelling, meal preparation, health education, field trips, bead work and mutual aid.

“The women in this group were all grandparents. They all had diabetes and Arthritis and were recovering from alcoholism. The purpose of the group was to offer these women an opportunity to deal with physical and emotional pain and to experience an intimate connection to each other. ...They shared stories about relatives, home remedies to relieve pain, and new ways to cook traditional foods.”

Key words: diabetes, alcohol abuse, native women, elderly, mutual aid, activity


Obesity is a common problem among people with mental health problems and a major risk factor for stroke. Noting the importance of self-care, self-efficacy and group support, the authors analyze how empowerment might alleviate obesity in this population. They argue that interventions based on lifestyle and behavioural approaches that do not consider the wider psychosocial and environmental factors might not produce the desired change in individuals with health-risk behaviour. Conversely, an autonomous individual with raised self-esteem and efficacy acquired through membership of a group could become self-empowered, thus enabling individuals and groups to take control of factors affecting their health—such as obesity. The nurse’s role in the empowerment process involves being an advocate, mediator, networker and partner in the development of patient-led supports.

Key words: empowerment, mental health, obesity, role of self-care and empowerment, patient-led support groups


This study evaluated whether patients who are treated in 12-step programs (rather in cognitive behavioural programs) rely less on professionally provided services and more on self-help groups after discharge, thereby reducing long-term health care costs. Using a larger sample from an ongoing research project, 887 male substance-dependent patients were evaluated in terms of involvement in self-help groups (e.g., Alcoholics Anonymous), costs of mental health services and clinical outcomes. Patients treated in cognitive
behavioural programs averaged almost twice as many outpatient visits after discharge (22.5 visits) as opposed to patients treated in 12-step treatment programs (13.1 visits), and also received significantly more days of inpatient care (17.0 days in CB versus 10.5 in 12-step), resulting in 64% higher annual costs in CB programs ($4729/patient). Psychiatric and substance abuse outcomes were comparable across treatments, except that 12-step patients had higher rates of abstinence at follow-up (45.7% versus 36.2% for patients from CB programs). **Key Words: alcohol abuse, self-Help groups, health care costs-offsets**


The authors studied adult patients (n=213) with insulin-treated diabetes from two outpatient clinics in Northern Finland. Using questionnaires, they developed measures for levels of self-care and social support (including emotional, informational, peer, and financial). The authors found that a fifth were neglecting their self-care due in part to poor metabolic control, smoking and living alone. However, with support from family and friends, living alone was not predictor of neglect of self-care. Those with poor metabolic control perceived themselves as getting peer support from other persons with diabetes (although this support did not lower their glucose levels). **Keywords: diabetes, self-care, social support, peer support**


The authors report on an extensive church based risk reduction program aimed at weight loss, improved nutrition and activity for African-American women aged 40 and over. Dividing participants into three groups, 1. activity 2. activity and spirituality 3. secular self-help group, they found those in the first and second groups saw the most change and expressed the highest levels of satisfaction. Those in the secular self-help group expressed the least satisfaction and had the least behavioural change. It is the opinion of the researchers that it is not possible to maintain non-spiritual health education program within the Black church system. **Key words: obesity, activity, diet and nutrition, race/ethnicity, Church-based support and education programs, self-help**
This is a thoughtful reflection on how a diabetes prevention initiative for pregnant Cree women in Northern Quebec could have been more successful. Reviewing the initiative, which involved individual counseling with pregnant women by a non-Cree nutritionist, the working group notes that physical activity and nutrition did not improve. They suggest future interventions need to include: Cree-led weekly mutual aid group sessions, Cree elders and midwives and culturally-specific education techniques. Although grateful for the ‘help’ with the prevalent diabetes issue in their community, the authors see no improvement without Cree leadership and the inclusion of experiential knowledge. **Key words: mutual aid, culturally specific groups for, Cree, diabetes**

Clark, N., Janz, N., Dodge, J., Schork, A., Fingerlin, T., Wheeler, J., Liang, J., Keteyian, S. and Santinga, J. T. (2000). Changes in functional health status of older women with heart disease: Evaluation of a program based on self-regulation. Journal of Gerontology (Social Sciences) 55B:S117-S126. 570 women over 60 were assigned to control or mutual aid program groups. The latter were composed of 6-8 people and were co-led by a health educator and a peer. Group activities included sharing information, talk and physical activity. At 12 months, participants demonstrated fewer symptoms (associated with heart disease), improved ‘ambulation’ and lost more body weight. **Key words: body mass index, age, sex, mutual aid, health education, brisk factors, heart disease, seniors**

In perhaps one of the most comprehensive and thoughtful studies on self-help groups written in the last 20 years, the authors measured voluntary participation in self-help groups for 20 disease categories in 4 metropolitan areas (New York, Chicago, Los Angeles, and Dallas) and on 2 on-line forums. They find self-help participation (in person and on-line) highest for diseases viewed as stigmatizing (e.g., AIDS, alcoholism, breast and prostate cancer) and lowest for less embarrassing but equally devastating disorders, such as heart disease and stroke. In addition, the authors note that although stroke is highly related to hypertension, those with high blood pressure will seek support after a stroke much more readily than before it. Individuals suffering
from hypertension may also attend other groups such as Overeaters Anonymous (for obesity), groups for diabetes and others that do not identify as stroke specific. **Key words: self-help groups, illness, age, obesity, hypertension, alcohol abuse, drug abuse, US, factors related to participation**

**Healy, P. (2000). Let patients with diabetes make their own decisions.** *Nursing Standard, 14(27): 8*

The author reports on a new British study by Walker et al. that questions the focus on compliance in diabetes care. According to the study, hospital-based specialist nurses believe that patient compliance is a key issue for them, but the study suggests nurses should instead be focusing on *empowering* patients to make informed choices. Compliance, the author writes, “is not a concept that is of any use in chronic illness management or care”. **Key words: empowerment, diabetes, informed choice, problems with compliance**


In the UK, establishing a smoking cessation support service has become a health priority. The authors report on the paramount role that *mutual aid* and peer support have played in these support services. In small groups (n=6), the effect of peer support is “encouraging and motivating, thus fostering a sense of belonging and camaraderie. Members of the smaller group were seen to share their experiences of attempting to quit and the difficulties associated with this. Sharing their feelings of guilt and pressure offered relief from the stress of cessation”. **Key words: smoking, UK, mutual aid, peer support**


This article describes a mutual aid and education intervention designed for inner-city, overweight African American adolescent women. Fifty-seven participants were recruited from four public housing developments to participate in the program over two years. Each program session included an educational activity, 30 to 60 minutes of physical activity, preparation of low-fat meals and *mutual aid*. Pre and post test questionnaires demonstrated significant changes in nutrition knowledge, low-fat practices, perceived changes in low-fat practices, and levels of social support. The authors suggest that the inclusion of African American peer educators would
improve the program. **Key words: mutual aid, education, activity, obesity, African American girls**

The authors explored self-help groups for overeating and obesity (Overeaters’ Anonymous) and professionally-led support groups for mental illness, investigating relationships between the groups’ helping characteristics (i.e., instilling hope, caring and concern) and two variables: participants’ subjective well-being and general satisfaction with the group. The research sample consisted of 117 participants belonging to 11 groups meeting in Israel. Comparison of the groups revealed that 12-step group members were far more satisfied with the group and gave higher evaluations for most of the helping characteristics. **Key words: self-help groups, support groups, obesity, mental health, hope, well-being, satisfaction**

Reviewing recent research on obesity, the authors note new recommendations of more modest 5% to 15% reduction in initial weight for significant reduction in risk. Noting current options for weight loss including behavioral or pharmacological management, they also suggest self-help approaches, such as Overeaters Anonymous (OA) and Take Off Pounds Sensibly (TOPS), are another option, “providing valuable group support” necessary for the maintenance of weight loss. **Key words: obesity, risk factor, self-help, weight loss options, group support**

The authors summarize research on self-management and patient empowerment, interventions with children and adolescents and depression. They highlight the considerable gap between this “encouraging research” and the infrequent incorporation of such contributions into practice, making suggestions for how it can be presented in a more convincing and accessible manner and integrated with other promising genetic, medical, nutritional, technology, health care, and policy opportunities. **Key words: empowerment, diabetes, research on, presentation of**
The authors studied the development and efficacy of ‘Hearts to God’, a risk reduction program for middle-aged, white women members of a parish in the US. The program included regular small group *mutual aid* meetings, education and the development of a manual integrating spirituality, stewardship and cardiovascular health promotion. Positive feedback from participants is used to demonstrate how this program fills a health education void regarding heart health and stroke prevention for women and how spiritual communities are important but often overlooked collaborators in risk reduction. **Key word: age, sex, spirituality, education, self-care, mutual aid**

Although the author does not offer any new research in this article, she draws on a good deal of literature to provide readers with a powerful argument and opportunity for reflection on *empowerment* in nursing care of individuals with diabetes. She also outlines how nurses can include empowerment in their practice in addition to the standard pharmacological and behavioural approaches. **Key words: diabetes, empowerment, practice models of**

The author reviews current models of drug treatment for women including 12 step programs that ‘emphasize powerlessness’. Using a feminist analysis, she outlines what she sees as a more *empowering* and woman-centric model of care that includes: cultural compatibility, treating women in context of their life circumstance and community, spirituality and the relational model of empowerment. **Key words: empowerment, drug abuse, treatments for, 12 step groups, critique of**

The author reviews research on *mutual aid/self-help groups (mash)* prior to 1995 with respect to various health issues. He cites a number of important studies that relate to risk factors for stroke.

1. **Obesity and weight loss**- One of the largest MASH studies ever conducted showed that a *peer-led self-help* organization in Norway produced significant weight loss among members. Average weight loss over 8 weeks in a sample of 10,000
participants was 15 pounds. Follow-up studies showed that most group participants maintained their weight loss a year later (Grimsmo, Helgesen & Borchgrevink, 1981).

2. Alcohol abuse-Using meta-analysis, Emrick and colleagues (1993) combined data from more than 50 studies of Alcoholics Anonymous (AA) and concluded that AA involvement is moderately associated with reduced alcohol problems and improved psychological adjustment.

3. Sickle Cell Disease-African Americans who have sickle-cell disease and become highly involved in MASH groups report reduced emotional upset and decreased interference of the disease with their work and relationships (Nash & Kramer, 1993).

4. Diabetes- A group of East Asians living in Coventry, U.K., have operated a successful MASH organization for diabetic immigrants for a number of years. The research team that helped start the group also evaluated its effects over a one-year period and found that individuals attending two or more times had a 22 percent increase in knowledge about diabetes (based on standardized interviews), and were 12 percent less likely to have high levels of glycated hemoglobin (Simmons, 1992). In contrast, individuals attending the group once or never showed little change on these important outcomes at 1-year follow-up. Another study supplemented traditional professionally-provided patient education with a professionally organized but patient-run MASH group. Male diabetic patients who had their diabetes education supplemented with MASH groups showed better knowledge of diabetes, higher quality of life, and lower depression than patients who received only the education component (Gilden et al., 1992).

Key words: self-help research on risk factors prior to 1997, alcohol abuse, obesity, weight loss, sick cell, diabetes

Results of this study indicated that more than 25 million Americans are estimated to have participated in a self-help group. More than one third of the participants are involved in groups for substance use problems. The second largest segment attended groups around food, obesity and weight issues. One distinctive finding is that those with lower levels of family support were more likely to participate in self-help groups than those with higher levels of support. Key words: self-help group participation, substance abuse, obesity, food

The authors compared the effectiveness of a culturally-specific Church-based quit program with the distribution of generic materials on smoking cessation. The Church-based program included one to four pastoral sermons on smoking, testimony during church services from individuals going through the quit process, training of volunteers as lay smoking-cessation counselors, access to individual or group support supplemented with spiritual audiotapes containing gospel music, a day-by-day scripturally guided stop-smoking booklet, and baseline and follow-up health fairs. Results showed participants in the culturally specific Church program were significantly more likely to make progress than those just receiving materials. In addition, Baptist participants in the intervention program were three times more likely to make progress than others. **Key words: smoking cessation, race/ethnicity, Church based self-help programs, success of**


The authors report on a community-wide education program and whether it changed cardiovascular risk factors and disease risk in Pawtucket, RI. After all citizens aged 18-64 participated in multilevel education, screening, mutual aid and counseling programs for 7 years, projected cardiovascular disease rates were significantly (16%) less, as were increases in body mass index. However, other results were less encouraging. The authors note that although cardiovascular risk reduction at the community level is feasible, maintenance requires a sustained community effort with reinforcement from state, regional, and national policies and programs. **Key words: population health, community education, mutual aid, risk factors, policy recommendations**


In this qualitative study, the authors tried to understand how social support works in a number of Swedish self-help groups for older adults with CHD. Run by the members and supported by the Swedish National Association for Heart and Lung Patients, ‘Heart ten’ participants expressed “a feeling of solidarity and fellowship” which encouraged members to share their experiences. This sharing, argue the authors, ‘enhanced their well-being and encouraged them to go ahead and sort of their situations’ (227). The authors suggest that “the self-help group related to CHD may be a cornerstone in a network of support” (231).** Key words: self-help, coronary heart disease, social support, Sweden**

The author, an MD, makes an overwhelming case for the importance and effect of thought, emotion, self-efficacy, *empowerment* and confidence on health. Citing multiple studies (including those on *self-help and empowerment*), “what goes on in a person's head”, he writes, “can have a dramatic effect on the onset of some diseases, the course of many, and the management of nearly all”. Nearly one-third of patients who visit a doctor have bodily symptoms as an expression of psychological distress. Another third have medical conditions that result from behavioral choices such as smoking, alcohol and drug abuse, poor diets, and so forth (also linked to emotion). Among the remaining patients with medical diseases such as arthritis, heart failure, or pneumonia, the course of their illness can be strongly influenced by their mood, coping skills, and social support.

**Key words:** emotion, mental health, empowerment, self-efficacy, social support as factors in health
Stroke Recovery and Secondary Prevention: Current Trends in the Research

**Ethnicity and Race**


The authors measured the overall rate of usage of tissue-type plasminogen activator (tPA) for ischemic stroke at academic medical centers to determine whether ethnicity was associated with usage. Between June and December 1999, 42 academic medical centers in the United States each identified 30 consecutive ischemic stroke cases. Medical records were reviewed and information on demographics, medical history, and treatment were abstracted. The authors found that African Americans were one fifth as likely to receive tPA as whites (1.1% African Americans versus 5.3%; *P* < 0.001), and the difference persisted after adjustment (OR 0.21, 95% CI 0.06 to 0.68; *P* < 0.01). Medical insurance type was independently associated with tPA treatment. After adjustment for ethnicity and other demographic characteristics, those with Medicaid or no insurance were one ninth as likely to receive tPA as those with private medical insurance (OR 0.11, 95% CI 0.02 to 0.17; *P* < 0.003). **Key Words: race, African American, association with poor treatment of stroke**

**Exercise**


30-90 days after stroke, twenty minimally and moderately impaired patients who had completed rehab were randomly placed in control and experimental groups. The experimental group received therapist-supervised, 3-times-per-week, home-based exercise program. The control group received usual care as prescribed by the patients’ physicians. The experimental group tended to improve more than the control group with respect to measures of neurological impairments and lower extremity function. **Key words: group exercise, stroke rehabilitation**

**Socioeconomic Status**

Reviewing information on all patients with acute stroke admitted to hospitals in Ontario between April 1994 and March 1997, socioeconomic status for each patient was inferred on the basis of median neighborhood income. Secondary analyses compared the use of medications, inpatient rehabilitation services, and carotid endarterectomy by socioeconomic status. Of 38,945 patients, each $10,000 increase in median neighborhood income was associated with a 9% reduction in the hazard of death at 30 days and a 5% reduction in the hazard of death at 1 year. Patients in the lowest income quintile were less likely than those in the highest to receive in-hospital physiotherapy, occupational therapy and speech pathology. There were no differences in the use of medications or carotid endarterectomy based on socioeconomic status. Waiting times for carotid surgery, however, were significantly longer in the lowest income quintile than the highest (90 days versus 60 days). “Other potential explanations for the higher mortality observed with lower socioeconomic status include greater disease severity or an increased prevalence of cerebrovascular disease risk factors and other comorbid conditions. In addition, medication adherence, stress, social isolation, and other unmeasured factors may all be important income-related determinants of survival after acute stroke”. **Key Words: ses, class, stroke outcome and treatment**


In all countries reviewed, manual classes had higher stroke mortality rates than non-manual classes. This difference was relatively large in England and Wales, Ireland, and Finland and relatively small in Sweden, Norway, Denmark, Italy, and Spain. In most countries (including the US), inequalities were much larger for stroke mortality than for ischemic heart disease mortality. Socioeconomic differences in stroke mortality are a problem common to all countries studied. **Key Words: SES, class, risk, stroke mortality**
Stroke Recovery and Social Support


Using data from the Canadian Study of Health and Aging II, the authors looked at a national sample of 5395 community-dwelling Canadian seniors and compared health, social and demographic characteristics for 339 stroke survivors to community-dwelling seniors who had not experienced a stroke. Stroke survivors reported a lower sense of well-being and worse mental health. However, both were eased by the presence of strong social supports.

"Social supports have elsewhere been found to be associated with a higher quality of life in stroke survivors...and our results help to explicate the operative role that social support plays as a moderator of the effects of disability on well-being....Collectively, these findings highlight the salience of support systems for well-being after stroke and emphasize the ongoing importance of developing appropriate programs that enhance and reinforce the social supports and social networks of stroke survivors. Not only are strong supportive social systems vital for the well-being of seniors who have had a stroke, but they may also operate indirectly to reduce further strain on the healthcare system.” (1020)

**Key Words:** aging, disability, evaluation, quality of life, social support

Chang, A., Mackenzie, Yip and Dhillon (1999). The psychosocial impact of stroke. *Journal of Clinical Nursing*, 8: 477-481. Using various scales in their Hong Kong study of stroke survivors and ‘healthy people’, the authors find that self-esteem and levels of social support are important factors in rehabilitation, affecting who recovers and how. **Key words:** social support, self-esteem, rehabilitation, stroke, Hong Kong

**Stroke Recovery and Self-help, Mutual aid, Empowerment or Adult education**


The author reports on a medical conference around new issues with stroke, the third leading cause of death world-wide. He highlights a presentation made by the leader of Different Strokes in the UK. Promoting self-help and fostering mutual support, the group was set up by younger stroke survivors for younger stroke survivors. The author concludes that the challenge now is to “maintain this momentum with government support” and increase public awareness and support for stroke. **Key words:** self-help, stroke survivors, medical acceptance of, proposed policy around

To examine the qualitative experience of patients and caregivers during the year of recovery after a stroke, the authors used semi-structured interviews with a purposively selected sample of 30 patients and 15 caregivers. Patients had very individual yardsticks for measuring their recovery including the degree of congruence between their lives before and after stroke. Four of the 30 patients mentioned the importance of social support in recovery and especially the *mutual aid* available in certain rehabilitation programs and stroke clubs.

They sent a taxi to take me to the Social Service Day Centre. I just go on a Monday now. I’ve tried to kid them on to take me more, but it’s nice you meet other people there and there’s all different ones and you say, well, they’re worse than me! You always see somebody worse. (509)

**Key words:** recovery, stroke, individual process of, social support, mutual aid


The authors did an ethnographic study of a *co-led self-help group* for stroke patients and caregivers. 10 participants of this on-going group met bi-weekly at the home of a group member. Six of the participants were stroke survivors and the remaining four participants were wives of the male stroke survivors. Group members ranged in age from 45-75 years and were all from middle and professional socioeconomic backgrounds. All resided, and had participated in rehabilitation programs in a major urban community. Length of time post-stroke ranged from eight months to five years. Ethnographic analysis identified a number of themes in group discussions including perceptions around ‘being dumped by the system too soon’, lack of individualized and personal care post stroke and lack of information about other supports in the community. The study suggests that members in such groups need more care post stroke. **Key words:** self-help group, stroke patients, caregivers, discussions in, themes of, poor perception of formal stroke care


The authors surveyed 11 German stroke *support/mutual aid groups* and found 80.3% had good symptom knowledge, 64.7% had good risk factor
knowledge, and 79.7% had good action knowledge. Stroke knowledge was excellent in 44.0% of subjects. The authors suggest that because of their knowledge and personal experience, support groups should be viewed as important partners in community stroke education. **Key words: self-help groups for stroke, knowledge of stroke in, potential role in community stroke education**

**Family/Caregivers and Social Support**

Stroke patients admitted to hospital in the north of Britain and their informal caregivers were randomly allocated to receive the FSO service or standard care. Assessments were done at 4 and 9 months after recruitment. The study found no significant differences in patients’ mood, independence or caregivers’ mood, strain, or independence. However, both patients and caregivers in the intervention group were significantly more knowledgeable about whom to contact for stroke information, practical help, community services, and emotional support. **Key Words: caregivers, stroke management, stroke knowledge, social support**

The authors report on a study of family caregivers in the UK and, following a series of lengthy interviews, identify various themes common to all. These include: uncertainty and confusion, a sense of isolation, relative lack of support, feelings that their own needs were overshadowed by those of the stroke survivor and that their *experiential knowledge* of their relative was often overlooked by professionals. The authors advocate for more collaboration between caregiver and professional and more attention to their support and information needs. **Key words: caregivers, lack of social support, experiential knowledge, neglect of by professionals**

Family support organizers (FSOs) were observed on home and hospital visits to stroke patients and their caregivers in the North-West and Midland regions of Britain. The majority (71%) of visits took place in the patient’s home, with both patients and carers (39%). The authors found that FSOs
spend more time engaged in practical rather than emotionally supportive activities, raising questions about their role in stroke recovery and care. **Key words:** recovery, social support, types needed by patients and caregivers following stroke

**Family/Caregivers and Self-help, Mutual aid, Empowerment or Adult education**


This small study (n=5) aimed to determine if caregivers of survivors of stroke were willing and able to use in-home mediated *on-line mutual aid* and information. Investigators developed a site called The Caring Web to provide interaction with a nurse specialist, educational information about stroke, caring, and caregivers using linked Web sites and opportunities for on-line mutual aid and discussion between caregivers. Despite some preliminary technical issues, findings suggest caregivers were willing and able to use Caring Web and receptive to using the Internet for health information and social support. **Key words:** on-line mutual aid, caregivers of stroke patients

**Policy Recommendations**


Noting that psychosocial and family issues have been neglected in stroke discourse, the authors point to the adult education model as well as self-help/mutual aid as valuable but neglected tools in stroke education. They argue that practitioners need to think more broadly in terms of tools and techniques. **Key words:** stroke education, practice, adult education


The author argues that “unhealthy habits account for about 54% of known contributions to heart disease”. Behavioral and biological interventions can reduce morbidity, disability, and death due to heart disease and stroke. The author proposes a new paradigm for risk factor management that should:
• develop the health promotion skills of health professionals and the public
• encourage patients, providers, and the healthcare system to work together as partners
• help patients make decisions about treatment
• develop a comprehensive approach to risk factor management, “The Compliance Action Program,” which will involve patients, providers, and the healthcare system.
• expand interdisciplinary health-focused models
• recognize the importance of the public’s growing use of self-help as well as cultural and ethical issues in communities and patients’ lives


Reviewing the history of cardiovascular medicine in the US and recent changes and issues, the author makes a number of recommendations for good medicine in the future: “risk factor modification should remain an important need”, system-wide approaches will be an increasing focus of prevention and rehabilitation in cardiology, home care or other nontraditional care forums (such as support groups) will be increasingly used, traditionally undeserved populations will need extra attention. **Key words: cardiovascular medicine, future recommendations for, importance of target groups and risk factors in prevention**
Bibliography


APPENDIX SIX

Examples of other SHRC Self-Help/Mutual Aid Projects directed towards newcomers and potentially marginalized populations.

The SHRC has been a leader in a number of Self-Help/Mutual Aid projects that have provided opportunities for newcomers (and other potentially marginalized groups) to participate in empowering and skills-building initiatives. Enclosed please find information pertaining to two projects: *Diversify the Source, Enhance the Force*; and *Mutually Ours*. 