

THE IMPACT OF A TELEPHONE CONTACT PROGRAM
ON PHYSICAL AND PSYCHOLOGICAL FUNCTIONING,
LEVEL OF PAIN AND PERCEIVED SOCIAL SUPPORT
AMONG ELDERLY FEMALES WITH ARTHRITIS

By

GREGORY TAYLOR

B.A., The University of British Columbia, 1986

B.S.W., The University of British Columbia, 1989

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SOCIAL WORK

in

THE SCHOOL OF SOCIAL WORK

in

THE FACULTY OF GRADUATE STUDIES
We accept this thesis as conforming

to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

November, 1990

© Gregory Taylor, 1990

In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of Social Work

The University of British Columbia
Vancouver, Canada

Date December 7, 1990

ABSTRACT

Having identified the need to provide services to elderly, homebound people with arthritis, the Social Work Department at the Vancouver Arthritis Centre initiated an Arthritis Telephone Contact Program in Autumn, 1989. The purpose of this study was to investigate whether or not a weekly telephone call from volunteers would impact positively on subjects' physical and psychological functioning, level of pain and perceived level of social support. The 11 subjects in this study were elderly, Caucasian women identified by health care professionals as being socially isolated due, in part, to the limits placed on them by either osteoarthritis or rheumatoid arthritis.

The one-group pretest-posttest research design was employed for this study. Quantitative measures used were the Arthritis Impact Measurement Scales (AIMS) and the Perceived Social Support From Friends and From Family Scale (PSS-Fr & Fa). Interviews of subjects were conducted in order to describe the efficacy of the Telephone Contact Program from more than one perspective.

Over 16 weeks, paired t-test found that the physical functioning of subjects had improved significantly. It was noted that there was a trend towards improved health status for the experimental group in that seven out of the eight subscales of AIMS measured improvement, while one subscale showed no change. Contrary to prediction, perception of social support from family members decreased significantly, as measured by the PSS-Fa scale. Pearson correlation coefficients found no association between changes in perception of social support and changes in health status. Interview data suggests that callers were perceived as sources of social support. Specifically, callers seemed to provide participants with emotional support, informational support, and positive social interaction.

Overall, the data suggested that the Telephone Contact Program had the capability to evoke small, but clinically meaningfully improvements in the health status of elderly women with arthritis. Further investigation into the use of telephone contact programs as a minimal intervention is advised.

TABLE OF CONTENTS

Abstract	ii
Table of Contents	iv
List of Tables	xiv
Acknowledgement	xv
 CHAPTER 1 BACKGROUND AND PROBLEM AREA OF THESIS	 1
Felt Need	2
Community Need	5
Definitions of Disability and Social Isolation	6
Arthritis and Quality of Life	8
The Importance of Social Support to the Health	
Status of the Elderly with Arthritis	11
Rationale for Thesis Research	14
Purpose of Thesis Research	15
 CHAPTER 2 LITERATURE REVIEW	 18
Arthritis and the Elderly	
1. Rheumatoid Arthritis	21

i	Definition	21
ii	Prevalence	21
iii	Features	24
iv	Progress and Prognosis	25
v	Treatment	27
2.	Osteoarthritis	28
i	Definition	28
ii	Prevalence	30
iii	Features	32
iv	Progress and Prognosis	33
v	Treatment	34
3.	The Aims of Rehabilitation for the Elderly with Arthritis	36
The Psychosocial Dimensions of Arthritis		
1.	Psychosocial Research in Rheumatic Diseases	39
i	History	39
ii	Methodology	40
iii	Focus Points of Research	41

2.	Physical and Social Features of Rheumatic Diseases which Evoke Psycho-emotional Responses	44
i	Pain	44
ii	Fatigue	45
iii	Loss of Function	45
iv	Change in Physical Appearance	46
v	Loss of Independence	46
vi	Financial Burden	46
vii	Loss of Sexual Function	47
viii	Disruption of Family Dynamics	48
3.	Psycho-emotional Responses Common to Arthritis	50
i	Anxiety	51
ii	Denial	51
iii	Anger	51
iv	Bargaining	52
v	Depression	52
vi	Coping	53
4.	Psychological and Social Effects of Rheumatic Disease Specific to the Elderly	55

An Overview of Social Support Theory

1.	Historical Development of Social Support Theory	60
2.	Definitions of Social Support	61
i	Functional Definitions	63
ii	Perceptual Definitions	64
iii	Definitional Problems	65
3.	Theories of Social Support	66
i	Buffering Hypothesis	66
ii	Main Effects Hypothesis	67
iii	Perceived Social Support Model ...	68
iv	Problems Arising from Social Support Theories	71
4.	Dynamics of Social Support	72
5.	Clinical Implications of Social Support	75

Social Support Interventions and Health

1.	Social Support and Utilization/Adherence to Treatment	77
2.	Social Support and Rehabilitation	79
3.	The Importance of Social Support for the Elderly	84

The Role of Lay Volunteers within Health Care to
Deliver Social Support Interventions

1.	Historical and Sociological Perspectives	87
2.	Risks and Benefits of Volunteer Participation	90
3.	Comparison between Professional- Volunteer Effectiveness	92
4.	Professional-Volunteer Collaboration within Health Care	97
5.	Voluntarism in an Economic Context	104

6.	Possible Implications of Increased Voluntarism in Health Care	106
Telephone Contact Programs		
1.	Telephone Usage in a Psychotherapeutic Context	109
2.	Telephone Contact Programs to Reduce Social Isolation amongst Arthritis Populations .	112
3.	Telephone Contact Programs to Reduce Social Isolation amongst the Elderly	117
CHAPTER 3	RESEARCH DESIGN	120
1.	Methodological Orientation	122
2.	Sampling Design	123
3.	Size of Sample	125
4.	Measures	127

5.	Measurement of Variables	127
i	Physical Function	127
ii	Psychological Function	130
iii	Pain Level	130
iv	Perceived Social Support from Friends	131
v	Perceived Social Support from Family	134
6.	Interview with Subjects	135
7.	Research Design	136
8.	Procedure	137
i	Pre-test Measure Procedure	141
ii	Post-test Measure Procedure	141
9.	Ethical Issues	143
10.	Limitations of the Study	143
CHAPTER 4	RESULTS	147
1.	Description of Sample	148

2.	Characteristics of Drop-outs	149
3.	Analysis of Results from Quantitative Measures	153
i	Hypothesis 1	158
ii	Hypothesis 2	158
iii	Hypothesis 3	159
iv	Hypothesis 4	159
v	Hypothesis 5	160
4.	Correlations between AIMS Scores and PSS Scores	162
i	Hypothesis 6	162
5.	Interviews with Subjects	167
6.	Summary of Main Themes	174
7.	Individual Scores and Comments Pre-Post .	179
CHAPTER 5	IMPLICATIONS AND CONCLUSIONS	187

1.	Summary of Quantitative Data	189
	i Implication	190
2.	Summary of Interview Data	191
	i Implications	193
3.	Minimal Intervention and Telephone Contact Programs	195
4.	Implications for Future Program Operations	197
5.	Client Satisfaction	200
6.	Implication for Policy Initiatives	201
7.	Recommendations for Further Study	202
8.	Summary	204
REFERENCES		206

xiii

Appendix A	Qualitative Data Questions and Variables Measured	235
Appendix B	Questionnaire Package	237
Appendix C	A Comparative Analysis of Two Social Support Questionnaires to Determine their Relative Adequacy for Use with an Elderly Population	252
Appendix D	Summary of Interview Locations and Dates	277
Appendix E	Structured Interview with Subject 02 .	279
Appendix F	Letters of Study Approval from Ethics Committees	290

LIST OF TABLES

CHAPTER 3

Table 1	Changes in Sample Size Throughout the Study	126
---------	---	-----

CHAPTER 4

Table 2	Experimental and Comparison Group Pre-test Scores - AIMS and PSS	150
Table 3	Differences in Demographic Variables Between Experimental and Comparison Groups	152
Table 4	Pre/Post Changes for Experimental Group	157
Table 5	Pearson Correlation Coefficients Between AIMS Subscales and PSS	164
Table 6	Pearson Correlation Coefficients Between AIMS Component Scales and PSS	166
Table 7	Elements of Functional Social Support	177
Table 8	Individual Subjects' Pre/Post Scores	180

ACKNOWLEDGEMENT

I would like to take this opportunity to thank all of the people who helped me complete this thesis.

I would like to thank the members of my thesis committee for their sound guidance and encouragement. I thank Dr. Mary Russell for the speed with which she provided me with very much appreciated feedback. I am thankful for the insight and enthusiasm that Patrick McGowan provided me for the work at hand. I am also indebted to Dr. Kathryn McCannell for her support throughout this past year and her willingness to share her expertise in the area of social support.

I also want to express my gratitude to my typists Erika Pedersen and Lisa-Marie Richardson for their assistance in helping me meeting deadly deadlines and their uncanny ability to decipher my horrendous handwriting. Their expertise on the computer reduced by anxiety considerably. In addition, Mish Vadasz and Dr. Jonathan Berkowitz deserve a thank you for their comments on the program and for statistical advice.

To my family, Jim and Irene Taylor and Lorna and Dennis Sova, I am appreciative for their love and concern - and for putting up with the occasional burst of grumpiness.

A special thanks is extend to Bert Forman and Dr. Sharon Manson-Willms for taking an interest in both my personal and professional life. Their advice and suggestions have helped me become a better social worker.

Since this thesis is largely to do with social support, it is appropriate I mention the people who helped me keep things in perspective: Dewey O'Donnell, Grant Kuzyk, and Jamie Munroe.

This thesis is dedicated to the memory of Bessie McIntyre.

CHAPTER 1

Background and Problem Area of Thesis

This project involves the investigation of the efficacy of a Telephone Contact Program, using lay volunteers as callers, to improve the quality of life and independence of seniors who have osteoarthritis and rheumatoid arthritis. The specific outreach program under investigation was conducted by the Social Work Department of the Arthritis Society in Vancouver. This research attempted to determine whether or not a weekly telephone call from a volunteer would impact positively on participants' physical and psychological functioning, level of pain and perceived level of social support.

Felt Need

Estimates of the prevalence of arthritis in the United States have been generated by the National Arthritis Data Workgroup (NADW). Using data collected in the 1983-1985 National Health Interview Survey (NHIS), the NADW estimated that an estimated 35 million Americans had arthritis, nonarticular rheumatism, gout or a combination of these diseases in 1985 (Lawrence et al., 1989). The raw NHIS data provided a count of disease reports, not individuals. However, for the above

adjusted rate, individuals who have more than one condition were not repeatedly counted. When this rate is applied to the 1989 U.S. population, about 37 million individuals are affected (Lawrence et al., 1989). The National Centre for Health Statistics (NCHS) has also analyzed the data from the 1983-1985 NHIS. This organization concluded that arthritis is the second most prevalent chronic condition (after sinusitis), affecting 30.3 million Americans. Among females, arthritis ranks as the most frequently reported condition with an annual rate of 164.3 cases per 1,000 persons. Among males, arthritis ranks fifth in prevalence with an annual average rate of 95.2 cases per 1,000 persons. In addition, for the age groups 45 - 64 years, 65 - 74 years, and 75 years and over, arthritis was the chronic condition reported most frequently (Collins, 1988). Other recent research (U.S. Department of Commerce, 1985; Health & Welfare Canada, 1983) found that the numbers of persons over the age of 65 years with arthritis ranged from 46% to 84%.

Approximately 12% of Canada's population is older than 65 years (Statistics Canada, 1986a). Current

projections indicate that Canadians in the 65 and over age group will constitute fully one fifth of our total population by the year 2020 (Health & Welfare Canada, 1989). According to Statistics Canada (1986b), there are approximately 280,000 persons over 55 years living in the Vancouver Lower Mainland (54% female, 44% male). Considering this age structure of people living in the Greater Vancouver area, it follows that there is a large number of older persons who are trying to cope with the pain and increasing disability caused by arthritis. In spite of the high prevalence of arthritis among the elderly, these individuals may not be seeking medical care (Potts, Yngve, Weinberger, & Brandt, 1983). Barney and Neukom (1979) found that in a free outpatient arthritis care program for people 55 years or older, only 17% of those who were aware of the program chose to participate. In the study conducted by Potts et al. (1983) 79% of seniors (N=47) did not seek medical advice for their arthritis because joint pain was viewed as an inevitable result of aging. Furthermore, as a result of the inception of the Long Term Care Program in Vancouver, the number of identifiable, lonely seniors has exceeded the number of available, mobile volunteers (Jansen,

1987). As the senior population continues to climb due to a decline in the mortality rates among the elderly, it will become an increasing challenge to find ways to slow or delay the decline in health status and functional capacity experienced by persons in later life.

Community Need

The following are key health promotion principles and processes which were identified by the Ottawa Charter for Health Promotion as being important for community involvement in health care (British Columbia Health Care Research Foundation, 1990):

1. Enabling people and communities to increase control over and improve their health.
2. Focusing on enabling rather than prescribing solutions.
3. Involving community members in implementation.
4. Creating supportive environments.
5. Strengthening community action.
6. Developing personal skills.
7. Reorienting health services.

The overall well-being of seniors is becoming an increasing concern among health care professionals and the public. With respect to enhancing coping for seniors, Health & Welfare Canada's 1989 policy framework, The Active Health Report on Seniors placed emphasis on combining use of seniors' individual and collective resources. This suggests that there is a move away from institutional care and towards greater independence by building community health care programs and social support networks. The aim appears to be to encourage seniors to remain as a viable part of the community for as long as possible. Implementation of telephone contact programs may be one useful strategy for achieving greater independence and enhancing quality of life for seniors.

Definitions of Disability and Social Isolation

Haber (1971) and Nagi (1976) have developed a now classic model of disease and disability. According to this model, pathophysiological changes (e.g. in the immune system among persons later diagnosed with rheumatoid arthritis) beget symptoms (e.g. joint pain) and disease (e.g. rheumatoid arthritis), which result in physical

impairment (e.g. inability to perform fine motor routines), reduced functional capacity (e.g. inability to dress), and, perhaps, an inability to function in actual activities (e.g. inability to socialize).

The term disability is applied to physical impairment as well as to limitations in functional capacity and reductions in actual functioning (Katz & Akpom, 1976). Physical impairment may be measured by the presence or extent of limitation in physical activities such as walking ten steps, stooping, lifting 25 pounds, or using fingers to grasp. Functional capacity may be measured by limitations in activities of daily living (e.g. bathing, dressing, eating, arising, walking, toileting) and instrumental activities of daily living (e.g. preparing meals, shopping, managing money, using the telephone, completing light and heavy housework) (Katz, Hedrick, & Henderson, 1979).

Cassileth (1986) found that arthritis limits independence which leads to social isolation and depression. Social isolation was described as follows by Lucy Stead, a seniors' counsellor (cited in Jansen, 1987):

A condition of severe loneliness together with a depletion of social skills. This tends to produce a feeling of fearfulness and inadequacy to seek new people and places. It generally comes on gradually as a series of losses are sustained: loss of family and friends through illness, death, departure or estrangement; of health and abilities; of familiar places and people with a move to a smaller and more manageable quarters; of feeling of usefulness in a job once held, whether in the home or in the professional world or both (pp. 4-5)

As will be discussed in this research arthritis is a disabling disease which can exacerbate the normal reductions in physical functioning experienced as a natural process of aging. The effects of disability on a person may lead to social isolation as the culmination of losses affect one's emotional and psychological functioning. This of course impacts on the quality of life for the individual affected in this manner.

Arthritis and Quality of Life

Since a cure for arthritis is not a realistic expectation for seniors, emphasis should be placed on improving the individual's quality of life, while coping with the disease (Burckhardt, 1985). Burckhardt's study (1985) explored the impact of pain and functional impairment on the quality of life experienced by persons

with arthritis. Using a cognitive framework, Burckhardt developed a causal model in which the disease related variables interacting with demographic and social factors were hypothesized to indirectly affect quality of life through psychological mediators. Ninety-four adults (74 women, 20 men) with various forms of arthritis were interviewed in their homes. Path analysis showed that the most important psychological mediators contributing directly to a higher quality of life were: positive self-esteem; internal control over health; low negative attitude toward the illness; and perceived support. This model explained 46% of the variance in quality of life.

Burckhardt (1985) found that the higher the severity of impairment, the lower the self-esteem. Age had an indirect effect on self-esteem through its direct effect on severity of impairment. Hence older persons with arthritis may be more susceptible to this loss of self-esteem because of greater impairment. Subjects who believed strongly that control over their health was their responsibility, and that they had the power to make themselves well had higher quality of life scores than those who did not hold these beliefs. This is an

important point because, as stated earlier, Potts et al. (1983) found that 74% of seniors in their study believed joint pain was an inevitable consequence of aging. In addition, Burckhardt's subjects who had a negative attitude toward their illness, that is, experienced depression, anger, worry and frustration about their disease, experienced lower quality of life. Of particular interest to this present research, Burckhardt found that perceived support contributed 10% of the explained variance in quality of life. Subjects who had several people in their social network on whom they could rely for physical help, social time and advice perceived a higher quality of life. In general, older persons in this study had larger social networks. However, there was a direct negative effect between age and perceived support. This finding suggests that older subjects were less willing to ask for support from their close associates even if it was available (Burckhardt, 1985). The importance of social support networks for the health of the elderly will be discussed in the following section.

The Importance of Social Support to the Health
Status of the Elderly with Arthritis

Burckhardt's research (1985) suggests that perceived social support has a positive correlation to perceived quality of life. However, seniors who face increasing disability due to their arthritis often experience increasing social isolation. Gallo (1982) researched the relationship between social support networks and the health of the elderly. The 300 respondents in this study ranged in age from 60 to 94, with females making up 62% of the sample. Gallo found that network size had a moderate positive relationship with health status. Homogeneity, the measure of how similar network members were to each other in characteristics of sex, age, marital status, ethnicity and occupation was slightly correlated with health status. One major policy implication is that there may be a simpler, less expensive and more effective way to shape health care programs (Gallo, 1982). It is likely that any support, advice or treatment offered within the social support network rather than the formal medical system would be

simpler and less expensive. Gallo's work however did not answer the question of effectiveness but other researchers have moved into this area of inquiry.

For example, Weinberger, Hiner and Tierney (1986) presented data from a longitudinal study of 134 patients with osteoarthritis who were telephoned bi-weekly for six months. Interviewers inquired about stressors that subjects were experiencing and obtained self-assessments of their health. The researchers hypothesized that telephone interviewers provide osteoarthritis patients with social support, and thus improve their functional status. This hypothesis was supported. Subjects also reported enhanced perceived levels of social support. Weinberger et al. (1986) attributed the improvement in functional status to the telephone interviewers being viewed as a source of social support to elderly persons who may have support deficits.

While this study will be replicating Weinberger's study, there are important differences between the present research and their research (Weinberger, Hiner & Tierney, (1986). First, Weinberger et al. used a

population which was 88% women, 82% black, and had a mean age of 66 years. Experimental group subjects for this study are 100% Caucasian women, with a mean age of 76 years. Interestingly, in the Weinberger et al. study, Caucasians reported worse physical and psychological disability. Second, in the previous study respondents were paid \$2 for each completed bi-weekly interview. Participants for this research received no monetary compensation. Third, this researcher decided to employ the Perceived Social Support from Friends and from Family measure as opposed to the Social Support Questionnaire used by Weinberger et al. after conducting a pilot study which suggested the former was more appropriate for use with an elderly population (see Appendix C). Fourth, participants for this study received calls once a week over 16 weeks as opposed to once every two weeks for six months. Fifth, this research had a separate category for respondents to identify callers as a source of support. This made it possible to determine whether increases in reported levels of social support could be attributed to the callers being mentioned. Sixth, since the caller remained constant throughout the study, callers were redefined from an unbiased data collector to a provider

of social support for this study. In the Weinberger et al. study, the researchers rotated four telephone interviewers to avoid strong interpersonal relationships which could have developed between patients and interviewers. For this present research, volunteer callers received a workshop on arthritis and their role within this program. It was hoped that, by having trained callers who have arthritis themselves follow their own panel of patients, continuity would be established which would further enhance social support and provide the greatest potential to improve subjects' functional status and psychological well-being.

Rationale for Thesis Research

Given the prevalence rates of arthritis among the elderly, it is clear that there is a large number of seniors with arthritis in the Lower Mainland who are experiencing difficulty in coping with the lifestyle adjustments brought about by their disease. In one study (Goodenow, Reisine & Grady, 1989) social support was associated with improved functioning and less depression in women with arthritis. It appears that the level of

perceived social support correlates highly with symptom severity (Pfieffer & Affleck, 1988). A relatively new approach in dealing with quality of life issues for older persons with arthritis is the use of telephone contact programs. The primary concern is that the Arthritis Society in Vancouver is providing service to only a small proportion of the elderly population with arthritis. To address this concern, the Telephone Contact Program was established to extend services to a previously difficult to reach population group for psychosocial support and the provision of resource information.

Purpose of Thesis Research

The purpose of this research is to investigate whether or not this telephone contact program will bring about the same positive health outcomes experienced by subjects in previous research (Weinberger, Hiner & Tierney, 1986). These researchers found that after regularly scheduled telephone calls, respondents reported significantly decreased physical disability ($p < .01$) and pain ($p < .0001$) as measured by the Arthritis Measurement Impact Scales. Respondents also reported significantly

higher levels of social support. Specifically, these changes occurred along the emotional, tangible and overall social support dimension scores as measured by the Social Support Questionnaire.

Thus, the objectives of this present study were to demonstrate that after 16 weeks of partaking in the Arthritis Society's Telephone Contact Program, participants would:

1. Study participants would show improved physical functioning after receiving 16 weeks of regular telephone calls, as measured by the Arthritis Measurement Impact Scales.
2. Study participants would show improved psychological functioning after receiving 16 weeks of regular telephone calls, as measured by the Arthritis Impact Measurement Scales.
3. Study participants would show improved pain levels after receiving 16 weeks of regular telephone calls, as measured by the Arthritis Impact Measurement Scales.

4. Study participants would show improved perception of social support from friends after receiving 16 weeks of regular telephone calls, as measured by the Perceived Social Support From Friends scale.
5. Study participants would show improved perception of social support from family members after receiving 16 weeks of regular telephone calls, as measured by the Perceived Social Support From Family scale.
6. There would be an association between the changes in perceived social support, as measured by the Perceived Social Support From Friends and From Family, and the changes in health status, as measured by the Arthritis Impact Measurement Scales, at 16 weeks.

CHAPTER 2
Literature Review

Arthritis and the Elderly

Arthritis is not a single disease. There are over 100 kinds of arthritis (Lorig & Fries, 1986). Quantitative estimates illustrate the proportion of the population which is elderly and demanding of medical attention. By retirement age, 80 per cent of the population has a rheumatic complaint (Kolodny & Klipper, 1976) and one-third of geriatric patients attending day hospitals have arthritis (Brocklehurst, 1978). The three disabling and chronic rheumatic conditions whose onset are especially prevalent in the aging population are osteoarthritis, periartthritis of the shoulder and polymyalgia rheumatica (Gibson & Grahame, 1981). However, most forms of joint disease are not exclusive to particular age groups and diseases acquired in middle life may pose special problems in the elderly by virtue of their chronicity. For example, half of all patients with rheumatoid arthritis are more than 50 years of age, but it is a minority which contracts the disease beyond this age (Kolodny & Klipper, 1976). It is clear that the elderly face heightened vulnerability to the stresses of joint disease due to the chronic nature of arthritis and

the multiple diseases/illnesses often experienced by elderly persons.

Precise diagnosis is a prerequisite to appropriate treatment and subsequent management. However this may be a difficult task with the elderly. For example, in a study of 59 patients with acute arthritis beginning beyond the age of 70, a confident diagnosis could not be established in one-quarter, despite very detailed investigations (Gibson & Grahame, 1973). This problem is evident within this present research in that six out of eleven subjects do not have a precise diagnosis in terms of the kind of arthritis which affects them. The two types of arthritis which were identified in the subjects of this research were osteoarthritis and rheumatoid arthritis, both of which will be described below. Rheumatoid arthritis and osteoarthritis are common, chronic diseases which run variable courses in individual patients and whose clinical manifestations show marked differences between patients (Kirwan & Silman, 1987). The problems they cause accumulate as the individual ages, and the burden of the disease in the elderly is particularly great.

Rheumatoid Arthritis

Definition. Rheumatoid arthritis (RA) is a variable and clinically heterogenous systemic disease affecting connective or supporting tissues (Wiener, 1975). Swelling and pain in one or more joints, lasting at least six weeks, are required for a diagnosis of rheumatoid arthritis (Fries, 1986, Lorig & Fries, 1986). It involves the inflammation of the synovial membrane lining in the joint. For reasons unknown, the cells in the membrane divide and grow, and inflammatory cells enter the joint. The bulk of these inflammatory cells causes the joint to swell. In addition these inflammatory cells release enzymes into the joint space, causing further irritation and pain. Indeed pain is the symptom of most concern to patients (Wright, 1985). If the process continues for years, the enzymes may gradually digest the cartilage and bone of the joint (Lorig & Fries, 1986).

Prevalence. In the United States, approximately 2.1 million adults have classical or definite rheumatoid arthritis (Lawrence, Hochberg, Kelsey et al., 1989).

Prevalence surveys of rheumatoid arthritis have relied primarily on the 1958 revised criteria of the American Rheumatism Association (ARA). It defines cases as follows: probable RA = 3 or 4 items, definite RA = 5 or 6 items, and classical RA = 7 or 8 items. The 1987 revised ARA criteria no longer use the definitions classical, definite and probable. Four or more items now define "rheumatoid arthritis". However, the prevalence rates described below are based on the earlier criteria. 0.9 percent of the American population (0.7% of males and 1.6% of females) have been classified as having definite RA. This rate translates into 600,000 males and 1.5 million females aged 18 or older. These estimates are record based on the 1960 - 1962 National Health Examination Survey conducted by the National Centre for Health Statistics, the most recent survey to examine the national population for this disease (Lawrence et al, 1989). There was also a significant association of increased prevalence with increased age. Definite RA was found in 2% of males 55 and older, 3% of women aged 55 - 64 and 5% of women aged 65 and older. It is noted that these estimates may differ substantially from other

sources of national estimates which use other diagnostic criteria or which include probable cases as well.

Features. Usually, both sides of the body are affected similarly and the arthritis is said to be "symmetrical". Often the right side may be slightly worse in right handed people and vice versa (Fries, 1986). The wrists and knuckles are almost always affected by rheumatoid arthritis. As a progressive disease, it can lead to dislocation of fingers and deformity of the hands (Wiener, 1975). It is also common to have involvement in the knees and the joints of the ball of the feet. Lumps, called rheumatoid nodules, may form beneath the skin, and are commonly located near the elbows. Each nodule represents an inflammation of a small blood vessel and may make sporadic appearances during the course of the disease. Other parts of the body aside from the joints may also become problematic. Most people with rheumatoid arthritis will complain of muscle aches, fatigue and morning stiffness (sometimes called the gel phenomenon). In addition, there may be fluid accumulation, particularly around the ankles (Lorig & Fries, 1986). A reduction of energy can also occur

because of the metabolic effect of the disease (its attack on connective tissue) and also by the circuitous nature of pain. In other words, pain drains energy and fatigue produces pain (Wiener, 1975). Most cases are marked by flare-up and remission. For example, even a mild case may have a sudden severe flare-up. Similarly, a very severe case may suddenly and inexplicably become arrested (Wiener, 1975).

Progress and prognosis. The variability of progression, severity, and areas of involvement between patients must be stressed (Kirwan & Silman, 1987, Wiener, 1975). For example, one may have reduced mobility but no skill impairment or perhaps reduced energy but no interference with mobility. Loss of skill will be variable if caused by swelling, but constant if it is caused by deformity. Mobility and energy may also fluctuate. On any given day, a person with rheumatoid arthritis will be uncertain about four characteristics of symptoms produced by rheumatoid arthritis: pressure (i.e. will there be any pain, swelling or stiffness); place (i.e. what part of the body will be involved); quantity (i.e. degree of disabling intensity);

temporality (i.e. will the onset be gradual or sudden, of what duration and frequency will be the flare-up) (Wiener, 1975).

Duthie, Brown and Truelove (1964) noted that there was no evidence to conclude that the disease passed from an active to an inactive stage, but rather that individuals maintained their own levels of disease activity or fluctuated between fairly narrow limits. The course of rheumatoid arthritis usually falls into one of three patterns (Lorig & Fries, 1986). Monocyclic rheumatoid arthritis is an illness which lasts at most a few months and leaves no disability. Polycyclic rheumatoid arthritis involves a series of episodes of illness, separated by periods of disease absence. Again there may be little physical impairment. Chronic rheumatoid arthritis will last for a number of years, if not life. The majority of persons with rheumatoid arthritis have this chronic form, and its presence is strongly suggested by the presence of the rheumatoid factor in a blood test or if the course of the disease has continued for an entire year. Chronic rheumatoid arthritis, with its flares and remissions, is the pattern of disease which is most commonly endured by elderly

persons. However, it is noted that the very uncertainty which makes rheumatoid arthritis so intolerable also mitigates against acceptance of invalidism - one can always hope for another remission (Wiener, 1975).

Treatment. Good treatment for rheumatoid arthritis reduces inflammation caused by synovitis and stops the damage. Painkillers increase comfort but do not change the course of the RA. Actually pain is helpful in that it discourages overuse of the joint. Thus with RA it is important that pain is treated by treating the inflammation which causes the pain (Fries, 1986). A proper balance between rest and exercise is also advised. Rest reduces the inflammation, but it also causes joint stiffness and weakened muscles. However, too much rest allows the bones to grow soft and reduces strength in the tendons.

Medications are required by most patients with rheumatoid arthritis. Aspirin is the most valuable single drug, although nonsteroidal anti-inflammatory drugs are also frequently used (Fries, 1986). Corticosteroids, most frequently prednisone, are strong

hormones which cause long-term side effects. For this reason, their use in RA is controversial. However, steroids and immunosuppressants are sometimes required for severe systemic complications, such as eye or nerve damage (Fries, 1986). Lastly, surgery can restore joint function. Knee, hip and shoulder replacements or synovectomy of the knee or knuckles are the most common surgeries for people with RA (Fries, 1986).

Osteoarthritis

Definition. A clinical definition of osteoarthritis employs morbidity as the pragmatic dividing line between the "disease" of osteoarthritis and the aging changes that take place to variable degrees in the body's joints, particularly those involved in bearing weight (Scilleppi, 1983). Osteoarthritis can be regarded as a degenerative joint disease strongly related to mechanical alterations in the joint. These changes are very common in the elderly, and are often asymptomatic. This led Hart (1974) to suggest that only if these changes cause symptoms should osteoarthritis be diagnosed. An alternative approach put forward by Kellgren (1961)

suggests that osteoarthritis can be defined as an expression of a joint's inadequacy to meet the mechanical stress placed upon it.

Large, weight-bearing joints, such as hips and knees, are the sites most commonly affected. The spine and the small joints of the fingers are also frequently involved (Gross, 1981). Osteoarthritis is characterized by deterioration of the joint cartilage that covers the ends of the bones within the joint, and that serves as both a shock absorber and a load-bearing surface to permit nearly frictionless movement. Initially the smooth surface of the joint cartilage becomes frayed and softened. Over the years, areas of cartilage may be worn away completely, leaving bone to rub on bone (Lorig & Fries, 1986). Bony growths (spurs) may form at the margins of the joint, further altering the normal shape and function of the joint (Gross, 1981). Osteoarthritis is often subdivided into primary (no known cause) and secondary types, and into localized (monoarticular) and generalized forms. From this viewpoint the concept of osteoarthritis as a single disease entity may complicate attempts at understanding it. It may prove more useful

to view osteoarthritis as a final common pathway for a number of joint conditions including inflammatory, endocrine, metabolic, developmental and biomechanical disorders (Kirwan & Silman, 1987).

Prevalence. Estimating the prevalence of osteoarthritis is difficult for several reasons. First, osteoarthritis is objectively diagnosed on the basis of readings of radiographs, yet symptoms may not accompany radiographic evidence. Second, assuming that a diagnosis requires radiography, it would be prohibitively expensive to radiograph all joints in all persons in a study of adequate sample size. Thus clinical evaluation is based on radiologic changes indicative of osteoarthritis in specific joints, usually the feet, knees, hip and hands. Third, prevalence rates vary depending on whether mild and moderate, as well as severe, radiologic changes are counted. Fourth, the oldest age groups have the highest prevalence rates, yet there is only limited data for person 80 years and older (Lawrence et al., 1989). The aging process in weight bearing joints begins surprisingly early. Radiographically visible signs of degeneration are present in 75 percent of the population

by the age of 45 years (Kirwan & Silman, 1987). Certainly by age 60, degenerative joint changes in weight bearing joints are virtually a universal occurrence in both ages (Scileppi, 1983).

Data on osteoarthritis in the National Health and Nutrition Examination Survey (1971-75) was based on a probability sample of the United States civilian, non-institutionalized population (ages 25-74). Each of the 6,913 subjects were given a thorough musculoskeletal evaluation by a physician, who also noted abnormalities of the spine, the knees, the hips, and the peripheral joints. On the basis of these examinations, 12.1% of the American population aged 25 - 74 (about 15 million people) have osteoarthritis (Lawrence et al., 1989). Age and sex specific prevalence rates were collected by the above survey and by the National Health Examination Survey of 1960 - 1962. If mild, moderate and severe osteoarthritis are included (in radiographs from this survey) the overall prevalence estimates are 32.5% for the hands (42.4 million persons), 22.2% for the feet (29 million persons), and 3.8% for the knees (5 million persons). For the hands, feet and knees males are

affected more frequently at younger ages while females are affected more frequently, and more severely in later life. Prevalence rates for each of the joints increase markedly with age in both sexes. Radiologic evidence is rare in persons younger than 25 years, whereas by age 75, almost every person shows radiologic evidence of osteoarthritis in their hands, and about half the population shows radiologic evidence in their feet.

Features. Osteoarthritis is the commonest of all the rheumatic diseases, and causes symptoms in a large proportion of elderly people (Wood, 1976). Until middle age the pattern of joint involvement is similar in both sexes but thereafter the disease is more severe and more generalized in females (Kellgren, Lawrence & Bier, 1963). Moskowitz (1981) described the symptoms of osteoarthritis as insidious in onset, local in character and not associated with systemic manifestations. In the presence of progressive cartilaginous degeneration, a characteristic pattern of clinical symptomatology occurs. The earliest symptoms are pain and stiffness in the joints. The pain is usually described as dull or aching in character, poorly localized and initially occurring

only with motion (Scileppi, 1983). Pain at rest and night pain may develop as the disease advances (Moskowitz, 1981).

Spasm and atrophy of muscles surrounding the diseased joint is common. Motion of the joint becomes limited, and the joint enlarges as a result of the bony swelling, fluid accumulation or thickening of the soft tissues (Gross, 1981). Persons with knee involvement are sometimes unable to ambulate because osteoarthritis will affect the inner or the outer half of the joint more than the other, resulting in the leg becoming bowed or splayed (Lorig & Fries, 1986). Physical examination of the older patient with early osteoarthritic symptoms typically reveals only muted signs of joint inflammation. A markedly hot or swollen joint strongly suggests a diagnosis of one of several other rheumatic conditions (Scileppi, 1983).

Progress and prognosis. Ultimate incapacitation of the afflicted joint is a consequence of chronic pain combined with joint instability owing to loss of articular cartilage. Incapacitation due to deterioration

of articular cartilage in the knee or hip is a fear of virtually all elderly people with arthritis (Scileppi, 1983). Furthermore, deviation and subluxation of the joints of the fingers may cause degraded motor strength and fine muscle control that threatens an elderly patient's ability to continue independent self-care.

Treatment. In the absence of more specific agents capable of preventing or reversing the pathological changes of osteoarthritis, current management is symptomatic and directed primarily toward pain relief. The essential medical intervention in osteoarthritis has become the intelligent choice and application of nonsteroidal anti-inflammatory drugs. Aspirin remains the therapeutic standard for this class of drugs although none of these agents can claim to influence the course of osteoarthritis (Scileppi, 1983). However symptomatic relief in itself is an important accomplishment.

Physical therapy holds a prominent position in treatment of osteoarthritis and involves principally the use of heat application, a specific exercise program, and occasionally manipulation and traction. Generally

moderate heat application for 15 to 20 minutes precedes each exercise session. The aim is to relieve pain and stiffness, maintain or improve range of joint movement, and strengthen muscles. However, fundamental to the treatment of osteoarthritis is adequate education about the condition and reassurance to the patient by the clinician. Other practical management techniques include advice about joint usage and weight reduction, or the use of mechanical aids such as walking sticks, shoe-raises or splinting devices.

Surgical procedures, such as joint replacement, are generally reserved for patients with advanced disease, persistent pain and significantly impaired function. Osteotomies correct malalignment while removal of free cartilage fragments may prevent rapid wear of joint surfaces and locking. Furthermore, arthroplasty and surgical removal of large osteophytes may increase range of motion. Arthrodesis, although permanently eliminating joint motion, may be the procedure of choice for those whose future activities will require heavy usage of the involved joint.

Osteoarthritis is not curable (Gross, 1981). However in most cases its symptoms can be alleviated and disability prevented or reduced. Since the excessive use of afflicted joints may lead to progressive degeneration of the joint, osteoarthritis patients are taught to reduce the stress on the affected joint. Canes, crutches and walkers are frequently used to reduce the load on weight-bearing joints. In advanced cases, total replacement of the damaged joints is a common orthopaedic procedure today (Gross, 1981).

The Aims of Rehabilitation for the Elderly with Arthritis

Clinical experience of osteoarthritis suggests that pain precipitates medical referral and that disability becomes noticeable only when the disease progresses (Kirwan & Silman, 1987). The treatment and rehabilitation of the elderly rheumatic patient may be hampered by supervening illnesses such as ischaemic heart disease, diabetes or fractures due to the combination of falls and osteoporosis (Gibson & Graham, 1981). Relegation of rheumatological treatment to secondary importance in favour of treatment for other illnesses may

cause the worsening of disability due to arthritis. There is little evidence that rheumatoid arthritis or osteoarthritis occurs more frequently in those who follow a particular lifestyle. Instead, lifestyle may influence the presentation of arthritis rather than its pathology (Kirwan & Silman, 1987).

The aims of rehabilitation for the rheumatic patient usually consist of the assessment of tolerance to exercise and activity, prevention of deformity, maintenance or improvement of joint movement and muscle strength, limitation of disability and restitution of independent function (Gibson & Grahame, 1981). Sensible rehabilitation of aging patients is dependent on several factors. These include the correct diagnosis, the recognition of coexisting disease, an awareness of the patient's home circumstances, optimal drug treatment and a realistic physical programme which does not make excessive demands on the patient (Gibson & Grahame, 1981). It is vital to determine what the patient expects and wishes. Ditunno and Ehrlich (1970) observed that the elderly with rheumatoid disease may have aims which are

unrealistically high or low, and therefore some aims may have to be modified accordingly.

Evaluation and treatment of an elderly person with arthritis must have as its goals not only the preservation of function and the amelioration of pain, but also the management of the emotional accoutrements of this disease. The following section will address the psychological, social and emotional components to this potentially debilitating illness.

The Psychosocial Dimensions of Arthritis

Arthritis often causes major changes in lifestyle and may impose a wide variety of losses on the people it affects, including losses of independence, mobility and function. Since one's personality is related to one's body image, major losses in physical function may also result in the loss of part of one's identity (Gross, 1981). The clinical features of arthritis such as its chronicity, unpredictability, variable disability, and potential to disfigure also help to make management a challenge (Rogers, Liang, & Partridge, 1982). In addition, the patient's reaction to the disease can be related to age, experience, personality and environment at home and at work (Rogers et al., 1982).

Psychosocial Research in Rheumatic Diseases

History. Current interest in the psychological concepts in rheumatic disease represents a renewal of research activity that began in the 1940's with the development of "psychosomatic medicine" within psychiatry. During the 1970's rheumatologists began to

emphasize the importance of addressing the psychological and functional outcomes of the disease process in addition to the outcomes based on laboratory tests and physical examinations (Bradley, 1985). At the same time, behavioural scientists were improving their techniques for assessing the psychological dimensions of arthritis. The above two changes helped to enhance the collaborative efforts between psychologists and rheumatologists (Bradley, 1985).

Methodology. Until recently, research into the psychological aspects of arthritis has not been guided by well-defined psychological theory, nor conducted in a systematic fashion (Bradley, 1985). Methods employed have ranged from personal viewpoints based upon clinical observation to intricate designs evaluating dependent and independent variables in controlled settings on multiple population samples. The methodology utilized in the present study was a case study approach which included a combination of interviews and paper and pencil measures in an attempt to gain more objective information.

Studies of psychosocial factors in arthritis have been conducted by researchers from a number of orientations and professions, including rheumatology, psychiatry, social work, sociology and psychology. Consequently those who have studied the psychological dimensions of arthritis have not communicated well with one another, partly due to the fact that they publish their work in unrelated sources (Bradley, 1985). One methodological problem which persists in the literature is the assumption that persons of one diagnostic category represent a homogenous group. However, people with rheumatoid arthritis, for instance, differ in terms of severity and activity of disease, physical disability, age, sex and chronicity. These differences should be stated and defined as completely as possible (Baum & Figley, 1981). This has relevancy for data interpretation for one cannot assume that subjects are homogenous simply on the basis that they share a common diagnosis.

Focus points of research. A number of researchers have investigated common personality patterns and characteristics which may exist among those with a

rheumatoid disease - i.e. is there an "arthritic personality"? It was suggested that persons with rheumatoid arthritis repress hostility and direct rage against themselves, or have endured negative life experiences such as poor parental or marital relationships (Baum & Figley, 1981). However methodological problems, such as reliance on retrospective research methods or excessive attention to negative personality characteristics, inherent in those studies have recently been emphasized in reviews (Bradley, 1985). It may be that these patterns are a result of the disease process rather than factors related to the development of arthritis (Baum & Figley, 1981).

Another category of research has investigated the relationship between physiological and psychological variables. It has been postulated that psychological and biological variables interact to influence the onset, pattern and course of arthritis. Stress is identified as a potential triggering factor in the autoimmune disorders (Weiner, 1977). This coupling is congruent with observations that the muscle tension in rheumatoid arthritis patients can be produced by psychological

stress (Rogers, Dubey, Reich, 1979). However, it is more likely that stress modifies expression of the disease or lowers the patient's pain threshold rather than solely causing the disease (Rogers, Liang, Partridge, 1982).

Evidence on the relationship between central nervous system function and immunity offers encouragement for continued investigation into the mind/body response, particularly with the types of arthritis that are believed to be autoimmune disorders (Achterberg-Lawlis, 1982). Future research should certainly continue to explore the relationship between the autoimmune factors involved in the various disease processes and the psychological factors. This line of investigation may enhance the delivery of comprehensive health care to patients with rheumatic diseases. Comprehensive health care includes a commitment to understanding emotional responses to chronic disease and knowledge sufficient to treat exaggerated reactions to chronic disease (Baum & Figley, 1981). Sensitive and knowledgeable appreciation of psychosocial issues will positively impact on disease course and outcome.

Physical and Social Features of Rheumatic Diseases which
Evoke Psycho-emotional Responses

The first psychological reactions to arthritis are evoked upon initial diagnosis. Many people consider the achievement and maintenance of good health as a principal goal in life. Others simply take good health for granted. One's perception of personal good health can be shattered by a diagnosis of a rheumatic condition. Good health is intimately related in some people to self-respect, and a change in health status may evoke a sense of loss and vulnerability (Baum & Figley, 1981). The diagnosis of arthritis, which is often associated with "wearing out" or "old age", can have a heightened negative meaning. The following physical and social features of rheumatic disease are based primarily on clinical observation rather than on empirical studies.

Pain. Pain, whether it be intermittent or persistent, interrupts one's well established patterns of behaviour and interferes with one's emotional and intellectual functioning (Petrie, 1969). The "chronic pain syndrome", in which pain becomes interwoven with a

variety of behavioural responses, is commonly seen in rheumatic diseases. Furthermore, the anticipation of pain may change activity patterns, including the pain-free segments of one's life, more than pain itself (Baum & Figley, 1981).

Fatigue. Those who value accomplishment and achievement seem particularly upset by lack of energy. In our culture, "strength" is often considered a personality characteristic rather than a measure of one's capability to perform physical work (Baum & Figley, 1981). Thus fatigue may represent to the patient a character flaw. This perception may be exacerbated by advice to rest and avoid physical labour as a component to treatment, which is in contrast to prominent adages such as, "fight the disease", or, "conquer the symptoms."

Loss of function. The loss of functional ability is often the result of the above two features. Functional impairment may result in the loss of one's ability to carry out tasks in his or her role as a cook, welder, mother or surgeon. The inability to continue in one of their roles in society may cause loss of social identity

and diminished self-esteem (Baum & Figley, 1981). This may be true even though function in another role is a viable alternative.

Change in physical appearance. A disrupted body image may also precipitate a loss of identity and a decrease in self-esteem. If a drug treatment is causing alterations to one's physical appearance, then there is a very real threat to continued adherence to the medical regimen. Noncompliance may be largely due to the patient's fear of rejection due to a changed physical appearance.

Loss of independence. Dependence means seeking and requesting assistance. Each request for help presents the risk of rejection. For most people, losing independence not only heightens fear of rejection but also symbolizes a return to previous states of immaturity (Baum & Figley, 1981).

Financial burden. The presence of a chronic illness may be a considerable burden on the finances of an individual or family. Travel for medical care, cost of

treatment and specialized equipment, and child and home care all have the potential to strain a patient's financial resources.

Meenan, Yelink, Nevitt and Epstein (1981) surveyed 245 respondents with rheumatoid arthritis by use of a detailed questionnaire and interview. These researchers found that major losses in the area of work and finances were extremely common. On the average, subjects in the group were earning only 50 percent of the income predicted for them had they not had arthritis. A majority of the working subjects (59 percent) had stopped working completely and others had to change occupations or reduce their hours of work as a direct result of their arthritis. Thus it appears that a diagnosis of arthritis may have a significant socioeconomic impact.

Loss of sexual function. Arthritis may significantly affect sexual function due to pain and fatigue (Ferguson & Figley, 1979). One's perception of self as a sexual person may be influenced by physical changes characteristic of arthritis. As stated earlier, some drugs used in the treatment of rheumatic diseases

may alter physical appearance and thus affect sexual interest or energy (Baum & Figley, 1981). To compound the problem, the unaffected partner may fear causing discomfort to the partner with arthritis, who may view unwillingness to engage in sexual activity as a loss of physical attraction (Rogers, Liang, & Partridge, 1982). Results of a survey of 121 patients with osteoarthritis revealed that of the 81 patients who expressed sexual difficulties resulting from this disease, 23 percent felt that these difficulties were the cause of marital unhappiness (Currey, 1970). However, at times arthritis may be an excuse for, not the cause of, the sexual problem. In such situations, poor communication may be a contributor to the problem. The following category expands on the effects of this illness on interpersonal relationships.

Disruption of family dynamics. For a couple, the development of arthritis in one partner will test the flexibility and depth of the relationship. A balance between dependence and independence is achieved primarily in the family (Rogers, Liang & Partridge, 1982). Certain members may need to shift roles and take responsibility

for household tasks formerly done by the patient. However, a problem may arise when the family stereotypes a patient in the sick role. At times it may be more important for a patient to struggle with a difficult task than to have it done by a family member (Rogers et al., 1982). It is important for family members to remember that the patient needs to feel that she or he can contribute.

Family discord can occur if family members are unable to manage their own emotional responses to the patient's arthritis. Other members may suffer to see the patient in pain, but lack awareness of the appropriate responses to the emotional concerns of the patient (Gross, 1981). Sometimes a patient will complain of a spouse not understanding his or her illness and may need help in communicating with family members and close friends (Rogers, Liang & Partridge, 1982). Certainly monitoring the impact of arthritis on family members is an essential component to disease management.

Psycho-emotional Responses Common to Arthritis

In general, a patient's response to the losses arthritis imposes is characterized by a fluidity between various emotional stages. As the arthritis progresses, the series of emotional reactions may be partially or completely repeated. It cannot be assumed that a particular response, as described below, will not reappear after it has seemed to pass. As with most illness, a unique interaction exists between the arthritis and the patient's stage in life, personality, life experience, and both work and home environment (Rogers, Liang & Partridge, 1982). Once again, the psychological effects of rheumatic disease described below are based on clinical observations rather than on empirical studies. It must be noted that it would be inaccurate to assume that all people with arthritis have psychosocial problems. Nor is it automatic that arthritis causes psychologic, social and emotional problems or vice versa (McGowan, 1990).

Anxiety. As the individual notices symptoms of arthritis, the initial response is anxiety (Baum & Figley, 1981). Fear and uneasiness grow as symptoms persist. Upon diagnosis, some people might be relieved to find out what they have after frustrating efforts to understand their symptoms. Others may relieve their uncertainty by attributing the arthritis to stress or punishment for some misdeed (Rogers, Liang, & Partridge, 1982). Anxiety may precipitate positive action such as seeking medical advice. Anxiety may also evoke denial.

Denial. Denial is common and helps the patient adapt to the arthritis. This is not harmful unless the patient insists the symptoms have no meaning and rejects medical assistance. Otherwise, denial can be a healthy defense against a reality which may initially be overwhelming to the patient.

Anger. Anger may begin to surface once the patient realizes the seriousness and chronicity of her or his illness. Anger may be engendered by the injustice of the disease or by the various features of arthritis just discussed. Unfortunately the anger may be directed

inappropriately towards family and friends. Health care providers may also be targets of the patient's anger as he or she comes to the realization that a cure for arthritis does not exist. If the anger is not expressed verbally, it may take the form of passive-aggressive behaviour such as failing to keep therapy appointments (Gross, 1981).

Bargaining. This response represents the partial acceptance of the disease by the patient. She or he may accept some parts of the illness, but not accept the situation in its entirety. For example, one may accept his or her present physical disability, and refuse to accept its chronic nature or its potential for progression (Gross, 1981).

Depression. Depression is a natural reaction to loss. The various losses associated with arthritis, whether it be specific losses such as physical limitations or abstract losses such as expectations for the future, may create low self-esteem, a strong factor in depression. If prolonged, depression results in loss of energy and motivation and appears to accentuate pain

in rheumatic diseases (Baum & Figley, 1981). This will of course negatively impact on therapy designed to restore physical functioning.

Coping. Due to the uncertainty inherent in the prognosis of osteoarthritis, patients will often develop strategies for normalizing their daily activities and maintaining a constant interaction with others. Two techniques are frequently employed. They are "covering up" (hiding the illness from the public) and "keeping up" (maintaining the previous level of activity) (Gross, 1981).

Covering up involves hiding the pain and disability. Patients may verbally deny any pain and are unwilling to use visible symbols of disability, such as a walker. Those who mask their pain may wonder why their family and friends are not more understanding. In fact, they may be proud that "no one knows", yet be distressed that "no one cares" (Gross, 1981). Patients may also attempt to keep up by maintaining their previous level of activity even though it may increase their joint pain. They may be able to keep up at work, only to arrive home experiencing

great pain and fatigue. It is important to note that because arthritis is not necessarily a visible illness, and is still considered by many to be a minor illness, lack of understanding by others can occur to those arthritis patients who are not covering up or keeping up.

The main normalization strategy employed by those with arthritis is "pacing" - identifying which activities one is able to do, how often, and under what circumstances (Wiener, 1975). Decisions on activities may be affected by the time which is lost when resting between activities. Daily tasks such as housecleaning, not only take longer to complete, but may also have to be planned around periods of respite. For some, rest becomes a ritualized part of the daily regimen. Unfortunately time expended in rest results in a further reduction of desired activities.

Lowering expectations and developing a new set of norms for action is directly related to the frequency and duration of flare-ups for those affected by rheumatoid arthritis (Wiener, 1975). Increased frequency and duration of flare-ups will spiral re-normalization into

lower and lower expectations. Part of this re-normalization, or adjustment to reduced activity, involves the acceptance of help. However, eliciting help may reinforce one's fear of dependency, or conversely, of rejection. Certainly, asking for help decreases the patient's potential for covering up and keeping up.

Consequently, people with arthritis may be engaged in a continuous balancing of options. Pacing decisions will require a weighing of potential benefit derived from different available courses of action. Each option may be met with an ad hoc response: whether to keep up and endure increased pain and fatigue; whether to cover up and risk the inability to justify inaction; or whether to elicit help and risk loss of normalizing (Wiener, 1975).

Psychologic and Social Effects of Rheumatic disease Specific to the Elderly

One standard chronological definition of old age that has been used since the advent of social security legislation is that of 65 years of age. However it is important to remember that this societal defined phase of

life can span 30 years or more. Gerontologists have divided this phase into two groups. The 65 to 74 year old group have been designated as the young-old and the 75 years and more group as the old-old (Blumenfield, 1986). The primary developmental tasks for the young-old group include coping with retirement, developing new relationships, restructuring time and coping with financial concerns. The old-old group, facing greater risk for illness and incapacity, must face the task of developing greater dependency on family members, coping with increased physical disability, and conserving remaining physical, emotional and financial reserves (Blumenfield, 1986). The subjects for this present research primarily belong to the old-old category.

Adjustments to chronic arthritis occur against a background of the patient's stage in life. Late life is a time when many people look forward to activities previously deferred because of career or family commitments. Arthritis may deny this pleasure. Notions about oneself as skilled, independent and able can be upset by the progression of arthritis. Energy that is needed for self-integration is diverted to developing new

life strategies to cope with the illness. Furthermore the uncertainty inherent in rheumatic disorders affects a person's ability to plan his or her activities. The person is never sure how she or he will be feeling on any given day, and therefore it may be easier to plan nothing, to rely only on spur of the moment activities, and to include few others (Blumenfield, 1986). As simple, everyday activities such as opening a jar or climbing a flight of stairs become more difficult to perform, the older person's motivation may diminish. The disease process has an additive effect on the normal changes of aging as pain, fatigue, stiffness and medication all serve to complicate the situation. Consequently losses are exacerbated and hastened. As has been discussed, stress modifies the expression of arthritis. The cost of assistance devices and environmental modifications can become an increasing stressor for an elderly person who is on a fixed income.

Research has shown that 80 percent of the care provided for elderly people living in the community is provided by family members, primarily daughters (Butler, 1975). In the process of helping the elderly parent,

difficulties between siblings may arise as tasks are distributed and claimed by family members (Blumenfield, 1986). Although no one pattern of family relationship can be cited, it is extremely likely that there will always be some effect on the family when an older member is stricken with arthritis.

In late life a person may rethink one's identity. This may involve the acceptance of one's place in the continuity of history, the coping with one's own anticipation of death, or the acceptance of responsibility for the course of one's life (Blumenfield, 1986). These developmental tasks can be made all the more difficult by the onset of arthritis, which is associated with a disruption of lifestyle, social interactions and personal feelings.

Social support may have particular importance for physically disabled people because social ties maintain or strengthen individual coping behaviour. Disabled people with higher levels of social support may have higher levels of self-esteem or morale that, in turn, help them cope with the everyday problems of being

disabled. Social support may also encourage problem-solving and provide advice and access to professional services or self-help groups. Social support may influence the health status of physically disabled people by reducing the impact of additional stresses such as adverse life events on their functioning (Patrick, Morgan, & Charlton, 1986). What follows is a discussion of social support and its importance for the physically disabled and the elderly.

An Overview of Social Support Theory

Research over the past 15 years has shown that social support has the power to buffer or moderate the effects of stress on physical and mental health. The presence of or perceived access to supportive others determines whether individuals develop untoward health consequences after being exposed to high levels of stress (Broder, 1988). This observation has important implications for identification of high risk groups and development of treatment programs (Lieberman, 1986). Observations in a variety of settings have highlighted the positive roles played by social attachments in

psychological adjustment and health. Physicians note the salutary effect of their attention and expressed concern on patients' well-being and health. Psychotherapists try to provide their clients with the acceptance needed to pursue self-examination (Sarason, Levine, Basham, & Sarason, 1985). It is also known that support systems, particularly families, can have a profound effect on outcomes after illness onset or during rehabilitation.

Historical Development of Social Support Theory

The field of social support developed out from research in effects of social environment on health (McColl & Skinner, 1988), particularly Holmes and Rahe's Study (1967) on the effect of stressful life events on health outcomes. That work showed that stressful events could be counted and evaluated in terms of their impact on the individual. Further, it asserted that those stressful changes which are unexpected, undesirable or uncontrollable placed one at greatest risk of subsequent illness.

An observation that stressful events did not have an entirely predictable effect on different individuals led researchers to explore the presence and nature of modifying effects on the relationship between stress and outcome. Cobb (1974) proposed a model in which these modifiers acted as filters on the effects of stress. These modifying or buffering variables were personal factors, coping style and social support. Research began to examine the relationship of social support to health outcome in a variety of situations in which stress was inherent, including physical illness (DiMatteo & Hays, 1981). These studies provided evidence that the three concepts of stress, social support and health were related in some way (McColl & Skinner, 1981).

Definitions of Social Support

There seems to be little agreement among researchers about the essential meaning of the term social support (Broder, 1988). However, it is generally agreed that social support is provided in the context of "social support systems" or "social networks" which are usually defined as those people (family members, friends, co-

workers and so on) to which an individual is linked by emotional bonds and/or behavioural interactions (Gottlieb, 1983; Saulnier, 1982). It is also becoming increasingly clear that social support is a multidimensional construct. A number of researchers have suggested the salience of dimensions of social support such as the structure of the social support network and the sources of support (e.g., spouse, friends, relatives). Kaplan, Cassel and Gore (1977) defined social support as the degree to which the need for affection, approval, belonging and security are met by others. Thus, they focused on the amount of support (e.g., the frequency and intensity of provision). Kahn (1985) defines support as interpersonal transactions that express affect, affirmation or aid, thereby introducing type of support as a dimension. Other dimensions include whether social support is perceived as accessible or actually utilized and whether it is generalized or focused on a particular problem.

Definitions of social support generally fall within two categories: those emphasizing functional aspects of social support networks, and those stressing the

cognitive appraisal of social support (Broder, 1988; Turner, 1983).

Functional definitions. Caplan (1974) defined social support as attachments which promote mastery, offer guidance, and provide identity-validating feedback about behaviour. He also wrote that social support was any input provided by individuals or groups that moves the recipient close to his or her goals. In an attempt to integrate the conceptualization of social support, House (1981) identified four interdependent types of socially supportive behaviours: emotional support (e.g., empathy, caring, trust), instrumental support (e.g., sharing tasks, loaning money), information support (e.g., teaching skills/providing information to assist in problem solution), and appraisal support (e.g., providing feedback on personal performance). Barrera and Ainlay (1983) identified six similar functions attributed to social support in the literature: directive guidance (e.g., providing information, instruction and advice), intimate interaction (e.g., expressions of intimacy, esteem, physical affection and trust), positive social interaction (e.g., discussing interests, involving in

recreational activities, joking), material aid (e.g., loaning money), behavioural assistance (e.g., sharing of tasks) and feedback. Similarly, Tolsdorf (1976) conceived psychosocial support as the product of all social bonds that provide an individual with (1) goods and services, such as financial aid or help with housework (2) information and guidance, such as suggestions about where and whom to consult for help and (3) psychosocial backing such as encouragement, emotional comfort and intimacy. Table 7 displays the conceptualizations of functional social support put forward by three leading researchers in this area.

Perceptual definitions. Some researchers have stressed respondents' cognitive appraisal or evaluation of their social interactions. Cobb (1976) saw social support as the experience of being esteemed and valued, cared for and loved, and a part of a network of mutual obligation. Procidano and Heller (1983) differentiated between perceived support and actual support, describing perceived support as, "the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled" (p. 2). Heller, Swindle and

Dusenbergr (1986) state that a social activity involves social support if it is perceived by its recipient as stress reducing or esteem enhancing. Thus social support is viewed as a subjective and personal experience from a perceptual perspective.

Definitional problems. The fact that some researchers do not make clear what they mean when they refer to social support has created some problems. Theory and measurement design are difficult when the construct remains vague or imprecise (Broder, 1988). Another problem relates to the confusion in the literature between social network analysis and social support. Gottlieb (1983) writes that individuals are embedded in social networks constituted of individuals who generate both support and stress at different times. Indeed, Saulnier (1982) suggests that there are direct negative effects of involvement in social networks. Negative experiences from interaction in a social support network lies in its potential ability to weaken self-esteem, to stifle or restrict access to new opportunities, and to reinforce or maintain problem behaviours (e.g., abusiveness, alcoholism, criminal

activity). Coyne and Delongis (1986) concur that potential sources of support may be more draining and demanding than nurturant. So it appears that social support is just one product of interaction in social networks. Thus social network analysis is broader than the study of social support.

Theories of Social Support

Theories of social support generally fall into three main categories. First social support has been specified as having a protective or buffering effect against the negative effects of stress. Second social support has been considered to be an independent etiological variable in the development of both physical and psychological disorders. Third the perceived social support model suggests it is an individual's interpretation of socially supportive behaviour by others which is most important in determining one's healthful behaviour.

Buffering hypothesis. Interpretations of the buffering hypothesis generally put forward one of two ways in which social support mediates the causal sequence

linking stress to illness. First, social support may attenuate or prevent a stress appraisal response. The perception that others will help to provide the necessary resources to combat stress may bolster one's perceived ability to cope with the situation, and consequently prevent a particular stressor from being appraised as highly stressful (Cohen & Wills, 1985). Second, adequate social support may intervene to suppress the stress reaction. Support may dampen the impact of stress by facilitating healthful behaviours, providing a solution to the problem, reducing the perceived importance of the problem, or inhibiting the neuroendocrine system (Cohen & Wills, 1985).

Main effects hypothesis. Cohen and Wills (1985) assign positive main effects of social support to its provision of positive affect, a sense of stability and recognition of self-worth. Involvement in a social support network may also directly promote avoidance of stressful or negative life experiences. However a corollary of the main effects model is that absence or removal of social support constitutes a source of stress in itself (Gottlieb, 1983; Turner, 1983).

The buffering and main effects models of social support are not mutually exclusive (Broder, 1988). This view postulates that social networks serve as both active support systems, furnishing the satisfaction of day to day expressive and instrumental needs, and as reactive support systems, available to respond to typical stressors (Dean & Ensel, 1983).

Perceived social support model. Oritt, Paul and Behrman (1985) have proposed a preliminary model of perceived social support. Recollections of past supportive interactions and outcomes provide data used by the individual to appraise the current support network, providing the foundation for current perceptions of social support. In turn, current perceptions of social support influence the degree to which support-seeking behaviours are initiated by the individual. Thus, if the appraisal process concludes that interaction with the support network is likely to reduce stress for the individual, the model assumes that the individual will engage in support-seeking behaviours.

The elements of perceived social support comprise those variables that are reviewed by the individual when recollecting past supportive encounters. Within the proposed framework, these variables possess at least one quality in common. All perceived social support variables are subjective in nature and modified by memory effects. This model assumes a discrepancy between real events and the distortions imposed on real events by an interpretive memory and the passage of time. It is the interpretation of the impact of past events that is presumed to play a crucial role in determining current perceptions of social support. The appraisal of past interactions and outcomes is likely to be affected by individual pathology. Oritt, Payl & Behrman found that less adjusted persons will probably report less perceived social support than their more adjusted counterparts.

Oritt, Paul and Behrman (1985) describe a number of perceived social support variables which can be viewed as falling within the subjective experience of the individual: Perceived network size is the number of supportive network members that a person believes to be available during times of stress; initiation of support-

seeking behaviours is the extent to which an individual actively solicits support from network members during stressful times; perceived availability of support refers to the perception of how readily available network members are for providing support during those times; satisfaction with support means the personal gratification resulting from the perceived effectiveness of the network member's support in reducing stress and restoring emotional and instrumental equilibrium; perceived multidimensionality refers to the number and types of support an individual believes she or he might expect to receive from a network member during a stressful event; perceived support reciprocity is the extent to which an individual believes reciprocity of support exists between him or her and the support network; Perceived network conflict is the term used to describe the extent to which an individual believes conflict exists between oneself and members of the support network.

Problems Arising from Social Support Theories

Conceptual difficulties in social support research have resulted in the existing lack of clarity as to what precisely social support instruments should assess and how they should be validated (Cohen & Wills, 1985). Certainly a strong theory is needed to direct the content of measures of social support. Conversely, without sensitive, validated instruments, the above questions will be extremely difficult to answer (Broder, 1988).

Research has been geared toward proving that support, stress and illness are related, and not toward attempts to understand the processes through which social support works (Eckenrode, 1983). Consequently measures of social support tend not to examine either this process or the specific factors which make social support effective (Thoits, 1982). To complicate matters, social support may function differently depending on the situation, and the needs and personal characteristics of individuals (Cohen & Wills, 1985).

Different aspects of social support may function according to different models (Broder, 1988). Cohen and Wills (1985) conclude that the buffering model is supported when perceived availability of social resources that are responsive to stress-elicited needs is assessed, while evidence for a main effects model is found when the support measure assesses the degree to which an individual is integrated in a social network. This implies the need for broad measures of social support which assess multiple aspects of social support (e.g., perceived versus available support) and which provide different scores summarizing different aspects of social support.

Dynamics of Social Support

Social support is a dynamic phenomenon rather than the static environmental exposure status of an individual. Social support may fluctuate and has its own determinants of variability. It has determinants which are internal to the individual (e.g., temperament or patterns of perceiving and interacting with the environment) and those which are externally mediated

(e.g., social role definitions). Both types of determinants are active at all stages of the life cycle (Broadhead et al., 1983). The internal determinants of social support are, in fact, coping strategies. Coping may occur at a behavioural, cognitive or physiologic level (Linden & Feuerstein, 1981). Although cognitive coping skills may affect perceptions of social support, it is the behaviour of an individual in the form of social coping skills which affect the availability of social supports. A person who is either self-reliant or resigned to helplessness and does not seek the advice of others when help is needed may have less actual social support than a person who copes actively by seeking advice, information, or simply someone to talk to about a problem (Billings & Moos, 1981). Likewise a person's tendency to seek affiliation or social contact with others even in the absence of a problem will partially determine the social supports available (Kaplan, Cassel & Gore, 1977). Thus, a person's temperament with regard to social affiliation should be considered if an understanding of the process is to be reached. Those psychologic characteristics which affect social support availability are under continuous change during

development and have far reaching effects into adulthood. The defenses used by the eventual adult in coping, and their social consequences, are primary determinants of social availability (Vaillant, 1979).

In addition to the cumulative effect of experience on one's skills or abilities to mobilize social support, a person's roles, needs and circumstances also change with age and experience. The form and amount of social support appropriate depends upon these changes, and the nature of one's roles after each life transition or life event determines not only the demands made by the environment, but the opportunities or resources for development of a social support system (Broadhead et al., 1983). Hence, the distribution of social support varies with demographic and other personal characteristics related to role and is not independent of life events.

The dynamics of social support involve a set of complex relationships between variables. Temperament and other individual psychological characteristics interact with the social environment during all stages of development to produce behavioural coping styles or

patterns. These, in turn, interact with the current social environment to allow mobilization of social support or recruitment of a social network.

Clinical Implications of Social Support

A clinician may wonder how knowledge of her or his client's social support will alter intervention strategy. Knowledge of the dynamics of social support and its mechanisms of association with mental and physical health or disease results in two categories of response - prevention and intervention. Prevention refers to the suggestion by Kaplan, Cassel and Gore (1977) of the need for early childhood education and adult training in affiliation and coping skills to teach a person to garner the necessary social resources to maintain his or her health and help withstand the onslaught of stressful life events which are the inevitable consequences of living.

In the realm of intervention, it has been suggested that physicians and other allied health professionals be trained to identify high risk individuals and families,

assess the nature and deficiencies of their social networks, and assist and teach them to manipulate their environments to acquire and maintain the social support necessary for health (Kaplan, Cassel & Gore, 1977). Intervention might also include direct mobilization of a client's informal support system (e.g., family, friends, neighbours, community volunteers) by the clinician. The quality of support might also be improved by engaging clients in mutual support groups with other people with similar problems or situations. The Telephone Contact Program presently under investigation is one such attempt to improve the social support available to people identified as being at risk for health deterioration. The following discussion will examine the importance of social support interventions within health care services.

Social Support Interventions and Health

Different processes may link social support to physical health at different stages of the health-illness cycles most people experience. Examples of such stages include illness onset, health service utilization,

adherence to regimen, and adaptation to chronic illness. At points along this cycle, the process by which social support operates as well as the amount, type or source of support that is optimal may differ (Wallston, Alagna, DeVellis, & DeVellis, 1983). This may be complicated further by other significant variables (e.g., person characteristics, environment) that may need consideration. Also, the measurement methods that are most appropriate may vary depending upon the stage of illness being examined. Taking these factors into consideration will result in a better understanding of patients' needs. This will ultimately lead to a more accurate understanding of the association between social support and health, thereby making social support a more useful clinical concept.

Social Support and Utilization/Adherence to Treatment

Strong emphasis has been placed on the potential influence of social networks on the seeking of health care. The assumption is that persons contemplating seeking care communicate with members of their network

who thus have an opportunity to influence actions taken. Since others could encourage or discourage use of services (e.g., by providing a professional referral versus folk remedies), research in this area has attempted to identify a relationship between network characteristics and utilization patterns. Several studies (McKinley, 1973; Salloway & Dillon, 1973) suggest that social ties to kin versus non-kin influence utilization. However, the important distinction is not whether one's ties are predominantly kin versus non-kin but the norms and values relevant to seeking care endorsed by one's network (Wallston, Alagna, DeVellis, & DeVellis, 1983).

Although there are some conflicting findings, there is evidence for a relationship between support and adherence. Caplan, Robinson, French, Caldwell and Shinn (1976) found in their study that perceived support from spouse, friends and health care providers was associated with increased motivation to adhere, increased perceived competence, decreased depression and heightened perception of negative consequences for noncompliance.

In turn, these four factors related directly to adherence.

Social Support and Rehabilitation

Disabled persons reporting more support received better staff ratings of functional improvement than those reporting less such support (Wallston, Alagna, DeVellis, & DeVellis, 1983). Research relating social support to rehabilitation fall into two categories: studies of natural or informal support networks where help is received from friends, relatives and so on, and studies of formal support interventions from traditional health professionals and service delivery systems. Natural support was a significant positive predictor of rehabilitation among disabled individuals as measured by a composite index of source of income, mobility, employment and health status (Smith, 1977). Similarly, Porritt (1979) found that among men hospitalized for road injuries, those who received practical and emotional support from a hospital social worker showed more favourable outcomes on a composite index of emotional

distress, life enjoyment, work adjustment, and health deterioration than controls.

A disabling illness may be seen as a source of stress in two respects. First, undesirable changes resulting from disability can be interpreted as a stressful life event. Changes in functional status, social roles and vocational performance, all of which are unexpected and uncontrollable, are strong risk factors for a negative outcome (McColl & Skinner, 1988). Caplan, Gibson and Weiss (1984) have attempted to estimate the actual numbers of stressful life events experienced by those who suffer from a disabling illness. They have found a greater number of stressful events in the post illness/injury phase which placed subjects at an elevated risk of illness outcomes, particularly depression. Second, alterations in functional status which require constant and continual readjustment may be interpreted as chronic strains (Wood & Turner, 1985). Within the stress-outcome model, this preponderance of stressful events and chronic strains predisposes disabled persons to further illness, particularly depression, poor

adjustment and reduced functional ability (McColl & Skinner, 1988).

The utility of the stress-outcome model is that it identifies intervening variables, such as social support and coping style, which offer guidance in terms of remediation (McColl & Skinner, 1988). Social support is of particular interest because of its potential for change and its amenability to intervention. The following studies investigated the potential of social support to moderate negative outcomes following the stressful event of a major injury using a stress-outcome approach. Schulz and Decker (1985) examined social support, among a number of other possible buffers (e.g., self-blame, locus of control). In a sample of 100 spinal cord injured people, they found that network size and satisfaction with social support were inversely related to depression, life satisfaction, and psychological well-being. McGowan and Roth (1987), in a sample of 41 paraplegic outpatients, discovered that family interaction related to effective emotional and role-related functioning. The empirical evidence strongly

suggests social support is important to rehabilitation.

Measurement of social support has some unique dimensions when applied to the disabled population. One must pay careful attention to the needs and issues disabled people experience. Wortman (1984) outlines three factors that influence the measurement of support for people who are disabled or ill: (1) logistical problems of developing and maintaining social ties when one is physically limited; (2) elevated need for support to overcome fears and concerns about disability; and (3) problems associated with other people's ignorance, fears and stigmatization around illness and disability. These factors emphasize the need for sensitivity to types of support that might be received by those who are physically constrained, and the critical importance of emotional support to deal with disability-related emotional issues.

Croog, Lipson and Levine (1973) also differentiated support issues among the disabled from those of the able-bodied community. They point to the need for intensive or special care, which may be threatening to some

potential supporters, and may decrease their willingness to become involved. Further, reluctance on the part of the supporters may be associated with the chance of gradual acceleration of the needs and demands of disabled people. This may lead to a fear that the burden of support will become overwhelming and unmanageable, precipitating a decline in support from the outset. This suggests the importance of a large, well-differentiated network with relatively specific functions to address the potential demands for practical help. It also underlines the importance of considering the types of support (i.e., informational, instrumental, emotional), and the extent to which each is perceived as available and satisfactory to the individual.

The identification of specific sources of support may be especially important when measuring support among disabled people for two reasons. First, special sources, such as professionals and paid attendants, are potentially important to disabled people. Second spouses, parents and other usual network constituents often have special demands placed on them (McColl & Skinner, 1988). As House (1981) emphasizes, the actual

network composition is of interest, but it is the perception of support which may be of more importance in terms of predicting health outcomes.

The growing body of evidence that health status is related to social support contributes to the development of well-targeted and constructive social experiments in rehabilitation and health maintenance. However community studies of chronically ill persons living at home are particularly important since the greatest proportion of both disability and care are found in the households of community residents, particularly among the elderly (Patrick, Morgan, & Charlton, 1986).

The Importance of Social Support for the Elderly

The elderly, like other age groups, turn first to an informal system for help before requesting formal services. The presence or absence of an informal support network is a crucial predictor of an elderly person's well-being and autonomy (Hooyman, 1983). However knowledge of how to develop effective interventions to create or strengthen informal support for older people is

recent and limited. In a time of scarce economic resources, it becomes imperative to formulate strategies to mobilize informal support systems for older people (Hooyman, 1983). For example, with respect to mortality, Pennebaker and Funkhouser (1980) found that an index of support predicted mortality among elderly persons. Also, institutionalized elderly who received regular visits from college students required less medication per day and were rated healthier by the activities director than controls who received no visits or visits at random (Schultz, 1976).

Typically, three types of housing responses emerge among older people who face increased losses and dependency with old age: (1) remaining in one's own home; (2) moving in with adult children and (3) entering a nursing home or Long Term Care facility. For each of these responses, carefully planned and implemented network intervention could ease the elderly's adjustment to loss and dependency (Hooyman, 1988). Older people and their families may not use available community resources as they confront issues surrounding home care and institutionalization for a number of reasons. These

reasons include lack of information about the availability of services, service inaccessibility, impersonalization of services, and service fragmentation (Hooyman, 1988). In response to these barriers to the use of services, a number of programs, such as telephone contact programs, volunteer linking and mutual help groups, have begun to strengthen social support as an intervention to reach and benefit older people.

The influence of social support on the physically disabled and the elderly is important in that it may prove possible to identify persons at high risk for deterioration in functioning by measuring their level, actual and perceived, of social support at a given moment in time. Promoting opportunities for social activities, improving opportunities and skills for social relationships, providing psychological treatment may all be possible social interventions for high risk individuals (Berkman, 1980). Telephone contact programs, home visiting and other types of social network intervention may reduce unwanted and unnecessary isolation. Many disabled people are aware of their need for increased social contact. Locker (1983) found that

his respondents, who suffered from rheumatoid arthritis, wished to maintain their social contacts to inject variety into their daily lives, and to prevent their homes from becoming the limits of their world. Increased social contact is also easier to provide than a guarantee of an intimate, confiding relationship. One of the ways of providing increased social contact is by use of volunteers.

The Role of Lay Volunteers Within Health Care to Deliver Social Support Interventions

Historical and Sociological Perspectives

In the past, self-care by lay persons has been the predominant mode of medical treatment for most illnesses. In the early 1800s in the United States, there was a large growth in self-care as a reaction to the broader social and political trends of the Jacksonian period which emphasized popular democracy and anti-elitism, and which broadened definitions of who could provide an array of professional services. A number of competing sects in

medicine have their roots in this period which witnessed the elimination of licensure for physicians in many states and the rise of new beliefs about the negative impact of standard drugs (Kett, 1968). More recently, the civil rights movement and the feminist movement that emerged from the 1960s questioned the authority and correctness of established institutions and points of view. Some of the premises of the self-care movement are that it is reasonable for individuals to perform for themselves many of the tasks associated with health care and that people with similar health problems may be able to provide as much guidance and insight into how to live with various health problems as can health professionals. These conceptions, which challenge the exclusivity of knowledge and competence of professionals, have become part of the self-care movement (Kronenfeld, 1986).

One line of sociological analysis which supports volunteer participation within social services holds that in seeking out opportunities for face-to-face interaction with peers and other individuals with similar problems, many persons are counteracting anomalous and isolating tendencies of society (Katz, 1970). The depersonalizing

trends in suburban life, industry and large academic institutions are to some extent countered by the innovation of a social form that allows people to group themselves according to common interests and common problems, and to attain a sense of cooperative activity for common purposes. This in turn helps to create and promote a sense of social identification. Katz (1970) writes that social scientists would probably suggest that such activity has become necessary to compensate for the decline of the extended family in contemporary life. When there was a large-scale, multi-generational family, it was not vital for the individual to affiliate with others outside the family for purposes of mutual support. However, under the present stresses of industrialization, urbanization and greater population mobility, the small nuclear family requires a supplement since it can no longer sustain the total burden of support hitherto carried out by the extended family. Volunteers can be utilized as tools of social work intervention to create or enhance clients' non-existent, nonfunctional or failing informal social support networks. A collaboration of social work and voluntarism can increase the coping skills of persons in crisis. Caplan (1981)

suggests that the provision of this psychological support during life crisis can prevent adverse health effects and reduce isolation and stress.

Risks and Benefits of Volunteer Participation

Utilizing the volunteer as a tool of intervention does not occur without risk for the organization, the client and the volunteer. The volunteer could potentially become the person in the middle, whose focus is on the client but is still bound by institutional policy and expectations, albeit to a lesser degree than the professional. The volunteer and social worker may differ in terms of their conceptualization of assistance with respect to the client. For example, the volunteer may not be practiced at being objective and non-judgemental in planned and purposeful intervention. Thus they may react subjectively and spontaneously, without accepting the client's values and behaviours (Mitchell, 1986). The risk for the volunteer is that counselling relationships can be anxiety provoking and stress producing. Thus the social worker must be in a position to train, prepare and inform volunteers of what to expect

from the client and the organization, as well as what they themselves can do.

The relationship afforded the client by the volunteer is person to person and, although not entirely equal, is of a more equal nature than that of client to social worker. The client-volunteer relationship has the potential of becoming mutual in its exchange of help and the sharing of other bases for relating, such as culture (Mitchell, 1986). Furthermore the social worker is seldom in a position to offer unconditional access to the client, even by telephone. The volunteer can exercise his or her ability to offer this service to a greater degree than the social worker. The degree to which a volunteer and a client can communicate functionally, that is, stating their case, clarifying and qualifying it if necessary, and asking for and being receptive to feedback, is of great importance to successful intervention.

Comparison Between Professional-Volunteer Effectiveness

Borkman (1976) distinguishes between experiential and professional knowledge. She defines experiential knowledge as truth learned from personal experience with a phenomenon while professional knowledge is truth acquired by discursive reasoning, observation or reflection on information provided by others. As sources of truth, Borkman does not see professional and experiential knowledge as being mutually exclusive. However, they do differ in important ways: experiential knowledge is pragmatic in that it emphasizes obtaining concrete observable results that 'work', as subjectively perceived by the individual who is going through an experience. Professional knowledge is also oriented to results, but emphasizes the accumulation of knowledge and defines results within a theoretical framework accepted by the professional community. Experiential knowledge is oriented to here-and-now action which emphasizes experiential fulfilment rather than didactic instruction. Finally, experiential knowledge is holistic in that it encompasses the total phenomenon experienced, that is,

that which individuals distinguish and perceive from their commonsense viewpoint.

Volunteers tend to emphasize experiential knowledge and therefore a peer counselling program can be defined as a voluntary human service organization of persons sharing a common problem who band together to resolve the problem through their mutual efforts, with experiential knowledge being a primary basis of authority in decision making (Borkman, 1976). It should be noted that competition is nothing new to human service professions. Professionals compete constantly to prove the superiority of their own models both within and across fields and each discipline has carved territories based on their own distinctive points of view. The diversity among health care professionals includes the extent to which experiential knowledge is seen as a legitimate aspect of their model. For some professionals, the premise that the source of truth is experience is a radical challenge to their authority.

In order to compare the effectiveness of professional and volunteer/paraprofessional helpers, one

must turn to the literature to find results which either support or refute the hypothesis that lay people should be considered as effective additions to the helping services, at least when compared with professionals. Based on a review of 42 studies, Durlak (1979) concluded that (a) paraprofessionals achieved clinical outcomes equal to or significantly better than those obtained by professionals; (b) in terms of outcome, professionals may not possess superior clinical skills compared with paraprofessionals; and (c) professional mental health education, training and experience may not be necessary prerequisites for an effective therapist. However, Nietzel and Fisher (1981) refute Durlak's findings because of three problems that seriously constrain the interpretability of the research: (a) inadequate internal validity; (b) inconsistent and inappropriate definitions of professional and paraprofessional status; and (c) the uncertain meaning of unrejected null hypotheses in studies with low power and insensitive designs. These researchers concluded that only 5 of the 42 studies reviewed by Durlak provide evidence on the comparative effectiveness of professional and paraprofessional therapists. Hattie, Sharpley and Rogers (1984) entered

the fray by using meta-analysis procedures to help resolve some of the contentious issues raised by these researchers. Effect sizes based on 154 comparisons from 39 studies indicated that clients who seek help from paraprofessionals are more likely to achieve resolution of their problem than those who consult professionals; moderators of this conclusion were related to experience, duration of treatment, and the manner in which effectiveness was measured. However Hattie et al. surmise that it is likely that the more experienced professionals receive referrals that require deeper psychological insight, or they work in an environment where the likelihood of a brief therapy leading to resolution is decreased. In a reply to Nietzel and Fisher, Durlak (1981) pointed out that they all agree that, although data are not definitive, it is sobering that research has failed to demonstrate significant differences in the outcomes obtained by paraprofessionals and professional helpers. Durlak recommends that efforts to ascertain the differential effectiveness of helpers focus on such characteristics as their behavioural interactions with clients and highly specific aspects of

the training and supervision they receive relative to their assigned clinical roles.

Truax and Lister (1970) conducted a study in which they compared the effectiveness of rehabilitation counsellors and untrained counsellor aides under three case management conditions (counsellor alone, counsellor assisted by aide, and aide alone) and two case load conditions (30 versus 60 clients each). Four experienced master's level counsellors and four aides recruited from the secretarial applicants provided the complete range of rehabilitation counselling services to 168 clients over a 14 month period. The researchers found: (a) greatest client improvement occurred when aides handled cases alone; (b) least client improvement resulted from counsellors assisted by aides; (c) case load was not systematically related to client improvement. These findings would suggest that the effective ingredients in interpersonal relationships are uniquely human qualities such as empathy, warmth and genuineness. Truax and Lister noted that there was no evidence of role conflict between the professional counsellors and aides. This fact should help allay many of the fears surrounding the

use of support personnel felt by professionals who believe aides would attempt to usurp many of the prerogatives of the professional counsellors.

Professional-Volunteer Collaboration Within Health Care

The extent to which volunteers will be used to extend, enrich and maximize human service effectiveness depends largely on professional gatekeepers who have, in the past, often displayed covert and overt resistance to professional-volunteer collaboration (Mitchell, 1986). The position of many professional organizations is that a high level of professional training and supervision is necessary for effective counselling and that support personnel, even under close supervision, must restrict themselves to 'simpler' tasks that the counsellor has decided are of value to the client (Truax & Lister, 1970). Despite this opposition to the use of supportive personnel in bona fide counselling activities, some agencies are utilizing non-professional personnel or counsellor aides under supervision in all aspects of the counselling process. This clearly demonstrates the need

for more attention to be given to voluntarism within social work practice (Mitchell, 1986).

Serious physical illness is an example of a crisis during which an individual responds to the life changes and grief resolutions consequent to chronic or terminal conditions. The long term adaptive needs of critically ill patients and their families for health care, counselling services and social support usually become more complex as the medical condition progresses. Bracht (1979) refers to the social nature of chronic disease or disability and the need for concrete social support services to provide continuity of care. Unfortunately due to hospital policy, the social worker is usually not available after discharge from the hospital to assist with problems of long duration. Acute responses such as fear, anxiety, denial, social isolation, anger, depression and guilt often result in alterations in role expectations and interpersonal relationships. Patients and their families may need extensive emotional and practical support to help them assimilate the diagnosis, prognosis, treatment, remissions and recurrence of disease (Simonson, 1987). Supplementary supportive

services to provide follow-up care should be integrated into the overall care of the patient and should be a routine component of the health care system. The concept of collaboration between social workers and volunteers can be significant in the development of these services to promote cognitive, affective and behavioural adjustment, to explore alternative coping strategies and to maximize optimal functioning.

Volunteer linking is a process in which social service agencies create an informal helping relationship between a client and a volunteer. The establishment of such a relationship is useful when social isolation or the lack of an adequate and positive social network is determined to be a source of emotional stress for the client and when intervention of this type is considered an appropriate treatment alternative (Mitchell, 1986). Providing clients with the opportunity to interact with another individual who may have experienced the same or similar event can help reduce the client's feelings of isolation. The overall purpose of this sort of intervention is to help clients develop or re-establish connections with their own positive, informal social

support network. Clients are thus able to maintain a healthy balance between their use of both formal and informal network systems (Mitchell, 1986).

Additionally, peer support can improve the communication process of patients and families with the social workers, physicians and other members of the health care team. Volunteer peer counsellors are often members of community support groups. Thus these volunteers provide links to prospective group members by encouraging a transition from one-to-one peer support to a formalized self-help group. This would lead hopefully to an increase in the patient's perceived level of social support. The effort of helping others appears to be one of the final steps in the grief and resolution process (Simonson, 1986). These individuals are able to reinvest in life goals and progress to self help activities. Reissman (1965) concluded that social work policy ought to develop ways to change recipients of help into dispensers of help.

There are models of social worker-volunteer collaboration which can be implemented for the benefit of

clients. One model put forward by Gartner and Riessman (1977) suggests a social worker could train a group of lay persons in becoming, for example assertive, and then may train them to become trainers of others. The lay trainers may return from time to time to the professionally led group for added skill training. The multiplier effect of this model is obvious: A small number of professionals have an effect that radiates out to many groups. In a second model one professional social worker would train a large number of lay people in mutual or reciprocal counselling, for example the offering of supportive counselling to help people cope with the impact of arthritis on their lives. Once again the exponential factor is very important. In one-to-one counselling, a social worker can only access a relatively few number of clients. However, a volunteer network of peer counsellors trained by one social worker can reach many times the number of potential clients at minimum cost to the agency (McGowan, 1989). The successful expansion of program services throughout hospital care units and into the community presents significant implications regarding the incorporation of a large base of trained volunteers into the discharge planning process

(Simonson, 1987). Peer support can be a therapeutic and cost-effective addition to social work services and long term health care.

Within the health care system volunteers have been used in other direct service capacities aside from counselling roles. For example, Cox (1979) implemented a project in which eight elderly persons from the community were recruited and trained to present classes in health education to other seniors. Cox writes that the fact that the speakers were able to identify with their audience and vice versa made them very effective. Similarly, Lorig, Feigenbaum, Regan, Ung, Chastain and Holman (1986) found the use of lay persons as providers of health care to be efficacious. These researchers cite several reasons for encouraging the use of lay persons as providers of health education. First, lay instructors serve as successful role models. Second, lay persons provide a large pool of potential volunteers which, if activated, may allow mass health education. The potential importance of this volunteer force can be demonstrated by using arthritis as an example. It is estimated that 30 million people in the United States

suffer from arthritis and related musculoskeletal diseases (Arthritis Foundation, 1981). If only one-third of these people might benefit from health education, and if only 10% actually attended group patient education courses with 20 persons in a group, 50 thousand groups would be required. This would be about 13 groups for every rheumatologist (Lorig et al., 1986). This number illustrates two problems in health education: lack of personnel and costs.

Lorig et al. (1986) randomly assigned 100 subjects into (1) lay taught, or (2) professional taught 12 hour arthritis self-management courses, or (3) a control group. After four months, professional taught groups demonstrated greater knowledge gain while lay taught groups had greater changes in relaxation ($p < .01$) and a tendency toward less disability. Thus this study suggests that lay leaders can teach arthritis self-management courses with results similar to those achieved by professionals. Based on these findings, cost becomes an important issue to both patients and providers. Taking the least and most optimistic projections, Lorig et al. calculated that the use of lay leaders instead of

professionals to teach the 500 arthritis self-management courses nationwide in the United States over one year would result in a projected savings of between \$20,000 to \$300,000 annually. Savings of this magnitude are naturally appealing to health care providers who are responsible for balancing budgets.

Voluntarism in an Economic Context

In today's health care system, in which quantitative measures are utilized for increasing productivity, the voluntarism approach may offer advances in productivity without equivalent cost increases. An economic approach to human service resources calls for a more selective use of highly trained and costly professional inputs and a much greater utilization of volunteer and self help resources. The health departments in Canada recognize and support voluntary action in developing and providing services to promote health and well-being. The annual value of volunteer labour is estimated at about \$1 billion in the health and social services sector in 1986-87 (Canada Yearbook, 1988). The Government of Canada suggests that the voluntary sector, with its

grassroots involvement, is in a position to be aware of emerging health problems, evolve innovative responses and mobilize rapidly to respond to perceived human needs. However, there may be other reasons for the government's support of volunteer services. Gartner and Riessman (1977) suggest that volunteer counsellors do not look to causes (environmental factors, economic circumstances, group behaviour) but to what will help the client feel better in the here-and-now. Thus volunteer counsellors run the risk of blaming the victim if the service fails in any way, because of their emphasis on individual responsibility rather than the social causation of problems. Health and Welfare Canada's 1987 policy framework, Achieving Health for All, places emphasis on self help as a core strategy for the delivery of services as we move in to the 21st century. This document refers to mutual aid, or people's efforts to deal with their health concerns by working together, as a major mechanism in the implementation of the government's health promotion policy. The report emphasizes the role of the family, the neighbourhood, the voluntary organizations and the self help groups as the fundamental (and most cost-effective) resource in the promotion of health.

Possible Implications of Increased Voluntarism in Health Care

The trend towards increased volunteer participation in the professional care giving system is a cause for concern should any of the following scenarios take place: increased use of volunteers may be used as an argument for the further curtailing of services; it may be used to reduce professional and system responsibility; the recent concern for accountability and evaluation may be watered down to mean no more than customer satisfaction and the goal of finding and developing objective indices of service performance may be surrendered (Gartner & Riessman, 1977).

There are several common background factors to the increase in voluntarism and self help groups: a more educated population; less funds for health care, an increase in chronic illness; and the trend toward community participation in health. Unfortunately there is the danger that official responsibility for a part of health may be shrugged off onto the voluntary organizations. However, Lock (1986) doubts this is a

major risk because most volunteer participation programs have been started to fill gaps in the health service that seemed unlikely to be plugged anyway. The social work profession has shown a considerable amount of interest in volunteer programs and self help groups. This is due, in part, to the commitment of social workers to help clients utilize their own skills to solve their own problems whenever possible, and the expanded awareness about the role of natural helping networks in the help seeking behaviour of clients. However, the results of a survey reveal that the majority of social service agencies have not developed policies that encourage social workers to use volunteers in their practice (Toseland & Hacker, 1985). When asked what formal written policies agencies should develop in regard to voluntarism and self help groups, respondents frequently mentioned procedures for referrals to volunteer programs, provision of concrete support and encouragement for these groups, and support for social workers' involvement in their development through professional consultation and training. The problem with this last policy objective is that volunteers face the danger of being absorbed by the agencies. Instead of using their experiential knowledge

on behalf of their clients, they become concerned with formalizing their education to facilitate their mobility in the system (Silverman, 1982).

Cost-benefit measures point to the institutional value of volunteer services. Volunteer assistance can enable social work programs to serve a greater number of patients and families and to meet more long term needs than is possible with a limited number of paid staff (Simonson, 1987). Coordination and cooperation of services can extend the scope of available resources. Social workers can become leaders in developing and implementing programs to expand social support resource systems in health care and in the community. The social work profession will have to examine its interrelatedness, not only with other human service professions, but also with both the formal and informal resources offered by the community in which the volunteer is but one such resource and in which the relationships developed can be mutually satisfying (Mitchell, 1986).

Telephone Contact Programs

Clinical and research literature dealing with use of the telephone is growing. The telephone is used frequently in clinical contexts such as crisis intervention, preliminary intake, client contact between appointments, information services, individual and group psychotherapy. Researchers have even investigated the benefits of conducting a clinical research interview via telephone (Tausig & Freeman, 1988). The focus of the following discussion will be on the efficacy of provision of information and social support to various populations - the physically disabled, the elderly, and the persons with arthritis, through phone contact.

Telephone Usage in a Psychotherapeutic Context

The telephone has been referred to by clinicians as an "emotional safety valve". For example, clinicians have structured patients' treatment programs to include telephone contacts with a mental health clinic at the most difficult time in their days (Chiles, 1974). The

telephone has also been used to follow up with alcoholics who might be unmotivated to seek help when faltering in their recovery process (Catanzaro & Green, 1970). Certainly telephoning may be the only way to intervene with hard to reach people (Chiles, 1974; Grumet, 1979).

Tausig and Freeman (1988) found that the primary advantage of telephone contact was that visual anonymity appeared to reduce self-consciousness, or the "interviewer effect", common to the face-to-face encounter. This lack of visual access to nonverbal cues when using the telephone can be both an asset and a liability. Clients feel safe and intimate when interviewed in the comfort of their own homes. They are able to dress and behave in a relaxed manner without worrying about visual scrutiny and its interpretations by the interviewer (Grumet, 1979). This may be liberating for both parties, and may come closer to a peer relationship because the visual anonymity afforded gives the patient a sense of greater control over what is said by or about her or him (Evans, Fox, Pritzl, & Halar, 1984). This may reduce defensiveness on the part of the client. On the negative side, the absence of visual cues

may inhibit the interviewer's ability to understand communication fully. Vigilance for auditory cues must be developed by the interviewer to compensate for lost visual observation (Tausig & Freeman, 1988).

Social workers have used telephone conference calling to conduct supportive group therapy with physically disabled adults who were experiencing feelings of loss, discouragement and social isolation (Evans, Fox, Pritzl, & Halar, 1984). A majority of the 29 participants reported being less anxious and more socially involved as a result of the intervention, which took place over eight weeks. The group composition was quite heterogenous in that no effort was made to influence group composition by type of disability. Emphasis in the phone therapy sessions was on providing a format for rehearsing new behaviour in coping with attitudes of others towards disabilities. Experimentation with new behaviour appeared to reduce emotional symptoms so that constructive problem solving could take place. The role of the counsellor was to facilitate the conversation so that each participant had the opportunity to share thoughts. The above research

suggests the need for evaluation of the cost effectiveness of phone intervention and exploration of the potential for treating affective problems with scheduled phone contact (Evans et al., 1984).

Telephone Contact Programs to Reduce Social Isolation Amongst Arthritis Populations

Intervention to combat the social isolation that accompanies physical disability is not well documented. However physical losses do pose a threat to a person's life style and to normal control of the environment (Evans, Fox, Pritzl, & Halar, 1984). A strong negative reaction to severe physical impairment often results in depression and a refusal of helping services (Evans et al., 1984). Furthermore, Feibel and Springer (1982) have shown that depression can be related to inactivity, and that physical trauma may put people at risk for affective disorder. This emotional reaction and interpersonal withdrawal adds strain to relationships which, in turn, increases anxiety and erodes self-esteem. The emphasis of most rehabilitative medicine programs has been on the use of activity oriented groups (Evans et al., 1984).

According to Lind (1982), physical therapy and recreational activities serve as a screen to prevent psychological problems from being dealt with, and these unresolved issues interfere with rehabilitation outcome. Telephone contact programs may be one method by which emotional support can be implemented to change both activity and mood.

The importance of provision of emotional or social support for physically disabled persons was recently highlighted through the work of Maisiak, Koplon and Heck (1989a). The subjects were 1670 consecutive callers of the Arthritis Information Service of Alabama, a statewide toll-free telephone information service, between July 1988 and February 1989. The goal of this service was to reduce ignorance and misinformation about arthritis by providing people with free telephone advice and printed materials about arthritis. The purpose of these researchers' study was to identify the characteristics of seekers of information about arthritis, to classify and estimate their needs for arthritis information, and to investigate the relation between the characteristics of the callers and their informational requests. The study

showed that user callers tended to be female patients with worsening symptoms. Information needs were related to the caller's age, sex and reported diagnosis. For example, younger callers had more need for symptom/test information because they were more likely to be recently diagnosed. However, the most surprising data from this study, according to its authors, was that emotional support was the most frequent need of symptomatic callers. Emotional support was defined as, "the need for encouragement because of anxiety or worry over a particular aspect of their arthritis symptoms or those of their loved ones" (Maisiak et al, 1989a). The need for emotional support was quite uniform across all demographic and diagnostic groups. In a follow up evaluation of the service, Maisiak et al., (1989b) found that the most frequently reported action (70% of respondents) by callers was sharing the information with others (N=227). Feeling less frustrated about arthritis was reported by 61% of the participants.

Social support for people with arthritis via the telephone has been demonstrated to have a role in improving health status (Weinberger, Hiner & Tierney,

1986). This research was discussed fully in the introductory chapter of this thesis. In a follow up study, Wienberger, Hiner and Booher (1989) randomly assigned 439 persons with osteoarthritis to a control group or to one of three intervention groups. The intervention differed only in method of delivery: telephone contact; person-to-person contact while at a clinic; both methods together. Intervention patients were offered suggestions by trained non-medical personnel on how to ask questions of their health-care providers, and received information on early warning signs for their osteoarthritis and barriers to care. On average, participants were 62 years of age and had nine years of education; 70% were black; 88% were female and 66% had annual income less than \$6,000. Only the telephone contact method improved functional status ($p = .03$) as measured by the Arthritis Impact Measurement Scales, in 379 subjects one year later. The researchers concluded that providing social support and information by telephone may enhance functional status in patients with osteoarthritis.

Telephone contact programs have also been employed to assist other arthritis population groups. Kroll (1987) writes about a telephone help-line support system for people with systemic lupus erythematosus (lupus), a chronic multisystem, autoimmune disorder usually affecting women. This help-line was operated by people who had lupus themselves and had developed positive coping strategies in living with the disease. Individuals with lupus are often homebound because of extreme fatigue and mobility problems. Therefore regular support meetings outside the home appear destined to failure due to low attendance. Hence it appeared logical to offer a type of mutual support group network which permitted its clients to stay at home (Kroll, 1987). Kroll did not evaluate the callers' satisfaction with the help-line, but she does suggest further investigation into the efficacy of such networks to aid the client whose environment is otherwise lacking in support. Certainly such programs provide an outlet for people to share accomplishments in dealing with chronic illness.

Telephone Contact Programs to Reduce Social Isolation
Amongst the Elderly

The literature is rather sparse pertaining to telephone contact programs assisting the elderly. In Louisville, Kentucky, the Kentucky Association for Older Persons (1989) established a program entitled Telecare for the purpose of providing a daily telephone reassurance call to the elderly and handicapped to enable them to remain living alone in their own homes. One of the biggest fears of Telecare's clients is that they will get sick or die and no one will find them. Telecare clients appear to identify with the Telecare volunteer as someone who does indeed care about them and they feel secure in the knowledge that if something untoward happens to them, Telecare is available to help assist in problem solution. Essentially about 100 volunteers provide a safety check call to over 300 elderly and handicapped persons in Louisville and Jefferson county. As with the Vancouver Arthritis Centre's program, the volunteer is an essential component.

Gerontologists have begun to focus on self-help networks as a means to improve general health amongst seniors. Social isolation and loneliness may well be the principal pathologic conditions of old age (Jansen, 1987). On a local level the West Health Unit Volunteer Program in Vancouver decided to adopt a "Telephone Tree" as a 12 month project in 1987. It focused on lonely seniors wishing to expand their social support networks, and those persons reported "at risk" as a result of various health problems (Jansen, 1987). At the time of its inception, there was no other existing support service of its kind in the West Side community area. Other goals of the program included acting as a resource for community groups and agencies, and providing opportunities for volunteering. In order to form ongoing relationships, calls were made on a reciprocal basis rather than solely at the discretion of the volunteer. The commonalities older persons possess among themselves, in terms of socio-economic status and value orientation, may facilitate greater social interaction (Jansen, 1987).

Users of telephone contact programs may use their common experiences to find solutions to problems and to

learn various coping strategies (Silverman & Murrow, 1976). Members who are anxious and uncertain about changes in body image receive encouragement and emotional support. The assumption is that a person who has undergone a similar experience can provide more effective support (Kroll, 1987). Volunteers who have been successful in coping can provide role modelling on how to maintain a satisfactory lifestyle within the limits of the disability caused by arthritis. The inadequacy of the socially isolated client in forming close ties with others may adversely affect medical treatment (Kroll, 1987). Telephone service may promote patients' adherence to needed medical treatment and enhance capacity for independent functioning and self-control (Evans, Fox, Pritzl, & Halar, 1984). Phone contact preserves privacy and provides a feeling of anonymity which may be conducive to establishing trusting relationships. Telephone contact may be the only viable intervention for those people inactive or immobile through the effects of old age/disability. The ease and cost effectiveness with which telephone contact programs can be conducted suggests that rehabilitation programs should further evaluate this mode of intervention.

CHAPTER 3

Research Design

The Arthritis Society's Telephone Contact Program was initiated by the Social Work Department at the Vancouver Arthritis Centre in Autumn, 1989. During the time of the program's inception, the Social Work Department felt that a research component should be included in the service delivery. The issue for research centred around one main objective: the production of scientific knowledge about the nature of therapeutic social support intervention using lay volunteers. The study was investigating a relatively unknown phenomenon, namely the effect of telephone contact programs for elderly caucasian women with arthritis, that has not been researched in the literature. The study would therefore contribute to the knowledge base in this area. It must be stressed that this research is only one aspect of an overall evaluation of the Telephone Contact Program.

Methodological Orientation

The methodological orientation chosen is best described as mixed qualitative and quantitative. In the present study, more than one technique was chosen in order to be able to describe the efficacy of the Telephone Contact Program from more than one perspective. It was thereby possible to gain a more in-depth picture of the nature of the phenomenon. The rationale for employing two different methods to collect different sources of information in the present study is supported by Patton's (1980) statements on qualitative evaluation:

Multiple sources of information are sought and multiple resources are used because no single source of information can be trusted to provide a comprehensive perspective on the program. By using a combination of observations. . . the evaluation fieldworker is able to use different data sources to validate and cross-check evaluation findings.

(Patton, cited in Rafael, 1987, p.54)

Quantitative research methodologies are used in the testing and validation of predictive, cause-effect hypotheses about social reality. Quantitative approaches tend to place emphasis on the perceptions that outside

observers bring to the study of social systems. On the other hand, qualitative methods assemble descriptions of social reality from the points of view of participants within the systems studied (Epstein, 1988). Both methods make meaningful contributions to our understanding of the social world and, when used together, can augment our understanding of the phenomena under investigation (Epstein, 1988).

Sampling Design

This study utilizes a form of selective sampling for which "units are chosen to display some behaviour the researcher wants to explore in depth" (Reid & Smith, 1981, cited in Rafael, 1987, p. 47). Specifically, a non-probability sampling procedure called availability sampling was employed. Availability sampling involves the use of the first available appropriate sampling units (Seaberg, 1988).

The sample was chosen using the following criteria:

1. Clinical diagnosis of arthritis

2. Not less than 65 years of age
3. Have difficulty leaving home due to physical functioning problems
4. Ability to read, write and understand English
5. Oriented and cognitive
6. Live within a toll-free region in and around Vancouver

People who did not fit the above criteria were excluded from participation.

Subjects were recruited through the Social Work Department at the Vancouver Arthritis Centre, referrals to the Social Work Department from the treatment departments at the Arthritis Centre, Long Term Care personnel in the Health Departments, and the Arthritis Affiliate Designates in the hospitals in metropolitan Vancouver. Referrals were solicited by having the above health care professionals contacting the coordinator if

potential participants expressed interest in the program upon hearing about it. Subjects were then screened by the project coordinator who ensured that subjects met the above criteria.

Size of Sample

Due to time-frame constraints placed on the researcher, only 11 subjects were recruited for the study. Of this number, seven subjects completed both pre and post interviews. Reasons for drop-out by four of the subjects were as follows: one subject had an extended stay at hospital; one subject felt the researcher's questionnaires were too intrusive; and two subjects did not feel a need to be called. Table 1 shows the changes in sample size through the various phases of the study.

CHANGES IN SAMPLE SIZE
THROUGHOUT THE STUDY

TABLE 1

NUMBER OF SUBJECTS (N=11)	PRE-TEST WITH QUANTITATIVE MEASURES	INTERVENTION PERIOD	POST-TEST WITH QUANTITATIVE MEASURES	QUALITATIVE DATA FROM STRUCTURED INTERVIEW
6	6 / AIMS \ PSS-Fr, PSS-Fa	X	6 / AIMS \ PSS-Fr, PSS-Fa	6
1	1 / AIMS \ PSS-Fr, PSS-Fa	X	1 / AIMS \ PSS-Fr, PSS-Fa	---
4	4 / AIMS \ PSS-Fr, PSS-Fa	DROP-OUT	---	---
	N=11		N=7	N=6

Measures

Pre and post measures were selected to measure the dependent variables of physical functioning, psychological functioning, pain level and perceived social support from friends and from family. The Arthritis Impact Measurement Scales (AIMS) and the Perceived Social Support From Friends (PSS-Fr) and From Family (PSS-Fa) appear to be the best existing measures in the literature to look at the practical and psychosocial aspects of subjects' daily lives (AIMS) and perception of social support (PSS-Fr & PSS-Fa). Both instruments of measurement have good reliability and validity. Appendix B contains the final questionnaire package which was presented to subjects.

Measurement of Variables

Physical Function

This variable was measured by the Arthritis Impact Measurement Scales (AIMS). AIMS are a combination of

previously studied and newly created health status scales that are designed to assess the physical, emotional and social well-being of individuals with rheumatic diseases (Meenan, German, Mason & Dunaif, 1982). This multidimensional index is practical in that it requires little time to collect the data and the questions are generally comprehensive. AIMS consists of reasonably discrete scales and the results are easy to score and interpret. Furthermore, AIMS meets accepted standards of reliability, scalability and validity (Meenan, German & Mason, 1980).

Meenan, German, Mason and Dunaif (1982) showed the AIMS instrument to be highly reliable. The AIMS scales had a test-retest correlation coefficient of 0.84. These researchers also report that the AIMS approach is valid. In terms of construct validity, AIMS was shown to be correlated with related constructs. Each of the component scales has been shown by factor analysis to identify a single factor. Potts and Brandt (1987) provided further evidence of the validity of AIMS. These researchers' findings support the validity of the pain and anxiety sub-scales of AIMS. It would appear that,

overall, this instrument generates reliable and valid measures of both aggregated and dis-aggregated health status, and is a useful tool to assess arthritis outcome in a clinical setting.

Factor analysis has shown that five of the basic AIMS scales can be combined into a physical function component. The five sub scales are mobility, physical activity, dexterity, household activity and activities of daily living. Potts and Brandt (1987) support the validity of the dexterity and physical activity sub-scales. However, these researchers found that the household activity sub-scale may not be appropriate for use with men, and the activities of daily living sub-scale may be insensitive to mild impairment. The scales contain 4 to 7 items, and each item, depending on the phrasing of the question, contains 2 to 6 responses. Item responses are summed by group to produce scale scores and then brought to a normal standard of 0 to 10 range, with 0 representing good health status and 10 representing poor status. In this way, five scale scores ranging from 0 to 10 can be obtained. The physical function component scale is estimated by adding the

normalized component scale scores and then dividing by five. A low value indicates a high health status.

Psychological Function

Factor analyses have shown that the two basic AIMS scales of anxiety and depression can be combined to create a component scale of psychological function. Both sub-scales contain six items with six possible responses for each question. Following the normalization procedure described above, the psychological function scale is computed by adding the two normalized anxiety and depression scale scores and then dividing by two. Once again a low value indicates high psychological functioning.

Pain Level

Pain level was measured by the pain sub scale of the Arthritis Impact Measurement Scales. The pain scale consists of four items, each with six possible responses. Item responses are summed to produce a scale score and

then brought to a normal standard of 0 to 10 range. A low value indicates a low pain level.

Perceived Social Support from Friends

The measurement of social support has traditionally been problematic. Researchers tend to utilize measures of either objective, structural characteristics of individuals' social networks or of respondents' perceived social support. This researcher opted for the latter position because the objective presence of social support networks is not sufficient for its use by respondents unless they perceive these systems as accessible. Weinberger, Hiner and Tierney (1986) used a scale called the Social Support Questionnaire (Sarason, Levine, Basham & Sarason, 1983) to measure perceived social support for their study on a telephone contact program. However, this researcher hoped to employ an instrument that not only measured perceived social support, but also would be simpler to administer to an elderly population relative to the Social Support Questionnaire.

A comparative analysis of the Social Support Questionnaire (SSQ) (Sarason, Levine, Basham, & Sarason, 1983) and the Perceived Social Support from Friends and from Family (PSS-Fr & Fa) (Procidano & Heller, 1983) was conducted with ten women over the age of 65 in order to determine the measures' relative effectiveness for use with an elderly population. Both qualitative and quantitative data supported the selection of the Perceived Social Support from Friends and from Family as the instrument of choice for use with the elderly. The significantly higher completion rate for the PSS-Fr & Fa indicated its clearer and more empathic structure for obtaining responses from the subjects. Consequently this researcher opted to use the PSS-Fr & Fa rather than the SSQ which was used by Weinberger et al. (1986). Appendix C contains the details of this pilot study.

This variable was measured by the Perceived Social Support from Friends (PSS-Fr) Scale. Items tap both support provision by respondents and support received, as well as support enactment and availability. Most of the items fall within the category of emotional support.

Procidano and Heller (1983) report on test-retest reliability of .83 over a one month interval for a preliminary version of the PSS-Fr. This instrument is short enough for rapid completion, easy to score and appears to have face validity. In three studies described by Procidano and Heller (1983) both PSS measures were internally consistent and appeared to measure valid constructs that were separated from each other and from social network measures. These researchers also reported that high PSS-Fr subjects were significantly lower in trait anxiety and talked about themselves more to friends than low PSS-Fr subjects.

The PSS-Fr is comprised of 20 declarative statements to which respondents answer "yes", "no", or "don't know". Responses indicating support are scored as +1, while the other responses are not scored. Scores thus range from 0 to 20, with higher scores indicating more perceived support. Items 2, 6, 7, 15, 18 and 20 are reverse scored on the PSS-Fr.

Perceived Social Support from Family

This variable was measured by the Perceived Social Support from Family (PSS-Fa) scale. As stated earlier, this measure is reported to have good test-retest reliability, internal consistency and construct validity. Procidano and Heller (1983) found that both the PSS-Fr and PSS-Fa were inversely related to symptoms of distress and psychopathology but the relationship was stronger for the PSS-Fa. Interestingly, the PSS-Fa was unaffected by either positive or negative mood states. This phenomena supports caution in interpreting correlations between support and depression. An inverse relationship between social support and depression does not necessarily mean low support is a causal factor in depression. Rather, the findings suggest the possibility that depressed individuals may simply perceive less support as part of their negative self-appraisal.

This measure is comprised of 20 declarative statements like the PSS-Fr, but items are worded for family members. Scores are calculated in the same manner as the PSS-Fr, although it is items 3, 4, 16, 19 and 20

which are reverse scored. Scores also range from 0 to 20, with higher scores indicating more perceived support.

Interview with Subjects

A standardized open-ended interview approach was used. This is one in which wording and question sequences are pre-determined so that the same questions are asked of each interviewee in the same order (Patton, 1980, cited in Rafael, 1987, p. 59).

The final interview questions and the variables they were designed to measure are shown in Appendix A. The selected open-ended questions are designed to allow the interviewee to use her own words to represent what she wants to weight pertaining to the variable associated with the question. Due to drop-out, this open-ended interview was given to only the six remaining subjects after the post test quantitative measures. It was thought that the application of quantitative measures first would stimulate interviewees' opinions and/or feelings about the Telephone Contact Program.

Research Design (The one-group pretest-posttest design)

The one-group pretest-posttest design can be diagrammed as follows:

$$O_1 \quad X \quad O_2$$

O_1 represents the subjects' scores on the pre test measures. X represents the independent variable, or in other words, the weekly telephone calls received by the subjects. O_2 represents the subjects' scores on the post test measures and the data collected from the structured interviews. O_2 is compared to O_1 to determine whether there has been any change to the dependent variables. Unfortunately this design can be threatened by a number of confounded extraneous variables that can jeopardize internal and external validity. These variables offer plausible hypotheses explaining an O_1 - O_2 difference, rival to the hypothesis that X caused the difference (McBurney, 1983). This will be further discussed in a section on limitations of the study. A true experiment was not possible to implement because this researcher was unable to obtain enough subjects for a control group nor randomly assign subjects to conditions. Furthermore, a

more complex single-subject research design, such as ABA or ABAB, was not possible due to the continuity of the telephone contact program. It was not possible to withdraw treatment for a period of time because the program expected the relationship between volunteer caller and participant to be of a continuous, or uninterrupted nature.

Data collected from subjects was analyzed on an individual and group basis. Analyses focused on trends which may appear in changes in the dependent variables measured for each subject. Subjects' health status and perception of social support should have been relatively stable before the treatment intervention was introduced. The comparison then is not between different groups of subjects, but between different time periods in the life of the same subject (Nelson, 1988).

Procedure

The Social Work Department at the Arthritis Centre hired a social worker to coordinate the Telephone Contact Program. She has the following responsibilities:

informing health care professionals about the program; recruiting and screening of participants; recruiting and screening of volunteer callers; developing an informational brochure; leading a workshop for the volunteer callers; and assigning volunteer callers to participants.

Volunteer callers were recruited from the eight Arthritis Centre support groups. Also, members of the Social Work Department developed a list of volunteers they believed would be capable and interested. All callers have been diagnosed with arthritis. Callers involved with the subjects in this study were all caucasian women between the ages of 60 and 70. Two subjects received calls from the same volunteer. All other callers were assigned different subjects. Each caller was required to make one call per week. Callers also keep a record by ticking off their weekly call in a log.

All volunteers received a one day workshop given by the coordinator. In the training session, callers were taught the following skills of effective communication:

listen without interruption, and accept what the person is telling you and what it means to them; show respect, concern and empathic understanding of how the world looks to the person; show respect for the person's feelings, regardless of your own reaction; make sure the person can hear you, speak clearly and not too quickly; ask 'open' questions to encourage the person to go on; share your own thoughts, feelings, experiences, only as they are relevant; and be brief - shift the focus back to the person you are calling.

Callers were instructed never to give advice, argue, criticize or pass judgement. Nor were they to attempt to diagnose a problem, or give detailed information about arthritis or medication. Instead, the caller was to refer the participant to her physician. If the caller believed the participant to be at risk, the coordinator was to be advised. Otherwise, respect for confidentiality of client data was to be respected. In order to control for extraneous variables, if a subject were to ask for her volunteer's telephone number, extra phone calls, or special help, the volunteer was to say, "I'm sorry, but I'm not allowed to do that - it's a

policy of the telephone contact program". All volunteers offered their services without remuneration.

After screening by the coordinator, eligible participants were informed over the phone by the coordinator that there was a research component to the program. The coordinator told participants that, if they agreed to be interviewed, the researcher would require about a half hour of their time and would visit them in their own homes. Those participants who agreed to become subjects were telephoned by this researcher to set up interview times at their convenience. Most subjects chose to be interviewed in the afternoon because their arthritis made it difficult for them to function well in the mornings. Conversely, some subjects chose to be interviewed in the morning because they felt fatigued by the afternoon. Appendix D summarizes locations and dates of interviews.

Baseline interviews were conducted between May 12 and May 21, 1990. Follow-up occurred four months later, between September 12 and September 24, 1990. During the intervening four month study period, 16 telephone calls

were received by subjects on a weekly basis. Each call was not to extend past 15 minutes in length. However, as friendships developed, conversations likely exceeded this time limitation.

Pre-test Measures Procedure

For pre-testing, this researcher read each question and its possible responses, as printed in AIMS and the PSS-Fr & PSS-Fa, to the subject. The subject's response was then transferred to the paper by this researcher. Occasionally the participant would go off-topic at which time an attempt was made to refocus the response onto the question at hand.

Post-test Measures Procedure

The above process was repeated for post-testing. The order in which the measures were given to the participants in both pre and post testing were as follows: AIMS, PSS-Fa, PSS-Fr. After subjects completed the quantitative measures, the open-ended structured questionnaire was given verbally to the subjects.

However first permission was requested and granted by the subjects to have their responses audio-taped. This clinical research interview which asked open-ended questions about personal feelings and opinions aroused interview process dynamics such as relationship formation, interviewer effect and probing for deeper information (Tausig & Freeman, 1988). Total interview time per subject ranged between 60 and 90 minutes. Data from the quantitative measures was transferred to coding sheets. Data gathered from the structured interview was transcribed from tape to paper for further analysis. The student researcher scrutinized the full transcriptions for meaningful data. Appendix E contains the interview with subject 02 in its entirety. It was felt by this researcher to contain the greatest number of typical responses from all six subjects who were interviewed. An unedited transcript was chosen in order to give the reader an insight into the nature of the interview process and dynamics.

Ethical Issues

Forms were written and presented to both the Arthritis Society Research Committee and the University of British Columbia Ethics Committee for review. Both ethic committees approved this study (see Appendix F). There are no known risks to the subjects.

Limitations of the Study

A constraint of the study may be the four month time-limited framework. A longer intervention period was not feasible due to the time-frame of the student researcher's academic year. However, there is no data in the literature to suggest that four months is not a sufficient amount of time to effect change in the dependent variables measured. Compared to the Weinberger, Hiner and Tierney study (1986) in which 12 telephone calls were made to subjects over six months, this study's intervention may be considered to be more intensive in that 16 calls were placed to subjects over four months.

The study's small sample size ($N=7$) with no control or randomization posed threats to internal and external validity. Campbell and Stanley (1966) outline several of the threats to internal validity that are relevant to this present study. One threat is 'history' in that it was not possible to control for other change-producing events which may have occurred in addition to the study's intervention. 'Maturation' is also an issue because one cannot control for the psychological or physical processes which might have influenced outcome, independent of external events (Campbell & Stanley, 1966). This threat is all the more important with a population with a chronic condition. In respect to 'testing', the effects of the subjects being measured was not controlled. However, the reactivity of the measuring instruments appeared to be minimal as the testing process was more a passive recording of behaviour and perceptions than a stimulus to change.

The threats to external validity, or interaction effects, involve the intervention and some other variable. They thus represent a potential specificity of the effect of the intervention to some limited set of

conditions (Campbell & Stanley, 1966). Possible threats to the generalization of research findings are 'practitioner effect' and 'differences in clients'. Regarding 'practitioner effect', or the interaction of testing and the intervention, the particular interviewing style of the researcher may have influenced outcome. It is possible the pretest sensitized subjects to the dependent variables measured although the researcher did not explain the research hypotheses to subjects.

'Differences in clients', or the interaction of selection and X, was also a threat to external validity. The difficulty in getting subjects for this study may have increased the nonrepresentative nature of the sample (Campbell & Stanley, 1986). The high drop-out rate (4 out of 11 subjects) also increased the opportunity for selection-specificity effects. It should be noted that three out of the four drop-outs lived in Long Term Care facilities, as opposed to their own homes. This also represents three out of the five subjects who lived in Long Term Care facilities. This part will be more fully discussed in the Implications and Conclusions section. Subjects who completed both pre and post-testing also

represent a specialized group (elderly caucasian females with arthritis) which may affect the generalization of results.

CHAPTER 4

RESULTS

Following are the results for: comparison between experimental and comparison group; experimental scores on pre and post measures; Pearson correlation coefficients for group scores on the AIMS and PSS; an examination of the qualitative data gleaned from the interviews; and discussion on individual differences amongst the sample.

Description of the Sample

All eleven women were Caucasian. Two were married while the other nine were widowed. All were retired. Three women had one to four years of college, while the rest had reached various levels of secondary schooling. Five subjects earned less than \$5,000 a year, four earned between \$5,000 - 15,000, and two earned between \$15,000 - \$20,000. Five subjects lived in care facilities, two subjects lived with their spouses in apartments, three lived alone in apartments and one lived by herself in a house.

Characteristics of Drop-Outs

The seven subjects who completed the 16 weeks of phone calls are referred to as the "experimental group". Four subjects who completed pre measures and discontinued the program will be called the "comparison group". The purpose of comparing the experimental and comparison groups is to determine if the drop-outs differed in any significant way from those who completed the program phase. The pre scores on individual AIMS subscales did not show any significant difference between the comparison and experimental group. Table 2 compares the means and standard deviations for pre-test scores on the AIMS component scales and the PSS-Fr and PSS-Fa.

TABLE 2

Experimental and Comparison Group Pre-test Scores - AIMS
and PSS

MEASURE	EXPERIMENTAL			COMPARISON	
	<u>SCALE</u>	<u>MEAN</u>	<u>S. D.</u>	<u>MEAN</u>	<u>S. D.</u>
AIMS Component Scales	Physical	5.13	1.59	5.64	.41
	Psychological	4.03	1.79	3.83	2.08
	Pain	4.92	3.19	6.37	2.25
PSS	Family	10.14	6.44	13.25	2.63
	Friends	9.71	6.23	6.50	4.79

There does not appear to be much difference between the experimental and comparison groups on pre-test scores. Subjects experienced slightly elevated pain levels in the comparison group. PSS scores show that comparison group members perceived more social support from family, while experimental group members perceived more social support from friends.

Frequency tables were constructed for other categorical variables. Sample sizes are too small to do more than comment on them informally. The two groups did not appear to differ in terms of medication usage for problems other than arthritis and number of physician visits in the past year.

The two groups did differ in two important aspects: age and years with arthritis. Table 3 highlights these differences.

TABLE 3

Differences in Demographic Variables Between Experimental
and Comparison Groups

		<u>MEAN</u>	<u>S. D.</u>
EXPERIMENTAL	Age	76.14	13.10
	Years with Arthritis	26.00	20.11
COMPARISON	Age	88.75	2.98
	Years with Arthritis	19.25	13.98

The comparison group had a mean age of nearly 89 years, much older as a group than the experimental group which had a mean age of 76 years. The significance of this difference will be highlighted under the Implications and Conclusions section. Interestingly, the experimental group had a mean of 26 years for number of years with arthritis. Although older, the comparison group had a mean of only 19 years. Unfortunately since three out of four subjects were unable to identify the specific type of arthritis they had, an analysis of differences based on specific arthritis conditions was not possible.

Analysis of Results from Quantitative Measures

Analysis of Quantitative Measures

There are two primary sets of response variables: AIMS scores and PSS scores. AIMS consists of 11 subscale scores (although only eight of the subscales were used for the purposes of this research) and three component scores. PSS has two subscales, corresponding to support from family and support from friends. In all cases, the

scores were computed by summing up individual responses on a number of ordinal scales. In the case of the PSS scores, each score was the sum of 20 items, each item being 0 or 1. For AIMS, scores are the sums of fewer items, but each item has more possible responses. According to the Central Limit Theorem, summed ordinal data behave very much like normally distributed data. Therefore the PSS and AIMS scores can be treated as interval data having approximately bell-shaped histograms. Thus the usual parametric tests of means, such as t-tests, can be employed (Berkowitz, 1990).

The effect of the intervention for the experimental group was assessed by paired t-tests on each of the AIMS and PSS scores. The paired t-test compares "before intervention" scores with "after-intervention" scores by computing the difference from "pre" to "post" and examining whether the average difference is zero. If it is, then there is no intervention effect because the average score before intervention is no different than the average score after intervention. The paired t-test is appropriate for before-and-after designs because it takes into account that the same subject is being

measured twice. The usual two-sample t-test would assume a different set of subjects had been measured post than had been measured pre and is therefore not a meaningful design for this work (Berkowitz, 1990). A two-tailed t-test was performed because it is a more conservative measure than a one-tailed t-test. For this research, it was important to determine if negative change had occurred as well as any positive change.

With the seven subjects who completed pre and post measures, the effect of the intervention was assessed by using paired t-tests on each of the AIMS and PSS scores. Correlation coefficients between AIMS scores and PSS scores were computed. These Pearson correlations measure linear association between two variables. Data analysis was performed using Statistical Package for Social Sciences (SPSSx) software.

The eight subscales and three component scales of AIMS were used to determine whether or not the impact of arthritis was lessened over the period of the study. The AIMS scales are scored consistently so that a low value is an indication of arthritis having less impact on the

individual. The PSS-Fr and PSS-Fa scales are scored consistently so that a high value is an indication of high perceived social support. Table 4 shows the results of the pre and post measures of the experimental group.

TABLE 4

Pre/Post Changes for Experimental Group

AIMS SUBSCALES	PRE PROGRAM		POST PROGRAM		2-TAIL PROBABILITY
	\bar{X}	S. D.	\bar{X}	S. D.	
Mobility	5.54	2.03	5.54	4.12	1.000
Physical Activity	8.00	3.06	7.43	3.21	0.356
Dexterity	5.43	4.58	4.57	3.95	0.407
Household Activity	4.73	2.15	3.63	2.73	0.211
Activities of Daily Living	1.96	1.59	0.89	0.95	0.017*
Depression	3.96	1.89	3.02	1.66	0.165
Anxiety	4.10	1.96	3.21	1.49	0.144
Pain	4.93	3.19	3.36	3.56	0.118
<u>AIMS COMPONENT SCALES</u>					
Physical Function	5.13	1.59	4.41	1.85	0.009**
Psychological Function	4.03	1.79	3.11	0.87	0.073
Pain Level	4.93	3.19	3.36	3.56	0.118
<u>PSS Scales</u>					
Family	10.14	6.44	6.86	6.15	0.007*
Friends	9.71	6.24	10.14	6.23	0.772

* Significant at .05

** Significant at .01

Hypothesis 1

This hypothesis stated that study participants would show improved physical functioning after receiving 16 weeks of regular telephone calls, as measured by the Arthritis Impact Measurement Scales.

Only the "Activities of Daily Living" subscale achieved significance ($P=.017$) out of the five subscales computed to measure the physical functioning component scale. However the two-tailed t-test for the component scale of physical function achieved significant improvement ($P=.009$). Therefore Hypothesis 1 is supported by the data.

Hypothesis 2

This hypothesis stated that study participants would show improved psychological functioning after receiving 16 weeks of regular telephone calls, as measured by the Arthritis Impact Measurement Scales. The two-tailed t-test for psychological functioning was .073. On the basis of this value, hypothesis 2 is not supported because the level of change does not reach statistical significance.

Hypothesis 3

This hypothesis stated that study participants would show improved pain levels after receiving 16 weeks of regular telephone calls, as measured by the Arthritis Impact Measurement Scales.

The two-tailed t-test for pain level was .118. Consequently, hypothesis 3 is not supported because there is no statistically significant difference between pre and post measures.

Hypothesis 4

This hypothesis stated that study participants would show improved perception of social support from friends after receiving 16 weeks of regular telephone calls, as measured by the Perceived Social Support From Friends scale. Quantitative data shows no evidence of significant change in perception of social support from friends. Consequently, hypothesis 4 cannot be supported based on the 2-tailed t-test of .772 for the PSS-Fr subscale.

Hypothesis 5

This hypothesis stated that study participants would show improved perception of social support from family members after receiving 16 weeks of regular calls, as measured by the Perceived Social Support From Family scale.

The result of the t-test is rather interesting. Instead of an increase in perception of social support from family members, the 2-tailed t-test of .007 indicates that perception of social support actually decreased significantly. Obviously, hypothesis 5 cannot be supported based on this result, whereas the alternative hypothesis that perception of family support will decrease, does receive empirical support.

It must be noted that significance tests are highly sensitive to the size of the samples. This is because the test statistic takes into account the sample size; the bigger the sample, the smaller the standard error on the sampling distribution, and hence the larger the ratio of the observed difference to the standard error. With a small sample size of seven, there is a large average

variation in the values of t . Extreme values of t are expected relatively more frequently than with larger sample sizes. Consequently it is less likely with this small sample size that any true difference in the groups means can be detected by the test. The 'power' of the test refers to the likelihood of such detection.

There are other problems with multiple testing. If each significance test is performed at the .05 level, then there is a 5% chance that the result is a false positive, or spurious significance (Berkowitz, 1990). Thus caution must be exercised in interpreting a couple of significant P-values as very important results.

Trends

When the sample size is too small to expect to get statistically significant differences, it is sometimes possible to comment on trends. As displayed, seven of the eight AIMS subscales showed an improvement. The mobility subscale showed no change. If the intervention had had no effect at all, one would have expected half the subscale scores to show improvement and half to show deterioration

(Berkowitz, 1990). It is comforting that there is a positive trend towards increased health status amongst subjects.

Correlations Between AIMS Scores and PSS Scores

Hypothesis 6

Hypothesis 6 stated that there would be an association between the changes in perceived social support, as measured by the Perceived Social Support From Friends and From Family Scale, and the changes in health status, as measured by the Arthritis Impact Measurement Scales, at 16 weeks.

The statistic chosen was the Pearson Product Moment Correlation formula applied to the differences of the interval data. Pearson correlations measured the linear association between AIMS scores and PSS scores. Since the sample size is seven, each observation is quite influential in determining the size of the correlation. Therefore the correlations must be very large before they can be

considered meaningful and even then must be interpreted with caution (Berkowitz, 1990).

Correlations were made between a) the AIMS subscales, b) the AIMS component scales and the two subscales of the Perceived Social Support From Friends and From Family. Scores on the scales were computed by subtracting the pre-test change score means for each scale from the post-test change score means for each scale. The Pearson correlation formula was then applied to the size of the differences. A correlation greater than .70 roughly correlates to a P-value of about .05. Table 5 shows the Pearson correlation coefficients between AIMS subscales and PSS subscales. The sign of the correlation is important. Since higher PSS scores indicate higher perceived social support and lower AIMS scores indicate higher health status, negative values indicate a positive association. Table 6 shows the Pearson correlation coefficients between AIMS component scales and PSS subscales.

TABLE 5

Pearson Correlation Coefficients Between AIMS Subscales and PSS

AIMS	PSS	
	FAMILY	FRIENDS
Mobility	-.122 p=.397	.536 p=.107
Physical Activity	.044 p=.463	-.363 p=.212
Dexterity	.070 p=.441	-.411 p=.180
Household Activity	.495 p=.129	-.392 p=.192
Activities of Daily Living	-.194 p=.339	.813 p=.013*
Depression	-.714 p=.036*	.239 p=.303
Anxiety	-.245 p=.298	-.605 p=.075
Pain	.269 p=.280	-.406 p=.183

* Significant at .05

It can be seen from Table 5 that there are only two significant correlations. There appeared to be a positive association between the PSS-Fa and AIMS Depression subscale. In other words, the stronger the perception of change in social support from family members, the less one might experience change in depression. Interestingly there is a negative correlation between PSS-Fr and AIMS Activities of Daily Living subscale. This result suggests that the larger the perception of change in social support from friends, the less change there is in ability to perform activities of daily living. A cautionary note is that since correlations are unstable with small sample sizes they may or may not reflect any true association present in the population. In order to explore this possibility further, Table 6 shows the results of the correlations between PSS subscales and the three component scales of AIMS.

TABLE 6

Pearson Correlation Coefficients Between AIMS Component Scales and PSS.

AIMS	PSS	
	FAMILY	FRIENDS
Physical Functioning	.327 p=.237	-.170 p=.357
Psychological Functioning	-.655 p=.055	-.212 p=.324
Pain Level	.269 p=.280	-.407 p=.183

It can be seen from Table 6 that there are no significant correlations between the PSS scores and scores on the AIMS component scales. With a P-value of .055, the correlation between a high perception of social support from family members and higher psychological functioning comes closest to achieving significance. Consequently the hypothesis that there would be an association between changes in perception of social support and changes in health status at 16 weeks cannot be supported.

Interviews with Subjects

Six women were interviewed using the structured, open-ended questionnaire described in Chapter 3. Although seven women completed post questionnaires, one of the women could not remember receiving calls (although the student researcher later verified through the coordinator that she did, in fact, receive calls) and was not requested to participate in an interview. Interviews were transcribed from the audio tapes and then summarized. The following is a summary of the range of responses for variable measured.

In describing the current impact of arthritis on their lives, two women stated they were not currently affected. One stated that, "it depresses me at times" while another admitted it made her "angry and depressed". This woman complained that "it hurts to walk". Another participant noted that it affected her functional status in that she was unable to lift her arm. One person noted a general feeling of malaise, "It just doesn't make you feel very comfortable. It's the reality of having it such a long time. You take it. You can't do anything about it".

In reporting on changes in health status since the intervention, five out of six participants stated that they did not notice any change in their arthritis. The sixth woman stated, "I haven't had so much arthritis" but qualified her statement by adding, "But I sort of expect it now when the rains come on, it's just the general weather condition with me."

In exploring participant's motivation for participation, two women indicated that they agreed to take part in the program because they were lonely. One of these women stated " I get so few calls and so few visitors. I

thought this is just another contact with the outside world and somebody to share, to learn... Just to be able to talk to somebody different." One woman became a participant because her physician recommended the program to her and she respected his opinion. Three persons were unable to identify their motivation for participation. However one participant stated that "I know the Arthritis Centre would never put out a program it didn't think would work or would be to your disadvantage". Thus an association with a respected institution by the Telephone Contact Program may have helped act as an incentive to participation.

The level of perceived homogeneity with their callers varied among participants. Participants 01 and 05 did not believe themselves to be similar to their callers. Participant 03 stated that her caller's "voice and cheerful laugh reminds me of this very close friend of mine I knew many years ago". Another said, "She's very pleasant on the phone and I think I am too". Two participants felt they were similar to their callers in past and present experiences. Participant 04 stated, "She says she's lonesome. She is in the house alone most of the time and she figures I'm pretty well the same as her - the

depression part of it ." Another commented, "We talk about happenings and past experiences and we both just seem to have the same dislikes and likes".

Interview data strongly suggests that participants perceived their callers as a source of social support. All six women gave glowing accounts of their callers. Callers were described as "a lovely person", "great", "a very nice person". Participants 01 and 02 said they "look forward to her calls". Participant 03 said, "I'd love to meet her some time" while Participant 06 stated "I enjoy getting her call because she's very nice. Participant 04 gave the best indication of perceiving her caller as a source of social support by replying "Yes. She's a very nice person to talk to ... It seems like she's more a friend than a stranger." However Participant 05 had a different opinion, "I'll be honest, I didn't - I have nothing against her. I wouldn't like getting calls from anybody... maybe it's just my frame of mind."

Aside from simply reporting whether or not participants perceived their callers as a source of support, it interested this researcher to understand what

types of functional social support callers were perceived to provide to the participants. Participants 05 and 06 did not perceive their callers to be helpful. However Participant 06 did sense some reciprocity in enjoyment, "She always tells me I sound so happy - so I think she enjoys talking to me". Similarly Participant 02 reported that, "Neither one of us dominates the conversation - each one of us gives something to the other." Participant 04 affirmed that she and her caller worried about each other, "I'm sure I'd be depressed if I didn't get her call. I'd be worried in case there's something wrong that she couldn't phone. She's a good friend, even though I've never met her". Another liked "the fact that somebody is thinking of you. Someone outside your family and friends... It's so nice they take the time to call you.

Other participants did find the calls helpful in terms of emotional support. The range of responses for liking the calls included:

"A chance to talk to someone, I enjoy getting different perspectives.";

"They cheer me up";

"I suppose while your mind is busy thinking about something else, it relieves the arthritis. You can forget about things";

"We laugh a lot, ... we can talk about our little problems, but it's not in a down sort of way. It's an uplifting conversation with her. You feel good after you've had a conversation".

As indicated by Participant 02, it appears callers provided informational support, as well as emotional support, to the participants, "because she is very involved with the Arthritis Centre and she's told me about different programs going on that I didn't know anything about. I find it very interesting learning about these things... as well as our personal things that we seem to share."

None of the participants could offer suggestions for improvement of the telephone contact program. Five women appeared satisfied with the program. However Participant 05 did not want to continue receiving calls. She stated,

"Another person might not be depressed and really enjoy these calls. So you can't really compare me with somebody else". Upon further explanation, this participant felt her depression contributed to her lack of interest in the telephone contact.

Satisfaction with the program also seemed to extend to the clients' families. According to the six women, family and friends appeared to have a positive view of their involvement with the Telephone Contact Program. Husbands of Participants 02 and 06 thought it was "great" and "fabulous" respectively. Participant 06's sister "thought it was nice" as did Participant 05's daughter and Subject 04's daughter-in-law. Participant 03's daughter is reported to be "happy about it because we seem to have things in common and the way I can talk to her." Similarly Participant 01 stated that her friends "think it's good for me. They say 'You're lonely' and they're glad they hear she calls".

Summary of Main Themes

Although subjects were interviewed separately several recurring responses to questions were noted. Also several generalities, or themes, can be drawn from the data.

Four out of six interviewees noticed that arthritis was impacting on their lives at the time of the interview. However only one of the subjects perceived a noticeable change in their arthritis since participating in the program. However, one must consider whether it is realistic for this population, who have had arthritis for many years, to have been able to detect any difference in the impact of their arthritis in a relatively short time. Indeed, none of the participants seemed to be motivated by expectation that the impact of their arthritis would in fact be altered.

It does appear that five out of six participants perceived their callers as being socially supportive. Subject 04 appeared to be inspired that her caller was successfully coping with severe arthritis and yet was still cheerful. "I really appreciate having it because before,

say a month ago, I was really depressed" she concluded. It also points to the value of using callers as successful role models. Callers were referred to as "friends" by two of the subjects. It appears that perceived homogeneity between subject and caller in experience and interest is extremely important to developing a supportive relationship. Subject 02 stated, "I gave the name to Mary of a friend of mine. I would imagine she'll benefit as long as the two are compatible." When asked if having a caller with similar interest is above all the most important, this subject replied "It would go a long way in establishing a good relationship". Along with this perceived homogeneity, subjects indicated perceived reciprocity as also an important element in the relationship.

Theorists of social support have identified a number of functional aspects to the delivery of social support. Table 7 shows the various categories in which leading social support theorists have divided the elements of functional social support. Of interest to this research is the elements of this functional social support that subjects perceive themselves to be recipients of from their

callers. Comments from the participants indicated that five out of six of them reviewed benefitted from the following elements of functional support as interpreted by Barrera & Ainley (1983):

Intimate interaction; Directive guidance; and Positive social interaction.

Subjects may also have received feedback from the callers although this was not mentioned. Of course, callers were not allowed to provide behavioral assistance or material aid due to the constraints placed on them by program policy.

TABLE 7

Elements of Functional Social Support

Barrera and Ainley, 1983

House, 1981

Tolsdorf, 1976

1. INTIMATE INTERACTION (expressing intimacy, esteem, trust)	1. EMOTIONAL SUPPORT (empathy, caring, trust)	1. PSYCHOSOCIAL BACKING (encouragement, emotional comfort, intimacy)
2. DIRECTIVE GUIDANCE (providing information, instruction, advice)	2. INFORMATIONAL SUPPORT (teaching skills, pro- viding information to assist in problem solution)	2. INFORMATION AND GUIDANCE (suggestion on whom and where to consult)
3. POSITIVE SOCIAL INTERACTION (discussing interests, joking)		
4. FEEDBACK	3. APPRAISAL SUPPORT (providing feedback on personal performance)	
5. BEHAVIORAL ASSISTANCE (sharing of tasks)	4. INSTRUMENTAL SUPPORT (sharing of tasks)	3. GOODS AND SERVICES (financial aid, house- work)
6. MATERIAL AID (loaning money)		

None of the participants were able to suggest ways to improve the program. Client satisfaction also seemed to extend to those friends and family members who were aware of the subjects' participation, although this data comes from secondary sources. In probing subjects' appraisal of the program's effectiveness, two subjects were particularly insightful and open:

Subject 01 stated that the program should continue

"because I think a lot of people like myself who are in the middle 60's and who will find themselves suddenly, after all the travelling and work they've done, being confined. It's excellent for people like us. We all need someone to phone."

When asked if the program was a good idea, Subject 04 responded:

"Particularly for people that are shut in because I have found I used to have a lot of friends and I used to be out in the community. But when you are all of a sudden in the house and gradually get more and more housebound, your friends, you lose track of them. They lead very busy lives and you can't keep up with them. So gradually, little by little, you lose all contact with your friends that you've had in the past. They've dwindled down to so few. My husband meets them and they always ask how I am, but I never see them, or there's never phone calls. So after a while you feel isolated."

Individual Scores and Comments Pre-Post for Experimental Group

Statistical analysis alone cannot determine whether or not the observed differences are clinically important. A brief analysis of individuals' scores and comments may be useful in assessing the clinical importance of the Telephone Contact Program for subjects.

Table 8 shows the pre/post differences of the subjects' scores on the three AIMS component scales and the two scales of the PSS. Some comments from the individual's interview are also included. In addition, each subject rated her caller as a source of social support on a six-point scale ranging from strongly agree to strongly disagree. For the AIMS scores, a negative value denotes an improvement in health status, whereas a negative value on the PSS scores indicates a lowered perception of social support.

TABLE 8

Individual Subjects' Pre/Post Scores

	<u>PRE</u>	<u>POST</u>	<u>DIFFERENCE</u>
Subject 01's Pre/Post Scores			
AIMS			
Physical	5.48	5.48	.00
Psychological	6.76	3.96	-2.80
Pain	5.50	3.50	-2.00
PSS			
Family	.00	.00	.00
Friends	16.00	19.00	3.00
Subject 02's Pre/Post Scores			
AIMS			
Physical	4.89	3.91	-.98
Psychological	3.13	3.30	.17
Pain	6.50	.50	-6.00
PSS			
Family	12.00	6.00	-6.00
Friends	2.00	7.00	5.00
Subject 03's Pre/Post Scores			
AIMS			
Physical	6.08	5.03	-1.05
Psychological	3.63	3.13	-0.49
Pain	4.50	3.50	-1.00
PSS			
Family	15.00	11.00	-4.00
Friends	11.00	7.00	-4.00

— — — — — CONTINUED

TABLE 8 - Continued Individual Subjects Pre/Post Scores

	<u>PRE</u>	<u>POST</u>	<u>DIFFERENCE</u>
Subject 04's Pre/Post Scores			
AIMS			
Physical	2.57	1.76	-.81
Psychological	2.47	2.31	-.17
Pain	.50	.00	-.50
PSS			
Family	18.00	17.00	-1.00
Friends	12.00	13.00	1.00
Subject 05's Pre/Post Scores			
AIMS			
Physical	4.02	2.56	-1.45
Psychological	6.43	4.29	-2.15
Pain	1.00	.00	-1.00
PSS			
Family	4.00	1.00	-3.00
Friends	12.00	15.00	3.00
Subject 06's Pre/Post Scores			
AIMS			
Physical	5.26	4.90	-.35
Psychological	2.64	1.81	-.82
Pain	9.00	7.00	-2.00
PSS			
Family	14.00	10.00	-4.00
Friends	15.00	10.00	-5.00
Subject 11's Pre/Post Scores			
AIMS			
Physical	7.64	7.24	-.40
Psychological	3.13	2.97	-.17
Pain	7.50	9.00	1.50
PSS			
Family	8.00	3.00	-5.00
Friends	.00	.00	.00

Participant 01

Participant 01 seemed to have perceived an increase in her social support from friends. Indeed, she stated that since she started participating in the program, "I've built up a few more friends". She continued, "I hope they'll keep it up. Just to hear from somebody else". She moderately agreed that her caller was a source of social support for her.

Participant 02

Participant 02's pain level decreased quite a bit over the study period. She thought her family were giving her less social support, but her friends more. She strongly agreed that her caller was a source of social support for her. A full transcription of her interview is given in Appendix E.

Participant 03

Participant 03 moderately agreed that her caller was a source of social support. However it appears overall that her perception of social support decreased. Her

health status improved slightly. This might be explained by her comment, "I have a lot of things to do and maybe I forget about my arthritis - you know, the busier you are, the more you forget about it."

Participant 04

Although change is marginal, participant 04 strongly agrees that her caller was a source of social support. However there is not a strong change in her perception of social support from family and friends. This is in spite of her recent decision to attend an adult day centre. When asked if the telephone contact program offered something different from the adult day centre, she responded, "Yes. It comes in when you least expect it. You might be really down that day and that telephone call comes and pull you right out of it."

Participant 05

Participant 05's trend towards improvement in health status is interesting because her comments about the program were not flattering. She stated "As far as I'm

concerned, I don't think it makes any difference to me one way or the other." She also moderately disagreed that her caller was a source of social support for her. Of course it is possible that improvement for this subject is due to an intervening variable and not the telephone contact program.

Participant 06

This woman somewhat agreed that her caller was a source of social support for her. The deterioration in her perception of social support was a surprise given her answer to the interviewer's question about the program increasing her number of contacts, "Yes... I've found that people that I knew, but not all that friendly, I thought I'd give them a call and see how they are. I think that by doing that to me has made me do it to other people... It makes you stop and think how nice it is to get calls."

Participant 11

The trend for Participant 11 was for improved health status. This woman is different from the other

experimental group members in that she had no recollection of being a recipient of calls from the volunteer. She is 92 years of age and is currently living in a Long Term Care facility. Given her memory loss, this subject may not have been a suitable candidate for the program. Nevertheless her scores on the measures are consistent with other group members.

Burchardt's research (1985) suggests that perceived social support has a positive correlation to perceived quality of life. Seniors who face increasing disability due to their arthritis often experience increasing social isolation. The following quote from Subject 02 vividly describes this process:

"After a while you get to the point where you just can't phone them. The longer you put off making the phone calls, the harder it is... I don't know anything about what's going on in the outside world any more, so how can you carry on a conversation? My life is all going to see people in white coats. So I'm involved in the medical - just trying to survive from one week to the next and you miss your friends. I'd like to have them in for a nice dinner, but it's too much... I still am a people person, but it's getting harder and harder to even think about going out to the outside world. It's much easier to stay home... I escape with my books. But you get bored with a book after a while.

Although five out of six subjects interviewed did not perceive a change in the status of their arthritis, they did seem to perceive their callers as providers of social support. On a six-point scale measuring perception of social support, five out of six subjects strongly, moderately, or somewhat agreed the caller was a source of social support. All six women felt their callers were very nice people and five appeared to desire a continued relationship. Friendships appeared to be developing and more than one subject was curious about her caller and expressed interest in meeting her in person. In addition, four out of six subjects thought they were similar to their callers in some fashion. This is important because several researchers have pointed to the importance of perceived homogeneity to the establishment of a supportive relationship (Evans, Fox, Pritzl, and Halar, 1984; Gallo, 1982; Kroll, 1987; Mitchell, 1986; Potts, Yngve, Weinberger and Brandt, 1983).

CHAPTER 5

Implications and Conclusions

Demographic analysis has shown that there is a high prevalence of arthritis, particularly among seniors, in the population of the Lower Mainland. Early in 1989, it was ascertained that the Arthritis Centre was not reaching the population of seniors with arthritis who were unable to leave their homes because of physical incapacitation or because social isolation had made it extremely difficult to meet and interact with strangers in a group situation. In order to remediate this situation, an Arthritis Telephone Contact Program was initiated to provide a service to this previously difficult to reach population.

This study investigates the effects of a telephone contact program for elderly Caucasian women with arthritis. It was also hoped that it would contribute to the knowledge base about the nature of therapeutic social support intervention by using lay volunteers. The purpose of this study was to investigate whether or not this Telephone Contact Program would bring about the same positive health outcomes experienced by subjects in previous research (Weinberger, Hiner, & Tierney, 1986). The working hypothesis was that there would be no

differences between this research and the study conducted by Weinberger et al. (1986).

Summary of Quantitative Data

Results indicated that participants did, in fact, show significantly improved functional status after receiving 16 weeks of regular telephone calls. This study also support the work of Weinberger, Hiner and Booher (1986) who found that telephone contact alone improved functional status ($P=.03$), as measured by AIMS, for osteoarthritis patients. However based on the results, participants did not show improved psychological functioning or improved pain levels. There was not an association between the changes in perceived social support from family or from friends and the changes in health status after 16 weeks. However it may have been unrealistic to expect statistically significant changes pre to post over a short monitoring period of four months. However there are trends in the expected direction. Results indicated that seven out of eight subscales showed improvement, and one showed no change.

The hypotheses that the perception of social support from friends and from family members would be increased over the period of the study could not be supported. It is possible that participants did not perceive their callers as friends, although qualitative data indicates otherwise. A second explanation is that the measure developed by Procidano and Heller requires refinement prior to it being used in this population. Perhaps the instrument is not sensitive to subtle changes in perception of social support by an elderly population. Even more surprisingly, the 2-tailed t-tests yielded a probability of .007 for the PSS-Family subscale indicates that perception of social support from family members by subjects actually decreased. This researcher makes the supposition that as participants began to perceive their callers as providers of functional support, their perception of family members to being the sole providers of social support decreased.

Implication

The results from the quantitative data analysis has

one very important implication. Since the results for this study appear to be similar to those presented by Weinberger, Hiner and Tierney (1986), it follows that there is a possibility that intervention through telephone contact to improve physical functioning for people with arthritis is appropriate for British Columbia seniors. The two studies used quite different populations. Weinberger et al. used a population primarily made up of black women who were receiving regular care at a clinic and who had a mean age of 66 years. In contrast, this study's population sample was composed entirely of Caucasian women with a mean age of 76 years. However this present study found that subjects did not need monetary compensation to achieve similar results. Preliminary indications suggest that significant improvements in physical functioning may be achieved with a variety of population groups. This of course merits further investigation.

Summary of Interview Data

The buffering model of social support argues that

social support buffers negative health-related consequences invoked by stress. The main effects hypothesis suggest that strong social support systems may foster good health regardless of whether stressors are present. In all likelihood, both models operate. This researcher used a measurement of perceived social support because the actual presence of social support networks is not sufficient for its use by respondents unless they perceive these systems as accessible. House (1981) emphasizes it is the perception of social support which may be of primary importance in terms of predicting health outcomes.

Croog, Lipson and Levine (1973) note that the gradual acceleration of the needs and demands of disabled people may precipitate a decline in support from the outset. This suggests the importance of a large well-differentiated network with relatively specific functions to address potential demands for practical help. It also underlines the importance of considering the types of support and the extent to which each is perceived as available and satisfactory to the individual.

Interview data indicated that participants perceived three types of functional support as being accessible from callers: Intimate interaction; directive guidance; and positive social interaction (see Table 2, Barerra and Ainley, 1983). It appeared to this researcher that subjects most frequently commented of the element of intimate interaction, or the ability of subjects and callers to express intimacy, esteem, trust, empathy, and encouragement to each other, over all other elements of functional social support. This finding supports the work of Maisiak, Koplon and Heck (1989) who found that emotional need was the most frequent need of symptomatic callers to an Arthritis Information Service.

Implications

It appears that interview data supports the contention that participants perceive their callers as providers of functional support. This has important implications. First, Caplan, Robinson, French, Caldwell and Shinn (1976) found that perceived support from friends, spouse and health care providers was associated with increased motivation to adhere to medical treatment.

Second, the presence or absence of an informal support network is a crucial predictor of an elderly person's well-being and autonomy (Hooyman, 1983). Thus the creation of an informal support system through telephone contact may promote capacity for independent functioning (Evans, Fox, Pritzl and Halar, 1984). This implication is quite plausible because other researchers have shown that volunteers who have been successful in coping can provide role models on how to maintain a satisfactory lifestyle within the limit of the disability caused by arthritis (Kroll, 1987; Lorig et al, 1986). Third, these volunteers have the capacity to notice functional deterioration in the participant and then relay this information to the program coordinator who, in turn, can make the appropriate referral to a health care professional. Fourth, volunteer callers are often members of community support groups and can encourage a transition by the participant from one-to-one peer support to a formalized self-help group, when and if applicable. This transition may further increase the client's perceived level of social support.

A fifth implication is that any support, advice or

treatment offered within the social support network rather than the formal medical system would be simpler and less expensive (Gallo, 1982). If one social worker trained several volunteers to offer peer support through a telephone contract program, many times the number of potential clients could be reached at minimum cost to the agency. Also, more importantly it would become an economically feasible program. Otherwise the program would be too expensive to implement. Thus volunteer assistance can enable social work programs to serve a greater number of clients than is possible with a limited number of paid staff.

Minimal Intervention and Telephone Contact Programs

The quest for treatments that yield statistically significant and clinically important results can distract health care professionals from recognizing minimal interventions that may produce meaningful improvements. Minimal interventions are defined as therapeutic or preventative services that (a) result in either small effects in a large proportion of the population or large effects in a small proportion of the population (b) do

not require much money, technology, personnel or time and (c) involve minimal or no side effects. Interventions that meet either part of the first condition and both of the other conditions are considered most useful because of their potential of producing benefits at limited cost (Hovell and Black, 1989).

The public health perspective defines clinically important interventions as those that affect as few as five percent of the population as enormously important (Hovel and Black, 1989). This perspective conceptualizes the entire population with arthritis. There is a need for clinicians to re-examine treatments from a public health perspective which may involve the "stepped approach" model that introduces increasingly costly and invasive interventions in sequence, but only on an 'as needed' basis (Hovell and Black, 1989). As an example, for physicians treating arthritis, minimal intervention common today is the use of low to moderate dose aspirin to treat many forms of arthritis.

The provision of social support through a telephone contact program is minimal intervention that holds

special promise for adjunctive treatment of arthritis. Since minimal interventions result in small therapeutic effects, they will be difficult to detect. Therefore it will require the use of sensitive and multiple scales measuring quality of life in large group tests in order to identify reliable treatments and avoid Type II error, the failure to identify reliable treatments (Hovell and Black, 1989). It is suggested that both physicians and participants receive feedback regarding the effectiveness of the program in order to ensure continued participation in the program. If the program is effective, free of side effects, and can be administered inexpensively, it would follow that the provision of social support, through telephone contact programs, for the treatment of arthritis will be worth careful consideration and further investigation.

Implications for Future Program Operations

During the course of program implementation, this researcher encountered an unexpected obstacle that future program developers should take into account. Recruitment of participants was too optimistic and the growth rate

was slower than expected. It is possible that the target population was genuinely not interested in this type of program. Another exploration is that the method of accessing older homebound people was inadequate. If this is true, two recommendations pertaining to recruitment are forthcoming.

First, it is recommended that medical institutions intent on starting similar minimal intervention programs for previous patients should first analyze, and if necessary revise, their current medical records system in order to ensure that contact with these clients can be initiated. It is also recommended that there be further exploration of effective ways of recruiting the older homebound population experiencing chronic illness. One suggestion is to link the program to an institution well respected in the community. One subject told this researcher that an association between the Telephone Contact Program and the Arthritis Centre was an incentive to participate.

One cause for concern was that three out of the four subjects who dropped out lived in Long Term Care

facilities. This group of drop outs has a mean age of 89 years, whereas the mean age of the people who stayed in the program is 76 years. At first this researcher assumed that the high rate of drop out for Long Term Care residents could be explained by their advanced age and increased deterioration in physical and psychological functioning. It was thought by the researcher that a minimal intervention strategy such as the Telephone Contact Program may not be sufficient to evoke positive changes in persons who are extremely disabled. This, in turn, would create disinterest in the program and the subject's eventual drop out. However, analysis indicated that there was no real difference between this 'comparison' group and the 'experimental' group on the AIMS component scales. Thus the above explanation does not appear to have validity. This researcher now surmises that the recruitment method may be to blame for the Long Term Care residents' drop out. These residents joined the program largely because the head nurse or social worker on the ward put forward their names. Therefore they may not have perceived any control over their participation in the program, and consequently exercised their choice to drop out at the first

opportunity. In any event it is recommended that future research follow up on subjects who drop out in order to ascertain their reasons for nonadherence.

Client Selection

Analysis of individuals' scores and comments produced an important implication for client selection in future programs of this nature. It would appear that 'minimal intervention' through telephone contact is not appropriate for those people exhibiting certain personal adversities that go beyond social isolation. Participants 02 and 04 appeared to like their calls the most. Indeed, it struck this researcher during the interviews that they were the most comfortable in conversation of all the interviewees. Participants 01, 03, and 06 also seemed to derive benefits from the program. However, Participant 05 was unable to mention anything she liked about the program and has since terminated her involvement. She admitted that her depression likely contributed to her lack of interest. Similarly, Participant 11 has discontinued her involvement because her memory loss had reached the point

where she could not recall being a participant. Although both participants showed gains in health status, in retrospect they were not appropriate candidates for the program. Consequently, it is recommended that potential participants in future programs undergo a more rigorous screening process in order to identify those who may be mentally confused, clinically depressed and so on, and who therefore would be a threat for drop-out.

Implication for Policy Initiatives

This Telephone Contact Program is functioning in accordance with the health promotion principles and processes identified by the Ottawa Charter for Health Promotion (British Columbia Health Care Research Foundation, 1990). Such a program strengthens community action by allowing community members to partake in its implementation and allows for an increase in control of a health care program. In addition, personal skills are allowed to develop in a supportive environment. Finally, the focus is on enabling people rather than on prescribing solutions. Implementation of similar programs will require reorientation of health services

away from institutional care and towards greater independence by building community health care programs and social support networks. One major policy implication is that encouragement of minimal intervention programs with a community health perspective would be less expensive and would provide greater accessibility to those who need it.

Recommendations for Further Study

The question of effectiveness is not answered by the quantitative data presented in the results. However the data does lay the foundation for a rigorous experimental design.

One such experiment could involve a randomized control trial comparing medical treatment alone with medical treatment in combination with telephone contact intervention. The latter group would be the experimental group and would include regular contact from a 'networker'. The purpose of this networker would be to put persons in contact with information and support that might not exist in the natural social support network.

The main hypothesis would be that the people in the experimental group will have better health status, measured prospectively, than those in the control group.

The findings in this study raises questions for further research. For example, if this study was replicated with a population of nursing home residents, would the results be the same? Perhaps a telephone contact program to create informal social support networks would benefit most those people waiting for placement in Long Term Care facilities and who may face several losses as a result of the transition. Perhaps the transition to an institution would be made easier if the person knew that her or his caller would continue to be a link to the community outside the walls of the Long Term Care facility. Replication of this study, using a pretest-posttest control group design, with different groups of elderly could help answer important health research questions and provide evidence to either support or refute clinical intervention at the social support network level.

Summary

This research serves as a pilot study on the nature of social support intervention through a telephone contact program. Although caution must be exercised, results indicated subjects' physical functioning improved significantly. Perhaps more meaningful is the subjects' trend towards improved health status, as measured by AIMS, over the study period. This study lends support to the results of previous research in the area.

Interviews with subjects proved to be quite revealing. Callers appeared to offer participants emotional and informational support, and the positive social interaction seemed to foster the development of friendships. Subjects appeared to see the telephone contact as an opportunity to inject variety into their daily lives, and to prevent their homes from becoming the "limits of their world". It would seem that volunteers can work with social workers to create or enhance clients' informal social support networks.

There is a consensus of opinion among health care planners that there is need to develop health services for people that increase independence by providing environmental supports and greater availability of home supports. Due to the chronicity of arthritis, and the multiplicity of ailments often found among the elderly, services will have to be developed that will ensure continuity of care. As a minimal intervention, telephone contact programs may have the potential to evoke small, but nevertheless clinically important improvements in the health status of a large segment of the population, given the prevalence of arthritis in our society. Furthermore, this can be achieved at little cost to the agency and runs minimal risk of side effects. As an adjunctive treatment for arthritis, the provision of social support by telephone contact programs seems to hold promise for the elderly and socially isolated persons affected by these chronic conditions. Certainly, evidence would suggest that further investigation of this phenomenon is merited.

REFERENCES

- Achterberg-Lawlis, J. (1982). The psychological dimensions of arthritis, Journal of Consulting and Clinical Psychology, 50 (6), 984-992.
- Arthritis Foundation. (1981). 1981 Annual Report. Atlanta: Arthritis Foundation.
- Barney, J. L., & Neukom, J. E. (1979). Use of arthritis care by the elderly. Gerontologist, 19, 548-554.
- Barrera, M. Jr., & Ainlay, S. L. (1983). The structure of social support: A conceptual and empirical analysis. Journal of Community Psychology, 11, 133-143.
- Baum, J., & Figley, b. a. (1981). Psychological and sexual health in rheumatic diseases. In Kelly, Harn, Ruddy & Sledge (Eds.), Textbook of Rheumatology (pp. 501-510). New York: Saunders Company.

- Berkman, L. (1980). Physical health and the social environment: A social epidemiological perspective. In L. Eisenberg & A. Kleinman (Eds.), The relevance of social sciences for medicine (pp. 51 - 75). Riedel: Dordrecht.
- Berkowitz, J. Statistical and Mathematical Consultant, Berkowitz & Associates. Personal Interview. October, 1990.
- Billings, A. G. & Moos, R. H. (1981). The role of coping responses and social resources in attenuating the stress of life events. Journal of Behaviourial Medicine, 4, 139-157.
- Blumenfield, S. (1986). Psychologic and social effects of rheumatic disease during late life. Clinical Rheumatology in Practice, January/February, 5-10.
- Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. Social Service Review. University of Chicago.

Bracht, N. (1979). The social nature of chronic disease and disability. Social Work in Health Care, 5(2), 129-144.

Bradley, L. A. (1985). Psychological aspects of arthritis. Bulletin on the Rheumatic Diseases, 35(4), 1-11.

British Columbia Health Care Research Foundation (1990). Special Research Demonstration Projects Competition: Health Promotion. Science Council of British Columbia, 2-4.

Broadhead, W. E., Kaplan, B. H., James, S. A., Wagner, E. H., Schoenbach, V. J., Grimson, R., Heyden, S., Tibblin, G., & Gehlbach (1983). The epidemiological evidence for a relationship between social support and health. Journal of Epidemiology, 117(5), 521-537.

Brocklehurst, J. C. (1978). Geriatric services and the day hospital. In J. C. Brocklehurst (Ed), Geriatric Medicine and Gerontology (pp. 747-762). London: Churchill Livingstone.

- Broder, R., (1988). Assessment of the construct of social support as measured by five self-report instruments. Unpublished master's thesis, University of Manitoba, Winnipeg.
- Burckhardt, C. S. (1985). The impact of arthritis on quality of life. Nursing Research, 34(1), 11-15.
- Butler, R. (1974). Why survive? Being old in America. New York: Harper & Row Publishers.
- Campbell, D.T., & Stanley, J.C. (1966). Experimental and Quasi-Experimental Designs for Research. Chicago: Rand McNally.
- Canada Yearbook (1988). Health. Ottawa: Government of Canada
- Caplan, G. (1974). Support systems and community mental health. New York: Behaviourial Publication.
- Caplan, G. (1981). The mastery of stress; Psychosocial aspects. The American Journal of Psychiatry. 138(4), 413-420.

- Caplan, B., Gibson, C. J., & Weiss, R. C. (1984).
Stressful sequelae of disabling illness.
International Rehabilitation Medicine, 6, 58-62.
- Caplan, R. K., Robinson, E. A. R., French, J. R. P. Jr.,
Caldwell, J. R., & Shinn, M. (1976). Adherence to
medical regimens: Pilot experiments in patient
education and social support. University of
Michigan: Research Centre for Group Dynamics,
Institute for Social Research.
- Cassileth, B. R. (1986). Psychosocial status in chronic
illness. A comparative analysis of six diagnostic
groups. The New England Journal of Medicine, 311(8).
- Catanzaro, R. J., & Green, W. G. (1970). WATS telephone
therapy: New follow-up technique for alcoholics.
American Journal of Psychiatry, 126, 1024-1027.
- Chiles, J. A. (1974). A practical therapeutic use of the
telephone. American Journal of Psychiatry, 131,
1030-1031.

- Cobb, S., (1974). A model for life events and their consequences. In B. S. & B. P. Dohrenwend (Eds.), Stressful life events: Their nature and consequences. New York: John Wiley & Sons.
- Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.
- Cohen, S., & Wills, T. A. (1985). Stress, social support and the buffering hypothesis. Psychological Bulletin, 98, 310-357.
- Collins, J. G. (1988). Prevalence of selected chronic conditions, United States, 1983-85. Vital and Health Statistics of the National Center for Health Statistics, Hyattsville, MD: DHEW publication no. 155.
- Cox, C. (1979). A pilot study: Using the elderly as community health educators. International Journal of Health Educators. 22, 49-54.

- Coyne, J. C., & DeLongis, A., (1986). Going beyond social support: The role of social relationships in adaption. Journal of Consulting and Clinical Psychology, 54, 454-460.
- Croog, S. H., Lipson, A., & Levine, S. (1972). Help patterns in severe illness: The roles of kin networks, non-family resources and institutions. Journal of Marriage and Family, 32-41.
- Currey, H. L. F. (1970). Osteoarthritis of the hip joint and sexual activity. Annals of Rheumatic Disease, 29, 488.
- Dean, A., & Ensel, W. M. (1983). Socially structured depression in men and women. In J. R. Greenley (ed.), Research In community and mental health, 3, Greenwich, Ct.: JAI Press.
- DiMatteo, M. R., & Hays, R. (1981). Social support and serious illness. In B. H. Gottlieb (ed.), Social networks and social support. Beverley Hills: Sage.

Ditunno, J., & Ehrlich, G. E. (1970). Care and training of elderly patients with rheumatoid arthritis. Geriatrics, 25, 164-172.

Durlak, J. A. (1979). Comparative effectiveness of paraprofessional and professional helpers. Psychological Bulletin, 86(1), 80-92.

Durlak, J. A. (1981). Evaluating comparative studies of paraprofessional and professional helpers: A reply to Nietzel and Fisher. Psychological Bulletin, 89 (3), 566-569.

Duthie, J. J. R., Brown, P. E., & Truelove, L. H. (1964). Course and prognosis in rheumatoid arthritis, a further report. Annals of the Rheumatic Diseases, 23, 193-204.

Eckenrode, J. (1983). The mobilization of social supports: Some individual constraints. American Journal of Community Psychology, 11, 509-528.

Epp, J. (1987). Achieving health for all: A framework for health promotion. Ottawa: Ministry of Supply and Services Canada.

Epstein, I. (1988). Quantitative and Qualitative Methods. In. R.M. Grinnell Jr. (Ed.), Social work research and evaluations. Itasca: F.E. Peacock Publishers Inc.

Evans, R. L., Fox, H. R. Pritzl, D. O., & Halar, E. M. (1984). Group treatment of physically disabled adults by telephone. Social Work in Health Care, 9(3), 77-84.

Feibel, J., & Springer, C. (1982). Depression and failure to resume social activity after stroke. Archives of Physical Medicine and Rehabilitation, 63(6), 276-278.

Ferguson, K., & Figley, B. (1979). Sexuality and rheumatic diseases: A prospective study. Sex Disability, 2, 130-138.

Fries, J. F. (1986). Arthritis: A comprehensive guide to understanding your arthritis. Reading: Addison - Wesley Publishing Company.

Gallo, F. (1983). The effects of social support networks on the health of the elderly. Social Work in Health Care, 8(2), 65-74.

Gartner, A., & Riessman, F. (1977). Self-help in the human services. San Francisco: Josey-Bass Publishers.

Gibson, T., & Grahame, R. (1973). Acute arthritis in the elderly. Age and Ageing, 2, 3-13.

Gibson, T., & Grahame, R. (1981). Rehabilitation of the elderly arthritic patient. Clinics in Rheumatic Diseases, 7(2), 485-495. (1973) Acute arthritis in the elderly. Age and Ageing, 2, 3-13.

- Goodenow, C., Reisine, S. T., & Grady, K. E. (1989).
Social support dimension associated with role functioning and depression in women with arthritis.
Farmington: University of Connecticut School of Medicine.
- Gottlieb, B. H. (1983). Social support strategies: Guidelines for mental health practice. (Sage studies in Community Mental Health, Vol. 7).
Beverly Hills: Sage Publications.
- Gross, M. (1981). psychosocial aspects of osteoarthritis: Helping patients cope. National Association of Social Workers, 40-46.
- Grumet, G. W. (1979. Telephone therapy: A review and case report. American Journal of Orthopsychiatry, 49, 574-584.
- Haber, L. (1971). Disabling effects of chronic disease and impairments. J. Chron Dis, 24(7), 469-487.

- Hart, F. A. (1974). Pain in osteoarthritis. Practitioner, 212, 244-250.
- Hattie, J. A., Sharpley, C. F., & Rogers, H. J. (1984). Comparative effectiveness of professional and paraprofessional helpers. Psychological Bulletin, 95(3), 534-541.
- Health & Welfare Canada (1989). The Active Health Report on Seniors. Ottawa: Minister of Supply and Services Canada.
- Health & Welfare Canada, Statistics Canada. (1983). Catalogue 83-538E.
- Heller, K., Swindle, R. W. Jr., & Dusenberg, L. (1986). Component social support processes: Comments and integration. Journal of Consulting and Clinical Psychology, 54, 466-470.
- Holmes, T. H. & Rahe, R. H. (1967). The social readjustment rating scale. Journal of Psychosomatic Research, 11, 213-218.

- Hooyman, N. (1983). Social support networks in services to elderly. In J. Whittaker & J. Gorbolino (Eds.). Social support networks: informal helping in the human services. New York: Aldine Publishing Co.
- House, J. S. (1981). Work stress and social support. Reading: Addison-Wesley.
- Hovell, M. F. & Black, D. R. (1989). Minimal intervention and arthritis treatment: Implications for Patient and physician compliance. Arthritis Health Professions Association. 2(3), 65 - 70.
- Jansen, K. (1987). A telephone tree: Organization and implementation. Unpublished manuscript, Vancouver Community College, Langara Campus, Certificate in Volunteer Management, Vancouver, British Columbia.
- Kahn, R. L. (1985). Social support and social networks: Content discussion. In A. M. Ostfield & E. D. Eaker (Eds.), Measuring psychosocial variables. U. S. Department of Health and Human Services.

- Kaplan, B., Cassel, J., & Gore, S., (1977). Social support and health. Medical Care, 15, 47-58.
- Katz, A. H. (1970). Self-help organizations and volunteer participation in social welfare. Los Angeles: University of California.
- Katz, S., & Akpom, C. (1976). A measure of primary sociobiological functions. Int J. Health Serv, 6, 493-508.
- Katz, S., Hedrick, S., & Henderson, N. (1979). The measurement of long-term care needs and impact. Health Med Care Serv Rev, 2(1), 1-21.
- Kellgren, J. H. (1961). Osteoarthritis in patients and population. British Medical Journal, 2, 1-6.
- Kellgren, J. H., Lawrence, J. S., & Bier, f. (1963). Genetic factors in generalised osteoarthritis. Annals of the Rheumatic Diseases, 22, 237-255.
- Kentucky Association for Older Persons (1989). Telecare A program of the Kentucky Association for Older Persons, Louisville, Ky: Author.

Kett, J. F. (1968). The formulation of the American medical profession: The role of institutions, 1780-1860. New Haven: Yale University Press.

Kirwan, J. R., & Silman, A. J. (1987). Epidemiological, sociological and environmental aspects of rheumatoid arthritis and osteoarthritis. Bailliere's Clinical Rheumatology, 1(3), 467-489.

Kolodny, A. L., & Klipper, A. R. (1976). Bone and joint diseases in the elderly. Hospital Practice, 11, 91-101.

Kroll, C. J. (1987). Lupus clients assisting one another: A model for supportive services. Rehabilitation Nursing, 12(5), 239-241.

Kronenfeld, J. J. (1986). Self-help and self-care as social movements. Advances in Health Education and Promotion, 1, 105-127.

- Lawrence, R. C., Hochberg, M. C., Kelsey, J. L., McDuffie, F. C., Medsger, T. A., Felts, W. R., & Shulman, L. E. (1989). Estimates of the prevalence of selected arthritic and musculoskeletal diseases in the United States. Journal of Rheumatology, 16, 427-441.
- Lieberman, M. A. (1986). Social supports - the consequences of psychologizing: A commentary. Journal of Consulting and Clinical Psychology, 54, 461-465.
- Lind, K. (1982). A synthesis of studies on stroke rehabilitation. Journal of Chronic Disease, 35(1), 133-149.
- Linden, W., & Feuerstein, M. (1981). Essential hypertension and social coping behaviour. J. Human Stress, 7(1), 28-34.
- Lock, S. (1986). Self help groups: The fourth estate of medicine? British Medical Journal, 293, 1596-1600.

- Locker, D., (1983). Disability and disadvantage: The consequences of chronic illness. London. 130-166.
- Lorig, K., Feigenbaum, P., Regan, C., Ung, E., Chastain, R. L., & Holman, H. R. (1986). A comparison of lay-taught and professional-taught arthritis self-management courses. Journal of Rheumatology, 13, 763-767.
- Lorig, K. & Fries, J. F. (1986). The arthritis helpbook
A tested self-management program for coping with your arthritis. Reading: Addison-Wesley Publishing Company, Inc.
- Maisiak, R., Koplon, S., & Heck, L. (1989b). User evaluation of an arthritis information telephone service. Arthritis Care and Research, 2(2), 75-79.
- Maisiak, R., Koplon, S., & Heck., L., Jr. (1989a). Users of a public arthritis information service and their needs. The Journal of Rheumatology, 16(11), 1474-1479.

McBurney, D.H. (1983). Experimental psychology. Belmont: Woodsworth Publishing Company.

McColl, M. A., & Skinner, H. A. (1988). Concepts and measurement of social support in a rehabilitation setting. Canadian Journal of Rehabilitation, 2(2), 93-107.

McGowan, P. Director of Social Work Services, Arthritis Centre. Personal Interview. December, 1989.

McGowan, M. B., & Roth, S. (1987). Family functioning and functional independence in spinal cord injury adjustment. Paraplegia, 225, 357-365.

McGowan, P. (1990). Psychologic, social, emotional and practical problems of patients with arthritis. Can. Fam. Physician, 36, 503-507.

McKinlay, J. B. (1973). Social networks, lay consultation and help-seeking behaviour. Social Forces, 51, 275-292.

- Meenan, R.F., Gertman, P.M., & Mason, J.H. (1980).
Measuring health status in arthritis: The Arthritis
Impact Measurement Scales. Arthritis and
Rheumatism, 23(2), 146-152
- Meenan, R.F., Gertman, P.M. Mason, J.M. & Dunaif, R.
(1982). The Arthritis Impact Measurement Scales.
Further investigations of a health status measure.
Arthritis and Rheumatism, 25(9), 1048-1053.
- Meenan, R. F., Yelin, E. H., Nevitt, M., & Epstein, W.
V. (1981). The impact of chronic disease. A
sociomedical profile of rheumatoid arthritis.
Arthritis and Rheumatism, 24(3), 544-549.
- Mitchell, M. (1986). Utilizing volunteers to enhance
informal social networks. Social Casework: The
Journal of Contemporary Social Work. 290-298.
- Moskowitz, R. W. (1981). Management of osteoarthritis.
Bulletin on the Rheumatic Diseases, 31, 31-35.

Nagi, S. (1976). An epidemiology of disability among adults in the United States. Milbank Mem Fund Q, 54(4), 439-468.

Nelson, J.C. (1988). Single-subject research. In R.M. Grinnell Jr. (Ed.), Social work research and evaluation. Itasca: F.E. Peacock Publishers, Inc.

Nietzel, M. T., & Fisher, S. G., (1981). Effectiveness of professional and paraprofessional helpers: A comment on Durlak. Psychological Bulletin, 89(3), 555-565.

Oritt, E. J., Paul, S. C., & Behrman, J. A. (1985). The Perceived Support Network Inventory. American Journal of Community Psychology, 13(5), 565-582.

Patrick, K., Morgan, M., & Charlton, J. R. H. (1986). Psychosocial support and change in the health status of physically disabled people. Social Science Medicine, 22(12), 1347-1354.

Patton, M.Q. (1980). Qualitative Evaluation Methods, Beverly Hills, California: Sage Publications.

Pennebaker, J. W., & Funkhouse, J. E. (1980). Influence of social support, activity and life change on medication use and health deterioration among the elderly. Unpublished manuscript.

Petrie, A. (1969). Individuality in pain and suffering. Chicago: University of Chicago Press.

Pfieffer, C. A., & Affleck, G. (1988). Social support and mood state in rheumatoid arthritis. Farmington: University of Connecticut School of Medicine.

Porritt, K. (1979). Social support in crisis: Quantity or quality. Social Science and Medicine, 13, 715-721.

Potts, M.K., & Brandt, K.D. (1987). Evidence of the validity of the Arthritis Impact Measurement Scales. Arthritis and Rheumatism, 30(1), 93-96.

Potts, M., Yngve, D. N., Weinberger, M., & Brandt, K. D. (1983). Educational needs of elderly people with arthritis. Clinical Rheumatology in Practice, November/December, 255-259.

Procidano, M. E., & Heller, K. (1983). Measures of perceived social support from friends and family: Three validation studies. American Journal of Community Psychology, 11, 1-24.

Rafael, R. (1987). Evaluation of the Arthritis Men's Group. Master's thesis. University of British Columbia, School of Social Work, Vancouver.

Reid, W.J., & Smith, A.D. (1981). Research in social work, New York: Columbia University Press.

Reissman, F. (1965). The helper therapy principle. Social Work, 10, 27-32.

Rogers, M. P., Dubey, D., & Reich, P. (1979). The influence of the psyche and the brain on immunity and disease susceptibility: A critical review. Psychosomatic Medicine, 41, 147-164.

Rogers, M. P., Liang, M. H., & Partridge, A. J. (1982). Psychological care of adults with rheumatoid arthritis. Annals of Internal Medicine, 96, 344-348.

Salloway, J. C., & Dillon, P. B. (1973). A comparison of family networks and friends networks in health care utilization. Journal of Comparative Family Studies, 4, 131-142.

Sarason, I.G., Levine, H.M., Basham, R.B. & Sarason, B.R. (1983). Assessing social support: The Social Support Questionnaire. Journal of Personality and Social Psychology, 1, 127-139.

Saulnier, K. (1982). Networks, change and crisis: The web of support. Canadian Journal of Community Mental Health, 1, 5-22.

- Schultz, R. (1976). Effects of control and predictability on the physical and psychological well-being of the institutionalized aged. Journal of Personality and Social Psychology, 33, 563-573.
- Schulz, R., & Decker, S., (1985). Long term adjustment to physical disability: The role of social support, perceived control and self-blame. Journal of Personality and Social Psychology, 48(5), 1162-1172.
- Scileppi, K. P. (1983). Bone and joint disease in the elderly. Medical Clinics of North America, 67(2), 517-530.
- Seaberg, J.R. (1988). Utilizing sampling procedures. In. R.M. Grinnell Jr. (Ed.), Social work research and evaluation. Itasca: F.E. Peacock Publishers Inc.

Silverman, P. R. (1982). People helping people: Beyond the professional model. In H. C. Schulberger and M. Peterson (Eds.). The Modern practice of community mental health. San Francisco: Josey-Bass Publishers.

Silverman, P. R., & Murrow, H. G. (1976). Mutual help during critical role transitions. Journal of Applied Behavioural Science, 12(3), 410-418.

Simonson, S. K. (1987). Peer counselling in health care: A collaboration of social work and voluntarism. Social Work in Health Care, 12(4), 1-19.

Smith, R. T. (1985). Social support measurement. American Journal of Community Psychology, 13, 187-202.

Statistics Canada. (1986a). Population projections. 1986 Census Base Projections. Computer printout catalogue no. 91-520.

Statistics Canada. (1986b). 1986 Census B.C. Part 1.

Profile-Catalogue #94-119.

Tausig, J. E., & Freeman, E. W;. (1988). The next best thing to being there: Conducting the clinical research interview by telephone. American Journal of Orthopsychiatry, 58(3), 418-427.

Thoits, P. A. (1982). Conceptual, methodological and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behaviour, 23, 145-159.

Tolsdorf, C. (1976). Social networks, social support and coping: An exploratory study. Family Process, 15, 407-417.

Toseland, R. W., & Hacker, L. (1985). Social worker's use of self-help groups as a resource for clients. National Association of Social Workers.

Truax, C. B., & Lister, J. L. (1970). Effectiveness of counsellors and counsellor aides. Journal of Counselling Psychology, 17(4), 331-334.

Turner, R. T. (1983). Direct, indirect and moderating effects of social support upon psychological distress and associated conditions. In H. B. Kaplan (ed.), Psychosocial stress: Trends in theory and research. New York: Academic Press.

U. S. Department of Commerce, Bureau of the Census.
(1985). Statistical Abstract of the U. S.

Vaillant, G. E. (1979). Health consequences of adaptation to life. American Journal of Medicine, 67, 732-734.

Wallston, B. S., Alagna, S. W., DeVellis, B. M., & DeVellis, R. F. (1983). Social support and physical health. Health Psychology, 2(4), 367-391.

Weinberger, M., Tierney, W. M., & Booher, P. (1989, June). Providing information and support to patients with osteoarthritis: A randomized, controlled trial. Paper presented at the 24th Annual National Scientific Meeting, Arthritis Health Professions Association, Cincinnati, OH.

Weinberger, M., Hiner, S. L., & Tierney, W. M. (1986). Improving functional status in arthritis: The effect of social support. Soc. Sci. Med., 23, 899-904.

Weiner, H. M. (1977). Psychobiology and human diseases, New York: Elsevier.

Wiener, C. L. (1975). The burden of rheumatoid arthritis. In A. L. Strauss (ed.), Chronic illness and the quality of life (pp. 71-80).

Wood, D. W., & Turner, R. J. (1985). Depression and disability: The stress process in a chronically strained population. Research in Community Mental Health, 5, 77-109.

Wood, P. H. N. (1976). Osteoarthritis in the community.

Clinics in Rheumatic Diseases, 2, 495-507.

Wortman, C. B. (1984). Social support and the cancer

patient: Conceptual and methodological issues.

Cancer, 53(10), 2339-2360.

Wright, V. (1985). Measurement of outcome in rheumatic diseases. Journal of the Royal Society of

Medicine, 78, 985-994.

APPENDIX A

Qualitative Data Questions and Variables Measured

VARIABLE/DIMENSION	QUESTION/SEQUENCE
Focusing on impact of arthritis	1. You've got arthritis? Pain? How does it affect you?
Changes in health status (as measured by AIMS)	2. Since you've been talking to _____, have you noticed any difference in your arthritis? Any change at all?
Motivation for participation (program implementation)	3. Why did you agree to be called?
Introduction to social support	4. Can we talk about _____? What do you think about her?
Perceived homogeneity	5. Would you say _____ and you are similar in any ways? Both of you have arthritis. Anything else?
Perceived social support	6. Do you like getting calls from her?
Functional social support	7. Why do you like her calls? Have you found it helpful? Can you tell me more?
	8. What is the one thing you like best about being called by _____? Can you tell me more about that?
Client satisfaction (program evaluation)	9. Is there anything you don't like? How would you make that better?
Client satisfaction	10. Have you told your family, friends about this? What do they think about it?

APPENDIX B

Questionnaire Package:

Arthritis Impact Measurement Scales
Perceived Social Support From Friends
and From Family

Arthritis Impact Measurement Scales

Instructions: Please answer the following questions about the way your arthritis affects your health. Circle the appropriate number to indicate your answer. Try to answer every question.

1. When you travel around your community, does someone have to assist you because of your health? (circle one number)
 - Yes 1
 - No 2
2. Are you able to use public transportation?
 - No, because of my health 1
 - No, for some other reason 2
 - Yes, able to use public transportation 3
3. Do you have to stay indoors most or all of the day because of your health?
 - Yes 1
 - No 2
4. Are you in bed or in a chair for most or all of the day because of your health?
 - Yes 1
 - No 2
5. Does your health limit the kind of vigorous activities you can do such as running, lifting heavy objects or participating in strenuous sports?
 - Yes 1
 - No 2
6. Do you have any trouble either walking several blocks or climbing a few flights of stairs because of your health?
 - Yes 1
 - No 2
7. Do you have trouble bending, lifting or stooping because of your health?
 - Yes 1
 - No 2

(circle one number for each question)

8. Do you have any trouble either walking **one** block or climbing **one** flight of stairs because of your health?

Yes1

No2

9. Are you unable to walk unless you are assisted by another person or by a cane, crutches, artificial limbs, or braces?

Yes1

No2

10. Can you easily write with a pen or pencil?

Yes1

No2

11. Can you easily button articles of clothing?

Yes1

No2

12. Can you easily turn a key in a lock?

Yes1

No.....2

13. Can you easily tie a pair of shoes?

Yes1

No2

14. Can you easily open a new jar of food?

Yes1

No..... 2

15. If you have the necessary transportation:

Could you go shopping for groceries or clothes...

Without help (taking care of all shopping needs yourself)1

With some help (need someone to go with you to help on all shopping trips)2

Or are you completely unable to do any shopping3

(circle one number for each question)

16. If you had a kitchen:

Could you prepare your own meals...

Without help (plan and cook full meals yourself) 1

With some help (can prepare some things but unable to
cook full meals yourself) 2

Or are you completely unable to prepare any meals 3

17. If you had household tools and appliances (vacuum, mops, etc.):

Could you do your own housework...

Without help (can clean floors, windows, refrigerator, etc.) 1

With some help (can do light housework, but need
help with some heavy work) 2

Or are you completely unable to do any housework 3

18. If you had laundry facilities (washer, dryer, etc.):

Could you do your own laundry...

Without help (take care of all laundry yourself) 1

With some help (can do small items only) 2

Or are you completely unable to do any laundry 3

19. If you have to take medicine:

Could you take all of your own medicine...

Without help (in the right doses at the right time) 1

With some help (able to take medicine if someone
prepares it for you and/or reminds you to take it) 2

20. Do you handle your own money?

Without help (write checks, pay bills, etc.) 1

With some help (day to day, but need help budgeting, etc.) 2

Or are you completely unable to handle any money 3

21. If you have a telephone would you be able to use it?

Without help 1

With some help (can answer phone or dial operator in an emergency,
but need a special phone or help in getting the number or dialing) 2

Or are you completely unable to use the telephone 3

(circle one number for each question)

22. During the **past month**, about how often did you get together with friends or relatives?

- Every day 1
- Several days a week2
- About once a week3
- Two or three times in the past month4
- Once in the past month 5
- Not at all in the past month 6

23. During the past month, about how often have you had friends or relatives over to your home?

- Every day 1
- Several days a week2
- About once a week3
- Two or three time in the past month4
- Once in the past month 5
- Not at all in the past month 6

24. During the past month, how often have you visited with friends, or relatives at their homes?

- Every day 1
- Several days a week2
- About once a week3
- Two or three times in the past month..... 4
- Once in the past month 5
- Not at all in the past month 6

25. About how often were you on the telephone with close friends or relatives during the past month?

- Every day 1
- Several days a week2
- About once a week3
- Two or three times in the past month..... 4
- Once in the past month 5
- Not at all in the past month 6

26. When you bathe, either a sponge bath, tub or shower, how much help do you need?

- No help at all 1
- Help with bathing one part of your body, like back or leg2
- Help in bathing more than one part of your body 3

(circle one number for each question)

27. How much help do you need in getting dressed?

- No help at all 1
- Only need help in tying shoes 2
- Need help in getting dressed 3

28. How much help do you need to use the toilet?

- No help at all 1
- Only need help in getting to or using the toilet 2
- Not able to get to the bathroom at all 3

29. How well are you able to move around?

- Able to get in and out of bed or chairs without the help of another person 1
- Need the help of another person to get in and out of bed or chair 2
- Not able to get out of bed 3

30. During the **past month**, how would you describe the arthritis pain you usually have?

- Very severe 1
- Severe 2
- Moderate 3
- Mild 4
- Very mild 5
- None 6

31. During the past month how often have you had severe pain from your arthritis?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

32. During the past month, how long has your morning stiffness usually lasted from the time you wake up?

- Over four hours 1
- Two to four hours 2
- One to two hours 3
- Thirty minutes to an hour 4
- Less than thirty minutes 5
- Do not have morning stiffness 6

(circle one number for each question)

33. During the **past month**, how often have you had pain in two or more joints at the same time?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

34. During the past month, how much of the time have you enjoyed the things you do?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

35. During the past month, how much of the time have you felt tense or "high strung"?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

36. How much have you been bothered by nervousness, or your "nerves" during the past month?

- Extremely so, to the point where I could not take care of things..... 1
- Very much bothered 2
- Bothered quite a bit by nerves 3
- Bothered some, enough to take notice 4
- Bothered just a little bit by nerves 5
- Not bothered at all by this 6

37. How often during the past month did you find yourself having difficulty trying to calm down?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

(circle one number for each question)

38. During the **past month**, how much of the time have you been in low or very low spirits?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

39. How much of the time during the past month did you feel relaxed and free of tension?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

40. How much of the time during the past month have you felt downhearted and blue?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

41. How often during the past month did you feel that nothing turned out the way you wanted it to?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

42. How much of the time during the past month have you felt calm and peaceful?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

(circle one number for each question)

43. During the **past month**, how often did you feel that others would be better off if you were dead?

- Always1
- Very often2
- Fairly often3
- Sometimes4
- Almost never5
- Never6

44. How much of the time during the past month were you able to relax without difficulty?

- All of the time1
- Most of the time2
- A good bit of the time3
- Some of the time4
- A little of the time5
- None of the time6

45. How often during the past month have you felt so down in the dumps that nothing could cheer you up?

- Always1
- Very often2
- Fairly often3
- Sometimes4
- Almost never5
- Never6

46. In general would you say your health is excellent, good, fair or poor?

- Excellent1
- Good2
- Fair3
- Poor4

47. Thinking about the past month, how much of the time has your health kept you from doing the kinds of things that you should be able to do?

- All of the time1
- Most of the time2
- Some of the time3
- None of the time4

(circle one number for each question)

48. During the **past month** how active has your arthritis been?

- Very active1
- Moderately active2
- Mildly active3
- Not at all active4

Note: In answering the next four questions, please circle the number that best describes how you feel about each statement.

49. I seem to get sick a little easier than other people.

- Definitely true 1
- Mostly true2
- Don't know3
- Mostly false 4
- Definitely false5

50. I never worry about my health.

- Definitely true 1
- Mostly true2
- Don't know3
- Mostly false 4
- Definitely false5

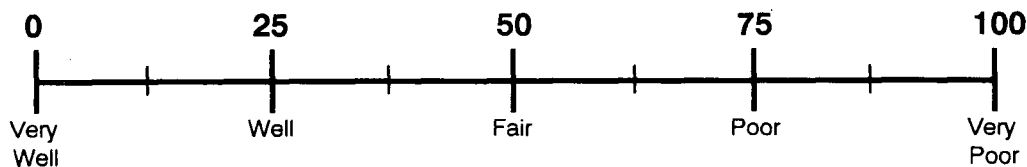
51. My body seems to resist illness very well.

- Definitely true 1
- Mostly true2
- Don't know3
- Mostly false 4
- Definitely false5

52. When there is something going around, I usually catch it.

- Definitely true 1
- Mostly true2
- Don't know3
- Mostly false 4
- Definitely false5

53. Considering all the ways your arthritis affects you, mark (X) on the scale for how well²⁴⁷ you are doing.



(circle one number for each question)

54. During the **past month** how often have you had to take medication for your arthritis?

- Always1
- Very often2
- Fairly often3
- Sometimes4
- Almost never5
- Never6

55. Is your health currently affected by any of the following medical problems?
(please circle yes or no for **each one**)

	1	2
High blood pressure	Yes	No
Heart disease	Yes	No
Mental illness	Yes	No
Diabetes	Yes	No
Cancer	Yes	No
Alcohol or drug abuse	Yes	No
Lung disease	Yes	No
Kidney disease	Yes	No
Liver disease	Yes	No
Stomach or blood disease	Yes	No

56. Do you take medicine every day for any problem other than your arthritis?

- Yes1
- No2

57. Did you see a doctor more than three times last year for any problem other than arthritis?

- Yes1
- No2

Please provide the following information about yourself:

58. What is your age at this time? (please fill in) _____

59. How many years have you had your arthritis? _____

60. What is your sex?

Male 1

Female 2

61. What is your racial background?

White..... 1

Black 2

Hispanic 3

Oriental or Pacific Islander 4

American Indian or Alaskan Native 5

Other 6

62. What is your current marital status?

Married 1

Separated 2

Divorced 3

Widowed 4

Never married 5

63. What is your occupation? Indicate student, housewife, disabled, retired or unemployed, if appropriate.

64. If you are retired, disabled or unemployed, what was your previous occupation?

65. Please circle the highest level of education you received.

- Professional or graduate school1
- College graduate2
- One to four years of college3
- High school graduate4
- Grades ten through eleven5
- Grades seven through nine6
- Less than seven years of school7

66. What is your approximate family income"

- Less than 5,0001
- \$5,000-\$10,0002
- \$10,000-\$15,0003
- \$15,000-\$20,0004
- \$20,000-\$25,0005
- \$25,000-\$40,0006
- \$40,000-\$65,0007
- More than \$65,0008

What type of residence do you live in?

- Apartment1
- House2
- Nursing Home3
- Long Term Care Facility4
- Other5

How many people do you live with?

- Live alone1
- One2
- Two3
- Three4
- Four5
- Five6
- More than five7
- More than ten8
- More than twenty9

This is the end of the AIMS questionnaire.

Thank you very much for your help.

PSS -Fa

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, Don't Know.

Please circle one answer

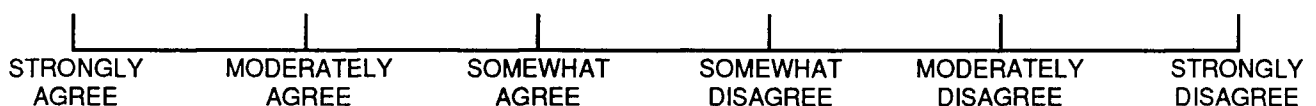
1. My family gives me the moral support I need.	Yes	No	Don't know
2. I get good ideas about how to do things or make things from my family.	Yes	No	Don't know
3. Most other people are closer to their family than I am.	Yes	No	Don't know
4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.	Yes	No	Don't know
5. My family enjoys hearing about what I think.	Yes	No	Don't know
6. Members of my family share many of my interests .	Yes	No	Don't know
7. Certain members of my family come to me when they have problems or need advice.	Yes	No	Don't know
8. I rely on my family for emotional support.	Yes	No	Don't know
9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.	Yes	No	Don't know
10. My family and I are very open about what we think about things.	Yes	No	Don't know
11. My family is sensitive to my personal needs.	Yes	No	Don't know
12. Members of my family come to me for emotional support.	Yes	No	Don't know
13. Members of my family are good at helping me solve problems.	Yes	No	Don't know
14. I have a deep sharing relationship with a number of members of my family.	Yes	No	Don't know
15. Members of my family get good ideas about how to do things or make things from me.	Yes	No	Don't know
16. When I confide in members of my family, it makes me uncomfortable.	Yes	No	Don't know
17. Members of my family seek me out for companionship.	Yes	No	Don't know
18. I think that my family feels that I'm good at helping them solve problems.	Yes	No	Don't know
19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.	Yes	No	Don't know
20. I wish my family were much different	Yes	No	Don't know

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, Don't know.

Please circle one answer

1. My friends give me the moral support I need.	Yes	No	Don't know
2. Most other people are closer to their friends than I am.	Yes	No	Don't know
3. My friends enjoy hearing about what I think.	Yes	No	Don't know
4. Certain friends come to me when they have problems or need advice.	Yes	No	Don't know
5. I rely on my friends for emotional support.	Yes	No	Don't know
6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself.	Yes	No	Don't know
7. I feel that I'm on the fringe in my circle of friends.	Yes	No	Don't know
8. There is a friend I could go to if I were just feeling down, without feeling funny about it later.	Yes	No	Don't know
9. My friends and I are very open about what we think about things.	Yes	No	Don't know
10. My friends are sensitive to my personal needs.	Yes	No	Don't know
11. My friends come to me for emotional support.	Yes	No	Don't know
12. My friends are good at helping me solve problems.	Yes	No	Don't know
13. I have a deep sharing relationship with a number of friends.	Yes	No	Don't know
14. My friends get good ideas about how to do things or make things from me.	Yes	No	Don't know
15. When I confide in friends, it makes me feel uncomfortable.	Yes	No	Don't know
16. My friends seek me out for companionship.	Yes	No	Don't know
17. I think that my friends feel that I'm good at helping them solve problems.	Yes	No	Don't know
18. I don't have a relationship with a friend that is as intimate as other people's relationships with friends.	Yes	No	Don't know
19. I've recently gotten a good idea about how to do something from a friend.	Yes	No	Don't know
20. I wish my friends were much different.	Yes	No	Don't know

My volunteer caller is a source of support for me.



APPENDIX C

A Comparative Analysis of Two Social Support
Questionnaires to Determine Their Relative
Adequacy for Use With an Elderly Population

The purpose of this research project is to select the best choice between two instruments that measure the dependent variable of perceived level of social support. This inquiry is important because it will determine the adequacy of the two social support questionnaires for work with an elderly population. It is expected that the result of this pilot project, which will use respondents similar in characteristic to respondents who will be participating in the main survey, will illuminate the instrument which will be best understood and most easily completed by the elderly. These factors are crucial in order to ensure an adequate response rate. The selection of an appropriate social support instrument will contribute to the power of these result. In turn, these results would lend more weight to the conclusion of whether or not telephone contact program participants perceive an increase in their social support. Thus, this pilot project will help make a small contribution in the area of social support intervention.

The measurement of social support is one of the principal obstacles to a more unified approach to the construct (Broder, 1988). This may, in part, be due to the intuitive nature of social support. Unlike many other psychosocial constructs, social support can be understood from a purely personal standpoint; we all know what it is like to feel either supported or not supported. This characteristic may have prompted investigators to develop measurements of social support based on an intuitive conceptualization rather than on an empirically-supported theoretical model (McColl & Skinner, 1988).

The most common categorization classifies measures into three basic types: those emphasizing structural aspects of support networks, those which measure subjective evaluations of support, and those which attempt to quantify the activities involved in the provision of support (Broder, 1988).

STRUCTURAL MEASURES: Measures of this type assume that social support is a by-product of participation in social relationships. This assessment strategy focuses on the differentiation of the salient characteristics of social relationships. There are two types of measures in this category; those utilizing network analysis techniques, and those using demographic indicators. Network analysis has been used to quantify characteristics of

supportive networks. Characteristics such as number of members, frequency of contact, strength of ties, and durability of relationships have been examined. The other type of measure investigates factors such as marital status or the presence of both parents in a household. These are used as indirect indicators of the extent to which individuals are linked to other people, the assumption being that they thus have opportunities to obtain social support.

Social network analysis has been criticized for a number of assumptions. For example, it assumes that having relationships means having support. It often fails to take into account that some ties may be counter-supportive. This approach also assumes that various aspects of the network can be added to give a meaningful score. Finally, it assumes that benefits are accrued from the network proportional to size (Schaeffer, Coyne, & Lazarus, 1981). Kessler (1982) suggests that structural factors should instead be used as predictors of support.

EVALUATIVE MEASURES: Instruments in this category emphasize an individual's subjective appraisals of social support which is either received or accessible. This approach emphasizes the quality of relationships. An example would be an instrument that measures perceived social support from friends and from family (Procidano & Heller, 1983).

These measures have been criticized for assessing potential rather than actual support. In other words, they do not address the issue of whether or not these supports can be utilized in a stressful situation. It is possible to imagine a situation in which an individual feels embedded in a large and seemingly active support network, but in fact does not have access to the necessary supports in time of stress (McColl & Skinner, 1988).

FUNCTIONAL MEASURES: This approach to measurement of social support involved the assessment of the specific supportive behaviours of which individuals are the recipient (Broder, 1988). These behaviours are usually defined on an intuitive or empirical basis as being socially supportive.

The lack of development of reliable, valid, theory-based measures of social support is a common criticism of

the social support literature (Cohen & Wills, 1985). As a result, they tend to be both overinclusive (i.e., to lack discriminative validity) and to ignore important content (i.e., to lack content validity). In addition, many of the newer instruments, with the exception of the Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983), are scored unidimensionally and thus 'lose' potentially important data. Furthermore, interpretations of closeness and intimacy vary across individual characteristics such as ethnicity or culture (Johnson, 1977).

Most instruments constructed to measure aspects of social support have been developed solely for the purpose of measuring variables relevant to the study in which they were used (Oritt, Paul & Behrman, 1985). The simultaneous use of different types of social support instruments would enable examination of their interrelationships, and would take into account the multi-dimensional nature of social support. In addition, a multi-method approach would allow for investigation of aspects of social support which are most reliable for different populations and/or for different types of adjustment (Gottlieb, 1983). Despite the consensus that assessment of social support should employ multi-dimensional and/or multi-method strategies, there is a gap between conceptualization and measurement.

The absence of precise measures of social support hinders both theory development and the application of research finding (Tardy, 1985). Measures generally provide one or a small number of summary "social support" scores, combining multiple dimensions into unidimensional representations (Kessler, 1982). This flaw is likely to blame for the difficulty in identifying specific distress-relieving or health-promoting aspects of social support (Thoits, 1982). Cohen and Wills (1985) conclude that not all measures of social support are related to adjustment in similar ways. Thus the establishment of how different measures of social support interrelate will be crucial to the development of social support theory.

The Social Support Questionnaires Under Comparative Analysis

For this comparative analysis, it was advisable for this researcher to select two existing scales because it

would allow for comparison across studies. After a review of the literature, this researcher selected the following two instruments for further examination:

Perceived Social Support from Friends and From Family (PSS-Fr & PSS-Fa):

Procidano and Heller (1983) reported a series of three studies assessing two similar measures of perceived social support, one quantifying perceived support from friends, and the other perceived support from family members. Items tap both support provision by respondents and support received, as well as support enactment and availability. Most of the items fall within the category of emotional support.

The two measures are comprised of twenty declarative statements to which respondents answer "yes", "no", or "don't know". In one (PSS-Fa), the items are worded for family members and in the other for friends (PSS-Fr). Responses indicating support are scored as +1, while other responses are not scored. Scores thus range from 0 to 20, with higher scores indicting more perceived support. The authors report a test-retest reliability of .83 over a one month interval for a preliminary 35-item version of the scales.

Social Support Questionnaire (SSQ):

Sarason, Levine, Basham and Sarason (1983) constructed an instrument which measure availability of and satisfaction with social support. Most of the items focus on emotional support. Respondents are asked to identify up to nine individuals to whom they would or could turn in each of twenty-seven situations. Respondents are also asked to rate the level of their satisfaction with the overall support they receive in each situation on a 6-point scale in which 1 equals very satisfied and 6 equals very dissatisfied.

The instrument yields two scores. One, ranging from 0 to 9, describes the availability of support (SSQ-N). It is calculated by dividing the total number of people listed by the number of items. The second score (SSQ-S) represents respondents' satisfaction with available support. This score, which ranges from 1 to 6, is the average satisfaction rating indicated over the 27 items.

On this scale, higher scores indicates lower overall satisfaction.

Sarason et al. (1983) reported a series of four studies which provide evidence of the reliability and validity of this instrument. According to these researchers, other evidence for the validity of the SSQ has been found in the significant correlations of SSQ-N and SSQ-S with measures of depression. The SSQ was chosen for this comparative analysis primarily because it has been used in a previous study measuring social support change due to a telephone contact program (Weinberger, Hinner, & Tierney, 1986). These researchers found that the SSQ measured significantly higher levels of overall social support, as well as along the emotional and tangible dimension. It therefore appears that telephone interviewers may well have been perceived as a source of social support to the participants.

Problem Statement

The purpose of this comparative analysis is to select between the PSS-Fr and Fa and the SSQ in order to provide the best possible instrument for future use in a larger research project. Thus the problem is TO DETERMINE THE RELATIVE EFFECTIVENESS OF EACH INSTRUMENT FOR USE WITH AN ELDERLY POPULATION. Both qualitative and quantitative data will be analyzed to provide an answer to the above question. Although it would be desirable to use both instruments for a more complete picture of subjects' social support, it is believed that a large questionnaire package which would include the above instruments and the Arthritis Impact Measurement Scales would negatively impact on the response rate.

Research Design

A descriptive, comparative design is the appropriate level of research design for this project. Basic to scientific evidence is the process of comparison, of recording differences, or of contrast. Securing scientific evidence involves making at least one comparison. For such a comparison to be useful, both sides of the comparison should be made with similar care and precision (Campbell & Stanley, 1966).

Materials

The SSQ and the PSS-Fr & FA were originally developed with different formatting. In order to control for the intervening variable of the visual formatting, the SSQ and the PSS-Fr and Fa were retyped so that respondents would be presented with a similar format (i.e. size of type) for both questionnaires.

In order to obtain qualitative and quantitative data for the comparison, this researcher developed a short questionnaire to explore the respondents' opinion of the two social support questionnaires. A rough draft of this questionnaire (Appendix 1) was presented to Patrick McGowan, Director of Social Work Services at the Arthritis Centre, for critique. Mr. McGowan's input resulted in refinements being made to the finished questionnaire (Appendix 2), including changes to the wording of the scales and changes to the questions themselves. Some questions were added, while others were collapsed or deleted completely from the questionnaire. Each of the nine questions contained a 6-point scale which rated the satisfaction subjects had for each social support questionnaire.

Subjects

The first step is to define the population to be covered. Here it is useful to distinguish between the population for which the results are required the target population, and the population actually covered, the survey population (Moser & Kalton, 1972). The definition of the population involved the fixing of limits.

For the purpose of this pilot project, it was desirable to obtain subjects who would closely resemble the respondents in the main study. Consequently five volunteers were recruited from the Never Surrender support group which meets at the Arthritis Centre. An additional five volunteers were recruited from participants of an Arthritis Self-Management Program Leader's Training Course which was also meeting at the Arthritis Centre.

All subjects for this research project were women who had arthritis themselves. All subjects appeared to be over the age of fifty-five (a prerequisite for the

Never Surrender Group) and were able to read, write, and understand English.

Procedure

This researcher attended the meeting for both the Never Surrender Group and the Arthritis Self-Management Course. After briefly describing the research for the thesis work and the purpose of this pilot study, a request was made by this researcher for volunteers to complete the questionnaire package.

To control for order effects, volunteers were alternatively given either the SSQ first and the PSS-Fr and Fa second, or vice versa. The questionnaire developed specifically for this pilot study was always the last questionnaire completed by participants.

This researcher was present while subjects completed the questionnaires in order to obtain a more complete picture of the subjects' attitude towards the SSQ and the PSS Fr & Fa. All comments made by subjects to each other were noted by this researcher. However, the researcher avoided instructing subjects on how to complete the questionnaire. It was left to the subjects to fill out the questionnaire to the best of their abilities.

Analysis

Analysis of results were conducted on two levels:

QUALITATIVE DATA: Qualitative data was obtained from three sources:

- A. Verbal comments made by subjects while they were completing the two social support questionnaires.
- B. The extent to which subjects successfully completed the two social support questionnaires. Observations were made on mistakes made by subjects in their attempt to complete the questionnaires.
- C. Written comments made by subjects on the questionnaire developed for this pilot study.

QUANTITATIVE DATA: Quantitative data was obtained from two sources:

- A. The results obtained from the completed social support questionnaires. Major deviations from the norm (i.e. too great a bunching of answers at one extreme) were to be noted for it may indicate a problem with that particular questionnaire - especially if the other questionnaire does not show a similar pattern.
- B. The average score that subjects gave for individual questions on this researcher's structured questionnaire. Each respondent's total score from the nine questions were also to be tabulated for each social support questionnaire. From this data, it is then possible to calculate the average total score for each questionnaire.

Results

QUALITATIVE DATA: The following verbal comments were made by subjects while they were completing the social support questionnaires:

COMMENTS ON THE PSS-Fa:

1. "I don't have a family, so do I need to complete it?"

COMMENTS ON THE SSQ:

1. "Do I rate each person on the satisfaction scale?"
2. "Do I need to write down the same people again if I have already listed them on the previous question?"
3. "This is too long." Six out of ten subjects made this comment.
4. Some subjects had difficulty relating to question #4 and #10 because the questions asked subjects to suppose they were married, employed, or students.

The following observations were made by this researcher upon examining the completed questionnaires:

1. Three of the PSS-Fa questionnaire results were invalidated because the subjects did not complete both sides of the page. It appears that they turned the page but did not realize that there were questions on the page of the page. Two of the SSQ's suffered the same mishap.
2. Five of the SSQ scores on the 'satisfaction with social support' scale were invalidated because subjects did not complete all of the items.
3. Four of the SSQ scores on the 'availability of social support' scale were invalidated because subjects wrote, "family, neighbours or friends" rather than the names of the individuals. Thus it was impossible to determine the exact size of their social network.

The following written comments were made by subjects who completed this researcher's questionnaire:

One subject wrote a general comment "Questionnaire A (SSQ) might be more specific or limiting in the number of people you can include in your social network."

Other comments were directed at specific questions:

Question #1: The questions were straightforward.

COMMENT - "Except for spelling errors and grammar mistakes."

Question #3: The wording to the questions was simple and clear.

COMMENT - "Many of the questions were too similar in their nature."

Question #4: The questions provided sufficient information for me to give a sensible answer."

COMMENT - "'Love' has many meanings to many people. It's hard to interpret."

Question #9: The questionnaire is a good way of measuring social support.

COMMENT - "Define social support? I guess if you can interpret the data."

QUANTITATIVE DATA: The PSS-Fr and PSS-Fa average scores of 15.6 and 16.4 respectively out of a possible total of 20 suggests that subjects in general perceived they had quite a bit of social support. In concurrence with these findings, the availability of social support (SSQ-N) averaged 4.1 out of a possible score of 9 for each item. The satisfaction with available support scale (SSQ-S) revealed that subjects appeared to be satisfied with their network size because the average score was 1.3 in which 1 is rated the best possible satisfaction on a 6-point scale.

Table 1

Results of Quantitative Measures

<u>Subjects</u>	<u>PSS</u>		<u>SSQ</u>	
	<u>Fr</u>	<u>Fa</u>	<u>SSQ-N</u>	<u>SSQ-S</u>
1	11	--	--	--
2	15	--	--	--
3	13	--	--	--
4	16	12	5.1	1.6
5	20	20	5.1	1
6	17	20	--	--
7	16	19	--	--
8	13	9	2.1	1.8
9	17	20	2.9	1.1
10	18	15	5.4	1
<u>Average</u>	15.6	16.4	4.1	1.3

Completion Rate:

100%	70%	50%	50%
------	-----	-----	-----

Thus it would appear that the two social support questionnaires complemented each other well in giving an accurate picture of the respondents' social support. The SSQ recorded that people were very satisfied with an average support network size of four people per "problem situation". The respondents' perception of social

support from family (PSS-Fa) and from Friends (PSS-Fr) was shown to be quite high. The combined PSS-Fa and PSS-Fr yielded an average score of 16 out of 20 in which higher scores indicates increased perception of support.

Perhaps one of the most crucial calculations shown in Table 1 is the completion rate for the two questionnaires. Significantly, both scales (SSQ-N, SSQ-S) of the SSQ had only a 50% completion rate by subjects. In contrast, the PSS-Fr enjoyed a 100% completion rate. The PSS-Fa had a completion rate of 70%. The three subjects who did not complete the PSS-Fa did not do so because they likely did not realise the questionnaire was on both on both sides of the page.

In order to test for an order effect, subjects' scores were compared when the SSQ and PSS-Fr & Fa were completed first versus when they were completed last. Table 2 shows subjects' scores on the questionnaires when they completed the PSS-Fr and PSS-Fa first.

Table 2

Order Effect

<u>Subjects</u>	PSS		SSQ	
	<u>Fr</u>	<u>Fa</u>	<u>SSQ-N</u>	<u>SSQ-S</u>
1	11	--	--	--
2	15	--	--	--
3	13	--	--	--
4	16	12	5.1	1.6
5	20	20	5.1	1
<u>Average</u>	15	16	5.1	1.3

Table 3 show subjects' scores on the questionnaires when they completed the SSQ first.

Table 3

Order Effect

<u>Subjects</u>	<u>SSQ</u>		<u>PSS</u>	
	<u>SSQ-N</u>	<u>SSQ-S</u>	<u>Fr</u>	<u>Fa</u>
1	--	--	17	20
2	--	--	16	19
3	2.1	1.8	13	9
4	2.9	1.1	17	20
5	5.4	1	18	15
<u>Average</u>	3.5	1.3	16.2	16.6

Table 4 shows the average score subjects gave on the PSS-Fr, PSS-Fa and the two subscales of the SSQ. When subjects completed the PSS-Fr & Fa second, they recorded a slight increase in scores of 1.2 and 0.6 respectively. On the SSQ-N, subjects reported a slight increase (1.6) when they completed it second. There was no difference in scores for the SSQ-S. Although scores were slightly higher for the PSS-Fr, PSS-Fa and the SSQ-N when they were given to subjects second in the order, increases are minimal. Thus the order effect appears to be not significant.

Table 4

Order Effect: Average Scores

	<u>1st</u>	<u>2nd</u>	<u>Difference</u>
<u>PSS</u>			
Fr	15	16.2	1.2
Fa	16	16.6	0.6
<u>SSQ</u>			
SSQ-N	3.5	5.1	1.6
SSQ-S	1.3	1.3	0

Table 5

Results of Comparative Scales

<u>Question</u>	<u>PSS-Fr & PSS-Fa</u>	<u>SSQ</u>
1	5.0	4.7
2	5.6	5.7
3	4.9	4.9
4	4.9	4.7
5	5.0	4.3
6	5.4	5.4
7	5.0	4.4
8	5.0	4.8
9	4.3	4.4

Nine out of ten subjects completed the questionnaire developed specifically for this comparative analysis. The scale for each question ranged from 0 to 6, with 6 indicating highest satisfaction.

Subjects indicated higher satisfaction for the Perceived Social Support from Friends and Family over the Social Support Questionnaire for the following questions:

- #1. The questions were straightforward.
- #4. The questions provided sufficient information for me to give a sensible answer.
- #5. The questions had answers which allowed me to respond the way I wanted to.
- #7. The questions were relevant to my life experiences.
- #8. After I read the instructions, the questions were easy to complete.

Subjects indicated higher satisfaction for the Social Support Questionnaire over the Perceived Social Support from Friends and from Family for the following questions:

- #2. The questions were free of uncommon words and technical terms.
- #9. The questionnaire is a good way of measuring social support.

Questions #3 and #6 were rated equal for each questionnaire by the subjects.

Table 6

Average Total Scores from Comparative Measure

<u>Respondent</u>	<u>PSS</u>	<u>SSQ</u>
1	54	50
2	50	50
3	34	34
4	47	47
5	28	41
6	49	41
7	52	46
8	43	32
9	44	44
<u>Average Total Score</u>	44.6	42.8

Table 6 presents a tabulation of the total score on the nine questions for each questionnaire as rated by each respondent. Scores could range from a lowest possible score of nine to a highest possible score of fifty-four. From these results, an average total score was calculated for each questionnaire. The Perceived Social Support from Friends and from Family achieved an average total score of 44.6. The Social Support Questionnaire trailed this mark with an average total score of 42.8.

Discussion

It is the opinion of this researcher that both the qualitative and quantitative data supports the selection of the Perceived Social Support from Friends and from Family as the instrument of choice for the main research work.

The strongest support for the selection of the PSS-Fr & Fa comes from an analysis of completion rates. The SSQ only achieved a 50% completion rate while the PSS-Fr and PSS-Fa enjoyed a 100% and 70% completion rate respectively. Qualitative data lends some evidence as to why the SSQ fared worse on completion rates. Six out of ten subjects stated the SSQ was too long. Furthermore, subjects appeared confused as to how to complete the SSQ. Some subjects wrote down, "family, friends or neighbours on the SSQ-N scale, thereby invalidating the results.

Others did not seem to understand the instruction for completing the SSQ-S scale, and consequently omitted rating their satisfaction with their overall support.

Perhaps because of the complexity of the SSQ, respondents felt that it measured social support more thoroughly than the PSS-Fr & Fa. This is indicated by the marginally better score the SSQ obtained on the question, "The questionnaire is a good way of measuring social support". However, one subject reported that she felt that the SSQ limited the number of people she could include in her social network. The fact that the SSQ scored significantly lower than the PSS-Fr & Fa on the question, "The questions had answers which allowed me to respond the way I wanted to" suggests others also felt that the SSQ limited their responses.

Further evidence of the superiority of the PSS-Fr & Fa for use with an elderly population comes from the data supplied by the comparative questionnaire. It is clear that subjects found the PSS-Fr & Fa instructions and questions (see question #1 and #8) to be more straightforward than those of the SSQ. As significant, subjects also reported that the PSS-Fr & Fa was more relevant to their life experiences (see Question #7). This data was also supported by comments made by some subjects about questions #4 and #10 of the SSQ. These subjects were unable to identify with being married/separated, or as an employee/student. This may be particularly true of elderly women who may have lost their husbands and/or been out of the workforce for many years.

The final significant piece of data is that the PSS-Fr & Fa achieved a higher average total score for the subjects' ratings over all nine questions. It would indeed seem that the PSS-Fr & Fa fared significantly better than the SSQ upon examination of both the qualitative and quantitative data.

Conclusion

While the distinction is one of degree, definitions of social support fall into two categories. Those emphasizing functional aspects of social support networks, and those stressing the cognitive appraisal of social support (Turner, 1983). The PSS-Fr & Fa is a questionnaire which adheres to a perceptual definition of

social support. Indeed, many researchers have placed emphasis on respondents' cognitive appraisal or evaluation of their social interactions. Procidano and Heller (1983) differentiated between perceived support and actual support, describing perceived support as, "the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled." Finally, according to Heller, Swindle and Dusenberry (1986), a social activity involves social support if it is perceived by its recipients as esteem enhancing or stress reducing. From the perceptual perspective then, social support is viewed as a subjective and personal experience.

Unfortunately there does not seem to be an instrument in the social support literature which measures a synthesis of the characteristics generally ascribed to social support. Consequently it was left to this researcher to choose amongst instruments that measured aspects within a fairly narrow definition of social support.

Given that respondents in the larger body of research are elderly, it was imperative that this researcher chose an instrument which was simple to complete. Data from this pilot study strongly supports the selection of the Perceived Social Support from Friends and from Family as the instrument of choice. The very high completion rate of the PSS-Fr & Fa by pilot study subjects was a very strong factor in its selection. It is hoped that it will be indicative of a higher response rate for the main project. Furthermore, most of the respondents in the thesis project are homebound, and it is not expected that they will have an extensive social network. Thus it may be more important to measure these respondents' subjective experience of what support there is available to them. The PSS-Fr and Fa has the capability to fulfil this requirement.

The Social Support Questionnaire, like the Perceived Social Support from Friends and from Family, has been shown to be a valid, reliable instrument. However, given the population to be tested, it appears to be a less viable instrument for either a mailed survey or an in-person interview with an elderly population. Consequently, this researcher concludes that the PSS-Fr & Fa to be a simpler questionnaire to complete, based on the quantitative and qualitative data collected by this

pilot study. It is hope this decision will be reflected in a higher response rate by subjects in this researcher's thesis work.

References

- Broder, R. (1988). Assessment of the construct of social support as measured by five self-report instruments. Thesis. University of Manitoba, Winnipeg.
- Campbell, D. T., & Stanley, J. C. (1966) Experimental and quasi-experimental designs for research. Chicago: Rand McNally.
- Cohen, S., & Wills, T. A. (1985). Stress, social support and the buffering hypothesis. Psychological Bulletin, 98, 310 - 357.
- Gottlieb, B. H. (1983). Social support strategies: guidelines for mental health practice. (Sage Studies in Community Mental Health, Vol. 7). Beverley Hills: Sage Publications.
- Heller, K., Swindle, R. W. Jr., & Dusenberg, L. (1986). Component social support processes: comments and integration. Journal of Consulting and Clinical Psychology, 54, 466 - 470.
- Johnson, C. L. (1977). Interdependence, reciprocity and indeptedness: An analysis of Japanese-American kinship relations. Journal of Marriage and the Family, 39, 351 - 363.
- Kessler, R. C. (1982). Life events, social support and mental illness. In W. R. Grove (ed.). Deviance and Mental Illness. Beverley Hills: Sage.
- McColl, M. A. & Skinner, H. A. (1988). Concepts and measurements of social support in a rehabilitation setting. Canadian Journal of Rehabilitation. 2, (2), 93 - 107.
- Moser, C. A., & Kalton, G. (1972). Survey Methods in Social Investigation (2nd ed.). New York: Basic Books Inc.
- Oritt, E. J., Paul, S. C., & Behrman, J. A. (1985). The perceived support network inventory. American Journal of Community Psychology. 13(5), 565 - 582.
- Procidano, M. E. & Heller, K. (1983). Measures of

perceived social support from friends and from family: Three validation studies. American Journal of Community Psychology, 11, 1 - 24.

Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: The Social Support Questionnaire. Journal of Personality and Social Psychology, 1, 127-139.

Schaeffer, C., Coyne, J. C., & Lazarus, R. S. (1981). The health-related function of social support. Journal of Behavioral Medicine, 4, 381 - 405.

Tardy, C. H. (1985). Social support measurement. American Journal of Community Psychology, 13, 187 - 202.

Thoits, P. A. (1982). Conceptual, methodological and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behavior, 23, 145 - 159.

Turner, R. T. (1983). Direct, indirect and moderating effects of social support upon psychological distress and associated conditions. In H. B. Kaplan (ed.), Psychosocial Stress: Trends in Theory and Research. New York: Academic Press.

Weinberger, M., Hiner, S. L., & Tierney, W. (1986). Improving functional status in arthritis: The effect of social support. Soc. Sci. Med. 23(9), 899 -904.

Appendix 1

COMPARATIVE ANALYSIS OF TWO SOCIAL SUPPORT QUESTIONNAIRES

INSTRUCTIONS: The following questions ask your opinion of the two social support questionnaires you have just completed. After each question, please rate each questionnaire on the scale provided by placing an 'X' on the appropriate line. For the second part, please add any comments you may have with regard to the question.

1. To what extent did you find the questions to be unambiguous?

QUESTIONNAIRE A	___ VERY SATISFIED	___ QUESTIONNAIRE B
	___ MODERATELY SATISFIED	___
	___ SOMEWHAT SATISFIED	___
	___ SOMEWHAT UNSATISFIED	___
	___ MODERATELY UNSATISFIED	___
	___ VERY UNSATISFIED	___

COMMENTS:

2. To what extent did you find the questions to be free of uncommon words and technical terms?
3. To what extent was the wording to the questions simple and clear?
4. To what extent were you sufficiently informed to give a sensible answer?
5. To what extent did the questions put too much strain on your memory?
6. To what extent were the questions surrounded by many qualifications for which you needed additional information?
7. To what extent did the questions stay within your realm of feelings.
8. To what extent did the questions stay within your realm of experience?
9. To what extent did you find the format of the questionnaire to be free from confusion.
10. To what extent do you think the questionnaire measured social support?

Appendix 2

COMPARATIVE ANALYSIS OF TWO SOCIAL SUPPORT QUESTIONNAIRES

INSTRUCTIONS: The following questions ask your opinion of the two social support questionnaires you have just completed - Questionnaire A and Questionnaire B. After each question, please rate each questionnaire on the scale provided by placing an 'X' on the appropriate line. For the second part, please add any comments you may have with regard to the question.

1. The questions were straightforward.

QUESTIONNAIRE A	___ STRONGLY AGREE	___ QUESTIONNAIRE B
	___ MODERATELY AGREE	___
	___ SOMEWHAT AGREE	___
	___ SOMEWHAT DISAGREE	___
	___ MODERATELY DISAGREE	___
	___ VERY STRONGLY DISAGREE	___

COMMENTS:**2. The questions were free of uncommon words and technical terms.**

QUESTIONNAIRE A	___ STRONGLY AGREE	___ QUESTIONNAIRE B
	___ MODERATELY AGREE	___
	___ SOMEWHAT AGREE	___
	___ SOMEWHAT DISAGREE	___
	___ MODERATELY DISAGREE	___
	___ VERY STRONGLY DISAGREE	___

COMMENTS:**3. The wording to the questions was simple and clear.**

QUESTIONNAIRE A	___ STRONGLY AGREE	___ QUESTIONNAIRE B
	___ MODERATELY AGREE	___
	___ SOMEWHAT AGREE	___
	___ SOMEWHAT DISAGREE	___
	___ MODERATELY DISAGREE	___
	___ VERY STRONGLY DISAGREE	___

COMMENTS:

4. The questions provided sufficient information for me to give a sensible answer.

QUESTIONNAIRE A	<input type="checkbox"/> STRONGLY AGREE	<input type="checkbox"/> QUESTIONNAIRE B
	<input type="checkbox"/> MODERATELY AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> MODERATELY DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> VERY STRONGLY DISAGREE	<input type="checkbox"/>

COMMENTS:

5. The questions had answers which allowed me to respond the way I wanted to.

QUESTIONNAIRE A	<input type="checkbox"/> STRONGLY AGREE	<input type="checkbox"/> QUESTIONNAIRE B
	<input type="checkbox"/> MODERATELY AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> MODERATELY DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> VERY STRONGLY DISAGREE	<input type="checkbox"/>

COMMENTS:

6. The questions did not put too much strain on my memory.

QUESTIONNAIRE A	<input type="checkbox"/> STRONGLY AGREE	<input type="checkbox"/> QUESTIONNAIRE B
	<input type="checkbox"/> MODERATELY AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> MODERATELY DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> VERY STRONGLY DISAGREE	<input type="checkbox"/>

COMMENTS:

7. The questions were relevant to my life experiences.

QUESTIONNAIRE A	<input type="checkbox"/> STRONGLY AGREE	<input type="checkbox"/> QUESTIONNAIRE B
	<input type="checkbox"/> MODERATELY AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT AGREE	<input type="checkbox"/>
	<input type="checkbox"/> SOMEWHAT DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> MODERATELY DISAGREE	<input type="checkbox"/>
	<input type="checkbox"/> VERY STRONGLY DISAGREE	<input type="checkbox"/>

COMMENTS:

8. After I read the instructions, the questions were easy to complete.

QUESTIONNAIRE A				QUESTIONNAIRE B
	___	STRONGLY AGREE		___
	___	MODERATELY AGREE		___
	___	SOMEWHAT AGREE		___
	___	SOMEWHAT DISAGREE		___
	___	MODERATELY DISAGREE		___
	___	VERY STRONGLY DISAGREE		___

COMMENTS:

9. The questionnaire is a good way of measuring social support.

QUESTIONNAIRE A				QUESTIONNAIRE B
	___	STRONGLY AGREE		___
	___	MODERATELY AGREE		___
	___	SOMEWHAT AGREE		___
	___	SOMEWHAT DISAGREE		___
	___	MODERATELY DISAGREE		___
	___	VERY STRONGLY DISAGREE		___

COMMENTS:

THANK YOU FOR YOUR PARTICIPATION

APPENDIX D

Summary of Interview Locations and Dates

SUBJECT	LOCATION	ARTHRITIS	DATE OF PRE- TESTING	DATE OF POST- TESTING
01	OWN APARTMENT	OSTEOARTHRITIS	MAY 12	SEPT. 12
02	OWN APARTMENT	RHEUMATOID ARTHRITIS	MAY 21	SEPT. 24
03	LONG TERM CARE FACILITY	?	MAY 12	SEPT. 12
04	OWN HOUSE	?	MAY 12	SEPT. 15
05	OWN APARTMENT	OSTEOARTHRITIS LUPUS	MAY 13	SEPT. 18
06	OWN APARTMENT	RHEUMATOID ARTHRITIS	MAY 14	SEPT. 19
07	LONG TERM CARE FACILITY	OSTEOARTHRITIS	MAY 17	----
08	LONG TERM CARE FACILITY	?	MAY 12	----
09	LONG TERM CARE FACILITY	?	MAY 18	----
10	OWN APARTMENT	?	MAY 21	----
11	LONG TERM CARE FACILITY	?	MAY 18	SEPT. 12

APPENDIX E

STRUCTURED INTERVIEW
WITH SUBJECT 02

Date of Interview: September 24, 1990

Interviewer: Greg Taylor

Question #1: So, you've got arthritis and a lot of pain. How does it affect you, in your own words?

Well, right now my arthritis is very good. But I have arthritis in the eyes and this is a real difficulty. It really restricts me in what I do, but painwise, this past month, I've been pretty good.

Yeah, that's what you were saying when we were doing the questionnaire - that over the past month or so your arthritis hasn't been severe at all.

No, it's been excellent. Just excellent.

Question #2: Since you've been talking to Mary, have you noticed any difference in your arthritis? Any change at all?

No, I would say it's been really under control for several months now.

O.K. Even back to when I first interviewed you?

I would say, yeah.

That's about four months ago, now.

Yes, the arthritis has been just fine all along, and that's with - you know that's with medication - it's under control very, very well.

And you're taking the medication every day?

Yes.

Question #3: Why did you agree to be called?

Well, I get so little - so few phone calls and so few visitors - I thought well this is just another contact with the outside world and somebody to share, to learn, and I was all for it, just to be able to talk to somebody different.

O.K. Did you have any expectations about the relationship?

No.

You didn't really know what to expect?

I didn't - I just thought well, whoever it is - if we get along fine, great, there are some people maybe I would have thought that you couldn't communicate as well with, but with Mary we just communicate so, so well - you'd think we'd been friends all our life.

Question #4: Great. Well, lets talk about Mary? What do you think of her?

Oh, I just think she's great. I really enjoy her conversations. We laugh a lot, and you know we can talk about our little problems, but it's not in a down sort of way. It's an uplifting conversation with her. You feel good after you've had a conversation.

Question #5: O.K. Can we say Mary and you are similar in any ways? You both have arthritis, is there anything else that your similar...?

Well, I presume we're about the same age, more or less. And we talk about happenings and past experiences and we both just seem to have the same likes and dislikes.

Question #6: Do you like getting calls from her?

Very much so. Yes, I look forward to her calls.

She calls once a week?

Yes.

Question #7: Why do you like her calls? Have you found it helpful?

Yes, I find her calls very helpful and in another way because she is very involved with the Arthritis Centre and she's told me about different programs going on that I didn't know anything about. So, with her knowledge and that, I find it very interesting, you know, hearing about these things at the Arthritis Centre as well as our personal things that we seem to share. We seem to have so many similarities. We seem to have so many similar likes and dislikes, you know, even the books that we read, well - I listen to, but she still reads, and it just, as I say, as if we've been friends for years.

Sounds like she's helpful in you're saying she's a source of information for you about arthritis, secondly it sounds like she's a good source of emotional support for you.

Oh, she is.

Is there any ways that you think she's been helpful?

It's, well, I like her because she's been just a very uplifting type of person to begin with. Some people are more or less down all the time even when they're feeling well. I know one lady that I don't phone her any more because she's always down, but yet, and that's her - the way she is all the time.

You were telling me about her last time.

That's another problem. But with Mary, you look forward to her conversations because you know you're going to have a few laughs and you feel good about her conversations. You enjoy them

So on the Friday when she calls you're looking forward to when you wake up in the morning.

Oh, yes, absolutely.

How do you feel afterwards? After you get off the phone? Do you feel quite good?

Oh yes.

Question #8: What is the one thing you like best about being called by Mary?

One thing I like best? Oh, I don't know how I'd put that. I just enjoy her.... oh, being an uplifting person. She's not a down sort of person. She's always up. And I know that she has her problems too, but when she phones me it just gives you a happy feeling.

Do you get good ideas about how to cope with arthritis, or other...

We try not to talk - we don't talk too much about arthritis. You know, we might say how are you doing today and we'll tell each other and that's over and done with and we go on to talking about - like today when I was talking to her, I mentioned a year ago today I was on a cruise ship. I wish I was there right now and that took up the rest of the conversation because she wants to go on a cruise and doesn't know what it's like and I told her about some of the things that happened on the ship and we had a

good, nice conversation. It was a happy conversation.

That sounds like you're both benefiting from the conversations. You know, it's not just her calling you up to see how you're doing. You're also giving something back.

It goes both ways.

Kind of reciprocal.

Yeah, neither one of us dominates the conversation - each one of us gives something to the other.

Well, that must feel good too.

It does. Compared to this one lady that - I don't know how to deal with her. I don't want to talk about that right now.

Question #9: Is there anything you don't like about the calls, Mary, the program?

No.

Anything that you think we can improve on, or make better?

No, I don't think so. I mentioned to her one day about the magazine here. I think this magazine is just an excellent one. But I said, you know, because it's on shiny paper and blue print, I can't read it. I think the complaint went in from somebody else, too, and now I look at this one and this is all in black print now. I don't think it's as shiny a paper, and I can, with the help of my magnifying glass I can see this, but when it was in blue and on shiny paper with my eyes the way they were, I couldn't even begin to see.

That's fantastic, because a lot of people are affected by...

Oh, a lot of people have dry eyes let alone other problems. With dry eyes, you can't read very good, either. Because every time you blink you see differently. But now that they've got the black and just these titles in blue, that's fine. The message has got across somewhere.

Question #10: What does your family or friends think about this program?

The phone program?

Yeah, have you talked to them about it?

Oh, I don't think my two boys are even aware of it, but my husband thinks it's great.

What sort of comments has he made about it? Or does he -

He just leaves it - well, that's your phone calls and.... I 'don't even think I've told the boys about this. They're so busy with their own children and that, that I haven't even thought about mentioning it to them.

O.K. Well, I've been asking you a lot of questions in the past hour or so. Do you have any questions for me or any other comments about the program, that you'd like to tell me about?

No, I don't think so. I think we've covered just about everything. I know I feel the Arthritis Centre to me is - oh, I don't know what I would do without it. Because I feel that if I had any problems of any kind, emotional, or what, there's somebody there that can help me. And just knowing that the Centre is there - you know, that's an awful lot of peace of

mind to begin with - knowing that you can phone there anytime and get help, whether it's a nurse, a doctor, or whatever, or social services.

Was it easier to accept, or to get involved with this telephone contact program knowing that it was through the Arthritis Centre? Did that give it some sort of credibility.

Yes. It did because I know the Arthritis Centre would never put out a program it didn't think would work or would be to your disadvantage. I think everything there at the Arthritis does - they're trying to help the patients.

When you heard about this program, did it strike you as a good idea, or something worth trying out?

Something worth trying out - a good idea. Particularly for people that are shut in because I have found I used to have a lot of friends, I like people, and I used to be out in the community, but when you are all of a sudden in the house and gradually get more and more homebound, your friends, you lose track of them, and they lead very busy lives and you can't keep up to them so gradually, little by little you lose all contact with your friends that you've had in the past and I could name all my friends on one hand, you know they've dwindled down so few, and yet, - my husband meets them and they always ask how I am but I never see them or there's never phone calls or anything so after a while you feel isolated and ...

With that isolation, did you feel that your ability to converse with others might have been a problem if you had left it alone long enough?

After a while you get to the point where

you just can't phone them. The longer you put off making the phone calls, the harder it is. Because there are some people I would like to phone but I hesitate because it's just hard to - when they go and - I don't know anything about what's going on much in the outside world any more, so how can you carry on a conversation. My life is all going to see people wearing white coats. So, I'm involved with the medical - just trying to survive from one week to the next and you miss your friends. You wish you could have them. I'd like to have them in for a nice dinner, but it's too much. I had a friend in yesterday but by the time she left, I was worn out, and she's a real close friend, but I guess it's just after all this - past surgery, you know... Because I used to be a real people person. I still am a people person, but it's getting harder and harder to even think about going out to the outside world. It's much easier to stay home. And that's not good, but there's so many things to cope with trying to keep your eyes and everything... I get discouraged, and I escape with my books. But even that, you get bored with a book after a while.

Who do you think would benefit most from telephone contact programs like this one? People in similar situations to yourself who are gradually becoming a bit more housebound?

Oh, I think that people who are housebound should benefit a lot. I gave the name to Mary of a friend of mine in North Vancouver that she's all alone and she lives in a great big house and she's pretty well housebound except for medical appointments so I know she's got a phone contact now, but I haven't talked to her just lately, so I don't know how she's responding to it. But when I asked her

if she would be willing for me to give her name she was all for it. And when I have talked to her since, I keep forgetting to ask her, you know, like how she's making out with her phone calls. But I know at the time she was all for it.

Oh, that's good. It's just nice to hear that you're recommending it to friends, because I guess that's how the program will expand - by word of mouth.

It will. By word of mouth. You know, I enjoyed Mary so much right from the very first phone call, I thought oh, gee, this is what Sophie should have. She has very few friends, she's all alone in this house, and so I approached her and she said oh, yes, she'd like it. So, I would imagine she'll benefit as long as the two of them are sort of compatible.

Right. That's I guess the trick.

That's the trick is to get a compatible... Sophie has been a concert pianist in the past as well as a teacher and she had to give up ... because of arthritis. But I think because she has given up piano because her hands were so bad - I think that's been a real problem for her. So if she ever got a telephone contact that was interested in music too, it would just be that much better for her.

So I guess having a caller with similar interest is above all the most important, did you say?

I think it would go a long way in establishing a good relationship. And I told Mary that Sophie had been a concert pianist and was very involved at one time with music so whether she found somebody with similar interests, I don't know.

But I know Mary told me they had found a telephone person for her. So I must phone so I can see how she's responding, but I know she was very, very much in favour of it.

APPENDIX F**Letters of Study Approval
from Ethics Committees**