

To: Health Canada, Division of Aging
Ray Amiro and Lisa Lacroix

**“The Use of Mutual Support/Self-Help
in the Prevention, Management
and Care of Chronic Physical Disease
in Older Canadians”**

From: The Self-Help Resource Centre
of Greater Toronto
Margaret McGovern

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TERMS OF REFERENCE

The Division of Aging and Seniors (DAS), Health Canada has contracted a report and recommendations on the use of mutual support/peer support for the prevention, care and management of chronic physical disease in older Canadians. This analysis is to include the following:

a literature review and evaluation of mutual support/peer support groups directed towards the prevention, care and management of chronic physical disease in Canada and the United States, and assess their value for older Canadians

consultations with experiential self-helpers and with theoretical experts to assess their experiences in mutual support/self-help with seniors

preparation of recommendations and guidelines for the use of mutual support/peer support strategies in the prevention, management and care of chronic disease in older Canadians.

Health Canada wishes to contract this work from the Division of Aging and Seniors. The Self-Help Resource Centre has responsibility for conducting the study in consultation with the staff from the Division and for preparing the final report and recommendations for the Division.

SCOPE OF THE PROJECT

The assignment will be limited to the following:

1. Analysis of:

Literature review

Consultations in the field

The role of the health care providers and volunteers

Common characteristics of successful mutual support/peer support programs

Precautionary measures for working in diverse situations

Support structures and agencies necessary to successful programs including materials and other aids

Training and recruitment of both health care providers and volunteers

Evaluation of mutual support/peer support programs

2. Literature Review

The literature review will include descriptions of programs and research undertaken with older people in both Canada and the U.S.A. There will be definitions of terms that are being used throughout North America in order that we may arrive at some commonly acceptable terms for our future direction with this and other projects for Health Canada and related organizations. The review will focus on the use of mutual support/peer support strategies in relation to older individuals with general issues and/or chronic health conditions. It will include definitions in the literature, benefits that have been documented including health care savings, and some

discussion of ongoing barriers to the use of these strategies in a senior population.

3. Consultations in the Field

A description of the agencies and individuals interviewed will include the kinds of experiences that have been used by the various groups. National organizations with Mutual Support/peer support programs across the country are being targeted. As well, some organizations in Ontario with long time experience in mutual support are being included (See Appendix A). Also health care providers and/or theoretical experts are being interviewed regarding their experiences and/or research.

4. Role of the Health Care Provider and the Volunteer

A discussion of the respective and complementary roles of the "professional" or health care provider and the "volunteer" will include aspects of their responsibilities. What experiences and/or knowledge each of these individuals brings to the relationship will also be described.

5. Common Characteristics of Successful Mutual Support/Peer Support Programs

The essence of mutual support/self-help has often been described as the magic of self-help. An attempt will be made to capture that magic in defining why it works without destroying the magic. There are common elements across programs that occur which may lead us to describe them as essential to the process.

Cautionary Measures

Barriers, the targeted population and its known use of these strategies will be reported. Also included are diverse situations, urban/rural, ethnocultural issues.

Support Structures, Agencies and Resources

While many view mutual aid/peer support as "free" there is the need for support systems to the programs. A description of ongoing human resources and the development of resource manuals will be included.

Training and Recruitment

Organizations have training programs for their volunteers with common characteristics across them. The analysis will include who is involved in the planning, needs assessment, timing and content. The need for ongoing volunteer development and support will also be addressed.

Evaluation of Programs

An analysis of the evaluation of programs will attempt to capture not only the benefits of the mutual support/peer support programs, but what evaluative methods may be used successfully with these strategies. There is a difference of opinion among researchers about the validity of

some evaluative approaches. The use of mutual support/peer support in prevention as well as ongoing management and care will also be addressed.

APPROACH

We intend to meet these objectives by performing the following tasks:

Literature review and evaluation

Consultations

with organizations across Canada who offer mutual support/peer support to people with chronic diseases.

with key informants

Review material accumulated and begin writing report

Conference call with advisory group (Appendix B)

The Use of Mutual Support/Peer Support/Self-Help Strategies for the Prevention, Care and Management of Chronic Disease in Older Canadians

INTRODUCTION

As our population in Canada ages, alternative strategies are being sought to enhance and maintain the quality of life of its citizens. Mutual support/self-help and peer support initiatives are self-care strategies which may be considered as we move to empowering older Canadians to take charge of their own health.

While it has been noted that older adults tend to use self-help groups less than the general population (Lieberman 1990), there has been an increase in involvement (Mellinger and Bolter in 1983 cite 3.7% of people between 50 and 64 years and 0.9% over 65 years, while in 1998 Wister et al noted that 10% of their older adults participated). I would suggest these numbers will continue to increase as our "younger" seniors who have had a positive experience in group support will continue using this strategy.

Many of the present mutual support/self-help initiatives, though not geared specifically to older Canadians, certainly have significant percentages of seniors as members.

DEFINITIONS

There are several terms, which may be used interchangeably in this area of support. I would like to propose the following usage in this paper.

Self-care

Care undertaken by individuals themselves. It may be facilitated by education programs, participation in mutual support/self-help or support groups.

Mutual Support/Self-Help

They are defined as a process of sharing common experiences, situations, or problems. Self-help is participatory in nature and involves getting help, giving help, and learning to help oneself, as well as sharing knowledge and experience. There is no charge to participate, although a nominal donation to cover expenses is sometimes requested, but not required. Self-help initiatives meet on an ongoing basis, are voluntary in nature, rather than mandatory, and are open to new members. Self-help initiatives are run by and for the participants. The primary focus of self-help is emotional support, practical support and information exchange.
(Canadian Health Network, 1999
Resource Mapping for Self-Help)

This definition, it will be noted, has changed the term mutual aid to mutual support which is

perhaps more descriptive of what happens.

Self-Help Groups

This category includes traditional face-to-face groups (open or closed), transitioning groups (moving from a professionally led educational/support group model to a self-help group), and Internet/online self-help groups.

(Canadian Health Network)

Peer Support

This category involves one-on-one contact and support for people who share, or have shared, a common concern (i.e. telephone support networks, issue specific pen-pal networks or e-mail exchanges).

(Canadian Health Network)

There is a need for clarity in the understanding of these definitions and acceptance of them prior to program development. For example, recruitment of facilitators for groups will be dependent on acceptance of the concept that mutual support among those with a similar disease, life situation or condition is central to the group's success. A recommendation regarding definitions will be made in the concluding section of this report. As well, see Appendix C for a chart outlining the place of mutual support, etc. in relation to social support and the other determinants of health.

THE ELEMENTS OF MUTUAL SUPPORT/SELF-HELP

Common Characteristics of Programs

The characteristic which was mentioned by all groups consulted as well as appearing in the literature, was the need for the group facilitator or the telephone buddy to have "been there", i.e. to have had breast cancer, to be a bereaved parent, or to have a disability. The mutual respect and sharing, especially within groups, was facilitated by the equality of the group members.

Jean-Marie Romeder captures many of the common elements in "The Self-Help Way: Mutual Support and Health" (1990). He describes self-help groups as small, autonomous, open groups, which meet regularly. Members share common experiences of suffering or stress as a result of a personal crisis - life event, illness. They meet each other as equals. The primary activities of the group are to share support (mutual), information and coping strategies. Sometimes members also engage in social change. Group activities are voluntary and essentially free of charge. All of the groups consulted contain many, if not all, of these elements. Some of the organizations, recognizing their limited resources, request a serious commitment from their participants to attend their programs. The actual groups seem to have a fair degree of autonomy. Several of those interviewed stressed that group members "owned" the group and its life.

Few of the groups or organizations consulted have mutual support groups "just for seniors". Their focus may be a bereavement or disease-specific issue. In fact, these "mixed age" groups

may in some instances be a better alternative, because they avoid grouping of seniors with other seniors. In a mixed age group there may be more opportunity for integration of seniors with younger members of the community. There may be benefits accruing to all as a result.

However, it was recognized that in some situations because of distance, frailty, etc. or when face-to-face meetings are not an option (e.g. transportation problems) one on one telephone peer support may be more appropriate to the context and other methods of support needed to be offered. One organization has instituted a telephone buddy system between a "senior" bereaved parent volunteer and a senior parent who has experienced the death of an adult son or daughter. Another organization has their volunteers visit in the homes of people with a debilitating physical disease.

Support Structures and Agencies

Many mutual support/self-help groups are being offered to members of the community through disease-specific organizations or self-help organizations. These "structures" provide program coordination, public awareness of programs, training and support of facilitator/participants, as well as space and resource to factual, accurate health information. An emphasis on targeting seniors with outreach programs that emphasize self-help approaches may be appropriate with some organizations. Providing these organizations and their clients with literature and workshops on how to form self-help groups may be needed so that self-help can be viewed as one approach that may be of use.

In the major communities there are also free-standing Self-Help Resource Centres whose primary purpose is to nurture mutual support/self-help initiatives in their communities (e.g. Halifax, Toronto, Vancouver). As well, some provinces have self-help networks to assist in the development of local self-help centres (British Columbia, Manitoba, New Brunswick, Nova Scotia, Ontario and Saskatchewan).

Materials and Other Aids

Several of the organizations contacted have developed manuals for the use of their volunteers. One such publication is "The Sharing Network: A Handbook on Self-Help Programs for People with Multiple Sclerosis and Their Families", revised in 1997, published by the Multiple Sclerosis Society of Canada.

The Self-Help Resource Centre of Greater Toronto produced a video and booklet entitled "Getting Started and Making it Work" in 1997. It describes how to initiate a self-help group and keep it going. The Self-Help Resource Centres across the country act as clearinghouses for information about initiatives in their own communities, as well as providing journal articles and other resources. Their purpose is to help individuals and organizations develop self-help. The Ontario Self-Help Network has developed "Making Self-Help/Mutual Support Work: The Resource Kit" which is available to anyone interested in developing programs.

Precautionary Measures, Barriers

It is disappointing to report that a major barrier to the use of mutual support/self-help programs

in communities across the country is the lack of referrals from health care providers. This was reported, not only in the literature (Gottlieb 2000) but in some of the consultations. Some of the organizations do have public and professional awareness programs, but were discouraged that these initiatives did not increase the referral of older Canadians to their programs. It would seem a more concerted effort is needed to place social support as one of the coping or health maintenance strategies and indeed a complementary strategy to that of health care providers working with seniors and people with chronic diseases.

The logistical barriers of working with individuals who may have mobility restrictions, the diverse ethno-cultural nature of many of our communities, especially the larger urban centres, have long been recognized as barriers. Some success has been demonstrated by the use of telephone support groups (Stewart, Lavoie and Rootman 1998) and also demonstrated by the West Island Advocacy Centre and Cancer Connection. More evaluative research is needed to prove its efficacy. There are "pockets" of mutual support/self-help groups within some of our ethno-specific communities; these need to be explored and replicated if effective.

Another barrier stated in the literature is the preference of older Canadians for professional as opposed to peer assistance (Malone 1999). This may be changing as witness participants' preference for a facilitator with the same condition, i.e. chronic disease in the Self-Management Program of Vancouver Richmond (personal discussion with Patrick McGowan).

Other program coordinators also found that when programs were facilitated by people with not only the same situation/condition, but who could role-model a sense of coping with the disease (breast cancer) or surviving life-style changes (diabetes diagnosis), participants were more likely to continue their involvement.

Lack of information about mutual support/self-help in general and its relevance to older Canadians continues to be identified as a major barrier. More effort by mutual support organizations, Self-Help Resource Centres, professional associations to endorse and support the efficacy of mutual support/self-help needs to be encouraged for older Canadians with chronic diseases. The complementary role of mutual support strategies needs to be stressed.

More attention may need to be given to "matching" participants. Some of the organizations pay particular attention to matching members of groups - on the "crisis or condition", the age (young-old, old-old), on gender, ethno-cultural background, etc. Some of those consulted suggested that age was not as important as the "condition". It has been observed that older Canadians like more structure in a group, clearer guidelines than some mutual support groups may offer. Also "younger" seniors participate more than "older" seniors. It has been suggested that this is a function of mobility.

Training and Recruitment of Volunteers

Most of the organizations consulted recruited their participant/facilitators from their own programs. The only exception will be at the beginning of a new program when others may be used. However, all groups stated clearly that their goal was to use participant/facilitators. All of the groups used two facilitators per group for support, continuity and the "modelling" of two different responses to the same situation.

Training programs ranged from "a long weekend", to four evening sessions, to a full four day program. Content would include information about the sponsoring organization and all its activities, perhaps material on group dynamics, some skills training (non-judgmental exercises, empowering others, assisting/allowing others to make own decisions. In the disease-specific organizations and bereavement organizations, the participant facilitators also were given factual, relevant and accurate information about the condition or disease. Where seniors are targeted, more flexibility in attendance, more options in program delivery may need to be considered.

Many of the organizations had regular updates or refreshers for their participant/facilitators. The content for these sessions were planned from needs identified by the participants. These sessions may take place in an evening, or a full day may be devoted to them, often on the weekend! Older Canadians participate in these sessions along with their younger counterparts.

LITERATURE REVIEW

An extensive and thorough literature has been prepared separate from this report. It is focussed on major research findings of the past twenty-five years as it relates to self-help/mutual support for seniors in the U.S.A. and Canada.

A few highlights will be noted here:

Benefits

- Increased access to social support and health information
- More opportunities for problem-solving
- Less alienation and isolation
- Improved self-esteem, skill-building and participation in self-care activities
- On-line participation decreases geographical, physical or other barriers to participation
- Greater and more immediate access to accurate health information database, although we need to know what is accurate
- Fostering of self-advocacy

These benefits would increase the independence, self-care and leadership skills of seniors who participated.

Health Care Savings

Several studies cite the health care savings costs as well as transforming passive patients into "responsible health care providers" (Ferguson and Madara 2000). In Canada, Morrongiello and Gottlieb (2000) note that investing in self-care programs have found first year savings in the range of \$2.50 for every dollar spent. However, it is noted by researchers, practitioners and participants that these initiatives complement rather than replace other types of care. They may reduce the amount of care needed from more

costly sources. These are significant benefits to seniors where they are empowered to look after their own health, rather than being passive recipients.

Evaluation and Research

While much of the effectiveness of self-help/mutual support is described in anecdotal terms, there have been some studies where research methodology has been employed. More discussion regarding barriers to research will be addressed in a later section. However, in our literature review there are some studies where participants in self-help groups have been compared to those not in groups with definite differences in behaviour outcomes.

Lund and Casserta (1993) - recently bereaved adults aged 50 and older, who participated in self-help groups experienced less depression and grief when compared to those who did not participate, if their initial levels of interpersonal and coping skills were low. Marmar et al (cited in Kyruz and Humphreys 1998) randomly assigned bereaved women to either professional psychotherapy or self-help groups. These women had sought treatment for grief after the death of a spouse. Using a number of tests, the researchers found that self-help groups worked just as well as the therapy ones.

Lorig et al (1999) recruited 900 older adults with heart disease, lung disease, stroke or arthritis. The "treatment" subjects participated in a six month program of health information, mutual support and self-care, taught by trained "lay" leaders (older adults with the same conditions). Compared to a control group, program participants demonstrated improvements in weekly minutes of exercise, cognitive symptom management, communication with physicians, self-reported health and a reduction in fatigue, disability and perceived activity limitations. They also experienced fewer hospitalizations and days in the hospital.

Two studies on seniors with diabetes (Wilson & Pratt 1987 and Gilden et al 1992) demonstrated that those people who had participated in self-help support groups showed positive behaviour changes when compared to control or education only groups. Behaviour changes included significant weight loss, glycemic control, less depression, and better diabetes knowledge and quality of life.

While these studies are encouraging, much remains to be done. Other issues addressed in the literature review will be discussed in the appropriate sections.

PROGRAMS FOR OLDER CANADIANS

Mutual support/self-help groups are found meeting needs in a variety of situations. The range of subjects covers the range of the human condition. Perhaps the best known is Alcoholics Anonymous but in the "Guide to Self-Help/Mutual Support Initiatives" which The Self-Help Resource of Greater Toronto published in 1999, there are over 320 self-help groups/organizations listed. Some disease-specific organizations such as the Canadian Diabetes Association, the Multiple Sclerosis Society of Canada and the Canadian Cancer Society offer

"self-help programs" as one of their support services. Some organizations and self-help groups such as Bereaved Families of Ontario and the Osteoporosis Society of Canada, view the self-help programs as an integrated part of their services. The latter organizations involve "self-helpers" in all aspects of the organization's programs from board of director membership to program planning and delivery of the self-help groups.

There may not be specific agencies for older Canadians, but by virtue of the disease entity e.g. people with diabetes or heart disease or parents whose adult children have a disability or have died, support groups may be tailored to the needs of seniors. This is especially true in situations where participants are "matched" - by age, disease entity, or life situation.

Then there are organizations tailored to the older generation such as the Older Women's Network whose two-fold purpose is to focus on the specific needs of older women and to provide solidarity and support to them. There are large national organizations such as the Canadian Cancer Society which provide province wide telephone support in Ontario through their Cancer Connection telephone line and 450 volunteers. There is also a "Reach to Recovery" group in Dartmouth that provides one-on-one visiting support as well as telephone support to women newly diagnosed with breast cancer.

Programs have certain commonalities, but also some adaptation to needs of individuals within groups. Some groups set their own structure, others are set by the sponsoring organization.

I Group Support

(i) *Ongoing Weekly Groups*

"Open Up Your Heart" is an ongoing group based on the Dean Ornish program, which meets weekly for three hours. The program is based on a research program of Dr. Dean Ornish, a cardiologist. The first hour may address a lifestyle issue facilitated by the group leader and perhaps an educational speaker. The second hour is devoted to a stress-reducing activity such as yoga, and the third hour to a "feelings" discussion or emotional disclosure. There are usually 8-12 members per group, this is considered an optimal size; when the group increases the members split into two groups. All of the decision-making, beyond following the program structure, remains with the group members.

(ii) *Time-Limited*

Several organizations offer time-limited groups which means everyone starts together and is committed to staying with the group for the life of the group. The groups may meet weekly for 12 weeks (Bereaved Families of Ontario) or monthly from September until June (Canadian Diabetes Association). The facilitators are usually people who have the same disease or life crisis or event as the group members and have a knowledge base of the disease or situation. Though much education takes place in the groups, group members "own the discussion".

One-on-one Support

The Canadian Cancer Society described two different types of one-on-one support:

Reach to Recovery Program of Dartmouth, Nova Scotia. Women who have been cancer-free for one year will initially visit, in their homes, women who have been newly diagnosed with breast cancer. Follow up may include one more home visit and then telephone support.

Cancer Connection in Ontario offers telephone support throughout the province using 450 volunteers who are recruited through word of mouth. Staff members (3) do the initial telephone intake.

The West Island Advocacy Centre in Pointe Claire, Quebec has been offering home support to the handicapped, seniors and the disadvantaged for a considerable period. They offer advocacy as well as support on a one-to-one basis in the home and on the telephone. While many of the volunteers are not self-helpers, some are, e.g. handicapped persons may converse by phone with other handicapped persons

(iv) New Programs

The Ontario arm of the Osteoporosis Society of Canada is developing self-help "chapters" across the province. The Manager of Chapter Development gathers names of individuals from various communities who are interested in developing self-help groups locally. A 1-800 telephone line and other sources are used to facilitate this function. When there are sufficient names from one community, a local self-help initiative is encouraged. The Manager nurtures chapter development and has used the resources of the Ontario Self-Help Network to complement her efforts. In all aspects of the work of this organization, people with osteoporosis are partners. It is part of the organizational philosophy.

In the Vancouver-Richmond Health Region, Patrick McGowan of the Institute of Health Promotion and Research at the University of British Columbia is directing a Self-Management Program for Seniors with a chronic disease. Its goal is to promote self-care in the population. The program is modelled on one developed by Lorig et al (1999) and was introduced to Vancouver-Richmond in April 2000. It is a structured, six-week program, facilitated by two volunteers, one of whom is a person with a chronic disease.

[The goal is to eventually to have both facilitators as members of the seniors' cohort when they have completed the program themselves]. While it is true there is more structure to this program than some of the more informal self-help groups, there are elements of self-help and a recognition of the modelling and empathetic role of the facilitators who themselves have a chronic disease. There is an evaluation component to this project. Using a pre-test, post-test design outcome measures [quantitative study] are being evaluated. The one year study will be finished at the end of March 2001.

The Arthritis Society of British Columbia and the Yukon has just initiated an Internet-based train-the-trainer program for self-management of arthritis. The program is being offered via the Internet to identified leaders in their own communities. They in turn will share this program with

others with arthritis in their own communities, again via the Internet. Individuals who are “housebound” or living in rural or isolated communities will be able to participate. Computers are being accessed through churches, libraries and community centers; individuals do not need to own a personal one at this time.

As can be observed from these descriptions, there are myriad approaches and designs to self-help/mutual support programs. As programs develop across the country, they reflect the diverse nature of our needs, our responses to them and the resources available. There is richness in this approach as no one method will ever meet the needs of our diverse population. However, there was consensus amongst the individuals with whom I consulted that an educationally-focussed approach, using mutual support/self-help strategies, would be effective in addressing the health needs of seniors with chronic disease in Canada. Some suggested a “wellness” approach, with an emphasis on healthy life-styles, may be more positive than focussing on changes needed to avoid or reduce the effects of chronic disease.

THE COMPLEMENTARY ROLES OF THE HEALTH CARE PROVIDER AND THE PARTICIPANT/FACILITATOR

While there is recognition that there are support groups in the community, which are facilitated by health care providers, this paper addresses those facilitated by lay people. In all of the groups contacted, there was some relationship with health care providers. Some groups were initiated as an educational session with health professionals as speakers and then these groups evolved into mutual support/self-help initiatives with leadership emerging from the group. These “leaders” were then given additional training.

Most of the organizations contacted view the role of the health care provider as complementary to the role of the self-helper. The health care provider assists in the training of the latter, acts as a supporter or back up (not to group leadership, but as someone who may help problem-solve outside of the group). As one consultant stated “The professional's role is at the back of the room, not at the front of the group.” Experts in various fields (e.g. financial expert) may be brought into a group to deal with a specific issue. Their stay may be one meeting, several meetings, but it would definitely be short term!

Many groups have specific “rules” regarding what happens in their groups. For example, there will be no doctor bashing and individuals’ medical conditions will not be discussed and “treated”.

MUTUAL SUPPORT/SELF-HELP IN THE PREVENTION, CARE AND MANAGEMENT OF CHRONIC DISEASE IN OLDER CANADIANS

It would seem the time has come for Mutual Support/Self-Help. Canadians are living longer with chronic disease, but, at a time when the official health care system is being stretched to its limits, there is a community resource, which may be tapped. Ferguson and Madara (2000) have noted that many self-help groups transform passive patients into “responsible health care providers”, capable of partnering with health professionals in education, research, service delivery and evaluation and becoming resources rather than “drains” of the system. There was consensus among the individuals consulted that secondary prevention, management and care of

older Canadians could be achieved using mutual support/self-help approaches. There was little consensus regarding its use for primary prevention.

The participant/facilitator in an “Open Up Your Heart” Program did note, however, that he believed primary prevention programs could be offered to families, friends and co-workers of people newly diagnosed with heart disease, especially those who had had a heart attack. It was his observation that his family and colleagues were “open” to behaviour changes after he had experienced a heart attack.

Observations included the following:

People come together in a mutual support milieu because they share a common concern/crisis. Staying healthy would not constitute a common concern.

Most older Canadians probably have at least one chronic disease, so why focus on primary prevention anyway?

It was generally agreed across most groups and organizations that what was achieved in their programs was indeed secondary prevention. Further deterioration of conditions/diseases was arrested, participants’ quality of life was improved and there was less depression. Individuals feel more in control of their lives and can make independent decisions. This is a primary purpose of mutual support/self-help, not just a by-product.

The older Canadian of 2001 is not the older Canadian of 1990. It was acknowledged by discussants that especially the “younger” older Canadians have had group experiences, which help them to be comfortable in groups. They also come to these situations with more leadership and group skills.

It was also acknowledged that there should be more experimentation and evaluation of strategies that do not necessarily involve the traditional face-to-face approach. Groups using telephone support on a one-to-one basis are enthusiastic about its possibilities and would recommend it to others to explore. Such barriers as geographic distance, mobility and lack of confidence with a group structure could be addressed with this format.

It has been reported by Statistics Canada and others that older Canadians are “getting on the Internet” at a rate faster than all other populations. The use of on-line mutual support/self-help groups is an important recent development in providing support to hundreds of thousands of people with a variety of concerns, including many who have disabilities (Finn 1999). On-line support networks could be sponsored by existing organizations. Information is now available to assist with rules, confidentiality, etc. Self-Help Resource Centres are gaining expertise to assist organizations with the development of this option.

Though at least one recent Canadian study (Wister et al 1998) reported that 10% of older adults in B.C. had belonged to a self-help group in the previous twelve month period and that this is an increase from previous studies, there is obviously room for a further increase. We do not know which older Canadians benefit most from mutual support strategies. What characteristics will take them to this type of support, what will “make them stay”, and how will it

benefit their quality of life. These are all significant questions, which should be addressed in future programming and research (to the extent that research is a component of any programming).

Lieberman (1990) observed that the recruitment of older adults is more successful when it capitalizes on existing ties to trusted and credible voluntary associations or contacts with community gatekeepers. Certainly the disease specific associations sponsoring much of the present mutual support initiatives would fall into this category. What is the role of organizations such as Canadian Pensioners Concerned, Canadian Association for the 50+, Older Women's Network and community seniors' organizations? Creating partnerships among chronic disease organizations, older Canadian organizations and Self-Help Resource Centres for a concerted effort to combat the growing epidemic of chronic disease in older Canadians is a strategy we must employ. Health Canada will need to coordinate a National Action Plan.

RECOMMENDATIONS AND GUIDELINES FOR THE DEVELOPMENT AND USE OF MUTUAL SUPPORT/SELF-HELP GROUPS AND OTHER STRATEGIES

Mutual support/self-help is a complementary strategy to that provided by other parts of the health care system. Its role as a legitimate, effective option has been recognized since the time of the Lalonde report of the 1970's. As a means to empower individuals and encourage responsibility for one's own health it is without peer. Rather than being passive recipients of health care, older Canadians need and want to be responsible partners.

From both the literature review and the consultations across Canada, educational programs, many targeted to older Canadians, are already happening. Some of the educational programs are wellness centred, some are geared to specific chronic diseases or life crises. Seniors participate in some age-specific groups, but often with people of other ages.

Two approaches would seem to be indicated. One, a top down approach that originates with chronic disease organizations and targets their clients. The second would be a bottom up approach that targets individuals and groups of seniors. In the top down approach, after a time-limited educational program on a chronic physical disease, we would encourage the development of a mutual support/self-help group, which would not be time-limited. Natural leaders would emerge from the group and could be nurtured by the trained facilitators (Appendix D).

This ongoing group would act as a catalyst for supporting and sustaining lifestyle changes which had been suggested in the educational program. (See Appendix D for a transitioning focus).

In the bottom up approach, the focus could be on initiating and sustaining the setting up of mutual support/self-help groups targeted at seniors. The focus could be on individual seniors who may wish to set up a group independent of a disease associated group. Outreach could be focused on community centers, shopping malls, churches, seniors groups, libraries, casinos and other places where seniors might be found.

The Self-Help Resource Centre of Greater Toronto distributes "How to Start and Maintain a Self-Help Group". It is included as Appendix E with full permission. Each province has mutual

support/self-help resource centers whose mandates are to promote and sustain self-help in their communities. Some have web sites (such as www.selfhelp.on.ca for the Ontario Resource). All could be involved in the above mentioned two pronged approach. A coordinated focus on promoting mutual support/self-help with seniors' groups across Canada could be the stimulus for seniors to set up their own mutual support/self-help groups related to health or other issues of importance to their wellbeing. Partnerships with seniors' organizations interested in a bottom up approach would be ideal.

Particular issues which will need to be considered for older persons include:

(i) Accessibility

Should programs be taken to where older Canadians are? Seniors' residences, day centers, areas where older people congregate. Mall walks are becoming increasingly popular in many of our cities and towns. Could other programming be entertained there?

For the lonely, the isolated, or the housebound individual, a buddy system may be the effective strategy. Older persons with a similar situation/disease could have contact on a regular basis by phone or visiting in the home. In rural areas this strategy may also be effective. The Internet is now being considered as another point of access as older Canadians become more comfortable with the technology.

(ii) Flexibility of Programming

Many non-profit organizations who sponsor mutual support/self-help groups have firm attendance requirements, especially those with time-limited programs. Support groups for older persons may need to be of the "drop in" variety. Frailty, illness, physician appointments may prohibit regular attendance.

As well, some individuals may do better in a group setting while others benefit more from one-on-one situations (peer support). Because mutual support/self-help is a voluntary strategy older Canadians, where feasible, should be given a choice to be part of a group or meet individually in their homes, community centers, or residences. The choice should be the individual's where resources are available.

(iii) Ethnicity

Many communities across Canada have ethnospecific cultural centers, ethnospecific community centres and ethnospecific residences for older persons. These could be considered as potential sites for accessing older persons whose native language is not French or English. Not only could these be sites for educational programs, but also sources of volunteers with facility in languages other than English or French. In the past, some ethnic groups valued professional health care more, but observations by those consulted, say this is changing.

(iv) The Workplace

Many older persons are still in the workforce. As attitudes to mandatory retirement at 65 years continue to change, the workplace will be a significant place to offer educational programs and transitioning mutual support/self-help groups.

(v) Content of Programs

In mutual support/self-help programs, the group members determine their needs, whether educational, informational or supportive. Health care providers or non-profit disease-specific organizations may facilitate access to relevant, accurate and current information regarding the chronic disease.

Some of those consulted suggested the focus be on a wellness program stressing lifestyle behaviour change such as nutrition, activities, exercise, positive attitudes to feeling healthy, rather than being disease-specific. This position has merit and is the focus of the program described earlier in Vancouver-Richmond, B.C.

(vi) Who benefits from Mutual Support/Self-Help?

It must be recognized that not all older Canadians will seek mutual support whether in their community, or in their homes or on the web. It has been stated earlier that a recent study (1999) indicated 10% of older persons participated in mutual support programs. This is an increase from earlier times. Also, as our population continues to age, those who have used group support successfully at a younger age seek it again.

However, opportunities should continue to be sought to collaborate with those health care providers identified as believing in the value of mutual support/self-help. Opportunities should be sought to present program information at professional conferences, to undergraduate students. Collaboration with the professional associations at local levels may be an especially rewarding source of referrals. This contact may also provide health care providers to give educational training sessions to lay volunteers.

RECOMMENDATIONS REGARDING THE PLACE OF MUTUAL SUPPORT/SELF-HELP IN THE HEALTH DELIVERY SYSTEM

1. Consensus must be achieved on the definitions used within the Mutual Support/Self-Help Strategy. We recommend the definitions put forth by the Canadian Health Network in 1999 in their publication "Resource Mapping for Self-Help.
2. Lack of information regarding existing resources is evident. It is recommended that the Canadian Health Network develop a Mutual Support/Self-Help Directory listing the resources across Canada and that they work with provincial self-help resource centres to keep this list updated.
3. It is recommended that a coalition of older Canadian organizations and mutual support/self-help organizations be convened under the sponsorship of Health Canada to develop an action plan for the development of programming to maintain/improve the quality of life for older Canadians. The purpose of the plan will be to inform and direct government policy in developing a framework and guidelines to minimize the affects of chronic physical disease in older Canadians. Best practices of existing programs would be shared, along with learning tools. Since most of the disease-specific organizations are national organizations, as are the Seniors' organizations, discussion will need to determine whether a national forum or regional forums may be more effective.

4. Health care providers are important to the referral process for Social Support strategies. It is recommended that Health Canada, with the assistance of Mutual Support/Self-Helpers, meet with the National bodies of the various health professional groups or with the Canadian body representing the Universities and Colleges, which prepare the health professionals. The purpose of this meeting would be to request curriculum input regarding the role of Mutual Support/Self-Help within our social support system.

It is strongly recommended that as part of undergraduate experiences, all health professionals be required to experience a practicum in an organization which sponsors a mutual support/self-help program.

5. Gottlieb (2000) calls for more research on the personal and network characteristics of those who benefit most and least from mutual support/self-help. He also suggests assessment of prolonged group exposure for those coping with diseases/conditions such as diabetes and cancer. It is recommended that such research be instituted and part of any study contemplated in the near future.
6. The final recommendation is strictly a financial one. Mutual support/self-help may be cost-effective, but it is not free. Agencies and organizations need to have some funding to provide the infrastructure i.e. the mutual support/self-help resources necessary to nurture these programs.

It is important that community partners come together to articulate to funding sources (all levels of government and other funders) that, while cost-effective, supporting and promoting the development of mutual support/self-help is not without some financial cost.

Submitted by Margaret McGovern
Self-Help Resource Centre of Greater Toronto

March 2001

APPENDIX A Consultations

Individuals (Experts)

Thomasina Borkman, Author of "Understanding Self-Help/Mutual Support by e-mail

Jayne Butler, President of the Board of Directors, Self-Help Resource Centre of Greater Toronto

Randi Fine, former Executive Director of The Self-Help Resource Centre of Greater Toronto

Patrick McGowan, Institute of Health Promotion Research, University of British Columbia

Bonnie Pape, Director of Programs and Research, Canadian Mental Health Association, National Office

Organizations and Mutual Support/Self-Help Groups

Arthritis Society of B.C. & Yukon,
Jennifer Scrubb, Coordinator, Health Education, Vancouver, B.C.

Bereaved Families of Ontario
Gloria Murrant, Executive Director, Toronto

Canadian Cancer Society
Cancer Connection, Asha Croggan, Program Manager, Hamilton, Ontario

Reach to Recovery Program, Sylvia Glenny, Dartmouth, Nova Scotia

Canadian Diabetes Association
John McGroat and April McCann, Kingston, Ontario
Chris Fitzgerald, Public Education and Service Coordinator; Ottawa, Ontario
Diane Alvarito, Public Education and Service Coordinator; Kim Carson, Volunteer Coordinator; Charlene Magee, Information Officer, Toronto, Ontario

Multiple Sclerosis Society of Canada
Lynn Laccohee, Manager of Services

Older Women's Network,
Bea Levis

Open Up Your Heart
Tom O'Hara, Toronto, Facilitator

Osteoporosis Society of Canada

Sue Berlove, Manager of Chapter Development

Vancouver-Richmond Health Region Project

Barbara Henn-Pander, Coordinator, Vancouver, B.C.

West Island Advocacy Centre

Mary Claire Tanguay, Executive Director, Point Claire, P.Q.

APPENDIX B

Advisory Group

Barbara Black, President, Canadian Pensioners Concerned

Margaret Morris, Volunteer Coordinator, Toronto Intergenerational Partnership

Roya Rabbani, Executive Director, Self-Help Resource Centre of Greater Toronto

Irv Rootman, Director, Centre for Health Promotion, University of Toronto

Wayne Sigen, Family Caregiver

Al Strong, Program Coordinator, The Wellness Network, Kitchener, Ontario

Sharon Zeiler, Senior Manager, Canadian Diabetes Association