

THE UNIVERSITY OF MANITOBA

AN EVALUATION OF THE EFFECTIVENESS OF A
SUPPORT GROUP FOR CAREGIVERS OF ALZHEIMER PATIENTS
LIVING IN A NON-INSTITUTIONAL SETTING

by Esther Gill

A PRACTICUM REPORT
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
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FOR THE DEGREE OF MASTERS OF SOCIAL WORK

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DEDICATION

This practicum study is dedicated to the memory of my dear parents, Jacob and Dora Gill, whose example of strength and ability to overcome overwhelming odds sustain and encourage me.

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ABSTRACT

Alzheimer Disease is the most common cause of irreversible dementia in persons aged 45 to 65 years and accounts for over 20% of persons aged over 80 who suffer from cognitive impairment. Contrary to popular belief, most Alzheimer victims are cared for in the community and are placed in an institution only as a last resort. There are significant costs to the families who provide care: chronic fatigue, high stress levels, depression and social isolation, to name a few. As there is at present no medical intervention which can cure or reverse the process of the disease, one of the primary interventions which has been used to date is that of family support groups. In reviewing the literature on Alzheimer Family Support Groups, many perceived benefits are reported. However, evaluative measurements are often not employed and subjective reports attest to the benefits of the group. This practicum was undertaken to assess this method of intervention, using measurements in the areas of education, depression, stress management and support in an attempt to objectively measure the intervention. Caregivers of non-institutionalized Alzheimer patients took part in this study. The measurements were administered at three points pre-group, post-group and at seven week follow-up in order to determine whether any changes occurred following the intervention and whether there were any carry-over effects. Group members rated the experience positively and there

were improvements noted in knowledge levels and depression scores, and the group members rated the stress management techniques as helpful. This study clarified the benefit of support groups as a method of intervention with the caregiving populations.

INTRODUCTION

This practicum was undertaken in an attempt to determine the effectiveness of an Alzheimer support group in reducing caregivers' levels of stress and depression. The focus of this study was to determine whether an educational and supportive group could contribute to a reduction of the participants' stress levels and a decrease in their depression scores.

The student has utilized an educational and supportive group model with caregivers, who were providing the major caregiving to victims who were still residing at home, and who have Alzheimer Disease (or other related cognitive disorders¹). The intent of the practicum was to determine whether Alzheimer support groups were effective in helping caregivers cope with their responsibilities. The practicum also focused on the question of whether these groups assist the caregivers with their emotional and psychological acceptance of and adaptation to their situations.

This practicum entailed collaboration with the Manitoba Alzheimer Society, and others such as social workers and physicians who acted as referral agents.

¹As diagnosis is at present made only by ruling out all other possible causes of cognitive impairment, and can only be verified by autopsy, for the purposes of this practicum cognitive disorders will be referred to as Alzheimer Disease, cognitive impairment and dementia (Cohen and Eisdorfer, 1986; Reisberg, 1981; U.S. Congress, 1987; Tanner and Shaw, 1985).

RATIONALE

Alzheimer Disease is the most common cause of irreversible dementia in persons aged 45 to 65 years (Ware and Carper, 1982; Zarit, 1986). It is considered to be responsible for 50% to 70% of all cases of dementia (Resiberg, 1981; Tanner and Shaw, 1985; U.S. Congress, 1987). Somewhere between 100,000 and 300,000 persons in Canada may be affected to varying degrees by this disease, with roughly 15,000 Manitobans being impaired (Figures obtained from National Alzheimer's Society of Canada).

Contrary to popular belief, most Alzheimer victims are cared for in the community and are placed in an institution only as a last resort (Cohen and Eisdorfer, 1988).

Caregivers are faced with many difficulties and challenges in their roles. Barnes et al. (1981) identified the following problems of families caring for a cognitively impaired relative: 1) lack of information about the disease and the behavioral changes resulting from it; 2) denial that the disease has impaired their relative; 3) the demands of providing care; 4) isolation from friends; and, 5) embarrassment in public due to the actions and behaviors of the impaired person.

Further to this, Rabins et al. (1982) found that 87% of the caregivers in a sample of 55 families reported chronic fatigue, anger and depression. Half of the sample also listed the following

as difficult problems: loss of friends and the support of relatives, loss of social activities, and family conflict.

There are many conflicting demands placed on the caregiver. There may also be significant role changes required. The caregiver may be forced to perform roles for which he or she has had little preparation. Caregivers, who may be overwhelmed by the task of caring for their afflicted relative may neglect their own needs. They may be coping with emotional and physical stresses and receiving no support.

As there is at present no medical intervention which can cure or reverse the process of Alzheimer Disease, one of the primary interventions which has been used to date is that of family support groups. Perhaps more than any other disease, Alzheimer Disease has an impact on the family.

In reviewing the literature on Alzheimer Family Support Groups, many perceived benefits are reported. Some of these are: shared feelings; a reduced sense of isolation; increased knowledge of the disease process; increased understanding of the impaired person's behavioral and personality changes; and increased awareness of available community resources (Zarit and Zarit, 1982; Davis et al., 1986; Aronson et al., 1984; Barnes et al., 1981). As well, group members provide a variety of perspectives which enables others in the group to re-examine their own motivations and expectations.

Therefore, as support groups are a major intervention with this population, this study was undertaken to answer the following questions: Does increased knowledge and understanding of the disease assist caregivers to cope with the behavioural changes of the Alzheimer victim? Can group participants' levels of stress be reduced with stress management techniques? Does increased knowledge and understanding lead to a greater sense of control over the situation, thus reducing the level of depression?

Other questions also arise, although they will not be answered by this study. They include the following: To what degree does one's support have an impact on one's adaptation to the caregiver role? How much of the anticipated benefit of group participation can be attributed to the creation of a new social network? Can one's cognitive appraisal of the situation be changed through group intervention?

Definitions

The following definitions are provided as they are used in this practicum:

ALZHEIMER DISEASE:

A degenerative process in the brain which produces intellectual impairment (Gwyther and Matteson, 1983). It is a lethal, progressive disease which leads to loss or impairment of mental abilities, confusion, memory loss and disorientation (Ware

and Carper, 1982). It also leads to behavior and personality changes (Chenoweth and Spencer, 1986). It is marked by the appearance of abnormal structures peculiar to this disease such as senile plaques, neurofibrillary tangles and granuvascular structures (Zarit and Zarit, 1982).

SUPPORT GROUPS:

Levy defines support groups as being "composed of members who share a common status or predicament that entails some degree of stress, and the aim of these groups is generally the amelioration of this stress through mutual support and the sharing of coping strategies and advice"² (Levy, 1979).

STRESS:

"The sum of the biological reactions to any adverse stimulus, physical, mental or emotional, internal or external, that tends to disturb the organism's homeostasis; should these compensating reactions be inadequate or inappropriate, they may lead to disorders. The term is also used to refer to the stimuli that elicit the reactions"³ (Doreland's Illustrated Medical Dictionary, 1988).

²Levy, L. H. (1979). Process and activities in groups. In M. A. Lieberman, L. D. Borman and Associates (Eds.), Self-help groups for coping with crisis, pg. 236. Jossey-Bass Inc., Publishers.

³Dorland's Illustrated Medical Dictionary (1988), 27th Edition. W. B. Saunders Company, Harcourt Brace Jovanovich Inc., West Washington Square, Philadelphia, P.A. (pg. 1593).

Caregiver stress is viewed as a consequence of a process comprising a number of interrelated conditions, including the socio-economic characteristics and resources of caregivers and the primary and secondary stressors are hardships and problems anchored directly in caregiving. Secondary stressors fall into two categories: the strains experienced in roles and activities outside of caregiving, and intrapsychic strains, involving the diminishment of self-concepts. Coping and social support can potentially intervene at multiple points along the stress process (Pearlin et al., 1990).

DEPRESSION:

"A mental state of depressed mood characterized by feelings of sadness, despair and discouragement. Depression ranges from normal feelings of the "blues" through dysthymia to major depression ... there are often feelings of low self-esteem, guilt, and self-reproach, withdrawal from interpersonal contact, and somatic symptoms such as eating and sleep disturbances"⁴ (Dorland's Illustrated Medical Dictionary, 1988).

The definitions being provided for the Educational Component and for the Facilitator are specific to the purposes of this

⁴Dorland's Illustrated Medical Dictionary (1988)., 27th Edition. W. B. Saunders Company, Harcourt Brace Jovanovich Inc., West Washington Square, Philadelphia, P.A. (pg. 449).

practicum. These definitions are intended to describe those aspects and qualifications which are desirable for this particular program.

EDUCATIONAL COMPONENT:

The part of the program of the support group which imparts an understanding of the disease, its progression, its effect on behavior, the incidence of the disease, recent research, the effect on caregivers, legal implications, community resources and information on the nature of stress.

FACILITATOR:

The facilitator is the initiator of the group, who is responsible for recruitment of group members and the practical considerations such as locating a meeting room, advertising, etc. The facilitator also provides structure and norms for the group and assists with mutual problem-solving. The facilitator has a working knowledge of group dynamics. The facilitator also has an understanding of Alzheimer Disease, its effects upon the patient and the family and the community resources which are available.

OBJECTIVES:

The student's practicum objectives were:

1. To determine the effectiveness of an educational and support group in reducing levels of depression and stress for caregivers of non-institutionalized Alzheimer victims.

2. To evaluate this educational and support group using measurements of knowledge, stress, depression and support.

3. To increase the student's knowledge of the major concerns and issues affecting caregivers of Alzheimer victims.

4. To gain greater insight into and an understanding of the coping and adjustment styles of these caregivers.

5. To enhance the student's skills as a group facilitator so that my intervention with Alzheimer caregivers will improve.

6. To develop an educational package, which could be utilized by Alzheimer support groups. The goal of this package would be to enhance and increase knowledge of the disease and of the resources available for caregivers.

7. To make this educational package available to other support groups and Alzheimer Society Chapters throughout Canada.

ORGANIZATION OF PRACTICUM

This practicum report has been organized in the following order:

- a) Review of the literature pertinent to Alzheimer Disease, caregiving issues and support group work concepts,
- b) Theoretical framework of support group work,
- c) Methodology utilized in this study,
- d) Evaluation procedures,
- e) Description of caregivers,

- f) Results of the study,
- g) Personal learning, and,
- h) Limitations and conclusions.

CHAPTER 1

LITERATURE REVIEW

The literature review will be divided into two parts. The first portion will include a review of the literature as it pertains to Alzheimer Disease and its effect upon the victim and the caregiver. The second part will be a review of support group work concepts and previous evaluations of this method of intervention.

PART ONE

ALZHEIMER DISEASE:

Alzheimer Disease is a degenerative process in the brain which produces intellectual impairment (Gwyther and Matteson, 1983; Nathan, 1986; Ware and Carper, 1982; Simank and Strickland, 1986; Pratt et al., 1985; Zarit and Zarit, 1982). It was first discovered in 1907, by Dr. Alois Alzheimer (Nathan, 1986). It is marked by the appearance of abnormal structures in the brain peculiar to this disease, senile plaques, neurofibrillary tangles and granuovascular degeneration (Nathan, 1986; Zarit and Zarit, 1982). It is a lethal, progressive disease which leads to loss or impairment of mental abilities, confusion, memory loss and disorientation (Ware and Cooper, 1982; Nathan, 1982; Pratt et al., 1986; Chenoweth and Spencer, 1986). Behavioral changes are also common (Chenoweth and Spencer, 1986; Ware and Carper, 1982; Zarit and Zarit, 1982).

DIAGNOSIS:

The symptoms of Alzheimer Disease are the same as those of dementia (Cohen and Eisdorfer, 1986; U.S. Congress, 1987). The term dementia refers to a group of syndromes characterized by loss or impairment of intellectual capabilities as a result of chronic progressive degenerative diseases of the brain (Pratt et al., 1986; Cohen and Eisdorfer, 1986). Dementia consists of four major elements:

- a. Loss of intellectual abilities to such an extent as to interfere with social and/or occupational functioning.
- b. Impairment of memory.
- c. Impairment of judgment, loss of spontaneity and impairment of abstract thinking.
- d. Lack of the presence of clear consciousness (DSM-III).

The most common type of senile dementia is Alzheimer Disease. In the U.S., it accounts for approximately 60% of dementia cases (Zarit and Zarit, 1982; Tanner and Shaw, 1985; U.S. Congress, 1987).

A diagnosis of Alzheimer Disease is made by a process of elimination, as there are no specific tests which determine the presence of the disease while the patient is still alive. Confirmation of the disease is made through a brain biopsy at the time of autopsy (Cohen and Eisdorfer, 1986; Zarit, Orr and Zarit, 1985). As there are reversible causes of dementia, a thorough

examination to rule out the possibility that the disease process can be reversed is essential. Some of these treatable conditions include depression, drug interactions, toxins, infections and vitamin deficiency (Pratt et al., 1986).

As diagnosis is at present made only by ruling out all other possible causes of cognitive impairment and can only be verified with an autopsy, and as the impact upon the caregiver is essentially similar whether the impaired relative has Alzheimer Disease or another irreversible cognitive impairment, a diagnosis of Alzheimer Disease or some other related cognitive disorder in the victim will be the criterion for inclusion of caregivers into the group being studied.

INCIDENCE:

Alzheimer Disease does not discriminate among social, racial and economic backgrounds, and is equally prevalent regardless of intellect. It affects a significant proportion of the aged population, and becomes increasingly prevalent with advancing age. It is the most common cause of dementia in persons aged 45 to 65 years (Ware and Carper, 1982). It occurs in 2 to 3% of the general population over the age of 60, and in 20 to 30% of people over the age of 80 (Gwyther and Matteson, 1983; Simank and Strickland, 1986). As our population is demographically aging in both Canada and the United States, and as the greatest increase in the population is

occurring in the over-75 age bracket, there will be substantially more individuals with this illness in the next century, unless a cure can be found (Schneck, Reisberg and Ferris, 1982).

Somewhere between 100,000 and 300,000 Canadians may be affected by this disease to varying degrees, with roughly 15,000 Manitobans suffering from it (Alzheimer Society of Canada, 1988). It is the 3rd most common cause of death in Canada, with an estimated 10,000 deaths per year resulting from this disease.

It is further estimated that for every patient with Alzheimer Disease residing in an institution, there are five persons being cared for at home (Figures obtained through the National Alzheimer Society of Canada).

STAGES OF THE DISEASE:

EARLY STAGE

(APPROXIMATELY 2 TO 4 YEARS)

IMPAIRED MEMORY - cannot remember recent events; inability to learn new things; loss of short-term memory, disoriented to time and place on occasion; some difficulty communicating.

IMPAIRED JUDGMENT - difficulty making decisions; unable to cope with anything new; spatial disorientation and loss of sense of direction.

BEHAVIOR CHANGES - outbursts of temper; depression; flat personality characterized by loss of range of emotions and a loss of sense of

humour; irritability and agitation; loss of interest in personal hygiene and appearance.

MIDDLE STAGE

(MAY CONTINUE FOR SEVERAL YEARS)

PROGRESSIVE MEMORY LOSS - may forget who they are; lose ability to recognize the significance of what is seen, heard, touched; unable to understand, write and use language; disoriented to time and place.

BEHAVIOR CHANGES - repetitive movements such as tapping, lip-licking, chewing; increased or decreased interest in food; day/night reversal; inability to look after personal hygiene and dress; incontinence; aggressive behavior.

TERMINAL STAGE

(USUALLY NO LONGER THAN ONE YEAR)

EMACIATED; COMPLETE LOSS OF COMMUNICATION; INCONTINENCE (both of bowel and bladder); DETERIORATED PHYSICAL HEALTH - small seizures; prone to pneumonia and bed sores; reappearance of such primitive reflexes as sucking of thumb and lying in a fetal position; progressive deterioration in motor abilities and interest.

Each Alzheimer victim varies in terms of whether, when and how severely they are affected by any particular symptom (U.S. Congress, 1987; Zarit, Orr and Zarit, 1985). It must be kept in mind that any division into stages is difficult, as it is not possible to

determine at what particular point a patient might progress from one stage to the next. Rather, the decision to categorize a particular patient in a particular stage is somewhat arbitrary, as their memory, judgment or behavior may fluctuate and no clear distinctions can be made. The delineation into stages is a general listing which serves only as a guideline.

The average length of this illness is 7 to 10 years, but this can vary from as short as 2 years to as long as 25 years (Tanner and Shaw, 1985; U.S. Congress, 1987).

Many families first notice memory problems such as forgetfulness, but choose to ignore these first signs and dismiss them as a natural part of aging. Therefore, when queried, families have a great deal of difficulty determining when the first signs of the illness appeared.

CAREGIVERS:

Caring for the cognitively impaired person causes more problems and strains than caring for the physically infirm elderly (Grad and Sainsbury, , 1965; Isaacs et al., 1972). Because of the impaired person's severe cognitive, personality and behavioral deterioration, it is likely that Alzheimer caregivers experience unique stressors (Haley et al., 1987). Zarit and Zarit (1982) report that caregiving for a cognitively impaired person can become a bewildering and overwhelming experience.

Yet, 80 to 90% of all dependent elderly are cared for by their families (U.S. Congress, 1987), and a significant proportion of these dependent elderly are cognitively impaired. Families provide care in such areas as personal care, help with household tasks, transportation and shopping. Additionally, it is usually a family member who will sort out the formal support system, and who is available to deal with crises. Not only are family available to assist with practical tasks, they also provide the elderly with emotional support (Brody, 1985).

Horowitz (1985) reported that the primary caregiver will generally be a spouse if there is one available and able. Spousal caregivers, who are usually themselves aged and have health problems, are especially at risk (Hess and Soldo, 1985). Johnson (1983) found that when the spouse is the primary caregiver, rather than an adult child, the patient is less likely to be institutionalized. If there is no adult child available, the impaired person is even more likely to be institutionalized (Matthews and Rosner, 1988).

The majority of caregiving is provided by women, firstly wives, and when they are unable or unavailable, secondarily daughters (Malonebeach and Zarit, 1991). Even when spouses are providing care, they are likely to be assisted in their tasks by their daughters (Stone, Caffereta and Sangl, 1987). Sometimes, when

an adult daughter is not available, it is the daughter-in-law who will provide the care (Brody, 1985). Killeen (1989) makes this point clearly by stating, "the term caregiving is today's euphemism for an unpaid female relative".

Sons do provide care, but this is more in the realm of financial support and decision-making (Bahr, 1979; Stoller, 1983). In fact, though, daughters provide four times as much care as do sons (Brody, 1990).

EFFECTS OF CAREGIVING:

Caregiving for a cognitively impaired person creates a great many demands on the caregiver and entails both physical and emotional adjustments. Exploratory studies reveal that a significant proportion of caregivers are spending more than 40 hours per week in direct personal care (Robins and Mace, 1981). In a study that focused specifically upon family caregiving to demented patients, 87% of caregivers cited chronic fatigue, anger or depression as a problem (Robins et al., 1982).

Families may have to learn to cope with the loss of a job, either on the part of the Alzheimer victim or the primary caregiver, and the resulting strains of a decreased income, loss of benefits and shattered dreams.

Significant role changes are another factor which caregivers must learn to cope with. Pruchno and Resch (1989) report that older

women, looking to their later years as a time for more personal opportunity and growth, may resent becoming caregivers to their husbands (Steinberg and Shulman, 1981). Although these elderly wives may have fewer roles to perform than the younger spouse, this situation may in itself isolate them, contributing to feelings of stress and depression (Given et al., 1988). While dependency of the impaired husband is found to be most upsetting to wives, husbands caring for their impaired wives report having more problems assuming household responsibilities (Zarit, Todd and Zarit, 1986). Having to learn new roles and responsibilities at a time when one is already overburdened and challenged creates additional stress and strain on the caregiver. Barnes et al. (1981) note that new roles are often adopted with reluctance and feelings of inadequacy. Not only does the spouse have to take over household and financial management, but also has to make all of the major decisions.

In terms of spousal caregiving, sexual needs of both the caregiver and the carereceiver are another often-neglected area of concern. Sexuality is rarely discussed, but the patient with dementia may lack sexual interest, be emotionally insensitive to their spouse's needs or may make incessant, inappropriate demands. Barnes et al. (1981) reported that affectional and sexual needs of the caregiver go unsatisfied. Affection becomes very much

one-sided, only going from the caregiver to the carereceiver (Pearlin et al., 1990).

For the adult daughters providing care, the majority are in the 45 to 54 year old age group, and 60% of these women are employed outside of the home (Brody, 1981). These middle-aged females are faced with a number of competing demands for their time. They have the major responsibility in the family for the emotional support of other family members, have primary responsibility for household management tasks and childrearing (Horowitz, 1985). These competing demands for time and attention can create a number of stresses for these female caregivers, which in turn may lead to signs of mental and physical dysfunction (Kiecolt-Glaser et al., 1987; Zarit, Reever, and Bach-Peterson, 1980). As well, with increasing numbers of women returning to the workforce, yet another demand is placed upon these female caregivers. However, Brody (1985) reported that roughly equal amounts of care were provided by working and non-working women to their parent.

Other significant differences exist between the way caregiving is perceived by the sons and daughters who provide for their elderly parent(s). Sons generally report that they face no problems in providing care, that they are less likely to feel that they have had to give anything up due to their caregiving responsibilities or to feel that they had to neglect other family responsibilities. These

sons also reported less interruption in their leisure activities, that there was no change in their emotional state or that their plans for the future had not been affected in a negative way. Daughters reported being significantly more affected in all of these ways (Horowitz, 1985).

Another stressful situation may develop amongst siblings, particularly when one is responsible for the primary caregiving. Brody, in her 1989 report, found that 45 to 60% of primary caregivers felt that they did not receive as much support as they should from their siblings, while these siblings reported not feeling appreciated for the help that they did provide.

However, when siblings felt close and valued each other's contributions to caregiving, more satisfaction was derived from sharing their common burden (Lerner et al., 1991).

Caregivers have frequently reported feeling isolated from families and friends and from such previous activities as community-based hobbies and interests (Barnes et al., 1981; Chenoweth and Spencer, 1986; Morycz, 1985; Scott et al., 1986). As the disease progresses, the caregiver's free time becomes increasingly limited, as all of their resources are required for the caregiving role. Little or no time is left to meet personal needs, and shared activities decrease (Aronson et al., 1984). Another

effect of these stresses and isolation may be abuse or neglect of the impaired person.

The caregiver's health status is also affected adversely by their caregiving responsibilities. Poulshock and Deimling (1984), state in their report that caregivers with lower levels of mental and physical well-being have difficulty responding to the caregiving demands. Caregivers' responsibilities, their need for rest and recreation and the extensive physical and emotional costs of providing care all impact upon the caregiver's health (Zarit, Anthony and Boutselis, 1987). In one study, it was found that there is no relationship between the caregiver's physical health and the amount of physical help received. There was, however, a relationship between amount of help received and the caregiver's mental health, with those receiving the least amount of support describing themselves as having less life satisfaction. (Clipp, Elizabeth and George, Lindak, 1990). Spouses, in particular, may be at greater risk because they are elderly and are likely to have diminished physical capacity for the demands of the caregiving tasks (Motenko, 1989).

STRESS OF CAREGIVING:

Stress, as defined by Lazarus (1985) "refers to any event in which environmental demands, internal demands or both tax or exceed

the adaptive resources of an individual, social system or tissue system" (Monat and Lazarus, 1985, p. 3).

Most caregivers of dementia victims experience a great deal of emotional stress throughout their relative's illness, but the stress varies and takes on different forms during different phases of the illness (Chenoweth and Spencer, 1986). Further, it is reported that caregivers can tolerate different types of stress, but what leads to a breakdown of the caregiving role are the particular stressors which are significant to a particular caregiver (Zarit, 1986). These stressors are defined as "the conditions, experiences, and activities that are problematic for people" (Pearlin et al., 1990, p. 586). Some of the stressors experienced by the caregiver to an Alzheimer patient are the cognitive status of the impaired person, their behavior, particularly if it is problematic, how dependent the impaired person is upon the caregiver, whether the caregiver feels overwhelmed or burnt out, and whether they have been deprived of interaction with their support system.

Marples (1986) conceptualized stress experienced by the caregiver in the following way:

1. Family disruption, which includes role changes, role overload, role ambiguities, family conflicts and sibling rivalries;
2. Psychological stresses, which include resentment or ambivalence of caregiving responsibilities, pain of watching a loved

one deteriorate, social isolation, and competing demands for time and energy; and,

3. Physical fatigue and caregiver's health, which includes dealing with day/night reversal, incontinence and providing physical assistance to the impaired person.

In a study by Daniels and Irwin (1989), it was reported that physical health measures did not differ significantly between caregivers and noncaregivers. However, in terms of mental health measures, caregivers reported less life satisfaction, reported significantly more stress related symptoms and used more psychotropic drugs than did a comparison non-caregiving group. This was also the finding of George and Gwyther's (1936) study of 570 caregivers to the cognitively impaired, who also reported more symptoms of stress and low life satisfaction.

Stress also results from the destruction of future plans and dreams. It is not Alzheimer Disease which necessarily causes distress in caregivers, but rather the disruption to their lifestyles and anticipations for their future (Mcetenko, 1989).

Many factors appear to impinge upon the degree of stress that the caregiver experiences. These may include the prior relationship with the carereceiver, the functional level or stage of the disease process the individual is at, the amount and type of care that is required, and the age of both the caregiver and carereceiver

(Bunting, 1989). Other factors may include the amount of disruption to the household, particularly for adult child caregivers and the amount of support received by the spouses of these adult children. Again, for the children, lack of privacy and freedom are major stressors (Newman, 1976).

Many studies have reported on the factors which play a significant role in reducing stress (Pearlin and Schooler, 1978; Morycz, 1985; Haley et al., 1987; Eagles et al., 1987; Zarit and Zarit, 1986; Wasow, 1986; and Motenko, 1989). Pearlin and Schooler (1978), suggest that one's attitude toward oneself, and the extent to which one perceives control over one's situation, can have an impact upon reducing the stressful consequences of strain for caregivers. Zarit (1989) suggests that the cognitive coping style of the caregiver may explain the variation in how distressing patient symptoms are to different caregivers. Thus, how the caregiver views their situation is a significant indication of how stressful they find their situation.

Morycz (1985) relates that social support has a significant impact upon caregiver stress levels, with less support implying more strain. Because of the increased need for support, caregivers to Alzheimer patients report more dissatisfaction with the adequacy of their support network. This was reported in a study which also included 44 matched controls who did not provide caregiving. These

controls were not caregivers of impaired persons, but were matched as much as possible for age, sex, race and marital status (Haley et al., 1987). Another study indicated that the amount of perceived support from family and friends is actually more significant than the actual amount of support received in determining whether the caregiver feels supported in their role (Gwen et al., 1988). Those caregivers who are suffering from poor health, severe demands of caregiving and who are stressed are more likely to perceive the support they receive as inadequate (Clipp and George, 1990).

Zarit (1986) reports that in larger households, caregivers of the cognitively impaired reported lower stress. Wasow (1986) also suggests that social and family supports play a role in coping with stress, with increased supports resulting in decreased stress.

Researchers generally agree that social support reduces the impact of stress on well-being (Arling, 1987; Cohen and Syme, 1985; Krause, 1987; Turner, 1981; Williams et al., 1981). A long-standing, meaningful marital relationship remains a critical social support for spousal caregivers. Therefore, it is the quality of the relationship pre-illness which is indicative of whether the spouse willingly provides care (Given et al., 1988). Caregivers who reported that their emotional relationship with the impaired person prior to the onset of the illness had not been close were significantly more stressed than those who had close or very close

relationships before the disease developed (Pratt, Schmall and Wright, 1986). If there are a number of unresolved issues and feelings of resentment or anger about past events, it is likely that the caregiver will feel more stressed (Keizer and Fiens, 1991).

Both Eagles et al. (1987) and Zarit and Zarit (1986) reported that the degree of stress felt related to the behavior of the impaired person. Stress experienced increased significantly when caregivers reported behavioral dysfunctions, but Zarit and Zarit also observed that the ability to tolerate problem behaviors actually increases as the disease progresses. This ability to adapt may be a result of becoming used to the behavioral changes over time.

Not only must attention be paid to the stressors that may result from caregiving, but attention must also be paid to the stressors which are impacting upon the caregiver in the other aspects of their life. It must be noted that the results of any study into this area cannot control the life events that are occurring outside of the caregiving situation.

Few studies exist on the effects of chronic stressors on elderly caregivers, particularly when the major stressor is the spouse's cognitive impairment (George and Gwyther, 1986).

Even though there is considerable attention given to how the stress experienced by caregivers can be relieved, there has been

little research to date on the effectiveness of clinical interventions in reducing stress levels (Zarit, Anthony and Boutsellis, 1987). In fact, we know relatively little about which aspects of caregiving are most stressful to the typical caregiver and whether these change during the course of the illness (Niederehe and Frugé, 1983). In reviewing the literature, it appears that there is still a great deal of confusion regarding the most effective intervention strategies for stress reduction.

DEPRESSION OF THE CAREGIVER:

Virtually all caregivers experience some level of depression (Poulshock and Deimling, 1984). In a study by Dura et al. (1990), it was reported that 30% of caregivers to the cognitively impaired experienced a depressive disorder while 1% of matched controls who were not providing care experienced a depressive disorder. It appears that it is actually the experience of caregiving that makes people vulnerable to depression, rather than a personal or family history of depression (Dura et al., 1990). Cohen and Eisdorfer (1988) reported that 55% of primary caregivers, usually spouses, experienced clinical depression. Caregivers often experience feelings of uselessness and helplessness at some point during the course of the disease. There may also be feelings of powerlessness experienced by spousal caregivers, leading to depressive symptoms (Cohen and Eisdorfer, 1988). This may lead to feelings of decreased

physical vitality, decreased stamina, loss of appetite, insomnia and withdrawal from usual activities (Teusink and Mahler, 1984; Zarit, 1986). Haley et al. (1987) found in their study that caregivers of those with dementia were more likely to report poorer health, more prescription medication use and higher usage of health care services when compared to a control group who were not providing care. Killeen (1989) stated in her report that length of time having provided care does not have a negative impact upon perceptions of health, but amount of care provided was significant when caregivers evaluated their health status. The more care provided, the less positively caregivers rated their own health. These are all classic symptoms of depression (Simank and Strickland, 1986).

Many factors have been noted to be the cause of the depressive symptomatology. The emotional strain of watching a relative's deterioration in cognitive status with resulting behavioral and personality changes, while the caregiver loses companionship and intimacy is a likely contributor to depressive symptoms (Mortiz et al., 1989). Loss of one's social network, or lack of perceived adequate support, has been noted as one of the best predictors of depression (Fiore et al., 1983). One's vulnerability to depression when confronted by a difficult situation is significantly increased if the individual does not have a close confidante with whom they

can express their fears and concerns and who they feel supported by (Lowenthal and Haven, 1968).

The perception that one lacks control over one's situation increases the likelihood of feeling depressed (Cohen and Eisdorfer, 1988). Depressive symptoms, measured by the Beck Depression Inventory were significantly higher for relatives who were residing with the impaired person. None of those living away from the patient were clinically depressed (Cohen and Eisdorfer, 1988).

In a study conducted by Moritz et al. (1989), it was found that husband caregivers were not depressed if their cognitively impaired wives were unable to dress or wash themselves. Also, these husbands were not negatively affected by increased household responsibilities nor by lack of participation in social/leisure activities.

In another study by Fitting et al. (1986) it was found that caregiving wives, as opposed to caregiving husbands, were more likely to experience a deteriorating relationship with their impaired spouse. Both husbands and wives were influenced by the perceived availability of financial support from family or friends, and when they felt they were financially unsupported, they reported depressive symptoms.

Other factors have been found not to have a significant impact upon depression in the caregiver. Duration of dementia symptoms was

not significantly associated with depression (Newbigging, 1981). Also found not to be significant are differences in age or the severity of the illness (Coehn and Eisdorfer, 1988). In fact, the caregiver's appraisal of their spouse's disability was a better predictor of depression rather than the objective severity of the situation (Haley et al., 1987).

PART TWO

LITERATURE REVIEW OF SUPPORT GROUP WORK

A support group is a gathering of persons experiencing common problems resulting from critical life situations (Scott, Roberto and Hutton, 1986; Alzheimer Society of Canada Leadership Training Guide). Group members share feelings and exchange ideas on how to cope (Middleton, 1984; Barnes et al., 1981; Davies et al., 1986; Marks, 1988). Support groups may serve different purposes for family members at different times during the course of the illness. For example, information about the disease, prognosis, and expected behavior changes in the Alzheimer victim would provide caregivers with knowledge which will assist them in coping, particularly in the early stages of the disease. In general, support groups provide a forum for the caregiver to deal intellectually and emotionally with Alzheimer Disease.

Providing care to an Alzheimer victim can be a "36 hour day", (Mace and Rabins, 1981). Caregivers have no time to maintain their

social contacts and often lose touch with family and friends. These social contacts may not know how to interact with the impaired person and feel uncomfortable or embarrassed by the situation. They stop visiting, which exacerbates the reduction in contact with the social network. Establishing friendships with others who understand the caregiver's situation and who are not uncomfortable or embarrassed by the impaired person, helps the caregiver to rebuild a social network, which in turn helps them to maintain their self-esteem (Aronson, et al., 1984; Davies et al., 1986; Gwyther, 1982). These caregivers are also often overwhelmed by the care needs of the impaired person, and, as a result neglect their own emotional and social needs. The group experience helps these caregivers to understand the importance of caring for the caregiver.

Coping techniques are a central focus of support groups (Barnes et al., 1981; Cohen, 1983; Glasser and Wexler, 1985; Hepburn and Wasow, 1986; Kapust, 1982; Marks, 1988). The strengthening of coping skills results in the strengthening of the ability to maintain the caregiving role. Middleton (1984) relates that the focus of support groups is to aid the primary caregiver in understanding, managing and coping with his/her life situation as it relates to the impaired relative. Coping techniques are learned through sharing experiences and ways of handling behaviors and/or situations with others who have already dealt with it. Modelling on

one another is another benefit of a shared group experience (Zarit et al., 1987; Glasser and Wexler, 1985).

The groups can be useful in helping members reframe their experiences. Although the presence or course of the disease cannot be changed, the way one views the situation and the meaning given to the situation can be changed.

Support groups also serve an educational role. This may focus on helping families to readjust their expectations, on providing specialized education regarding the particular patient's condition and on supplying practical management advice. For example, knowledge of behavior changes in the Alzheimer patient may greatly enhance the ability of the caregiver to continue providing care. If the caregiver realizes that hallucinations are not a result of mental illness but due to the physical brain changes resulting from Alzheimer Disease, or that their relative is not behaving in a certain manner just to annoy the caregiver, it is anticipated that the caregiver will be better able to cope. Wright et al. (1987) relate that one of the positive features of support groups is knowledge building.

Providing information about community resources and how to access them is yet another role for these groups. The facilitator should have a good knowledge of the services and resources which are

available in their particular community and be able to pass this on to group members.

Other purposes served by support groups include increasing the caregivers' feelings of self-worth and increasing their sense of control over their lives (Alzheimer Support Groups: Leadership Training Guide); assisting in decision-making (Aronson et al., 1984); facilitating mutual problem-solving (Gwyther, 1982); and an advocacy role, lobbying for a better understanding of the condition and for more research funds (Lock, 1986).

It must also be noted that support groups are not always necessarily beneficial. Expectations may not always be met, and thus, some participants may feel that they did not benefit from the experience and it was of little or no advantage to them. Coping styles vary and there are different reactions to the role of caregiver, so that some individuals may not benefit from the experience of having attended a support group. Although the client may be provided with a supportive relationship in a support group, this does not necessarily ensure that they will, in fact, feel supported (Goodman, 1991).

Most of the studies reported on in the literature are subjective reports that do not include quantitative research. In each of these reports, benefits to the members are determined by their verbal and, on occasion, written appraisals of the groups.

Usually, no objective measurements of the changes that occurred as a result of group participation are utilized.

Several reports measured benefits more objectively. Shibbal-Champagne and Lipinska-Stachow (1986) evaluated the benefits of a support group they facilitated by utilizing Zarit's "Burden Interview" both before and after the group sessions, and at three months post-group. Greene and Monahan (1987) did a comparison study of the rate of institutionalization of the carereceiver for those caregivers who participated in a support group as compared to control group subjects. Findings of this study are that the rate of institutionalization was 56% lower in the treatment group than in the control group.

Another evaluative study was done by Haley et al. (1987), comparing two support groups, one which included a stress management component, and one which did not. Measurements included the Beck Depression Inventory, Life Satisfaction Index, Negative Impact on Elderly-Caregiver Family Relationship, social activity measures, and participant satisfaction, which was measured by use of the Impressions of the Caregiver Group form. This study concluded that the group participants did not show significantly greater improvement over time compared to waiting list controls. On the measures of the caregivers' psychological and social functioning,

group members did not show significant change after participation in the group process when compared to those on the waiting list.

Toseland, Rossiter and Labrecque (1989) did, in their study, report significant improvements for those who attended support groups, but the least improvement was noted in the area of caregiver's perceived burden. Although Zarit, Anthony and Boutselis (1987) found improvements for those in groups, these improvements were not significantly different from those in a non treatment control group.

Although Haley et al. (1987) compared a support group with a support group having a stress management component, these groups did not include an educational component in their programs. Kahan et al. (1985) studied a group which included educational and supportive activities, but did not include the stress management component. As well, Kahan et al. (1985) studied levels of burden and depression, rather than stress and depression. The Haley et al. (1987) study looked at depression levels as well as life satisfaction, but did not address the stress levels of the caregivers. Greene and Monahan (1989) report on a group with the three components of support, education and relaxation training, for family caregivers to frail elderly persons. Their findings indicate that a highly stressed caregiving group were able to achieve statistically significant reductions in anxiety and depression through support group

intervention. These effects were greatest immediately post intervention and decreased somewhat over time. Gallagher et al. (1986) reported that emotional support groups that are also educational in their focus, resulted in a significant reduction in depression scores in comparing pre-group and post-group testing.

Whitlach, Zarit and von Eye (1991) in a report on the effectiveness of interventions with caregivers, reported in their findings that brief educational and supportive interventions were more beneficial than previously found. They feel these interventions would be even more beneficial if the stressors that caregivers experience were not of such a chronic nature and if the interventions were of a long-term nature.

Haley (1989) appears to contradict these findings. He states that there have been few controlled studies to determine the effectiveness of support group intervention, and that results of one study of 54 family caregivers who attended such a group showed no significant changes after treatment on any of the objective caregiver outcome measures. When compared to caregivers on a waiting list, there were no significant changes in the areas of depression, life satisfaction, coping and social activity. However, most participants rated the group as helpful in coping.

This review of the literature indicates that few studies have been done which include the components of education, emotional

support and stress management, and which utilize objective measurements to determine the effectiveness of such a program on reducing levels of stress and depression. There are discrepancies found in previous studies and it is hoped that this study might provide yet another opportunity to evaluate the effectiveness of these support groups.

Therefore, this practicum studied an educational and supportive group which included a stress management component. This study attempted to determine whether a group program which incorporated each of these components was beneficial in reducing caregivers' levels of stress and depression. This was determined through the use of suitable measurements which will be described later in this report. As there was no control group, conclusions as to the effectiveness of this program can only be inferential. As well, other intervening variables may have an effect upon the caregiver and cannot be controlled for. Those variables which may affect the caregiver's perceptions of their situations may include such events as deterioration of their health or that of their relative, events occurring for other family members, changes in their support system over which they have no control, etc. Through informal feedback at the end of each session, some of these events became known and will be included in the findings. However, there

is no assurance that the group participants shared all of the changes occurring during the period of the group program.

CHAPTER 2

THEORETICAL FRAMEWORK FOR GROUP WORK

This chapter will describe the theoretical framework which was the foundation of the intervention approach used in this practicum. As well, the distinction between support groups and self-help groups will be discussed.

The intervention approach in this practicum was a support group model. Katz and Bender (1976) define a social support group as including a) small, face-to-face group interaction, b) emphasis on personal participation, c) voluntary attendance, d) acknowledged purpose for coming together such as to solve a problem or to help individuals cope with handicaps or illnesses, and e) provision of emotional support.

GROUP DEVELOPMENT

The support group being studied fits the criteria of the Katz and Bender (1976) definition. This was a small, face-to-face group with twelve group members who met weekly. Group members were encouraged to participate in the group experience, to relate their issues and concerns and to shape the group agenda. Although group members were encouraged to attend all meetings, their attendance was certainly voluntary and based solely upon their own interest. The group members had a common purpose for coming together and that was to help them to cope with their caregiving responsibilities, to

increase their knowledge about the disease and the resources available to them and to provide each other with emotional support.

The support group studied went through different stages, which has been referred to in the literature as group development (Hartford, 1971). These stages included the planning or forming phase, and the beginning, middle and end phases.

PLANNING PHASE

This involved the planning and preparation which the facilitator needed to do before the group assembled. This included the tasks of initiating, setting up and coordinating the group.

The facilitator, in this planning phase, had to determine the purpose of forming such a group. One of the purposes of such a group would be to meet the social-emotional needs of caregivers. Decreasing the feeling of being isolated or alone with the problem and learning that one's problems are not unique, assists caregivers in coping (Getzel, 1983; Scott et al., 1986; Zarit et al., 1987).

Another purpose of such a group is giving caregivers an opportunity to ventilate their feelings of anger, guilt, sadness and helplessness. According to Barnes et al. (1981a), strengthening the morale, emotional well-being and treatment skills of the care-providing family is essential in attaining optimal health and maximum effectiveness in coping.

Socialization is another important benefit of such groups. Support groups also provide an opportunity to emphasize the need for caregivers to attend to their own needs (Barnes et al., 1981; Cohen, 1983; Kelly & Sykes, 1989).

As well, other purposes for forming such a group include learning new coping techniques, providing an educational role and providing information about community resources.

These support groups have come about in part as the result of the existing health care system not addressing the needs of the caregivers. Interventions are often made to the patient, with little or no involvement of the family. These support groups are a response to a system that has not been willing or able to provide the education, support and guidance that the families need. Barnes et al. (1981) relate that as there is no specific medical treatment or rehabilitation available for the cognitively impaired patient, the family support group is one of the few interventions available. By aiding the caregiver in such areas as strengthening their emotional well-being, it is surmised that this will assist them in providing care to the impaired person.

BEGINNING PHASE

This phase included development of common purposes and goals, finding one's place in the group as it relates to the other group members, and defining oneself as a part of this specific group. The

facilitator needed to assist members in getting to know each other, to help them feel comfortable and create an atmosphere where sharing can take place. As well, it was the role of the facilitator, in this beginning phase, to help the group identify why it has been established.

In order to have group members become more comfortable in the group setting and help them to establish commonalities, the facilitator requested at the first group meeting that members break up into pairs, introduce themselves to each other and then introduce their partner to the group.

Common concerns and issues and common experiences were emphasized to help group members to identify with each other and to become more aware of their common purpose for joining such a group. Therefore, the facilitator often asked group members whether they had experienced situations as described by another of the participants. It was also a role of the facilitator in this phase to ensure that all members had an opportunity to express themselves so that each of the participants would feel that they contributed to this group and that their concerns were important.

It was also in this beginning phase that the facilitator began to emphasize that the group belonged to the members, that they could control the agenda and that the group existed to meet their concerns.

MIDDLE PHASE

It is generally in this phase that cohesion develops, members begin to develop norms, they become increasingly comfortable in sharing with others, and goals are achieved both for the group as a whole and for the individuals who comprise the group.

Cohesion, according to Yalom (1985) is the binding together of group members which results in greater participation, increased commitment to the group and greater satisfaction with the group experience. This results from positive interactions with others and from identifying with others who have a similar problem (Zarit et al., 1985).

In this group, cohesion did develop. All group members participated openly, discussing their situations, fears and problems. Members were respectful to each other even when opinions differed.

Members appeared comfortable, offered opinions and suggestions to each other. As well, there was quite a bit of humour, which created a comfortable, relaxed atmosphere even though the discussions were often about painful, difficult situations.

ENDING PHASE

This is the point at which the group ends or is terminated. This phase included the preparation for the ending of the contracted

8 week program, the last meeting of this phase and the planning for the future of the group.

At the seventh meeting, the facilitator discussed the ending of the group program and requested that members begin to consider whether they wished to continue meeting and if so, how often and in what type of format.

At the last meeting a lengthy discussion was held about the future of the group. The participants, with the exception of one of the members, decided to continue meeting on a less frequent basis for a further period of time. Group members developed a cohesiveness and bonding, and have thus decided that they wish to continue to meet for an indefinite period of time.

GROUP STRUCTURE

The facilitator is responsible for determining how to structure the group in order to make it effective in meeting the needs of the group members. This entails developing goals that will allow for successful group development. Toseland (1990) suggests that the practitioner needs to pay attention to goals that focus on the functioning and maintenance of the group.

In terms of the functioning and maintenance of the group, it is necessary to address such aspects as homogeneity or heterogeneity, size of the group, timing of the sessions, and whether to develop an open or closed group.

Homogeneity was characterized by group members sharing the common characteristic of being a caregiver to a cognitively impaired relative. This common characteristic created a common bond and helped group members identify with each other (Corey and Corey, 1977). Scott et al. (1986) reported in their study that family members expressed a desire to have the opportunity to talk and be able to share their problems with others who had or were presently having to cope with the same type of situation. As the group members have different coping skills and styles, different life experiences, background and expertise, as well as differing relationships with the carereceiver, heterogeneity existed (Toseland and Revis, 1984).

The group needed to be large enough to allow members to have a good exchange of coping skills, experiences and sharing of common concerns, but small enough to allow for intimacy and to allow all the members the time to discuss issues of concern to them. A group of twelve members was considered appropriate to meet these criteria.

Timing of the group meetings was another aspect of the group structure. The student determined that group members would meet for an 8-week period for two hours a session. This would allow adequate time both for group cohesion to develop, and for information sharing to take place. Group meetings were held in the evening, since most members worked outside of the home. Two hours appeared to be the

maximum length of time that members would wish to spend, and yet was long enough to address members' concerns and allow time to develop group cohesion.

The student determined that this should be a closed group. This closed membership allowed for a greater sense of cohesion, greater stability of roles and norms, and allowed the group to move through the stages of group development in a more predictable fashion (Toseland, 1990). This had to be balanced against an open membership which allows for increased new ideas and resources to be brought to the group. The student determined that for the purposes of this group, closed membership would be more appropriate.

SUPPORT GROUP VS. SELF-HELP GROUP

Many of the same goals can be identified for self-help and for support groups. These include mutual support, empathy, affirmation, sharing, morale building, imparting of information, having a feeling of social usefulness by being in a helping role and making group members aware of community resources.

The major distinguishing characteristics between these two types of groups appears to be in terms of the role of the professional. In support groups, a professional may act as a facilitator for the group or may act as a resource for training non-professionals to facilitate such groups. This professional

usually continues in their role as facilitator, group advisor and information provider throughout the existence of the group.

In self-help groups, the professional's role is in providing referrals, serving as a group advisor or consultant and in organizing the details of the meetings. Often, the professionals may be available, but will not be a participant in the group on an ongoing basis.

ROLE OF THE FACILITATOR

The role of the facilitator is multi-faceted, incorporating the following: initiation of the group, provision of referrals and information, provision of structure and norms for the group, normalization of experiences for group members, help in facilitating mutual problem-solving, validating experiences, and help in establishing a social group out of the membership (Gwyther, 1982; Zarit et al., 1985).

The facilitator must have a good understanding of Alzheimer Disease and its implications, and must be sensitive to the emotional and physical stresses placed on the caregiver. Accurate information about the medical and non-medical aspects of the disease, and about appropriate community resources is essential.

In contrast to a psychotherapeutic group setting, the emphasis for the facilitator is on stepping back when group members are able to work through issues on their own. The facilitator's role is

basically to guide the group so that the members are able to provide both practical and emotional assistance to each other.

The creation of a supportive, warm, non-threatening environment is crucial to the success of such a group. As caregivers have limited free time, are stressed and burdened by their caregiving roles, and are expressing feelings of isolation, they will only return to the support group if they perceive that it provides them with some benefits.

The support group model of intervention was chosen as an appropriate method for this caregiving population. This support group provided the members with an opportunity to share with each other and, through the course of the program, the members became more comfortable in this setting as they moved through the various phases of the group development.

CHAPTER 3

INTERVENTION METHODS

DESCRIPTION OF THE CONTEXT

The group met at the Alzheimer Society of Manitoba (ASM) offices. The ASM is a non-profit agency which was founded in 1982 to address issues of concern for caregivers of Alzheimer victims. The objectives of this agency are to provide information and emotional support to family members of Alzheimer victims, to encourage and support research in this area, to advocate on behalf of victims and their families for enhanced services, to provide education and increased coping skills for professional caregivers and to increase community awareness about Alzheimer disease.

This agency has a 22 person voluntary Board of Directors, the equivalent of 5.2 professional staff and 1.8 support staff. In addition, there are over 550 volunteers assisting in carrying out the mandate of the agency.

In the Province of Manitoba in 1989/90 there were 12 family support groups operating under the auspices of the ASM, servicing approximately 250 people.

These groups have evaluated the process of the intervention by utilizing Client Satisfaction Questionnaires, but have not measured changes to the caregivers resulting from the intervention. None of these groups, to date, have examined the impact of the intervention

in all three of the areas of knowledge, stress and depression by using measurement tools. The groups which have existed in Manitoba have been subjectively reported on, but have not often used objective measurements to evaluate their impact.

LOCATION OF GROUP MEETINGS

Practical arrangements had to be made in terms of a suitable location for holding the group meetings. A central location was deemed most appropriate as the referrals were from all parts of the city. A meeting room at the Alzheimer Society offices met the criteria for being centrally located and providing for privacy, and the use of this room was negotiated with the Alzheimer Society.

MODE OF INTERVENTION

The student utilized both educational and supportive strategies in a group setting for caregivers of Alzheimer victims. Three major areas are addressed in the intervention; these being knowledge, stress reduction and increased social support.

The group ran for an 8 week period. The total pre and post-group time period was 16 weeks. The group sessions were held weekly, for 2 hours per session. Group size was 12 members. This was a closed group, meaning no new members were allowed to join the group once membership had been established.

The educational component of the activities of support groups has been highly regarded by many authors (Hirst and Metcalf, 1986;

Pratt, Schmall and Wright, 1986; Wasow, 1986). They contend that an understanding of the disease itself, and its medical and behavioral aspects provide caregivers with crucial information which assists their coping. This knowledge helps to reduce self-blame, as well as blame directed toward the Alzheimer victim, and enhances the caregiver's confidence in dealing with the situation.

Educational aspects included a presentation on what the disease is, its incidence, medical aspects as well as the behavioral changes which may occur. Suggestions for coping were made. As well, information was provided on the legal issues which may be of interest to the caregivers. In addition, information on the availability of community resources was given.

Supportive aspects include the opportunity to discuss common concerns and issues with others who are having similar experiences. This activity has been reported to reduce the sense of isolation, to provide role models for learning how to deal with the impaired person, and to help in resolving some of the feelings and issues which are created by having a relative with this illness (Barnes et al., 1981; Zarit, Anthony and Boutsellis, 1987). The emphasis was on providing group participants with an opportunity to share their emotional reactions and to develop a network with others who are experiencing common concerns. A non-threatening, confidential, safe

environment for venting feelings and discussing coping strategies was the goal for these sessions.

Stress management was also discussed throughout the group sessions. The effects of both good and bad stress were outlined, as well as what can be done about stress. Stress management techniques were employed, and group members were able to practise these techniques at home. The format for presenting this stress management component included both short presentations as well as group exercises or activities.

The organizational structure of the group provided for some flexibility in permitting the group to control the agenda. For example, when group members wished to have unstructured agendas, or wished to use more group time on a particular topic of interest, the group was allowed the flexibility to make this decision. (Program outline found in Appendix A.)

MEMBER SELECTION CRITERIA

Initially, it had been proposed that spousal caregivers would be the focus of this study. Therefore, letters of introduction (in Appendix B) had been sent to health care agencies and geriatricians in Winnipeg who work with Alzheimer victims, requesting referrals based upon the following criteria:

1. Diagnosis from a physician that the impaired person has Alzheimer Disease. Diagnosis to be known for a period of no less

than three months and no longer than two years prior to acceptance into the group.

2. Caregivers to be the spouses of the impaired person and will reside with the carereceiver.

3. The group sessions would be available only to those spouses who have previously not attended an Alzheimer support group.

4. Caregivers to be between the ages of 50 and 80 years and not themselves display any signs of cognitive impairment.

5. Should be able to understand, read and write English.

6. Participation in the group to be voluntary, but agreement to complete all questionnaires and tests to be requested.

Prior to sending out letters requesting referrals from these health care agencies and geriatricians (in the Appendix) each was contacted by telephone to advise them of the letter to be received. It was anticipated that a personal contact made to the referral agents might increase the probability of their cooperation in making these referrals.

Two weeks following the mailing of these letters, another telephone call was made to encourage the referral of prospective clients.

At the end of a six week period of attempting to solicit names of possible clients, only two appropriate referrals had been made.

Several possibilities exist which may explain why so few spouses were referred to this program. Spouses may be reluctant to leave their impaired spouse at home with home care supports and may not have or may not wish to impose upon other family members. The spouses may be so overwhelmed with task of providing care the attendance at a group may be viewed as an additional burden rather than as a benefit. Another possibility may be that, in general, spousal caregivers may have preferred another method of intervention than a support group. As the majority of referrals came from the Alzheimer Society, and, as spouses were far less likely to contact the agency than were adult children, there were few names forwarded for referral to the group.

Therefore, criteria for the selection of clients for this group were changed to include the following:

1. Diagnosis that the impaired person has Alzheimer Disease or another related cognitive impairment.
2. Caregiver to be the spouse or an adult child or grandchild of the impaired person, and, at the point of acceptance into the group, that the impaired person is residing in a non-institutionalized setting.
3. Caregiver should be able to understand, read and write English.

4. Participation in the group to be voluntary, but agreement to complete all questionnaires and tests to be requested.

SOURCE OF REFERRALS

Recruitment of group members was attempted by contacting several sources: the Social Work departments of all hospitals in the City of Winnipeg, the Office of Continuing Care, the Alzheimer Society of Manitoba, all geriatricians in the City of Winnipeg, Age and Opportunity Centre, VON, and Jewish Child and Family Services.

As previously noted, all of these referral agents were contacted by telephone, a letter of introduction was sent to them and there was a follow-up telephone call made.

One referral was received from Age and Opportunity Centre, two referrals from a geriatrician, one referral from a hospital social work department and twenty-six from the Alzheimer Society of Manitoba.

Each potential participant was contacted by telephone to describe the purpose of the group and the expectations of each group member. Of these referrals, thirteen people expressed an interest in being a part of this study. The student met individually with these thirteen potential participants and the process and expectations of involvement were described in greater detail.

Eleven of these members attended on a regular basis and completed the program. The twelfth member was a 19 year old

grandson, who, upon further consideration did not feel comfortable attending this program with twelve middle-aged and elderly participants. The thirteenth member only attended two of the sessions, and gave a variety of reasons why she was unable to attend the rest of the meetings.

TIMING OF SESSIONS

Recruitment of group members was initially started in October of 1991. After waiting a period of several weeks for the referral of spouses to the group, and receiving only two appropriate referrals, the student determined that the group would become open to the children of the impaired person as well. Therefore, in November of 1991, the student recontacted all of the referral agents to advise them of the change. Referrals were received immediately from the Alzheimer Society and the student began the individual pre-group meetings in November. All of these individual interviews took place in November and December of 1991. The group meetings began on February 5th, 1992 and each group member was contacted by phone to remind them of the starting date. The group ran until March 25, 1992. The 7 week follow-up session was held on May 13, 1992.

Eight group meetings were held on a weekly basis, for a two hour period in the evening.

Prior to the group meetings, an individual interview was conducted with each of the potential clients. These meetings took place either in the participant's home or in the offices of the Alzheimer Society, based upon the preference of the potential participant. All of those interviewed indicated an interest in being a part of this study.

Generally, these individual interviews lasted between 45 minutes and 1½ hours. Basic information was obtained (in Appendix C), the Stress Quiz was administered as was the first part of the Alzheimer Disease Knowledge Test (in Appendix D). As well, all participants were requested to sign a consent form (in Appendix C), permitting the facilitator to report on the results of this study, ensuring confidentiality.

Meeting individually with each potential participant provided an opportunity for the facilitator to begin to establish rapport with the group members. Having these individual, face-to-face meetings allowed for a level of comfort to be developed before the group process began.

Having meetings on a weekly basis for an 8 week period allowed for a commitment to be made by the participants that was feasible given that a large proportion of those who attended worked full time outside of the home. This schedule also allowed for time to attend to the ongoing responsibilities that the impaired person demanded.

It was determined that meetings would be held on Wednesday evenings by the majority stating this as their preference on the Basic Information Sheet.

RESEARCH DESIGN TIME CHART

Pre-Group Interviews	Week One	Week Two	Week Three	Week Four	Week Five	Week Six	Week Seven	Week Eight	7 Week Follow up
Basic Member <u>Information</u>	Beck Depression <u>Inventory</u>	Post-Session Report	Post-Session Report	Post-Session Report	Post-Session Report	Post-Session Report	Post-Session Report	Beck Depression <u>Inventory</u>	Beck Depression <u>Inventory</u>
Consent Forms <u>To be Signed</u>	Stress <u>Quiz</u>							Stress <u>Quiz</u>	Stress <u>Quiz</u>
Social Support <u>Questionnaire</u>	Post-Session <u>Report</u>							% of the Questions of the Alzheimer Disease Knowledge <u>Test</u>	Social Support Question- <u>naire</u>
% of the Alzheimer Disease Knowledge <u>Test Questions</u>								Client Satisfaction <u>Questionnaire</u>	

CHAPTER 4

EVALUATION OF THE GROUP INTERVENTIONS

A quasi-experimental design was used in this study. Refer to the Time Chart (pg. 62) for scheduling of administration of the measurements which were utilized in this study.

In order to evaluate the effectiveness of the intervention, I utilized the following measurement instruments (in Appendix D and E):

1. The Alzheimer's Disease Knowledge Test (Dieckmann et al., 1988).
2. Beck Depression Inventory (Beck, Aaron T., 1967).
3. Stress Quiz.
4. Social Support Questionnaire.
5. Client Satisfaction Questionnaire.

Alzheimer's Disease Knowledge Test

The instrument utilized in this study was the Alzheimer's Disease Knowledge Test (Dieckmann et al., 1988). Permission to use this instrument was obtained from Dr. Steven Zarit (see Appendix F). The test consists of 20 multiple choice questions. For the purposes of this study 19 of these questions were chosen, as the 20th question related to the American health care system and was not relevant to this particular study.

For each question, there are 5 possible responses: the correct response, three distracters and an "I don't know" possible response. The three distracters are representative of common misconceptions individuals have about this disease. Having an "I don't know" category helped to differentiate between misinformation and lack of knowledge.

The questions covered a wide range of content areas including diagnosis, symptoms and behaviours. This test was sensitive to responses that indicate either a negative or positive bias. Answers indicating a positive bias refer to a tendency to underestimate the severity of the disease while those with a negative bias indicate that the respondent believes that the disease is in fact more severe than it actually is.

As Dieckmann et al. indicate, those with either a positive or negative bias in their responses may indicate increased difficulties in coping. Those with a positive bias may partake in activities which they feel may enhance or increase the intellectual functioning of the impaired person, while those with a negative bias may fail to use practical or management techniques which might assist the impaired person in their functioning.

Coefficient alpha was used to estimate the internal consistency of this test. These alpha coefficients were high, ranging from .71 to .92.

This test has satisfactory reliability and validity, when tested with undergraduate students, undergraduate gerontology students, graduate gerontological and social work students, and professionals working in the area of mental health.

The Beck Depression Inventory

Permission for use of this instrument was granted by Pauline Caras, University of Pennsylvania Press (in Appendix F).

The BDI is a 21-item self-rating depression scale which is clinically related to the depressive state. This inventory contains four possible responses in each of the 21 categories that the individual may respond to, ranging in severity from neutral (0) to a high of (3) for very severe. The instructions direct that each respondent read all of the statements in each group and select the response that most closely reflects the way they have been feeling at the particular point when the BDI is being completed. If more than one response is indicative of how the respondent is feeling, the instructions direct the person to circle each of the responses which reflects how they feel.

This inventory is scored by summing up the ratings, with a higher score indicating greater severity of depression. The range of scores is from 0 to 63. The cut-off scores which were used in this study were those recommended by Gallagher et al. (1982). These are as follows: normal range = 10 or below; mild depression = 11 to

16; moderate depression = 17 to 23; and severe depression = 24 or greater.

Keane and Sells (1990) report in their article that the BDI coefficient alpha reliabilities were sufficient to indicate that the BDI is a useful screening tool with an elderly population.

They also report that the BDI correlated significantly with ratings of depression that clinicians made ($r = .61$ and $.73$), with the Hamilton Rating Scale ($r = .75$ to $.82$) and with the SDS ($r = .72$ to $.76$) (Beck, 1973; Beck and Beamesderfer, 1974 and, Beck and Beck, 1972).

Beck et al. (1961), indicate that the BDI has high internal consistency and stability, which in turn indicates a high degree of reliability and validity.

This inventory has been found to be reliable in assessing adult depression and Gallagher et al. (1981) state: "(a) the BDI has respectable internal consistency and stability for use with older adults in research and (b) the BDI appears relatively adequate as a clinical screening instrument for use with the elderly".

Stress Quiz, Social Support Questionnaire and Client Satisfaction Questionnaire

All of these questionnaires were developed by the student. As a result, they were pre-tested on consumers and peers. The consumers were members of a support group for caregivers of the

physically disabled, which the student is also facilitating, as well as other caregivers that the student is working with. There were twenty-one clients who provided suggestions and changes to these questionnaires being developed. Peers were also asked for input and this included social workers and home care workers who work with the student in a geriatric health care centre. The questionnaires were distributed to eleven peers, who offered varied responses and suggestions.

Both specific changes and general comments were offered. Some of the specific changes included the organization of the questions, the ranking of the responses, and change of instructions. Most of the recommended changes were incorporated in the final draft of the questionnaires.

General comments included the following: direct, informative, straight-forward, as well as the following comment about the Social Support Questionnaire: "In my opinion this questionnaire would influence individuals into thinking about the quality and quantity of support which they receive. This could be beneficial to individuals." This statement was made by a consumer of service, a family caregiver.

Stress Quiz:

The stress quiz was developed by the student to determine the level of stress experienced by these caregivers. Respondents were

requested to complete the same stress quiz both pre and post group. It was hypothesized that through the group process, with an emphasis upon stress management techniques and caring for the caregiver, that the members would report decreased stress levels post group. The results of this testing would thus support this hypothesis or not support it.

The stress quiz has 23 different questions with "yes" or "no" responses. The instructions direct the person completing the quiz to relate their answers to their experiences or feelings during the past twelve months.

As this quiz was developed by the student, no cut-off level was established to determine whether an individual was highly or moderately stressed or not stressed at all. Rather, this quiz was developed to investigate changes between pre-group intervention compared with post-group intervention.

Social Support Questionnaire

This questionnaire was developed to attempt to determine whether social support was a mediating factor for these caregivers. One of the questions to be addressed is whether those caregivers who indicated feeling more supported would also indicate less stress and lower depression scores.

The Social Support Questionnaire was developed by the student. It is a Likert Scale, with responses ranging from "very much" to

"not at all". For each of the responses, the clients were asked to assess the amount of support received from family, friends and neighbours.

The questions were designed to solicit information on support from both the formal and informal support systems. Two questions were developed to try to obtain an understanding of how supported the respondent feels in a general sense.

These three questionnaires were administered at various points of the program. The Stress Quiz was administered at Week One of the program, Week Eight and again at the 7-week follow-up. The Social Support Questionnaire was administered in the pre-group individual interview and again at the 7-week follow-up session. The Client Satisfaction Questionnaire was utilized only once, at the last session of the program, Week 8.

Client Satisfaction Questionnaire

At the final group meeting a Client Satisfaction Questionnaire (in Appendix E) was administered, so that group participants could evaluate the group sessions with anonymity and confidentiality. The results of this questionnaire are reported on in a later chapter.

Post-Session Report

As well, at the end of each week's meeting, with the exception of Week 8, a Post-Session Report was completed by each of the participants (in Appendix E). This report provided a gauge of what

group members found the most useful, the least useful, and offered them the opportunity to make comments and suggestions about the program. This Post-Session Report was not utilized on Week 8 as the Client Satisfaction Questionnaire was completed, which is also a rating of the program. Comments as to what the group members rated as liking most and least about the group can be found in Appendix G.

CHAPTER 5

THE CAREGIVERS

The caregivers who were part of this study were both the spouses and the adult children of cognitively impaired persons. All of the caregivers were female, and were Caucasian. Age of the subjects ranged from mid-30's to mid-70's. Ages of the impaired carereceivers ranged from 66 years old to 90 years old. The mean age of these relatives was 76.3 years. The length of time that the impaired person displayed some of the signs of cognitive impairment ranged from 7 years to 6 months. The average length for all group members having noticed the onset of the disease was 3.7 years. While specific data relating to socioeconomic status and ethnicity was not collected, it appears that all of the group members are from low middle-class or higher socioeconomic status and are representative of different ethnic backgrounds (Anglo-Saxon, Ukrainian, Jewish), but were all Caucasian females and thus not representative of any visible minorities.

This sample is not representative of all caregivers of the cognitively impaired. Although a number of men were contacted, none expressed an interest in joining a support group at this time (with the exception of Client #13, a 19 year old grandson, who, after the initial interview, decided not to join as he did not wish to be the only male in the group). As well, the majority of group members

were adult children rather than spouses (only 3 out of the 12 members were spouses). This may be a result of the caregiving demands placed upon spouses, who would be unable to leave the impaired person alone, or had no one to care for their spouse. Although the original intent of this study had been an intervention planned with spouses, only two appropriate referrals were made. As the majority of referrals came from the Alzheimer Society, it would appear that most contacts to the agency are made by adult children, sometimes on behalf of their caregiving parent, and often on their own behalf.

In addition, those who contact the Alzheimer Society for information or services are not representative of the multi-cultural nature of our society. Generally speaking, most of those contacting the Alzheimer Society are middle-class individuals. As twenty-six of those originally contacted regarding inclusion in this study were referred by the Alzheimer Society and four referrals came from other sources, it is the Alzheimer Society referrals that make up the vast majority of those who participated. In fact, all but one of the group participants was referred by the Society, the exception being referred by Age and Opportunity Centre.

Of the caregivers in this study, three were spouses who were residing with the impaired person. For this group, the average age of the caregiver was 72, and the average age of the carereceiver was

73 years old. All of the spouses had first noticed the onset of the disease approximately 4 years ago. Two of these spouses were referred by the Alzheimer Society, one by Age and Opportunity Centre. Two of the spouses requested that one of their adult children be able to accompany them to the support group. One of these spouses had previously attended a support group which had been offered through the Alzheimer Society.

Nine adult children of a cognitively impaired parent attended the program. Of these, not one lived with the impaired person. Three of the parents, although cognitively impaired, were still able to reside alone in the community. All three of the spouses had their impaired husbands living with them. When the initial contact was made and the individual interviews were held, all of the Alzheimer victims were residing in a non-institutional setting. By the time the group convened, one family member had been placed in a personal care home and another was awaiting placement from an acute care hospital. During the course of the group, one other impaired person was panelled for personal care home placement, and two others were beginning to process the application. This appears to be indicative of the ongoing, rapid changes which family members must cope with due to this progressive, deteriorating illness.

One of the adult children attended only two of the sessions, the rest attending almost all of the sessions. One daughter

attended the first six meetings as she was away on vacation for the last two meetings (this was understood to be the arrangement made on the initial individual interview).

Three case profiles will be discussed here. These are representative of the members who attended this program in that one is a spouse, one an adult child whose relative lives alone in the community and one is an adult child who accompanied her mother to the support group meetings both to receive benefit to herself from the group experience and to lend support to her parent.

The other client profiles can be found in Appendix H.

The results of the individual evaluations are also discussed with these profiles. The findings for each member accompany the description of that member's circumstances.

CLIENT #4

This client has a 77 year old father who has recently been diagnosed as having dementia. She first noticed the onset of the disease five years ago. Her father had been living with her mother until two months ago when her mother separated from her husband. She stated that she was unable to handle the demands of caring for her cognitively impaired husband. Client #4's father now lives alone.

Client #4 is a mid-40's single parent of two teenage children. She works full-time. She has two brothers and two sisters, but

states that she receives no support from them in terms of her father as they are unwilling to accept that he is cognitively impaired.

This client provides a great deal of support to her mother, but only minimal support to her father. He views her as being at least somewhat responsible for his wife having left him.

There appears to be a great deal of conflict within the family, particularly as regards father's future. Client #4 aligns herself with her mother and has stated that her siblings will have to look after their father.

Client #4 deals with some of her stress by talking to a friend whose father has a more advanced stage of Alzheimer Disease. She has begun to be able to express her anger and frustration with one of her brothers and is finding that her mother is now able to be more assertive and direct with her children. She expresses that this makes her feel vindicated with her siblings. Client #4 is feeling a great deal of pressure from her family and would like to "get away from it".

This client showed some improvement in the area of knowledge. On the pre-group testing she was correct in her responses 3 out of 9 times, post-group she was correct 5 out of 10 times. This increased knowledge may have influenced her scores on the Beck Depression Inventory, which at the pre-group testing was 7, or within the normal range, to a post-group score of 13 or the mildly

depressed range. It is difficult to account for other intervening variables which may have an effect on these changed scores, but another hypothesis may be that this client, through the group process, became more aware of what the future may hold for her father and this may be difficult for her to handle.

Another explanation for the change in her depression scores, as well as the change in her pre and post group scores on the Stress Quiz, which went up from 10 out of 23 to 14 out of 23, are the alterations in her family circumstances. During the course of the program, this client's mother, who was the primary caregiver, moved away from her father, who is cognitively impaired. Her mother, who had a difficult time adjusting to her new single status, depended heavily upon this client for practical assistance and guidance. As well, this client described a great deal of family conflict as her siblings do not feel that there is anything wrong with their father. Through the group experience, where most of the other children described supportive siblings, this client may have become more aware of her circumstances and more dissatisfied with them.

Client #4 does not particularly feel that she is supported by her family and rated the support of her friends as higher than that of her family. She indicates that she is not supported by her neighbours. She does receive support from her co-workers. Client #4 indicated that she does not feel supported in her caregiving

role, but feels she gets a great deal of support for herself as a person.

CLIENT #7

This mid-70's wife is providing care to her 83 year old husband who was diagnosed with Alzheimer Disease two years ago. She began to notice signs of cognitive impairment four years ago. The couple live in a bungalow and Client #7 does all of the household management tasks.

This couple had three children, two sons and one daughter. One son died last year and this Client continues to have a great deal of difficulty coping with this loss. Her daughter resides in Winnipeg, the remaining son lives in Toronto. The daughter visits her mother and father at least once a week, takes them grocery shopping and is available if necessary. There are two university aged grandchildren who used to spend a great deal of time with their grandfather. This has substantially decreased as their grandfather no longer recognizes them and this is so disconcerting to them that they now often avoid him. The son living in Toronto is a doctor and has come to Winnipeg several times to help his mother sort out his father's medical needs.

Client #7 suffers from chest pains which her doctor has diagnosed as stress induced. She is anxious as her husband often wanders away, takes the bus and she must find him. During the

course of this program she registered him with the Wanderer's Registry and found it to be highly effective. She related that this has helped to decrease her anxiety level.

This client states that she also finds her husband's incessant talking very stressful. Other than attending the group sessions, she is with him almost all of the time. She takes him for bus rides as an outing and always lets him sit with someone else so that she gets a break from him. She also takes him to church every Sunday and lets the men take care of him while she goes elsewhere with the women.

Client #7 receives no home care supports and prior to her attendance in this program, had not initiated personal care home placement. During the course of the program, and at the urging of the other group members, she has begun to obtain the medical information for this application, has contacted the social worker from the Office of Continuing Care and is proceeding with having her husband panelled.

This client's largest change was in the testing done on the Beck Depression Inventory. Pre-group she had a score of 14 and on the post-group testing her score went down to 11. Both scores indicate that she is mildly depressed. The changes on the Alzheimer Disease Knowledge Test and the Stress Quiz were so minor that they are not significant.

Through the group process it appeared evident that this client was mildly depressed. Her husband's condition was deteriorating, she had some support from family, but not a great deal and her only outing away from her husband was to attend the support group. As well, this client had lost one of her children a year ago, and when she spoke of this it was evident that she was still having difficulty coping with this and was depressed about this loss.

Client #7 indicates quite a bit of support from her family and a moderate amount of support from friends and slightly less support from neighbours. She also receives support from church, club members and her in-laws. She feels quite supported in her caregiving role, but little support for herself as a person.

CLIENT #12

Client #12 is the daughter of Client #11. She is a late-40's mother and grandmother, who works full-time outside of her home.

Client #12 expressed a number of frustrations and concerns relating to her father's illness and behaviours. She states that she does not have the necessary patience to deal with her father. She describes him as having frustrated, violent outbursts. He also angers her when he gets involved in situations which entail arguments with his neighbour or the police. Usually she deals with this by trying to ignore the situation or changing the topic so that she does not have to deal with it.

This client feels that her father is at least somewhat responsible for the difficulties he encounters and that he often instigates the problems. As well, she becomes very frustrated when strangers view her father as a lovely man as she does not feel this way about him.

Client #12 also expressed past frustration with her siblings, all of whom lived in Winnipeg. She expressed that they had previously been unwilling to accept that there was anything wrong with their father, but now realize the extent of his cognitive impairment and provide more support to Client #12's mother. Her three siblings have become more responsive to the needs of their impaired father.

This client, as well as her mother, Client #11, have previously attended an Alzheimer Society support group, for about six sessions. They found it somewhat useful, but did not feel they could develop as open and sharing a relationship with others as it was an open group with new members at each session.

This client had a slight increase in the amount of knowledge she had in the area of Alzheimer Disease after she had completed the group program. Her pre-group score of correct responses was 5 out of 9 and this increased to 8 out of 10 correct responses post-group.

Her Beck Depression Inventory score did not change significantly as the pre-group results were 3 and were 1 on the

post-group testing. Both of these scores are not indicative of depression.

Client #12 did have a slightly higher score post-group on the Stress Quiz. Her score increased from a positive response on 3 of the items pre-group to 7 positive responses in the post-group testing.

This client did not indicate in the group sessions anything that would imply that she was more stressed. Client #12, who is the daughter of Client #11, may have tested more stressed as her father was becoming more difficult and running into more problems with the police. Although Client #12 tended to avoid her father and was not directly involved in his care, perhaps his behaviours and their effect on her mother were stressful to her.

Client #12 indicated that she receives a fair amount of support from family, a moderate amount from friends and less so from neighbours. In an overall sense she feels only moderately supported as a caregiver and only receives moderate support for herself as a person.

All of the caregivers who were a part of this study were struggling with adjustment to their relative's cognitive impairment. Although each of the members had their own coping styles, they shared many of the same frustrations and difficulties in coming to

terms with this devastating illness. They were able to share their experiences and coping techniques, thus providing the other members with alternative methods for coping, while reducing the feeling of isolation that most of the caregivers expressed.

CHAPTER 6

EVALUATION OF THE GROUP

Alzheimer Disease Knowledge Test

The student's objective was to administer two different halves of this instrument pre-group and at the last session. The first half of this test was administered to each of the participants when the student met with them individually for the pre-group interview. The second half of this test was administered to Client #6 after Week 6 of the program as she was unable to attend the last two meetings. This test was not administered to Client #3 as she attended only two of the meetings and therefore was not present for any of the testing other than that done pre-group. This test was administered to Clients #8 and #9 in their homes after the 8 week program, as they did not attend the 8th session, when the testing took place for all of the other participants.

As previously mentioned, the amount of information the members had with regards to Alzheimer Disease had been evaluated. The findings from this indicate that members had limited to moderate information about the disease. Scores ranged from 2 out of 9 correct responses to a high of 7 out of 9 correct answers. The average correct responses was 4.3 out of 9 questions answered. Spouses' responses ranged from 3 to 5, daughters' from 2 to 7. This would indicate that there is no significant difference between the

amount of information available to spouses vs. the adult children. However, the sampling size is small, and findings from the sample may or may not be indicative of the general caregiving population to the cognitively impaired.

Post-group testing found a range of scores from 2 out of 10 correct replies to a high of 9 out of 10 correct responses (refer to Table 1). The average of the group was 6.3 out of 10 correct answers. Spouses' responses ranged from a low of 2 out of 10 to a high of 7 out of 10. The daughters' responses ranged from 5 out of 10 to a high of 9 out of 10 correct replies.

These findings would indicate that there is a slight increase in the knowledge level post-group when compared to pre-group. The educational component was one of the major features of this support group, and there was a difference between the pre-group scores when compared with the scores at the completion of the 8-week program, with members' knowledge level increasing somewhat (refer to Table 1).

This test was sensitive to responses that indicate either a negative or positive bias. Answers indicating a positive bias refer to a tendency to underestimate the severity of the disease while those with a negative bias indicate that the respondent believes that the disease is in fact more severe than it actually is. For the group as a whole, there was a positive bias indicated on 13

occasions, a negative bias on 18 of the responses (Refer to Table #2 for bias reporting). This indicates a slightly more negative outlook regarding the management of this disease. This may actually be a result of having more information regarding the future expectations of this disease process. As this is a deteriorating illness with no chance for improvement, it is understandable that the group members had a tendency towards a negative bias.

Individual responses indicate no significance in bias. For Clients #10 and #1 no bias was established. For Client #12, there was a negative bias on 2 of the responses on the pre-group testing, but a positive bias on 2 of the responses on the post-group testing. For the other respondents there was only a difference of one response, either weighed negatively or positively, which is not significant of any bias.

In terms of the response "I don't know" group members indicated this as their choice 35 times out of a total of 209 possible responses. This is 15% of the responses where members had a lack of information or knowledge.

Table 1

Alzheimer's Disease Knowledge Test

	<u>Pre-Group Responses</u> (out of 9 questions)			<u>Post-Group Responses</u> (out of 10 questions)		
	Correct	Incorrect	I Don't Know	Correct	Incorrect	I Don't Know
Client #1	2	-	7	5	2	3
Client #2	6	2	1	9	1	-
Client #3	N/A	N/A	N/A	N/A	N/A	N/A
Client #4	3	4	2	5	4	1
Client #5	5	3	1	8	1	1
Client #6	7	-	2	8	1	1
Client #7	3	6	-	2	6	2
Client #8	6	1	2	7	3	-
Client #9	2	4	3	8	2	-
Client #10	5	-	4	6	1	3
Client #11	4	3	2	3	7	-
Client #12	5	3	1	8	2	-

Table 2

Alzheimer's Disease Knowledge Test

	<u>Number of Positive Bias Responses</u>		<u>Number of Negative Bias Responses</u>	
	Pre-Group	Post-Group	Pre-Group	Post-Group
Client #1	-	-	-	-
Client #2	-	-	-	-1
Client #3	N/A	N/A	N/A	N/A
Client #4	-	+1	-3	-1
Client #5	+1	+1	-	-1
Client #6	-	+1	-	-
Client #7	+1	+2	-2	-2
Client #8	+1	+1	-	-
Client #9	-	-	-2	-1
Client #10	-	-	-	-
Client #11	+1	+2	-2	-2
Client #12	-	+2	-2	-

Beck Depression Inventory (BDI)

There were some surprising findings in the area of depression. One finding of this study contradicts earlier studies (Paulshock and Deimling, 1984; Cohen and Bisdorfer, 1988) which state that caregivers of the cognitively impaired are likely to experience some level of depression. Only two of the eleven caregivers studied were mildly depressed, the others falling within the normal range. Perhaps as the majority of caregivers were not residing with the impaired person, this impacted upon the testing with these caregivers testing within the normal range. However, only one of the three caregivers living with the impaired person scored in the mildly depressed range.

For 6 of the clients, Client #1, 2, 4, 5, 6, and 11 there was a slight increase in the post-group testing on the BDI. For 5 of the clients, Client #7, 8, 9, 10 and 12 there was a slight improvement in the post-group testing. Using the cutoff scores suggested by Gallagher et al. (1983), only two of the clients, #4 and 7 were in the mildly depressed range on the post-group testing, all other group members being in the normal range with scores of 10 or below.

The results of the 7 week follow-up testing indicate that, for the majority of the group participants, there was a decrease in their BDI scores (Table 3). Only three of the respondents scored

higher in the follow-up testing, and one of these scored only one point higher than her post-group score. Clients #2 and 10's scores need to be examined more closely. Both of these participants scored in the mildly depressed range, whereas in the pre-group and post-group testing, neither scored as depressed. Client #2's father has been residing in a personal care home for several months, and she may be realizing that her father's lifestyle, capabilities and future are all severely impacted by this disease, and, as her father is in the later stages of the disease, these factors may all have affected Client #2's mood. Client #10 indicated that she is having a difficult time accepting the loss of a confidante, which is a relationship she used to have with her mother. As well, she indicated that her son is away for the summer and she misses her companionship with him. These losses may account for her score in the mildly depressed range.

These results appear to indicate that the support group experience, with the opportunity for increasing knowledge and being supported by others in similar circumstances, had an effect of improving the caregivers' feelings of depression in half of the cases. As indicated in Table 3, the pre and post-group scores did vary, but only Client #4 had a change in range from normal to mildly depressed. Client #4, on the pre-group testing, was in the normal range, but on post-group testing, scored in the mildly depressed

range. Therefore, this client actually rated more depressed following the group experience, which is opposite to what had been hypothesized. However, intervening variables, such as what else was occurring in her life, have to also be considered. This client had some major changes in her relationship with her parents. During the course of the group program, her mother moved away from her impaired father, who is now living alone. Her mother, who previously had never lived alone, was placing a great many requests for assistance in practical and emotional terms upon this client. As well, this client indicated in the group discussions that there is a great deal of conflict between her siblings and herself. Additionally, Client #4's father blames her for his wife's move away from him. All of these circumstances, as well as other factors in Client #4's life which the student may not be aware of could result in the change in her depressive state.

Six of the twelve participants improved in the post-group testing on the Beck Depression Inventory. One of the twelve group members' scores cannot be compared pre and post-testing as she only participated in the pre-group testing. Therefore, 50% of the participants improved in the area of depression following the intervention. One of the questions of this group program was whether it would benefit participants in the area of depression. It would appear from these results that half of the caregivers were

less depressed after the intervention and thus did benefit from this aspect of the support group program.

The results of the 7 week follow-up also indicate that six of the group members improved in their BDI scores from their post-group scores. Two of the respondent's scores remained the same when comparing the follow-up and the post-group scores. These results appear to support the finding that the group members did benefit from the group experience and were able to continue utilizing the skills and knowledge gained through the group experience, even after the termination of the 8 week group program.

Table 3

Evaluation - Beck Depression Inventory

			7 Week Follow-Up
	<u>Pre-Group Score</u>	<u>Post-Group Score</u>	<u>Evaluation Score</u>
Client #1	5	9	6
Client #2	7	8	11
Client #3	N/A	N/A	N/A
Client #4	7	13	3
Client #5	5	8	5
Client #6	1	2	2
Client #7	14	11	9
Client #8	8	6	5
Client #9	1	0	0
Client #10	7	4	16
Client #11	1	4	5
Client #12	3	1	0

Stress Quiz

Following the group experience, the results of testing utilizing the stress quiz were that the group as a whole indicated that they were more stressed.

By reviewing the pre and post-group scores as shown in Table 4, none of the respondents was less stressed post-group. In fact, in most cases the opposite is true. Respondents scored higher following the group experience in their stress responses (refer to Table 1). A number of theories may explain this. As the carereceiver progresses in the course of this disease, the caregiving responsibilities become increasingly demanding, which may, in turn, create a situation whereby the caregiver is more stressed. Another theory may be that through the group experience caregivers became more aware of what the future may hold for their impaired relative, and as this disease is progressive and deteriorating, the caregivers, through their heightened awareness, may feel increasingly stressed about their circumstances.

However, even though the group members tested as more stressed post-group, it is difficult to determine how they might have tested without the intervention. In almost all of their situations, the impaired person had deteriorated during the course of the program. Therefore, the change in scores might be attributed to the deterioration and might, in fact, have been even higher without the

group. Without a control group to compare the results with, it is not possible to determine what impact the intervention had upon the results.

When comparing the 7 week follow-up scores with the post-group responses seven of the respondents indicated being less stressed (Table 5). Of the four participants who scored higher on the 7 week follow-up, three were significantly more stressed. These results appear to indicate that, generally, the group members were able to utilize some of the stress management techniques that were a part of the group program, to their benefit. Although Alzheimer Disease is progressive and deteriorating, the majority of the group participants have adapted to their ever-changing caregiving roles over time, without becoming increasingly stressed.

Table 4

Stress Quiz

	<u>Pre-Group Responses</u>		<u>Post-Group Responses</u>	
	# of Not-Stressed Responses	# of Stressed Responses	# of Not-Stressed Responses	# of Stressed Responses
Client #1	15	8	15	8
Client #2	18	5	15	8
Client #3	N/A	N/A	N/A	N/A
Client #4	13	10	9	14
Client #5	13	10	12	11
Client #6	18	5	16	7
Client #7	15	8	14	9
Client #8	13	10	17	6
Client #9	17	6	20	3
Client #10	17	6	16	7
Client #11	22	1	15	8
Client #12	20	3	16	7

Table 5

Stress Quiz - 7 Week Follow-Up Responses

	# of Not-Stressed Responses	# of Stressed Responses
Client #1	17	6
Client #2	17	6
Client #3	N/A	N/A
Client #4	16	7
Client #5	11	12
Client #6	19	4
Client #7	15	8
Client #8	16	8
Client #9	17	6
Client #10	12	11
Client #11	18	5
Client #12	18	5

Social Support Questionnaire

The results of the social support questionnaire on the pre-group testing indicate that, on average, the caregivers feel most supported by family, somewhat less supported by friends and least supported by neighbours. These are the same results found when the 7 week follow-up scores are analyzed.

The results indicate that in the areas of support from friends and neighbours, the respondents' replies ranged from feeling very much supported (1) to not being supported at all (5). The average for the group for support from friends was 2.81 and for neighbours was 3.62. This indicates that friends on average provide some support, neighbours providing support only occasionally.

In the 7 week follow-up testing, the range of scores were from 1.71 to a score of 5.0. In both the areas of support from friends and neighbours, the average scores for the group indicate that the participants feel slightly less supported than on the pre-group testing. The average for the group for support from friends was 2.94 compared to the pre-group average of 2.81. For the area of support from neighbours, the pre-group average was 3.62 and the 7 week score was 3.75. These results indicate that, over time, the participants felt slightly less supported by friends and neighbours.

In the area of support from family, the results indicate a range of being very much supported (1) to a mid-range of support

(2.8). The average for the whole group was 1.9 on this 5 point scale. These results indicate that for most of the group members, family members are perceived as supportive to very supportive.

Family support scores in the 7 week follow-up testing ranged from 1.14 to 2.0. The average score for the group was 1.61. These results, when compared to a score of 1.9 on the pre-group testing, indicate that the participants, on average, feel more supported by their family over the course of time. Perhaps as the carereceiver's condition continues to deteriorate, other family members become involved, resulting in the caregiver feeling more supported.

Formal supports were also addressed in this questionnaire. Respondents were asked whether they received any help from Home Care and to list services received. They were also asked whether there were other people who are supportive to them (i.e., church, organizations to which they belong, etc.).

Clients, #1, 2, 10, 11 and 12 indicated that their family member was in receipt of Home Care supports. Clients #1, 4, 5, 6, 7 and 10 indicated that they received support from others besides family, friends and/or neighbours. The supports identified included the following: church, work colleagues, doctor, social worker and the Alzheimer Society.

These results indicate that most of the respondents were supported from both the informal and formal network. Family members

derived support from government programs (Home Care) as well as others with whom they were involved. This indicates that there are a variety of supports available which can be utilized. Family members were able to access the supports which enabled them to continue in their caregiving role. More emphasis needs to be placed upon the options available for support and how these can be accessed. However, for the caregiving group studied in this intervention, they already appear to be adept at seeking out the necessary supports for themselves.

The last part of this questionnaire requested that the respondents indicate, in an overall sense, whether they receive enough support both in their caregiving role and as a person. In the area of support as a caregiver, the responses ranged from 1 (very much) to 4 (5 being not at all). The average for the group was 2.36. In the area of support for themselves as a person, the responses ranged from 1 (very much) to 4 (5 being not at all). The average score for the group was 2.09. This indicates that most of the members felt quite supported in their caregiving role. (See Table 6 for Pre-Group Testing Average Scores, and Table 7 for the 7 Week Follow-Up Testing Average Scores.)

Table 6

Social Support Questionnaire Evaluation

<u>Pre-Group Testing Average Scores</u>			
	Very Much Supported: 1	Not Supported at All: 5	
	Family	Friend(s)	Neighbour(s)
Client #1	2.14	2.71	4.86
Client #2	2.28	3.67	4.83
Client #3	N/A	N/A	N/A
Client #4	3	2.86	4.71
Client #5	1.71	3.71	4.28
Client #6	1.86	2.71	5
Client #7	1.29	2.29	3.14
Client #8	1.0	1	1
Client #9	2.0	2.0	2.14
Client #10	2.14	2.29	4.86
Client #11	1.57	5.0	1.86
Client #12	1.86	2.71	3.14
Average for Group	1.9	2.81	3.62

Table 7

Social Support Questionnaire Evaluation

7 Week Follow-Up Testing Average Score			
	Very Much Supported: 1 Family	Not Supported at All: 5 Friend(s)	Neighbour(s)
<hr/>			
Client #1	1.71	2.14	4.71
Client #2	1.42	2.42	5.0
Client #3	N/A	N/A	N/A
Client #4	1.85	1.71	4.42
Client #5	1.42	4.0	4.28
Client #6	2.0	2.57	5.0
Client #7	1.14	1.85	3.14
Client #8	1.85	3.0	3.0
Client #9	1.42	3.42	2.14
Client #10	1.57	3.14	4.71
Client #11	1.42	5.0	1.86
Client #12	<u>2.0</u>	<u>3.14</u>	<u>3.0</u>
Average for Group	1.61	2.94	3.75

Social Support as it Relates to Stress

The data obtained through this study does not establish a link between the amount of support the caregivers perceive is available to them and the amount of stress they reported.

There are several examples of this. Three of the group members responded positively to being stressed in 10 out of a possible 23 responses. Two of these members, Clients #4 and #5, rated the amount of support they receive in the mid-range between being highly supported to not supported at all. The third client, Client #8, rated her support system as highly supportive. Although these three members scored the same on the Stress Quiz, the amount of support that Clients #4 and 5 perceive as available to them varied significantly from that of Client #8. Therefore, these findings do not indicate a link between social support and stress reaction.

From the results indicated in Table 5, Client #11 scored very low on the Stress Quiz but did not rate her support particularly high. When she is compared to Client #8, the link between social support and stress again cannot be established.

In comparing Clients #12 and #7, it again would appear that the amount of perceived support is not necessarily a mediating factor in the area of stress. Client #12 responded positively to being stressed only 3 times on the Stress Quiz, whereas Client #7

responded positively 8 times. Yet both of these clients appeared to rate the amount of support received as approximately the same, with Client #12 averaging her support in the three areas of family, friends and neighbours at 2.57 and Client #7 averaging at 2.24.

These results indicate that regardless of the amount of support the caregiver receives, they may or may not be highly stressed. This may be a result of several factors: their own coping styles; their ability to handle stress; whether they perceive the support they receive as helpful or not; their view of the future and the meaning they give to this and other stressors occurring in their lives that do not relate to being a caregiver.

An example of this is in the area of support received. Although assistance received from Home Care is intended to provide some relief to the caregiver, this assistance can actually result in increased stress. For example, when sitter service is provided, the carereceiver may become extremely agitated about being left alone with a stranger so that when the caregiver returns home they may, in fact, have to deal with a more difficult situation and this may increase their stress level.

Another example may be in the area of finances. One can speculate that even if a caregiver may receive emotional support from family and friends, they may not receive any financial support. If the carereceiver or the caregiver had to retire early due to the

illness, they may be having financial difficulties. The support they receive may not address this area, so that the caregiver may report being highly stressed in spite of the emotional support received.

This group addressed issues of stress and stress management techniques as it relates to Alzheimer Disease and issues of caregiving. Other life stressors for the group members were not addressed and may have a great deal of influence upon their reporting.

Therefore, it is difficult to account for the effect of support upon stress. From the findings of this study, no correlation was established.

Client Satisfaction Questionnaire (CSQ)

The majority of the group members rated the quality of service received as excellent (7 out of 11). Ten out of eleven of the respondents indicated that the program met most of their needs.

In the area of education, five members of the group rated the educational component as definitely meeting their needs, six of the members responding "I think so". This relates to how members scored on the Alzheimer Disease Knowledge Test on the post-group testing.

In the area of stress management, 3 of the respondents rated the group as definitely helping them in this area, with 7 stating "I

think so". This rating is contrary to the findings when comparing the pre and post-group testing on the Stress Quiz.

Most of the group members indicated that they developed new relationships with others who understand their problems through being a member of this group. Seven of the members responded "Yes, I think so", three "Yes, definitely" and one "No, I don't think so". It would appear that this support group resulted in the members feeling more supported and understood.

In a general sense, the group responded favorably to having been a part of this support group. Nine out of the eleven members stated that they would definitely recommend this service to other caregivers, and 8 of the 11 members reported that they were very satisfied with the services received (in Appendix G).

The group members rated the group experience as beneficial to them. It appears that having the opportunity to meet with others who are having similar experiences, who share the same concerns and where mutual support is offered is highly rated by caregivers of the cognitively impaired.

In fact, the members, when offered the opportunity to continue meeting as a group, opted for this. All but one of the members wished to continue. This appears to indicate that the group experience was found useful to the group members and that they found it helpful in coping with their caregiving responsibilities. Group

members were generally less depressed following the program, more knowledgeable about the disease and resources available to their impaired relative and expressed that they were strengthened by knowing that they were not alone in their caregiving roles.

Table 8

Pre-Group Testing

	Social Support Questionnaire	Stress Quiz
	Average Support Score	# of Stressed Responses
Client #1	3.23	8
Client #2	3.6	5
Client #3	N/A	N/A
Client #4	3.52	10
Client #5	3.23	10
Client #6	3.19	5
Client #7	2.24	8
Client #8	1	10
Client #9	2.04	6
Client #10	2.45	6
Client #11	2.81	1
Client #12	2.57	3

Post-Session Report

Group participants were requested to complete a Post-Session Report at the end of Meetings 1 through to 7, inclusive (in Appendix E). This evaluative tool was not used at the end of Session 8 as the participants were requested to complete a Client Satisfaction Questionnaire rating the entire program (in Appendix E).

The Post-Session Report was a rating of each individual session. The respondents were given five rating choices: (1) Not Useful at All; (2) Very Little Was Useful; (3) Not Sure; (4) Somewhat Useful, and (5) Very Useful. Refer to Table 9 for the results.

Group members generally rated the group highly. The category "Very Useful" was indicated by the majority of caregivers on all sessions with the exception of the first session. The second highest ranking, "Somewhat Useful" was the next more frequent response. The two categories rating the group experience most unfavorably, "Very Little Was Useful" and "Not Useful At All" received only one response for all of the sessions.

The group members' rating of the usefulness of this group would indicate that they did find it beneficial, informative and that it generally met their needs.

Table 9

POST-SESSION REPORT

Number of Responses to Each Ranking

Session #	1	2	3	4	5	6	7
Not Useful At All	0	0	0	0	0	0	0
Very Little Was Useful	1	0	0	0	0	0	0
Not Sure	3	0	2	0	0	0	0
Somewhat Useful	2	2	0	4	0	1	2
Very Useful	4	9	9	8	9	8	6

CHAPTER 7

PERSONAL LEARNING

EVALUATION OF MY LEARNING EXPERIENCE

As stated early, some of my objectives in undertaking such a study included increasing my knowledge level of the major issues and concerns affecting caregivers of the cognitively impaired, to gain greater insight and understanding of the coping skills and adjustment styles of these caregivers and to enhance my skills as a facilitator.

In terms of increasing my knowledge level in the area of cognitive impairment, through extensive reading and listening carefully to the participants of the group I facilitated, I was able to become more sensitive to the needs and issues that these caregivers face.

In terms of enhancing my understanding of the coping styles and skills of the careproviders, I encouraged the group members to share their coping skills with each other and I subsequently learned a great deal from the group members. I once again reviewed the literature available as regards this topic, and this also increased my understanding and knowledge in this area.

In the area of enhancing my own skills as a facilitator, a number of different methods were employed. These included

supervision, videotaping and utilizing a self-rating group leadership scale.

Throughout the eight week group program, I met with my Faculty of Social Work advisor every two weeks. We reviewed my facilitation role, my group work skills and the progress of the group members. A number of suggestions were offered by my advisor, and having the opportunity to discuss my skills with an objective, knowledgeable instructor enhanced my professional growth.

In the pre-group interview I had with each member, permission was asked to videotape the sessions. Group members were advised that the tapes would be used as a learning tool and were to be reviewed by myself and my advisor. They were also advised that no one else would be allowed to view these tapes. All of the group members agreed to be taped.

These videotapes provided my advisor with the opportunity to observe and assess my facilitation skills, as well as the progress of the group and its individual members.

Group leadership skills were also evaluated by using the Group Leadership Scale developed by Corey and Corey (1977), an example of which is found in the appendix. This instrument was used as an objective way of evaluating my performance as a group facilitator. This is not a standardized test as it has not been tested for

reliability and validity. This instrument was used after each session, and the results may be found in the appendix.

THE ROLE OF THE FACILITATOR: EVALUATION

Group work skills are an integral part of a program as described in this practicum. In order to examine my effectiveness as a facilitator with such a group, evaluation of my role was a part of this practicum. Several evaluative techniques were used.

All of the sessions were videotaped, reviewed individually by both myself and then my advisor, and then discussed between us. By viewing these tapes, I was more easily able to observe my leadership/facilitation style, to observe the group dynamics and both the verbal and non-verbal communication. By discussing these aspects with my advisor, a more objective evaluation of my performance could take place. My advisor's observations and supervision helped me address those areas which required attention or change.

Another means of evaluating my leadership/facilitation skills was by using the Corey and Corey Group Leadership Skills Rating Scale (in Appendix I). This tool provided me with a means to self-evaluate my group work skills on a weekly basis. As the same skills were being evaluated following each session, I was able to identify the areas of concern and to assess changes I could make in these specific skills.

Areas that I needed to address included the need to scan the group and thus become more aware of the non-verbal communication, and to be more flexible in terms of the agenda and thus allow the group increased opportunity to address the issues of concern to them. I also needed to pay more attention to giving all of the group members the opportunity to address the subjects raised.

Through these evaluative techniques I also became more aware of my strengths as a group leader. I am able to clarify issues, create linkages, point out commonalities, draw out the quiet members and create an atmosphere which is comfortable, open and conducive to sharing.

Areas that I continue to need to work on include scanning, active listening, interpreting, supporting and evaluating. Through this practicum experience I am more aware of my strengths and weaknesses and of the areas that continue to require my attention for ongoing growth and improvement.

RESULTS OF THE GROUP LEADERSHIP SKILLS RATING SCALE

The results of this scale were useful in helping me to identify my strengths and weaknesses, and to visually analyze each table and be able to make comparisons among the tables (in Appendix I).

Tables 3, 4, 6, 9, 10, 13, 14 and 15 of the appendix showed more stability than the other tables. These tables measured the

skills of clarifying, summarizing, questioning, supporting, blocking, facilitating, empathizing and terminating. Tables 1, 2, 5, 7, 8, 11, and 12 showed lower stability. These measured the skills of active listening, reflecting, interpreting, linking, confronting, diagnosing and evaluating. The most stable skill was confronting, which improved significantly over the eight sessions. The skill which had the highest average score was empathizing, the lowest average score was in the area of confronting, which corresponds directly with the most and least stable skills.

Utilizing this scale and assessing my skills in these 15 areas of leadership ability after each of the group sessions was helpful in providing me with another tool to become aware of the techniques that require my further attention.

CHAPTER 8

OBSERVATIONS AND CONCLUSIONS

There are a number of limitations in the study described in this practicum. These include the following:

- a) there is a need for specification of those persons who are most likely to benefit from group intervention
- b) there was no random assignment of caregivers to the group or to a control group, and, there was, in fact, no control group to draw comparisons with
- c) there were a small number of participants. Although more than 12 members in the group would have been difficult in terms of group development and cohesion, this is a small number to be drawing inferences from
- d) the facilitator/student administered the intervention and the testing, which may have increased demand effects
- e) although a 7-week follow-up was a part of this study, long-term effects of the intervention were not evaluated. That is, there will be no follow-up testing in 6 months, or one year, so the long-term benefits cannot be determined
- f) this study recognized that there may have been intervening life events which may have affected the results of the testing. However, the study was unable

to factor in those events which may have impacted upon the results

- g) previous coping history of the caregiver was not addressed in this practicum and this would have an effect upon the benefits which might or might not have resulted from the intervention.

Several findings resulted from this study. Family support groups appear to be beneficial for those who do attend these groups. However, attention needs to be paid to alternative forms of intervention for those who do not wish to attend a group setting.

As only female caregivers took part in this study, the male perspective was not addressed. In fact, the males contacted about joining the group were, with one exception, not interested in participating. Other methods of intervention need to be explored to encompass the needs of the male caregiver.

This group met some of the needs of white, middle-class females. Further exploration needs to be done to determine the needs of caregivers of other racial and socioeconomic groups. Attention needs to be placed on cultural differences and what methods of intervention would satisfy the needs of the multi-cultural mosaic of our society.

The caregiving population is not homogeneous. Spousal caregivers may be elderly, middle-aged, may be physically healthy or

may have health problems. They may be the adult child or grandchild of the impaired person. Their needs and abilities to cope vary as does their desire or ability to attend a group. The frail, elderly caregiver may be physically unable to attend the group due to such conditions as our long, cold winters, or may have no one to stay with their impaired relative. The younger caregiver may feel out of place in that their issues and concerns may be vastly different than that of the other caregivers. Therefore, interventions need to be designed to meet the unique needs of each of these specific groups of caregivers.

Support groups have been the main method of intervention offered to caregivers of the cognitively impaired. Other alternatives need to be developed and offered. These might include individual counselling, peer counselling, home visits for the isolated or elderly caregiver or a telephone network for those unable to leave their home and whose impaired relative would be uncomfortable with someone coming to the home to offer counselling.

The needs of the caregiver may also change rapidly and interventions should be designed to address these everchanging circumstances. In the group studied, the carereceivers were all at differing stages of the disease, and, as a result, the caregivers were at varying stages of adaptation and coping with their impaired relative. This created a diversity and richness of experience in

the group setting. As related in this study, group members were made aware, through the experience of others, of the varying stages of this disease. It is extremely difficult to have a group which focuses on a particular phase of this disease (i.e., middle phase). As the disease is progressive and as the course of the disease varies, the groups need to encompass the rapid changes which may occur. This was evidenced by the experience of this particular group. At the pre-group interviews, none of the carereceivers were institutionalized. By the first session, one carereceiver was residing in a personal care home setting. By the last session, one additional carereceiver was institutionalized and by the 7 week follow-up session yet another relative was living in a personal care home. As well, during the course of the 8 week program, another family member had begun the process of making application for placement.

Although the sample size of this study was small, the findings concur with previous studies that stated that group participants rate support groups favourably. As previously noted, the majority of participants reported that they would recommend this service to other caregivers and that the group experience was beneficial to them.

Results of this study indicate that the participants benefitted from the educational component and that several of the

members improved in the area of depression. As relates to the stress management component, the findings do not support that the caregivers were less stressed after the intervention, but the caregivers rated in the CSQ that they felt the stress management techniques were helpful to them. The findings of this study appear to indicate that although the participants' scores did not always significantly change after the intervention, they rated the group as helpful in all of the areas addressed. The perception of the group members was that they did derive benefit from this experience. In fact, the group members decided that they would like to continue meeting. This is an indication that the members viewed the group experience positively.

In conclusion, providing care to someone with a cognitive impairment can be challenging, frustrating and rewarding. The experience does not have to be overwhelming. With appropriate interventions, caregivers can become better equipped to handle the demands placed upon them. Professionals need to be responsive to the varying needs of caregivers and thus are challenged to develop interventions which will meet the different needs of caregivers, regardless of their unique circumstances.

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APPENDICES

APPENDIX A

EIGHT-WEEK GROUP PROGRAM - CONTENT

The content of the 8 week group program was as follows:

WEEK 1:

Purpose: introductory session; getting to meet each other; becoming acquainted with group format and its purposes; beginning to establish commonalities.

- Goals:
- a) to share common concerns
 - b) to begin discussion of stress and what can be done about it.

WEEK 2:

Purpose: members to begin to share common problems and concerns; to determine mutual goals; provide educational component.

- Goals:
- a) to have more open, member-to-member interaction
 - b) to learn about the causes of dementia, what reversible dementias are, and the stages of the disease
 - c) to discuss the issues of driving, repetitive questions, anger and agitation.

WEEK 3:

Purpose: introductions by reviewing how change can create stress; to develop increased group interaction and mutual support

- Goals:
- a) to begin review of stress reduction
 - b) examine interconnectedness of change and stress

c) discussed issues of eating patterns, what happens when the caregiver is unwell.

WEEK 4:

Purpose: introductions to focus upon sharing of coping skills and positive ways of coping; to provide information and suggestions on activities of daily living; to provide information on legal issues.

- Goals:
- a) to provide group members with role models for coping
 - b) to get the members to examine their own coping skills
 - c) to provide information on activities of daily living so as to establish that their relatives' behaviours are not intentional; to offer practical suggestions for coping
 - d) to provide information on legal issues so that caregivers are informed.

WEEK 5:

Purposes: to get members to become aware of caring for the caregiver; to discuss issue of what and when you tell your relative about their illness; to discuss behaviours of the impaired person; to discuss feelings of guilt

- Goals:
- a) to have caregivers begin to give themselves license to do things for themselves

b) to help those who are struggling with what and when to tell your relative about their illness by others relating their experiences with this issue

c) to help caregivers understand and accept the changed behaviours of the impaired carereceiver

d) to acknowledge feelings of guilt and attempt to come to terms with these feelings

WEEK 6:

Purposes: to discuss involuntary separation; to discuss issues and concerns raised by the group members

Goals: a) to discuss involuntary separation as finances are of concern to a number of the group members

b) to allow group members to bring up those issues and concerns which are of primary importance to them

WEEK 7:

Purposes: open session with discussion of those concerns which group members raise at the meeting

Goals: a) to allow group members to have increased control of agenda for meeting

b) to address those issues which group members find most pressing

c) to provide increased opportunity for member-to-member interaction

WEEK 8:

Purposes: to address issues of concern to group members; to complete questionnaires and tests; to determine future of group

Goals: a) to address any outstanding issues of concern as this was the last meeting of this series

b) to determine whether group wished to continue, in what format (i.e., open/closed), how often, and who would facilitate.

APPENDIX B

Dear

I am a Master of Social Work student doing a practicum in the area of Alzheimer support groups. The emphasis of my study will be on the effectiveness of a spousal support group for caregivers of Alzheimer patients who are residing in their homes with their spouse. The focus of my study will be to determine whether an educational and supportive group, with a stress management component, will be effective in reducing the participants' stress levels and assisting them in terms of feelings of depression.

I am hoping that you, and/or members of your Social Work department, might consider referring potential group members for this study. Inclusion criteria for participants are as follows:

1. Diagnosis from a physician that the impaired person has Alzheimer Disease or another related cognitive impairment.
2. The diagnosis will be known to the spousal caregiver for a period of no less than 3 months and no longer than 2 years.
3. Group members must be the spouse of the impaired person and must reside with the care receiver.
4. These spousal caregivers have not previously attended an Alzheimer support group.
5. Caregivers should be between the ages of 55 and 75 years and not display any signs of cognitive impairment.
6. Preferably, these caregivers should be able to read, write and understand English.

This group will be meeting for a period of eight weekly sessions, and it is anticipated that the group will begin shortly. These group meetings will each be of two hours duration and will be held either at Deer Lodge Centre or the Alzheimer Society offices on Edmonton Street. Participants will be requested to complete questionnaires and tests which are part of this study.

Participants will be advised that their participation is part of a study, and it will be requested that the findings may be used at a later date should I decide to present the material at workshops or conferences or as part of a published article. Group participants will be assured of confidentiality.

I anticipate meeting with each potential participant prior to acceptance into the group. This will give me an opportunity to determine whether these potential participants are appropriate for inclusion in this study.

I would be most appreciative if you would consider referring participants to this study. I am hopeful that these participants will benefit from this group setting and it will assist them to cope with their caregiving responsibilities as well as reduce their feelings of stress and depression.

I look forward to discussing this further with you and would like to call you within the next two weeks to explain this study further and to answer any questions you may have. I hope this will be suitable to you.

Should you have any questions regarding this request, or should you wish to refer participants to this program, please do not hesitate to contact me at

(work) or (home).

Thank you.

Yours truly,

Esther Gill, BSW,RSW
Department of Social Work
Deer Lodge Centre
2109 Portage Avenue
Winnipeg, Manitoba
R3J 0L3

Dear

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(work) or (home).

Thank you.

Yours truly,

Esther Gill, BSW,RSW
Department of Social Work
Deer Lodge Centre
2109 Portage Avenue
Winnipeg, Manitoba
R3J 0L3

APPENDIX C

BASIC INFORMATION SHEET

NAME: _____

ADDRESS: _____

POSTAL CODE: _____

TELEPHONE NUMBER: HOME: _____ WORK: _____

HAVE YOU RECEIVED A DIAGNOSIS FOR YOUR SPOUSE FROM A PHYSICIAN?

YES: _____ NO: _____

IF YES, WHAT DIAGNOSIS: _____

WHEN DID YOU RECEIVE THIS DIAGNOSIS? _____

HOW LONG HAS IT BEEN SINCE YOU FIRST NOTICED THE ONSET OF THE DISEASE?

IS THE IMPAIRED PERSON LIVING WITH YOU? _____

WITH ANOTHER FAMILY MEMBER? _____

ALONE? _____

AGE GROUP OF THE PERSON WITH THE IMPAIRMENT:

40 to 50 _____ 60 to 70 _____ 80 to 90 _____

50 to 60 _____ 70 to 80 _____

ARE THERE ANY OTHER FAMILY(S) DIRECTLY INVOLVED IN THE CARE OF YOUR SPOUSE? IF YES, WHOM, AND, ON AVERAGE, HOW MUCH TIME PER WEEK DO THEY PROVIDE THIS CARE? _____

DO YOU RECEIVE HELP FROM THE OFFICE OF CONTINUING CARE OR V.O.N.? WHAT SERVICES DO YOU RECEIVE AND HOW FREQUENTLY? _____

HAVE YOU EVER ATTENDED A SUPPORT GROUP IN THE PAST? _____

IF YES, WHAT WAS THE FOCUS OF THE GROUP? _____

WHAT ARE THE DIFFICULTIES, IF ANY, THAT WOULD PREVENT YOU FROM ATTENDING REGULAR MEETINGS:

NO TRANSPORTATION? _____
NO ONE TO CARE FOR SPOUSE? _____
NOT INTERESTED? _____
OTHER? _____

ABOUT THE MEETINGS, WOULD YOU PREFER:

MORNINGS: _____
AFTERNOON: _____
EVENINGS: _____

WHICH DAYS OF THE WEEK WOULD YOU PREFER:

WOULD YOU BE WILLING TO COMPLETE A QUIZ AND SOME QUESTIONNAIRES AS PART OF THIS PROGRAM? THIS WOULD ENTAIL A SMALL AMOUNT OF YOUR TIME OUTSIDE OF GROUP MEETING TIME: _____

WOULD YOU BE WILLING TO SHARE THE RESULTS OF THIS PROGRAM WITH OTHERS; EITHER CAREGIVERS AND/OR PROFESSIONALS? ALL FINDINGS WILL BE CONVEYED IN GENERAL TERMS AND STRICT CONFIDENTIALITY FOR ALL PARTICIPANTS WILL BE MAINTAINED. _____

APPENDIX

CONSENT FORM

I understand that the support group I will be attending will be reported on as part of Esther Gill's studies towards completion of a Master Degree in Social Work. The findings from this study may form the basis of an article or may be part of a presentation at workshops or conferences.

I agree that the findings may be used as part of Esther Gill's report, ensuring that confidentiality is maintained and that any identifying information will be eliminated.

I also agree to try to complete all of the questionnaires and tests to the best of my ability, before, during and after the group sessions.

Signed _____

APPENDIX D

1. The percentage of people over 65 who have severe dementia caused by Alzheimer disease or a related disorder is estimated to be
 - A. less than 2%
 - B. about 5%
 - C. about 10%
 - D. 20-25%
 - E. I don't know

2. The cause of Alzheimer disease is
 - A. old age
 - B. hardening of the arteries
 - C. senility
 - D. unknown
 - E. I don't know

3. Larger than normal amounts of aluminum have been found in the brains of some people with Alzheimer disease. Studies investigating the role of aluminum in causing Alzheimer disease
 - A. have determined that it is the major cause
 - B. have determined that it plays a role in the onset of the disease
 - C. are inconclusive
 - D. have proven that it is not a cause
 - E. I don't know

4. Which of the following procedures is required to confirm that symptoms are due to Alzheimer disease?
 - A. mental status testing
 - B. autopsy
 - C. CT scan
 - D. blood test
 - E. I don't know

5. Which of the following is always present in Alzheimer disease?
 - A. loss of memory
 - B. loss of memory, incontinence
 - C. loss of memory, incontinence, hallucinations
 - D. none of the above
 - E. I don't know

6. Most researchers investigating the use of lecithin as a treatment for Alzheimer disease have concluded that it
 - A. reverses symptoms
 - B. prevents further decline
 - C. reverses symptoms and prevents further decline
 - D. has no effect on the disease
 - E. I don't know

7. Sometimes Alzheimer disease patients wander away from home. Caregivers can best manage this problem by
 - A. reasoning with the patient about the potential dangers of wandering
 - B. sharing feelings of concern with the patient in a calm and reassuring manner
 - C. making use of practical solutions such as locked doors
 - D. remaining with the patient at all times to prevent the behavior
 - E. I don't know

8. What is the role of nutrition in Alzheimer disease?
 - A. proper nutrition can prevent Alzheimer disease
 - B. proper nutrition can reverse the symptoms of Alzheimer disease
 - C. poor nutrition can make the symptoms of Alzheimer disease worse
 - D. nutrition plays no role in Alzheimer disease
 - E. I don't know

9. People sometimes write notes to themselves as reminders. How effective is this technique for Alzheimer disease patients?

- A. it can never be used because reading and comprehension are too severely impaired
- B. it may be useful for the mildly demented patient
- C. it is a crutch which may contribute to further decline
- D. it may produce permanent gains in memory
- E. I don't know

1. The prevalence of Alzheimer disease in the general population of Canada is expected to
 - A. decrease slightly
 - B. remain approximately the same
 - C. increase in proportion to the number of people over 65
 - D. nearly triple by the year 2000
 - E. I don't know

2. Preliminary research concerning the role of heredity in Alzheimer disease suggests that
 - A. persons with a close relative with Alzheimer disease have an increased risk of becoming afflicted
 - B. Alzheimer disease is always transmitted genetically
 - C. Alzheimer disease is only inherited if both parents are carriers of the disease
 - D. Alzheimer disease is never inherited
 - E. I don't know

3. A person suspected of having Alzheimer disease should be evaluated as soon as possible because
 - A. prompt treatment of Alzheimer disease may prevent worsening of symptoms
 - B. prompt treatment of Alzheimer disease may reverse symptoms
 - C. it is important to rule out and treat reversible disorders
 - D. it is best to institutionalize an Alzheimer disease patient early in the course of the disease
 - E. I don't know

4. Which of the following conditions sometimes resembles Alzheimer disease?
 - A. Depression
 - B. Delirium
 - C. Stroke
 - D. All of the above
 - E. I don't know

5. Although the rate of progression of Alzheimer disease is variable, the average life expectancy after onset is
- A. 6 months - 1 year
 - B. 1-5 years
 - C. 6-12 years
 - D. 15-20 years
 - E. I don't know
6. Which of the following statements describes a reaction Alzheimer disease patients may have to their illness?
- A. They are unaware of their symptoms
 - B. They are depressed
 - C. They deny their symptoms
 - D. All of the above
 - E. I don't know
7. Which statement is true concerning treatment of Alzheimer disease patients who are depressed?
- A. It is usually useless to treat them for depression because feelings of sadness and inadequacy are part of the disease process
 - B. Treatments of depression may be effective in alleviating depressive symptoms
 - C. Anti-depressant medication should not be described
 - D. Proper medication may alleviate symptoms of depression and prevent further intellectual decline
 - E. I don't know

8. What is the effect of orienting information (i.e. reminders of the date and the place) on Alzheimer disease patients?
- A. It produces permanent gains in memory
 - B. It will slow down the course of the disease
 - C. It increases confusion in approximately 50% of patients
 - D. It has no lasting effect on the memory of patients
 - E. I don't know
9. When an Alzheimer disease patient begins to have difficulty performing self-care activities, many mental health professionals recommend that the caregiver
- A. Allow the patient to perform the activities regardless of the outcome
 - B. Assist with the activities so that the patient can remain as independent as possible
 - C. Take over the activities right away to prevent accidents
 - D. Make plans to have the patient moved to a nursing home
 - E. I don't know
10. Which of the following is a primary function of the Alzheimer Society of Manitoba?
- A. Conducting research
 - B. Providing medical advice
 - C. Family support and education
 - D. Providing day care for Alzheimer disease patients
 - E. I don't know

STRESS QUIZ

ANSWER ALL OF THE QUESTIONS BELOW BY CHECKING THE APPROPRIATE COLUMN FOR "YES" OR "NO". ANSWER THE QUESTIONS IN TERMS OF YOUR OWN PERSONAL EXPERIENCES AND FEELINGS DURING THE PAST TWELVE MONTHS.

	NO	YES
1. HAVE YOU CHANGED YOUR LIVING ACCOMMODATIONS OR MOVED?	_____	_____
2. HAVE YOU TAKEN OUT A LARGE LOAN OR MORTGAGE?	_____	_____
3. HAVE YOU FALLEN BEHIND WITH THE THINGS YOU WANT TO DO?	_____	_____
4. DO YOU HAVE DIFFICULTY CONCENTRATING?	_____	_____
5. DO YOU HAVE TROUBLE SLEEPING?	_____	_____
6. DO YOU FEEL YOU TEND TO EAT, DRINK OR SMOKE MORE THAN YOU REALLY SHOULD?	_____	_____
7. IF YOU ARE STILL EMPLOYED, HAVE YOU OR YOUR SPOUSE RECENTLY CHANGED JOBS OR WORK RESPONSIBILITIES?	_____	_____
8. DO YOU FEEL YOU HAVE AN EXCESSIVE AMOUNT OF RESPONSIBILITY?	_____	_____
9. HAS A CLOSE FRIEND PASSED AWAY?	_____	_____
10. HAVE YOU BEEN DISSATISFIED WITH YOUR SEX LIFE?	_____	_____
11. HAVE YOU BEEN WORRIED ABOUT FINANCES?	_____	_____
12. HAS A FAMILY MEMBER HAD BAD HEALTH?	_____	_____
13. HAVE YOU TAKEN TRANQUILIZERS OCCASIONALLY?	_____	_____
14. HAVE YOU FOUND YOURSELF OFTEN BECOMING FRUSTRATED WHEN THINGS DON'T GO WELL?	_____	_____
15. DO YOU HAVE DIFFICULTY RELATING TO YOUR SPOUSE?	_____	_____
16. DO YOU HAVE DIFFICULTY RELATING TO YOUR CHILDREN?	_____	_____
17. HAVE YOU FOUND THAT YOU ARE OFTEN IMPATIENT WITH FAMILY MEMBERS OR FRIENDS?	_____	_____
18. HAVE YOU TENDED TO FEEL RESTLESS OR NERVOUS OFTEN?	_____	_____
19. HAVE YOU HAD FREQUENT HEADACHES OR STOMACH ACHES?	_____	_____
20. DO YOU FEEL ANXIOUS OR WORRIED FOR DAYS AT A TIME?	_____	_____
21. HAVE YOU OFTEN FELT SO PREOCCUPIED THAT YOU HAVE FORGOTTEN WHERE YOU'VE PUT SOMETHING (I.E. GLASSES) OR FORGOTTEN WHETHER YOU'VE LEFT AN APPLIANCE ON?	_____	_____
22. HAVE YOU HAD AN ACCIDENT, MAJOR ILLNESS OR SURGERY IN THE PAST YEAR?	_____	_____
23. HAS ANYONE IN YOUR IMMEDIATE FAMILY DIED?	_____	_____

Beck Depression Inventory

by Aaron T. Beck

Read over the statements grouped with each letter, A through U. Pick out the statement within each group that best describes the way you feel today, that is, right at this moment. Circle the number next to the statement that you have chosen in each group. If two or more statements in a group describe the way you feel equally well, circle each one. Be sure to read over all of the statements in each group before you decide on one.

A. (Sadness)

- 0 I do not feel sad.
- 1 I feel blue or sad.
- 2a I am blue or sad all the time and I can't snap out of it.
- 2b I am so sad or unhappy that it is quite painful.
- 3 I am so sad or unhappy that I can't stand it.

B. (Pessimism)

- 0 I am not particularly pessimistic or discouraged about the future.
- 1 I feel discouraged about the future.
- 2a I feel I have nothing to look forward to.
- 2b I feel that I won't ever get over my troubles.
- 3 I feel that the future is hopeless and that things cannot improve.

C. (Sense of failure)

- 0 I do not feel like a failure.
- 1 I feel I have failed more than the average person.
- 2a I feel I have accomplished very little that is worthwhile or that means anything.
- 2b As I look back on my life all I can see is a lot of failures.
- 3 I feel I am a complete failure as a person (parent, husband, wife).

D. (Dissatisfaction)

- 0 I am not particularly dissatisfied.
- 1a I feel bored most of the time.
- 1b I don't enjoy things the way I used to.
- 2 I don't get satisfaction out of anything anymore.
- 3 I am dissatisfied with everything.

E. (Guilt)

- 0 I don't feel particularly guilty.
- 1 I feel bad or unworthy a good part of the time.
- 2a I feel quite guilty.
- 2b I feel bad or unworthy practically all the time now.
- 3 I feel as though I am very bad or worthless.

F. (Expectation of punishment)

- 0 I don't feel I am being punished.
- 1 I have a feeling that something bad may happen to me.
- 2 I feel I am being punished or will be punished.
- 3a I feel I deserve to be punished.
- 3b I want to be punished.

G. (Self-dislike)

- 0 I don't feel disappointed in myself.
- 1a I am disappointed in myself.
- 1b I don't like myself.
- 2 I am disgusted with myself.
- 3 I hate myself.

H. (Self-accusations)

- 0 I don't feel I am any worse than anybody else.
- 1 I am critical of myself for my weaknesses or mistakes.
- 2 I blame myself for my faults.
- 3 I blame myself for everything bad that happens.

I. (Suicidal ideas)

- 0 I don't have any thoughts of harming myself.
- 1 I have thoughts of harming myself but I would not carry them out.
- 2a I feel I would be better off dead.
- 2b I feel my family would be better off if I were dead.
- 3a I have definite plans about committing suicide.
- 3b I would kill myself if I could.

J. (Crying)

- 0 I don't cry any more than usual.
- 1 I cry more now than I used to.
- 2 I cry all the time now. I can't stop it.
- 3 I used to be able to cry but now I can't cry at all even though I want to.

K. (Irritability)

- 0 I am no more irritated now than I ever am.
- 1 I get annoyed or irritated more easily than I used to.
- 2 I feel irritated all the time.
- 3 I don't get irritated at all at the things that used to irritate me.

L. (Social withdrawal)

- 0 I have not lost interest in other people.
- 1 I am less interested in other people now than I used to be.
- 2 I have lost most of my interest in other people.
- 3 I have lost all my interest in other people and don't care about them at all.

- M. (Indecisiveness)
- 0 I make decisions about as well as ever.
 - 1 I try to put off making decisions.
 - 2 I have great difficulty in making decisions.
 - 3 I can't make decisions at all anymore.
- N. (Body image change)
- 0 I don't feel I look any worse than I used to.
 - 1 I am worried that I am looking old or unattractive.
 - 2 I feel that there are permanent changes in my appearance and they make me look unattractive.
 - 3 I feel that I am ugly or repulsive-looking.
- O. (Work retardation)
- 0 I can work about as well as before.
 - 1a It takes extra effort to get started at doing.
 - 1b I don't work as well as I used to.
 - 2 I have to push myself very hard to do anything.
 - 3 I can't do any work at all.
- P. (Insomnia)
- 0 I can sleep as well as usual.
 - 1 I wake up more tired in the morning than I used to.
 - 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
 - 3 I wake up early every day and can't get more than 5 hours sleep.
- Q. (Fatigability)
- 0 I don't get any more tired than usual.
 - 1 I get tired more easily than I used to.
 - 2 I get tired from doing anything.
 - 3 I get too tired to do anything.
- R. (Anorexia)
- 0 My appetite is no worse than usual.
 - 1 My appetite is not as good as it used to be.
 - 2 My appetite is much worse now.
 - 3 I have no appetite at all anymore.
- S. (Weight loss)
- 0 I haven't lost much weight, if any, lately.
 - 1 I have lost more than 5 pounds.
 - 2 I have lost more than 10 pounds.
 - 3 I have lost more than 15 pounds.
- T. (Somatic preoccupation)
- 0 I am no more concerned about my health than usual.
 - 1 I am concerned about aches and pains or upset stomach or constipation.
 - 2 I am so concerned with how I feel or what I feel that it's hard to think of much else.
 - 3 I am completely absorbed in what I feel.
- U. (Loss of libido)
- 0 I have not noticed any recent change in my interest in sex.
 - 1 I am less interested in sex than I used to be.
 - 2 I am much less interested in sex now.
 - 3 I have lost interest in sex completely.

SOCIAL SUPPORT QUESTIONNAIRE

PLEASE CIRCLE THE RESPONSE WHICH MOST CLOSELY REPRESENTS YOUR FEELINGS:

VERY MUCH

NOT AT ALL

IN YOUR CAREGIVING ROLE, DO YOU
FEEL SUPPORTED BY:

FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

DOES ANYONE HELP YOU WITH PRACTICAL
TASKS (I.E. GROCERY SHOPPING, HOUSE-
HOLD MANAGEMENT, ETC.)?

FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

DO YOU HAVE VISITORS TO YOUR HOME?

FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

DO YOU RECEIVE TELEPHONE CALLS FROM:

FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

DO YOU HAVE SOMEONE IN WHOM YOU CAN CONFIDE?

FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

DO YOU FEEL APPRECIATED IN YOUR CAREGIVING
ROLE BY:

FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

SOCIAL SUPPORT QUESTIONNAIRE (CONTINUED)

	VERY MUCH				NOT AT ALL
IN CASE OF EMERGENCY COULD YOU CALL UPON:					
FAMILY	1	2	3	4	5
FRIEND (S)	1	2	3	4	5
NEIGHBOUR (S)	1	2	3	4	5

ARE THERE OTHER PEOPLE WHO ARE SUPPORTIVE
TO YOU? (CIRCLE) YES NO
IF YES, PLEASE SPECIFY:

DO YOU RECEIVE ANY HELP FROM HOME CARE?
(CIRCLE) YES NO
IF YES, PLEASE LIST SERVICES RECEIVED
AND FREQUENCY BELOW:

	VERY MUCH				NOT AT ALL
DO YOU RECEIVE ENOUGH SUPPORT IN YOUR CAREGIVING ROLE?	1	2	3	4	5
DO YOU RECEIVE ENOUGH SUPPORT FOR YOURSELF AS A PERSON?	1	2	3	4	5

/OCT,91

APPENDIX E

POST - SESSION REPORT

PLEASE INDICATE HOW USEFUL YOU FOUND THIS SESSION:

¹
NOT USEFUL
AT ALL

²
VERY LITTLE
WAS USEFUL

³
NOT SURE

⁴
SOMEWHAT
USEFUL

⁵
VERY
USEFUL

WHAT DID YOU LIKE THE MOST ABOUT THIS SESSION?

WHAT DID YOU LIKE LEAST ABOUT THIS SESSION?

ADDITIONAL COMMENTS:

CLIENT SATISFACTION QUESTIONNAIRE (CSQ)

PLEASE HELP IMPROVE THIS SUPPORT GROUP BY ANSWERING SOME QUESTIONS ABOUT THE SERVICES YOU HAVE RECEIVED. PLEASE ANSWER HONESTLY, WHETHER YOUR OPINIONS ARE POSITIVE OR NEGATIVE. PLEASE ANSWER ALL OF THE QUESTIONS. YOUR COMMENTS AND SUGGESTIONS ARE WELCOME. THANK YOU VERY MUCH, YOUR HELP IS MUCH APPRECIATED

CIRCLE THE ANSWER WHICH MOST CLOSELY REFLECTS YOUR ASSESSMENT.

1. HOW WOULD YOU RATE THE QUALITY OF THE SERVICE YOU RECEIVED?

EXCELLENT	GOOD	FAIR	POOR
-----------	------	------	------

2. DID YOU GET THE SERVICE YOU WANTED?

NO, DEFINITELY NOT	NO, NOT REALLY	YES, GENERALLY	YES, DEFINITELY
-----------------------	-------------------	-------------------	--------------------

3. TO WHAT EXTENT DID THE PROGRAM MEET YOUR NEEDS?

ALL OF MY NEEDS HAVE BEEN MET	MOST OF MY NEEDS HAVE BEEN MET	ONLY A FEW OF MY NEEDS HAVE BEEN MET	NONE OF MY NEEDS HAVE BEEN MET
----------------------------------	--------------------------------------	--	--------------------------------------

4. DID THE EDUCATIONAL COMPONENT MEET YOUR INFORMATION NEEDS?

NOT AT ALL	NO, I DON'T THINK SO	YES, I THINK SO	YES, DEFINITELY
------------	-------------------------	--------------------	-----------------

5. DID YOU FIND THE STRESS MANAGEMENT TECHNIQUES USEFUL?

YES, DEFINITELY	YES, I THINK SO	NO, I DON'T THINK SO	NO, DEFINITELY NOT
-----------------	--------------------	-------------------------	-----------------------

6. DID YOU FEEL THAT YOU HAVE DEVELOPED NEW RELATIONSHIPS WITH OTHERS WHO UNDERSTAND YOUR PROBLEMS?

NO, DEFINITELY NOT	NO, I DON'T THINK SO	YES, I THINK SO	YES, DEFINITELY
-----------------------	-------------------------	--------------------	-----------------

7. WOULD YOU RECOMMEND THIS SERVICE TO OTHER CAREGIVERS?

YES, DEFINITELY	YES, I THINK SO	NO, I DON'T THINK SO	NO, DEFINITELY NOT
-----------------	--------------------	-------------------------	-----------------------

8. HOW SATISFIED ARE YOU WITH THE AMOUNT OF HELP YOU RECEIVED?

QUITE DISSATISFIED	INDIFFERENT OR MILDLY DISSATISFIED	MOSTLY SATISFIED	VERY SATISFIED
-----------------------	--	---------------------	-------------------

9. HAVE THE SERVICES YOU RECEIVED HELPED YOU TO DEAL MORE EFFECTIVELY WITH YOUR PROBLEMS?

YES, A GREAT DEAL	YES, SOMEWHAT	NO, NOT REALLY	NO, NOT AT ALL
----------------------	---------------	-------------------	-------------------

10. IN AN OVERALL SENSE, HOW SATISFIED ARE YOU WITH THE SERVICES YOU RECEIVED?

VERY SATISFIED	MOSTLY SATISFIED	INDIFFERENT OR MILDLY DISSATISFIED	VERY DISSATISFIED
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ADDITIONAL COMMENTS:

/OCT, 91

APPENDIX F

Dear Drs. Zarit:

I am a Master of Social Work student who is doing a practicum in the area of Alzheimer support groups. I will be studying the effectiveness of a spousal educational and support group for caregivers of Alzheimer patients who are residing in the community with their spouse. One of the purposes of this study is to determine whether increased knowledge regarding Alzheimer disease helps caregivers to cope. As a result, I am requesting permission to utilize "The Alzheimer's Disease Knowledge Test" which was found in the Gerontologist, Vol. 28, No. 3, 1988, pgs. 402-407. I will be incorporating the findings of this test in my larger study of the effectiveness of an educational and emotional support group, incorporating a stress management component on caregivers' stress and depression.

Therefore, I would very much appreciate it if I were to receive written permission from you to the effect that I can utilize this instrument for my study.

Thank you for your consideration of this matter.

Yours truly,

Esther Gill, B.S.W., R.S.W.

Home Address:

Permission granted -



UNIVERSITY of
PENNSYLVANIA
PRESS

October 19, 1990

Ms. Esther Gill, BSR, RSW

Dear Ms. Gill:

Thank you for your letter of October 11, 1990 regarding the use of the "Beck Depression" by Aaron I. Beck. I am not quite certain what you mean by the "Beck Depression" though I am presuming you are referring to items from Beck's book Depression.

In order to save time we are prepared to allow you to utilize material from Depression for use in your practicum without charge. However, should you wish to publish your work in due course you must apply again for permission. If you do, please send us all the information, including chapters and page numbers.

Please acknowledge Dr. Beck and the Press in your work.

Wishing you every success in your practicum.

Yours sincerely,

Pauline Caras
Rights & Information

APPENDIX G

POST-SESSION REPORT

Comments About What Members Liked Most

1. Sharing with each other feelings of coping (was expressed 14 times).
2. Others in same situation (was expressed 7 times).
3. Learning about the disease.
4. Sharing similarities and differences in dealing with relatives with Alzheimers.
5. The causes of Alzheimer Disease - what we can do or not do.
6. Discussing symptoms and effects.
7. Information on stages.
8. Educational component.
9. The reassurance that it's OK, we will make it.
10. I feel more confident about the way I handle my husband.
11. Discussion on nursing home placement and group discussion on stress.
12. No one ill at ease to discuss openly.
13. Learning how to handle my own stress.
14. Outside help one can receive such as Wanderer's Registry.
15. Legal information.
16. Information, re: Power of Attorney (expressed 5 times).

17. Feeling less guilty; being able to express guilt without recriminations.

18. Everyone was very open and honest about their feelings.

19. It was fun - great to hear ideas of what we can do to help ourselves.

Comments About What Members Liked Least

1. Too long of time for session.
2. Speaking about me, my feelings.
3. Would like more educational information.
4. It was over too soon.
5. No decaf coffee.
6. Not enough time to cover everything.
7. Sometimes off topic.
8. Stress sheets.
9. Introducing myself.
10. Not enough time to talk with everyone during break.

Additional Comments

1. Hopefully my feelings will get better with these sessions.
2. Enjoyed this session.
3. Like starting session with what is going to happen and review at end.
4. Everyone is different.
5. I appreciate you sticking to the topic. It was great.

6. I'd like to know how to get more help.
7. Very informative and helpful for both caregiver and relative.
8. Well run, very informative.
9. Look forward to session. Guilty if not here.

CLIENT SATISFACTION QUESTIONNAIRE

1. How would you rate the quality of the service you received?

	# of responses
Excellent	7
Good	3
Fair	1
Poor	-

2. Did you get the support you wanted?

	# of responses
No, definitely no	-
No, not really	-
Yes, generally	5
Yes, definitely	6

3. To what extent did the program meet your needs?

	# of responses
All of my needs have been met	1
Most of my needs have been met	10
Only a few of my needs have been met	-
None of my needs have been met	-

4. Did the educational component meet your information needs?

	# of responses
Not at all	-
No, I don't think so	-
Yes, I think so	6
Yes, definitely	5

5. Did you find the stress management techniques useful?

of responses

Yes, definitely	3
Yes, I think so	7
No, I don't think so	1
No, definitely not	-

6. Did you feel that you have developed new relationships with others who understand your problems?

of responses

No, definitely not	-
No, I don't think so	1
Yes, I think so	7
Yes, definitely	3

7. Would you recommend this service to other caregivers?

of responses

Yes, definitely	9
Yes, I think so	2
No, I don't think so	-
No, definitely not	-

*8. How satisfied are you with the amount of help you received?

of responses

Quite dissatisfied	2
Indifferent or mildly dissatisfied	-
Mostly satisfied	4
Very satisfied	5

9. Have the services you received helped you to deal more effectively with your parents/spouse?

	# of responses
Yes, a great deal	5
Yes, somewhat	5
No, not really	1
No, not at all	-

10. In an overall sense, how satisfied are you with the services you received?

	# of responses
Very satisfied	8
Mostly satisfied	3
Indifferent or mildly dissatisfied	-
Very dissatisfied	-

* Although two of the members recorded that they were quite dissatisfied with the amount of help they received, both of these respondents rated the quality of the service they received as excellent and rated the overall services received as very satisfied. This discrepancy may be in terms of having misunderstood the question or having misread the response, or may be the actual response intended.

APPENDIX H

APPENDIX

INDIVIDUAL EVALUATIONS

Of the thirteen clients who agreed to participate in this program, one did not attend any of the sessions. Another, Client #3, attended only two of the meetings. Client #6 attended six of the eight sessions, as she was away on vacation for the last two meeting dates. Client #9 was absent for three of the eight sessions due to illness of her children. Clients #2, 5, 7, 8, and 10 all attended seven out of the eight sessions. Client #1, 4, 11, and 12 attended all of the meetings.

CLIENT #1

Client #1 is a mid-40's daughter of a 71 year old mother who has had Alzheimer Disease for about 4 years. When the initial contact was made with her, both of her parents were residing in the community, with home care supports. These supports consisted of home care three days a week for 2 hours, Meals-On-Wheels five days a week and V.O.N. seven days a week for medication monitoring.

By the time the group started, both of her parents were in an acute care hospital, awaiting placement into a personal care home. The mother had been prioritized for placement, and Client #1's father had physical disabilities which precluded his return to the community. Both parents were awaiting placement into a rural personal care home.

Client #1 has one brother, who resides in the rural community where the parents will be moving. This client did indicate that she would be able to rely upon her brother in the case of an emergency.

Client #1 is employed full-time in a stressful, demanding position. She indicated that she was routinely required to work overtime. She does not drive a vehicle and therefore has had to rely upon the bus system or the generosity of her friends. She is very active in her church and volunteers with a youth program. She also enjoys reading and would like to travel.

Although her mother is hospitalized, Client #1 indicates that she continues to deal with on-going, stressful situations relating to her mother. Her mother calls from the hospital and is accusatory and threatening. The hospital also calls frequently, requesting that Client #1 try to calm her mother down. Her father also does not have a good understanding of Alzheimer Disease and becomes upset when his wife becomes irate with him and subsequently contacts his daughter to ventilate his frustrations (both parents are presently in the same hospital).

In addition, Client #1 has had to deal with her mother's hallucinations, her constant requests for money and questions about when she can return home. Client #1 feels that she copes by laughing about some of the funny situations.

This client reported through the testing a slight increase in her level of knowledge about the disease following the intervention.

Even though there was only the slight increase, this client appeared to feel more comfortable responding to questions posed post-group. In the pre-group testing she responded "I don't know" on 7 out of the 9 questions, but had this response 3 out of 10 times on the post-group testing. Although this client may not have significantly increased her knowledge level, she may have felt more comfortable about her understanding.

In terms of the Beck Depression Inventory, her score increased from 5 pre-group to 9 post-group. Using the cut off scores recommended by Gallagher et al., a score of 10 or below is in the normal range. Therefore, the difference in the scores pre and post group may relate to a number of intervening variables, but Client #1 is not clinically depressed.

The scores on the Stress Quiz remained exactly the same for this client.

These test results may relate, in part, to the fact that during the group program period, this client's parents were both hospitalized, panelled for personal care home placement and prioritized for a rural care home. This eliminated some of the practical tasks this daughter used to do for her parents, but may have decreased the amount of control this client felt she had over the situation, thus effecting her depression score to a small degree.

This client indicated on the Social Support Questionnaire pre-group testing that she receives some support from family and friends, but very little from neighbours. She also indicated that she feels supported by her church and co-workers. Client #1 appears to feel quite supported in her role as a caregiver.

CLIENT #2

This is a late-40's daughter, whose father is 84 and is cognitively impaired. Client #2 began to notice signs of her father's impairment in the spring of 1989. Her mother has been the primary caregiver, until the impaired father was placed into a personal care home this January. When initially interviewed, her father was still living at home with her mother. At that time her father had been receiving home care services 5 days a week and Meals-On-Wheels 3 times a week.

Client #2 is a divorced, single parent. Her daughter provided approximately 4 hours of care to her grandfather while he was still residing in the community. She prepared some of the meals for her grandparents and took them out once a week.

Client #2 has a sister who lives out of the province. She is available to provide some emotional support, but, due to geographical distance, is unable to provide any practical assistance.

This client works full time in a health care setting and was already aware of a great many of the resources available to the

cognitively impaired. She relates that she has not had much time for hobbies due to her caregiving responsibilities, but would like to read, garden and used to enjoy cross-country skiing and crocheting. A stress releaser for her is walking.

Client #2 expressed the difficulties she has had in assisting with her father's adjustment to personal care home placement. She felt a great deal of guilt in having to initiate the placement and had difficulty dealing with her father's anger about the move. Her father can be accusatory and Client #2 must often intervene to resolve conflicts between her mother and father. This client must still provide on-going support to her mother, who resides alone in the community, and, as this is a new experience for her, she finds it somewhat difficult.

This client scored the highest on the Alzheimer Disease Knowledge Test in the post-group testing, scoring 9 out of a possible 10 correct responses. This client indicated throughout the group meetings that she has a good understanding of the disease, the progression of it, anticipated behaviours and the available resources. Her score did increase from the pre-group testing, indicating that her knowledge level was enhanced through participation in the group.

The pre and post group scores on the Beck Depression Inventory were 7 and 8. This is not indicative of depression and the change is not significant.

With regards to the Stress Quiz, this client indicated that she was stressed in 5 areas of her life pre-group and in 8 areas post-group. This was a somewhat surprising finding, as between the pre-group testing and the end of the group sessions, this client's father was placed into a personal care home. It would be anticipated that the respondents caregiving responsibilities would have decreased and the concern for her father's safety and her mother's health as the primary caregiver, would have improved. The increase in the stress score indicates that although placement may address some of the concerns of the caregivers, it does not eliminate, nor does it necessarily decrease their feelings of stress. Rather, the stresses and stressors may change when the caregiving responsibilities change.

This client receives some support from family, little from friends and almost no support from neighbours. She also does not receive support from church, work or organizations. In an overall sense, she rated that she receives only an average amount of support as a caregiver and for herself as a person.

CLIENT #3

Client #3 is a 60 year old daughter to a cognitively impaired 79 year old mother, who is residing with another daughter. The first signs of cognitive impairment were noted in June of 1991. Her mother receives no supports from the Office of Continuing Care, but they do have privately hired help arranged for from Monday to

Friday, from 9:00 a.m. to 5:00 p.m. In addition, Client #3 provides her sister with respite by caring for her mother one evening a week and for six hours on Sunday.

Client #3 has stated that her caregiving sister suffers from long-standing chronic depression, for which she has been frequently hospitalized. Providing caregiving to her mother apparently exacerbates her depression, but she insists that she wishes to continue in this role.

This client works full-time, but is hoping to retire this summer. She copes with her stress by leaving town and "getting away from it all". She also has her mother-in-law, who is in her 90's and in good health, living with her.

This client attended only two out of the eight sessions, and, as a result, she will not be evaluated as part of this study.

The test results were not tabulated as this member attended only 2 out of the 8 sessions and did not participate in any of the post-group testing.

CLIENT #5

Client #5 is the primary caregiver to her father, who has been diagnosed with Alzheimer Disease about one year ago. Her father is 78 years old, lives alone in a suite, and presently receives no home care supports. His daughter first noticed signs of the illness seven years ago. She had arranged home care for her father, but he refuses to let them into his home. He does receive Meals-On-Wheels

5 days a week and this is for both his lunch and his supper. During the course of the group program, he was panelled and prioritized for personal care home placement.

This daughter is in her early 40's, married and has two children. She works full time outside of the home. She has two brothers and one sister, all living outside of the province. They each come to visit their father about once a year. Client #5 enjoys reading and skiing.

Client #5's major difficulties in coping include repeated phone calls from her father, usually about 5 each night, her anxiety about her father's safety while he is living alone and the impending placement. This client does not feel that she can discuss the application for personal care home with her father as she anticipates that this will anger him greatly and he would alienate himself from her. She is anxious about how she will get her father to the home when there is a bed available for him.

This client also is highly stressed as she is the only caregiver available to her father. Although she states that her siblings are supportive, they are not available to provide practical support nor to assist with day to day decision-making. Client #5 states that she is anticipating her anxiety level to decrease once her father is in the safe, supervised environment of the personal care home.

This client's scores on the Alzheimer Disease Knowledge Test increased from 5 out of 9 correct on the pre-group testing to 8 out of 10 correct in the post-group scores. It had been hypothesized that increased knowledge would lead to increased feelings of control which, in turn, might make caregivers feel less depressed. Although this client's scores on the Beck Depression Inventory remained within the normal range, they did go up from a score of 5 pre-group to 8 post-group. This would appear not to support the hypothesis regarding increasing the knowledge level of caregivers.

Client #5 responded positively 10 times in the pre-group testing and 11 times post-group. This change is not significant.

Basically, this client's scores did not change significantly. However, during the course of the program Client #5's father was panelled and prioritized for placement, and it was anticipated that this would effect her scores more significantly.

Client #5 feels quite supported by her family, moderately so from her friends and generally not supported by her neighbours. She indicated that she receives little support in her caregiving role and little support for herself as a person.

CLIENT #6

Client #6 is an only child of a widowed 90 year old, cognitively impaired mother. She first noticed signs of memory loss about 5 to 6 years ago. Her mother lives alone in an apartment and to this point has not been receiving any assistance from Home Care.

She continues to be able to shop, cook and clean for herself, but with increasing difficulty.

This client is in her late 40's, is married and has two children. She works part-time outside of the home. She has one cousin who has provided her with a great deal of support in the past, but this cousin's husband is now ill and she is available only for emotional support.

Client #6 attended the first six sessions and was away on vacation for the last two meetings. This was understood to be the arrangement at the time of the pre-group interview.

Client #6 relates that her mother is unaware that there is anything wrong with her, and when she does attempt to discuss the situation with her mother, she forgets. This client is having difficulty in accepting the changed relationship she has with her mother, and stated that she is having difficulty with accepting her mother's deterioration. She is grappling with how much she should do for her mother as opposed to allowing her to be as independent as possible.

During the course of the group meetings, Client #6 began the process of obtaining Power of Attorney over her mother and also began the process of obtaining a geriatric assessment.

The changes in this client's score in all the areas of testing pre-group and post-group showed no significant changes. In the knowledge test, her pre-group score was 7 out of 9 and 8 out of 10

post-group. On the Beck Depression Inventory she scored 1 before the group started and 2 after the program. On the Stress Quiz, this client responded positively 5 times as being stressed pre-group and 7 times at the last testing.

This client had no major changes occurring in her caregiving responsibilities during the course of the program. Although she stated on several occasions that finding out what the future may hold for her mother as being depressing, this did not effect her depression scores.

This client indicated that she feels quite supported by her family, only moderately supported by her friends and not at all supported by her neighbours. She also indicated that she receives support from her family physician. Client #6 feels quite supported in her caregiving role and feels she receives a fair amount of support for herself as a person.

CLIENT #8

This mid-60's wife provides care to her 66 year old husband who suffers from cognitive impairment. Client #8 began to notice signs of this in the summer of 1988.

Client #8 has four children, three sons and one daughter, all living in Winnipeg. None of her sons will admit that their father is cognitively impaired. Rather, they blame their mother for not stimulating her husband enough and feel that it is her responsibility to motivate him. Her daughter is extremely

supportive to her, to the extent that she accompanied her mother to the sessions.

This client is also frustrated that the doctor has not given her husband a diagnosis and just states that he is cognitively impaired. She would like a diagnosis as she feels it will help her in dealing with her sons.

Client #8 likes to read, do crossword puzzles, cryptograms, and likes to go to church but is restricted in all of these activities due to her caregiving role.

This client indicates that she finds it difficult to cope with her husband's repetitive questions. Her husband also has frustrated, violent outbursts. He likes to have an unvarying routine every day and becomes agitated when family come to visit or his wife takes him out on errands for other people.

Client #8 also describes that her husband is not the only stress factor in her life. She states that there are many family problems, the latest of which is post-natal complications relating to a grandchild. She stated that she does not mind the demands that her family places upon her as it is preferable to her to "staring at the four walls".

This client, when comparing her pre-group scores with the post-group ones, increased her knowledge level slightly, scored a bit lower on the Beck Depression Inventory and her Stress Quiz

scores indicate that she was slightly less stressed. The Beck Depression scores are indicative of the normal range.

Client #8's situation appeared to remain relatively stable during the course of the 8-week program. She did not relate any major changes in her husband's condition and her family life appeared to remain as stable as she was generally used to.

This client feels very much supported by family, friends and neighbours. She also indicated that she is supported by her parish priest. Client #8 indicated that she is very much supported in her caregiving role and is very supported for herself as a person.

CLIENT #9

Client #9 is the daughter of Client #8, and therefore it is her father who is cognitively impaired. She provides her mother with a great deal of support, particularly as her brothers are unwilling to accept their father's declining cognitive abilities.

The client is in her mid-30's, is married and has two small children. Her youngest child is about 6 months old. Her husband is unemployed and looking for work. Client #9 was working part-time when this group started, but was laid off during the period of the meetings.

This client was most frustrated by what she viewed as her brothers' unsupportive attitude. As she is the only female sibling, she stated that they discount her opinions and have told her that she is exaggerating the severity of their father's condition.

She related that she does not find it difficult to listen to her father's stories over and over again as he would always listen to her when she was a child.

This daughter of Client #8 had a significant change in her score on the Alzheimer Disease Knowledge Test when pre-group and post-group scores are compared. On the pre-group testing she responded correctly to 2 out of the 9 questions and on the post-group testing she answered 8 out of 10 questions accurately. This client's score of 1 pre-group and 0 post-group on the Beck Depression Inventory indicates that she is clearly not clinically depressed. The Stress Quiz changed from 6 positive responses pre-group to 3 post-group.

This client attended this group to increase her knowledge level and as a support for her mother. This may explain the low scores she had on the Beck Depression Inventory and the Stress Quiz.

Client #9 rated that she is supported by family and friends equally and feels quite supported by them. She rated the support of neighbours only as being slightly less. She feels very much supported as a caregiver and in an overall sense.

CLIENT #10

This mid-40's daughter has a 66 year old mother with Alzheimer Disease living with her spouse. Both parents are described by this client as alcoholic. As well, this client describes her mother as suffering from chronic depression.

Client #10 is married and has one son. She re-married last year. Her son is a university student and is very supportive to her. He had originally intended to join the group, but felt too intimidated in being the only male. This client works full-time in a highly stressful job. To relax, she works out at the gym. She also enjoys reading and going to movies and has recently started to practice Tai Chi.

This client has a number of frustrations relating to her mother's situation. The major one has been her father's reluctance to discuss his wife's condition. As well, she is frustrated by her parent's drinking history. She avoids her mother when she is depressed and then feels guilty about having neglected her.

Her parents live in a bungalow just outside of the city. They receive no home care supports and the client has been doing the cleaning for them. She is finding this increasingly stressful and has recently developed an allergic reaction to her parent's cat and dog.

During the course of the program, this client began to advocate for services for her parents. She has also encouraged her father to obtain Power of Attorney and he is in the process of doing so. She indicated that through the group experience she had to deal with issues which she previously had avoided, but which she felt needed to be dealt with.

This client's change in scores between the pre-group and post-group testing in the areas of knowledge and stress did not change significantly. Her score on the Beck Depression Inventory did decrease somewhat, from a score of 7 pre-group to a score of 4 post-group, both scores indicating that this client is in the normal range.

This client appeared to have a need to increase her knowledge of community resources and the legal issues and placed a great deal of her energies in trying to obtain this information. She indicated that the group helped her to act on the information obtained.

Client #10 indicated that she feels fairly supported by family and friends and almost not at all by neighbours. She also feels she has received support from the Alzheimer Society. In her caregiving role she indicated that she receives only some support, but rates the support for herself as a person very highly.

CLIENT #11

This 67 year old woman provides care to her 69 year old husband who has Alzheimer Disease. A diagnosis was received 4½ years ago, shortly after the first signs of the illness were noted. The couple receive home care supports once a week for three hours in the form of sitter service.

Client #11 has four children, all living in Winnipeg. She has 11 grandchildren and one great-grandchild. She cares for two of her grandchildren daily, in addition to caring for her husband. Her

hobbies include gardening, watching royalty on TV and she expresses a desire to travel but is unable to do so due to her husband's condition.

The client relates that her husband lives a regimented lifestyle with an unvarying routine. She states that he has to go for a walk every day. She describes him as a pack-rat and the original recycler, and on his walks he collects cans, bottles and other "treasures" he finds in people's garbage.

Client #11 related a number of stressful situations created by her husband's condition. He has had an ongoing feud with one of his neighbours, which has involved the police. In fact, the police have been to the home on numerous occasions and have threatened Client #11's husband with jail, even though they have been told that he has Alzheimer Disease. Another stressful situation is her husband's refusal to bath. He will soak his feet, but will not have a bath or shower.

This husband is paranoid about his wife, particularly in relationship to other men. His suspiciousness pre-dated his illness, but it has intensified with his cognitive impairment.

Client #11 gets support from her family, particularly one daughter who lives down the street from her and accompanied her mother to the group meetings. The other children had initially thought that there was nothing wrong with their father, but now are accepting of his condition.

This client is philosophical about her situation. She handles her husband's comments by considering where they come from and states that she is able to shrug most things off, accepting that she is unable to change the situation.

Client #11 had very little change in the area of knowledge, scoring 4 out of 9 correct responses on the pre-test and 3 out of 10 correct on the post-test. This would appear to indicate that this client did not benefit from this group experience in the area of increased knowledge.

There was a slight increase noted on the post-group score on the Beck Depression Inventory. The score of 1 pre-group increased to 4 post-group. Both of these scores are not indicative of depression.

The most significant change for this client was in the area of stress. Client #11 had a positive response in one of the areas on the pre-group answers to the Stress Quiz. Post-group she responded positively to 8 out of the questions, indicating that in spite of the stress management techniques that were a part of this program, this client's stress level increased.

Through the group program it was learned that this client's husband was displaying increased difficult behaviours and was becoming more argumentative with his neighbours and strangers. As well, the police had been called on a number of occasions, and this was very stressful for this client. Thus, it may be that, in spite

of the benefits this client may have derived from the group program, her husband's behaviours were so stressful that she had an increased score in this area.

Client #11 feels quite supported by her family and neighbours, but indicates that she receives no support from friends. She also indicated that she feels supported by home care. This client indicated that she feels very much supported in her caregiving role and for herself as a person.

EVALUATION

INDIVIDUAL MEMBER FINDINGS

Client #1

a) Alzheimer Disease Knowledge Test

Pre-group results: 2 out of 9 correct
7 out of 9 I don't know
Post-group results: 5 out of 10 correct
2 out of 10 incorrect
3 out of 10 I don't know

b) Beck Depression Inventory

Pre-group results: score of 5
Post-group results: score of 9

c) Stress Quiz

Pre-group results: No responses: 15
Yes responses: 8
Post-group results: No responses: 15
Yes responses: 8

Client #2

a) Alzheimer Disease Knowledge Test

Pre-group results: 6 out of 9 correct
2 out of 9 incorrect
1 out of 9 I don't know
Post-group results: 9 out of 10 correct
1 out of 10 incorrect

b) Beck Depression Inventory

Pre-group results: score of 7

Post-group results: score of 8

c) Stress Quiz

Pre-group results: No responses: 18

Yes responses: 5

Post-group results: No responses: 15

Yes responses: 8

Client #3

Test results not tabulated as this member attended only 2 out of the 8 sessions.

Client #4

a) Alzheimer Disease Knowledge Test

Pre-group results: 3 out of 9 correct

4 out of 9 incorrect

2 out of 9 I don't know

Post-group results: 5 out of 10 correct

4 out of 10 incorrect

1 out of 10 I don't know

b) Beck Depression Inventory

Pre-group results: score of 7

Post-group results: score of 13

c) Stress Quiz

Pre-group responses:	No responses:	13
	Yes responses:	10
Post-test results:	No responses:	9
	Yes responses:	14

Client #5

a) Alzheimer Disease Knowledge Test

Pre-group results:	5 out of 9 correct
	3 out of 9 incorrect
	1 out of 9 I don't know
Post-group results:	8 out of 10 correct
	1 out of 10 incorrect
	1 out of 10 I don't know

b) Beck Depression Inventory

Pre-group results:	score of 5
Post-group results:	score of 8

c) Stress Quiz

Pre-group results:	No responses:	13
	Yes responses:	10
Post-group results:	No responses:	12
	Yes responses:	11

Client #6

a) Alzheimer Disease Knowledge Test

Pre-group results: 7 out of 9 correct
 2 out of 9 I don't know

Post-group results: 8 out of 10 correct
 1 out of 10 incorrect
 1 out of 10 I don't know

b) Beck Depression Inventory

Pre-group results: score of 1
 Post-group results: score of 2

c) Stress Quiz

Pre-group results: No responses: 18
 Yes responses: 5

Post-group results: No responses: 16
 Yes responses: 7

Client #7

a) Alzheimer Disease Knowledge Test

Pre-group results: 3 out of 9 correct
 6 out of 9 incorrect

Post-group results: 2 out of 10 correct
 6 out of 10 incorrect
 2 out of 10 I don't know

b) Beck Depression Inventory

Pre-group results: score of 14

Post-group results: score of 11

c) Stress Quiz

Pre-group results: No responses: 15

Yes responses: 8

Post-group results: No responses: 14

Yes responses: 9

Client #8

a) Alzheimer Disease Knowledge Test

Pre-group results: 5 out of 9 correct

2 out of 9 incorrect

2 out of 9 I don't know

Post-group results: 7 out of 10 correct

3 out of 10 incorrect

b) Beck Depression Inventory

Pre-group results: score of 8

Post-group results: score of 6

c) Stress Quiz

Pre-group results: No responses: 13

Yes responses: 10

Post-group results: No responses: 17

Yes responses: 6

Client #9

a) Alzheimer Disease Knowledge Test

Pre-group results:	2 out of 9 correct
	4 out of 9 incorrect
	3 out of 9 I don't know
Post-group results:	8 out of 10 correct
	2 out of 10 incorrect

b) Beck Depression Inventory

Pre-group results: score of 1

Post-group results: score of 0

c) Stress Quiz

Pre-group results:	No responses:	17
	Yes responses:	6
Post-group results:	No responses:	20
	Yes responses:	3

Client #10

a) Alzheimer Disease Knowledge Test

Pre-group results:	5 out of 9 correct
	4 out of 9 incorrect
Post-group results:	6 out of 10 correct
	1 out of 10 incorrect
	3 out of 10 I don't know

b) Beck Depression Inventory

Pre-group results: score of 7

Post-group results: score of 4

c) Stress Quiz

Pre-group results: No responses: 17

Yes responses: 6

Post-group results: No responses: 16

Yes responses: 7

Client #11

a) Alzheimer Disease Knowledge Test

Pre-group results: 4 out of 9 correct

3 out of 9 incorrect

2 out of 9 I don't know

Post-group results: 3 out of 10 correct

7 out of 10 incorrect

b) Beck Depression Inventory

Pre-group results: score of 1

Post-group results: score of 4

c) Stress Quiz

Pre-group results: No responses: 22

Yes responses: 1

Post-group results: No responses: 15

Yes responses: 8

Client #12

a) Alzheimer Disease Knowledge Test

Pre-group results: 5 out of 9 correct
3 out of 9 incorrect
1 out of 9 I don't know

Post-group results: 8 out of 10 correct
2 out of 10 incorrect

b) Beck Depression Inventory

Pre-group results: score of 3
Post-group results: score of 1

c) Stress Quiz

Pre-group results: No responses: 20
Yes responses: 3

Post-group results: No responses: 16
Yes responses: 7

APPENDIX I

GROUP LEADERSHIP SKILLS RATING SCALE

Rate each item on a scale of 1 to 7.

1 = I am very poor at this.

7. = I am very good at this.

-
-
- 1. **Active Listening:** I am able to hear and understand both direct and subtle messages.
 - 2. **Reflecting:** I can mirror what another says, without being mechanical.
 - 3. **Clarifying:** I can focus on underlying issues and assist others to get a clearer picture of some of their conflicting feelings.
 - 4. **Summarizing:** When I function as a group leader, I'm able to identify key elements of a session and to present them as a summary of the proceedings.
 - 5. **Interpreting:** I can present a hunch to someone concerning the reasons for his or her behavior without dogmatically telling what the behavior means.
 - 6. **Questioning:** I avoid bombarding people with questions about their behavior.
 - 7. **Linking:** I find ways of relating what one person is doing or saying to the concerns of other members.
 - 8. **Confronting:** When I confront another, the confrontation usually has the effect of getting that person to look at his or her behavior in a nondefensive manner.
 - 9. **Supporting:** I'm usually able to tell when supporting another will be productive and when it will be counterproductive.
 - 10. **Blocking:** I'm able to intervene successfully, without seeming to be attacking, to stop counterproductive behaviors (such as intellectualizing) in a group.
 - 11. **Diagnosing:** I can generally get a sense of what specific problems people have, without feeling the need to label people.
 - 12. **Evaluating:** I appraise outcomes when I'm in a group, and I make some comments concerning the ongoing process of any

group I'm in.

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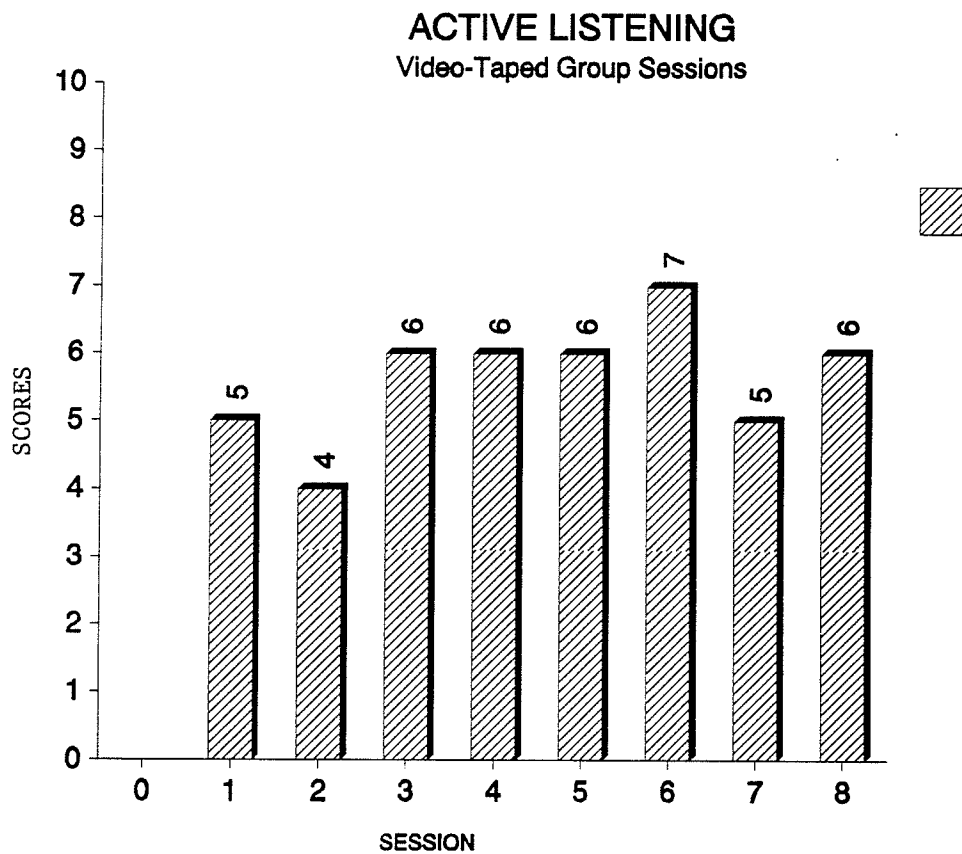
- 13. **Facilitating:** In a group, I'm able to help others openly express themselves and work through barriers to communication.
- 14. **Empathizing:** I can intuitively sense the subjective world of others in a group, and I have the capacity to understand much of what others are experiencing.
- 15. **Terminating:** At the end of group sessions, I'm able to create a climate that will foster a willingness in others to continue working after the session.

(Corey & Corey, 1977)

GROUP LEADERSHIP SKILLS RATING SCALE			
MEAN SCORES, STANDARD DEVIATION AND RANGE OF SCORES			
LEADERSHIP SKILL	MEAN	STANDARD DEVIATION	RANGE OF RESPONSES
Active Listening	5.63	0.86	4 to 7
Reflecting	5.88	0.60	5 to 7
Clarifying	5.25	0.43	5 to 6
Summarizing	5.50	0.50	5 to 6
Interpreting	5.88	0.78	5 to 7
Questioning	6.63	0.48	6 to 7
Linking	6.38	0.86	5 to 7
Confronting	4.50	1.22	2 to 6
Supporting	6.00	0.71	5 to 7
Blocking	5.13	0.60	4 to 6
Diagnosing	6.13	0.60	5 to 7
Evaluating	5.13	0.78	4 to 6
Facilitating	5.75	0.66	5 to 7
Empathizing	7.00	0.00	7
Terminating	5.50	0.50	5 to 6
NOTE: 1. Range of possible responses was 1 (very poor) to 7 (very good)			
NOTE: 2. Over all Mean Score was: 5.75 with a Standard Deviation of 0.62			

GROUP LEADERSHIP SKILLS RATING SCALE

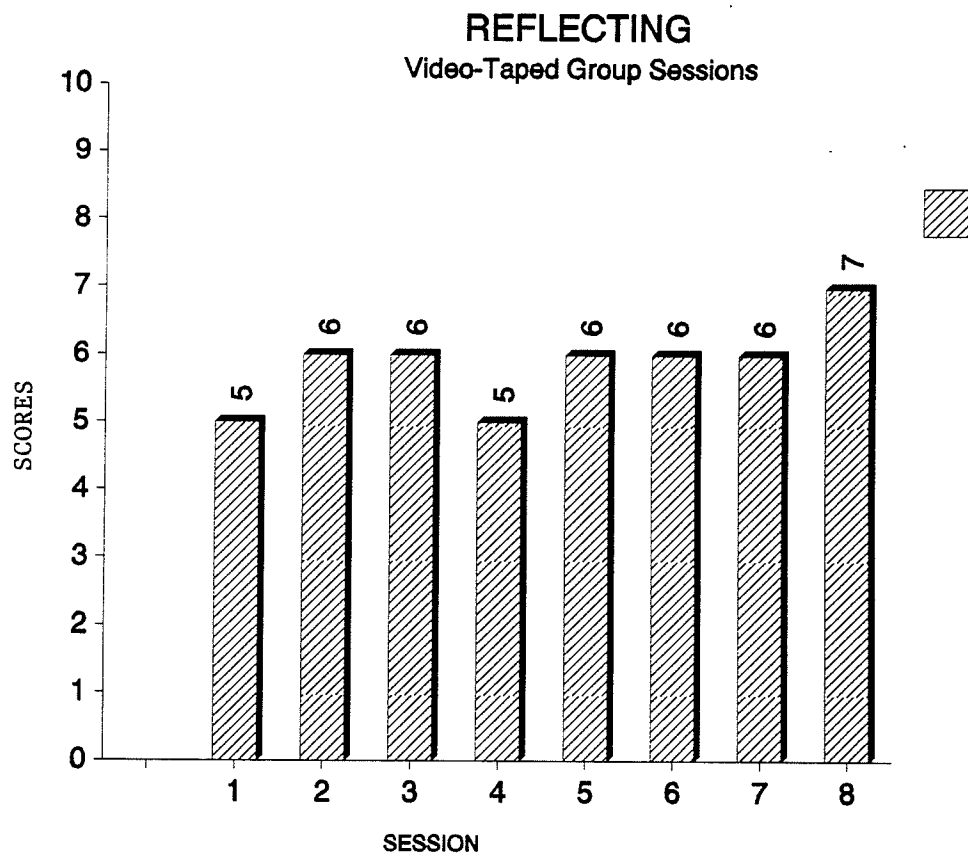
Table 1



Mean	5.63
Standard Deviation	0.86
Range	4-7

GROUP LEADERSHIP SKILLS RATING SCALE

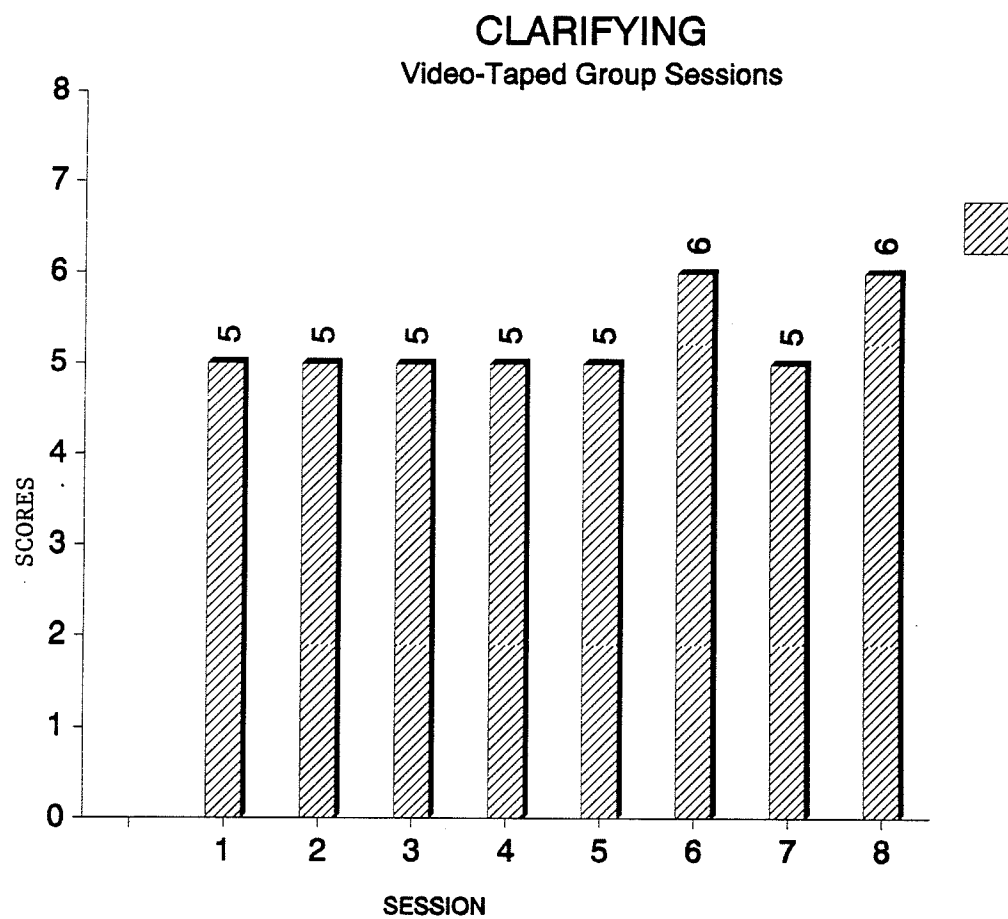
Table 2



Mean	5.88
Standard Deviation	0.60
Range	5 - 7

GROUP LEADERSHIP SKILLS RATING SCALE

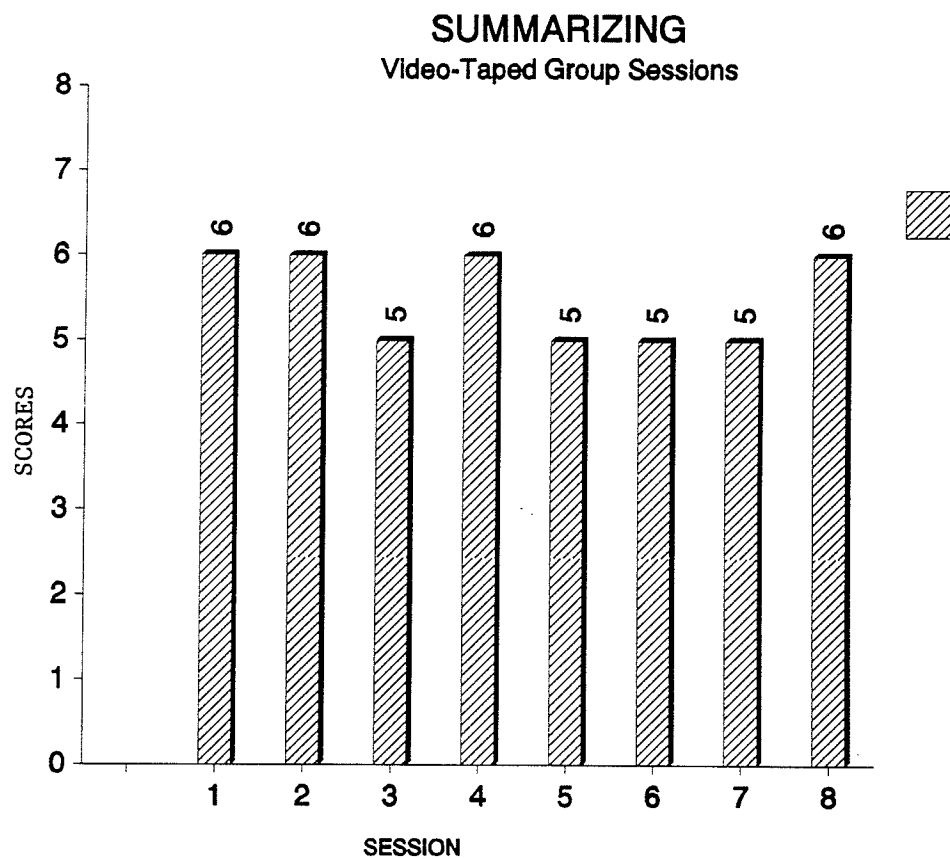
Table 3



Mean	5.25
Standard Deviation	0.43
Range	5-6

GROUP LEADERSHIP SKILLS RATING SCALE

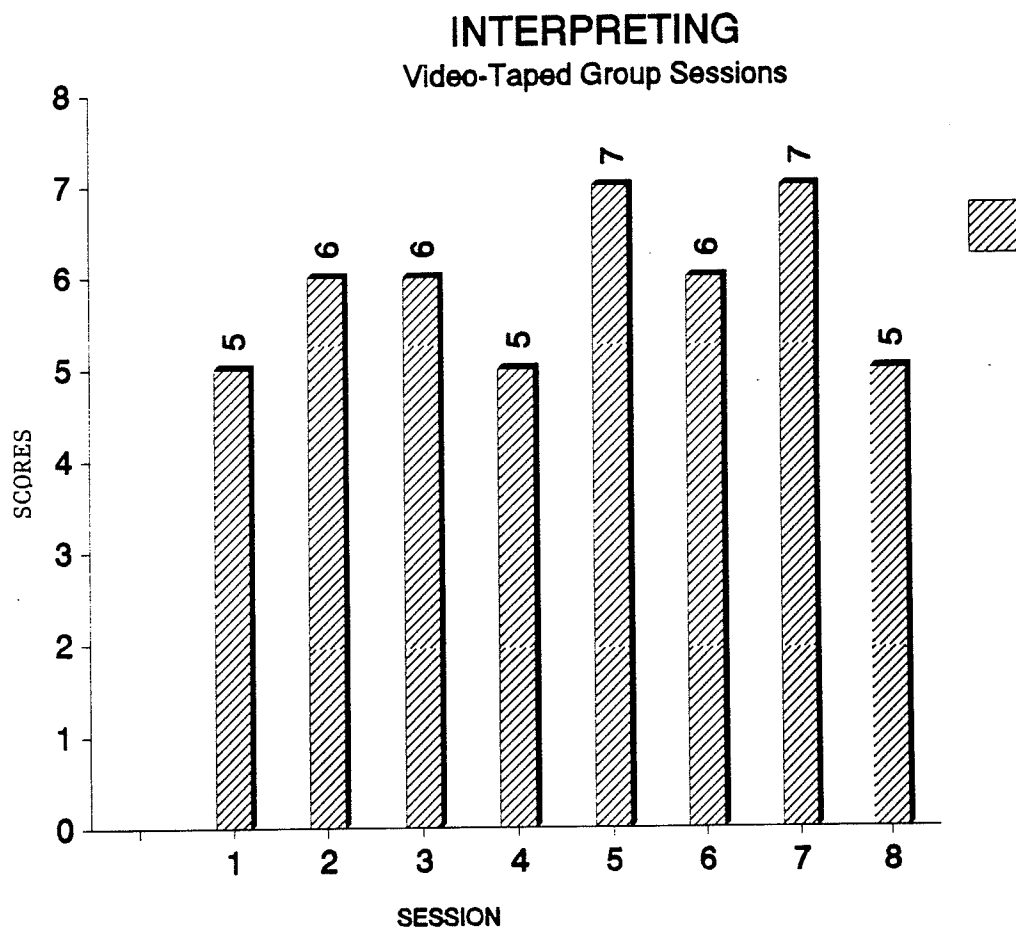
Table 4



Mean	5.50
Standard Deviation	0.50
Range	5-6

GROUP LEADERSHIP SKILLS RATING SCALE

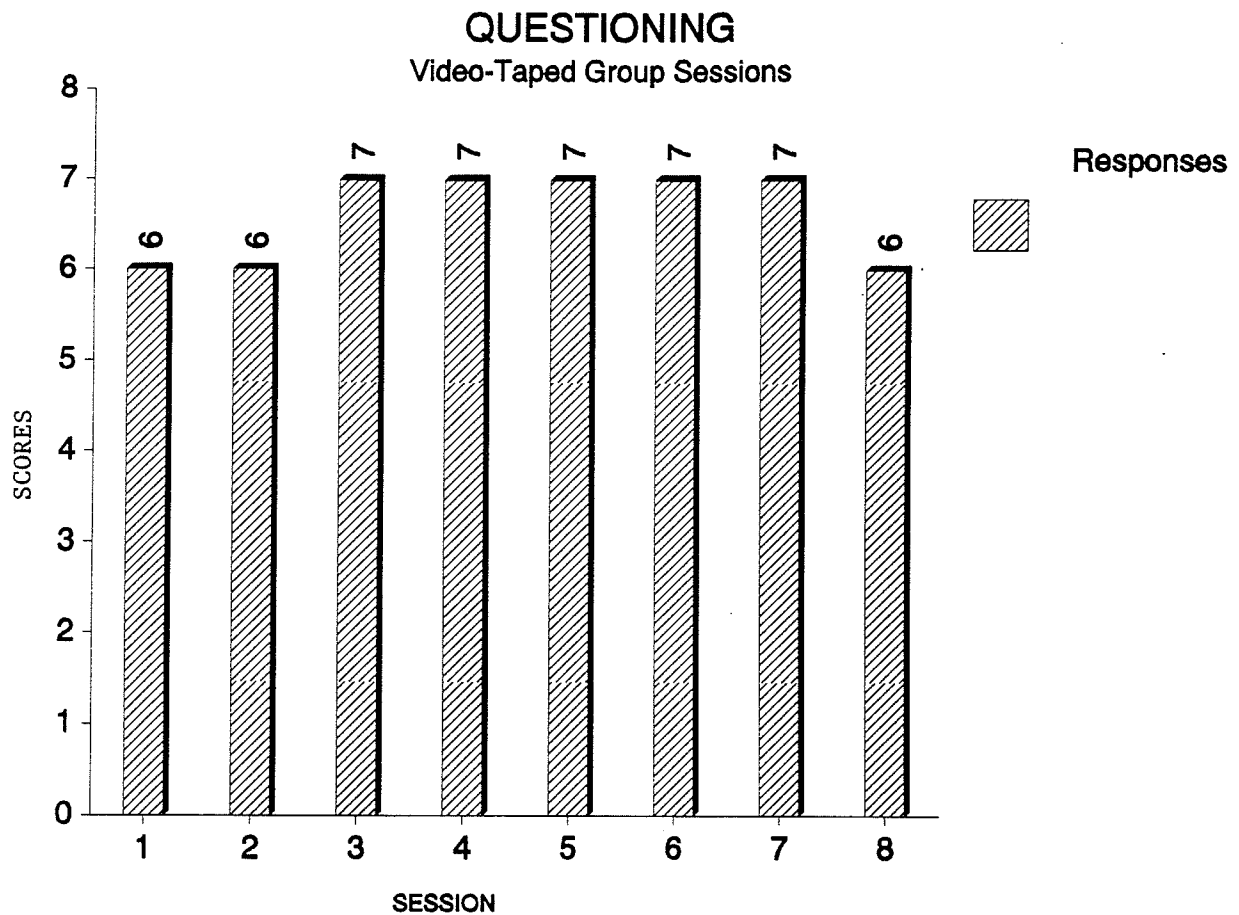
Table 5



Mean	5.88
Standard Deviation	0.78
Range	5-7

GROUP LEADERSHIP SKILLS RATING SCALE

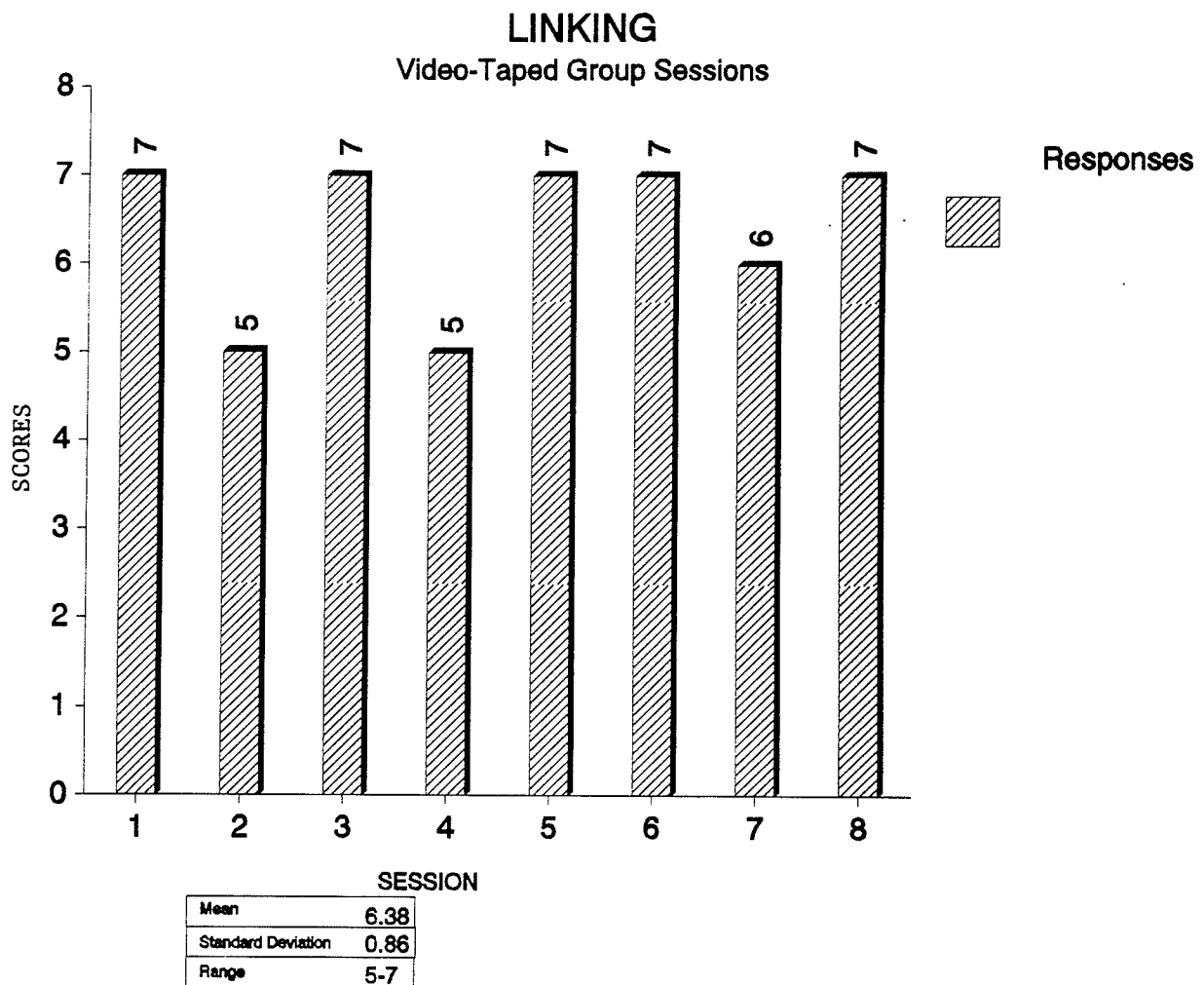
Table 6



Mean	6.63
Standard Deviation	0.48
Range	6-7

GROUP LEADERSHIP SKILLS RATING SCALE

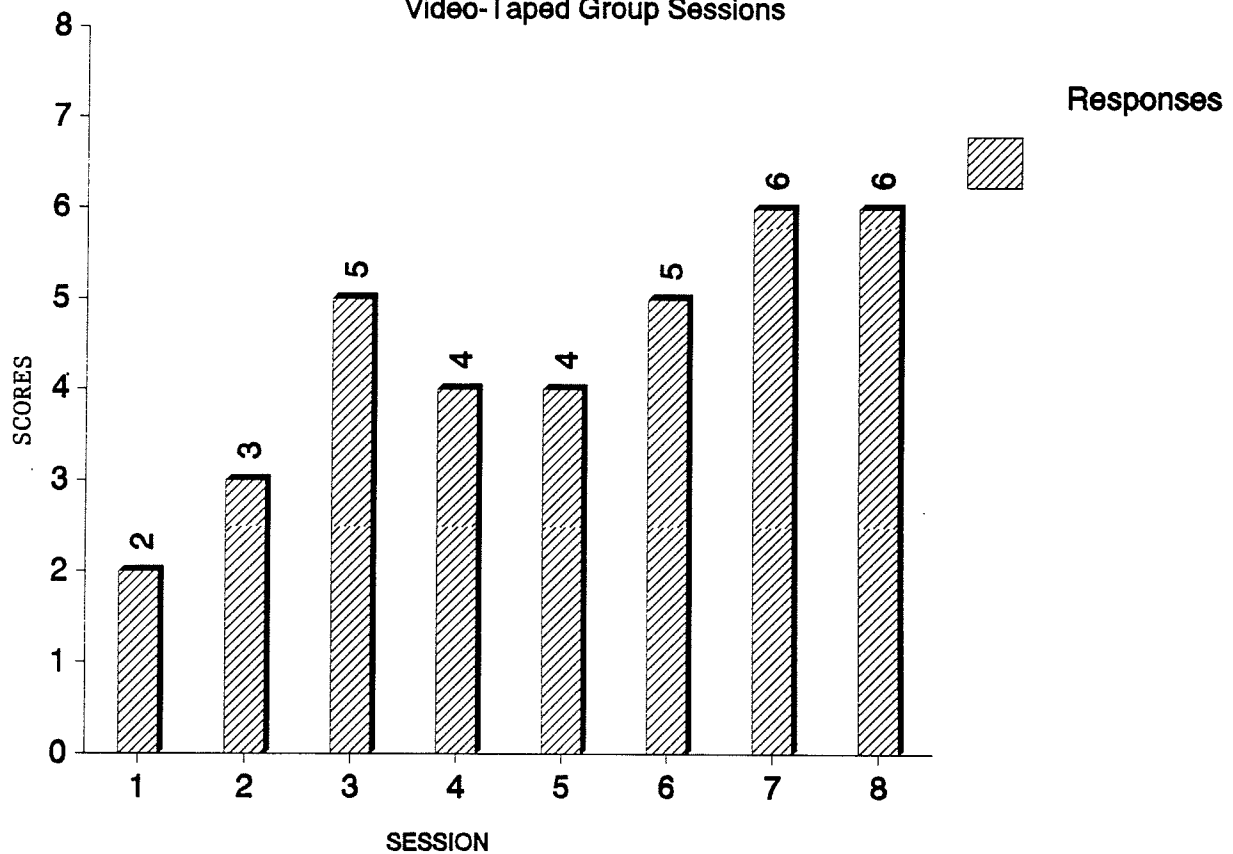
Table 7



GROUP LEADERSHIP SKILLS RATING SCALE

Table 8

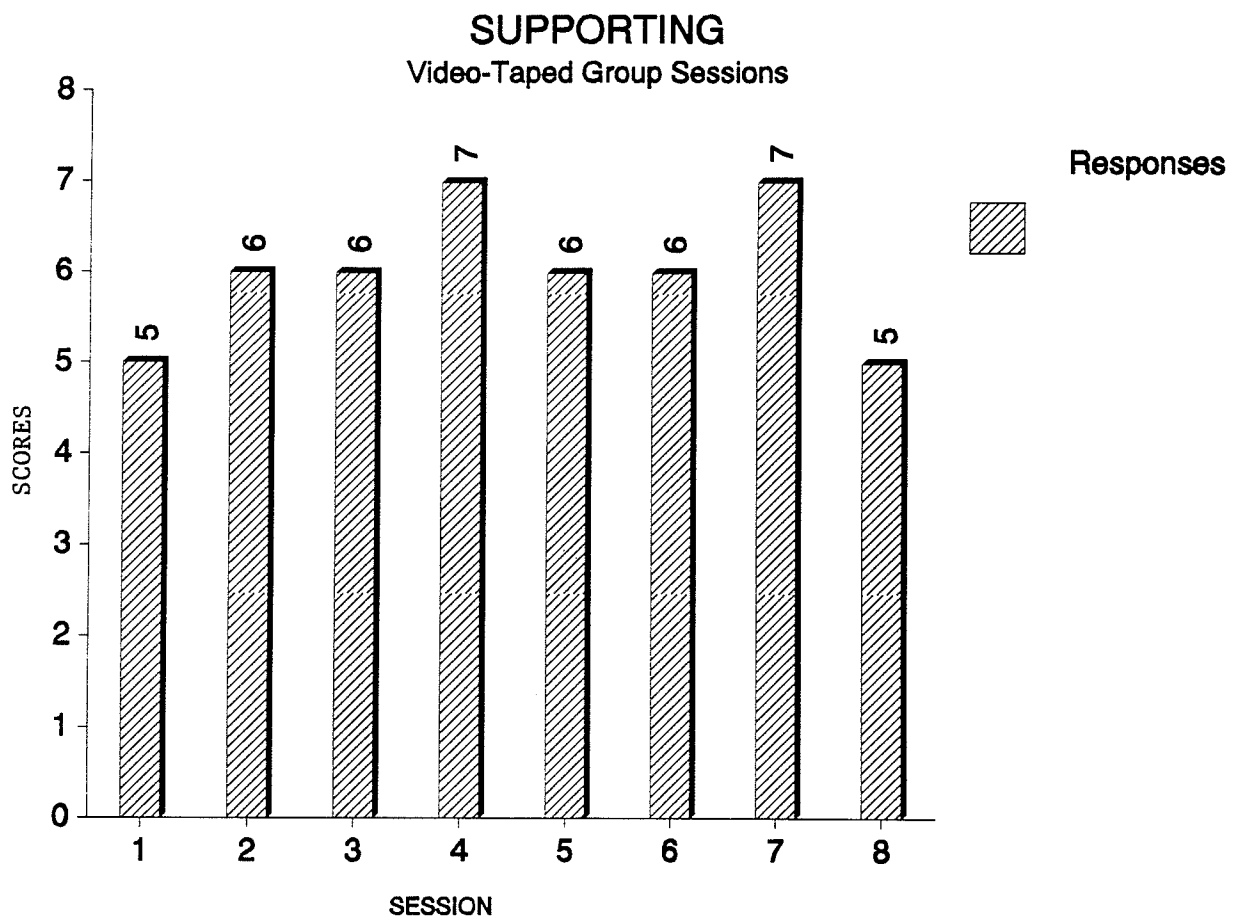
CONFRONTING Video-Taped Group Sessions



Mean	4.50
Standard Deviation	1.22
Range	2-6

GROUP LEADERSHIP SKILLS RATING SCALE

Table 9

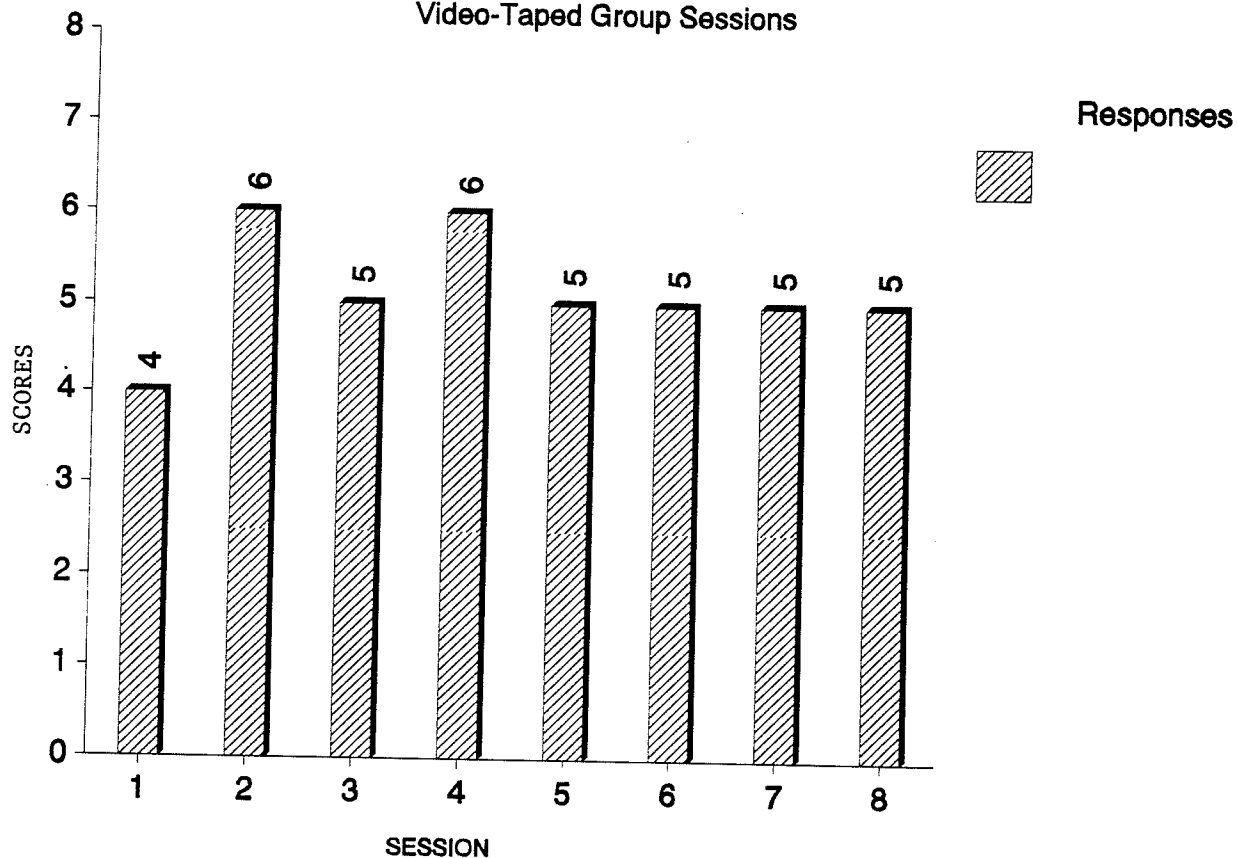


Mean	6.00
Standard Deviation	0.71
Range	5-7

GROUP LEADERSHIP SKILLS RATING SCALE

Table 10

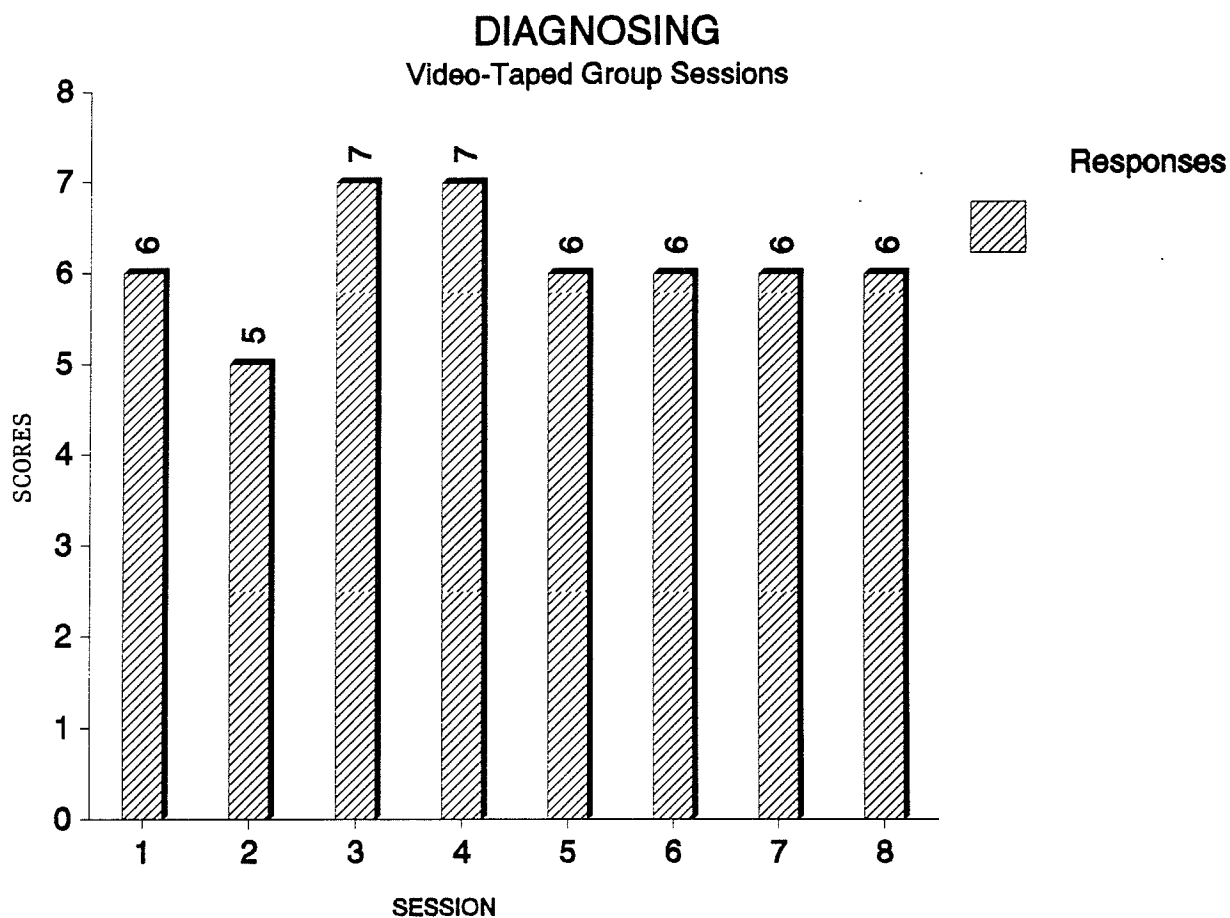
BLOCKING Video-Taped Group Sessions



Mean	5.13
Standard Deviation	0.60
Range	4-6

GROUP LEADERSHIP SKILLS RATING SCALE

Table 11

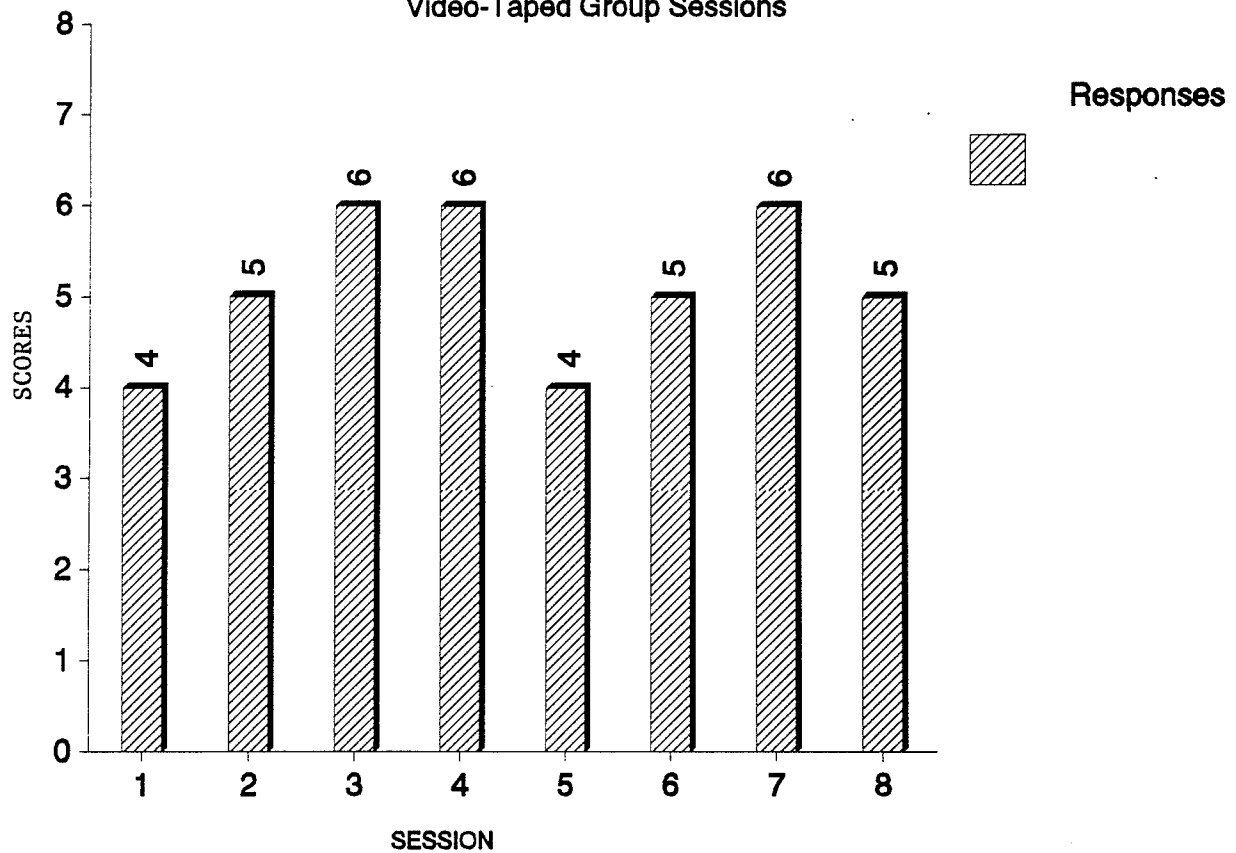


Mean	6.13
Standard Deviation	0.60
Range	5-7

GROUP LEADERSHIP SKILLS RATING SCALE

Table 12

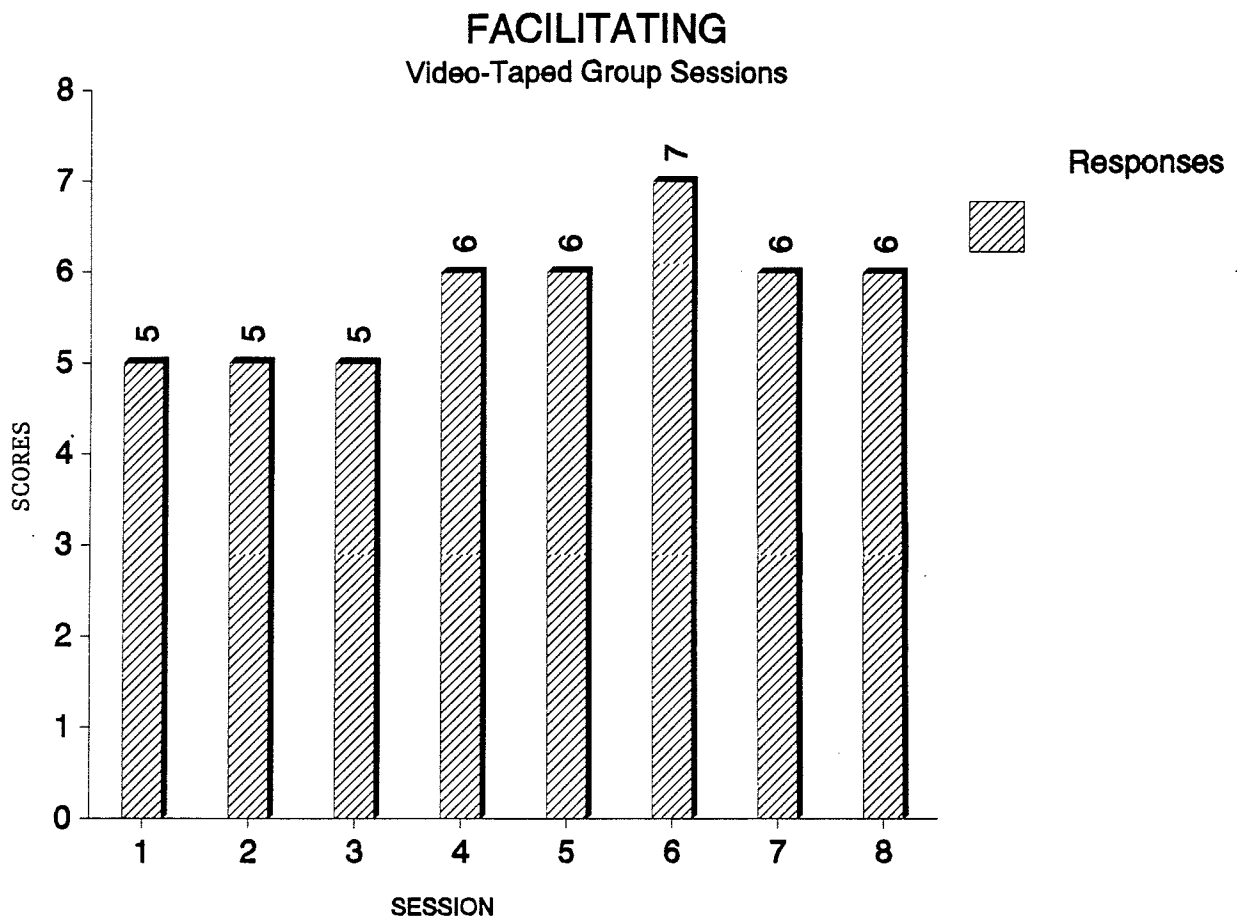
EVALUATING Video-Taped Group Sessions



Mean	5.13
Standard Deviation	0.78
Range	4-6

GROUP LEADERSHIP SKILLS RATING SCALE

Table 13

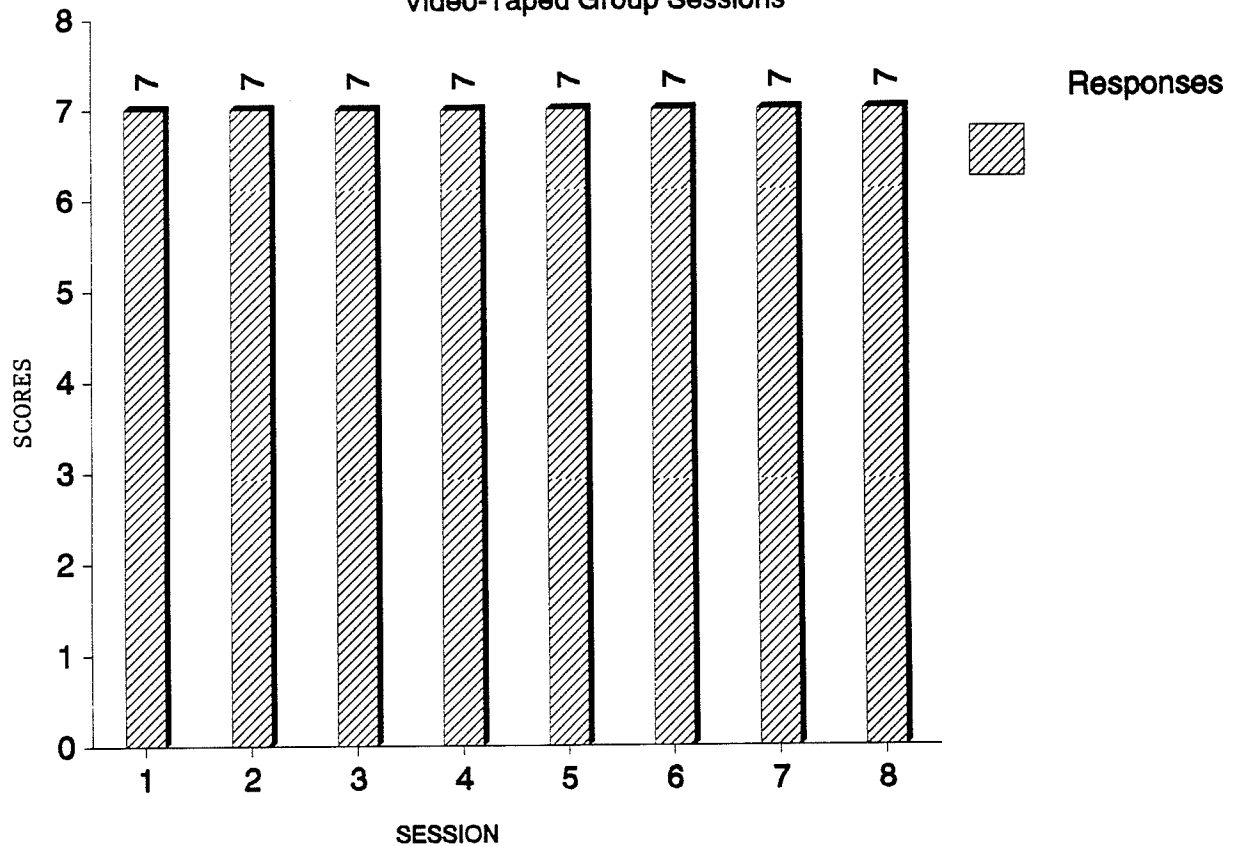


Mean	5.75
Standard Deviation	0.66
Range	5-7

GROUP LEADERSHIP SKILLS RATING SCALE

Table 14

EMPATHIZING Video-Taped Group Sessions

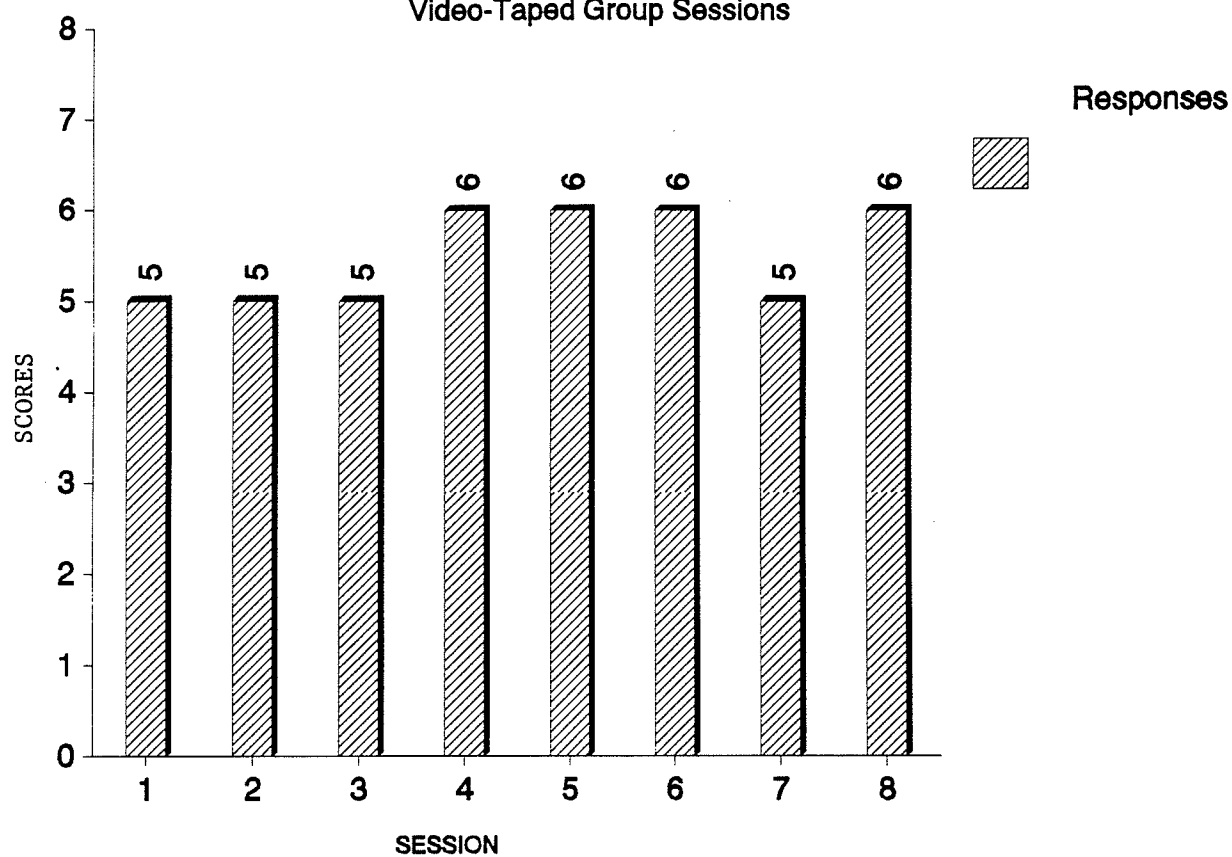


Mean	7.00
Standard Deviation	0.00
Range	7

GROUP LEADERSHIP SKILLS RATING SCALE

Table 15

TERMINATING Video-Taped Group Sessions



Mean	5.50
Standard Deviation	0.50
Range	5-6