

**THE ROLE OF SOCIAL SUPPORT IN SELF HELP
GROUP PARTICIPATION AMONG OLDER ADULTS
WITH A CHRONIC ILLNESS**

by

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ABSTRACT

This thesis examines the role of social support in self help group participation among older adults with a chronic illness. Bandura's (1977) Social Learning Theory is used to provide a theoretical rationale for a relationship between social support and self care behaviors. Essentially, self efficacy is viewed as a mediating factor between social support and self help group participation. Of particular interest is the examination of two potential mechanisms that are hypothesized to influence self efficacy: knowledge and perceived stress. In this study, it is hypothesized that greater levels of social support lead to a greater likelihood of participating in a self help group. Further, it is predicted that social support influences self efficacy, knowledge, and perceived stress which, in turn, impact self help group participation. Seven hypotheses were tested at the bivariate and multivariate levels of analyses (see p.43).

At the bivariate level, weak support was found for the relationship between social support and self efficacy, knowledge and self help group participation. Perceived stress, however, resulted in a positive relationship with social support and self help group participation, which was contrary to the expected direction. The multivariate analysis was conducted to determine the degree of predictability of social support, self efficacy, knowledge and perceived stress on self help group participation. Also, a set of independent control variables (sociodemographic, illness context) were included. Results reveal a positive relationship between social support and self help group participation, however, only one (received outside help) of seven social support variables predicted self help group participation when controlling for all other variables. Knowledge, and self efficacy were found to be significant predictors of self help group participation. Other

control variables were also found to be predictive. These included: age, education, and number of doctor's visits.

Overall, the results of this thesis indicate modest support for the Social Learning Theory applied to self help group involvement. Although support was found at the bivariate level for the intervening variables (self efficacy, knowledge and perceived stress), only partial support was found for self efficacy as a mediating factor between social support and self help group participation. It is suggested that perhaps other factors in combination with social support - such as personality or locus of control influence self care practices.

Furthermore, it is suggested that social support does not substitute for self care behaviors. Instead, social support seems to facilitate self care practices such as self help group participation. Implications are that a particular type of social support (outside the circle of family/friends) and knowledge are important for self help group participation. Recommendations are made in terms of future research.

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Chapter I

INTRODUCTION

The aging of the population, and its concurrent increases in longevity raises issues pertaining to the health and quality of life of elderly individuals. A greater proportion of elderly people is associated with greater numbers of elderly suffering from chronic illnesses and functional disabilities (Chappell et al., 1986). Approximately 75% of Canada's elderly suffer from some chronic conditions and 50% experience difficulties in daily functioning (Chappell, 1992). In fact, the number of chronic conditions seems to increase with age. During the last two decades there has been a decline in death rates due to stroke, heart disease, and other chronic conditions, however, and at the same time, there has been a concurrent increase in morbidity for heart disease, arthritis, diabetes, asthma and other chronic illnesses (Lorig, 1993).

The physical and emotional stress that accompanies these illnesses has led to extensive research on coping abilities, styles and consequences. Essentially, those with chronic conditions have various options in coping with the illness. Most turn to the formal healthcare system, relying on physicians and medications for their well-being. However, recent research has shown that many elderly people practice self care behaviors in addition to formal healthcare utilization (Defriese & Woomert, 1983; Wister, 1995).

One example of a self care behavior is participation in self help groups. Self help groups are defined as support groups in which members share a common problem, condition, symptom, heritage, or experience (Lieberman & Borman, 1979). Self help groups have been shown to have a positive influence on health and psychological well-

being (Katz & Bender, 1990). Through self help groups, individuals are able to share experiences, coping styles and information, thus they provide members with emotional and informational support (Romeder et al., 1990). These benefits may be particularly important for persons coping with chronic illness. Yet, there have been few studies on older adults and their involvement in self help groups, as well as few studies specific to chronic illness and self help group participation. Furthermore, little is known about why people get involved in self help groups (Lieberman & Borman, 1979) and the motivating factors that encourage elderly people to engage in self help groups especially as a form of illness management. In general, much of the research on self help groups has been either descriptive or specific to studies of certain groups, particularly, Alcoholics Anonymous and bereavement (Lieberman, 1987).

A consistent predictor of health and social service utilization has been social support. Typically, social support is defined as the resources provided by other persons (Cohen & Syme, 1985) such as assistance with instrumental activities of daily living, social companionship, information, and emotional support (Chappell, 1992). Cross sectional studies have found that elderly people with greater support networks have a greater tendency to use the formal healthcare system (Berkman, 1985) and tend to be more likely to engage in self care practices (Umberson, 1987; Potts et al., 1992). Yet, the mechanisms through which social support affects self care practices and healthcare utilization are unclear. One contention is that social support provides knowledge and information to access services and self care, enhances feelings of self efficacy, and lowers perceived stress (Bandura, 1977) over the illness condition. The acquisition of knowledge, self efficacy and lower stress tends to lead to a more positive outlook on

one's ability to cope with the illness (Lenker et al., 1984; Lorig et al., 1989b). One way of coping with an illness is to learn about the illness and to engage oneself with the services available to cope with the illness. One type of support may come in the form of self help groups, and this reasoning may also apply to participation in self help groups. However, the connection between social support and self efficacy requires further investigation, especially as it pertains to self help group involvement as a means to cope with chronic illness.

This thesis examines the role of social support in self help group participation among older adults with a chronic condition. The present study is based on the theoretical foundations of Bandura's (1977) Social Learning Theory which postulates that behavior is changed or initiated through the enhancement of self efficacy, knowledge and lower perceived stress. Thus, it is estimated that social support has an impact on self help group participation through self efficacy, the transfer of knowledge and lower stress. Furthermore, the topic involves an exploratory analysis of other potential predictors of self help group participation.

Background

A Broad Definition of Health

Health has been historically defined as the absence of disease, however, there has been a shift away from a medical model of health and illness to a more sociological model. More recently, health has been conceptualized as the interaction of biological, social, psychological and environmental factors. According to the World Health Organization (1946), health is defined “as a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” (World Health Organization, 1986).

In Canada, the Lalonde report acknowledged and discussed four elements that contribute to disease and death: (1) unhealthy lifestyles, (2) environmental hazards, (3) human biology or genetics, and (4) inadequacies in the healthcare system (Walker, 1994). The Ottawa Charter for Health Promotion suggests that certain prerequisites are essential for health. These prerequisites include: peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity. Epp (1986) in *Achieving Health for All ...* conceptualizes health as “a resource which gives people the ability to manage and even to change their surroundings... (as recognizing) freedom of choice... (and as) a basic and dynamic force in our daily lives, influenced by our circumstances, our beliefs, our culture, and our social, economic and physical environments.” Perceived in this way, health is dependent on a wide range of factors, not the least of which is the social environment of the individual. Social support, in its various forms, including self help group participation, is therefore an important facet of health.

Health Promotion, Self Care & Self Help

Health promotion is defined as “the process of enabling people to increase control over, and to improve, their health” (Ottawa Charter for Health Promotion, 1986). It is different from the earlier medical model of health in that it emphasizes individual and collective responsibility for health rather than health being solely determined by the formal healthcare system. Although this transition between the medical model and the health promotion perspective has occurred and improvements have been made in terms of supportive healthcare delivery systems (see Lorig, 1993 p.12), supportive health education programs (see Lorig, 1993 p.13) and the reduction in mortality rate for some chronic diseases (Lorig, 1993), the actual practices of health promotion are not entirely in place. For example, research shows that there is still an increase in morbidity due to chronic diseases (Lorig, 1993). Therefore, in recognition of the inequalities that still exist in health care, the health promotion movement focused upon a wider range of health determinants. According to Jake Epp’s (1986) “Achieving Health For All: A Framework for Health Promotion”, the health challenges Canada faces as a nation in achieving the goals set out by the health promotion perspective include: (1) reducing inequities in health status of low versus high income groups, (2) increasing efforts in prevention of illnesses, injuries and disabilities, and (3) enhancing people’s coping capacity to manage disabilities, chronic illness, and mental health problems (see Figure 1). The implementation strategies used to address these challenges include: fostering public participation, strengthening community health services, and coordinating healthy public policy (Epp, 1986). One way in which this framework may be applied is through the voluntary participation of elderly people in self help groups in order to help

A FRAMEWORK FOR HEALTH PROMOTION

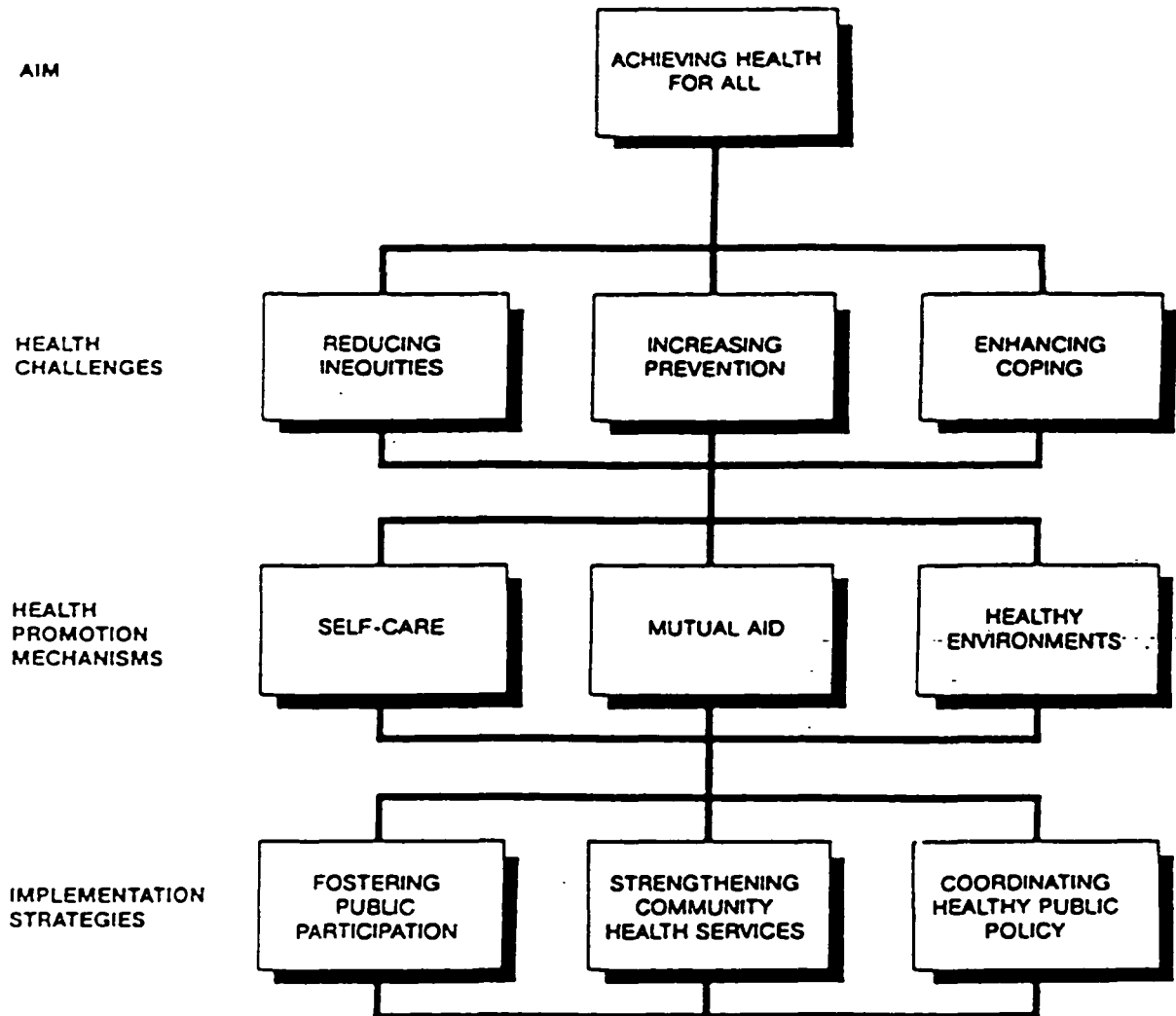


Figure 1. Achieving Health For All: A Framework for Health Promotion (Jake Epps, 1986)

cope with a specific chronic illness. Self care and mutual aid are viewed as mechanisms through which the implementation strategies will address health challenges (Epp, 1986). Self care refers to the “decisions taken and practices adopted by an individual specifically for the preservation of his or her own health” (Epp, 1986). Mutual aid refers to “people’s efforts to deal with their health concerns by working together. It implies “people helping each other, supporting each other emotionally, and sharing ideas, information and experiences” (Epp, 1986). Mutual aid may occur in the context of the family, the neighborhood, the voluntary organization, or the self help group (Epp, 1986). Thus, the two Canadian documents, *The Ottawa Charter* and *Achieving Health for All* indicate the importance of health promotion and cite mutual aid and self help groups as important mechanisms in the achievement of Canadian health goals. We require a more thorough understanding of how and why people try self help groups as a means of coping with health problems such as chronic illness. Furthermore, specialization of research is needed in order to focus on distinct groups of individuals, for example, older adults.

Population Aging and the Prevalence and Incidence of Chronic Illness

According to 1991 Statistics Canada, 11.6% of the Canadian population is age 65 and over. It is projected that by the year 2001 and 2011 that the proportion of elderly people will comprise 12.6% and 14.1% of the population, respectively. In fact, the fastest growing segment of the elderly population are the aged 85+. The combination of a greater proportion of elderly people and increased longevity indicates that more people will be living with functional disabilities as a result of chronic illness (Chappell et al., 1986).

Chronic illness plays a pervasive role in the lives of many older adults. In Canada, over 75% of the elderly population suffer from some chronic condition and about 50% experience interference in their ability to function on a day to day basis (Chappell, 1992). In the U.S., 80% of those aged sixty-five and over have at least one chronic condition (Luxenberg & Newcomer, 1997). Many older adults live with one or more chronic conditions for a good part of their older adult lives and it has been estimated that the percentage of chronic conditions increases with age. Among those aged eighty and over, 70% of females and 53% of males have two or more chronic conditions (Luxenberg & Newcomer, 1997). In one recent U.S. national study, 49% of non-institutionalized people aged sixty and above had two out of nine particular chronic conditions, 23% had three or more, and 8% had four or more (Guralnik et al., 1989).

According to the National Population Health Survey 1996/97 (NPHS), the chronic diseases with the highest incidence rates between 1994/95 and 1996/97 include: non arthritis back problems (males 8/100; females 9/100), arthritis (males 4/100; females 7.5/100) and high blood pressure (males 3.5/100; females 3.75) (Statistics Canada, 1998). In the U.S. the top three chronic conditions among persons aged 65 and over are: arthritis (48%), high blood pressure (35.7%), and heart disease (32%) (see Table 1) (Benson & Marano, 1994).

Although most older persons suffer from chronic conditions, an important question is to what degree the condition affects a person's daily functional ability. In Canada (1996-97), 71% of those aged 65 and over reported that they needed no help with

<i>A. By Age and Gender</i>					
<i>Condition</i>	<i>All Elderly</i>	<i>Male</i>		<i>Female</i>	
		<i>Age 65-74</i>	<i>Age 75+</i>	<i>Age 65-74</i>	<i>Age 75+</i>
Arthritis	481.9	364.8	417.2	508.7	611.2
High blood pressure	357.6	341.4	314.7	377.7	374.1
Heart disease	324.6	334.7	408.5	220.6	401.2
Hearing impairment	320.4	322.3	452.7	204.3	392.9
Deformity/ortho impairment	185.7	154.9	185.8	167.1	243.0
Cataracts	166.0	112.5	193.2	137.1	245.2
Chronic sinusitis	158.7	123.9	120.2	185.4	183.6
Diabetes	110.4	119.6	—	109.2	110.2
Tinnitus	89.4	95.5	113.7	—	—
Visual impairment	87.0	96.6	131.9	—	99.4
Hay fever/allergic rhinitis	—	—	—	103.0	—
Cerebrovascular disease	—	—	97.7	—	—
Varicose veins, lower extremities	—	—	—	84.4	101.0
Chronic bronchitis	—	—	—	—	—

Table 1. Top 10 Chronic Conditions, United States, 1992 (number of chronic conditions per 1000 persons) (Benson & Merano, 1994)

activities of daily living (ADLS) and instrumental activities (IADLS) of daily living (NPHS -Statistics Canada, 1998). However, in 1996/97, 55% reported that they needed no help with ADLS and IADLS (NPHS – Statistics Canada, 1998). Also, 16% of elderly people who were free of activity limitations in 1994/95 had become limited by 1996/97. In the U.S., the National Center for Health Statistics (1994) reported that 38.8% of persons over the age of 65 experienced limitations in their activities and 10.6% are unable to perform a major activity as a result of various chronic conditions (Luxenberg & Newcomer, 1997).

People with chronic illness such as arthritis, heart problems and hypertension often require support in order to reduce pain, to maintain health, and to function adequately in their day-to-day lives (Chappell, 1992). However, those with chronic illness may have difficulty obtaining adequate support since the illness may produce feelings of estrangement or alienation from family or friends (Kaplan & Tomishu, 1990). It has been suggested that the consequence of inadequate support is detrimental to the older adult's physical and mental health, and well-being. This thesis recognizes the importance of social support and attempts to investigate the mechanisms through which it is influential for self help group participation.

The Spread of Self Care

According to Perreault (1988), self care is defined as “the utilization of knowledge for health promotion and protection, diagnosis and treatment of disease, with or without professional contribution”. Similarly, Dean (1986) and Dean & Kickbush (1995) view self care as the range of activities undertaken by individuals to prevent

disease, enhance health, evaluate symptoms and restore health. Also, self care represents people's efforts to take control over their own health (Cassidy, 1977). Some examples of self care activities include exercising, dieting, reducing alcohol and smoking consumption, participating in self help groups, reading/researching the disease in question, monitoring blood pressure and the use of alternative health practices. Self care also involves the decision to do nothing (Dean, 1986) which may under some circumstances be the "best treatment for a self limiting decision ..." (Haug, Wykle & Namzi, 1989). Although the decision to do nothing is often conceptualized as ignoring symptoms or delays in seeking medical care, Dean (1986) contends that it is based on the belief that "time cures and symptoms will improve without medical consultation" (Krause, 1998).

The concept of self care is not new and one can review the impact of sociohistorical forces on the self care movement. First, the increasing proportion of elderly people has created a shift in the patterns of disease, from acute to chronic as well as an ideological shift from cure to care orientation (Padula, 1993). Factors such as the inadequacy of the healthcare system, the availability of the healthcare system, medical economics, increasing discontent with dehumanism and excessive technology, and the mistrust of the medical establishment have further encouraged the adoption of self care behaviors (Defriese et al., 1982; Hickey et al., 1986; Levin, 1976). Further, Hickey et al., (1986) contend that the increase in understanding of the role of lifestyle in disease prevention and the emerging better educated, healthier and financially stable cohort of elderly individuals impacted the self care movement. Other factors, include the struggle

for increased personal control over health, and the concern over the need to curtail the growing healthcare costs and the rising personal costs for the individual (Padula, 1993).

The concept of self care behaviors has had a regenerated interest among social scientists and health practitioners (Kart, 1992; Kart & Engler, 1994; Ory & Defriese, 1998). Self care and lay initiatives have been viewed as an important component of overall health care in different populations including older individuals (Hickey, Dean & Holstein, 1986). Interestingly, the literature indicates that professional care constitutes a minority of health care and that most healthcare is, in fact, self care. For example, Levin & Idler (1981) describe lay initiatives or non-professional care as a “hidden health care system” and states that as much as 75% of all health care is provided by lay individuals without professional involvement. Among the elderly, Kart & Engler (1994) found that although rates of chronic illness are highest among older adults, a medical practitioner is not always consulted regardless of the severity of symptoms and many people who do not seek professional attention have treated their disorder previously. Also, other studies have found that many people supplement formal healthcare utilization with self care behaviors (Defriese & Woomert, 1983; Wister, 1995).

Dean (1986) views “self health care as a major determinant of physical and psychological well being and of functional capacity.” Although the benefits of self care are well established in the literature, one of the major advances in recent research involves the specification and categorization of different types of self care behaviors (Ory, Defriese & Duncker, 1998). The three major categories of self care practices as they relate to health outcomes involve: (a) the adjustment to functional disabilities affecting activities of daily living through emotional and physical adaptations, (b) disease

prevention through health promotion or lifestyle modification, and (c) the self management of chronic health conditions or medical self care in the diagnosis and treatment of minor symptoms (Ory, Defriese & Duncker, 1998). Wister (1996) suggests that it may be useful to distinguish between general prevention (lowering a set of health risks) and specific prevention (self management/prevention of a specific disease such as arthritis). These conceptualizations are consistent with Barofsky's (1978) four primary functions of self care: regulating physiological processes; disease prevention; minimizing symptoms; and alleviating illness.

Among the elderly population, the self management of disease is critical given the increasing numbers of chronic illness and comorbidities. Self management refers to medical and procedural knowledge about the condition that work best in enhancing comfort and mobility (Haug, 1986). Segal & Goldstein (1989) view self management as "knowledge that is synthesized from multiple sources including past experience, the media, discussions with acquaintances with a similar condition, and previous consultations with lay and health professionals (Stoller, 1998). In fact, it is difficult to determine the type of self care that is instigated by older people themselves from the type that is taught and perhaps monitored by healthcare professionals (Kart & Engler, 1994).

Thus, the concern for independence and health in later life points to a potential wide interest in self care behaviors among older adults. It is therefore critical to acknowledge the need for more research on self care particularly illness self management, as well as specific self care strategies used by the elderly given the prevalence of chronic illness and disability. A major gap in the literature is the need for more research about the "epidemiology of readiness for acceptance of self care in the

older population... so that well designed and appropriate targeted campaigns can actually be implemented” (Ory & DeFries, 1998). As Konrad (1998) indicates, “self care behaviors take place in the context of attempts to maintain control over life and to do so with competence, autonomy and self reliance”. One self care activity that is of significant importance to the management and regaining of health and well being in older adults with chronic illness, is self help groups. We turn now to a discussion of this specific form of self care, which comprises the focus of this thesis.

Literature Review

Self Help and Mutual Aid

Definitions and Conceptualizations

Recently, the use of self help groups to cope with chronic conditions has been receiving increasing attention (Gottlieb, 1982; Kurtz, 1990; Katz, 1993). Traditionally, self help groups have been defined as groups composed of members who share a common condition, situation, heritage, symptom or experience (Lieberman & Borman, 1979). More specifically, Katz & Bender (1976) characterize self help groups as

“voluntary small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life disrupting problem, and bringing about desired social and or personal change. The initiators and members of such groups perceive that their needs are not and cannot be met by or through existing social institutions. Self help groups emphasize face to face social interactions and the assumption of personal responsibility by members. They often provide material assistance as well as emotional support: they are frequently cause oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity.”

Self help groups are based on the principles of working cooperatively and sharing. They are self reliant and self governing as well as self supporting rather than being dependent on external funding (Lieberman, 1990).

Although conceptually distinct, the terms self help group, mutual aid and social support group are often used interchangeably. Mutual aid is “a form of social support which consists of practical and psychological help, between people with a common

problem or issue who relate to one another as equals, focusing on emotional support, through the sharing of personal experiences, information and ways of coping” (Romeder, 1995). However, mutual aid can occur outside of self help groups through ordinary life (between friends, family, neighbors, coworkers etc.), voluntary action, education, and professional care/support (see Figure 2) (Romeder, 1995). For example, there are mutual aid activities associated with economic development, food production and distribution, educational programs and political lobbying (Gottlieb, in press). Social support groups, on the other hand, are considered a hybrid of self help groups and psychotherapy groups (Helgeson & Gottlieb, in press). They are different from self help groups in that they “have a closed membership, involve expert leaders, usually have a fixed duration, and do not engage in advocacy activities” (Helgeson & Gottlieb, in press). Further, support groups are different from psychotherapy groups in that members are not assigned according to a common diagnostic category or prognosis, and the group leader does not engage in clinical practices such as diagnostic assessments or psychological interpretation (Helgeson & Gottlieb, in press). Thus, for the purposes of this thesis, self help groups are broadly defined as “small autonomous and open groups whose primary activity is mutual aid (Romeder, 1990).

Historically, the beginning of the modern day self help group started with Alcoholics Anonymous in 1935 and led later to other groups such as Gamblers Anonymous (Kaye, 1997). Then, the growth of self help groups during the 1960s and 1970s occurred as a result of the Women’s Movement, which spawned social activism leading to the Gay Rights Movement and Mothers Against Drunk Driving (Kaye, 1997).

SELF HELP GROUPS, MUTUAL AID AND SOCIAL SUPPORT

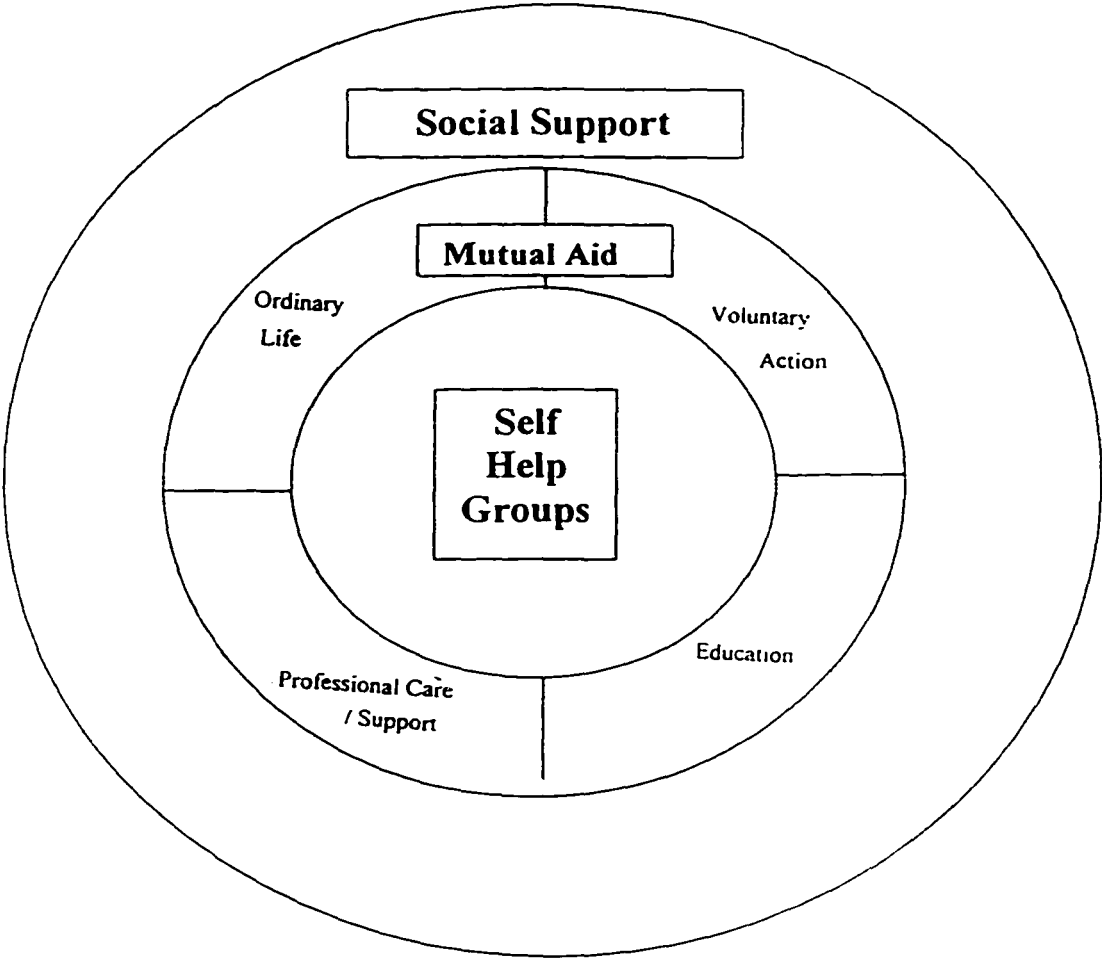


Figure 2. Self Help Groups, Mutual Aid and Social Support (Romecer, 1995).

At the end of the 1970s, Self Help Clearinghouses developed at the regional and local levels (Riessman & Carroll, 1995). The Self help Clearinghouses are organizations that compile information regarding the types and locations of various self help groups in the corresponding area. The Clearinghouses are a useful source of information to potential self help group members and also provide a rich database in which a self help group may develop and expand. Today, there are a multitude of self help programs for a variety of "physical and mental health concerns, social problems, addictions, family and marital issues, oppressed populations, lifestyle alternatives, and survivor groups, as well as for a broad range of personal growth activities" (Kaye, 1997). Some examples of self help groups related to chronic illness include the Arthritis Self Management Program (ASMP) and Mended Hearts. The ASMP is a 12 hour course, which is offered 2hrs/week for six weeks in a community setting such as a senior's center (Lorig, 1992). The courses are taught by non professional trained leaders, many who have also experienced arthritis. The aim of the program is to enhance self efficacy and coping with arthritis through participatory learning. Research on the ASMP has found that participants had "significant increases in behaviors such as exercise and practice of cognitive pain management techniques and a reduction in pain" (Lorig et al, 1985). An application of the ASMP to the First Nations Communities of British Columbia, was successful in improving personal control and pain management among the First Nations peoples (McGowan & Green, 1995). Greater control and responsibility in managing their health was seen as the underlying factor in the success of the program (McGowan & Green, 1995). The ASMP has been adopted by the Arthritis Foundations of the U.S. and Australia as well as the Arthritis Society of Canada. Another example of a self help

group specifically addressing chronic illness management pertains to coping with heart surgery. Mended Hearts is a national organization for heart surgery patients and their families. It involves local chapter meetings, visitation programs, training programs, and coordination with hospitals. Furthermore, Mended Hearts is considered a medical self help group because it involves medical professionals as well as lay persons (Lieberman & Borman, 1979).

Researchers have attempted to classify self help groups according to a variety of characteristics such as personal change vs. social change orientation; presence or absence of a specific ideology; and orientation to a particular problem (i.e. addictions) vs. general problems (Katz & Bender, 1990). The most comprehensive and current of the many classification schemes is found in Katz and Bender's 1990 book *Helping One Another: Self Help Groups in a Changing World* p.27 (see Figure 3). Katz and Bender (1990) distinguish five types of self help groups which include: (1) therapeutic, (2) social advocacy/action, (3) groups created to support alternative lifestyles, (4) groups to provide outcast/havens through 24 hour live in situation, and (5) mixed types (more than one primary focus). Further, Katz (1993) contends that the most important classifying distinction among current self help groups is whether the group is a 12 step group or a non 12 step group. An example of a 12 step self help group is Alcoholics Anonymous in which members are required to proceed through 12 specific steps to recovery. For this thesis, self help groups will be defined as support groups for people who share a common chronic condition.

In terms of the elderly, the self help groups available are as diverse as for other age groups, however, it has been observed that the participation in self help groups of all

Classification Scheme of Self-Help-Groups by Primary Focus

TYPE 1: THERAPEUTIC

- A. Mental Health Organizations: e.g. overcoming specific psychological-physical problems. Recovery Inc., National Alliance for the Mentally Ill, G.R.O.W., Neurotics Anonymous, Emotions Anonymous.
- B. Addiction Organizations: e.g., Alcoholics Anonymous, Alanton, Alateen, Narcotics Anonymous, Overeaters Anonymous.
- C. Physical Health Groups:
 - (i) Disease Specific: e.g., Make Today Count, Mended Hearts, The Lost Chord Club, Renal Dialysis
 - (ii) Parents of Children with Learning Disabilities, Candle Lighters, S.I.D.S., Friends and Family of Schizophrenics
 - (iii) Multi-Diagnostic: e.g., Centers for Independent Living
- D. Life-transition Groups: e.g., Widow-Widower Groups, Alone Again, Alone Together, Retiree Groups, Divorce Groups
- E. Stress Reduction: e.g., Santa Monica Senior Peer-Counseling Center

TYPE 2: SOCIAL ADVOCACY/ACTION

- A. Groups created to overcome a single problem: e.g., Mothers Against Drunk Driving, Welfare rights organizations, Coalition for the Rights of the Disabled
- B. Groups created on a basis of age: e.g., Gray Panthers
- C. Groups created to further ethnic/minorities: e.g., Alianza Hispano-Americana, Black Single Mothers Association

TYPE 3: GROUPS CREATED TO SUPPORT ALTERNATIVE LIFESTYLES

- A. Gay Liberation Groups
- B. Urban and Rural Residential Communes

TYPE 4: GROUPS TO PROVIDE OUTCAST/HAVENS THROUGH A 24-HOUR LIVE-IN SITUATION

Daytop Villiage, Delancy Street, Battered Women's Shelters

TYPE 5: MIXED TYPES (MORE THAN ONE PRIMARY FOCUS)

- A. Ex-prisoner association: e.g., the Fortune Society, the 7th Step Foundation
- B. Social-Therapeutic (family oriented): Parents Without Partners, Families Anonymous
- C. Economic:
 - (i) Food Banks
 - (ii) Self-help housing organizations
 - (iii) Consumer/producer cooperatives, e.g., The Amish, the Doukhobours, Hutterites
 - (iv) Other Economic: The +40 Club, Debtors Anonymous, Checks Anonymous

Figure 3. Classification Scheme of Self-help-groups by Primary Focus (Katz & Bender, 1990)

kinds. declines among the elderly (see below). Yet it is likely that there will be a growing number of elderly seeking self help groups for the self management of chronic illness such as arthritis and heart disease, since the prevalence of chronic conditions appears to be increasing as people live longer and do so outside of long term care facilities for as long as possible.

Prevalence of Self Help Group Participation

Few studies have investigated self help group participation among the elderly. It has been estimated that a relatively small proportion of people in general actually engage in self help groups (Lieberman, 1989). For example, Gottlieb and Peters (1991) in a national study of volunteerism, found that about 2% of the Canadian population participated in a self help/mutual aid group in the past year, and of these, persons aged 65+ constituted only 7%. Other research has found that about 6% of those aged 45 and over participated in a self help group to cope with a problem or condition (Government of Canada, 1993). Another Canadian study – the 1991 Survey on Aging and Independence, found that approximately 4% of people aged 45+ and 3% of people aged 65+ participated in self help groups during the previous year (Wister, 1995). A more recent study of self care behaviors among older adults with a chronic illness, found that 10% of the sample used self help groups in the preceding year (North Shore Self Care Study Newsletter, Aug.1996). In the same study, another 7.8% of older adults not participating in a self help group indicated that they have considered doing so.

In the U.S., Lieberman (1990) reports that the elderly are underrepresented in mutual aid/self help groups as well as in psychological services in general. In a national

study of 3,161 U.S. households, Mellinger and Balter (1983) found that approximately 2.9% of the adult population used self help groups. The same researchers also found that only 0.9% of those aged 65 and over engaged in a self help group during the past twelve months. In fact, Lieberman (1990) reports a drop off rate of 72% for elderly people and their participation in self help groups. Lieberman & Snowden (1994) found that 3.6% of adult males and 2.2% of adult females engaged in self help groups. Also, they found that of this group, the elderly consisted of 1.8%. Although self help group participation reduces with age, there is still an increased need for illness type self help groups. This is due to the increasing prevalence of chronic diseases as well as the increase in life expectancy among older adults.

Purpose of Self Help Groups

Although there are differences in the way that self help groups are structured and the way in which they function, there are some common elements (Kurtz, 1990a; Levine & Perkins, 1987; Riessman & Carroll, 1995). First, self help groups provide social support or a “sense of community and affiliation through provision of a network of social relationships” (Kaye, 1997). Lieberman (1990) notes that the most important element of self help groups is their ability to create a sense of belonging among the participants and a shared sense of suffering which leads to high levels of cohesiveness. The sense of isolation from the shared problem is broken and individuals view the self help group similar to a small community or family (Lieberman, 1990).

Second, self help groups embrace an ideology or paradigm that serves to change victims into helpers (Kaye, 1997; Levine, 1988). The ideology, which “develops its own

language and conceptual tags for common experiences” (Kaye, 1997), reduces feelings of uncertainty by providing support and knowledge, thereby encouraging group members to make choices (Suler, 1984). Thus, the ideology affects not only feelings, but choices as well as actions (Levine, 1988).

Third, self help groups teach effective coping strategies for the purposes of personal transformation (Kaye, 1997). Valuable education and information are disseminated through self help sessions. Levine (1988) notes that the usual type of knowledge shared in self help groups is orally transmitted and would be lost without this type of exchange. For example, useful information for coping with daily experiences of living with a chronic condition such as arthritis typically does not appear in patient handbooks, medical texts or from a general physician.

Fourth, self help groups provide role models for identity formation (Levine, 1988; Lieberman, 1990). A sense of hope and a positive identity is created through the sharing of successful coping and following deliberate or inadvertent imitation. Also, self help group members derive positive benefits from helping others. Mutual aid is the main component of self help groups which generates feelings of control, competence and a sense of value (Kaye, 1997).

Fifth, self help groups provide an opportunity for confession, catharsis, and mutual support (Kaye, 1997). Group members are able to openly discuss their concerns and to receive feedback, confrontation, insight, interpretation, opportunities for goal setting, and identification with veterans who have made a successful transformation (Powell, 1987). Last, self help groups provide the opportunity for advocacy and

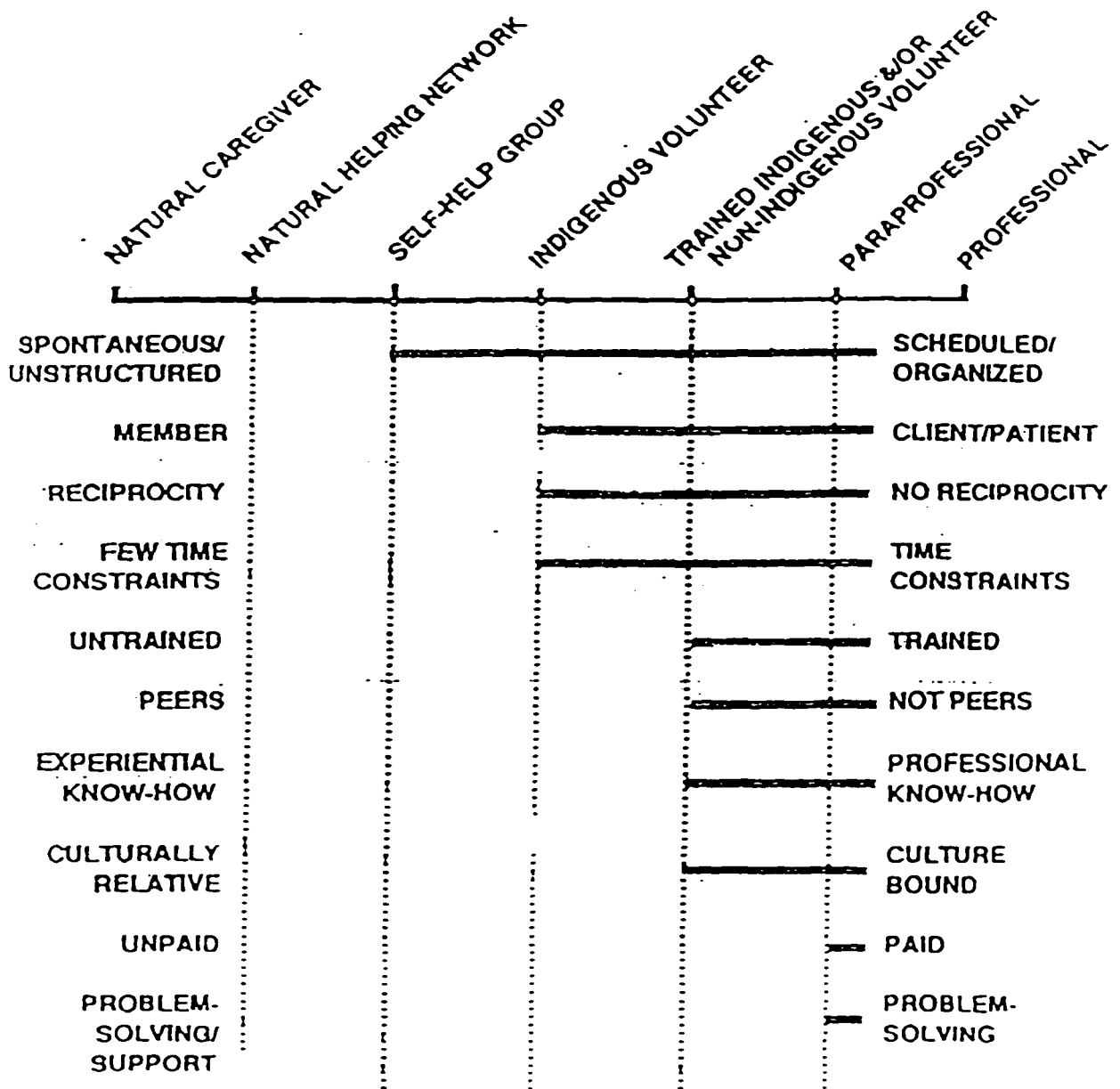
empowerment (Kaye, 1997). Members are given the psychological strength to take control over their condition and to make positive changes in their lives.

Furthermore, Farquharson (1990) clearly illustrates the different elements within self help groups and professional helping by conceptualizing all helping behaviors on a continuum (see Figure 4). According to Farquharson (1990), self help groups are similar to professional help in that they are scheduled/organized, however, they involve members as opposed to patients, reciprocity, few time constraints, untrained members, peers, experiential know-how, they are culturally relevant, unpaid and involve problem solving/support. In addition to the supportive nature of self help groups, the above factors are also relevant to the positive impact of self help groups.

Benefits of Self Help Groups

Recently, there has been an increasing amount of literature on the positive effects of self help groups on health status and quality of life. Some purported benefits of self help groups include: empowerment, an increase in social supports, an increase in self esteem, an increase in motivation through group intervention, a relief of anxiety and stress associated with the condition, reliable/hands on information, and feelings of unity and strength (The Self Help Connection, 1995). Studies of self help groups such as Recovery Inc., NDMDA and local peer mutual aid networks reported improved psychiatric symptomology, less nervousness, tension and depression (Galanter, 1988), a decline in the use of professional services, an increase in coping ability, and an increase in life satisfaction (Edmunson et al., 1984; Galanter, 1988; L.F. Kurtz, 1988). A study of

ELEMENTS OF LAY & PROFESSIONAL HELPING



Dr. Andy Farquharson

Figure 4. Elements of Lay & Professional Helping (Farquharson, 1990).

THEOS (a self help group for widows and widowers) found that group members had lowered anxiety, a decline in psychosomatic disorders, increased self esteem, increased wellbeing and an increased sense of control over life (Lieberman & Videcka-Sherman, 1986).

In terms of coping with illness, members of health-related self help groups report better adjustment, better coping, higher self esteem and improved acceptance of the illness compared to less active and non members (Hinrichsen et al., 1985; Sunde, 1985; Trainor, 1982; Videcka, 1979). For example, patients in a self help group for chronic airway obstructions (emphysema, chronic bronchitis, or asthma) were less likely to be hospitalized (20% vs. 64%), and were hospitalized for a shorter time (0.8 vs. 5 days) than patients who were not members of the self help group (Jensen, 1983). Cancer patients involved in a self help group called TOUCH, reported that they gained significant knowledge about their cancer, were better able to talk with people, had improved friendships and family life, and were better able to cope with cancer (Maisiak et al., 1981). Rheumatoid arthritis patients who participated in a self help group showed greater improvements in joint tenderness compared to a group of non participants (Shearn & Fireman, 1985). More recently, Nicholaichuk and Wollert (1989) suggest that a reduction in psychological distress and an increase in health service information are associated with involvement in self help groups particularly for persons with chronic physical diseases or psychiatric disorders. Also, self help groups have been found to reinforce health behaviors for patients experiencing heart surgery (Clark et al., 1991), as well as improve self efficacy, decrease pain and improve functional ability for people coping with arthritis (Lorig, 1989).

We now turn to the role of social support in health and preventive health behaviors, focusing on self help group participation.

Social Support and Self Help Group Participation

Definition of Social Support

Social support is defined as the resources provided by other persons (Cohen & Syme, 1985) which can include informal as well as formal resources (Chappell, 1992). Informal supports include support that is provided by family, extended family, friends, relatives, work acquaintances, and neighbors who coexist within a complex social network or structure. In contrast, formal supports include support that is paid and/or provided by the formal healthcare system. The needs of most elderly persons are met by an integrated support system involving both informal and formal supports (Chappell, 1992). However, for the purposes of this thesis, social support will be defined as unpaid support provided by informal sources and social systems. The elderly population in particular, are more vulnerable to alterations in social networks and support availability. This is due in large part to the many life changes and losses that are associated with aging, for example: loss of spouse, retirement, forced relocation, chronic illness and disability (Cohen & Syme, 1985).

Generally, in gerontology, social support refers to esteem/emotional support, appraisal, social companionship, informational support, instrumental support (House & Kahn, 1985; Chappell, 1992), and motivational support (Wills, 1985). Esteem support encompasses emotional support, ventilation, and a confidant relationship. The main mechanism through which this type of support has a beneficial impact on people is

unconditional positive regard (Wills, 1982, 1983). The supportive interactions involve listening attentively, reflecting on respondents statements, offering sympathy and reassurance, sharing personal experiences, and avoiding criticisms or exhortatory advice giving (Elliot et al., 1982). The concept of appraisal is related to esteem support in that it involves affirmation, feedback, and social comparison (House, 1981). Further, social companionship involves support from those with whom a person spends time and shares activities (Rook, 1990). It is different from confidants in that confidants are those with whom a person feels free to discuss personal matters and to share emotional feelings and events (Chappell, 1992).

Informational support involves the provision of information, advice, and guidance (Wills, 1985). According to the literature on help seeking, social networks are an important source of information and referral for both medical and psychological treatment (Wills, 1983). Instrumental support includes help with instrumental activities of daily living (IADLS) and activities of daily living (ADLS). Some examples of IADLS include: help with housework, preparing meals, household maintenance, transportation, shopping, and banking (Chappell, 1992). These activities are important for independence and in coping with problems such as chronic illness and disability. ADLS, on the other hand, are essential for survival and include physical and personal care activities such as “the ability to walk or to be personally mobile, to eat on one’s own, to wash and bathe, or to use the toilet” (Chappell, 1992). Finally, motivational support involves the important role of social networks in encouraging people to “persist in their efforts at problem solution, reassuring them that their efforts will ultimately be successful and that better things will come, helping them to endure frustration...” (Wills, 1985).

In research, the concept of social support is multidimensional. It has been conceptualized in terms of the (1) existence/quantity of social relationships – social integration/isolation, (2) structure – marital status, and (3) functional content (House & Kahn, 1985). However, social support is most commonly measured by functional content. Measures of functional content includes quantity or availability of support or adequacy of support, source of support, type of support, perceived availability of support, and occurrence of actual supportive behaviors (House & Kahn, 1985).

The term social network is “most often used to refer to the structures existing among a set of relationships” such as density, homogeneity, range, content, directedness or reciprocity, durability, intensity or emotional closeness, frequency, and dispersion (House & Kahn, 1985). The term social integration or isolation most often refers to the existence or quantity of relationships (House & Kahn, 1985). Measures of social integration/isolation can include marital status, amount of contact with friends, living arrangements, and belonging to a church or other organization.

Historically, all measures of social support have relied on the self report of a focal person about how he or she perceives his/her behavior or about how others behave (House & Kahn, 1985). House and Kahn (1985) suggest that all three aspects of social support should be considered because they are logically and empirically interrelated. For the purposes of this thesis, existence/quantity, structure and functional content variables will be examined as representative of informal social support. Despite its complexity, there is evidence regarding the importance of social support in maintaining positive functioning in older adults (Lowenthal & Robinson, 1976).

Direct and Buffering Effects of Social Support for Health Status

Much of the recent research on social support has centered upon its effects on health and the quality of life of individuals. However, the impact of social support on health is a controversial issue, and can be viewed in two different ways: in terms of its direct effects and buffering effects. In the direct effects view, social support is seen to have a positive effect on health regardless of whether stress is experienced or the level of stress experienced. Essentially, the direct effect suggests that social support is beneficial on a day to day basis and that higher levels of support lead to a generally better overall health status or perceived health status. Buffering effects, on the other hand, are positive effects that occur as a result of social support only during crisis events, or stressful events. In this way, social support is seen as protective or preventive against stressful conditions by intervening between the stressful event and the stress response or between the stressful event and the pathological outcome (Chappell, 1992). One purpose of this thesis is to investigate whether or not there is a buffering effect of social support on the ability to cope with a chronic illness. A buffering effect would indicate a lowered participation in self help groups due to social support.

Much of the previous research on social support has focused on quality of life factors, and reveals the complexity in the concept of quality of life (Birren et al., 1991). For example, researchers have investigated the effects of social support on physical, mental and social wellbeing, mortality, specific morbidity, life satisfaction, morale, mental impairment, and other indicators of illness such as: disability, days in bed, and days in a hospital (Chappell, 1992). Others have investigated the role of social support on healthcare utilization (Andersen & Newman, 1973) and social service utilization

(Wister, 1995). The multidimensionality of social support and the complexity of quality of life measures have led to a diversity of findings.

Most of the previous studies were conducted on social support, morbidity and mortality. For example, the Alameda County Study in California (Berkman & Breslow, 1983; Berkman & Syme, 1979) found a consistent pattern of increased mortality rates associated with decreases in social support (Berkman, 1985). Similarly, a mortality risk study on elderly individuals aged sixty-five and over, conducted in Durham County in North Carolina (Blazer, 1982), found that impairments in roles and attachments available, frequency of interaction, and perception of social support were predictive of increased mortality rates.

Mortality studies, however, do not tell us much about how social support impacts disease. Studies on morbidity can reveal how social support influences disease incidence, recovery, coping ability, and disease management. For example, the Japanese American Studies (Joseph, 1980; Joseph & Syme, 1981) of adult men living in the San Francisco Bay area, found that the prevalence of coronary heart disease (CHD) was predicted by social affiliation, age, physical inactivity, and family history of heart attack. In the Israeli Ischemic Heart Disease Study (Medalie & Goldbourt, 1976), researchers found that psychosocial problems (mainly family problems) and a lack of wife's love and support were important predictors of the development of angina pectoris over a five year follow-up. The Framingham Heart Disease Study (Haynes & Feinleib, 1980) found that women who had a non-supportive supervisor were at increased risk of developing CHD over an 8 year follow-up period" (Berkman, 1985). Thus, the effects of social support on morbidity and mortality are evident, however, it is unclear as to the mechanisms through

which social support impacts health status and death rates. Some research suggest that large social networks may encourage individuals to increase their utilization of health services thereby independently decreasing their risk for disease (Berkman, 1985).

Relatively consistent benefits of social support have been found for both the direct model (particularly in terms of the degree of integration within a social network and network size) and buffering model (mainly in terms of availability of resources) (Cohen & Syme, 1985). It has been suggested that both are not necessarily mutually exclusive. Researchers have found that some supports are buffering, while others are able to have direct health consequences (Berkman, 1985). Different sources of support, and types of support may be more beneficial for certain problems, particularly for the elderly, since they often have multiple stressors, role changes and more than one chronic condition.

This thesis will help fill these gaps by examining the buffering effect of social support on self help group participation as a form of self care among older adults with a chronic illness. Informal social support may be seen as a substitute for self help group involvement. It may also be that greater informal social support will lead to an increase in self help group participation through the enhancement of self efficacy, the reduction of stress, and the acquisition of knowledge. The concept of self efficacy as a mediating factor between social support and self help group participation, will be discussed in Chapter 2. The following section will review the important role of social support on self care behaviors.

Social Support and Self Care Behaviors

A small body of research has been concerned with the impact of social support on preventive health practices. In terms of social service utilization, it was found that social support was a predictor of the use of home support services (Wister, 1995). Further, Hickey et al., (1988) and Rakowski et al., (1987) found that a supportive family environment is associated with a variety of preventive health practices among the elderly. Similarly, Umberson (1987) found that social ties tend to facilitate the engagement in preventive health practices among the elderly. Potts et al., (1992) suggested that social support should be a strong predictor of preventive health behaviors since larger social networks are more likely than smaller ones to pressure individuals to engage in health promoting behaviors or to avoid deviant, health destructive behaviors. Also, a person may be more likely to engage in health promoting behaviors if he or she has a companion. Although there are few studies on the topic, preventive health behaviors may come in the form of formal healthcare utilization or self care practices such as participation in self help groups.

Social Support Explains Self Help Group Involvement

As noted earlier, research suggests a decline in self help group participation with age. A study by Wister (1995) found that the probability of self help group participation decreased by about half for those in the 65+ age group compared to persons aged 45-64. Some suggest that this may be explained by decreases in social support. For example, previous research has found that older adults who participated in self help groups were on average more likely to use other helping resources and tended to be slightly more socially

active than those who did not participate (Lieberman & Borman, 1979). Also, a study by Lieberman & Videcka-Sherman (1986) on widows and widowers found that self help group participants tended to be users of multiple services, perceived these services as productive, and generally had better social support networks in addition to the support of the group. when compared to non-participants of self help groups. For other social demographics such as marital status, gender, and income, it was found that those who are divorced or separated (4.7% males; 5.7% females), female (58%), and had attended or completed post secondary school (47%) were more likely to engage in self help groups (Gottlieb & Peters, (1991). Also, in terms of other health behaviors, factors such as mutual aid, self care practices, spiritual coping, and the use of professional assistance were found to predict self help group participation (Wister, 1995).

Although a relationship between social support and self care practices has been established, there is a lack of studies on the mechanisms through which social support influences self help group participation. This thesis will attempt to fill this gap. In order to understand factors that might influence the relationship between social support and self help group participation, it is now necessary to examine the underlying theory.

Chapter II

THEORETICAL APPROACH AND RESEARCH FINDINGS PERTAINING TO PREDICTORS OF SELF HELP GROUP PARTICIPATION

The role of social support and its effect on self help group participation remains relatively unexplored. Given the increase in the aging population and the accompanying increase in chronic illness, it is imperative that we expand our understanding of potential preventive or coping strategies, including self help group participation. The literature clearly shows that people with greater informal support display better health, greater coping ability, lowered morbidity, and a greater likelihood of help seeking behavior. This thesis extends the latter to self help groups. It has been postulated that the relationship between social support and positive health behaviors is mediated by “self efficacy”. Social Learning Theory will be used to explain how social processes affect self efficacy, which in turn, influences self help group participation.

Social Learning Theory

Definition and Conceptualization

Social Learning Theory is a cognitively oriented theory which suggests that “people are neither driven by inner forces nor buffeted by environmental stimuli...rather, psychological functioning is explained in terms of a continuous reciprocal interaction of personal and environmental determinants” (Bandura, 1977). Essentially, learning from response consequences is seen as involving cognitive processes (Bandura, 1977b).

Factors such as observational learning, modeling, the use of symbols, and self regulation play major roles in determining behavior. The Social Learning Theory states that virtually all behavior is learned through direct experience or vicariously through the observation of other people's behaviors and its consequences for them (Bandura, 1977). This ability to learn through observation allows people to acquire large, integrated patterns of behavior and points to the importance of social relations in learning behavior. It is suggested that behavior is initiated, modified, and maintained through the cognitive processing of personal and social experiences. One way in which the learning is transmitted is through the use of models. Modeling involves the observation of others engaging in a targeted or ideal behavior such as coping successfully with a specific chronic condition. The use of models in learning behaviors is said to be "indispensable" when combined with observational learning (Bandura, 1977).

The capacity to use verbal and imagined symbols allows people to process and preserve experiences that serve as guides or references for future behaviors. Through the use of symbols, people are able to solve problems without having to enact all possible behaviors and can foresee any possible positive or negative consequences of the behavior (Bandura, 1977). For example, through social relations, which often involves the provision of advice and the imparting of knowledge, people are able to make choices about their behavior based on other people's knowledge and experience. This can be very useful in enhancing a person's ability to cope with a chronic condition.

Other important factors in Social Learning Theory involve self regulation and motivation. Self regulation refers to the ability of people to exercise some control over their behavior through "arranging environmental inducements, generating cognitive

supports and producing consequences for their own actions” (Bandura, 1977). Motivation is partly rooted in cognitive activities and is concerned mainly with activation and persistence of behavior (Bandura, 1977b).

The conceptualization of human behavior based upon the interaction between cognition and social environmental processes has led to research regarding the explanatory mechanism that predicts and explains human behavior. Bandura (1977) states that the mechanism which influences behavior change is self efficacy. Self efficacy is seen as a mediator between social experiences and behavior.

The Mediating Role of Self Efficacy

Self efficacy is defined as “an individual’s assessment of his or her ability to perform behaviors in specific situations” (Bandura, 1977). Bandura (1977b) originally delineated two types of self efficacy: efficacy expectations and outcome expectations¹ (Hofstetter et al., 1990). However, both efficacy expectations and outcome expectations will not be examined in the present study due to a lack of existing variables. Furthermore, it is suggested that self efficacy is highly situational in that high levels of self efficacy in one area cannot be generalized to high levels of self efficacy in other domains (Bowsheer & Keep, 1995). Also, self efficacy is said to be enhanced through several sources of information. These include: performance accomplishments, vicarious experiences, verbal persuasion and emotional arousal (Bandura, 1977 p.80).

Performance accomplishments refer to one’s own personal experience with a consequent sense of ability (Elder et al., 1998). Vicarious experience involves social

¹ Efficacy expectations are defined as one’s confidence to perform specific behaviors in specific situations and outcome expectations are the belief that a specified behavior will produce a specified outcome.

comparison or learning through observation. The concept of verbal persuasion suggests that people are led, through suggestion to believe that they can cope with a stressful situation (Bandura, 1977b). Verbal persuasion can come from informal social support through the imparting of knowledge, and also from reading on the subject or the effects of the mass media. In fact, it is suggested that people who are socially persuaded benefit more from the addition of provisional aids for effective action and are thus more likely to mobilize greater efforts than those who only received provisional aids. This points to the importance of informal social supports in coping with stressful situations.

Another way in which self efficacy is affected is through emotional arousal. It is suggested that a highly aroused state may inhibit self efficacy (Baron & Byrne, 1994). This is consistent with the stress-buffering effect of social support (Cohen & Syme, 1985). Social support is said to buffer stress during times of crises, thereby reducing arousal and enhancing the ability to cope. According to Bandura (1977b), stressful situations generally elicit physiological responses associated with high arousal which impact perceived competency thereby debilitating performance.

For this thesis, self efficacy will be conceptualized in terms of its general definition. Self efficacy beliefs are considered to be an important mediator of lifestyle and behavior in many areas of life (McAvay et al., 1996). We now turn to a look at the impact of self efficacy on self care behaviors.

Self Efficacy and Self Care Behaviors

Researchers have examined the effects of self efficacy on a wide variety of self care behaviors and outcomes (Davis-Berman, 1988,1989; Grembowski et al., 1993;

Holahan & Holahan, 1987; Holahan et al., 1984; Holden, 1991; Lachman & Leff, 1989; O'Leary, 1985, 1992; Rodin & McAvay, 1992; Seeman et al, 1993; Tinetti et al., 1994). Areas in which self efficacy has been extensively studied include: alcoholism (Sitharthan & Kavanagh, 1990), pain management (Litt, 1988; Manning & Wright, 1983), recovery of cardiovascular function in postcoronary patients (Taylor et al., 1985), arthritis self management (O'Leary et al, 1988; Lorig, 1993), smoking (Carmody, 1992; Karanci, 1992; Devins & Edwards, 1988), physical exercise (Dzewaltowski et al, 1990; McAuley, 1992, 1993, and nutrition/weight control (Bernier & Avar, 1986; Shannon et al, 1990). The literature generally indicates that stronger self efficacy is associated with more positive health outcomes, the initiation of preventive care (Gecas, 1989), the maintenance of health-promoting behaviors (McAvay et al., 1996) and the tendency to be more optimistic about the effectiveness of treatment (Gecas, 1989). Also, chronically ill individuals with a strong sense of self efficacy are more likely to engage in more active coping practices regarding their illness condition (Hickey & Stilwell, 1992).

This thesis examines the role of self efficacy in predicting self help group participation. It is hypothesized that social support will have an impact on self efficacy which will then influence self help group participation.

Social Support and Self Efficacy

The relationship between social support and self efficacy is particularly important among the elderly population given the significant role changes (Roden, 1986) and decreases in informal supports that are experienced during later life. A reduction in the number and quality of informal supports is associated with chronic illness, and aging is

accompanied by experiences that may challenge an individual's perceptions of self efficacy in many areas of living including health (McAvay et al., 1996). However, there is a paucity of research on the effects of social support on self efficacy in the older adult population.

As noted earlier, there has been a multitude of research regarding the relationship between social support and psychological/physical health, chronic illness and disability, response to stress, and coping abilities. Generally, it has been found that people with greater support networks tend to have better self reported health, are able to cope more effectively with chronic conditions and have a greater capacity to deal with stress. Also, research has indicated that greater levels of support are associated with the adoption and maintenance of health behaviors. It is estimated that social support affects the above areas in a positive manner due to its influence on self efficacy. For example, a recent study by Seeman, McAvay & Rodin (1995) found that a decrease in self efficacy was related to a lower satisfaction with relationships and fewer ties with children for men, and less visual contact for women. Also, increases in self efficacy were associated with "being married, more frequent emotional support and feelings of instrumentality for men and with greater satisfaction with relationships for women". Another study by McAvay et al., (1996) found that improvements in self efficacy were associated with the availability of financial and emotional support resources. Thus, these studies suggest that social network contact and support are associated with self efficacy, which therefore highlights the importance of understanding the social support factors that may affect self efficacy beliefs among older adults.

As indicated earlier, Bandura (1977) suggested two mechanisms through which social support is expected to have a large impact on self efficacy. These include verbal persuasion and emotional arousal (see Figure 5). This thesis investigates the role of social support on predicting self help group participation by including the examination of factors such as self efficacy (illness efficacy, perceived coping), knowledge (reading on the subject), and perceived stress. It is hypothesized that social support will be associated with self help group participation, through its enhancement of self efficacy, its positive relationship with knowledge and its negative association with perceived stress (see Appendix A). Furthermore, it is hypothesized that greater self efficacy, the acquisition of knowledge and lower perceived stress will be associated with self help group participation.

An Application of Social Learning Theory to
Social Support and Self Help Group Participation

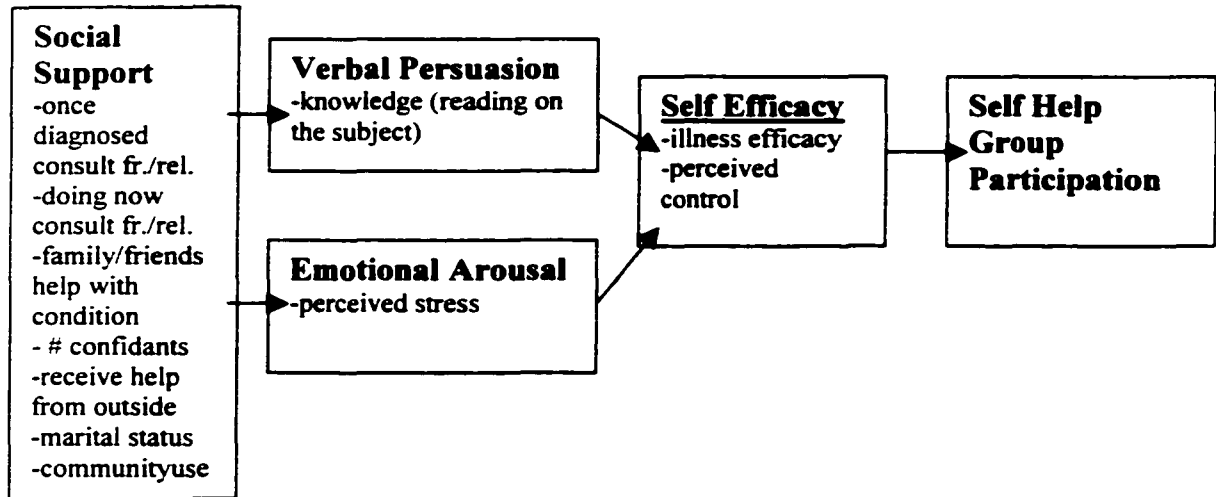


Figure 5. An Application of Social Learning Theory to Social Support and Self Help Group Participation.

Summary and Working Hypothesis

Although a review of the pertinent literature clearly demonstrates the benefits of social support on health and preventive health behaviors, there is a paucity of research focusing specifically on social support and self help group participation of older adults with a chronic illness. There is also a need to examine the mechanisms through which social support influences self help group participation. This study will investigate the role of social support and how it affects self help group participation through it's impact on self efficacy, knowledge and perceived stress.

- 1 Social support will be positively associated with self help group participation.
- 2 Social Support will be positively related to the acquisition of knowledge.
- 3 Social Support will show a negative relationship to perceived stress.
- 4 Social Support will exhibit a positive association with self efficacy.
- 5 Acquisition of knowledge will show a positive relationship to self help group participation
- 6 Perceived stress will be negatively associated with self help group participation
- 7 Self efficacy will be associated with self help group participation.

Chapter III

Methodology

This chapter describes the strategy used to investigate the relationship between social support and self help group participation among the elderly and, in particular, test the research question and hypotheses developed in Chapter 2. This will involve a description of the data source and the variables to be used in the subsequent univariate, bivariate, and multivariate analysis.

Data Source

The data for this research derive from Wave I (1995-96) of a longitudinal study entitled, "The North Shore Self Care Study" (Wister, Gutman & Mitchell, 1995). The project was funded by the Seniors Independence Research Program, Health Canada. Wave I consisted of phone interviews with 904 persons aged 50 years or older, living in private households in North and West Vancouver, British Columbia. The data are unique in that they represent the only information available on self care practices among older adults who were coping with a chronic illness. Waves II and III were conducted during 1996/97 and 1997/98 respectively, however, they will not be utilized in this thesis because the numbers of self help group participants are too low.

Measures of a variety of self care behaviors as well as self help and mutual aid practices were explored in the North Shore Self Care Study. Also, measures of health status, such as perceived health and perceived stress, and healthcare utilization, including prescription medications and doctors visits were investigated in the study. Other measures included social support, self efficacy, and background information (see

Appendix C). These measures provide the opportunity to address the research questions formulated in the previous chapters.

Collection of Data and Sample Description

Experienced interviewers conducted a telephone survey of 904 older adults using random digit dialing. The major criterion for participating in the study was that participants must have been professionally diagnosed with one of four major chronic illnesses: arthritis or rheumatism, heart problems, high blood pressure or stroke. The individual was asked to identify the condition affecting them the most, since many older people have more than one chronic condition. For this thesis, however, an investigation of only three of the four chronic illnesses will be conducted. These include arthritis/rheumatism (n=417, 47%), heart problems (n=229, 26%), and high blood pressure (n=233, 27%), since the sample size for those reporting stroke as their major chronic condition was too small to permit any significant findings in a statistical analysis. Thus, a final sample of 879 older individuals is used in the current study.

The age of the respondents ranged from 50-95, with 285 (32%) aged 50-64, 305 (35%) aged 65-74 and 289 (33%) aged 75+. There were 366 (42%) male and 513 (58%) female participants in the study.

Measurement

This section describes the measurement of variables chosen for descriptive purposes and those included in the bivariate and multivariate analysis (see Table 2).

Dependent Variable

The dichotomous dependent variable used in this study is “self help group participation,” which involves whether or not the respondent joined a self help group specifically to cope with the chronic condition. Self help group participation was coded 0=no and 1=yes. The total number of study participants that joined a self help group was 57 (6%) and the total number that did not was 822 (94%).

Independent Variables

This section describes the 22 variables that were used in the bivariate and multivariate analyses. Table 2 shows frequency distributions for the dependent variable (self help group participation) and the independent variables (sociodemographics, illness context, social support, self efficacy, knowledge and perceived stress). The independent variables will be described below according to the manner in which they were placed in blocks for the logistic regression, starting with sociodemographics and the illness context. A rationale will be provided to explain why they were chosen as control variables in the multivariate analysis. The other independent variables, including social support, self efficacy, and knowledge are central to this thesis and will be described following the control variables.

Table 2
Frequency Distributions for Dependent Variable and Independent Variables

Variables	Coding	Frequency	Valid %
Dependent Variable:			
Used self help group to cope with condition	0=no	822	93.5
	1=yes	57	6.5
Independent Variables:			
<i>Sociodemographic Variables</i>			
Age, at time of survey	1=50-64	285	32.4
	2=65-74	305	34.7
	3=75+	289	32.9
Sex	0=male	366	41.6
	1=female	513	58.4
Level of Education	1=some secondary or less	128	14.6
	2=completed secondary	218	24.8
	3=some college	61	6.9
	4=completed college	108	12.3
	5=some university	121	13.8
	6=completed university/other	243	27.6
Income	1=<\$20,000	211	24.0
	2=\$20,000-49,999	400	45.5
	3=\$50,000-69,999	145	16.5
	4=\$70,000-99,999	69	7.8
	5=\$100,000+	54	6.1
<i>Illness Context</i>			
Most Serious Health Condition	1=Arthritis	417	47.4
	2=Heart Problems	229	26.1
	3=High Blood Pressure	233	26.5
Perceived Seriousness	1=not at all	199	22.6
	2=slightly	257	29.2
	3=moderately	349	39.7
	4=extremely	74	8.4
Duration	1=<5yrs	275	31.3
	2=>5yrs - <15yrs	339	38.6
	3=>15yrs	265	30.1

Variables	Coding	Frequency	Valid %
Perceived Health	1=poor	51	5.8
	2=fair	158	18.0
	3=good	477	54.3
	4=excellent	193	22.0
Comorbidity	0=zero	217	24.7
	1=one	266	30.3
	2=two	211	24.0
	3=three	103	11.7
	4=four	50	5.7
	5=five	23	2.6
	6=six	7	.8
	7=seven	2	.2
# Doctor's visits	0=zero	135	15.4
	1=one	247	28.1
	2=two	162	18.4
	3=three	130	14.8
	4=four	69	7.8
	5=five-ten	96	10.9
	6=eleven-twenty	39	4.4
	7=twenty-one to forty-nine	1	.1
# Prescriptions	0=zero	129	14.7
	1=one	217	24.7
	2=two	210	23.9
	3=three	141	16.0
	4=four	74	8.4
	5=five-seven	84	9.6
	6=eight-ten	16	1.8
	7=eleven to twenty-one	8	.9
<i>Social Support</i>			
Once diagnosed: consult friends	0=no	600	68.3
	1=yes	279	31.7
Doing now: consult friends	0=no	639	72.7
	1=yes	240	27.3
Family/friends help with condition	0=no	535	60.9
	1=yes	344	39.1

Variables	Coding	Frequency	Valid %
# Confidants	0=zero	32	3.6
	1=one	152	17.3
	2=two	121	13.8
	3=three	157	17.9
	4=four	126	14.3
	5=five to fifty	291	33.1
Receive help from outside	1=never	388	44.1
	2=few times/year	55	6.3
	3=monthly	38	4.3
	4=few times/month	86	9.8
	5=weekly	74	8.4
	6=few times/week	81	9.2
	7=daily	157	17.9
Marital Status	1=married/common law	488	55.5
	2=separated	26	3.0
	3=divorced	88	10.0
	4=widowed	240	27.3
	5=single	37	4.2
Community use	0=zero	348	39.6
	1=one	240	27.3
	2=two	137	15.6
	3=three	86	9.8
	4=four	33	3.8
	5=five	19	2.2
	6=six	12	1.4
	7=seven	2	.2
8=eight	2	.2	
<i>Self Efficacy</i>			
Illness Efficacy	1=1 to 1.45	1	.1
	2=1.55 to 2.45	36	4.4
	3=2.55 to 3.45	203	24.5
	4=3.5 to 4.45	416	50.3
	5=4.5 to 5	171	20.7
Perceived Control over condition	0=no/little	206	23.4
	1=mod/complete	673	76.6
<i>Knowledge</i>			
Doing now: reading on the subject	0=no	445	50.6
	1=yes	434	49.4
<i>Perceived Stress</i>			
Perceived Stress	1=not at all	246	28.0
	2=a little	284	32.3
	3=moderately	260	29.6
	4=very	89	10.1

Sociodemographic Variables

Age. Age was determined by asking the respondents for their year of birth. The literature on self care behaviors clearly shows that people of a younger age are more likely to engage in these types of behaviors.

Sex. It has been found that women are more likely to engage in self care behaviors compared to men.

Education. Education originally included ten categories that were recoded into six categories (some secondary or less (n=128, 14.6%), completed secondary (n=218, 24.8%), some college (n=61, 6.95%), completed college (n=108, 12.3%), some university (n=121, 13.8), and completed university/other (n=243, 27.6%)) because of the small numbers in some categories. One would expect that those who are better educated would be more likely to engage in self care behaviors.

Income. The respondents' level of income was obtained from five choices ranging from <\$20,000 (n=211, 24%), \$20,000-49,999 (n=400, 45.5%), \$50,000-69,999 (n=145, 16.5%), \$70,000-99,999 (n=69, 7.8%) and \$100,000+ (n=54, 6.1%). According to the literature, those who report lower income are more likely to engage in self care behaviors. This question was left unanswered by 115 respondents.

Illness Context

The illness context included seven illness-related factors that may have an impact on participation in self help groups. They included: most serious health condition, perceived seriousness, duration, perceived health, comorbidity, number of doctor's visits, and number of prescriptions.

Most Serious Health Condition. Most serious health condition included three major chronic conditions: arthritis (n=417, 47.4%), heart problems (n=229, 26.1%), and high blood pressure (n=233, 26.5%). One would expect that persons experiencing more overt symptomology such as arthritic pain, would be more likely to engage in self care practices.

Perceived Seriousness. For perceived seriousness, respondents were asked, “How serious do you think that your condition is at the present time?” The variable consisted of four categories which included: not at all serious (n=199, 22.6%), slightly (n=257, 29.2%), moderately (n=349, 39.7%), and extremely serious (n=74, 8.4%). It was expected that those who perceived their illness condition as more serious may be more likely to engage in self care practices.

Duration. Duration is an interval variable consisting of the length of time since diagnoses of the chronic condition. The question asked was “Could you please tell me when you were first professionally diagnosed (by a doctor, nurse, physiotherapist etc.) with arthritis/heart problems/high blood pressure?” Originally, the month and the year or “do not recall” was recorded. The date specified was subtracted from the present year of the study (1995) in order to obtain “time since diagnoses.” For the bivariate analysis, duration was divided into three categories: <5 years (n=275, 31.3%), >5 years - <15 years (n=339, 38.6%), and >15 years (n=265, 30.1%). One would expect that those who experience a longer duration would be more likely to engage in self care practices.

Perceived Health. Perceived health was determined by response to the question “In general, compared to other people your age, would you say that your health is poor (n=51, 5.8%), fair (n=158, 18.0%), good (477, 54.3%), or excellent (193, 22%)?” It was

assumed that those who perceived their health as good or better, would be less likely to engage in self care behaviors.

Comorbidity. Comorbidity was computed based on the question: “Please tell me if you have been professionally diagnosed as currently having any of the following health problems: asthma/emphysema, anxiety, depression, cancer, diabetes, neurological diseases, Alzheimer’s or related condition, osteoporosis, vision problems, hearing problems, or other.” It is an additive scale comprising the total number of conditions reported. The number of comorbidities ranged from zero (n=217, 24.7%), one (n=266, 30.3%), two (n=211, 24%), three (n=103, 11.7%), four, (n=50, 5.7%), five (n=23, 2.6%), six (n=7, .8%), and seven (n=2, .2%). One would expect that those with a higher number of comorbidities would be more likely to engage in self care behaviors.

Number of Doctor’s Visits. The number of doctor’s visits is an interval variable ranging from zero to thirty. Respondents were asked “In the past three months, how many medical visits did you make to doctors?” For the bivariate analysis, this variable was recoded into eight categories: zero (n=135, 15.4%), one (n=247, 28.1%), two (n=162, 18.4%), three (n=130, 14.8%), four (n=69, 7.8%), five to ten (n=96, 10.9%), eleven to twenty (n=39, 4.4%), twenty-one to forty-nine (n=1, .1%). The literature indicates that those who have a greater number of doctor’s visits are more likely to engage in self care practices.

Number of Prescriptions. The number of prescriptions was determined by the question: “How many prescription medications are you presently taking on a regular basis?” For the bivariate analysis, this variable was recoded into eight categories: zero (n=129, 14.7%), one (n=217, 24.7%), two (n=210, 23.9%), three (n=141, 16%), four

(n=74, 8.4), five to seven (n=84, 9.6%), eight to ten (n=16, 1.8%), and eleven to twenty-one (n=8, .9%). One would expect that those who take more prescription medication would be less likely to try self care practices such as self help groups.

Social Support

The social support variables are key to the hypothesis formulated in chapter 2. The seven social support variables include: once diagnosed consult friends/relatives, doing now consult friends/relatives, family/friends help with the condition, number of confidants, receive help from outside, marital status, and community use. Some of these variables are derived from the social support section of the questionnaire, and others are from health status/healthcare utilization or the background section.

Once Diagnosed: Consult Friends/Relatives. Once diagnosed: consult friends/relatives is an interval, dichotomous variable based on the question “Once professionally diagnosed with (arthritis, heart problems, high blood pressure), did you consult friends or relatives?” (no=600, 68.3%; yes=279, 31.7%). The mean length of time since diagnosis for the three illness types were: arthritis=12.7 years, heart problems=10.3 years, and high blood pressure=12.6 years.

Doing Now: Consult Friends/Relatives. Doing now consult friends/relatives is a dichotomous, interval variable. The question was “Which of the following are you doing now... (consult friends/relatives)?” (no=639, 72.7%; yes=240, 27.3%).

Family/Friends Help with Condition. Family/friends help with the condition is also a dichotomous, interval variable. It refers to a question in the social support section,

“Does family or friend regularly help you with your condition?” (no=535, 60.9%; yes=344, 39.1%).

Number of Confidants. Number of confidants is a variable that was created from the question “How many people do you have with whom you can confide about personal matters?” Responses ranged from zero to fifty. For the bivariate analysis, number of confidantes was recoded into six categories: zero (n=32, 3.6%), one (n=152, 17.3%), two (n=121, 13.8%), three (n=157, 17.9%), four (n=126, 14.3%), and five-fifty (n=291, 33.1%).

Receive Help from Outside. Receive help from outside was based on the question, “How often do you receive help with such things as housework, shopping, driving, money management, or personal care?” This variable consisted of seven categories: never (n=388, 44.1%), a few times a year (n=55, 6.3%), monthly (n=38, 4.3%), a few times/month (n=86, 9.8%), weekly (n=74, 8.4%), a few times/week (81, 9.2%), and daily (n=157, 17.9%).

Marital Status. The question on marital status asked, “Are you currently married/common law, separated, divorced, widowed or single/never married?” For the bivariate and multivariate analysis, marital status was recoded into a dichotomous variable and included married (n=488, 55.5%) vs. not married (n=391, 45.5%) .

Community Use. Community use was created by summing the number of variables in which respondents reported using various community services. The question was: “Have you ever used: Handy Dart, North Shore Health, North Shore Home Support Services, North Shore Keep Well Society, North Shore Meals on Wheels, North Shore Neighborhood House, North Shore Seniors’ Peer Counsellors, North Shore Stroke

Recovery Center, North Shore Volunteers for Residents in Care Facilities, Seniors' Hub, Seniors' One Stop Information Line, West Vancouver Seniors' Special Services, Silver Harbour Centre, West Vancouver Seniors' Activity Centre?" Community use was categorized as follows: zero (n=348, 39.6%), one (n=240, 27.3%), two (n=137, 15.6%), three (n=86, 9.8%), four (n=33, 3.8%), five (n=19, 2.2%), six (n=12, 1.4%), seven (n=2, .2%), and eight (n=2, .2%). The literature indicates that those who participate in self help groups are also more likely to use other helping services as well.

Self Efficacy, Knowledge, and Perceived Stress

Self efficacy, knowledge and perceived stress are hypothesized to be important intervening variables between social support and self help group participation. Illness efficacy and perceived control are variables that represent self efficacy.

Illness Efficacy. The illness self efficacy scale was based on Lorig et al.'s (1989) arthritis scale modified to measure heart problem self efficacy and high blood pressure self efficacy. The scale involved eleven questions pertaining to the respondents' confidence in controlling certain aspects of their condition. Each response was rated on a 5 point Likert scale ranging from 1 (not confident at all) to 5 (totally confident). For example, arthritis repondents were asked, "On a scale of 1 to 5, where one is not at all confident, and 5 is totally confident, how confident are you that you can: control fatigue, regulate your activities so as to be active without aggravating your arthritis, do something to help yourself feel better if you are feeling blue, manage arthritis pain during your daily activities [compared to other people with arthritis like yours], manage your arthritis symptoms so that you can do the things you enjoy doing, deal with the frustration of

arthritis. decrease your pain quite a bit, continue most of your daily activities, keep arthritis pain from interfering with your sleep, make a small-to-moderate reduction in your arthritis pain by using methods other than taking extra medication, and make a large reduction in your arthritis pain by using methods other than taking extra medications.” For the heart problems, and high blood pressure groups there were nine and eight questions respectively. Cronbach’s Alphas were computed for each scale: arthritis self efficacy= .89; heart problem self efficacy=.84; high blood pressure self efficacy=.74 indicating good reliability. For “illness efficacy” each specific illness - self efficacy scale was combined into one measure. The total Alpha reliability for illness efficacy was .80. The frequencies for the five categories are: 1= (not at all confident, n=1, 1%), 2= (a little, n=36, 4.4%), 3= (moderately, n=203, 24.5%), 4= (very, n=416, 50.3%), and 5= (totally confident, n=171, 20.7%).

Perceived Control. Perceived Control was determined by the question, “How much control do you think you currently have over your (arthritis, heart problems, high blood pressure)?” This variable consisted of four categories: no control, a little control, moderate control, and complete control. For the multivariate analysis, perceived control was recoded into two categories: no/little control (n=206, 23.4) and moderate/complete control (n=673, 76.6%).

Doing Now: Reading on the Subject. Knowledge was represented by the variable “doing now: reading on the subject (specific illness condition).” Doing now reading on the subject was measured by a yes (n=434, 49.4%) or no (n=445, 50.6%) response to the question: “Which of these are you doing now...some reading on the subject?”

Perceived Stress. For perceived stress, respondents were asked, “How stressful is your life in your opinion?” The variable consisted of four categories: not stressful at all (n=246, 28%), a little stressful (284, 32.3%), moderately stressful (n=260, 29.6%) very stressful (n=89, 10.1%).

Missing Data

Due to the small number of missing cases for all variables except income, mean or modal substitution was used to recode these cases for categorical and continuous variables, respectively. The large amount of missing data for income (114, 15%) was substituted for using income distributions across three other variables. The three other variables included: three age groups (50-64, 65-74, and 75+), two sex groups (male, female), and three education groups (some secondary or less, completed secondary, some post secondary or more). According to Wister et al. (in press), this method “results in more accurate substituted missing data, because of the associations between income and these three variables, and does not seriously decrease the standard deviation of the derived income variable.”

Chapter IV

RESULTS

This chapter presents and interprets results related to the hypotheses stated in Chapter 2. First, a review of the bivariate analysis conducted to test the hypotheses is presented, followed by a multivariate analysis conducted for the purposes of determining which variables provide predictive power in self help group participation. The Statistical Package for Social Sciences (SPSS for MS WINDOWS 8.0) provided statistical programs for the univariate (descriptive), bivariate and multivariate analyses.

Bivariate Analyses

Bivariate analyses permit the investigation of the magnitude of difference between the dependent variable and the independent variable. As a rule of thumb, correlations ranging from zero to .20 are considered weak, those between .20 and .40 are considered moderate, and those over .40 are considered moderate to strong. A negative sign before the correlation indicates an inverse relationship. Positive scores, on the other hand, indicate a positive relationship. For this thesis, the dependent variable is self help group participation which is coded as 0=no and 1=yes. Thus, a positive correlation would indicate higher scores for those who participated in self help groups. Further, social support is hypothesized to impact self help group participation through its effects on self efficacy, knowledge and perceived stress. Therefore, the relationship will also be examined between social support and self efficacy, knowledge and perceived stress. Some of the independent variables used to test the hypotheses are ordinal while others are interval. Kendall's tau C and Pearson's r have been used to indicate the magnitude of

difference between the independent and dependent variables. Kendall's tau C is used for ordinal variables in which the number of cells are unequal. Pearson's r is used when both the dependent and independent variables are interval.

To test the 7 hypotheses developed in Chapter 2, crosstabulations were performed between the dependent variable (self help group participation) and the independent variables (social support, self efficacy, knowledge, and perceived stress). Also, crosstabulations were conducted between the intervening variables (self efficacy, knowledge and perceived stress) and social support. The independent variables included: 1) once diagnosed consult friends/rel., 2) doing now consult friends/rel., 3) family/friends help with condition, 4) # of confidants, 5) receive help from outside, 6) marital status, 7) community use, 8) perceived control, 9) illness efficacy, 10) doing now reading on the subject, and 11) perceived stress.

Hypothesis 1

Social Support will be positively associated with self help group participation.

This hypothesis states that older individuals who have greater supports are more likely to participate in a self help group to cope with their condition compared with those who have little or no supports. To test this hypothesis, seven individual social support items were investigated. These included: consult friends/rel. when once diagnosed, consult friends/rel. now, family/friends to help with their condition, #of confidants, receive help from outside, marital status, and community use.

First, for the independent variable, consult friends/rel. when once diagnosed, a statistically significant, weak, positive association was found. Those who consulted friends/rel. once diagnosed, were more likely to engage in self help groups, $r=.11, p<.001$.

Table 3
Crosstabulation of Once diagnosed:consult friends/relatives and Self help group participation

Self help	Once diagnosed: consult friends			
	No		Yes	
	(N)	%	(N)	%
No	572	95.3	250	89.6
Yes	28	4.7	29	10.4
Total	600	100	279	100

$r=.11, p<.001$

Second, the independent variable “doing now: consult friends/rel.,” was also found to be significant. The crosstabulation resulted in a weak, positive relationship ($r=.10, p<.01$) with those who are consulting friends/rel. now more likely to participate in self help groups.

Table 4
Crosstabulation of Doing now: consult friends/relatives and Self help group participation

Self help	Doing now: consult friends			
	No		Yes	
	(N)	%	(N)	%
No	607	95.0	215	89.6
Yes	32	5.0	25	10.4
Total	639	100	240	100

$r=.10, p<.01$

Third, the crosstabulation between “family/friends help with the condition” and self help group participation was found to be statistically significant. Again, a positive, weak association was found. Those who had family/friends to help with the condition

were more likely to get involved in self help groups to cope with their condition ($r=.08$, $p<.05$).

Table 5
Crosstabulation of Family/friends help with condition and Self help group participation

Self help	Family/friends help with condition			
	No		Yes	
	(N)	%	(N)	%
No	509	95.1	313	91.0
Yes	26	4.9	31	9.0
Total	535	100	344	100

$r= .08$, $p< .05$

Fourth, the association between number of confidants and self help group participation was not statistically significant (Kendall's tau $c=.03$, ns).

Table 6
Crosstabulation of # of Confidants and Self help group participation

Self help	# of Confidants											
	0		1		2		3		4		5-50	
	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%
No	32	100	146	96.1	112	92.6	145	92.4	117	92.9	270	92.8
Yes			6	3.9	9	7.4	12	7.6	9	7.1	21	7.2
Total	32	100	152	100	121	100	157	100	126	100	291	100

tau $c= .03$, ns

Fifth, a positive, weak statistical significance was found for the variable "how often receive outside help". Those who receive outside help are more likely to engage in self help groups to cope with their condition compared to those who never receive outside help (Kendall's tau $c=.06$, $p<.05$).

Table 7**Crosstabulation of Receive outside help and Self help group participation**

Self help	Receive outside help													
	Never		Few times/Year		Monthly		Few times/Month		Weekly		Few times/week		Daily	
	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%
No	375	96.6	50	90.9	34	89.5	77	89.5	69	93.2	76	93.8	141	89.8
Yes	13	3.4	5	9.1	4	10.5	9	10.5	5	6.8	5	6.2	16	10.2
Total	389	100	55	100	38	100	86	100	74	100	81	100	157	100

tau c= .06, p<.05

Sixth, the relationship between marital status and self help group participation was not found to be statistically significant ($r=-.02$, ns).

Table 8**Crosstabulation of Marital Status and Self help group participation**

Self help	Marital Status			
	Not married		Married	
	(N)	%	(N)	%
No	364	93.1	458	93.9
Yes	27	6.9	30	6.1
Total	391	100	488	100

 $r= -.02$, ns

Seventh, the relationship between community use and self help group participation was found to be statistically significant. The crosstabulation resulted in a weak, positive association. Those who use community services more often are more likely to participate in self help groups (tau c=.04, p<.05).

Table 9**Crosstabulation of Community Use and Self help group participation**

Self Help	Community Use											
	0		1		2		3		4		5	
	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%
No	333	95.7	221	92.1	129	94.2	79	91.9	30	90.9	30	80.7
Yes	15	4.3	19	7.9	8	5.8	7	8.1	3	9.1	5	14.3
Total	348	100	240	100	137	100	86	100	33	100	35	100

tau c=.04, p<.05

Hypothesis 2

Social Support will be positively related to the acquisition of knowledge

This hypothesis states that those with greater support (once diagnosed: consult friends/rel., doing now: consult friends/rel., family/friends help with condition, #confidants, receive help from outside, marital status, community use) will be associated with an acquisition of knowledge (doing now: read on the subject). Statistical significance was found for four of the social support variables: once diagnosed consult friends/rel. ($r=.197, p<.001$), doing now consult friends/rel. ($r=.186, p<.001$), family/friends help with condition ($r=.066, p<.05$), and number of confidants (tau c=.169, $p<.001$). The results were positive and reflected a weak association between the four variables and self help group participation. The other three variables, receive help from outside (tau c=.016, ns), marital status ($r=.000, ns$) and community use (tau c= -.042, ns) were not significant.

Table 10**Association between Social Support and Acquisition of Knowledge**

Variables

Once diagnosed: consult friends/relatives	r=.20***
Doing now: consult friends/relatives	r=.19***
Family/friends help with condition	r=.07*
# of confidants	Tau c=.17***
Receive outside help	Tau c=.02 (ns)
Marital status	r=.00 (ns)
Community use	Tau c=-.04 (ns)

* p<.05; **p<.01; ***p<.001; ns=not significant

Hypothesis 3

Social support will show a negative relationship to perceived stress.

It was expected that greater social support (once diagnosed: consult friends/rel., doing now: consult friends/rel., family/friends help with condition, # confidants, receive help from outside, marital status, community use) would be associated with lower perceived stress. The crosstabulations found weak support for four of the six social support variables: once diagnosed consult friends/rel. (tau c= .08, p<.05), doing now consult friends/rel. (tau c= .09, p<.01), family/friends help with condition (tau c= .12, p<.001), and receive outside help (tau c= .06, p<.05). All of the significant variables resulted in a positive association. Those who currently consulted friends/rel., consulted friends/rel. when once diagnosed, had family/friend to help with condition and received outside help were more likely to report higher levels of stress. Although these findings are contrary to the expected hypothesis, the results indicate that those who tend to seek support more often are experiencing greater levels of stress. Number of confidants (tau

c= -.02, ns), marital status (tau c= .02, ns), and community use (tau c= .01, ns) were not significant.

Table 11

Association between Social Support and Perceived Stress

Variables

Once diagnosed: consult friends/relatives	Tau c=.08*
Doing now: consult friends/relatives	Tau c=.09**
Family/friends help with condition	Tau c=.12***
# of confidants	Tau c=-.02 (ns)
Receive help from outside	Tau c=.06*
Marital status	Tau c=.02 (ns)
Community use	Tau c=.01 (ns)

*p<.05; **p<.01; ***p<.001; ns= not significant

Hypothesis 4

Social Support will exhibit a positive association with self efficacy.

This hypothesis states that greater support (once diagnosed: consult friends/rel., doing now: consult friends/rel., family/friends help with condition, # of confidants, receive help from outside, marital status, community use) is associated with a higher level of self efficacy (perceived control, illness efficacy). In the crosstabulations between the social support variables and perceived control, only number of confidants was found to be significant. A weak and positive association was found between the two variables. Those who had greater numbers of confidants were more likely to report greater control over their illness condition (tau c=.09, p<.01). The other social support variables, once diagnosed consult friends/rel. (r=.02, ns), doing now consult friends/rel. (r=.01, ns), family/friends help with condition (r= -.05, ns), receive help from outside (tau c= -.04, ns), marital status (r= -.02, ns), and community use (tau c=.04, ns) were not significant.

Table 12**Association between Social Support and Perceived Control**

Variables	
Once diagnosed: consult friends	r=.02 (ns)
Doing now: consult friends	r=.01 (ns)
Family/friends help with condition	r=-.05(ns)
# of confidants	Tau c=.09**
Receive help from outside	Tau c=-.04 (ns)
Marital status	r=-.02 (ns)
Community use	Tau c=.04 (ns)

*p<.05; **p<.01; ***p<.001; ns= not significant

For the bivariate analysis of social support and illness efficacy, all of the social support variables were significant except doing now consult friends/rel. (tau c=-.06, ns) and marital status (tau c=-.06, ns). The variables that were found to be significant included: once diagnosed consult friends/rel. (tau c=-.09, p<.01), family/friends help with condition (tau c=-.15, p<.001, number of confidants (tau c=.06, p<.05), receive help from outside (tau c=-.10, p<.001), and community use (tau c=-.09, p<.001). As indicated in Table 13, only number of confidants yielded results in the expected direction, while the others were negative. Those who reported greater numbers of confidants were more likely to report higher levels of self efficacy while those who consulted friends/rel. when once diagnosed, had family/friends to help with the condition, received outside help more often, and used community services more often, were more likely to report lower levels of self efficacy.

Table 13**Association between Social Support and Illness Efficacy**

Variables	
Once diagnosed: consult friends	Tau c= -.09**
Doing now: consult friends	Tau c= -.06 (ns)
Family/friends help with condition	Tau c= -.15***
# of confidants	Tau c= .06*
Receive help from outside	Tau c= -.10***
Marital status	Tau c= .06 (ns)
Community use	Tau c= -.09***

*p<.05; **p<.01; ***p<.001; ns= not significant

Hypothesis 5

Acquisition of knowledge will show a positive relationship to self help group participation.

This hypothesis states that acquisition of knowledge (doing now: reading on the subject) is associated with the likelihood of participating in self help groups. The bivariate association confirmed this hypothesis. A weak, positive, statistical significance was found between reading on the subject and self help group participation. Those who are currently reading on the subject are more likely to participate in self help groups ($r=.15, p<.001$).

Table 14**Crosstabulation of Doing now: reading on the subject and Self help group participation**

Self help	"Doing now: reading on the subject			
	No (N)	%	Yes (N)	%
No	432	97.1	390	89.9
Yes	13	2.9	44	10.1

$R=.15, p<.001$

Hypothesis 6

Perceived stress will be negatively associated with self help group participation.

This hypothesis states that those who report lower stress will be more likely to participate in a self help group to cope with their condition. A weak, positive, statistically significant relationship was found for this relationship. Those who reported higher levels of stress were more likely to participate in self help groups (tau c=.05, p<.01).

Table 15

Crosstabulation of Perceived stress and Self help group participation

Self help	Perceived stress							
	Not at all		A little		Moderately		Very	
	(N)	%	(N)	%	(N)	%	(N)	%
No	239	97.2	264	93.0	239	91.9	80	89.9
Yes	7	2.8	20	7.0	21	8.1	9	10.1

tau c=.05, p<.01

Hypothesis 7

Self efficacy will be associated with self help group participation.

This hypothesis states that self efficacy (illness efficacy, perceived control) will be related to participating in self help groups. Both illness efficacy (tau c= -.03, ns) and perceived control (r=.06, ns) were not statistically significant.

Table 16

Association between Self Efficacy and Self help group participation

Variables

Illness efficacy	Tau c= -.03 (ns)
Perceived control	R= .06 (ns)

*p<.05; **p<.01; ***p<.001; ns= not significant

Summary

The previous section accepted or rejected hypotheses according to statistically significant differences in association found between self help group participation (dependent variable), and social support, self efficacy, knowledge, and perceived stress (independent variables). Also, results were obtained for the intervening variables self efficacy, knowledge and perceived stress and the independent variable, social support. Overall, hypotheses 1, 2, 4, and 5 were confirmed. Hypotheses 3 and 6 were also statistically significant, however, results were in the opposite direction to the predicted. Hypothesis 7 did not show statistical significance.

The major findings were that:

- 1) social support (once diagnosed consult friends/relatives, doing now consult friends/relatives, friends/family help with condition, receive outside help), and knowledge (reading on the subject) were positively associated with self help group participation.
- 2) higher levels of stress were associated with self help group participation.

In terms of the intervening variables it was found that:

- 3) social support (once diagnosed consult friends/relatives, doing now consult friends/relatives, family/friends help with condition, #confidants) was positively associated with the acquisition of knowledge (reading on the subject).
- 4) social support (once diagnosed consult friends/relatives, doing now consult friends/relatives, family/friends help with condition and received outside help) was positively related to perceived stress.
- 5) social support (#confidants) showed a positive relationship with self efficacy (perceived control, illness efficacy).
- 6) However, other social support variables (once diagnosed consult friends/relatives, family/friends help with condition, receive outside help, community use) resulted in a negative association with self efficacy (illness efficacy). Thus, those who reported higher levels of social support were more likely to report lower levels of self efficacy.

Multivariate Analysis

Multivariate analysis is required to examine the independent effects of each explanatory variable under study, while controlling for the effects of others. A logistic regression is a suitable statistical technique since it uses a variety of independent variables with one dichotomous dependent variable (Howell, 1992). Since the main dependent variable in this study is dichotomous (self help group participation: 0=no, 1=yes), a logistic regression was conducted in order to test the hypotheses under study in a more rigorous manner.

This thesis investigated the role of social support in predicting self help group participation. Also, it was hypothesized that the mechanisms through which social support impacts self help group participation include: self efficacy, knowledge and perceived stress. Therefore, eleven independent variables (1. once diagnosed: consult friends/rel., 2. doing now: consult friends/rel., 3. family/friends help with condition, 4. # of confidants, 5. receive help from outside, 6. marital status, 7. community use, 8. doing now: read on the subject, 9. perceived stress, 10. perceived control, and 11. illness efficacy) were chosen as potentially relevant factors involved in self help group participation.

Furthermore, four sociodemographic (age, sex, education, income) and seven illness context (most serious health condition, perceived seriousness, duration, perceived health, comorbidity, number of doctor's visits, number of prescriptions) correlates were examined individually in the logistic regression. The sociodemographic and illness context variables were viewed as potential covariates of participation in self help groups among older adults.

Four hierarchical models were performed (see Appendix B). Model 1 included the four sociodemographic variables and Model 2 examined the seven illness context variables in addition to the sociodemographic variables. Model 3 entailed the eleven control variables from Model 2, and seven social support variables. Finally, Model 4 involved the four variables representing self efficacy, knowledge and perceived stress, in addition to the eighteen variables in Model 3. The rationale for the ordering of variables lay in the antecedent nature of the sociodemographic and illness context variables, as well as the proposed relationship between social support and self help group participation, which was considered to be mediated by self efficacy, knowledge and perceived stress.

The logistic regression beta coefficient, its standard error, its odds ratio, and the level of significance are presented. The logistic regression beta coefficient (B) represents the change in the log odds of participating in self help groups (compared to not participating) for a one-unit change in an independent variable, while statistically controlling for all others (Menard, 1995). The odds ratio is “the estimated odds ratio for those who are a unit apart on a given explanatory variable, after other variables in the model have been statistically controlled” (Wister et al., in press). For this thesis, the odds ratio is the probability of engaging in self help groups for one category of an explanatory variable compared to the reference category. A positive value for an odds ratio ranges between 1 and infinity, while a negative value ranges between singularity and zero (but never reaches zero) (Wister et al., in press). For example, an odds ratio of 1.5 for an explanatory variable would indicate that the probability of engaging in self help groups to cope with the condition is one and a half times larger for the specified category of that variable compared to the reference category, while statistically controlling for all other

explanatory variables (DeMaris, 1995). The level of significance is reported by using the Log Likelihood Chi Square. A statistically significant result indicates that “the overall model does not significantly differ from the “perfect” model using all of the independent variables” (Wister, 1995). In this study, models 1, 2, 3, and 4 were found to be statistically significant and each block of variables was also observed to be statistically significant (see Table 17).

Table 17

Logistic Regression				
	Block Chi-Square	Block Significance	Model Chi-Square	Model Significance
Model 1	32.42	.0001	32.42	.0001
Model 2	35.46	.0004	67.88	.0000
Model 3	20.83	.0529	88.71	.0000
Model 4	24.74	.0004	113.45	.0000

Table 18
Logistic Regression for Self help Group Participation and Independent Variables

	Model 1			Model 2		
	B	S.E.	Odds Ratio	B	S.E.	Odds Ratio
Age	-.05**	.02	.96	-.05**	.02	.95
Sex	.03	.30	-	.25	.34	-
Education						
Some sec/less (ref)						
Completed secondary	1.33*	.64	3.8	1.2	.65	-
Some college	.80	.84	-	.96	.85	-
Completed college	-.91	1.17	-	-.92	1.17	-
Some university	1.17	.70	-	1.05	.71	-
Completed univ/other	1.75**	.63	5.7	1.73**	.64	5.7
Income	-.44**	.16	.65	-.27	.16	-
Most serious condition						
Arthritis (ref)						
Heart problems				.44	.36	-
High blood pressure				-.85	.46	-
Perceived Seriousness						
Not at all (ref)						
Slightly				-.07	.53	-
Moderately				.65	.46	-
Extremely				.18	.66	-
Duration				-.00	.01	-
Perceived health						
Poor (ref)						
Fair				-.20	.51	-
Good				-1.0	.52	-
Excellent				-1.2*	.64	.29
Comorbidity				-.08	.12	-
# Doctor's visits				.10*	.04	1.1
# Prescriptions				.01	.07	-

* p< .05

**p< .01

Model Chi-Square = 32.415, p<.001 (Model 1)

Model Chi-Square = 67.877, p<.001 (Model 2)

Logistic Regression for Self help Group Participation and Independent Variables con'd

	Model 3			Model 4		
	B	S.E.	Odds Ratio	B	S.E.	Odds Ratio
Age	-.05**	.02	.95	-.05**	.02	.95
Sex	.10	.38	-	-.09	.41	-
Education						
Some sec/less (ref)						
Completed secondary	1.2	.67	-	1.2	.70	-
Some college	1.04	.89	-	1.2	.91	-
Completed college	-1.2	1.20	-	-1.4	1.23	-
Some university	1.07	.73	-	1.1	.76	-
Completed university	1.7*	.67	5.2	1.6*	.69	5.1
Income	-.32	.18	-	-.37	.20	-
Most serious condition						
Arthritis (ref)						
Heart problems	.37	.38	-	.25	.41	-
High blood pressure	-.77	.48	-	-.86	.50	-
Perceived Seriousness						
Not at all (ref)						
Slightly	.05	.54	-	-.01	.56	-
Moderately	.67	.48	-	.57	.51	-
Extremely	.22	.69	-	.26	.75	-
Duration	-.004	.01	-	-.01	.02	-
Perceived health						
Poor (ref)						
Fair	.10	.54	-	-.19	.58	-
Good	-.83	.57	-	-1.1	.62	-
Excellent	-.97	.70	-	-1.1	.76	-
Comorbidity	-.14	.12	-	-.17	.13	-
# Doctor's visits	.10*	.04	1.1	.12*	.05	1.1
# Prescriptions	.02	.07	-	.01	.08	-

* p< .05

**p< .01

Model Chi-Square = 88.707, p<.0001 (Model 3)

Logistic Regression for Self help Group Participation and Independent Variables con'd						
	Model 3			Model 4		
	B	S.E.	Odds Ratio	B	S.E.	Odds Ratio
Once diagnosed: consult friends/relatives	.74	.45	-	.55	.47	-
Doing now: consult friends/relatives	-.10	.47	-	-.17	.49	-
Family/friends help with condition	.19	.32	-	.11	.33	-
# of Confidants	-.01	.04	-	-.03	.04	-
Receive help from outside						
Never (ref)						
Few times/year	.92	.61	-	1.09	.63	-
Monthly	1.2	.66	-	1.14	.69	-
Few times/month	1.0*	.52	2.9	1.15*	.55	3.2
Weekly	.75	.63	-	.84	.66	-
Few times/week	.09	.62	-	.04	.64	-
Daily	1.1*	.44	2.9	1.22**	.46	3.4
Marital Status	.19	.39	-	.10	.41	-
Community use	.21	.13	-	.21	.13	-
Doing now: reading on the subject				1.19**	.37	3.2
Perceived Stress						
Not at all (ref)						
A little				.77	.50	-
Moderately				.85	.52	-
Very				.88	.64	-
Perceived Control				1.19*	.49	3.3
Illness Efficacy				-.02	.25	-

*p<.01
**p<.05
Model Chi Square = 113.446, p<.001 (Model 4)

In Model 1, the sociodemographic variables that were statistically significant include: age, education, and income. An inverse association between self help group participation and age is supported. The odds of participating in a self help group are .96 lower for each succeeding age category, controlling for all other variables in the equation. For education, the likelihood of participating in a self help group is almost four times (odds ratio=3.8) greater for those who completed secondary compared to those who have only some secondary or less. Interestingly, the odds of participating in self help groups are about 6 times (odds ratio=5.7) greater for those who completed university compared to those who have some secondary or less. In terms of income, an inverse relationship was found. The likelihood of participating in a self help group is .65 lower for those who have higher income compared to lower income, controlling for all other variables in the equation.

When the illness context variables were included in Model 2, two statistically significant relationships were found for the sociodemographic variables in addition to two illness context variables. The same two variables, age and the highest level of education again showed a statistically significant association similar to that described for model 1, however, completed secondary education and income were not found to be significant when controlling for all variables. The two illness context variables that were significant were perceived health and number of doctor's visits. Those who perceived their health as excellent were .29 less likely to participate in a self help group compared to those who perceive their health as poor. Furthermore, the odds of participating in a self help group are 1.1 times higher for each doctor's visit.

Model three involved the addition of seven social support variables. Interestingly, a statistically significant relationship was found for one of the social support variables. In this model, age, education, number of doctor's visits, and receive help from outside were statistically significant. Again, age and number of doctors visits resulted in similar odds ratios to model 2, however, the odds ratio for the education variable (completed university vs. some secondary education or less) was reduced by almost one. The odds of participating in a self help group is about 5 times (odds ratio = 5.2) greater for those who completed university compared to those who had some secondary or less. In terms of social support, the model provided support for predicting self help group participation while controlling for all other independent variables, particularly the sociodemographic and illness context factors. The odds of participating in a self help group are about 3 times (odds ratio=2.9) greater for those who receive help a few times per month and on a daily basis compared to those who never receive help.

In the final model, six variables resulted in a statistically significant relationship with self help group participation. Support was found for social support, knowledge, and self efficacy. With the addition of the self efficacy, knowledge and perceived stress variables in model 4, age, education, number of doctor's visits, receive help from outside, doing now: reading on the subject and perceived control resulted in statistical significance. Again, age, education and number of doctor's visits resulted in similar odds ratios to model 3, when self efficacy, knowledge, and perceived stress variables were included. However, model four resulted in greater odds ratios for receiving outside help. Those who received outside help a few times per month were 3.2 times more likely to participate in self help groups compared to those who never received outside help.

Similarly, the odds of participating in a self help group are 3.4 times greater for those who receive help on a daily basis compared to never. In terms of the knowledge variable, “doing now: reading on the subject,” the odds of participating in a self help group are 3.2 times greater for those who are currently reading on the subject compared to those who are not. Finally, for perceived control, it was found that those who perceive moderate/complete control were 3.3 times more likely to participate in a self help group to cope with their condition compared to those who perceive a little/no control. Model 4 also indicates that perceived stress is not a significant predictor of self help group participation when all other independent variables are controlled.

In sum, multivariate analyses reveal that social support, self efficacy, and knowledge are predictive of self help group participation. Also, selected covariates - particularly age, education and number of doctor’s visits are predictive of self help group participation. All of the significant variables in model 4 resulted in a positive relationship except age, which was negative and in the expected direction. Furthermore, the overall predictability of the models increased as successive variables were included. In model 4, the model chi-square was greater (model chi-square=113.446) compared to model 1 (model chi-square = 32.415). Finally, while the block representing illness context exhibited the largest block chi square (35.46), the others were also statistically significant.

Chapter V

DISCUSSION

This thesis has attempted to investigate the role of social support in predicting self help group participation. In an effort to explain the significance of the findings from chapter IV, the first section of the discussion will present a summary of the research issues. Then, a discussion of the results as they pertain to Bandura's (1977) Social Learning Theory will be presented, followed by a discussion of the implications and limitations of the research, as well as directions for future research.

The literature has indicated that the aging of the population is associated with concurrent increases in chronic illness and disability. Research on social support shows that informal social networks are related to better physical and psychological functioning, as well as a greater ability to cope with chronic illness. Coping with a chronic illness may involve engaging in self care practices such as participating in self help groups. This thesis investigates the role of social support in predicting self help group participation. It has been hypothesized that the relationship between social support and self help group participation is influenced by certain intervening factors. These intervening factors are based on Bandura's Social Learning Theory, and include: self efficacy, knowledge, and perceived stress. However, there has been a lack of research pertaining to social support and self help group participation among older adults with a chronic illness. Also, the role of self efficacy, knowledge and perceived stress as intervening variables between social support and self help group participation has not been investigated.

Based on a critical review of key research in social support and Social Learning Theory, the following variables were chosen to examine the issues under study: a) consult friends/rel. when once diagnosed, b) consulting friends/rel. now, c) family/friends help with the condition, d) number of confidants, e) receive help from outside, f) marital status, g) community use, h) illness efficacy, i) perceived control, j) reading on the subject now, and k) perceived stress. In order to examine the role of these variables in self help group participation, seven hypotheses were tested at the bivariate level of analysis. Subsequently, multivariate analysis included the above variables as well as several relevant control variables that were selected based on a review of the literature.

Main Results and Theoretical Integration

Bandura's (1979) Social Learning Theory suggests that self efficacy is the mediating factor between social experiences and behavior. The self efficacy variables, perceived control and illness efficacy measured levels of confidence respondents had in coping with their chronic illness. Further, it has been postulated by Social Learning Theory that two mechanisms which enhance self efficacy include verbal persuasion and emotional arousal. Verbal persuasion was conceptualized as knowledge (reading on the subject), and emotional arousal was represented by perceived stress. Since the main tenet of Social Learning Theory involves behavior as determined by the reciprocal interaction of cognition and observational learning (environment), this thesis examined the effects of the social environment (informal social support) on self help group participation. Further, self efficacy, knowledge and perceived stress were investigated as intervening variables.

Hypothesis 1 tested the relationship between social support and self help group participation. The hypothesis states that older individuals who have greater informal supports are more likely to participate in self help groups than those who have little or no informal supports. Bivariate analysis indicated a positive association between these variables. When examined individually, weak, statistically significant associations were found for five of the seven measures of social support. Those who consulted friends/rel. when diagnosed, who are currently consulting friends/rel., who have family/friends to help with the condition, who receive outside help and who report higher levels of community use are more likely to participate in a self help group. These findings are consistent with earlier research regarding the relationship between social ties and preventive health behaviors (Umberson et al., 1987; Wister, 1995; Hickey et al., 1988; Rakowski et al., 1987; Potts et al., 1992). Multivariate analysis confirmed this hypothesis, however, only one of the social support variables (received outside help) resulted in a statistically significant relationship when all other variables were included. Receiving outside help a few times per month, when compared to never, tripled the likelihood of participating in a self help group when controlling for all other variables. Also, the odds of participating in a self help group were about three times greater for those who received outside help on a daily basis compared to those who never received outside help when controlling for sociodemographic, illness context and other social support variables. When self efficacy, knowledge and perceived stress were included in model 4, the likelihood of participating in a self help group increased slightly (3.2 times more likely) for those who received outside help on a daily basis compared to never. These results support previous research findings in which older adults who participated in

self help groups were more likely to use other helping resources (Lieberman & Borman, 1979).

The lack of statistically significant relationships found in the multivariate analysis for the other social support variables may be explained by the fact that a specific type of support related to connecting people or providing knowledge is needed to encourage self care behaviors such as participating in a self help group. For example, receiving outside help is an instrumental type of support which may encourage more social interaction with people from outside the circle of family and friends. Also, the outside help may involve people who are knowledgeable about chronic conditions. Similarly, community use resulted in a statistically significant relationship at the bivariate level. Although only a weak association was found, community use is also a type of social support that involves interacting with people besides family and friends. Furthermore, a control variable - number of doctors visits, resulted in a statistically significant relationship at the multivariate level, when controlling for all other variables. Again, number of doctors visits involves social interaction with others who are not family and friends. This "outside" social connection may be a distinguishing factor in explaining why only one social support variable (receiving outside help) was statistically significant when controlling for all other variables.

Hypothesis 2 stated that social support would be related to an acquisition of knowledge. Again, the seven individual social support items were tested, and a weak, positive, statistically significant relationship was found for four variables. Those who consulted friends/rel. when once diagnosed, are consulting friends/rel. now, have family/friends help with the condition and have greater numbers of confidants were more

likely to be reading on the subject compared to those who did not consult friends/rel., have family/friends to help with the condition, and who had fewer numbers of confidants. Thus, these results suggest that social support has a positive impact on knowledge through verbal persuasion. Also, the findings support earlier research (Wills, 1983) stating that social networks are an important source of information and referral for both medical and psychological treatment. Although the bivariate analysis provides partial support for the Social Learning Theory, this hypothesis was not examined using multivariate methods as it is beyond the scope of this thesis.

Hypothesis 3 stipulates that social support will be related to lower levels of perceived stress. At the bivariate level, seven social support variables were tested, and four variables resulted in statistically significant relationships. The significant variables resulted in a weak, positive association. The respondents who consulted friends/rel. when they were once diagnosed, consult friends/rel. now, have family/friends help with their condition, and received outside help were more likely to report higher levels of perceived stress compared to those who did not consult friends/rel., have family/friends help with the condition and receive outside help. Although these findings are contrary to the expected hypothesis, the results may indicate that those who tend to seek support more often, are experiencing greater levels of stress. This hypothesis was also not investigated at the multivariate level as it would entail expansion of the thesis beyond its scope.

Hypothesis 4 states that social support will be related to higher levels of self efficacy. Self efficacy was represented by two variables: perceived control and illness efficacy. Of the seven social support variables, only number of confidants showed a

statistically significant, weak relationship with perceived control. Those who had greater numbers of confidants, were more likely to report higher levels of perceived control over their illness condition compared to those who had fewer confidants. Also, consulting friends/rel. when once diagnosed, help from family/friends, number of confidants, receive outside help, and community use resulted in a weak, statistically significant association with illness efficacy. However, only number of confidants yielded results in the expected direction, while the others were negative. A greater number of confidants was related to higher levels of illness efficacy compared to those with fewer confidants. Again, partial support was found for the Social Learning Theory in that social support is related to increases in self efficacy, however, the relationship is only found for the variable "number of confidants". Surprisingly, the respondents who consulted friends/rel. when once diagnosed, had family/friends to help with the condition, received outside help more often, and used community services more often, were more likely to report lower levels of illness efficacy. These results suggest that perhaps those with lower levels of self efficacy are more likely to seek social support. Again, this hypothesis was not examined in the multivariate analysis as it raises analytical issues that are beyond the scope of this thesis.

The next three hypotheses tested self efficacy, knowledge and perceived stress in relation to self help group participation. According to the Social Learning Theory, those with greater levels of self efficacy are expected to report a greater ability to cope with their condition. Further, it is hypothesized that greater knowledge and lower perceived stress would be associated with a greater propensity to participate in self help groups.

Hypothesis 5 tested the relationship between knowledge and self help group participation. It was expected that knowledge (reading on the subject) would be related to a greater likelihood of participating in a self help group. This hypothesis was confirmed at the bivariate level. A weak, statistically significant relationship was found for reading on the subject. Those who were currently reading on the subject were more likely to participate in self help groups. Furthermore, multivariate analysis also confirmed this hypothesis. Currently reading on the subject compared to not reading on the subject tripled the likelihood of participating in a self help group when controlling for all other variables.

Hypothesis 6 stated that those who report lower stress will be more likely to participate in self help groups. However, a weak, positive statistically significant association was found for this relationship at the bivariate level. Interestingly, the respondents who reported higher levels of perceived stress were more likely to engage in self help groups. However, since it is difficult to determine true causation, this result may also reflect the potential negative effects of self help groups. Further, the multivariate analysis did not lend support for this variable, after controlling for all other variables.

Hypothesis 7 tested whether or not self efficacy (perceived control, illness efficacy) was associated with self help group participation. At the bivariate level, both perceived control and illness efficacy were not statistically significant. However, at the multivariate level, perceived control showed a statistically significant relationship when controlling for all other variables (sociodemographic, illness context, social support, knowledge, self efficacy). The odds of participating in a self help group were 3.3 times

greater for those who perceived moderate or complete control over their illness condition compared to those who perceived little or no control. These results are consistent with other research findings which suggest that chronically ill individuals with a strong sense of self efficacy are more likely to participate in more active coping practices (Hickey & Stilwell, 1992; Gecas, 1989).

Thus, self efficacy (perceived control) is moderately supported in the multivariate analysis when controlling for all other variables in the study. Also, knowledge (reading on the subject) was strongly supported as indicated in the bivariate and multivariate analysis. However, perceived stress was not supported. These results may reflect the fact that the measures used to represent self efficacy and emotional arousal were not adequate or comprehensive enough to test the theory. For example, future research could investigate self efficacy in different domains of the illness condition or more behavior specific self efficacy. Also, a more objective measure of emotional arousal such as physiological arousal could be examined as opposed to perceived stress which may be unreliable due to inaccurate reporting. Furthermore, it may be that the theory is incomplete and needs further development in its application to this thesis. For example, personality, coping styles, and locus of control have been found to be important factors in behavior change and adoption. Personality, coping styles and locus of control may have an impact on self efficacy, and thus should be investigated. Although Rotter's (1954, 1966, 1982) Social Learning Theory of Personality involves the combination of self efficacy and locus of control, it was not utilized in this study because of the inability to test locus of control as the result of the absence of existing variables.

Several control variables also revealed statistically significant associations with self help group participation in the multivariate analysis. These include: age, education, income, perceived health and number of doctor's visits. The other variables: sex, most serious condition, perceived seriousness, duration, comorbidity, and number of prescriptions were not statistically significant. A statistically significant relationship was found for age in all four models. As expected, a negative association was found, in that those who are older in age are .95 times less likely to participate in self help groups for each age increment. This finding is consistent with the literature on age and self help group participation.

The relationship between education and self help group participation was also shown to be statistically significant. In Model 4, those who completed university/other were 5 times more likely to participate in self help groups compared to those who had some secondary or less, when controlling for all other variables. These findings reflect the relationship between education and knowledge, which has been found to be associated with a greater likelihood of engaging in self care practices such as self help group participation (Gottlieb & Peters, 1991).

Income was statistically significant only in Model 1. A negative association suggests that those with higher incomes are .65 times less likely to participate in self help groups. Interestingly, this finding is contrary to the literature, which suggests that higher income levels are associated with a greater propensity to engage in self care behaviors. Further, income is often closely related to educational status, and therefore would be expected to result in the same positive association. However, when the illness context,

social support, self efficacy, knowledge and perceived stress variables were controlled for in models 2, 3 and 4, income was not statistically significant.

Perceived health showed a statistically significant relationship in Model 2. A negative association revealed that those who reported their health as excellent compared to poor were less likely to participate in self help groups compared to those who reported their health as poor, while controlling for other sociodemographic and illness context variables. This particular result was found in the expected direction. However, when the social support variables were added in Model 3 and the self efficacy, knowledge and perceived stress variables were added to Model 4, perceived health was not statistically significant.

A statistically significant relationship was found for number of doctor's visits in Models 2, 3 and 4. Those who reported greater numbers of doctor's visits were 1.1 times more likely to participate in self help groups for each visit when controlling for all other variables. This is consistent with the literature, which shows that those who have greater numbers of doctors visits are more likely to engage in self care practices such as self help group participation.

In sum, multivariate analysis revealed that social support (receiving outside help) is predictive of self help group participation (hypothesis 1). The discussion of the bivariate analysis examined the individual items within the seven composite variables which significantly predicted self help group participation: 1) consulting friends/rel. when once diagnosed, 2) consulting friends/rel. now, 3) family/friends help with condition, 4) receive help from outside, and 5) community use. Also, a weak, statistically significant relationship was found at the bivariate level between social

support and self efficacy and knowledge. Furthermore, the logistic regression revealed that knowledge (hypothesis 5) and self efficacy (perceived control) are positively related to self help group participation (hypothesis 7). Hypothesis 5 was confirmed at the bivariate level, however, hypothesis 7 was not. In addition, it was found that social support encourages self help group participation through the imparting of knowledge (hypothesis 2) and an increase in self efficacy (hypothesis 4).

Overall, this study provides partial, yet modest support for the Social Learning Theory in that social support does impact self efficacy and knowledge, however only at the bivariate level. Also, social support (receiving outside help), knowledge (reading on the subject), and self efficacy (perceived control) were significant predictors of self help group participation at the multivariate level. Perceived stress, however, was found to be contrary to the expected negative direction. Partial, modest support for the Social Learning Theory may reflect the fact that the theory is incomplete or that the measures used to represent self efficacy and emotional arousal are unreliable.

The weak support found for the relationship between social support and self help group participation may be due to unreliable or invalid social support measures, which highlights the complexity of the concept of “social support”. Also, the cross sectional design of the study may have limited the effects of social support, since benefits of social support may occur over longer periods of time (lag effect). Furthermore, weak support for the intervening variables (self efficacy, knowledge and perceived stress) may be partly the result of the weak social support findings. However, the results suggest that a certain type of social support is predictive of self help group participation. The variable “receiving outside help” was statistically significant at both the bivariate and multivariate

levels, and reflects social contact that occurs outside the circle of family and friends. Similarly, knowledge was statistically significant at both levels. It is presumed that knowledge is strongly related to education which was also statistically significant in the logistic regression. Also, the number of doctor's visits was significant at the multivariate level. Perhaps social contact with others (such as home support workers), and use of the health care system (doctors visits) involves greater information sharing that is particular to the illness type and self help behavior. However, the degree of complementarity of the informal and formal health systems remains controversial and in need of further study.

With regards to self efficacy, the multivariate analysis revealed that only perceived control was a predictor of self help group participation. At the bivariate level, only higher numbers of confidantes was associated with higher levels of perceived control. Although this thesis presents some evidence for the mediating role of self efficacy as dictated by the Social Learning Theory, the results overall, are modest.

Implications

The results of this thesis reveal that there is a positive relationship between social support and self help group participation, but a modest one. Receiving outside help from others points to the importance of social contact outside the circle of family and friends. It seems that outside contact with others may be a significant way of gaining knowledge and support regarding the chronic condition. This knowledge and support may lead to information and thus inclination to participate in a self help group. Similarly, the number of doctors visits was found to be positively related to self help group participation.

Again, health care utilization may be another avenue through which support and knowledge is transferred for health promotion.

The relationship between knowledge and self help group participation was found to be strong in both the bivariate and multivariate analyses. This reflects the importance of information in encouraging people to engage in self help groups. It may be that greater knowledge about the illness condition may lead to a greater sense of control or self efficacy over coping with the condition. Therefore, a desire to take greater charge of one's illness condition may lead to self help group involvement. It would be beneficial to provide reading materials regarding chronic conditions and self help groups at hospitals and doctor's offices. Further, print advertising/information provided at community centers and senior's centers would be useful for those who do not visit the doctor often, and those who do not interact with others than family and friends. Finally, media advertising and internet information and access would be useful for those who are socially isolated.

In addition, it was found that those who are younger and better educated are more likely to participate in self help groups. This is consistent with the literature and suggests that perhaps those in most need of support or self help groups may be among the older and less educated. This particular group has a greater tendency to suffer from multiple chronic conditions, as well as lower levels of social support and greater levels of disability. One way of improving coping and access to support such as self help groups may be through knowledge and education. Again, the provision of and access to information regarding chronic conditions and self help groups are strongly needed.

Overall, this study does not support the stress-buffering hypothesis of social support. The results indicate that social support does not act as a buffer during times of stress thereby leading to a decline in self help group participation. In fact, there is a positive relationship between social support and self help group participation which indicates that social support does not substitute for other support services. It appears that social support may encourage self care behaviors thus stressing the dual importance of support networks and knowledge for coping with chronic illness.

Limitations of Research

Several methodological issues regarding this thesis indicate some limitations of this research. First, the study used a cross sectional research design. The information from Wave I of the North Shore Self Care Study was collected during telephone interviews, at one point in time. This limitation creates a difficulty in drawing causal relationships between the independent and dependent variables. However, it is possible to make assumptions about causation based on a review of the pertinent literature. A longitudinal analysis of the North Shore Self Care Study would have permitted the investigation of the role of social support in predicting self help group participation over three years, thus enabling conclusions about causation to be drawn.

Second, the sample (n=879) consisted of an elderly population that resided on the North Shore of Vancouver, British Columbia. This particular population is considered predominately Caucasian with upper to middle income levels. This creates problems regarding generalizability to other populations. For example, one cannot generalize the result of this study to elderly populations living in small rural towns, or in areas in which

there is a diversity in ethnic backgrounds and income levels. However, a review of the descriptive statistics indicates that there was a range in income levels within the study thereby making it possible to test the hypotheses using multivariate analysis.

Third, this research is based on a secondary analysis in which all ideal variables were not available for the analysis. For example, it would be interesting to investigate other self efficacy measures such as “efficacy expectancies” and “outcome expectancies” with regards to self help group participation. However, the variables in this data set were sufficient for hypotheses testing.

Future Research

Future research should overcome the limitations outlined above. Ideally, a longitudinal study dedicated primarily to investigating factors that predict self help group participation among older adults with various chronic illnesses would be useful. Also, a larger sample size including variation in ethnic backgrounds and socioeconomic status would be useful in terms of the study’s generalizability.

A longitudinal analysis would allow investigators to test how social support, self efficacy and knowledge factors change over the course of the chronic condition. Also, it would allow for assumption about causation, thus increasing our understanding of the role of social support in self help group participation, over time.

Further, a study that specifically addresses the topic of this thesis would permit the testing of many relevant variables. For example, it would be interesting to test social support in terms of the different types of supports, sources of support, network size, and

quality of the supports. This would determine the exact types of social support that is predictive of self help group participation.

Other measures of self efficacy such as “efficacy expectancy” and “outcome expectancy” would be helpful in determining an individual’s beliefs about one’s self in relation to self help groups. This would involve a measure of the person’s ability to attend, and the person’s view regarding the self help group’s ability to be useful. In the self efficacy literature, both factors have been found to be predictive of other self care behaviors.

Another interesting area of investigation would also involve an examination of the role of personality factors in accounting for coping ability and in predicting self help group participation. For example, health locus of control is considered a stable trait over time, which has implications for a person’s self efficacy, or ability to cope with a stressful situation such as a chronic illness. Also, other personality traits such as introversion/extroversion (Eysenck, 1967) as well as monitoring and blunting styles of coping would be worthy of investigation in future research.

Knowledge was a key predictor of self help groups in this particular study, and should be further investigated in an in-depth manner, in subsequent studies. For example, evaluating specific sources of knowledge such as health care centers, media, books and pamphlets as well as types of advice would be useful in determining the types of advice that are predictive of self help group participation, and how information is transmitted. This would assist in the advertising and recruitment of people who are in need of services such as self help groups.

In addition, it may be useful to incorporate the Theory of Reasoned Action (Ajzen & Fishbein, 1980) or the Theory of Planned Behavior (Ajzen, 1985) as a theoretical basis for future research. The Theory of Reasoned Action requires the investigation of several variables including, behavioral and normative beliefs, attitudes, subjective norms, intention to perform behavior, and the behavior itself (Salazar, 1991). The Theory of Planned Behavior is an expansion of the Theory of Reasoned Action and includes consideration of perceived behavioral control (Millstein, 1996). Perceived behavioral control “reflects personal beliefs as to how easy or difficult adoption of the behavior is likely to be, and how beliefs about resources and opportunities may thus be viewed as underlying perceived behavioral control” (Godin, 1994). Thus, the Theory of Reasoned Action or the Theory of Planned Behavior may be utilized to alleviate the potential inadequacy of the Social Learning Theory (Bandura, 1977) in predicting self help group participation among older adults with a chronic illness.

Chapter VI

Summary and Conclusion

The principal goal of this thesis was to investigate the role of social support in predicting self help group participation. Of particular interest was the role of the intervening factors (self efficacy, knowledge, perceived control) which were hypothesized to mediate the relationship between social support and self help group participation.

The review of the literature (Chapter 1) clearly demonstrated the benefits of self help groups and the role of social support in predicting self care behaviors. Interestingly, the overall prevalence of self help group participation among the elderly has been low, despite the increasing numbers of elderly suffering from chronic conditions.

Chapter 2 presented a review of Bandura's Social Learning Theory. Seven hypothesis were developed from this review and investigated the role of self efficacy, knowledge and perceived stress as mediating factors between social support and self help group participation.

Chapter 3 described the research methodology including the data source, and sample. Information about measurement, frequencies and missing data was presented.

Chapter 4 described the bivariate and multivariate analyses. At the bivariate level, the main findings were that 1) social support (consult friends/relatives when once diagnosed, consulting friends/relatives now, family/friends help with the condition, receive outside help) and knowledge (reading on the subject) were positively related to self help group participation, 2) higher stress was associated with self help group

participation, 3) social support (consult friends/relatives when once diagnosed, consulting friends/relatives now, family/friends help with condition, # of confidants) was positively associated with knowledge (reading on the subject), 4) social support (consult friends/relatives when once diagnosed, consulting friends/relatives now, family/friends help with the condition, received outside help) was positively related to perceived stress, 5) one social support variable (# of confidants) showed a positive relationship with self efficacy, 6) other social support variables (consult friends/relatives when once diagnosed, family/friends help with the condition, receive outside help, community use) resulted in a negative association with self efficacy. Multivariate analyses revealed that receiving outside help, reading on the subject and perceived control were predictive of self help group participation, after controlling for all other variables. Those who received outside help a few times per week or on a daily basis were more likely to participate in self help groups. Similarly, those who were reading on the subject and who perceived greater control over their condition were more likely to participate in self help groups. Also, age, education and number of doctor's visits were predictive of engaging in a self help group. Younger elderly, who have more education and a greater number of doctors visits were more likely to participate in a self help group.

A discussion of results and their integration into Bandura's Social Learning Theory were provided in Chapter 5. The results of this thesis, indicate modest support for the hypotheses which were based on the Social Learning Theory. Most of the social support variables were predictive of self help group participation, however, only at the bivariate level. Receiving outside help was the only social support variable that predicted self help group participation after controlling for all other variables. Similarly, social

support was predictive of knowledge and self efficacy at the bivariate level. Yet, the relationship between social support and perceived stress resulted in a negative association. Furthermore, of the two self efficacy variables, only perceived control was predictive of self help group participation after controlling for all other variables. Also, knowledge was a consistent predictor of self help group participation at both the bivariate and multivariate levels. Thus, the findings indicate that, compared to knowledge, the mediating role of self efficacy and perceived stress are less clear. Also, the finding that “receiving outside help” was the only social support variable that was statistically significant in the logistic regression suggests that a certain type of social support involving others besides family and friends may be important in terms of the provision of knowledge and thus self help group participation.

Limitations of the research as well as suggestions for future research were also discussed. It was suggested that future research should involve a longitudinal study dedicated to the investigation of the role of social support in predicting self help group participation among older adults. Also, issues involving generalizability, and the inclusion of relevant variables for in-depth testing of social support, self efficacy and knowledge were presented. It is hoped that this thesis will encourage other researchers to take such limitations into consideration, in the investigation of the important role of social support, self efficacy, and knowledge in predicting self help group participation among older adults with chronic illnesses.

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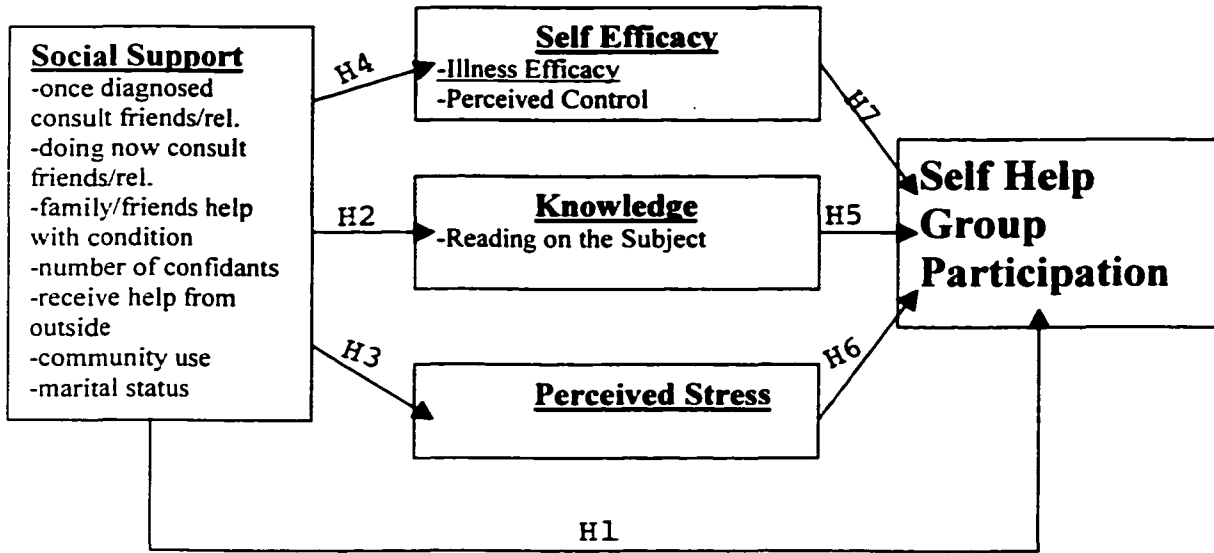
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Appendix A: Bivariate Analyses



Appendix B: Multivariate Analyses

Logistic Regression				
Dependent Variable: Self Help Group Participation				
Independent Variables:				
Blocks	1	2	3	4
	<u>Demographics</u> -age -sex -education -income	<u>Demographics</u> -age -sex -education -income	<u>Demographics</u> -age -sex -education -income	<u>Demographics</u> -age -sex -education -income
		<u>Illness Context</u> -most serious condition -perceived seriousness -duration -perceived health -comorbidity -# doctors visits -# prescriptions	<u>Illness Context</u> -most serious condition -perceived seriousness -duration -perceived health -comorbidity -# doctors visits -# prescriptions	<u>Illness Context</u> -most serious condition -perceived seriousness -duration -perceived health -comorbidity -# doctors visits -# prescriptions
			<u>Social Support</u> -once diagnosed consult friends -doing now consult friends -family/friends help with condition -# confidants -receive help from outside -marital status -community use	<u>Social Support</u> -once diagnosed consult friends -doing now consult friends -family/friends help with condition -# confidants -receive help from outside -marital status -community use
				<u>Knowledge</u> -reading on the subject
				<u>Perceived Stress</u>
				<u>Self Efficacy</u> -illness efficacy -perceived control

Appendix C: North Shore Self Care Study Questionnaire

North Shore Self-Care Project

INITIAL CALL/PITCH CONSENT STATEMENT AND SCREEN

Hello, my name is _____ and I work for Points of View Research Inc.

North Shore Health and Simon Fraser University are conducting a telephone survey to find out how people cope with chronic health problems.

Have you, or any one else in your household aged 50 or older, been professionally diagnosed as having arthritis/rheumatism, heart problems, a stroke or high blood pressure?

We want to invite you (**OR A NAMED PERSON IN THE HOUSEHOLD**) to participate in a three-part study. The first part of this study will take place this month. It will consist of a 1/2 hour telephone survey. We will call you back in one year's time for another 1/2 hour, and then for the last time 1 year after that.

This study is very important and will help us to plan better health care for people living on the North Shore and elsewhere in Canada. All participants will have a chance to win \$500 in the study lottery for taking part and will receive information about community health resources.

Any information that you give us will be kept strictly confidential. Your name will not appear on any written reports. We will use a numbering system to link your answers to the three phone calls. For example, you might be number 27. Also, no one will be given your name or personal information. You may withdraw from the study at any time and you may refuse to answer any question that you do not feel comfortable in answering.

Your phone number has been selected by a random digit dialing system. Would this be a good time for you?

IF THEY SAY YES:

First I need to ask you a few questions to see if you fit our study criteria. **[GO TO SCREEN]**

IF UNDECIDED/TOO BUSY/UNSURE:

We would be happy to mail you some additional information if you want to think about it. We can call you at a later date. Could you please give me your name and address? Thank you

Name and Address: _____

IF THEY DO NOT FIT THE STUDY CRITERIA OR THEY ARE NOT INTERESTED:

Is there anyone else in your household aged 50 or older who is trying to cope with one of these illnesses and who might like to participate? **[IF YES, REPEAT STUDY DESCRIPTION AND SCREEN].**

IF THEY FIT CRITERIA, ASK:

Would this be a convenient time for you to do the 1/2 hour phone interview? **[IF NOT, MAKE APPOINTMENT]**

[Get name & address for everyone - if they are reluctant, explain that this is the 1st of 3 interviews so we need to keep in touch]

Name, Phone Number, Date and Time of Interview:

Screen:

1. What is the month and year of your birth?

___ month ___ year

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
month		year	

2. As an adult, have you ever been told by a health professional (such as a doctor, nurse, or physiotherapist) that you have arthritis or rheumatism?

- 1 Yes
2 No

3. As an adult, have you ever been told by a health professional (such as a doctor, nurse, or physiotherapist) that you have any of the following specific heart problems?

- ___ angina
- ___ irregular heart beat (rhythmic heart beat,
heart murmur, valve problem)
- ___ heart attack (ischemic)
- ___ congestive heart failure (CHF)
- ___ stroke
- ___ other (specify) _____

4. As an adult, have you ever been told by a health professional (such as a doctor, nurse or physiotherapist) that you have high blood pressure?

- 1 Yes
2 No

[IF MORE THAN ONE CONDITION; ASK: "WHICH CONDITION (ARTHRITIS/HEART PROBLEMS/STROKE/HIGH BLOOD PRESSURE) IS THE MOST LIMITING IN YOUR DAY-TO-DAY ACTIVITIES/WHICH HEALTH PROBLEM DO YOU FEEL IS MORE SERIOUS?"] [IF NECESSARY: "WHICH ONE DO YOU FEEL COULD POTENTIALLY BE THE MOST SERIOUS?"]

5. Most serious health problem [EVERYONE] (Circle One):

ARTHRITIS

STROKE

HEART PROBLEMS

HIGH BLOOD PRESSURE

SECTION A: STAGES OF CHANGE MEASUREMENT

IF AN APPOINTMENT WAS MADE:

"During our initial contact, you said that you had been professionally diagnosed as having [REPEAT MOST SERIOUS HEALTH PROBLEM]

1. I'm going to read you a list of specific things that some people do to cope with their condition. Please tell me if you are already doing it, or you are seriously intending to try each of the following things to cope with your (ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)? USE ANSWER #6 ONLY IF ABSOLUTELY NECESSARY [READ and MARK ALL THAT APPLY AND PROBE: "Anything else?"

- 1 Already been doing for six months or more
- 2 Tried for less than six months and still doing it
- 3 Tried for less than six months and stopped (or tried a bit)
- 4 Intending to try
- 5 Not intending to try
- 6 Do not feel it is necessary/NA

- | | |
|---|-----------------------------|
| 1 Engage in regular exercise, sports or physical activity for 15 minutes or more, at least three times per week | 1 <input type="checkbox"/> |
| 2 Increase exercise, sports or physical activity | 2 <input type="checkbox"/> |
| 3 Lose weight | 3 <input type="checkbox"/> |
| 4 Change diet or eating habits | 4 <input type="checkbox"/> |
| 5 Quit smoking/reduce amount smoked | 5 <input type="checkbox"/> |
| 6 Reduce drug/medication use | 6 <input type="checkbox"/> |
| 7 Drink less alcohol | 7 <input type="checkbox"/> |
| 8 Manage or reduce cholesterol | 8 <input type="checkbox"/> |
| 9 Learn to manage or reduce stress, such as relaxation | 9 <input type="checkbox"/> |
| 10 Change physical environment, such as install a grab bar or railings | 10 <input type="checkbox"/> |
| 11 Receive medical treatment, not inclu. medication | 11 <input type="checkbox"/> |
| 12 Sleep more | 12 <input type="checkbox"/> |
| 13 Begin to meditate | 13 <input type="checkbox"/> |
| 14 Increase or change amount of meditation → | 14 <input type="checkbox"/> |
| 15 Get more social/emotional support from friends, family or others | 15 <input type="checkbox"/> |
| 16 Try herbal medicine | 16 <input type="checkbox"/> |
| 17 Try alternative therapies, such as acupuncture or hypnosis | 17 <input type="checkbox"/> |
| 18 Nothing | 18 <input type="checkbox"/> |
| 19 Other (specify) _____ | 19 <input type="checkbox"/> |
| 20 Other (specify) _____ | 20 <input type="checkbox"/> |

2. [INTERVIEWER: REPEAT CODE 1 AND 2 ANSWERS FROM #4 AND ASK:] Which one of these health behaviours do you believe is the most important one for you to cope with or improve your condition? (98=Don't Know/No Answer)

_____ (number)

3. How serious do you think that your condition is at the present time?

- 0 Not at all serious
- 1 Slightly serious
- 2 Moderately serious
- 3 Extremely serious

SECTION B: SELF-HELP, SELF CARE, MUTUAL AID,

1. The next questions are about self-help groups of any kind. By self-help group, we mean a community group where people voluntarily come together to share and discuss a common interest, or experience. For example, groups for people who have had a stroke, groups for recently widowed or divorced people, or Alcoholic Anonymous, and so on. Are you aware of any of self-help groups in your community?

- 1 Yes
- 2 No (Go to #8)
- 9 Don't Know/Not Sure

2. During the past twelve months, did you participate in a self-help group in which people with a common problem help each other?

- 1 Yes (Go to #4a)
- 2 No (Go to #3)
- 9 Don't Know/Not Sure(Go to #3)

3. Have you ever belonged to a self-help group of any kind?

- 1 Yes (Go to #4a)
- 2 No (Go to #8)
- 9 Don't know (Go to #8)

4a. If YES: Could you please tell me the name of the group, and when you joined the group? [INTERVIEWER: PROBE - "Were there any other groups? Use two digits each to identify month/year]

<u>Organization</u>	<u>Start Date</u>	<u>End Date</u>	<u>Start Month/Year</u>	<u>End Month/Year</u>
1. _____	_____	_____	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	month/year	month/year		
2. _____	_____	_____	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	month/year	month/year		
3. _____	_____	_____	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	month/year	month/year		
4. _____	_____	_____	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
	month/year	month/year		

4b. Were any of these groups specifically joined to cope with your condition? Which were they? [CHECK ANY THAT APPLY TO Q4A]

1.

2.

3.

4.

5. What initially led you to join _____? [REPEAT NAME OF GROUP ONE AT A TIME] [CHOOSE ONE ANSWER ONLY]

	#1	#2	#3
1 Friend/neighbour/family member referred me to the group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 A health professional recommended it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Read about the group in the paper and called for further information/attended a meeting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Made a decision to join the group after exhausting other options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Do you plan on continuing or resuming participation in _____? [READ NAME OF EACH GROUP]

	#1	#2	#3
1 Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 No (Go to #11)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Not sure/Maybe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. For how long? [READ NAME OF EACH GROUP]

- 1 Indefinitely
- 2 Until condition improves
- 3 As long as the group meets
- 4 Not sure (Go to #12)

#1	#2	#3
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

GO TO #12

FOR NO ANSWERS: (Go To #3)

8. Have you ever seriously considered joining a self-help group to help improve your _____ (ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)?

- 1 Yes
- 2 No (Go to #10)

9. IF YES,

What has kept you from participating? [PROBE]

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

10. For what reason(s) did you not seriously consider joining a self-help group?

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

11. Do you seriously plan to join a self-help group in the next year?

- 1 Yes
- 2 No
- 3 Maybe
- 9 Don't Know

12. "I'm going to read you a list of services or organizations and then ask you some questions about them, which you can answer with a yes or no. Have you heard of..." [INTERVIEWER]:

	a	b	c	d	e
	<u>Have You</u> <u>Heard of?</u> (If No, Go To Next Service)	<u>Do You</u> <u>Know What</u> <u>They Do?</u> (If No, Go To Next Service)	<u>Have You</u> <u>Ever Used?</u>	<u>Do You</u> <u>Seriously</u> <u>Intend To</u> <u>Use (Again)?</u>	<u>Do You Think</u> <u>That They</u> <u>Could (Have)</u> <u>Help(ed) You?</u>
Type of Organization/Service					
a. Handy Dart	_____	_____	_____	_____	_____
b. North Shore Health	_____	_____	_____	_____	_____
c. North Shore Home Support Services	_____	_____	_____	_____	_____
d. North Shore Keep Well Society	_____	_____	_____	_____	_____
e. North Shore Meals on Wheels	_____	_____	_____	_____	_____
f. North Shore Neighbourhood House	_____	_____	_____	_____	_____
g. North Shore Seniors' Peer Counsellors	_____	_____	_____	_____	_____
h. North Shore Stroke Recovery Centre (CVA)	_____	_____	_____	_____	_____
i. North Shore Volunteers for Residents In Care Facilities	_____	_____	_____	_____	_____
j. S.A.F.E.R.	_____	_____	_____	_____	_____
k. Seniors' Hub	_____	_____	_____	_____	_____
l. Seniors' One-Stop Information Line	_____	_____	_____	_____	_____
m. West Vancouver Seniors' Special Services	_____	_____	_____	_____	_____
n. Silver Harbour Centre	_____	_____	_____	_____	_____
o. West Vancouver Seniors' Activity Centre	_____	_____	_____	_____	_____

SECTION C: HEALTH STATUS AND HEALTH CARE UTILIZATION

"Now I would like to ask you a few questions about your health"

1. In general, compared to other people your age, would you say that your health is...
- 1 Excellent?
 - 2 Good?
 - 3 Fair?
 - 4 Poor?



2. On average over the last 6 months, how many times per week are you physically active for at least 15 minutes, such as brisk walking, jogging, dance classes, and weight lifting?

- a Daily
- b 5 -6 times a week
- c 3 - 4 times a week
- d 1 - 2 times a week
- e Less than once a week
- f Never
- g Don't Know

3. How often do you smoke cigarettes?

- 1 Regularly
- 2 Occasionally
- 3 Never

4. On average, how many drinks do you have per week, or month?
 [IF IN WEEKS, CONVERT TO MONTHS=MULTIPLY BY 4.3 AND AVERAGE TO WHOLE NUMBER]

5. How stressful is your life in your opinion?

- 0 Not stressful at all
- 1 A little stressful
- 2 Moderately stressful
- 3 Very stressful

6. How much control do you think you currently have over your _____
 (ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)?

- 0 No control
- 1 A little control
- 2 Moderate control
- 3 Complete control

7. I'm going to read you a list of health problems. Please tell me if you have been professionally diagnosed as currently having any other of these conditions.

- | | | |
|--|----|--------------------------|
| 1. Asthma/Emphysema | 1 | <input type="checkbox"/> |
| 2. Anxiety | 2 | <input type="checkbox"/> |
| 3. Depression | 3 | <input type="checkbox"/> |
| 4. Cancer | 4 | <input type="checkbox"/> |
| 5. Diabetes | 5 | <input type="checkbox"/> |
| 6. Neurological Diseases, such as Parkinson's Disease, M.S. or Cerebral Palsey | 6 | <input type="checkbox"/> |
| 7. Alzheimer's or Related Condition. | 7 | <input type="checkbox"/> |
| 8. Osteoporosis | 8 | <input type="checkbox"/> |
| 9. Vision Problems | 9 | <input type="checkbox"/> |
| 10. Hearing Problems | 10 | <input type="checkbox"/> |
| 11. Other (Specify) _____ | 11 | <input type="checkbox"/> |
| 12. Other (Specify) _____ | 12 | <input type="checkbox"/> |

"Now I would like to ask you about your use of medicines and pills"

8. How many prescription medications are you presently taking on a regular basis?
[Circle Correct Number]

- | | |
|---------|--------------|
| 0 none | 11 eleven |
| 1 one | 12 twelve |
| 2 two | 13 thirteen |
| 3 three | 14 fourteen |
| 4 four | 15 fifteen |
| 5 five | 16 sixteen |
| 6 six | 17 seventeen |
| 7 seven | 18 eighteen |
| 8 eight | 19 nineteen |
| 9 nine | 20 twenty |
| 10 ten | |

9. In the past three months have you regularly used....

- a) Tranquilizers such as Valium?
- b) Diet pills or stimulants?
- c) Anti-depressants?
- d) Codeine, Demerol or Morphine?
- e) Sleeping pills?
- f) Aspirin or Tylenol?
- g) Entrophine
- h) other anti-inflammatories
- i) diuretics
- j) other _____
- k) other _____

a

b

c

d

e

f

g

h

i

j

k

10a. In the past three months, how many medical visits did you make to:

- a. any health professional
- b. doctors

a

b

c

c. How many of these visits were specifically for your _____ (CONDITION)

10b. In the last three months, how many visits did you make for:

d. rehabilitation, physiotherapy, or occupational therapy (but not massage therapy) with regards to your specific condition?

d

e. Massage therapy for your condition?

e

11. In the last three months, were you admitted to a hospital?

- 0 Yes
- 1 No (Go to #13)

12. If yes, for what reason and for how long?

Reason #1 _____

1

Number of Days _____

Reason #2 _____

2

Number of Days _____

Reason #3 _____

3

Number of Days _____

13. In the last three months, how many days were you away from work or unable to do the things you normally do because you were sick, or disabled? (Don't Know = 98)

_____ days

14. Are you restricted in the things that you like to do? Would you say[READ]:

- 1 most of the time?
- 2 some of the time?
- 3 seldom?
- 4 never?

15. Overall, how well do you feel that you are coping with your _____
(ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)?

- 0 Not at all successful
- 1 A little successful
- 2 Moderately successful
- 3 Very successful

16. I am going to ask you how important each of the following things are in coping with your
 _____ (ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)?

How important is/are:

- 0 Not at all important
 1 A little bit
 2 Moderately important
 3 Very important
 9 = NA

a) Medical treatment that you receive?

a

b) Your family or friends?

b

c) Your general state of health?

c

d) Your own determination?

d

e) Prayer or spiritual help?

e

f) Alternative remedies or medicines, such as herbs, acupuncture
 and hypnosis

f

g) A positive attitude?

g

h) A higher income?

h

i) Exercising more or being more physically active?

i

j) Losing weight?

j

k) Stopping smoking?

k

l) Cutting down on drinking?

l

m) Changing drug use or medications?

m

n) Learning to relax more and worry less?

n

o) Joining a self-help group?

o

1. Could you tell me when you were first professionally diagnosed (by a doctor, nurse, physiotherapist etc.) with _____ (ARTHRITIS/A HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)

_____ MONTH _____ YEAR

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

_____ DO NOT RECALL

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

[DON'T KNOW 9999]

2. Who was this health professional?

- 1 family doctor
- 2 community nurse
- 3 specialist
- 4 physiotherapist
- 5 other (SPECIFY) _____

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

3. People try various things to improve their health problem:

A. Thinking back, before you were professionally diagnosed with _____ (ARTHRITIS/ HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE), did you: [READ LIST BELOW, THEN ASK A4,5,6 & 7 ON NEXT PAGE]

B. Once professionally diagnosed with _____ (ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE), did you [READ LIST BELOW, THEN ASK B4,5,6 & 7 ON NEXT PAGE]

C. Which of these are you doing now? [READ LIST BELOW, THEN ASK C4, 5, 6, & 7 ON NEXT PAGE]

- | | A | B | C |
|---|--------------------------|--------------------------|--------------------------|
| 1 take any non-prescription medications, such as ASA | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 take someone else's prescribed medications | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 take medications as prescribed by your doctor [READ ONLY FOR B AND C] | | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 try alternative remedies, such as herbs, acupuncture and hypnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 consult friends/relatives | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 consult anyone who has the same condition as you | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7 do some reading on the subject | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 exercise, or become physically active | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 change your physical environment, such as add railings | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10 change your diet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11 reduce your salt intake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 lose or gain weight | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13 join a self-help group | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14 try meditation or praying | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 15 reduce your alcohol consumption [9=DIDN'T DRINK/DON'T DRINK]
- 16 cut back on smoking [9=DIDN'T SMOKE/DON'T SMOKE]
- 17 quit smoking [9=DIDN'T SMOKE/DON'T SMOKE]
- 18 try to reduce stress
- 19 sleep or rest more
- 20 wait to see if it would improve

A	B	C
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

[READ BACK ALL YES ANSWERS FOR 'A' COLUMN]

A4. Which of these did you do first?
(98=Don't Know, 99=NA, 30=About Same)

A5. Which did you do second?
(98=Don't Know, 99=NA, 30=About Same)

A6. Which did you do third?
(98=Don't Know, 99=NA, 30=About Same)

A7. What or who prompted you to do this? [VERBATIM]

[READ BACK ALL YES ANSWERS FOR 'B' COLUMN]

B4. Which of these did you do first?
(98=Don't Know, 99=NA, 30=About Same)

B5. Which did you do second?
(98=Don't Know, 99=NA, 30=About Same)

B6. Which did you do third?
(98=Don't Know, 99=NA, 30=About Same)

B7. What or who prompted you to do this? [VERBATIM]

[READ BACK ALL YES ANSWERS FOR 'C' COLUMN]

C4. Which of these did you do first?
(98=Don't Know, 99=NA, 30=About Same)

C5. Which did you do second?
(98=Don't Know, 99=NA, 30=About Same)

C6. Which did you do third?
(98=Don't Know, 99=NA, 30=About Same)

C7. What or who prompted you to do this? [VERBATIM]

SELF-CARE:

1. Regarding your blood pressure, how many months ago did you last have your blood pressure checked?

_____ months

2. Do you take your own blood pressure either at home or at the drug store?

- 1 Yes
- 2 No

MUTUAL AID

1. About how often do you discuss your condition with another person who also has
_____ (ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)?

- 1 daily
- 2 at least once a week
- 3 every two weeks
- 4 at least once a month
- 5 every couple of months
- 6 few times a year
- 7 never (Go to #4)

2. In what ways would you say this person helped you to improve your _____
(ARTHRITIS/HEART PROBLEM/STROKE/HIGH BLOOD PRESSURE)? [VERBATIM]

3. How helpful is this person in managing your condition?

- 0 Not helpful
- 1 A little helpful
- 2 Moderately helpful
- 3 Extremely helpful

4. How good a job do you feel that you are doing in taking care of your condition? Would you say...

- 1 Excellent?
- 2 Good?
- 3 Fair?
- 4 Poor?

SECTION D: SOCIAL SUPPORT

1. There are many ways in which people help one another. How often do you provide help to someone else inside or out of your household, such as housework, shopping, driving, money management, or personal care?

- 0 Never
- 1 A few times per year
- 2 Monthly
- 3 A few times per month
- 4 Weekly
- 5 A few times per week
- 6 Daily

2. I am now going to ask you about help you have received on a regular basis.

How often do you receive help with such things as housework, shopping, driving, money management, or personal care?

- 0 Never
- 1 A few times per year
- 2 Monthly
- 3 A few times per month
- 4 Weekly
- 5 A few times per week
- 6 Daily

3. How many people do you have with whom you can confide about personal matters?

4a. Does family or a friend regularly help you with your condition?

- 1 Yes
- 2 No

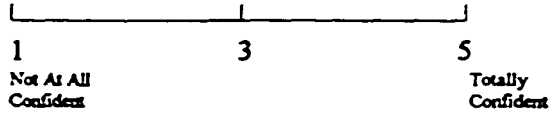
4b. How often do you receive this assistance?

- 0 Never
- 1 A few times per year
- 2 Monthly
- 3 A few times per month
- 4 Weekly
- 5 A few times per week
- 6 Daily

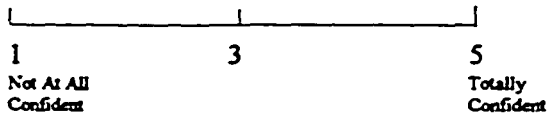
[ARTHRITIS ONLY, (HEART PROBLEMS GO TO #6, STROKE GO TO #7, HIGH BLOOD PRESSURE GO TO #8)]

5. I am going to ask you how confident you are about your ability to control different aspects of your condition. On a scale of 1 to 5, where 1 is not at all confident, and 5 is totally confident, how confident are you that you can... [9=NOT APPLICABLE]
(Circle Number)

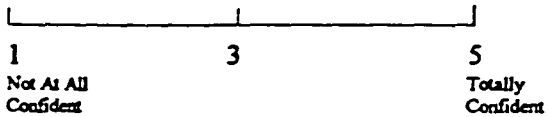
a) Control your fatigue?



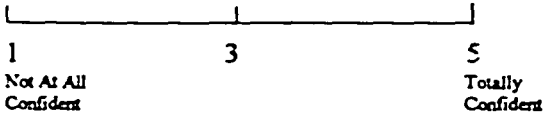
b) Regulate your activities so as to be active without aggravating your arthritis?



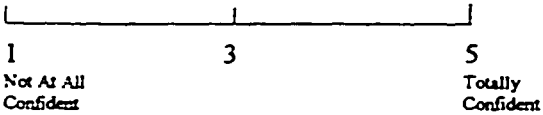
c) Do something to help yourself feel better if you are feeling blue?



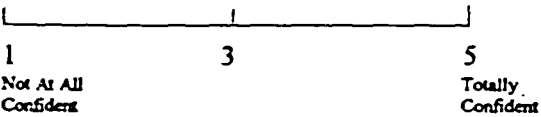
d) Manage arthritis pain during your daily activities (compared to other people with arthritis like yours)?



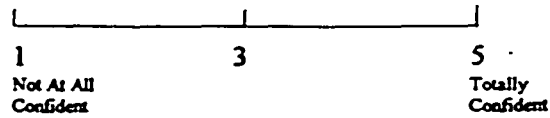
e) Manage your arthritis symptoms so that you can do the things you enjoy doing?



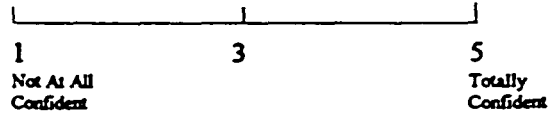
f) Deal with the frustration of arthritis?



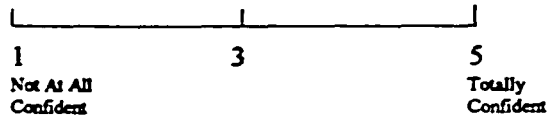
g) Decrease your pain quite a bit?



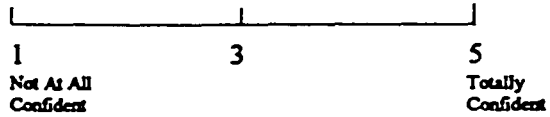
h) Continue most of your daily activities?



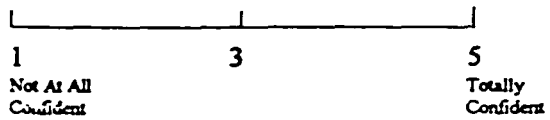
i) Keep arthritis pain from interfering with your sleep?



j) Make a small-to-moderate reduction in your arthritis pain by using methods other than taking extra medication?



k) Make a large reduction in your arthritis pain by using methods other than taking extra medications?

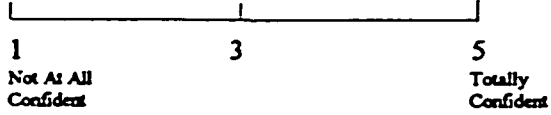


[Go to #9]

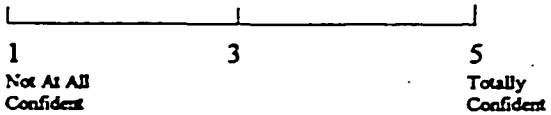
[HEART PROBLEMS ONLY, (STROKE GO TO #7, HIGH BLOOD PRESSURE GO TO #8)]

6. I am going to ask you how confident you are about your ability to control different aspects of your condition. On a scale of 1 to 5, where 1 is not at all confident and 5 is totally confident, how confident are you that you can... [9=NOT APPLICABLE]
(Circle Number)

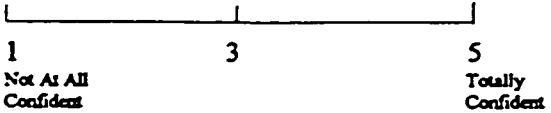
a) Control your fatigue?



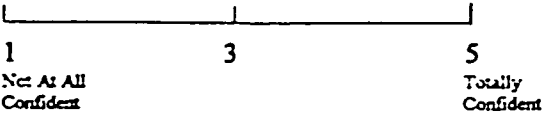
b) Regulate your activity so as to be active without aggravating your heart problem?



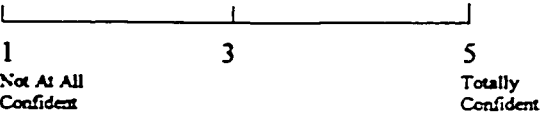
c) Do something to help yourself feel better if you are feeling blue?



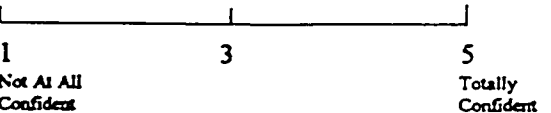
d) Manage your heart problem symptoms so that you can do the things you enjoy doing?



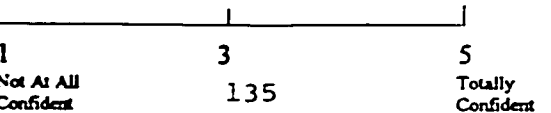
e) Deal with the frustration of heart problems?



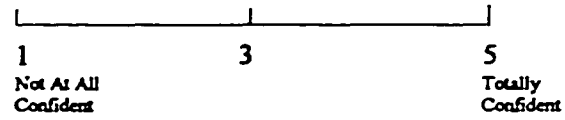
f) Continue most of your daily activities?



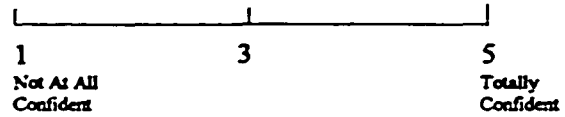
g) Keep your heart problems from interfering with your sleep?



h) Make a small-to-moderate reduction in your heart problems by using methods other than taking extra medication?



i) Make a large reduction in your heart problems by using methods other than taking extra medication?

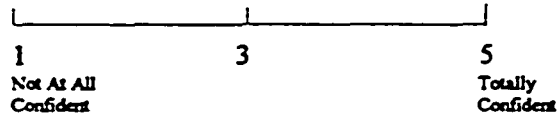


[Go to #9]

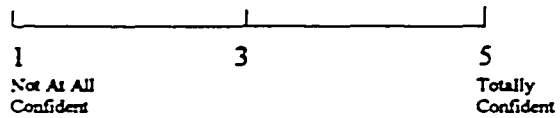
[STROKE ONLY, (HIGH BLOOD PRESSURE GO TO #8)]

7. I am going to ask you how confident you are about your ability to control certain aspects of your condition. On a scale of 1 to 5, where 1 is not at all confident and 5 is totally confident, how confident are you that you can... [9=NOT APPLICABLE] (Circle Number)

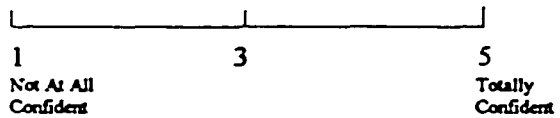
a) Control your fatigue?



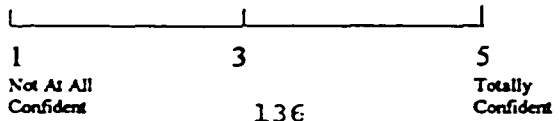
b) Regulate your activity so as to be active without bringing on another stroke?



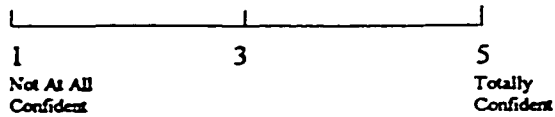
c) Do something to help yourself feel better if you are feeling blue?



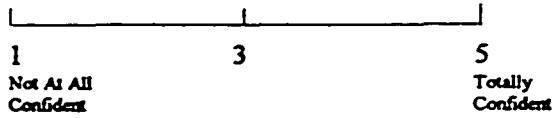
d) Manage your stroke symptoms so that you can do the things you enjoy doing?



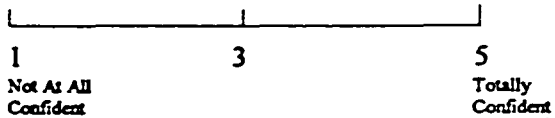
e) Deal with the frustration of stroke problems?



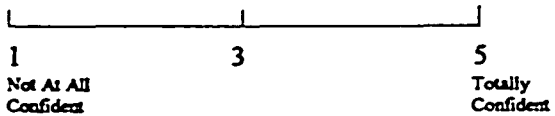
f) Continue most of your daily activities?



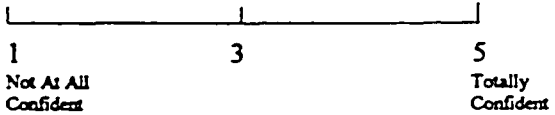
g) Keep your stroke problems from interfering with your sleep?



h) Make a small-to-moderate reduction in problems related to your stroke by using methods other than taking extra medication?



i) Make a large reduction in the problems that resulted from your stroke by using methods other than taking extra medication?

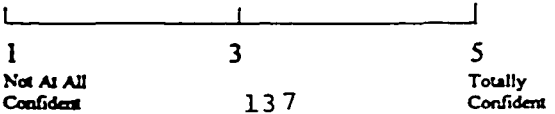


[Go to #9]

HIGH BLOOD PRESSURE

8. I am going to ask you how confident you are about your ability to control certain aspects of your condition. On a scale of 1 to 5, where 1 is not at all confident and 5 is totally confident, how confident are you that you can... [9=NOT APPLICABLE]
(Circle Number)

a) Control your fatigue?



b) Regulate your activity so as to be active without aggravating your high blood pressure?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

c) Do something to help yourself feel better if you are feeling blue?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

d) Manage your high blood pressure symptoms so that you can do the things you enjoy doing?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

e) Deal with the frustration of high blood pressure?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

f) Continue most of your daily activities?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

g) Make a small-to-moderate reduction in your high blood pressure by using methods other than taking extra medication?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

h) Make a large reduction in your high blood pressure by using methods other than taking extra medication?

-----			<input type="checkbox"/>
1	3	5	
Not At All		Totally	
Confident		Confident	

ASK EVERYONE:

9. These questions are about how you feel and how things have been with you during the past month.

How much time during the past month.... [PROBE FOR LEVEL]

	<u>None of the time (1)</u>	<u>Little/ Some of the time (2)</u>	<u>Most of the time(3)</u>	<u>All of the time(4)</u>	
a) Did you feel depressed?	_____	_____	_____	_____	a. <input type="checkbox"/>
b) Have you been in firm control of your behaviour, thoughts, emotions and feeling?	_____	_____	_____	_____	b. <input type="checkbox"/>
c) Did you feel that you had nothing to look forward to?	_____	_____	_____	_____	c. <input type="checkbox"/>
d) Have you felt emotionally stable?	_____	_____	_____	_____	d. <input type="checkbox"/>
e) Were you generally satisfied with your life?	_____	_____	_____	_____	e. <input type="checkbox"/>
f) Did you have enough energy to do the things you wanted to do?	_____	_____	_____	_____	f. <input type="checkbox"/>
g) Has your daily life been full of things that were interesting to you?	_____	_____	_____	_____	g. <input type="checkbox"/>

SECTION E: BACKGROUND INFORMATION

"I would like to finish by asking you some background questions."

1. Sex: [INTERVIEWER CODE] _____ 0 male or _____ 1 female?

2. Are you currently married/common-law, separated, divorced, or widowed and how long?

- 1 married/common law # months / # years _____ 1
- 2 separated # months / # years _____ 2
- 3 divorced # months / # years _____ 3
- 4 widowed # months / # years _____ 4
- 5 single, never married [99] _____ 5

3. Are you currently living alone? yes (1) _____ no (2) _____

IF NO, IS THIS...

- a) a spouse/partner? 1 yes _____ 0 no _____ a
- b) a son or daughter (or son/daughter in law) 1 yes _____ 0 no _____ b
- c) a sibling (sister/brother) 1 yes _____ 0 no _____ c
- d) other (specify) _____ d

4. I would like to know which of the following income categories best describes your total annual household income:

- 1 less than \$20,000
- 2 \$20,000 - 49,999
- 3 \$50,000 - 69,999
- 4 \$70,000 - 99,999
- 5 over \$100,000
- 6 not stated

5. What type of home do you live in?

- 1 your own, single detached house
- 2 your own condominium
- 3 a rented single, detached house
- 4 a rented apartment
- 5 townhouse
- 6 suite in someone else's home
- 7 other (specify) _____

6. To which ethnic or cultural group do you belong? [VERBATIM]

7. What is the highest grade or level of education that you have ever attended or completed? [MARK ONLY ONE]

- 1 No schooling
- 2 Some Elementary
- 3 Completed Elementary
- 4 Some Secondary
- 5 Completed Secondary
- 6 Some Community College, technical college, CEGEP
- 7 Completed Community College, technical college, or nurse's training
- 8 Some University
- 9 Completed University such as, B.A., M.A., Ph.D. or teachers college
- 10 Other education or training

8. Which of the following best describes your main activity during the last three months? Were you mainly...

- 1 Working at a job or business
- 2 Looking for work
- 3 A student
- 4 Retired?
- 5 Keeping house
- 6 Other

9. How many weeks did you work at a job or business during the last three months? (Include paid and unpaid work eg. volunteer, homemaking, etc.)

_____ Weeks

10. What kind of work do (did) you do?

11. Finally, are you currently participating in any other research studies? If so, could you please tell me the name of the study (or a little bit about the study/who is carrying out/sponsoring)? [99=NOT APPLICABLE]

Name of Study _____

Purpose _____

12. [INTERVIEWER INFORMATION] DATE AND TIME OF INTERVIEW

TIME _____
(Do not code)

<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Day	Month	Year

Thank-you for your participation.....