

COGNITIVE THERAPY  
WITH  
SPOUSAL CAREGIVERS OF  
INDIVIDUALS WITH  
ALZHEIMER'S DISEASE

A PRACTICUM REPORT  
SUBMITTED TO  
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OF THE REQUIREMENTS  
FOR THE DEGREE  
MASTER OF SOCIAL WORK

BY  
ELIZABETH ANNE MCKEAN

JUNE, 1989

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COGNITIVE THERAPY WITH SPOUSAL CAREGIVERS OF  
INDIVIDUALS WITH ALZHEIMER'S DISEASE

BY

ELIZABETH ANNE MCKEAN

A practicum submitted to the Faculty of Graduate Studies  
of the University of Manitoba in partial fulfillment of the  
requirements of the degree of

MASTER OF SOCIAL WORK

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ABSTRACT

The objective of this practicum was to implement and evaluate the effectiveness of a program of short term individual counselling with spousal caregivers of individuals with Alzheimer's Disease. Two cognitive therapies, Zarit, Orr and Zarit's Stress-Management Model and Ellis's Rational-Emotive Therapy, were used as the theoretical framework of the intervention. The results of this practicum support the usefulness of the application of cognitive therapy with this population.

This practicum identified three different categories of spousal caregivers; the frail older spousal caregiver, the older spousal caregiver and the young spousal caregiver. Each of these categories of spousal caregivers appeared to have unique problems and needs. The results of this practicum also indicated that caregivers go through unique stages that parallel stages of the illness. Interventions with caregivers needs to reflect the diversity of this population and specific stage of the illness.

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CHAPTER 1Introduction

Alzheimer's Disease is a progressive neurological disorder that is presently the fourth leading cause of death in North America (Tanner & Shaw, 1985; U.S.Congress, 1987). There is presently no available medical treatment that can cure or halt the inevitable destruction of the patient's intellect, memory and personality (Tanner & Shaw, 1985; Zarit, Orr & Zarit, 1985). The person afflicted with this disease is not the only victim, as the family also suffers through the long years of caregiving.

In the absence of any medical cure or treatment, the focus of present interventions with this disease have primarily been directed towards the caregiver (U.S.Congress, 1987). This focus is based on the assumption that if the caregiver's ability to cope is maximized there will be a corresponding improvement in the quality of life for the patient.



The objective of my practicum was to implement and evaluate the effectiveness of a program of short term individual counselling with spousal caregivers of patients with Alzheimer's Disease. Zarit, Orr & Zarit 's Stress-Management Model and A. Ellis 's Rational-Emotive Therapy, two cognitive-behavioral therapies, were used as the theoretical framework of my practicum.

My learning objectives for this practicum were:

1. To design, implement and evaluate a program of short term individual counselling with spousal caregivers of individuals with Alzheimer's Disease.

2. To develop a thorough knowledge about Alzheimer's Disease and its impact on the patient.

3. To develop a thorough understanding of the impact of caregiving on the caregiver, specifically the spousal caregiver.

4. To develop a comprehensive knowledge about problem-solving therapies in general and specifically Zarit, Orr & Zarit's Stress Management Model.

5. To develop a comprehensive knowledge about cognitive restructuring therapies, specifically Ellis's Rational-Emotive Therapy.

6. To develop skills and experience in the provision of short term individual counselling theoretically based on a Problem-solving Model.

7. To develop skills and experience in the application of the techniques of Rational-Emotive Therapy.

CHAPTER 2Alzheimer's Disease**INCIDENCE:**

Until recently Alzheimer's Disease tended to be underdiagnosed. Currently, physicians are likely to make a diagnosis of Alzheimer's Disease any time a patient has notable intellectual or memory impairment. Hence, at present the disease tends to be over diagnosed (U.S.Congress, 1987). The factors identified in the U.S.Congress report as being associated with this diagnostic error are:

1. Ageism.
2. Failure to use strict diagnostic criteria.
3. Insufficient time devoted to obtaining a history or examining patients.
4. Inadequate recourse to special tests.
5. Incompatibility between diagnostician and patient as a result of cultural, educational or ethnic background.

As a result of diagnostic errors, statistics on the incidence of Alzheimer's Disease often vary widely. The

present most commonly accepted statistics on incidence are that 5-10% of the population over 65, and 20-25% of the population over 80 are afflicted (Burns & Buckwalter, 1988; Kapust & Weintraub, 1984; Mace & Rabins, 1981; Tanner & Shaw, 1985; U.S. Congress, 1987; Zarit, Orr & Zarit, 1985).

While Alzheimer's Disease is normally associated with individuals over age 65, the disease can occur in middle age but the prevalence is very small (Tanner & Shaw; Zarit, Orr & Zarit). The incidence of Alzheimer's Disease does not appear to be influenced by race, occupation, socioeconomic group or sex (Tanner & Shaw).

Considering these facts on the incidence of Alzheimer's Disease, one would expect that a representative sample of caregivers of individuals with Alzheimer's Disease would be heterogeneous in all factors excluding age, and the mean age of the sample would be over 65. While the participants in my study did reflect different occupational and socioeconomic groups, they were all Caucasian females. Also, the mean age of my sample was 62.5 years which is younger than expected in a representative sample. My project sample, therefore, cannot be considered representative of all caregivers of individuals with Alzheimer's Disease.

**ETIOLOGY AND TREATMENT:**

Presently, the actual etiology of Alzheimer's Disease is unknown, but Reisberg (1981) suggests that there are certain processes which may predispose an individual to the ultimate development of Alzheimer's Disease. These processes include: aging (this may be the most important one), transmissible agents called "viroids", hereditary and familial predispositions, Down's Syndrome, and environmental toxins.

To date, there is no available treatment that can cure, reverse or halt the progression of Alzheimer's Disease (Cohen & Eisdorfer, 1986; Reisberg, 1981; U.S.Congress, 1987; Tanner & Shah, 1985).

As families are often concerned that something they, or the individual afflicted, did or failed to do, has either caused or worsened the disease, any program designed for this population must include an educational component that addresses these concerns.

**DIAGNOSIS:**

The symptoms of Alzheimer's Disease are those of dementia (Cohen & Eisdorfer, 1986; U.S.Congress, 1987;

Zarit, Orr & Zarit, 1985). The term dementia refers to a group of symptoms that describe a loss or impairment of mental capabilities (Cohen & Eisdorfer; Zarit, Orr & Zarit). According to the DSM-III, the four major elements that must be present in order to make a diagnosis of dementia are:

1. A loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning.
2. Memory impairment.
3. An impairment of one other aspect of cognition such as abstract thinking or judgment.
4. The presence of clear consciousness.

The symptoms of dementia can be caused by many diseases, some of which are reversible and some of which are irreversible. Alzheimer's Disease is considered to be responsible for 50% to 70% of all cases of dementia (Burns & Buckwalter, 1988; Reisberg, 1981; Tanner & Shaw, 1985; U.S.Congress, 1987).

The diagnosis of Alzheimer's Disease is one of exclusion as there are no specific tests, except a brain biopsy at time of autopsy, that can confirm that the dementia is due to Alzheimer's Disease (Cohen & Eisdorfer,

1986; Zarit, Orr & Zarit, 1985). Since there are reversible causes of dementia it is essential that anyone exhibiting symptoms of dementia be carefully examined to determine the cause (Cohen & Eisdorfer; Zarit, Orr & Zarit). This examination must include a medical examination, including the taking of a comprehensive medical history and a thorough physical examination including a neurological examination and specific laboratory tests. The examination must also include a social history, which has collateral verification from a significant other, and a psychiatric examination which includes the completion of a mental status examination.

An important element of any program designed for caregivers of individuals with Alzheimer's Disease must include an evaluation of the medical diagnostic process. As there are reversible causes of dementia it is imperative to determine that the possibility of a reversible dementia has been ruled out. In my program this issue was addressed in the initial assessment stage.

As it is not possible to be absolutely certain of a diagnosis of Alzheimer's Disease, and in reality for the caregiver the experience of caring is similar whether the

dementia has resulted from Alzheimer's Disease or one of the other causes of irreversible dementia, in my program I used the presence of irreversible dementia rather than a diagnosis of Alzheimer's Disease as a criteria for eligibility for inclusion in the program.

#### DISEASE PROCESS:

The average length of illness is 7 to 10 years, but this can vary from as short as 2 years to as long as 20-25 years (Tanner & Shaw, 1985; U.S. Congress, 1987).

Symptoms of this disease can be grouped into four categories (U.S.Congress):

1. Cognitive or neurological symptoms (memory loss, aphasia, apraxia, disorientation).
2. Functional symptoms (loss of the ability to do the tasks of daily living).
3. Behavioral or psychiatric symptoms (depression, agitation, paranoia, hallucinations).
4. Disabilities caused by outside factors (other illnesses, medication reactions, sensory impairments and external stressors).

Each victim of this disease varies in regards to whether, when and in how severely they might experience any particular symptom (U.S.Congress, Zarit, Orr & Zarit).

Researchers (Burnside, 1979; Hall, 1988; Reisberg, 1986; Tanner & Shaw, 1985) often divide the deterioration of the patient with Alzheimer's Disease into stages based on the level of the individual's functional or cognitive impairment. Any division into stages is, however, an arbitrary one as it is impossible to precisely determine when a particular patient enters any particular stage.

In my practicum I used Hall's four stages; the forgetful stage, the confused stage, the ambulatory dementia stage and the terminal stage, to assess the level of the impairment of my sample's spouses. Since in my practicum I did not intend to interview the individual with Alzheimer's disease or conduct psychological tests on the individual, I could only assess the level of impairment in my sample's spouses by considering the information provided by my client's on what their spouses could and could not still do. I, therefore, had to select a model, such as Hall's four stages, which bases the stages of the disease primarily on functional decrements.



#### The Forgetfulness Stage:

The onset of symptoms in the forgetfulness phase of Alzheimer's disease is subtle and diffuse and, although there is usually no measurable evidence of a decrement, the individual and those closest to them slowly become aware that something is wrong. In this stage although they can still compensate for their errors, the individual slowly and with increasing frequency begins to forget and lose things. Depression in the individual is common.

#### The Confused Stage:

In the confused stage the individual starts exhibiting a decreased ability to perform complex occupational and social activities such as money management, legal decisions, working, driving and household tasks. Overlearned skills are generally retained. Personality changes occur as the person experiences mood swings, becomes socially withdrawn, is easily distracted and shows less initiative. Denial and depression are common as the individual attempts to hide, with decreasing ability, the problem from those around them. The individual has increasing difficulty functioning in environments other than their home.

#### The Ambulatory Dementia Stage:

In the ambulatory dementia stage the person now needs assistance with all activities of daily living and may develop incontinence of bladder and bowel. The individual is increasingly self-absorbed, has difficulty concentrating and is often disorientated to time and place. The individual is largely unaware of all recent events and experiences although they can often still remember events of the distant past. They can no longer learn and they show poor judgement. Frequently, they become increasingly resistant to having anyone but the primary caregiver in the home. Mood swings become more frequent in this stage and the individual may sleep poorly at night, become agitated, pace, wander, become paranoid and/or suffer from delusions or hallucinations.

#### The Terminal Stage:

In the terminal stage of this disease the person has no recent or remote memory and no observable cognitive functioning. They become easily agitated and appear oblivious of the environment around them. The person may lose their ability to speak or be limited to just one or two words. They are often unable to understand what is being

said to them. The individual will require extensive assistance with even the most basic activities of daily living. Physically the individual gradually loses their ability to sit, then smile and finally to hold up their head. The ability to swallow is slowly lost and the person may go into a coma. If death is not caused by a secondary infection, the person most likely dies from a failure in the central regulation of a vital function such as respiration. Most individuals are either in institutions or are institutionalized by this stage.

In order to classify the spouses of my client sample into stages, I used information provided by my clients, and in the three situations where I met the spouse, I also used my own observations. In my client sample, 4 clients were caring for spouses in the confused stage and 5 clients were caring for spouses in the ambulatory dementia stage (See Appendix I).

**SUMMARY:**

Considering the duration and nature of this disease, most caregivers of individuals with Alzheimer's Disease face long, unpredictable years of caregiving. Short term programs developed for this population need to focus on the development of skills and coping strategies in the caregiver that will help the caregiver manage through the entire caregiving process.

CHAPTER 3The Caregivers

80% to 90% of all dependent elderly are cared for by their family and, for those with dementing illnesses, most are cared for by their families for the majority of their illness (U.S.Congress, 1987).

**TYPE OF CARE PROVIDED:**

Families need to provide a wide range of care and the care they provide must be individualized to meet the idiosyncratic needs of the patient (U.S.Congress, 1987). The nature of the care will also need to change as the illness progresses (U.S.Congress). A major complication for families trying to provide care is that, throughout the disease process, persons with dementia usually deny any need for care and respond to offers of assistance with resistance and /or anger (U.S.Congress).

In the early stages of the disease, the nature of the care needed is mostly in the area of decision making as the family must slowly assume responsibility for making the

patient's decisions. Unfortunately for families, there are no rules and often little agreement among professionals as to when a particular individual is incapable or is legally incompetent to manage tasks such as financial management or driving. In the later stages of the disease the patient requires increasing assistance with personal care and, as a result of their impaired judgment, constant supervision. The nature of the care needed in these later stages is, therefore, very task specific. Interventions with families need to reflect the changing nature of the care that the family is providing to the patient.

#### FAMILY CAREGIVERS:

In most instances, regardless of family size, one person assumes the majority of the responsibility for caregiving (Marples, 1986). Howowitz (1985) states that this primary caregiver will first be the spouse, and if there is no spouse, will then be a child. She also found that if there was no child, the caregiver will then be another relative or friend/neighbour. The report by the U.S. Congress warns, however, that this data was based on research done mostly on white, middle-classed families and

patterns for other cultural or socioeconomic groups are unknown.

Although there is usually just one primary caregiver, it is important to remember that this person does exist within a family and social network. In my practicum, while I focused on the primary caregiver, I did, however, complete an assessment of the caregiver's family and social network. I did this because the family and social network can be potentially either an untapped resource or a source of conflict for the caregiver.

As more than half of all elderly live with a spouse, spouses frequently are the primary caregiver (Hess & Soldo, 1985). Spousal caregivers are especially at risk because they themselves are older and have their own health problems (Hess & Soldo). Cantor (1983) also found that spousal caregivers are more at risk in caring because the closer the relationship of the caregiver to carereceiver the higher the strain on the caregiver (ie. spouses were more stressed than children). As spousal caregivers are especially at risk in caregiving, I focused my practicum on spousal caregivers.

**EFFECTS OF CAREGIVING:**

Caregiving someone with Alzheimer's Disease has emotional, social, physical and financial costs for the caregiver (Cohen & Eisdorfer, 1986; Grad & Sainsbury, 1963; Zarit, Orr & Zarit, 1985). Sainsbury & Grad (1970) found that in 75% of the families they studied, 63% of the caregivers reported decreased mental health, 58% reported decreased physical health and 50% reported a decline in leisure activities. Rabins, Mace & Lucas (1982) found that 87% of caregivers they studied showed chronic fatigue, feelings of anger and depression; 56% reported family conflict; 55% reported loss of friends, hobbies and personal time; 31% worried about their health and 25% reported guilt feelings. Cantor (1983) found in her study that emotional burden was more significant than physical or financial burden.

As the research demonstrates that caregiving can affect the caregiver's physical, emotional, social and financial health, in the assessment process of my practicum I explored the impact caregiving was having on the emotional, social, physical and financial health of each caregiver in my study. This information provided me with a full understanding of



the impact of caregiving for that particular individual.

**BURDEN:**

There is great variability in the amount of caregiver burden felt by families (Zarit, Orr & Zarit, 1985). Pollack (1983) found no relationship between burden and the degree of impairment or the severity of symptoms. Machin (1980) and Novak & Guest (1989) found no relationship between length of time caregiving and burden. In fact, Gilhooly (1984) found that the longer people care for a demented relative the better their morale and mental health, and Novak & Guest (1986) found that the higher the burden the more recent the diagnosis. While Novak and Guest (1989) did find a significant, moderate correlation between caregiver burden and the patient's functional ability, the subjective feelings the caregiver has about the caregiving have been found to be the factor that best predicts caregiver burden (Novak & Guest, 1989; Ory et al, 1985; Zarit, Todd & Zarit, 1986). The results of these studies indicate that if a caregiver feels his/her life has been negatively affected by the caregiving then he/she will feel burdened.

Considering the research on burden one cannot make

assumptions about caregiver burden or try to measure caregiver burden using data based on the stage of the illness or on the functional level of the patient. For the purposes of my practicum I will use instruments designed to measure an individual's subjective feelings about their caregiving experiences.

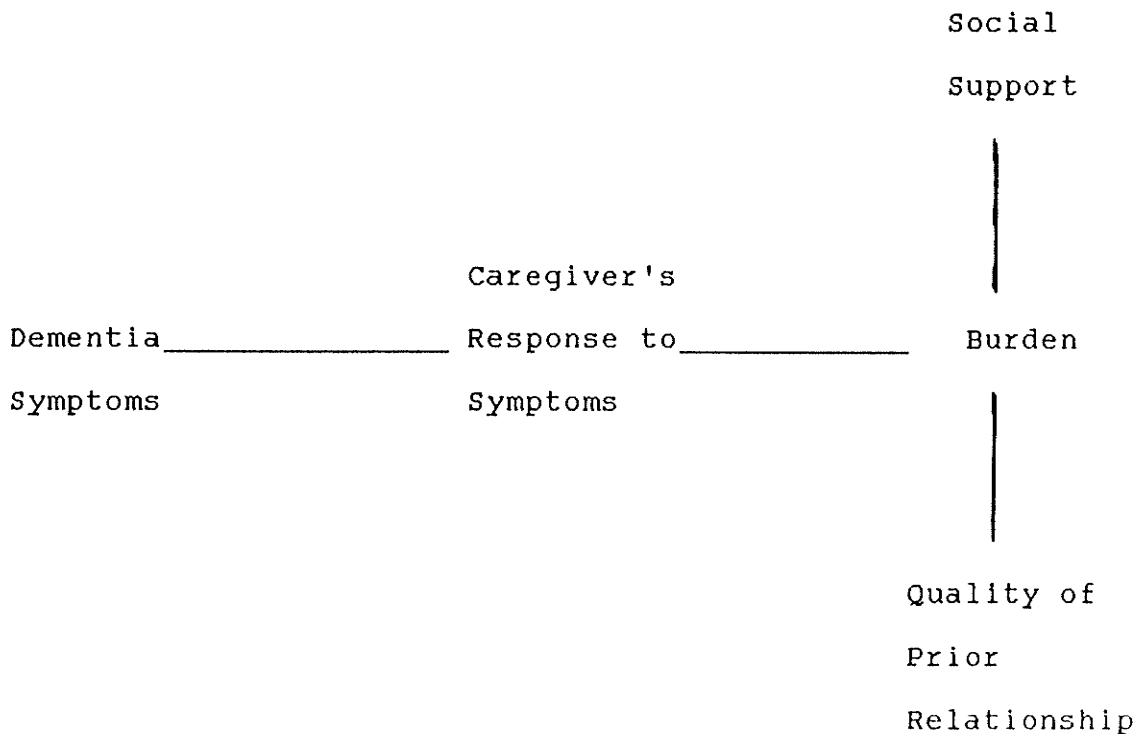
Zarit, Orr & Zarit's visualization of caregiver burden is demonstrated in Figure 1. They found that the most important predictors of caregiver burden are:

1. How well the caregiver manages memory and behaviour problems. They found that if the caregiver is flexible in their coping style and accepting of the brain damage, caring is experienced as less stressful.

2. The social supports available to the caregiver. This may be more complicated than just a quantitative assessment of social supports. Zarit and Zarit (1982) found that the caregiver's perception of social supports as adequate or inadequate was more important than the actual amount of support. Novak & Guest (1986) also found that caregiver's subjective evaluation of their level of social activity correlated better with burden than an objective measurement of their activity.

3. The quality of the relationship prior to the caregiving. They found that caregivers who report a better past relationship will face current problems with less stress. Ory et al (1985) also found that the better the relationship between caregiver and carereceiver prior to the onset of the disease the lower the burden.

Figure I



**SUMMARY:**

As the caregiver's subjective evaluation of their burden and their situation has been found to be the most effective measurement of burden, for the purposes of my practicum, I defined burden as the spousal caregiver's subjective impression of the impact of the changes in cognition and behaviour of the Alzheimer patient on the caregiver's emotional, social, physical and financial life. In evaluating my practicum I used measurement instruments that could tap into these subjective feelings.

Based on the work of Zarit, Orr and Zarit, the focus of the assessment phase of my program was in exploring the client's coping skills and their understanding of the disease and the disease's impact on their spouse. I also examined the caregiver's perceptions of their social supports and the quality of their marriage prior to the onset of the disease. I then designed a specific intervention strategy for each client based on this assessment.

## CHAPTER 4

### The Intervention

Caregivers of individuals with Alzheimer's Disease need to understand the disease and the impact it is having on their relative (Cohen & Elsdorfer, 1986; Mace & Rabins, 1981; Marples, 1986; Zarit, Orr & Zarit, 1985). They need to know how to effectively problem-solve if they are to successfully manage the long years of caregiving (Marples; Zarit, Orr & Zarit). Caregivers are also often emotionally distressed by their situation and their caregiving, and this distress can prevent adequate coping. They need, not only the opportunity to be able to acknowledge and ventilate these feelings, but a method of changing their maladaptive belief systems which motivate and maintain their emotional distress to more functional and adaptive belief systems (Oliver & Bock, 1985, 1987; Zarit, Orr & Zarit, 1985). In order to address these needs of caregivers I derived the theory of my intervention on two Cognitive-Behavioral Therapies; a Problem-Solving Therapy, Zarit, Orr & Zarit's Stress-Management Model; and a Cognitive-Restructuring

Therapy, A. Ellis's Rational-Emotive Therapy (RET).

I selected the Stress-Management Model because Zarit, Orr & Zarit (1985), who have worked with caregivers of Alzheimer's disease for many years, recommend their Stress-Management Model as the theoretical base for intervening with this population. I selected RET because Zarit, Orr & Zarit recommend the Cognitive Restructuring Therapies as an adjunct to their model for those caregivers that have difficulty absorbing information or learning how to problem solve as a result of their distressed emotional state. Oliver & Bock (1987) specifically recommended Albert Ellis's Rational-Emotive Therapy, one of the Cognitive Restructuring Therapies, as an effective treatment model for achieving the desired cognitive, affective and behavioral changes in the caregiver.

#### COGNITIVE-BEHAVIORAL THERAPY:

Kazdin (Dobson, 1988) defined Cognitive-Behavioral Therapy as encompassing any treatment that attempts to change a client's overt behaviour by altering the client's thoughts, beliefs or assumptions.

Dobson & Block (Dobson, 1988) state that the core of

all Cognitive-Behavioral Therapies are the fundamental beliefs that:

1. Cognitive activity affects behaviour.
2. Cognitive activity may be monitored and altered.
3. Desired change may be affected through cognitive change.

According to Dobson & Block (Dobson, 1988) and Wilson (Foreyt & Rathjen, 1978) the contemporary cognitive-behavioral therapies can be divided into three major divisions:

1. Cognitive Restructuring Therapies.
2. Coping-Skills Therapies.
3. Problem-Solving Therapies.

Cognitive Restructuring Therapies:

According to the theory of Cognitive Restructuring Therapies there are three main psychological aspects of human functioning; thoughts (cognitions), feelings and behaviour. Dryden & Ellis (Dobson, 1988) state that cognitions, feelings and behaviour should not, however, be viewed as separate psychological processes, but as processes that are highly interdependent and reactive. The Cognitive

Restructuring Therapies assume that emotional distress is the consequence of an individual's maladaptive cognitions. The goal of these therapies is to change these maladaptive thoughts to more adaptive thought patterns in the individual. Examples of Cognitive Restructuring Theories are Beck's Cognitive Therapy, Ellis's Rational-Emotive Therapy, Meichenbaum's Self-Instructional Training and Guidano & Liotti's Structural Psychotherapy (Dobson, 1988).

#### The Coping-Skills Therapies:

The Coping-Skills Therapies represent a heterogeneous collection of techniques that focus on client skill development. The rationale of these therapies is the assumption that if the client learns how to cope with mildly stressful situations, these learned coping skills will be transferable to higher stress situations and the client will also be able to cope in these situations. Examples of Coping-Skills Therapies include Meichenbaum's Stress Inoculation Training, Suin & Richardson's Anxiety-Management Training and Goldfried's Systematic Rational Restructuring (Dobson, 1988).



### The Problem-Solving Therapies:

The Problem-Solving Therapies are a combination of the cognitive restructuring techniques and coping-skills training. D'Zurilla (Dobson, 1988) defined problem-solving as a cognitive-affective-behavioral process where an individual or group attempts to identify, discover or invent adaptive means of coping with everyday problems. D'Zurilla & Goldfried (Dobson, 1988) defined problem-solving therapy as a form of self control training. They state that an individual's general effectiveness is most efficiently facilitated by educating that individual in general skills that will allow them to deal independently in the future with problematic situations. Examples of Problem-Solving Therapies include D'Zurilla & Goldfried's Problem-Solving Therapy, Spivack & Shure's Problem-Solving Therapy and Rehm's Self-Control Therapy (Dobson, 1988).

### THE STRESS-MANAGEMENT MODEL:

Zarit, Orr & Zarit (1985) see the major difference between their Model and other Problem-Solving Therapies is that, because of the complexity of dementia, the amount of information that must be provided is greater. They,

therefore, divide their Model into two sections, the educational component and the problem-solving component.

Educational Component:

Zarit, Orr & Zarit found that many of the problems faced by caregivers arise because caregivers do not have accurate information about the disease and the disease process. As a result of this gap in knowledge, caregivers do not know what to do or how to respond to the changes in the patient. In the educational component of their Model the therapist provides the caregiver with this needed information. I found when implementing my program that the educational needs of clients was more than just a need to be informed about the disease and the disease process. Caregivers also needed to understand the impact the disease was having on their spouse and how this relates specifically to their spouse's behaviour and symptoms.

I found the Educational Component to be an important element of my intervention with the subjects in my program. This was true for even those with whom I had limited contact. In my program, once I determined specifically what clients wanted to know, and to what depth they wanted or

could understand the information, I met this need by providing information through the use of informational pamphlets, by referring subjects to reference material, and by mini-lectures.

As the Educational Component of the intervention with this population is so important, it is essential that therapists designing and implementing programs for this population have a thorough and comprehensive knowledge about the disease, the disease process and the impact the disease has on the afflicted person's behaviour. Having this knowledge base is also an important factor in establishing rapport and developing a relationship with these clients. I found that it was very important to the clients to know that I, as a therapist, truly understood the day-to-day reality of their situation.

#### Problem-Solving Component:

In the problem-solving component of Zarit, Orr & Zarit's Model, the therapist focuses on developing in the caregiver knowledge about how to find the solutions for the problems confronting them. The aim is not to just find practical solutions but to teach the process of problem-

solving so that the caregiver can independently apply the process in the future to new problems. The steps in problem-solving identified by Zarit et al are:

1. To identify the problem.
2. To generate alternative solutions.
3. To select a solution based on determining the pros and cons of each potential solution.
4. Cognitive rehearsal.
5. To carry out solution.
6. To evaluate the outcome.

I did not find that the problem-solving component was an important part of my intervention strategy with the clients in my practicum. When assessing clients I found that generally the clients in my practicum already had fairly good problem-solving skills. As my sample, however, is very small and cannot be considered a representative sample of all caregivers, I cannot conclude that this component of the Stress-Management Model would not be applicable and useful for intervening with some caregivers.

#### Effectiveness of Stress-Management Model:

Dobson & Block (Dobson,1988) state that there is data

available to support the claim of a relationship between problem-solving skills and psychopathology. They do feel, however, that the evidence regarding the importance of the process of problem-solving is weaker.

Unfortunately, Zarit, Orr & Zarit do not provide us with specifics on if, or how, they evaluated their Stress-Management Model. They simply state that based on their experience their Stress-Management Model is effective in intervening with caregivers of Alzheimer's Disease.

#### RATIONAL-EMOTIVE THERAPY:

Oliver & Bock (1985) state that caregivers of Alzheimer's patients bring to the situation a set of irrational beliefs that exacerbate the caregiver's emotional reactions and prevent the development of effective methods of coping. The goal of Rational-Emotive Therapy in this situation, as in all RET Therapy, is to identify and challenge these irrational beliefs and dysfunctional attitudes, and help the client change these attitudes and beliefs to more adaptive emotions and behaviours.

The basis of RET is Ellis's ABC Model which is a simple conceptual schema for illustrating the relationship between

cognitions, emotions and behaviour. According to this Model, neurotic symptoms or emotional distress (C), is determined by the person's belief system (B) regarding particular activating events or experiences (A). In RET terms, the A (Activating event) does not directly cause C (emotional and behavioral consequence); but B (your beliefs) does (Dobson, 1988; Ellis & Grieger, 1977; Walen, DiGiuseppe & Wessler, 1980).

Clarifying the client's idiosyncratic A's (perceptions), B's (beliefs), and C's (emotions) is the assessment segment of RET. The therapist needs to understand the relationship between the client's perceptions, beliefs and emotions so that during the therapeutic process they can point out these relationships to the client. The client needs to understand the relationship between their perceptions about the events in their lives, their emotions and their beliefs, so that they see the relevance of working on changing their irrational beliefs. It is the disputing of the client's distorted perceptions and their irrational beliefs that is the work or intervention segment of Rational-Emotive Therapy (Ellis & Grieger, 1977; Walen et al, 1980).

### Activating Events:

A, the activating event, can be any external activity, action or agent in the client's experience (Roberts, 1982). Walen, DiGiuseppe & Wessler (1980) state there are two aspects of the A. The A can be an objective reality, a social consensus of what happened, and/or the A can be a perceived reality, the event as the client believes it to be. They expand the ABC Model to:

- A (confirmable)- the event as validated by a group of others.
- A (perceived)- the client's subjective description of the event.
- B- the client's evaluation of what they perceived.
- C- the emotional and behavioral consequences

Beck (Beck et al, 1979) states there are two main kinds of cognitive errors that result in distorted perceptions:

1. Errors in gathering data.
2. Errors in drawing conclusions.

The two primary errors of data collection are selective abstraction and magnification/minimization (Beck et al). In selective abstraction the client is focussing on some detail that has been taken out of context, ignoring other more salient details, and conceptualizing the situation on the basis of this detail. In magnification/minimization the

client is either magnifying or minimizing the situation so much that the A has become grossly distorted.

Beck (Beck et al, 1979) outlines three errors commonly made in drawing conclusions from data. First, is arbitrary inference. This is the process of drawing a conclusion in the absence of supporting evidence or in the face of contrary evidence. Second, is overgeneralization. This is a pattern of drawing general conclusions on the basis of a single incident. Finally, is personalization, which is the tendency to relate external events to oneself when there is no basis for making such a connection.

In my client sample I found that clients often had perceptual distortions of the events in their lives. I found that the event most commonly distorted by my clients was their perceptions of their spouse's behaviour. The clients in my sample frequently would ascribe the behaviour of their spouse to causes other than that of the disease i.e. something they as caregiver had done (an error of selective abstraction) or would conclude that the behaviour meant that their spouse no longer loved them (an error of arbitrary inference).

If in my assessment I identified that a client's



misperceptions of the behaviour of their spouse was the source of their emotional distress, my intervention focused on:

1. Educating the client on the nature and course of the disease.
2. Helping the client recognize that the behaviour was a result of the disease and not of a desire to harass or manipulate the client.
3. Assisting the client in establishing realistic expectations of their spouse's behaviour.

Oliver & Bock (1985) state that the unconditional acceptance of certain A's (events) in the caregiver's life are prerequisites to optimal caregiver coping. These A's are the unconditional acceptance of the patient, their growing deficits and the present negative prognosis. One of the important goals of my intervention was to assist clients in accepting these unchangeable events. There are, however, A's (events) that can be changed, such as the patient's behaviour or the caregiver's social isolation. Another important part of my intervention was to help my clients identify the changeable events in their life, and then assist them in changing them.

### Belief Systems:

B's are the individual's evaluations of their reality not their descriptions or predictions about it. Ellis states that while all humans probably have a tendency to easily learn irrational thoughts, the culture in which they live furnishes the specific content of those irrational thoughts (Walen, DiGiuseppe & Wessler).

Ellis states that belief systems (B) come in two forms: Rational Beliefs (RB) and Irrational Beliefs (IB) (Dobson, 1988; Ellis & Grieger, 1977; Walen et al, 1980). Ellis has codified the major irrational beliefs into 12 categories (Dobson, 1988; Ellis & Grieger, 1977; Walen, Diguseppe, & Wessler, 1980). These are:

1. All-or-nothing thinking- If I fail at any task I'm a total failure and I'm completely unlovable.
2. Jumping to conclusions and negative non sequiturs- Since others have seen me fail, as I shouldn't have done, they will view me as incompetent.
3. Fortune telling- Because they are laughing at me for failing they will despise me forever.
4. Focusing on the negative- Because I can't stand things, and life shouldn't be like this, it will never get better.
5. Disqualifying the positive- When people compliment me they are only being kind and are forgetting all of the stupid things I shouldn't have done.
6. Allness and Neverness- Because life ought to be good but is really intolerable, it will always be this way.
7. Minimization- My successes are because of luck and

are unimportant but my mistakes are as bad as they could be and are unforgivable.

8. Emotional reasoning- Because I have performed so poorly I feel like a total fool and my strong feelings proves that I am no good.
9. Labeling and overgeneralizations- Because I must not fail and I have done so I am no good.
10. Personalizing- Since I have failed and they are laughing, they must be laughing at me.
11. Phonyism- When I don't do as well as I ought to, and they still praise me, I must be a phony. I will soon fail and show them how awful I really am.
12. Perfectionism- I know I did well but I should have been perfect, therefore, I must be incompetent.

Walton, DiGiuseppe & Wessler state that the criteria for determining whether a belief is rational or irrational are:

1. A rational belief (RB) is true and can be supported by some empirical evidence. An irrational belief (IB) is not true and may begin with an inaccurate premise or lead to an inaccurate deduction. IB's tend to be extreme evaluative exaggerations of a situation. They are often found in statements that include such descriptors as "awful", "terrible" and "horrible". For example, for the caregiver of the Alzheimer patient, an irrational belief may be that their life is hopeless; while the more appropriate rational belief would be that, while the patient's future may be

inevitable, the caregiver can work to improve their future.

2. A rational belief is conditional. It is stated as a hope or want. In contrast, irrational beliefs are absolutistic and are expressed as commands or demands. Irrational beliefs are often based on grandiose demands on self (I must), others (They must), or the universe (The world owes me). For example, the caregiver with irrational beliefs may believe that they must be a perfect caregiver; while the caregiver with rational beliefs realizes that they are human and are likely to have limitations and flaws.

3. Rational beliefs lead to emotions that, even though they range in intensity from mild to strong, are not upsetting to the individual. These emotions promote personal growth and assist the individual in the achievement of their personal goals. In contrast, irrational beliefs lead to disturbed emotions that are debilitating and nonproductive. For example, the caregiver with irrational beliefs might feel angry because it is not fair that they are in this position and life should be fair. They are unable to think of anything beyond their anger. The caregiver with rational beliefs might feel sad because the world isn't fair; but they realize that life is not always fair, and you just have

to accept this and go on.

4. A rational belief helps you achieve your goals while an irrational one prevents you. Rational beliefs are congruent with satisfaction with living, enabling affiliation and minimizing intrapsychic conflict. In contrast, irrational beliefs prevent goal attainment. When caregivers are tied up with dysfunctional emotions they cannot work towards the goal of maximizing the quality of life of the patient while minimizing the emotional costs to themselves (Oliver & Bock, 1985). Cohen & Eisdorfer (1986) state that the caregiving period does not have to be a bleak, lost period of time for the caregiver. They found that many caregivers have found the caregiving experience to be a period of enormous personal growth.

In my client sample I did find that some caregivers held irrational beliefs about themselves and/or their situation. For example, some caregivers felt that they could be the perfect caregiver and/or that only they could provide care for their spouse.

Once the specific irrational beliefs of a client are identified, the focus of the intervention is directed at changing these irrational belief systems through a process

called Disputation. RET employs a wide range of cognitive, behavioral and emotive techniques to achieve the desired change in the client's belief system. This includes self-monitoring of thoughts, bibliotherapy, role playing, modeling, skill training, shame-attacking exercises, relaxation methods, operant conditioning and rational emotive imagery (Dobson, 1988). The major therapeutic tool of RET, and the one that I used in my intervention most frequently, is "a logico-empirical method of scientific questioning (Ellis & Grieger, 1977; Dobson, 1988; Walen et al, 1980).

#### Understanding the C:

People come to therapy because of the C, the affective and behavioral consequence of an event. Assisting clients in identifying and ventilating their emotions (C) was a major component of my intervention strategy. It was important, however, to discuss their emotional reaction within the context of the ABC model since Oliver & Bock (1985) warn that uncontrolled emotional ventilation can just reinforce the client's distortions of A and their irrational beliefs.

Some emotions (C's) are frequently associated with

specific situations or clinical problems. Oliver and Bock (1985) have found denial, guilt, anger, self-pity and depression to be common in caregivers of individuals with Alzheimer's Disease. I found that guilt, anger and depression were the emotions most frequently experienced by the clients in my sample.

The cognitions of guilt have two phases. First, the client believes that they are or have been doing something wrong. Second, they condemn themselves for doing the wrong thing. Guilt is a very common emotion in caregivers of Alzheimer's Disease. I think this may be partly due to the long years of not knowing what the problem is and, therefore, wondering if they caused or accelerated the symptoms in the patient. It also may be due to the extreme difficulty in caring for someone who is demented. Caregivers are bound to have days when they do not have the energy to cope effectively with the patient. They need to be able to forgive themselves for not always being able to manage.

People expect predictability in other people's behaviour, especially in those they have known well for years. When this predictability is violated, people often become angry (Oliver & Bock, 1985, 1987). The behaviour of

an individual with Alzheimer's Disease is completely unpredictable, but I found in my sample that my clients often had difficulty accepting this fact, and therefore, often became very angry at their spouse's frequently illogical behaviour. This anger was only dissipated when the caregiver could understand and accept the impact of the disease on their spouse's behaviour.

Depression, according to Beck, is cognitively based on a negative view of self, a negative view of the world and a negative view of the future (Beck et al, 1979). The caregiver sees themselves as a failure and the world as a bleak, hopeless place. Walen et al (1980) states depression can also develop as a result of self-blame; I am a failure as a caregiver, I should be perfect, therefore, I am bad and deserve punishment, or from self-pity; I want my way, life should not be like this, and it is awful if I do not have life the way I want it. I found that depression in my clients was often based on all three; self-pity, self-blame, and a negative view of self, world and future. I found that it was important to dispute all of the irrational beliefs underlying the depression before the client's depression would begin to alleviate.



The intensity and nature of the emotional or behavioural consequence of an event (C) is often determined by the nature of the error the client has made in perceiving the event (A) and/or their belief system (B). Walen et al (1980) states that the client that misperceives the event (A) and also holds irrational beliefs (B) about the event is more likely to be upset than the client who just has irrational beliefs. They also state that the client that thinks rationally, but continues to distort reality, can still experience negative affect, but this negative affect will be less intense than the client who distorts A and is irrational at B. For example, if we consider the caregiver of the Alzheimer patient:

Situation I: Client has distorted perceptions and has irrational beliefs.

A (confirmable)- My spouse doesn't interact with me as much as he/she used to.

A (perceived) - I think he no longer loves me.

B- It is terrible and awful that he/she doesn't love me.

C- Depression

Situation II: Client has a distorted perceptions but has rational beliefs.

- A (confirmable)- My spouse doesn't interact with me as much as he/she used to.
- A (perceived) - I think he/she no longer loves me.
- B- It's unfortunate that he/she doesn't love me but not the end of the world.
- C- Disappointment

Situation III- Client has irrational beliefs.

- A (confirmable)- My spouse doesn't interact with me as much as he/she used to.
- A (perceived)- This is typical of the disease process.
- B- It's not fair that they are ill.
- C- Anger

Situation IV- Client has an adequate perception of the event and rational beliefs.

- A (confirmable) My spouse doesn't interact with me as much as he/she used to.
- A (perceived) This is typical of the disease process.
- B- It's unfortunate that they are ill.
- C- Sad but accepting.

It is important to note that not all emotions (C's) are inappropriate or targets for change. RET theory does not see emotion as undesirable but as a normal part of life. RET is only interested in changing the harmful emotions, the ones that impede the client's ability to cope with life. In the above example, the client in situation IV is feeling emotion

but the emotion felt is not necessarily preventing adequate caregiver coping and may, in fact, be facilitating caregiver coping. The role of the therapist in therapy is to identify and validate the productive emotions while identifying and challenging harmful emotions.

#### Effectiveness of Rational-Emotive Therapy:

Unfortunately, Oliver & Bock do not provide any information on if, or how they have evaluated the effectiveness of this therapy on caregivers of Alzheimer patients. Ellis (Ellis & Grieger, 1977) states that RET's main propositions were tested in an unusually large number of studies in the 1950s and 1960s and that over 90% of the studies offered statistical evidence strongly supporting RET hypotheses. DiGiuseppe & Miller (Ellis & Grieger, 1977) state that if you include all the studies on therapies similar to RET, such as Beck's Cognitive Therapy, there is a growing body of literature that supports the efficacy of the RET therapeutic approach. A note of caution is given by Dobson & Block (Dobson, 1988). They state that, while RET has generated a large body of literature, most articles were by enthused advocates of RET rather than by researchers

concerned with collecting objective data. Dobson & Block also state that while Beck's work, a therapy very similar to RET, has been subjected to a substantial degree of empirical scrutiny, most of this work is on clinically depressed subjects and the issue of the generalizability of this model to other disorders has not been fully evaluated.

**SUMMARY:**

I found that basing my interventions with spousal caregivers of individuals with Alzheimer's Disease on the theory of Zarit, Orr & Zarit's Stress-Management Model and Ellis's Rational-Emotive Therapy was useful and had merit. The Educational component of the Stress-Management Model was essential in meeting my clients' need to understand what was happening in their situation. While I found the Problem-Solving component less useful, this may be just a result of limitations of my small sample, because certainly caregivers of individuals with Alzheimer's Disease need to have effective problem-solving skills if they are to cope with the long, ever changing years of caring. Rational-Emotive Therapy was also a useful theoretical framework for intervening with clients. I found that the spousal

caregivers in my sample did have distorted perceptions of their situation, and this perceptual distortion often prevented them from effectively coping. I also found that some clients in my sample had unrealistic expectations and evaluations of themselves and their situation, and these irrational beliefs also prevented them from effectively coping. Finally, one of the most positive features of the Stress-Management Model and Rational-Emotive Therapy is that they provide hope to clients. As Oliver & Bock (1985) state this is not the false hope of a "cure", but the hope that comes once people realize that they can again have control over their lives.

CHAPTER 5Methodology

## OBJECTIVE OF INTERVENTION:

The objective of my intervention was to improve the coping ability of caregivers with their caregiving by increasing their knowledge about the disease, by providing the caregiver with effective problem-solving skills and by altering the irrational beliefs the caregiver brought to the caregiving that were preventing effective coping. This objective assumes that adequate caregiver coping occurs when caregivers can accurately perceive and evaluate their situation and, as a result, make decisions that meet not only the needs of their carereceiver but their own needs as well.

## MODE OF INTERVENTION:

While group therapy has been the common method of intervening with this population Cole, Griffin & Ruiz (1986) state that individual counselling is also a useful method of intervening with caregivers of Alzheimer patients. Zarit,

Orr & Zarit (1985) also recommend individual counselling as the starting point in counselling caregivers. They state that at the point that caregivers seek help they are under a great deal of stress and require the intensive, individual attention that an empathetic, well-informed counsellor can provide. In their experience attempting family or group counselling prior to individual counselling is unsuccessful.

**SAMPLE SELECTION CRITERIA:**

The criteria for the selection of subjects was:

1. Subjects were to be spousal caregivers, either male or female, of individuals exhibiting symptoms of dementia.
2. They were to be residing with the patient at the time of the initial referral.
3. They were to be the primary caregiver of the patient.
4. At the initial point of referral subjects were to be indicating some difficulty in coping with some aspect of the caregiving or caregiving relationship.
5. They were to be capable of speaking and understanding English.

6. There was to be no apparent major psychiatric or social problems with the caregiver.

SOURCE OF REFERRALS:

Referrals to the practicum were made by the Manitoba Alzheimer Society. This organization is well known in the community as a resource centre for families caring for Alzheimer's patients. Families and professionals, on the behalf of families, regularly contact the Society when a caregiver is having difficulty coping.

Potential clients were identified by the professional staff of the Society on the basis of the previously given criteria. The professional staff would then discuss the practicum with the subject, and if the subject was agreeable, the individual was referred to the program.

The staff originally sought out referrals for the project by reviewing the files of all known cases. Clients # 1, # 2, # 3, and # 4 were identified by this approach. Although, each of these subjects originally agreed to participate in the project, after preliminary contact, only one of the four indicated any interest in further participation. At this point it was decided that the



professional staff would not actively seek out participants, but that future referrals would be composed of individuals who met the given criteria and who were presently contacting the Society requesting help.

Clients # 6, # 7, and # 8 learned about the program from an announcement made at a Family Support Group meeting. They felt they needed the more frequent, intensive support provided by individual counselling. Client # 5 was referred to the Society by her husband's physician because the doctor felt she was not coping well with her situation. Client # 9 was referred to the Society by her family who felt she was not coping.

#### SETTING:

Counselling sessions were conducted either in the home of the caregiver or in office space provided by the Alzheimer Society. The selection of location was the choice of the subject.

Of the 8 subjects with whom I had interviews, 5 requested home visits and 3 requested office visits (See Appendix I). The reasons given for their selection of interview site were:

1. Clients # 2 and # 3 felt that their physical health was too poor for them to easily leave home. These two clients were elderly, physically frail ladies who did not drive and found taking public transportation, especially in winter, very difficult. This was also the reason given why they did not attend other Society programs.

2. Clients # 2, # 3, and # 9 felt that they could not leave their spouse alone while they went out to a program. Clients # 2 and # 3 were receiving Home Care but did not like to ask for more Home Care or use the Home Care they were receiving for this purpose.

3. Client # 5 had child care responsibilities which limited her ability to leave the home. She also required evening sessions as she worked all day.

4. Clients # 4, # 5, and # 9 found that considering all of their multiple responsibilities it was easier to have someone come to their home.

5. Clients # 6, # 7, and # 8 requested office visits because it was too difficult to openly talk in front of their spouses.

Home visits were my preferred location of sessions, despite the fact that in three instances the spouse became so agitated by my presence the session had to be prematurely terminated. I believe that I gained a more comprehensive understanding of the situation by seeing the home environment. It was also easier to select appropriate coping strategies if one was aware of the physical limitations of the home environment. For example, suggesting using time outs as a way of coping with stress is a more useful intervention if the client lives in a three story house rather than a one bedroom suite.

Since client situations are so different it is important when planning programs for this population that there be flexibility in the setting of the program. During the earlier stages of the illness, when the caregiver feels restricted in what they can say in front of their spouse, program sites outside the home can be more appropriate. Programs that can be delivered in the home, however, are essential for the older, physically frail caregiver who is restricted in their ability to leave their home. Caregivers with multiple role responsibilities (employment, child care responsibilities) need flexibility in the setting and timing

of programs if they are to fit them into the demands of their very demanding schedules.

#### TIMING OF SESSIONS:

I had originally planned to meet weekly with each client but I found that this schedule was not feasible for this clientele. Of the five subjects that continued beyond the initial interview, four subjects agreed to meet every other week (clients # 5, # 6, # 8, and # 9) and one subject could only meet once per month (client # 7). Clients # 5, # 6, # 7, and # 8 felt that, because of their many responsibilities, they did not have the time to meet weekly. Client # 9 felt she wanted to only meet every other week so that she would have adequate time between sessions to absorb and contemplate the material presented in each session.

Zarit, Orr & Zarit (1985) found that, in their individual counselling program, clients averaged about seven sessions. In my program, I found that the number of sessions per client varied from 1 to 5 (see Appendix I). The difference between my finding and that of Zarit, Orr & Zarit's finding may be related to the length of each session. Zarit, Orr & Zarit do not state how long each

session lasted in their program but, in my program most sessions lasted at least two hours in length and some were as long as four hours.

#### PROCESS:

Of the nine subjects of my client sample, I had 0 sessions with one client, 1 session with three clients, 2 sessions with one client, 3 sessions with two clients and 5 sessions with two clients (See Appendix 1). For a detailed description of specific contact and process on each client see Chapter 6 and Appendix II.

#### EVALUATION:

The basic premise of my practicum was that short term individual counselling theoretically based on Zarit, Orr & Zarit's Stress-Management Model and Ellis's Rational-Emotive Therapy would reduce the burden of caregiving of spousal caregivers of patients with Alzheimer's Disease and that this reduced burden would facilitate improved caregiver coping.

In order to evaluate the effectiveness of my intervention I originally intended to use the following

measurement instruments:

1. The Caregiver Burden Inventory CBI (Novak & Guest, 1987) (Appendix III).
2. The Burden Interview BI (J.Zarit, 1982) (Appendix IV).
3. Memory and Problems Checklist MPC (Zarit & Zarit, 1983) (Appendix V).

The Caregiver Burden Inventory:

Permission to use this instrument was obtained from M.Novak (see Appendix VII,A).

This multi-dimensional, 24 item questionnaire is designed to measure the impact of burden on caregivers. The five dimensions of the instrument are time dependence, developmental burden, physical burden, social burden and emotional burden. Scoring ranges from 0-20, except for physical burden which scores 0-16. Total score ranges from 0-96. For graphing purposes the score for physical burden was adjusted so that it was also out of 20.

Reliability estimates for the total instrument is Chronbach's alpha = .8935. Alpha for each factor is: .8569; .8497; .8654; .7453; .7766 (Novak & Guest, 1987a).

My objective was to administer this instrument at the initial session, at the final session and one month after the completion of the therapy. I completed the CBI in the initial session on 8 clients. The CBI was not completed on Client # 1 as contact with this client was limited to phone contact only. I completed the CBI in the final session on 3 clients (# 6, #8, and # 9). I completed the CBI in the follow-up session on 2 clients (# 8 and # 9).

A detailed discussion of the global CBI scores, scores on each of the dimensions for each client, and an evaluation of changes in scores from the initial application through to follow-up score is available on each client in Chapter 6, Chapter 7, and Appendix II.

#### The Burden Interview:

Permission to use this instrument was received by S. Zarit and J. Zarit (see Appendix VII,B).

The BI is a 22 item questionnaire. Answers range from never (0) to nearly always (4). Range of total score is 0-88. Zarit states that while there are no norms for this scale, he has made some estimates. These are:

Scores of 0-20 = Little or no burden  
Scores of 21-40 = Mild to moderate burden  
Scores of 41-60 = Moderate to severe burden  
Scores of 61-88 = Severe burden

Zarit & Zarit (1987) report that internal reliability for the BI using Chronbach's alpha has been estimated in various studies as varying from .88 to .91. Test-retest reliability is reported at .71 (Zarit & Zarit, 1987).

My objective was to administer this instrument at the initial session, the final session and one month following completion of the therapy. I administered this instrument to 7 clients in the initial session. Contact with Client # 1 was limited to phone contact only. Testing on Client # 2 could not be completed because her husband became very agitated and interview was prematurely terminated. I administered this instrument to 3 clients in the final session (# 6, # 8, and # 9). I administered this instrument to 2 clients in the follow-up session (# 8 and # 9).

A detailed discussion of BI scores on each client is found in Chapter 6, Chapter 7 and Appendix II.



I had originally not planned to use the BI and only use the CBI. It was the suggestion of M. Novak, the co-developer of the CBI, that I use both tools. Both instruments are designed to measure subjective burden but, as the CBI is a very new measurement instrument and the BI has been the instrument most commonly used in studies for measuring burden, it was felt that I could be more certain of the scores on the CBI if they were found to strongly correlated with the scores on the BI. As there are some similar questions on the two instruments, M. Novak suggested that for the purposes of implementation I meld the two instruments together (Appendix VI). After implementation the data was separated out for the purposes of analysis.

A comparison between each client's CBI and BI scores is presented in Appendix VIII. The percentage difference between each client's CBI score and BI score ranged from .1% to 15.6%. On the basis of this data it would appear that the CBI and BI are strongly correlated.

I did find that for the purposes of evaluating the impact of burden on the caregiver, since the CBI does separate burden into different dimensions, it was a more useful instrument than the BI.

The Memory and Behaviour Checklist:

Permission to use this instrument was received by S. Zarit and J. Zarit (see Appendix VII,B).

This 30 item scale was developed to determine the frequency of current symptoms and the caregiver reaction to each symptom. The scale lists 30 symptoms common to Alzheimer's Disease. The caregiver rates the frequency of each symptom over the last week. Answers vary from 0 = never has occurred to 4 = occurs daily or more often or 7 = it would occur without supervision. Range of scores vary from 0 - 210. The caregiver also rates how much the presence of each symptom bothers them. Answers vary from 0 = not at all to 4 = extremely. Total score in this dimension would vary from 0 - 120.

Zarit & Zarit (1987) report that the Guttman split-half reliability for the frequency of problems was found to be .65. Split-half reliability for the distress ratings are .66 (Zarit & Zarit, 1987). Test-re-test reliability is .80 for the frequency measure and .56 for the distress measure (Zarit & Zarit, 1987).

My objective was to use this instrument at the beginning of each weekly session. As it is a long

questionnaire I intended to eliminate, after the second application, asking about symptoms that the caregiver had indicated were not occurring. I planned to again administer the entire instrument at the final session and one month after the termination of therapy. I had intended to use the data collected from this instrument during therapy as a method of evaluating an individual's therapy using Single System methods of analysis (Bloom & Fischer, 1982).

I had major problems in using this instrument. With some clients the instrument was useful in facilitating the telling of their story, but for other clients the instrument was definitely obstructive to the interview process. I also found there were major problems in scoring the instrument, especially in regards to the questions concerning the functional status of the patient. For example, when a client is asked to rate how often they had to assist their spouse with dressing, this question does not define what is meant by assisting with dressing. Assistance with dressing may mean anything from just taking away the dirty clothes so that the individual must put on clean clothes to completely dressing the patient. Because of the complexity of these issues, the responses made by clients varied wildly from

week to week. Clients also found my attempts to repeatedly implement this long, ambiguous instrument boring and irritating. As a result of these problems I quit using this instrument by midway through the practicum.

#### Single System Evaluation:

Since, after I discarded the Memory and Behaviour Checklist, I no longer had data on which to do an evaluation of client's therapy using Single System evaluation, I decided at this point to add a new instrument. Clients were requested to rate the previous week's level of stressfulness on a scale of 0 (not stressful at all) to 10 (very stressful). This scale was recommended by Zarit, Orr & Zarit (1985). My intention was that, by analyzing the data from this self-anchored scale using the techniques of Single System Evaluation Theory, I would then be able to evaluate the effectiveness of the individual client's therapy (Bloom & Fischer, 1982).

I found two major problems in evaluating the data from this self-anchored scale. First, since I did not decide upon using this instrument until after I had started intervening with some clients, I could not establish a baseline for

these clients. Without this baseline, evaluation of the data is very limited. Second, I identified a major flaw in the construction of this scale. I discovered this error when a number of clients, whose rating of stress was remaining stable, started saying "but I coped with last week so much better than before". I had intended the scale to measure the level of stress the client was feeling in a week. My assumption had been that if therapy was successful, clients would feel less stressed by the events in their lives and their ratings of the level of the week's stress would decrease. Instead, some clients were using the scale to rate the actual number of stressors in their week. Since my intervention was not aimed at changing the number of stressors in their lives, their rating of the week's stress did not provide me with data I could use to evaluate the effectiveness of my intervention. As result of these two major design flaws, the evaluation of the results of a client's therapy based on this scale is of very limited use.

Detailed discussion of results on each client is presented in Chapter 6 and Appendix II.

As a result of the problems I encountered with the Memory and Behaviour Checklist and the Self-Anchored Scale, in order to evaluate the success of my intervention, in addition to the burden scores, I decided to consider the client's self-evaluation at final and follow-up session as to whether they felt the intervention had improved their ability to provide care and my clinical evaluation of any improvement in each client's ability to caregive. My clinical evaluation of any improvement in a client's ability to caregive was based on whether or not I observed any changes, from initial to final session, in the client's ability to accurately perceive and/or evaluate their situation.

Data on each of these measurements for each client is presented in Chapter 6, Chapter 7 and Appendix II. Caution needs to be used when drawing conclusions based on this type of subjective measurement instruments since validity and reliability is unknown.

CHAPTER 6The Spousal Caregivers

The caregivers in my sample consisted of 9 Caucasian females. Age of the subjects ranged from 40 to 88 years of age. Mean age of the sample was 62.5 years. Ages of the dependent spouses ranged from 42 to 90 years of age. The mean age of the spouse was 66.3 years. The length of time married ranged from 10 years to 59 years, with the average length of marriage 34.9 years. While specific data was not collected on socioeconomic status and ethnicity, the sample did appear to contain individuals from the different socioeconomic classes and from different ethnic backgrounds (Jewish, Ukrainian, Anglo-Saxon). See Appendix I for statistical information on each case.

As stated earlier this sample cannot be considered representative of all caregivers of individuals with Alzheimer's Disease. Based on the facts on the incidence of Alzheimer's Disease, a representative sample would be heterogeneous in all factors, excluding age, and the mean age of the sample would be over 65. While I believe that the

small size of my sample is a major reason for its nonrepresentativeness, I also feel there are other factors that may be contributing to this result.

First, the Alzheimer Society has acknowledged that the racial and ethnic distribution of its membership and of those using their services is not representative of the multi-cultural nature of our society. As my sample was exclusively drawn from referrals from the Alzheimer Society it also reflects this bias.

Second, males may be less disturbed by the caregiving process and, therefore, may be less interested in participating in programs. When questioning the staff of the Society as to why no men were referred to the program they responded that, while they did have husbands seeking help during the referral period, these husbands were usually seeking very concrete help. They also stated that the male caregivers appeared to be less emotionally disturbed by the caregiving than the female caregivers were. The research by Fitting et al (1986) supports this assertion. They found in their study that female caregivers appeared to be more distressed than male caregivers and they suggested two possible explanations for this finding. One, women may just



be tired of the caregiving role after raising children and caring for aging parents. Two, the model that women use for caregiving may be based on a parent-infant model while men might be basing their caregiving on a different model. The male caregiving model may be one that they brought from the work world, that is it is based on delegation of responsibility and the recognition of the limitations necessary to do a good job.

Fitting et al warn that there are limitations to their study because their sample was nonrandom in selection and was cross-sectional in design. They recommend, and I concur, that further investigation of possible differences in male and female caregivers is required if we are to be confident that men are underrepresented in support programs, not because they have less need than female caregivers, but because, while their need is the same, as a result of their socialization, they are less comfortable seeking help.

Third, younger spouses may be more distressed by the caregiving process and, hence, more likely to be overrepresented in client samples. More telling than the mean age of my sample, is the fact that of the five subjects who were interested in more than one session, four were younger

then 65 years of age. Fitting et al also found in their study that younger caregivers often feel lonelier and more resentful of their role than older caregivers. In my opinion there are two possible reasons for this result.

First, caring for a sick husband is not as expected when you are 40 versus when you are 70. The older caregivers in my sample had expected that either they or their husband would end up sick and having to care for the other one. They also had friends who were in the same position with whom they could share their frustrations. The younger caregivers in my sample had never anticipated something like this happening at this point of their lives. They felt alienated and socially isolated from their friends who were still busy working or enjoying early retirement.

Second, I also found that for the younger caregiver the usual available resources are less helpful. The Society's usual way of meeting the needs of caregivers is through educational forums and support groups. An important philosophy of the Society is that it is therapeutic to meet and share experiences with others in a similar situation. Unfortunately, for the younger spousal caregiver, attending group meetings at the Society can just increase her sense of

uniqueness and isolation. As one client said, when she goes to the Society's support group, she is surrounded by wives thirty years older than her. She cannot develop a bond with these women because she does not feel it is the same experience to have a sick husband at eighty as it is at the age of fifty. She also could not feel connected to the women of her generation at the group, because they were concerned about how to care for a sick parent, which is not the same emotional experience as caring for a sick husband.

#### Caregiver Differences

The literature has generally tended to treat all caregivers as a homogeneous group, and at best, has only differentiated between caregivers based on relational categories, such as spousal or children caregivers. I found in my sample, despite its small size, considerable diversity in the circumstances and needs of spousal caregivers. To illustrate this diversity I will now present two case examples from my sample.

The Younger Spousal CaregiverClient # 5

## Contact:

Referred to the practicum in December, 1988. Her husband's physician referred her to the Society, with her consent, because it was felt that she was not coping well with the situation. Three interviews, averaging two and one half hours in length, were completed. Client had to move March 1, 1989, so she took a few weeks off to deal with move. She was to contact me once settled to resume sessions, but she never did this. I was unable to contact her further.

## Assessment:

Client is a 40 year old lady caring for her 42 year old husband. Couple have been married for 10 years and had lived together for 3 years prior to their marriage. Client reported that there had been a long history of marital discord, including one incident of physical abuse of client by her husband early in the marriage. Client was very afraid of further abuse. Husband had a history of alcohol abuse and

was still periodically abusing alcohol.

Client's husband was on extended sick leave from his job as a fire fighter. Client was presently working full time in a clerical position. Finances were a major problem as husband was refusing to contribute financially to the household.

Couple had one child, a 5 year old daughter. Client was very concerned about the impact the deterioration in her husband was having on this child. Client also had a 16 year old son from a previous relationship. The relationship between her son and her husband had been deteriorating for several years and this son was now away from home at boarding school. The impact of this disease on minor children has not been well studied in the literature. I was only able to locate one article that focussed on this issue (Aronson, 1988). The impact of the disease on children is a major concern of the younger spousal caregiver and if we are to effectively meet their needs we need further research in this area.

Client had a long history of a poor relationship with her husband's parents and brother. His family tended to deny that there were any problems with his health and saw the

client as the cause of couple's marital problems. Client's parents and three brothers and one sister lived in Winnipeg. Client did receive some emotional support from her parents, especially her mother.

Client had noticed deterioration in her husband over the last two to five years. He was becoming increasingly forgetful, was having episodes of getting lost, had lost interest in his personal hygiene and was having episodes of urinary incontinence. He was diagnosed with Alzheimer's Disease in October, 1988 after five years of extensive medical investigation by internists, neurologists and psychiatrists. While I had some questions about the cause of his dementia, there was no doubt that he had been adequately assessed for the possibility of a reversible dementia. At this time, client's husband appeared to be in the Confusional stage of the illness.

Through the long years of medical investigation, client had never anticipated this diagnosis. At the time of the referral client was in a state of shock. She knew nothing about the disease or how it was impacting on her husband's behaviour. Considering that her husband was a chronic smoker and was still driving, although the disease was impacting on

his ability to do these activities safely, she needed to know how to protect herself and her children. This client was also emotionally distraught and depressed as she attempted to cope with the caregiving, with raising her children and with coping with a full time job. She was not even sure if she wanted to learn how to cope with this situation.

Intervention:

My intervention strategy with this client encompassed three areas; education about the disease and it's impact on her husband's behaviour, examining the accuracy of her perceptions of the events (A's) in her life and identifying and challenging her irrational beliefs (B's). While each session addressed all three issues I found that the first session mainly focussed on the education component, while the second and third sessions mainly focussed on her perceptions. We were just beginning to examine her belief system when client terminated therapy.

Zarit, Orr & Zarit (1985) suggest a therapist begin the educational process by asking the caregiver what questions they have. They found that questions by caregivers generally

fall into two categories:

1. Questions about the disease.
2. Questions about how to manage behaviour problems.

Client # 5 had both types of questions.

I found that for all of my clients the questions about the disease were the easiest to answer. One just provided accurate information, through the use of pamphlets, minilectures and discussions, at the level and speed that the specific client could assimilate.

The second type of question is much more difficult to answer because there are no behaviour management techniques that will work for every patient, or that will work all the time on the same patient. This client had behaviour management questions in two areas.

First, her husband was a chronic smoker and was frequently burning holes in the furniture. Client was very concerned about the potential for a house fire. As client was not going to get her husband to stop smoking, and lecturing him about fire safety was not going to do any good since he would forget the discussion minutes after they had it, the only approach she could take was to take steps to



ensure the safety of herself and the child. To that end, in our sessions we discussed the placement of smoke detectors near to where her husband liked to sit, having a fire extinguisher easily available in the home and having an escape route planned out in case of fire.

Second, client was concerned about her husband's driving skills. She knew from driving with him that he frequently drove through stop signs and red lights and that he often just got lost when he was out driving. This was a major source of stress for client because her husband was out everyday, all day, just driving around and she was sure he was going to eventually cause a major accident. Her sense of helplessness about being unable to deal with this problem was complicated by their physician, who refused to report her husband to the motor vehicle branch because he was reluctant to take away her husband's last area of independence. In our sessions we could only focus on what was within her power to change, such as deciding whether or not she and her children would continue to drive with him.

The second focus of my intervention with this client was examining this client's perceptions of the events in her life. This client was making an error in the gathering of

data, that of selective abstraction. Her error of selective abstraction was that she was focussing on some detail that had been taken out of context e.g. her husband saying he would do some task and then not doing it. Then, ignoring that this type of behaviour is common in demented people, she conceptualized the situation as being that her husband did not do the task because he wanted to frustrate or anger her. This client was also making an error in drawing conclusions, that of arbitrary inference. She continually concluded that her husband's behaviour was deliberate and aimed at angering her, in face of the contrary evidence, that his behaviour was the result of his disease and was beyond his control.

The final focus of my intervention with this client was to identify this client's belief system and challenge the irrational beliefs that were causing her emotional distress. One irrational belief that did surface very early in the therapy was her belief that she, and only she, could care for her husband. In attempting to challenge this belief one had to not only look at the logic of this belief, i.e. if she was not there, would not his family or the formal system be able to meet his needs, but we had to examine the hedonic

value of her belief system, i.e. is it worth it for her to keep trying to care for her husband and perhaps place herself and her children at risk of physical abuse. Unfortunately, therapy was terminated before this area was fully explored.

Evaluation:

Clinically, client did appear to make some progress in the therapy. As her knowledge about the disease increased, and she became more adept at recognizing the errors she was making in perceiving her husband's behaviour, there appeared to be a reduction in the intensity of her emotional responses to her husband's behaviour.

Client also stated that she felt that the intervention had improved her ability to cope, but as she did drop out of therapy before completion, her action may contradict this statement. I was unable to contact her to explore with her the reasons for her termination of therapy.

Client scored 43 (44.8%) on the CBI and 51 (57.9%) on the BI at the initial session. Her score on the BI places her in the moderately to severely burdened range. Scores on the different dimensions of the CBI were (see Client V,

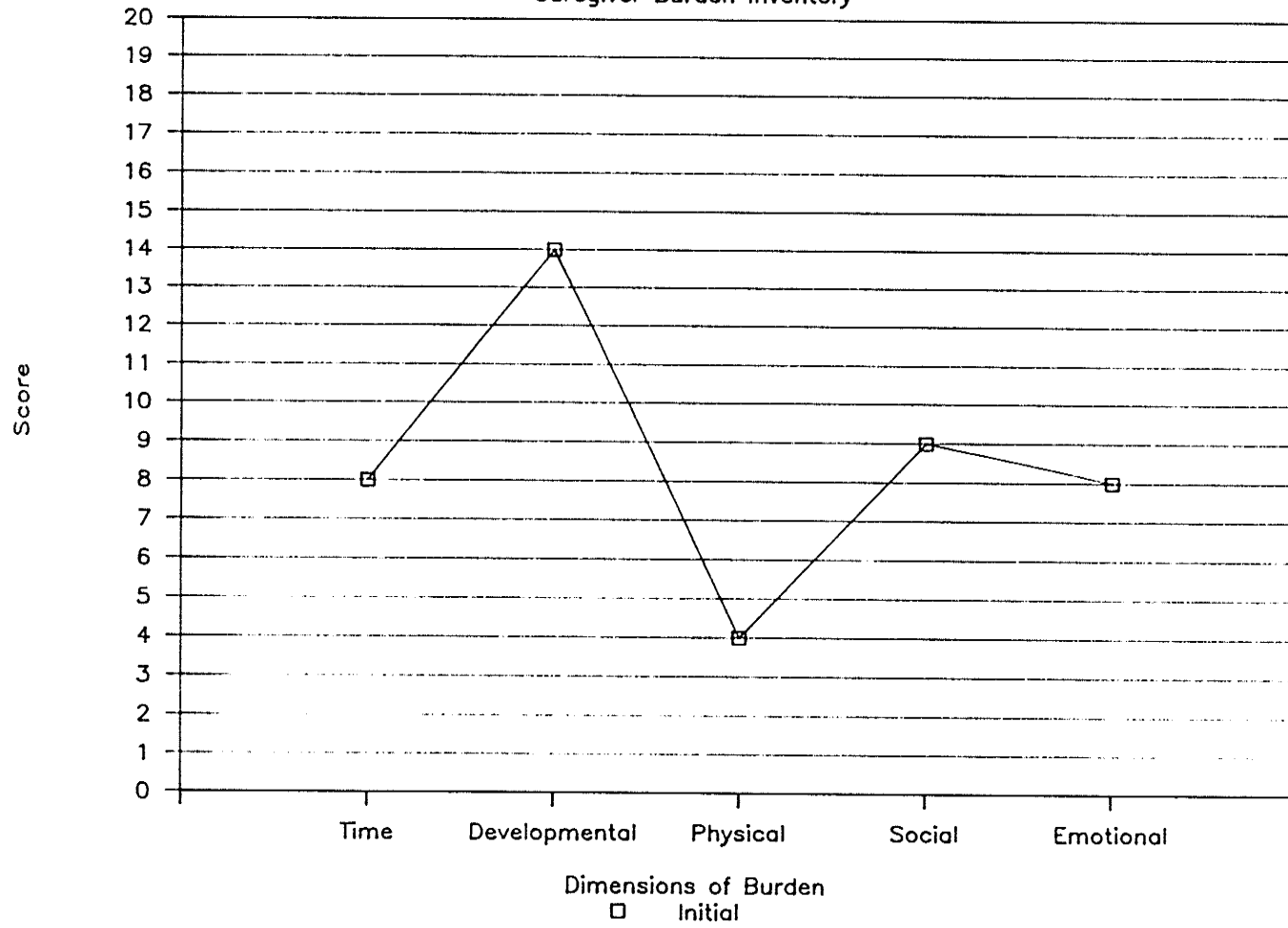
## Graph A):

Time Dimension	=	8
Developmental Burden	=	14
Physical Burden	=	4
Social Burden	=	9
Emotional Burden	=	8

Unfortunately, since client dropped out of therapy, there is no comparative data available upon which to evaluate the success of the intervention using the BI and CBI.

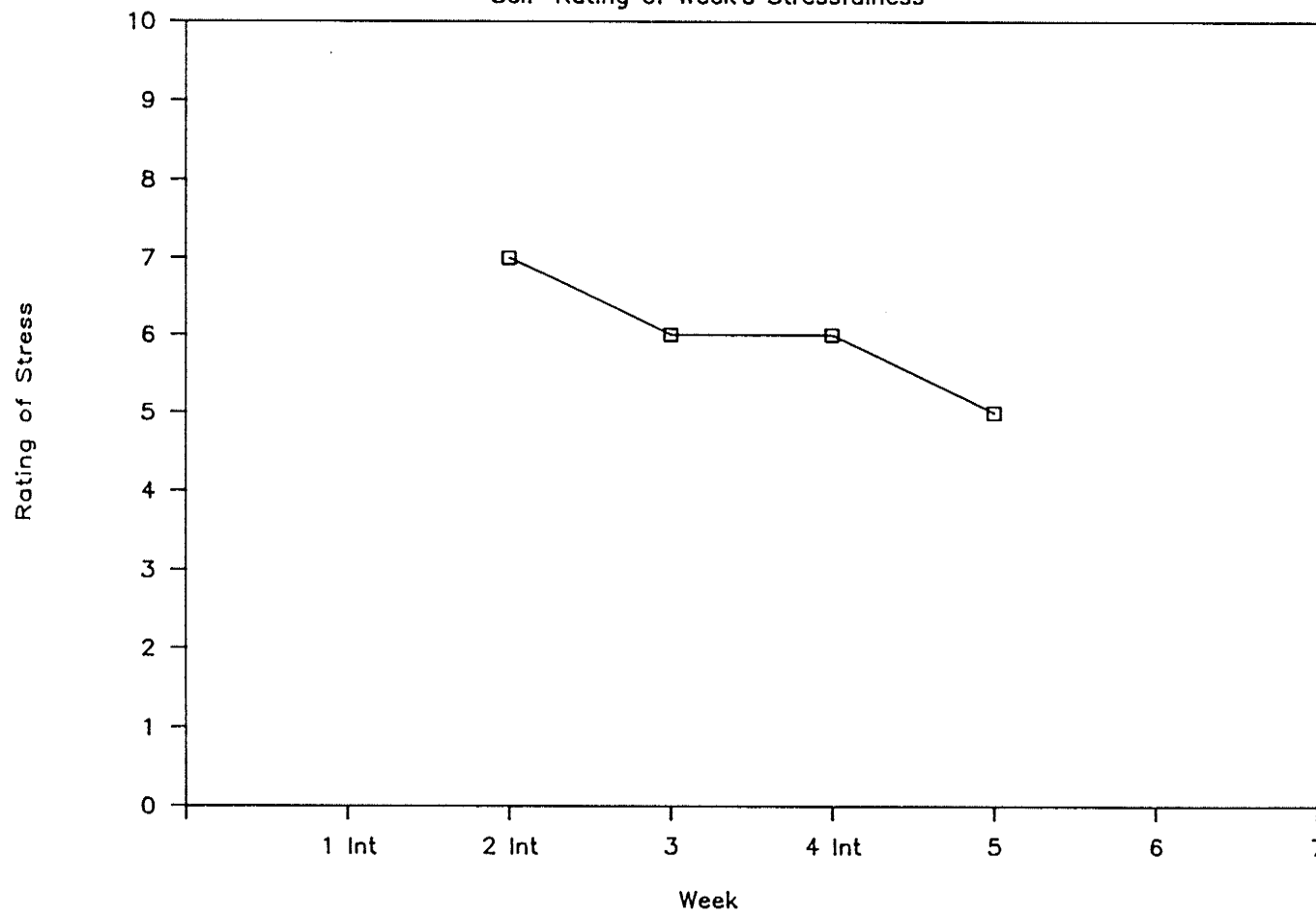
Client V, Graph B is of this client's self rating of the week's stressfulness. Examining the data visually we might conclude that the intervention was having success because the client's rating of the week's stressfulness was gradually dropping. Unfortunately, as I did not introduce this measure until the second session, there is no available baseline, therefore, no way to determine if this change is statistically significant.

Client V, Graph A  
Caregiver Burden Inventory



# Client V, Graph B

Self-Rating of Week's Stressfulness



**Summary:**

I found that the issues of concern to client # 5, such as her concern about how her husband's disease was impacting on her young daughter, were reflective of the types of concerns common to younger spousal caregivers. Client # 5 's situation and concerns are, however, quite different from the concerns expressed by other caregivers in my sample, such as client # 6. Client # 6 is typical of the older spousal caregiver.

The Older Spousal CaregiverClient # 6**Contact:**

Referred to practicum January, 1989. Client volunteered to participate in the practicum after information about the practicum was presented at a Family Support Group meeting. Client felt she required the more frequent and individual attention that would be provided by the practicum. Five sessions, averaging two hours in length, were completed.

A follow-up telephone interview was completed four weeks after the termination of therapy.

**Assessment:**

Client is a 66 year old lady caring for her 75 year old husband. Couple have been married for 31 years. Client stated the marital relationship prior to the onset of the disease was very good. Husband ran his own restaurant for over twenty years. He retired five years ago. Client worked, until her retirement five years ago, at Burns Meats. Couple were really enjoying their retirement and were travelling extensively until client's husband became ill. At the time of the initial referral client was grieving their loss of mobility.

Couple had no children but client has one son from a previous marriage. Client states her son, daughter-in-law, and two grandchildren are very supportive. Client's husband has one friend who is very supportive. He also has one niece and one nephew, but client states they provide little support. This is a source of irritation for client as she feels his family should assist her with his care. Client has 6 sisters and 2 brothers. Client states she has always been



the family member that helped out when others were in need. She feels angry that now, in her time of need, none of her siblings offer to help.

Client's 95 year old mother presently is living in a nursing home in Winnipeg. Client cared for her mother for several years prior to this placement and still is the main source of support for this woman. Client's mother is an alert, orientated lady. She denies seeing any health problems in client's husband and becomes angry and depressed if client does not come to visit at least three times per week. Client states she is the only sibling that visits regularly. She feels that as the needs of her husband increase she will have to reduce the amount of support she provides for her mother. She was angry that her siblings have not offered to take over providing the emotional support their mother needs.

Over the last two years client has noticed steady deterioration in her husband's memory, in his ability to manage their financial affairs and in his ability to manage his personal care. He was diagnosed with Alzheimer's Disease in 1988 after what appears to be a very thorough medical investigation. He appeared to be, at the time of the initial

interview, in the Confusional stage of the disease but, as he was steadily deteriorating, he will not be in this stage much longer. Husband appeared to be aware at times of his mental deterioration and as a result was periodically very depressed and suicidal.

Client had her own health problems, specifically a heart condition that is aggravated at times by the strain of caregiving.

While this client had a minimal understanding of the disease and the disease process, she had little appreciation about how the disease was actually impacting on her husband's behaviour. There were two areas of her husband's behaviour which were of specific concern to this client. First, she was frustrated and angry because her husband would not give up driving, even though the disease was affecting his ability to manage this activity. Second, she also felt hurt because her husband was always accusing her of mismanaging their finances, a task she had reluctantly taken on because he no longer could successfully manage it. She was especially confused because at times he would acknowledge that he could not cope in these areas, but in the next minute he would harangue her about wanting to go

out driving or accuse her of hiding his money.

Intervention:

The focus of my intervention with this client was fourfold:

First, to provide this client with the opportunity to ventilate her anger towards her family and her grief over the loss of her relationship with her husband.

Second, to provide this client with education about the disease. The focus of the educational component of the intervention was specifically directed at increasing her general knowledge about how the disease impacts on its victims. It was only after this client understood the impact of the disease on her husband's cognitive processes that she could comprehend his contradictory comments and behaviours.

The third objective of my intervention was to challenge this client's distorted perceptions of the events in her life (A). Not only was this client confused by the inconsistencies in her husband's behaviour, she was also constantly misinterpreting his behaviour (A). For example, when he accused her of hiding his money, she interpreted this to mean that he did not trust her. In her opinion, this

suggested that he had never trusted or loved her. These distorted perceptions were just increasing the intensity of her emotional response (C) to the situation, further exhausting her and reducing her ability to cope.

Finally, this client's husband was rapidly reaching the stage where client would need practical assistance with his daily care needs. Throughout therapy client was encouraged to establish contact with the Continuing Care Program, a program designed to provide practical assistance to caregivers. By the termination of therapy client's husband had been enrolled on the Continuing Care Program and was in receipt of a sitter once per week.

**Evaluation:**

Clinically, I observed improvements in this client's understanding of the situation and in her ability to cope with the situation. In the early sessions, client would describe a specific behaviour exhibited by her husband in the previous week and angrily ask "Why does he act in such an illogical manner?". By the final session she might describe the same behaviour but say "I know he just acts that way because of his illness". She still felt sadness by

the changes in her husband but she was not exhausted by her emotional response and, therefore, had more energy left to cope with her husband's daily care needs.

This client agreed with my clinical impressions on the success of the intervention. She felt she was coping much better with her situation as a result of her increased understanding of what was happening to her husband. During the follow-up telephone interview she stated that her improved ability to cope with her husband's behaviour had continued, despite his steady deterioration, and that, as a result of the intervention, she was much more patient with her husband.

The results on her CBI and BI support my clinical observations and her opinion about the success of the intervention. Client's original score on the BI was 64 (72.7%), a score that placed her in the severely burdened range. Her BI score at time of the final session had dropped to 42 (47.7%), a score that placed her in the moderately to severely burdened range. A similar drop occurred in the CBI global score. Her original CBI score was 73 (76%) and her final CBI score was 43 (47.8%). The scores on the sub-scales of the CBI were (see Client VI, Graph A):

	Initial	Final
Time Dependence	19	15
Developmental Burden	17	13
Physical Burden	16	10
Social Burden	13	2
Emotional Burden	8	3

In comparing the results of the administrations of this instrument one notices while the scores on each dimension dropped, the overall pattern of this client's rating of the different dimensions generally does not change. In both administrations this client rated Time Dependence the highest, then Developmental Burden and Physical Burden, and finally Social and Emotional Burden. One also notices that while each of the sub-scales change from initial to final administration, the degree of change in each sub-scale varies e.g. Time Dependence dropped 4 points while Social Burden dropped 11 points.

Client scored highest in the area of Time Dependence. This result may be surprising since I had assessed her husband as being in the Confusional stage of the illness, and this stage usually demands less of the caregiver in

terms of daily hands on care then the individual in the Ambulatory Demented stage. But, these stages really are not discrete and the care needs of individuals with Alzheimer's Disease can best be viewed as a continuum. This specific client's husband may still be assessed as being in the Confusional stage but on the continuum he is closer to the Ambulatory Demented stage than the Forgetfulness Stage.

Client scored second highest in the area of Developmental Burden. The major change in her score from first to final administration was caused by her rating of 4 in the initial session to the question " I wish I could escape from this situation" and only 1 to this question in the final session. This change in attitude may be attributable to this client's more accurate perceptions of the situation by the final session.

Client then scored Physical Burden as the third highest area of burden. This woman's health was being affected by her caregiving as the number of angina attacks she experienced increased when she was feeling stressed by the caregiving. As she learned to cope more effectively with the situation, the actual number of her angina attacks decreased reducing the impact of caregiving on her health.

The Social Burden sub-scale experienced the largest drop of all the dimensions from the initial to final sessions. This may demonstrate the importance and effectiveness of providing this client with the opportunity to ventilate her negative feelings about her family in a safe, nonjudgemental environment.

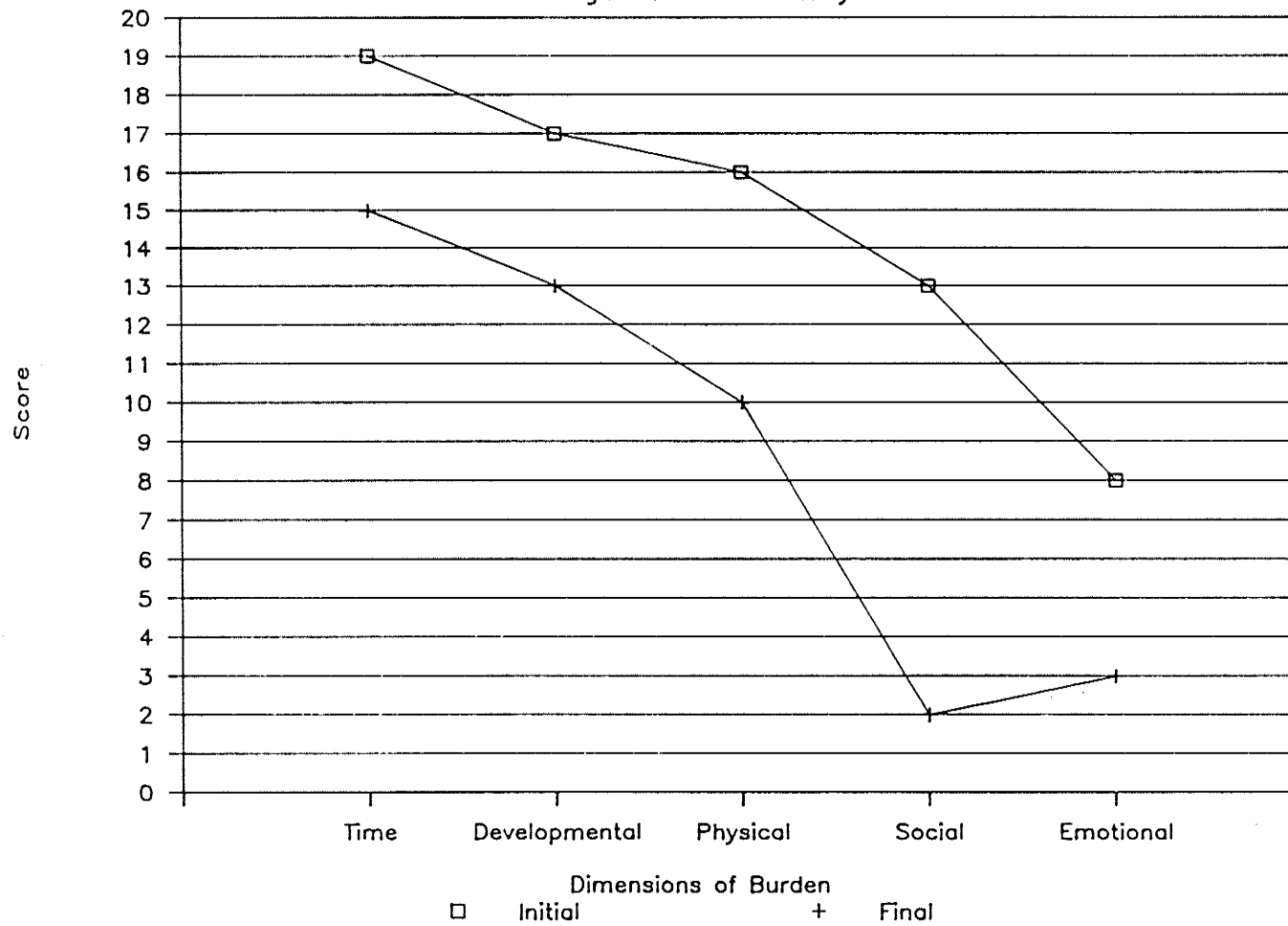
Finally, the drop in the score on the Emotional Burden sub-scale may be the result of her improved understanding of the cause of her husband's symptoms.

Client's self-rating of the week's stressfulness is found in Client VI, Graph B. This instrument was not helpful in evaluating the effectiveness of the intervention because this client used this scale to indicate the number of stressors she was experiencing in a week not to indicate how stressed she was feeling. I did not realize this until the final few sessions where, after rating the previous week as a 10, she would then state " but I coped much better with the week".



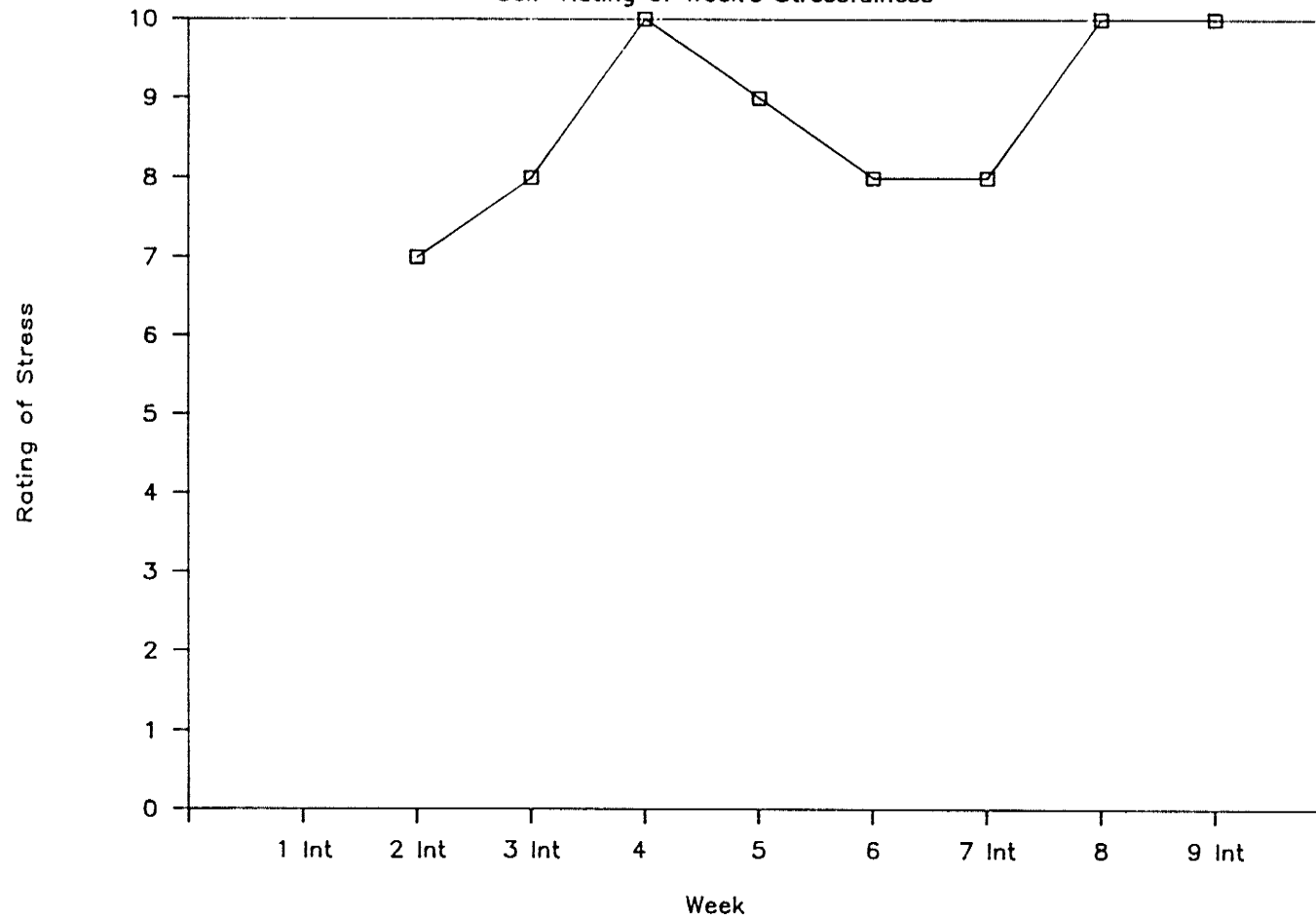
# Client VI, Graph A

## Caregiver Burden Inventory



# Client VI, Graph B

## Self-Rating of Week's Stressfulness



**Summary:**

Unlike the younger spousal caregiver, the older spousal caregiver is usually financially stable. She or he also, often has adult children who can be a potential source of support and assistance. The older spousal caregiver does, however, have their own concerns. For example, the older spousal caregiver is often beginning to develop their own health problems. These health problems can be significantly worsened by the demands of their caregiving. The older spousal caregiver can also often have competing caregiving demands and these competing caregiver demands can impact on their ability to provide care and on their feelings of burden.

A third category of spousal caregiver identified in my sample was the frail, older spousal caregiver. Client # 2 is an example of this category of spousal caregiver. Her case summary, and that of clients # 1, # 3, # 4, # 7 and # 8, are presented in Appendix II. A further discussion of the unique concerns and needs of the three different categories of spousal caregivers is found in Chapter 8.

The second difference I found in my sample concerned the relationship of caregiver burden to caregiver coping. Originally, I had assumed that decreasing caregiver burden would be associated with improved caregiver coping. Based on this assumption the original objective of my intervention had been to reduce caregiver burden in order to maximize caregiver coping. In most cases, such as client # 6, I found this assumption to be true. The following case, however, illustrates that for some caregivers this assumption is not necessarily valid.

#### Burden and Caregiver Coping

##### Client # 9

#### Contact:

Client was referred to practicum in February, 1989. Professional staff referred this client to the practicum after her daughters approached the Society requesting help for their mother because they felt she was not coping well with the situation. A total of three sessions, averaging two and one half hours in length, were completed with this

client. A follow-up session of approximately two hours was completed four weeks after the termination of therapy.

**Assessment:**

Client was a 64 year old lady who was caring for her 62 year old husband. Couple had been married for 41 years. Client stated the marital relationship had always been very good. Client stated that her husband had always done all the "thinking" for the couple. Client was overwhelmed by required changes in their roles brought about by the deterioration in her husband's functioning i.e. client now had to manage the couple's finances.

Husband had been a very successful salesperson until he had been fired two years ago, most likely because of reduced functioning caused by the onset of the disease. Couple were always very well off financially but are now very limited in their income and are basically living off of their savings. Client had never worked during the marriage but the present financial stress of the couple had pushed her into taking part time employment as a salesclerk. Client really enjoyed working and found it a pleasant escape from her present home situation. Client, however, did feel guilty about this

escape and wondered if she should quit and stay home full time to care for her husband.

Couple had two daughters who lived in Winnipeg. Daughters were very supportive and had been instrumental in insisting their father be adequately assessed medically and that their mother seek help. Client was feeling very socially isolated. She felt that none of her friends understood what she was experiencing and that, for the most part, her friends were avoiding her.

In December 1988 after a thorough medical evaluation client's husband had been diagnosed with Alzheimer's Disease. Initially it had been very difficult for me to assess the stage of the disease as client denied and minimized her husband's symptoms. It was only by the final session that client could admit that her husband had been deteriorating for at least three years and that he now had significant memory and cognitive impairment. Based on information from our final session and on my meeting with her husband, it was apparent that he was in the Ambulatory Demented stage of the illness.

Client was overwhelmed by the multiple shocks and changes that had occurred in her life over the last six

months. Her response was one of denial and depression. Client had little understanding about the disease or the impact it was having on her husband's behaviour. She knew little about the principles of behaviour management.

**Intervention:**

The focus of the intervention with this client included providing her with general education about the disease and techniques of behaviour management; providing her with the opportunity to ventilate her emotions in a safe and supportive environment; and changing her irrational beliefs, that were fostering her emotional distress, to more rational ones.

One of the primary objectives of the intervention was to replace client's denial with a more appropriate realistic understanding of the situation. Oliver and Bock (1987) state that, in the early stages of the disease, denial by family can have an adaptive function as it provides the family with time to slowly accept the deterioration in their family member. But, they state, as the patient deteriorates, denial becomes maladaptive because it prevents the family from being able to realistically assess the situation and reach

out for the help they require. For example, in this case client's denial was preventing her from recognizing the degree of her husband's confusion and the implications this had on the safety of leaving him alone. Only by assisting her to give up her denial was she able to seek the help she needed in meeting his care needs.

One of the irrational beliefs held by this client was that her husband's illness was a punishment sent to her because her entire life had been so easy. The consequence of this belief was that she felt very guilty about the pleasure she received when she was away from her husband working. After challenging this belief, client was able to realistically evaluate the pros and cons of working. She eventually decided she would continue to work, but that she would request help from her family and Home Care so that her husband's care needs would be met while she was away from home.

**Evaluation:**

Clinically, I felt that client benefited from the intervention. By the final session client seemed generally less depressed and socially withdrawn and she appeared to



have a better understanding about the disease and the impact it was having on her husband. She was capable of describing her husband's deficits more realistically and was beginning to reach out to the resources available to her for help.

Client agreed with my evaluation. She felt the therapy had been instrumental in improving her ability to cope with the situation.

I feel her changes in her BI and CBI scores from the initial to final session support my clinical observations. Her BI score increased from 29 (32.9%) at the initial session to 50 (56.8%) at the final session. Her follow-up BI score was 65 (73.9%). She moved from the mildly to moderately burdened range in the initial session to the moderately to severely burdened range in the final session to the severely burdened range in the follow-up session. On the CBI, her score increased from 34 (35.4%) at the initial session, to 44 (45.8%) at the final session, to 61 (63.5%) at the follow-up session. The scores of the sub-scales of the CBI were (see Client IX, Graph A):

		Initial	Final	Follow- Up
Time Dependence	=	6	17	20
Developmental Burden	=	9	13	15
Physical Burden	=	11	11	12
Social Burden	=	2	3	6
Emotional Burden	=	2	4	8

Why do I feel an increase in this client's burden is indicative of success in the intervention? The increase in her score from the initial to final session occurs mostly because of increases in the Time Dependence and Developmental Burden sub-scales. I feel her low initial scores in these dimensions were reflective of the high degree of denial and minimization this client was having about her husband's symptoms and the care he needed. It was only in the final, and even more so in the follow-up session, could this client openly acknowledge the severe degree of cognitive impairment of her husband and his resultant need for constant care and supervision. In my opinion the scores from the final and follow-up session better reflect the actual burden being experienced by this

client in these areas and demonstrate that the intervention was effective in overcoming her denial.

This client's rating of the previous week's stressfulness is presented in Client IX, Graph B. Client's extreme emotional distress in the first session made it very difficult for her to provide the information necessary to develop a reconstructed baseline. Without a baseline, and considering the limited number of data points, statistical and visual analysis of this data is not possible.

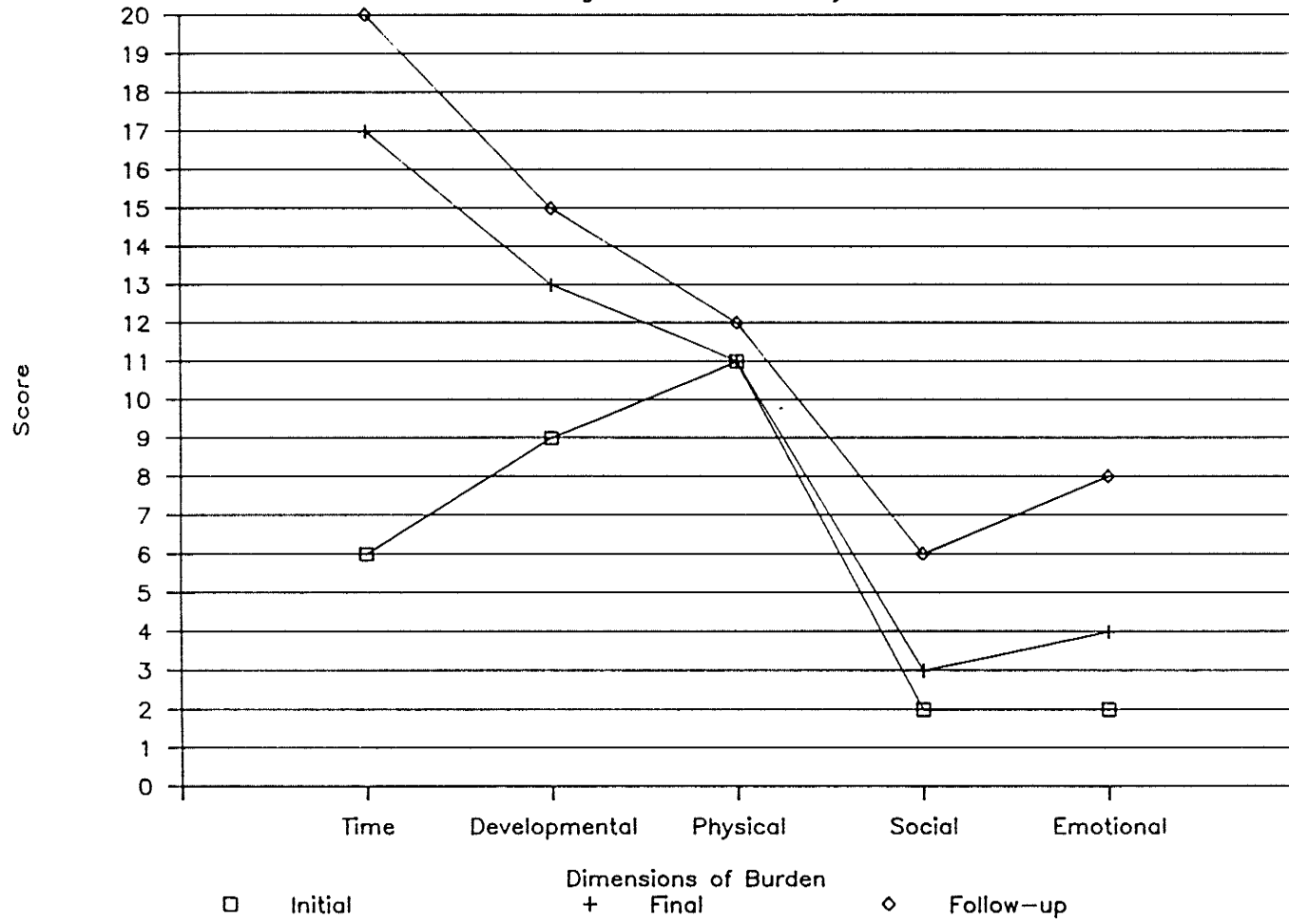
**Summary:**

The increase in client # 9 's burden scores from pre to post intervention were indicative of her improving ability to accurately perceive her situation. As a result her more accurate perceptions, this client was then better able to make decisions that would appropriately meet her needs and the needs of her spouse.

This case illustrates that we cannot necessarily assume that decreasing burden will be associated with improved caregiver coping. Further research into the relationship between caregiver burden and caregiver coping appears indicated.

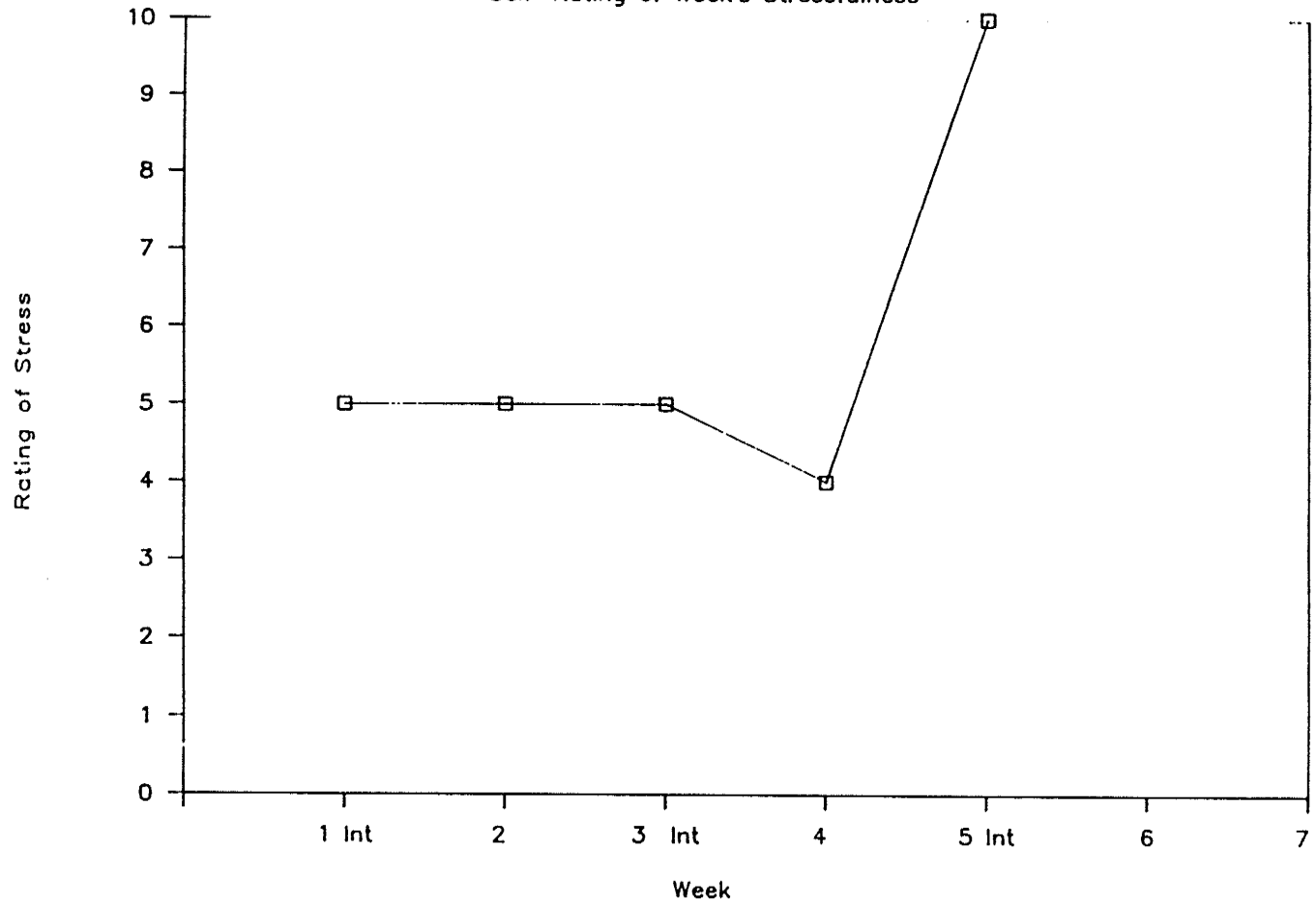
# Client IX, Graph A

## Caregiver Burden Inventory



# Client IX, Graph B

Self-Rating of Week's Stressfulness



**SUMMARY:**

Since my sample consisted of only Caucasian females it cannot be considered representative of all spousal caregivers of individuals with Alzheimer's Disease. Further research into the needs of male caregivers and the needs of caregivers of different ethnic groups is required if we are to ensure that the needs of all caregivers are met.

Spousal caregivers do not appear to be a homogeneous group. In my sample I identified three different categories of spousal caregivers; the younger spousal caregiver, the older spousal caregiver and the frail older spousal caregiver. Further research into the differences between spousal caregivers is required if we are to design interventions appropriate for their different needs.

Finally, caregivers appear to differ in how caregiver burden impacts on their ability to effectively cope with their situation. Further research into the relationship between caregiver burden and caregiver coping appears indicated.

CHAPTER 7The Results

The objective of my intervention was to improve the coping ability of my clients with their caregiving. In order to evaluate the success of my intervention in meeting this objective I considered my clinical evaluation of any observed improvement in their caregiver coping, the client's self-evaluation on whether the intervention had improved their ability to provide care, and changes in their burden scores, pre and post intervention, obtained on the Caregiver Burden Inventory and the Burden Interview.

Of the nine clients referred to the practicum, five continued beyond the initial assessment interview into the intervention stage of the practicum (clients # 5, # 6, # 7, # 8 and # 9). The evaluation of the effectiveness of my intervention will be limited to these five clients.

**CLINICAL OBSERVATIONS:**

Of the five clients, I observed improvements in clients # 6, # 8 and # 9 's ability to cope with their caregiving

from pre to post therapy. For example, prior to therapy, client # 8 felt considerable guilt whenever her husband became depressed or moody. As a result of this specific emotional response, her ability to cope with her husband's symptoms would then deteriorate for the rest of that particular day. After therapy, once she accepted that her husband's emotional responses were just a symptom of the disease and not a reaction to her personally, she no longer reacted emotionally to his moodiness and she was more effective in coping with his moody spells.

I also felt client # 5 was showing some progress in her ability to understand the disease and its impact on her husband, and in her ability to accurately perceive her husband's behaviour. Unfortunately, she dropped out of therapy before the stability of these gains had been demonstrated and before the entire intervention strategy had been addressed.

I observed no obvious improvement in client # 7's ability to cope. One possible reason for this finding is that an important element of the needed intervention with this client was omitted. This client was very emotionally disturbed by her situation and often found herself crying



uncontrollably. I felt an important focus of the intervention with this client should include an exploration of her feelings about the caregiving. This client refused to include this area in the intervention and, therefore, the intervention with this client was limited to some minimal education about the disease and a discussion of the impact of the disease on her minor children.

**Summary:**

Clinically, three clients (# 6, # 8 and # 9) appeared to improve in their ability to cope with their caregiving from pre to post intervention. One client (# 5) may have made some improvements in her ability to cope during therapy but terminated therapy before this could be fully assessed. One client (# 7) did not appear to improve in her ability to cope with the caregiving from pre to post intervention.

**CLIENT EVALUATION:**

Three of the clients felt that their ability to provide care had been improved by the intervention (clients # 6, # 8 and # 9). Each of these clients specifically felt that the mode of the intervention, individual counselling, had been a

fundamental element in their improvement. They felt that the focused, intensive attention of individual counselling had facilitated their ability to change.

Client # 5 also stated that she felt that the intervention was of benefit to her, but as she did drop out of therapy before its completion, her action may contradict this statement. I was unable to contact her to explore with her the reasons for her termination of therapy.

Client # 7 did not feel she had benefited from the intervention. My practicum, and the basic philosophy of the Alzheimer's Society, is based on the tenet that caregivers benefit if they can explore and ventilate their feelings in a safe, supportive environment. This client did not believe in this philosophy. She saw no purpose in either the ventilation of emotions or in exploring the cognitive aspects of her emotions. She felt that the intense emotional responses she was having to the situation would dissipate naturally over time. Her actual objective in seeking therapy was to learn specific skills and techniques that would allow her to suppress the expression of her emotions, especially at what she believed were inappropriate times, such as, in front of her children. I feel it was this basic clash in

values that made my practicum, and the other support services of the Society, of limited value to this client.

**Summary:**

Based on their own evaluation of the intervention, three clients (# 6, # 8 and # 9) felt they had benefited from the intervention. Client # 5 also felt she had benefited, but as she terminated therapy prematurely this evaluation is questionable. One client (# 7) felt she had not benefited from the intervention.

**BURDEN INSTRUMENTS:**

I used two instruments, the Caregiver Burden Inventory and the Burden Interview to measure the burden felt by the clients in my sample. My original assumption had been that a decrease in burden scores would be associated with improved caregiver coping and effectiveness. But, as I discussed in Chapter 6, I did find that there may be exceptions to this assumption, such as client # 9. One of the primary objectives of my intervention with this client was to replace this client's complete denial of the situation with a more realistic self evaluation of her situation. The

increase in this client's scores from pre to post intervention suggests that I had accomplished this objective. Therefore, while I generally will assume that a decrease in burden scores is associated with increased caregiver coping, under certain circumstances, an increase in the burden score may more appropriately reflect improved caregiver coping.

Of the five clients that continued beyond the initial assessment interview, only three (clients # 6, # 8 and # 9) completed the burden instruments pre and post intervention. Client # 5 dropped out of therapy prior to completion. Client # 7 refused to complete the measurement instruments at the final session. Of the four clients (# 6, # 7, # 8, and # 9) with whom I had follow-up contact with after the termination of therapy, only two clients (# 8 and # 9) completed the CBI and BI at the follow-up session. The small size of the sample limits the statistical analysis that can be completed on this data.

#### The Caregiver Burden Inventory (CBI):

Table # 1 summarizes the CBI scores obtained on each client.

TABLE # 1

Caregiver Burden Inventory Scores

Client		CBI	Factor				
			I	II	III	IV	V
# 1		na					
# 2	i	39	15	9	9	4	2
# 3	f	54	19	16	12	3	4
# 4	i	52	18	16	6	4	8
# 5	i	43	8	14	4	9	8
# 6	i	73	19	17	16	13	8
	f	43	15	13	10	2	3
# 7	i	30	5	8	6	6	5
# 8	i	39	8	14	5	2	10
	f	33	9	15	1	1	7
	fu	40	8	15	0	4	11
# 9	i	34	6	9	11	2	2
	f	44	17	13	11	3	4
	fu	61	20	15	12	6	8

i= initial session f= final session fu= follow-up session

The range of the global CBI scores varied from 30 to 73. The range of scores on Factors I through V were: 5 to 20, 8 to 16, 0 to 16, 1 to 13, and 2 to 11.

There is only comparative data available for three clients (# 6, # 8 and # 9). The CBI scores of client # 6 declined from pre (73) to post (43) intervention. While the statistical significance of this change is unknown, the decline in the CBI appears to suggest the intervention was successful for client # 6.

The results on the CBI are more ambivalent for client # 8. Her CBI score did decline slightly from the initial session (39) to the final session (33) but, by the follow-up session, it had increased to 40. These results may suggest that the intervention was successful but that the effect of the intervention had worn off by the follow-up session, or these results may suggest that the slight changes in this client's CBI scores were not statistically significant. On the basis of client # 8's CBI scores one cannot reach a conclusion as to whether or not the intervention was successful.

The CBI scores on client # 9 increased from the initial (34) to final session (44), and then increased again from

the final to follow-up session (61). As discussed earlier, however, I feel this case is an exception to the general rule that a decrease in burden scores is associated with improved caregiver coping, and contend that the increase in this client's CBI scores actually demonstrates that the intervention with this client was successful.

Clients # 2, # 3, # 4, # 6 and # 9 all scored highest in Factor I, Time Dependence (based on client # 9's score from final session). Except for client # 6, each of these clients is caring for someone in the Ambulatory Dementia stage of the illness (see Appendix I). The fact that clients caring for individuals in the later stages of the illness score highest in the Time Dependence factor is not that surprising a finding. The reality of this disease is that, as the disease progresses, the more actual daily care demands are placed on the caregiver and the greater the demands on the time of the caregiver. The problem is that if the Time Dimension factor is highly correlated to the staging of the illness, and since M. Novak states that generally this factor tends to account for a significant amount of the variance in burden scores between subjects,

the global CBI score may be more indicative of the stage of the illness rather than the subject's perceptions of burden. Until further evaluation of this instrument are completed, caution should be used when using this tool.

Clients # 5, # 7 and # 8 all scored highest in Factor II, Developmental Burden. This is also not necessarily unexpected because these three clients were also the three youngest spousal caregivers in my sample. For the younger spousal caregiver, caregiving is more likely to be negatively impacting on their ability to meet the usual demands of their developmental life stage e.g. child rearing. As a result, the younger spousal caregiver is more likely to score high in the Developmental burden dimension.

#### The Burden Interview (BI):

Table # 2 summarizes the BI scores obtained on each client.



TABLE # 2Burden Interview Scores

Client	BI	Range of Burden
# 1	na	
# 2	na	
# 3 f	49	Mod. to Severe
# 4 i	48	Mod. to Severe
# 5 i	51	Mod. to Severe
# 6 i	64	Severe
f	42	Mod. to Severe
# 7 i	35	Mild to Mod.
# 8 i	43	Mod. to Severe
f	44	Mod. to Severe
fu	33	Mild to Mod.
# 9 i	29	Mild to Mod.
f	50	Mod. to Severe
fu	65	Severe

i= initial session    f= final session    fu= follow-up session

The range of BI scores varied from 29 to 65.

Of the six clients that completed the BI at the initial session; two (# 7 and # 9) were in the mildly to moderately burdened range, three (# 3, # 4, # 5 and # 8,) were in the moderately to severely burdened range, and one client (# 6) was in the severely burdened range. Of the four clients (# 3, # 6, # 8 and # 9) that completed the BI at the final session, all scored in the moderately to severely burdened range. Of the two clients (# 8 and # 9) who completed the BI at the follow-up session, client # 8 scored in the mildly to moderately burdened range and client # 9 scored in the severely burdened range.

The BI scores of client # 6 decreased from pre (64) to post (42) intervention. This resulted in this client moving from the severely burdened range in the initial session to the moderately to severely burdened range in the final session. The decrease in the BI scores on this client suggest that the intervention with this client was successful.

Client # 8 's BI scores place her in the moderately to severely burdened range at both pre (43) and post (44) intervention. Her BI scores are relatively unchanged from

pre to post intervention suggesting that the intervention with this client was not successful in decreasing her burden. However, this client's BI score in the follow-up session did decrease to 33, moving her into the mildly to moderately burdened range. Since the statistical significance of this decline is unknown, and since there was a month break between the final and follow-up session, it is impossible to know if this decline actually demonstrates a delayed reaction to a successful intervention or if some other change in her life caused her burden level to decrease.

Client # 9's BI scores steadily increased from the initial session (29), to the final session (50) and to the follow-up session (65). This resulted in her changing from the mildly to moderately burdened range in the initial session, to the moderately to severely burdened range in the final session, to the severely burdened range in the follow-up session. As stated earlier, in this situation, I contend that this increase in the burden scores actually suggests that the intervention with this client was successful.

**Summary:**

As only three clients (# 6, # 8 and # 9) have pre and post intervention CBI and BI scores available, the evaluation of the intervention using comparative burden scores is limited to these three cases. A t-test was done to determine if there was a statistically significant difference between the means of the CBI and BI scores from initial to final sessions. No significant statistical difference was found by the t-test.

Client # 6's CBI and BI scores both declined from pre to post intervention. Although the statistical significance of the changes in her scores is unknown, since both burden instruments experienced similar changes I conclude that the intervention was successful with this client on the basis of the data provided by the burden instruments.

The results of client # 8's burden scores are inconclusive as to whether the intervention was successful or not. Her CBI scores did decline slightly from pre to post intervention suggesting that the intervention was successful, but her CBI score in the follow-up session had increased again to 40. Her BI scores were basically unchanged from pre (43) to post (44), but in the follow-up

session her BI score had dropped to 33.

Client # 9's CBI and BI scores both increased from the initial session to the final session. They also increased again by the follow-up session. As discussed earlier, in this situation I contend that the increase in her burden scores actually demonstrate that the intervention was successful, and as the changes in her CBI and BI are similar in direction and degree, I can feel confident that the changes in the burden scores do support my contention that the intervention for this client was successful.

#### CONCLUSION:

The three criteria which I used to evaluate the effectiveness of the intervention phase of my practicum are summarized in Table # 3.

TABLE # 3Summary of Intervention Evaluation Criteria

Client	Clinical Observations	Self Evaluation	Burden Instruments CBI	Instruments BI
# 5	Inconclusive	Inconclusive	no comparative data available	
# 6	YES	YES	YES	YES
# 7	NO	NO	no comparative data available	
# 8	YES	YES	Inconclusive	
# 9	YES	YES	YES	YES

For clients # 6 and # 9, it appears that my clinical observations, their self evaluations, and the results of the burden instruments, all suggest that the interventions in these two cases were successful in improving their ability to cope with their caregiving.

I would also conclude that the intervention was successful for client # 8, although the evidence is slightly weaker in this case because of the inconclusive results of the burden instruments.

While there is no comparative burden data available on client # 7, based on the results of my clinical observations and her self evaluation, client # 7's ability to cope with her caregiving did not appear to have improved as a result of the intervention.

No conclusion as to the effectiveness of the intervention with client # 5 can be made.

CHAPTER 8Influences on the Caregiving Experience

While the small size of my sample limits my ability to make definitive conclusions about the experience of caregiving for spousal caregivers, as I listened to the anecdotal stories of these nine caregivers I developed certain specific impressions about the caregiving experience. First, I identified at least three different categories of spousal caregivers; the frail older spousal caregiver, the older spousal caregiver and the young spousal caregiver. Each of these categories of spousal caregivers appeared to have very unique problems and needs. Second, I found that I could identify certain common caregiving experiences that were specific to each stage of the illness. It also became apparent that each stage of the illness places unique demands and stresses on the caregiver. In this chapter I will discuss these two observations and discuss how each of these issues impacts on the caregiving experience.



#### THE INFLUENCE OF CAREGIVER AGE ON THE CAREGIVING EXPERIENCE:

While the literature has generally tended to treat all caregivers of patients with Alzheimer's Disease as a homogeneous group and, at best, has divided caregivers into relational categories, such as spousal or children caregivers, in my sample I could identify at least three different categories of spousal caregiver: the frail, older spousal caregiver; the older, spousal caregiver; and the young, spousal caregiver.

#### The Frail, Older Caregiver:

This particular category of spousal caregiver is often very old (over 80), but what is more important is that, like their carereceiver, their health, either physically or mentally, is also very poor. As a result of this frailty this caregiver often has difficulty meeting the care needs of their dementing spouse, especially in the later stages of the disease when the daily care needs of the patient are so demanding. Their frailty also often precludes them from being able to get out of the home to attend any services that are being offered in the community.

Client # 3 is an example of the older, physically frail

spousal caregiver, although she is probable younger than most in this category. Client # 3 is a 76 year old woman caring for her 87 year old husband. Couple have been married 47 years. They have one adult son who is very supportive. Her husband is a large man who, except for his dementia, is in good physical health. Client is a very small, frail lady with multiple health problems. As a result of her health problems, she found it especially difficult to cope with her husband's high energy level. For example, her husband would happily walk all day long but, considering his level of confusion and disorientation, he was not safe walking alone. Client did not have the physical stamina to supervise his constant walks, but if she tried to restrict his activities so she could rest, he would become very agitated.

This client's physical limitations also severely limited her ability to leave their home and, as a result, as much as she wanted to, and would have benefited from, attending the Society's educational forums and Support Group meetings, she was limited in her ability to access these programs. Her situation was further complicated by the fact that, if someone came into the home to visit with her, her husband became very agitated.

Meeting the educational and supportive counselling needs of this category of spousal caregiver is very difficult and requires careful and innovative program design. For example, technology might address some of the access problems of this group if programs could be designed for delivery utilizing TV and/or telephone. This type of spousal caregiver also appears to really benefit from practical supports, such as Home Care, that can, by taking over some of the daily care, allow the person rest so they can maintain their own health status as much as possible.

The Older Spousal Caregiver:

This type of spousal caregiver is the type we most likely think of when considering spousal caregivers as a whole. Client # 6 is a good example of this category of spousal caregivers. This client was a 66 years old lady who was caring for her 75 year old husband. Couple had been married 31 years. She had one adult son who was very supportive. As a result of their combined pensions, couple were financially stable. Client had health problems but they were not severe enough to prevent her from getting out of the home to sessions with me, or to Support Group meetings,

or to the special educational forums offered by the Society.

One of the unique problems of this group of spousal caregivers is that they may also have competing caregiving responsibilities. Client # 6 had cared for her mother for several years prior to the onset of her husband's illness. Her 95 year old mother was now in nursing home, but her mother still expected visits, two to three times per week, from her daughter. This was an obligation the client was having increasing difficulty meeting as her husband's care needs grew. Client # 4, another older spousal caregiver, had a slightly different problem because she had assumed caregiving responsibilities for her grandchildren and her responsibilities to her grandchildren complicated her ability to meet her husband's care needs. This category of spousal caregiver really is the "sandwich generation", because they are often pulled by the conflicting demands of their spouse and the generation in front and behind them.

While the older, spousal caregiver does not have the difficulty in accessing services that the older, frail spouse caregiver does, they may lack the time in which to access services. This group requires very practical support if they are to meet their many responsibilities. This type

of spousal caregiver may also require counselling if they are to effectively prioritize the competing demands for their time.

The Younger Spousal Caregiver:

The third category of spousal caregiver that I identified was the young spousal caregiver. Client # 7 is an example of this category of caregiver. She is a 49 year old lady who was caring for her 49 year old husband. Couple had two children, aged 13 and 17. She was very concerned about the impact of the situation on her children, and her concern may have some validity because there were some indications that the situation was impacting negatively on the children, at least scholastically. This client was physically exhausted by trying to meet her responsibilities at work, in trying to meet the needs of her children and in trying to meet her husband's needs. She frequently found her multiple responsibilities were in conflict. For example, the disease had disrupted her husband's sleep pattern and he often wanted to talk to her all night. She found it very difficult to provide him with the necessary support at night when she knew she had to get up early to get the children ready for

school and then put in an eight hour day at work. While this particular client did not have any financial concerns, finances do appear to be a major issue for the younger spousal caregiver. For example, client # 8 spent over a year trying to obtain the documentation to prove her husband's eligibility for disability pension. As she did not work outside the home, for this year she had a very limited income with which she had to support herself, her husband and a son who was living at home while he attended university.

In my sample I found the younger spousal caregiver to be the most vulnerable to emotional distress. I also found that the younger spousal caregiver was the spousal caregiver least likely to benefit from the presently available support programs, the Family Support group and Educational forums. In fact, I found that the emotional distress of the younger spousal caregiver was often aggravated by attendance at educational forums and Family Support Group meetings, because attendance at the Support Group just increased the younger spousal caregiver's feelings of uniqueness, isolation, and anger about their situation.

Since the presently available resources do not appear

to be helpful to the young, spousal caregiver, alternative methods of intervening with this group are needed. While individual counselling may address some of the special needs of this population, one client in this study suggested that her needs might best be met by the formation of a special support group, one whose membership would be limited to younger spousal caregivers only. She felt this group would be better able to focus on, and address, the special concerns of this population. The difficulty with this suggestion is that, since statistically dementia occurs so infrequently in younger populations, it may be difficult to identify and recruit enough potential participants for such a group.

The burden scores of the younger caregivers in my sample do not support my clinical observation that the younger spousal caregiver is most vulnerable to emotional distress. One possible reason for this is that, because dementia statistically occurs so infrequently in those below 65 years of age, these scales were mostly developed using data from populations of spouses over 65. As the result of this, the unique concerns of the younger, spousal caregiver may not be adequately reflected by these burden instruments.

These instruments may require further changes if they are to accurately measure the burden experienced by all categories of caregivers. Until this is done, cautious utilization of these instruments with younger spousal caregivers is required.

#### THE INFLUENCE OF THE STAGES OF ILLNESS ON THE CAREGIVER EXPERIENCE:

Do caregivers go through unique stages that parallel the deterioration of the carereceiver? After listening to the experiences of the clients in my sample, I found that there were common caregiver experiences and concerns associated with each stage of the illness. Other researchers (Gwyther & Matteson, 1983; Berman & Rappaport, 1984) have also identified specific caregiver issues associated with the level of deterioration of the carereceiver.

One recent study by Novak & Guest (1989) did not substantiate these findings, as they only found moderate evidence that caregivers go through stages parallel to the deterioration of the carereceiver. I feel there are two possible explanations for the contradictory findings of the Novak & Guest study.



First, the Novak & Guest study drew their sample from recipients of the Manitoba Home Care program only. Since the established guidelines of the Home Care program effectively prevents admittance into the program until the later stages of the disease, most of the Novak & Guest sample were in the later stages of the illness. It is not surprising then that Novak & Guest found little evidence of caregiver stages since their sample was predominantly made up of individuals in one stage of the disease.

Second, a major assumption of the Novak & Guest study, was that, if there are caregiver stages, caregiver burden would accumulate over time. They, therefore, looked for the presence of caregiver stages by looking for a correlation between the severity of the dementia and caregiver burden. Since that only found a moderate correlation between the severity of the dementia and caregiver burden, they concluded that there was only moderate evidence that caregivers go through stages that parallel the deterioration of the carereceiver. The problem with this conclusion is that I feel that the original assumption is erroneous. In my study I found that each stage of the illness placed unique demands and stresses on the caregiver, and that each stage

had the potential to be equally burdensome to the caregiver. In fact, because of the nature of the concerns in the earlier stages, I found that it is the earlier stages that may have the greater potential to be burdensome to the caregiver.

Now, using Hall's (1988) four stages of the illness, I will discuss the specific concerns and needs of caregivers which I found to be associated with each stage of the illness.

#### The Forgetfulness Stage:

The spousal caregivers in my study were usually aware that something was wrong, for at least two to four years, before they could actually identify the problem. During this Forgetfulness stage of the illness, the established patterns of their marriages, whether good or bad, were inexplicably altered as communication between the couple deteriorated, sexual problems developed, and the social life of the couple gradually changed. All of these changes occurred in response to a problem that the caregiver could not quite define. The well partner, depending upon how they perceived the problem, often pushed their ill spouse to seek marital or individual

counselling. For example, client # 4 tried to get her husband into counselling for the alcohol problem that she thought he had suddenly developed, while client # 7 wanted the couple to seek marital counselling because she felt the marriage was faltering. The ill spouse tended to resist this push towards counselling but, even if they agreed to participate, it is unlikely that this type of intervention would be very effective since it would not address the real problem.

As the illness continued to progress, the well spouse gradually realized that the problem lay within their partner's mental functioning but, unfortunately, often their family, friends, and their family physician did not see the problem. As a result, often the caregiver's initial attempts to seek medical investigation were ignored. For example, client # 7 pushed her husband to discuss his growing memory problems with their family physician, only to have the doctor negate her concerns with the comment to her husband that "women are such worriers over nothing".

Since the symptoms of the disease develop so insidiously and become so intertwined with other problems (marital or alcohol abuse), the caregiver often confuses the

symptoms of the disease, i.e. memory impairment, from the consequences of the symptoms, i.e. social isolation.

Caregivers in this stage of the illness need help not only in identifying the problem, but they also need to learn how to effectively communicate the problem to others, especially physicians, so that the problem can be taken seriously. For example, if the spouse goes to her doctor and only discusses the problems she is having with communicating with her husband, the couple is more likely to be referred to a marriage counsellor than to a neurologist.

For the caregiver, the Forgetfulness stage of the disease is fraught with emotional upheaval. By the time the presence of the disease is established, their relationship with their spouse and other family members have been under intense stress for a long time. While the diagnosis often results in feelings of relief by the caregiver, because their concerns have been validated, caregivers can also feel intense guilt over how they treated the afflicted person during the time prior to diagnosis, or anger at other family members or friends who failed to identify the developing problem. Caregivers often require counselling if they are to cope with these emotional reactions. Family therapy may also

be necessary to repair the rifts that have developed in the family unit.

A serious medical investigation does not normally take place until an outside party, sometimes other family members but usually the employer, also identifies the problem. In my client sample, diagnosis usually occurred at the end of the Forgetfulness stage or in the beginning of the Confusional stage.

#### The Confusional Stage:

Among my clients I found that the Confusional stage of the illness was a time of great frustration for the caregiver. A major reason for this is that there are no easy answers to the issues facing caregivers in the Confusional stage of the illness. The type of problem the caregiver is usually trying to cope with in this stage involve issues of control and independence, such as, is my spouse safe driving. There are no established protocols or guidelines available to assist caregivers in their decision making. These issues also involve very real implementation problems, such as, if my spouse is not safe driving, how can I stop him. In this stage the caregiver has very little control

over the patient and their actions. For example, client # 5 had no way of preventing her husband from driving around all day, although, she knew he was a danger to others when he was driving.

I found that, clinically, the caregivers coping with this stage of the illness were more emotionally distressed than the caregivers in the later stages. I identified two possible reasons for this finding. One, the type of issue confronting caregivers in the Confusional stage, and the difficulty caregivers have in trying to implement any decisions they make, leaves the caregiver feeling powerless and helpless. The caregiver often needs assistance in being able to identify the issues that she/he can realistically change, and assistance in accepting those in which he/she is powerless to change.

Two, the present existing resources often do not meet the needs of the caregivers in the Confusional stage of the illness. Their spouses do not require the type of assistance provided by Home Care programs, and Support groups and Educational forums are often too frightening for the caregiver in this stage because the caregiver does not want to hear all about what is in the future. As one client said

"After her husband was diagnosed, the doctor did not want to see her again because there was nothing he could do. She attended a support group meeting but she became overwhelmed listening to the experiences of caregivers in the later stages of the disease. As her husband was not sick enough to need Home Care supports, she was left, for years, just drifting along trying to cope on her own with her husband's increasingly erratic behaviour".

I found that the burden instruments were limited in their ability to measure the burden of the caregivers caring for individuals in the early stages of the illness. A possible reason for this may be that, because these instruments were mostly designed based on populations in the later stages of the disease, these instruments may fail to measure the particular concerns of caregivers in the earlier stages. Until further evaluation of these instruments is completed on populations of caregivers coping with individuals in the early stages of the illness, caution should be used when utilizing these instruments.

#### The Ambulatory Dementia Stage:

Caring for someone in the Ambulatory Dementia stage of

the illness is physically and mentally hard work. For example, client # 9's morning schedule of care included getting her husband up, dressing him, brushing his teeth, and shaving him. Each one of these activities might take her up to an hour, depending upon how resistant her husband was that day. She then spent her day feeding her husband, toileting him, and providing constant supervision, because if she failed to meet his need for constant supervision for even a minute he would get out of the house or start ripping an appliance apart in the desire to "fix" it. Finally, in the evening she would spend one or two hours getting her husband into his pajamas and into bed. But, as his sleep pattern was affected by the disease, she often had to continue supervising him, as he wandered the house, until three or four A.M. when he would finally fall to sleep. Every day required the same level of vigilance if her husband's care needs were to be met.

At some point, the care needs of the demented individual grow beyond what is possible for one person to provide. The caregiver must then accept help from others, either the informal system, family and friends, and/or the formal system, Home Care. Realizing when they need help, and



accepting help, appears to be a very difficult step for spousal caregivers and caregivers often require supportive counselling in order to reach this decision.

Once the caregiver can accept help, programs that provide practical assistance, such as help with personal care, Day Care, and/or Respite Care, become invaluable in supporting the caregiver and preventing premature institutionalization. Caregivers and their situations are unique, however, and they vary in what type of program will be of benefit to them. For example, one caregiver's burden may be reduced through the use of a regular program of institutional respite care, while another caregiver might find the respite program very stressful and find that obtaining help with her/his spouse's bath is more helpful. Programs that provide practical supports to caregivers must recognize the uniqueness of caregivers and individualize the help they provide to the specific situation.

Caregivers of individuals in the Ambulatory Dementia stage of the illness require extensive education on how to manage the disease and emotional support if they are to cope with the heavy demands of this stage. Caregivers of individuals in this stage are, however, often just too

exhausted to go out to Support programs or Educational forums, therefore, alternative methods of providing basic education and emotional support needs to be considered for this population.

**The Terminal Stage:**

Eventually as the disease progresses and the patient's daily needs grow beyond what can be provided in a community setting, institutionalization becomes inevitable. The decision to institutionalize by spousal caregivers appears to occur towards the end of the Ambulatory Dementia stage or at the beginning of the Terminal stage.

Deciding to place your spouse in a nursing home appears to be a very difficult and traumatic decision for spousal caregivers. Caregivers reaching this point have often cared for their spouse for years, if not decades, and placement is often perceived as a failure rather than as a natural part of the disease process. Counselling is often necessary if the caregiver is to make this important decision at the appropriate time.

One of the key issues for spousal caregivers trying to make this decision is deciding what they are going to do

with the rest of their life. By this point, caregivers have devoted all of their time and energy for years in caring for their mate. They are often physically and emotionally exhausted and completely socially isolated. Spousal caregivers may require counselling and assistance in picking up the threads of their lives.

While the caregiver has grieved the loss of their spouse throughout the illness, it may not be until after placement that the caregiver has the time to deal with this grief. Support groups and/or individual counselling may be important in facilitating the appropriate expression of this grief.

#### CONCLUSIONS:

Spousal caregivers appear to be a heterogeneous group. I found in my study that I could identify at least three types of spousal caregivers; the frail, older spousal caregiver, the older spousal caregiver, and the young spousal caregiver. Each of these categories appear to have unique problems and needs, and interventions with these groups will have to reflect these differences if we are going to successfully meet the needs of all spousal

caregivers.

The experience of caring for someone with Alzheimer's Disease is difficult and stressful no matter what stage of the disease the patient is in. To date, most of the interventions designed to support caregivers have been designed to meet the needs of the caregiver in the Ambulatory Dementia and Terminal stages of the disease. Further research into the special needs of caregivers in the earlier stages of this disease needs to be completed if we are going to be able to design appropriate interventions for all caregivers.

CHAPTER 9Conclusions

This chapter provides a summary of the major findings of this practicum. Each issue has been previously discussed in greater detail in the earlier chapters of this document. It is important to remember that, because my sample is so small and is based only on cross-sectional data, my conclusions can only be considered impressionistic.

First, the research available on caregivers is, for the most part, based on white, middle-classed populations. We need research into the caregiving experience of other racial and socioeconomic groups if we are to understand the specific needs of these groups.

Second, the consumers of the presently offered services also tends to be white, middle-class and female. Further investigation into the possible differences between caregivers of different cultures and into the differences between male and female caregivers is required if we are to

be sure that we are designing effective interventions that meet the needs of all caregivers.

Third, my findings support the contention that caregivers go through stages that parallel the stages of the disease. I found that each stage of the disease appears to place unique demands and stresses on the caregiver and that each stage has the potential to be burdensome to the caregiver. Further research into the special needs of caregivers at each stage of the disease is needed, if we are to be able to effectively intervene with caregivers throughout the caregiving process.

Fourth, caregivers do not appear to be a homogeneous group. Even within my very small sample, I could identify at least three different categories of spousal caregivers; the frail, older spousal caregiver; the older spousal caregiver; and the young spousal caregiver. The needs and circumstances of each of these categories of spousal caregivers appears to be quite different and, as a result, interventions need to be specifically designed with the uniqueness of each of these groups in mind. For example, the frail, older

caregiver is frequently housebound as a result of his/her poor health, especially in our long, cold winters. This category of spousal caregiver still has the need for continued education and emotional support but, since they are limited in their ability to access Educational forums and Family Support Groups, alternative modes of intervening with this population must be identified.

In my sample, the younger spousal caregiver appeared to be clinically the most emotionally distressed by their caregiving experience. While the older spouses generally expected that, at their age, either they or their husband would eventually end up sick, and that the well spouse would end up being a caregiver, the younger spouses in my sample had never anticipated that they would end up caregivers at this point of their lives. As a result the younger spouse often feels alienated and socially isolated. Attending the presently existing resources, the Educational Forum and the Family Support Group, often appears to just intensify the younger spouses' sense of uniqueness and isolation. Alternative modes of intervening with younger spousal caregivers need to be developed if we are to successfully address the specific concerns of this population.

Fifth, our present instruments designed to measure caregiver burden may be flawed. These instruments were generally developed based on populations of older caregivers caring for individuals in the later stages of the disease. As a result they may fail to reflect the issues of concern of specific categories of caregivers, such as caregivers of individuals in the earlier stages of the illness or younger spousal caregivers. Until further evaluation of these instruments is completed, caution should be used when interpreting data generated by these instruments.

Sixth, the Family Support group, as it is presently structured, may not be effective in meeting the needs of all caregivers. The caregivers in my sample felt that it was not always helpful to mix caregivers of individuals in the various stages of the disease together in the same group or to mix together the different categories of spousal caregivers i.e. the younger spousal caregiver with the older spousal caregiver. Further research into the effectiveness of the support group as a mode of intervention and some experimentation with group composition appears indicated.



Seventh, the effectiveness of alternative modes of intervening with caregivers needs to be further explored. One alternative mode of intervening with caregivers may be individual counselling. Subjects in my sample generally felt that individual counselling was a more effective mode of intervention than the support group. They found that individual counselling allowed for a more intense, focussed approach to their specific caregiver problems.

It is essential, however, that the therapist providing individual counselling have a thorough knowledge of Alzheimer's Disease and the impact this disease has on the caregiver. Therefore, although Alzheimer Societies have been reluctant in the past to provide ongoing, individual counselling directly to clients, it may be that only the Alzheimer Societies have the staff with the necessary expertise to provide this type of service.

Eighth, no matter what the mode of the intervention, program content for this population needs to include: an assessment of the medical diagnostic procedure; a thorough social assessment, including an analysis of the previous relationship between the caregiver and carereceiver and the

client's self assessment of available social supports; an analysis of how well the caregiver is coping with the carereceiver's memory and behaviour problems; and an analysis of possible perceptual distortions and irrational beliefs held by the client that may be preventing effective caregiver coping. Depending upon the specific case situation, the intervention component of the program needs to include an educational segment and, for those caregivers in a distressed emotional state as a result of distorted perceptions and/or irrational beliefs, a segment which focuses on the cognitive-emotional aspects of the caregiving.

I did find that basing the educational segment of my intervention on the Educational component of Zarit, Orr and Zarit's Stress Management Model useful. I did not find Zarit, Orr and Zarit's Problem-Solving component of their Model useful, but that may just be a result of my small sample, because certainly if caregivers do not have effective problem-solving skills, they will need to be taught them.

I also found that basing the cognitive-emotional segment of my intervention on Ellis's Rational-Emotive

Therapy useful. Caregivers of individuals with Alzheimer's Disease do appear to often have distorted perceptions and irrational beliefs that impair their ability to caregive. Rational-Emotive Therapy provides a useful theoretical framework for understanding the client's perceptual distortions and irrational beliefs and a wide range of effective cognitive, behavioural and emotive techniques with which to challenge the client's distorted perceptions and beliefs.

In conclusion, caregiving someone with Alzheimer's Disease is one of the most challenging tasks that people can ever be asked to face. The experience, however, does not have to be overwhelming because, with effective interventions, the distressed and overburdened caregiver can once again obtain control over their life. The challenge facing us as professionals is to ensure that we have effectively designed interventions that will meet the different needs of caregivers no matter what their specific circumstances.

Appendix ICase Summaries

Client	Age	Spouse's Age	Length of Marriage	Stage* of Disease	Setting of Int.**	No.*** of Sessions
#1	uk	uk	uk	AD	uk	0
#2	88	90	59	AD	H	1
#3	76	87	47	AD	H	1
#4	64	70	41	AD	H	1
#5	40	42	10	C	H	3
#6	66	75	31	C	O	5
#7	49	48	20	C	O	2
#8	53	56	30	C	O	5
#9	64	62	41	AD	H	3

Mean age of Clients = 62.5 years

Mean age of Spouse = 66.3 years

Mean length of marriage = 34.9 years

\* Stage of Disease - C = Confusional Stage  
AD= Ambulatory Demented Stage

\*\* Setting of Interview - H = in client's home  
O = in Society office

\*\*\* Number of sessions does not include follow-up session

Appendix II

Client # 1

Contact:

Client was referred to the practicum in November, 1988. Client had been identified by Society's professional staff as a potential candidate for the practicum after they reviewed existing case files. Contact was limited to one phone call as client was not interested in participating further in practicum.

Assessment:

Client's spouse appeared to be in the Ambulatory Demented stage of the illness. Client felt she was receiving adequate support from her family and friends. Husband was in receipt of Home Care services and wife was satisfied with present support from Home Care. Client was not interested in participating in practicum as she felt her present situation

was stable. Her identified present need was that she felt she needed more private time for herself.

**Intervention:**

Client was encouraged to express her need for more private time to family, friends, and Home Care case coordinator.

**Evaluation:**

No evaluation was conducted on this case.

Client # 2**Contact:**

Client was referred to practicum in November, 1988. Client was identified by the Society's professional staff after reviewing existing case files. Contact consisted of only one interview of approximately two hours as client did not see any use to her in meeting "just to talk". This interview was terminated prematurely as husband became very agitated by my presence in the home.

**Assessment:**

Client was a 88 year old lady who was caring for her 90 year old husband. Couple had been married 59 years. Client reported that the marital relationship had always been very good. Client's husband was an educated man. He had owned his own jewelry business for over 50 years. He was presently retired. Until the onset of his illness, he had always been a very active man, especially within his synagogue. Client had minimal formal education. Presently, she was a very physically frail lady with multiple health problems of her own. As a result of her physical frailty she was limited in

her ability to leave the suite.

Client had few social supports. Couple had one son, but he was living in British Columbia. Client had two elderly sisters living in Winnipeg, but they were limited in the support they could provide as they had their own responsibilities. Couple were in receipt of Home Care. Client was not satisfied with present Home Care services.

Over the last one to two years client had noticed deterioration in her husband's ability to communicate, in his ability to manage their financial affairs and in his ability to manage his own activities of daily living. Husband appeared to be presently in the Ambulatory Demented stage of the illness. While client had little understanding of the disease and the disease process, she had no difficulty accepting the fact that her husband's symptoms were caused by his illness. As a result of this understanding she was not unduly upset by his occasionally bizarre behaviour.

Her major concerns at this time were: 1. Should she agree to have her husband admitted to hospital in order that his dementia could be investigated further? 2. She was



unable to manage her grocery shopping and wanted a volunteer to do this task for her. 3. She required assistance with her husband's foot care.

Intervention:

In this situation the possibility that the dementia was either caused or worsened by the presence of a treatable factor e.g. depression had not been entirely ruled out. The initial objective of my intervention was to increase client's awareness of the disease and the disease process so that she would recognize the need for further medical investigation.

I had limited success with achieving this objective. This client saw no benefit for her husband or herself in obtaining further medical assessment. She saw dementia as part of normal aging not as a potentially treatable condition depending upon the etiology of the symptoms. She also was very fearful that if her husband was admitted to hospital, as recommended by the physician, her husband would deteriorate to the degree that he would be unable to return home. Her concern had some validity because demented

individuals often functionally deteriorate when placed in unfamiliar environments. Despite my intervention this client remained unconvinced of any value in seeking further medical investigation. The session ended with me encouraging her to discuss with the doctor her concern over hospitalization and explore with him the possibility of whether testing could be completed as an out-patient.

This client's other concerns reflected the very concrete needs of the elderly, physically frail caregiver who is caring for someone in the ambulatory demented stage of this disease. In order to meet these needs I referred her to Age & Opportunity, Home Care and a podiatrist that I knew did home visits.

**Evaluation:**

Only the CBI was completed on this client, as the interview had to be prematurely terminated as a result of her husband becoming very agitated by my presence. Client's total CBI score was 39 (40.6%). Her scores on each dimension were (see Client II, Graph A):

Time Dependence Burden:	15
Developmental Burden :	9
Physical Burden :	9
Social Burden :	4
Emotional Burden :	2

Questions in the Time Dependence dimension ask the client to rate how much care they perceive their spouse as requiring e.g "I have to watch my carereceiver constantly". The care provided by a caregiver of an individual in the AD stage of this disease is extensive and it is not surprising that this client had a high score in this dimension.

The Developmental burden sub-scale measures a person's sense of being trapped and out of phase with their expectations about this time of their life. When examining the specific answers given by this client in this dimension I had the sense that this client was feeling more trapped by the amount of care she was providing than feeling out of phase with her life expectations (she scored 3 on the question "I wish I could escape from this situation", but scored 0 on the question "I feel that I am missing out on life").

The Physical Burden sub-scale measures the impact the caregiver feels the care is causing on her/his health e.g. "My health has suffered". This was a difficult section for this client because she had difficulty separating her own health problems from health problems caused by her caregiving.

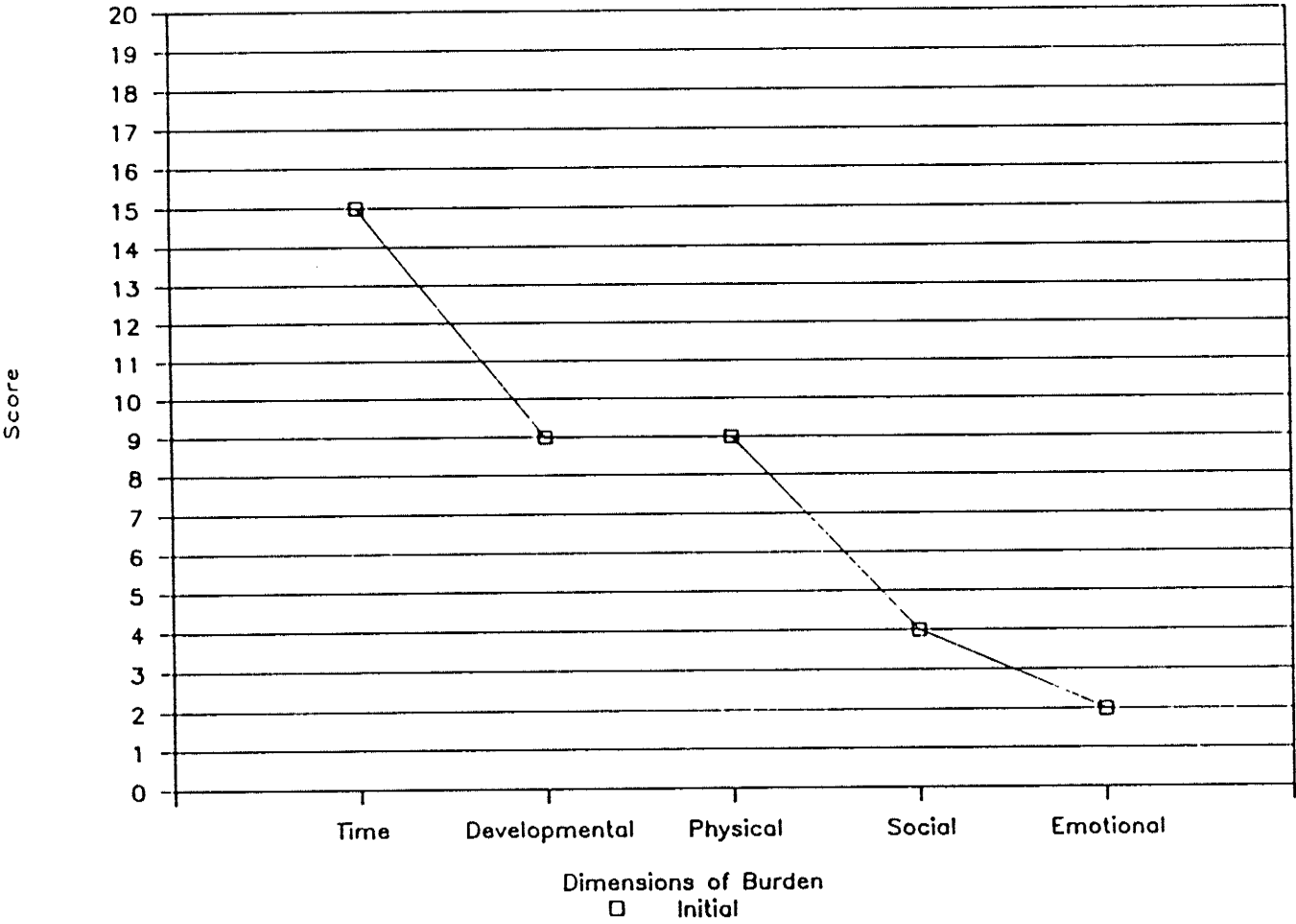
The Social Burden sub-scale measures the caregiver's perceptions of the impact of the caregiving on her social relationships e.g. "I don't get along with other family members as well as I used to". This client scored very low in this dimension but this may just be a reflection of her lack of social supports.

Finally, the Emotional Burden sub-scale measures the emotional distress the caregiver feels about the carereceiver and their behaviour. e.g. "I feel ashamed of my carereceiver". This client scored very low in this dimension and this was not surprising. This client felt very little distress over her husband's behaviour because she understood that his symptoms were the just the result of his illness.

As contact was limited to just one interview with this client, I have no other test results on this client to compare with these results.

# Client II, Graph A

## Caregiver Burden Inventory



Client # 3**Contact:**

Client was referred to the practicum in November, 1988. Client was identified by the Society's professional staff after reviewing existing case files. Contact with this client consisted of one 1 hour interview in her home. After this initial session client was not interested in further involvement in the practicum because she felt her situation was stable. Three follow-up calls were made to this client in January, February and March 1989.

**Assessment:**

This client was a 76 year old lady caring for her 87 year old husband. Couple had been married for 47 years. Client reported that the marital relationship had always been very positive. Couple had one son who lived in Winnipeg. Client felt she received very good support from her son. Husband was in receipt of Home Care services and client was very satisfied with the present level of help.

Couple lived in a small one bedroom townhouse. Client

found that, because of her own physical health problems and that the nearest bus stop was two long blocks away, she rarely could get away from the situation. This, in combination with the fact that her husband became very agitated if visitors came into the home, resulted in her being very socially isolated.

Client had noticed deterioration in her husband's memory and functional status over the previous 4 to 5 years. He presently appeared to be in the Ambulatory Demented stage of the illness. Husband's dementia appeared to have been adequately medically investigated.

Client appeared to have a good understanding of the disease and the disease process. She appeared to have good problem-solving skills. She also had no difficulty accepting that his behaviour was the result of his disease and, therefore, was not unduly distressed by his symptoms. Client appeared to have a good understanding of the principles of behaviour management.

Client's major concern at this time was her fear that her husband would become physically violent towards her in the future. There had been no incidence of physical abuse to

date, but her husband was having frequent episodes of severe agitation. She had discussed this problem with her physician, who had recently prescribed medication that should decrease her husband's agitation. Client indicated in follow-up calls that medication had effectively stabilized her husband's agitation. Client also found she could discontinue the medications in the spring time, because with the longer hours of daylight and with the onset of better weather so she could take her husband out for walks, she found him generally less agitated.

Demented individuals are often more confused after sunset when the decrease in light makes it even more difficult for their damaged brains to orientate themselves. Demented individuals also have very high energy levels and need physical activity to wear off this energy. Our winters, with the shortened hours of day light, and the winter climate that causes the frail caregiver to become house bound, can be very stressful periods of caring.

**Intervention:**

The main objective of my intervention with this client was to review with her the principles of behaviour



management, reassure her that she was managing her husband's symptoms appropriately, and to develop a safety plan for her if she found herself in a situation where her husband was becoming physically violent towards her.

While this client was effectively coping with her caregiving she wanted, and would benefit, from having regular contact with someone knowledgeable about the disease and it's problems. She also needs the opportunity to be able to ventilate her feelings and frustrations and to be reassured that she is doing fine. The difficulty for the older, physically frail caregiver is that they can not get out to programs, therefore, the usual way of providing support to caregivers, the support group, is inappropriate for this caregiver. This client had an additional problem, and there are most likely many caregivers with this same problem, in that her husband became very agitated if visitors came into the home. For these caregivers the telephone can become an invaluable instrument through which services can be provided.

Evaluation:

Since this client had not wanted to participate in the

practicum I had not administered the instruments during our initial interview. Later, for comparative purposes, I administered the CBI and BI on this client.

This client scored 49 (55.7%) on the BI and 54 (56.3%) on the CBI. Her BI score of 49 places her in the moderately to severely burdened range. Her scores on the different dimensions of the CBI were (see Client III, Graph A):

Time Dependence	=	19
Developmental Burden	=	16
Physical Burden	=	12
Social Burden	=	3
Emotional Burden	=	4

This client scored highest in the Time Dependence dimension. This score can be partially explained because caring for someone in the Ambulatory Demented stage is very time consuming and hard work.

When one examines this client's responses in the Developmental Burden sub-scale one obtains the impression that not only does she feel trapped by the care, she felt

out of phase with her life expectations.

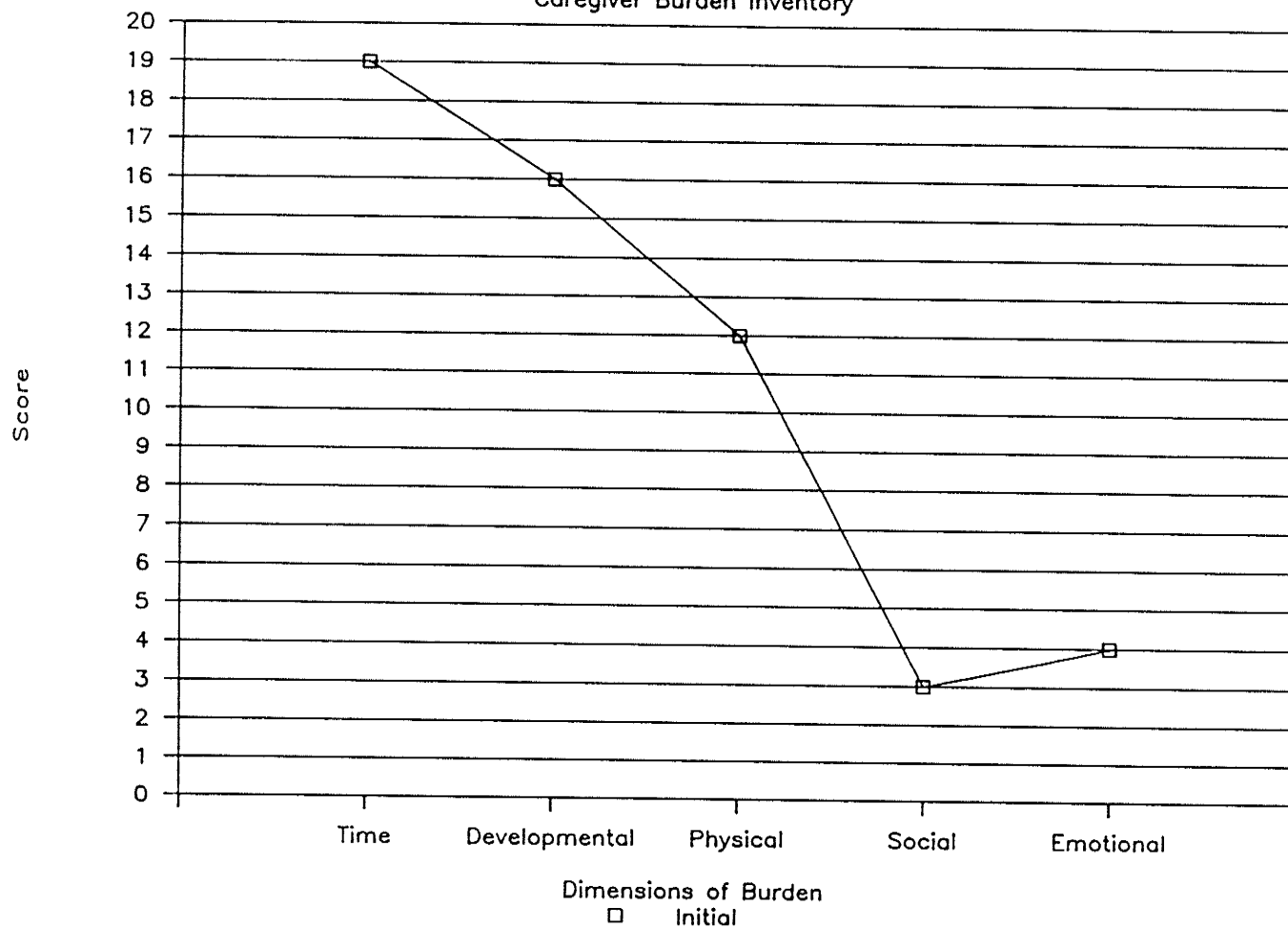
This client appeared to feel that her health problems were directly attributable to her caregiving responsibilities and that if she had not been a caregiver she would have been healthier. This feeling may account for her score in the Physical Burden sub-scale.

This client was satisfied with the social support she was receiving. She also recognized that her husband's illness accounted for his symptoms. Her scores on the Social and Emotional Burden dimensions appear to reflect these feelings.

No other BI or CBI scores are available for comparison.

# Client III, Graph A

## Caregiver Burden Inventory



Client # 4

## Contact:

Client was referred to the practicum in November, 1988. Client was identified by Society's professional staff after reviewing existing case files. Only an initial interview of approximately two and one half hours was completed with this client despite client's expressed interest in participating in the practicum. Client cancelled two appointments in December 1988; first because she was ill and later, because she was too busy before Christmas. Client then contacted me in February, 1989 requesting an appointment, but was not home for this scheduled visit. Despite numerous telephone calls I was unable to reestablish contact with this client.

## Assessment:

Client is a 64 year old lady caring for her 70 year old husband. Couple have been married 41 years. Client stated they had a long history of marital problems and client still had a great deal of anger about how she had been treated by her husband in the early years of their marriage. Husband

had been a laborer until his retirement at age 65. Client was presently working part time as a caterer. Client was in fairly good physical health except for a chronic ulcer problem.

Couple had 3 children. One daughter was undergoing treatment for an alcohol problem and client presently had custody of two grandchildren. Client appeared to be a major source of emotional and financial support for her children. Husband was in receipt of Home Care services and attended Day Programs two times per week. Client was satisfied with the level of services.

Client began to notice changes in her husband's behaviour 5 to 7 years ago. Initially, her husband became increasingly depressed, socially withdrawn, and he began to abuse alcohol. Gradually he became increasingly confused and disorientated, and he required increasing assistance with his personal care. He presently appeared to be in the Ambulatory Demented stage of the illness. Client's husband appeared to have been adequately medically assessed.

Client appeared to have a good understanding of the illness and behaviour management. Her major identified

problem was that she often felt very angry towards her husband and then felt guilty about this anger.

**Intervention:**

This client's emotional responses (C) to her husband's symptoms appeared to be associated with the old marital issues. For example, as she provided him with assistance with his personal care she remembered how he treated her when she needed help, such as when she had just delivered her children. She would then treat him roughly as a result of her remembered anger but, as she knew he was very ill, she then felt guilty about how she treated him. The focus of the intervention would have been, if client had continued in therapy, to identify the various emotional feelings she was having, and then seek to identify and dispute the irrational beliefs underlying these feelings.

**Evaluation:**

Client scored 52 (54.2%) on the CBI and 48 (54.5%) on the BI. The score on the BI placed her in the moderately to severely burdened range. The scores she had on the different

dimensions of the CBI were (see Client IV, Graph A):

Time Dependence	=	18
Developmental Burden	=	16
Physical Burden	=	6
Social Burden	=	4
Emotional Burden	=	8

Like Clients # 2 and # 3. this client scored high in the Time Dependence dimension. All three caregivers are caring for someone in the Ambulatory Demented stage and by necessity in this stage the caregiver must provide a great deal of physical and supportive care to their carereceiver.

When examining her scores in the Developmental Burden sub-scale not only did this client appear to indicate a sense of feeling trapped by the caregiving but she felt very much out of step with her life expectations e.g. she scored 4 on each of the questions " I am missing out on life" and " I expected things would be different at this stage of my life". These results are not surprising considering the young age of this client (64).



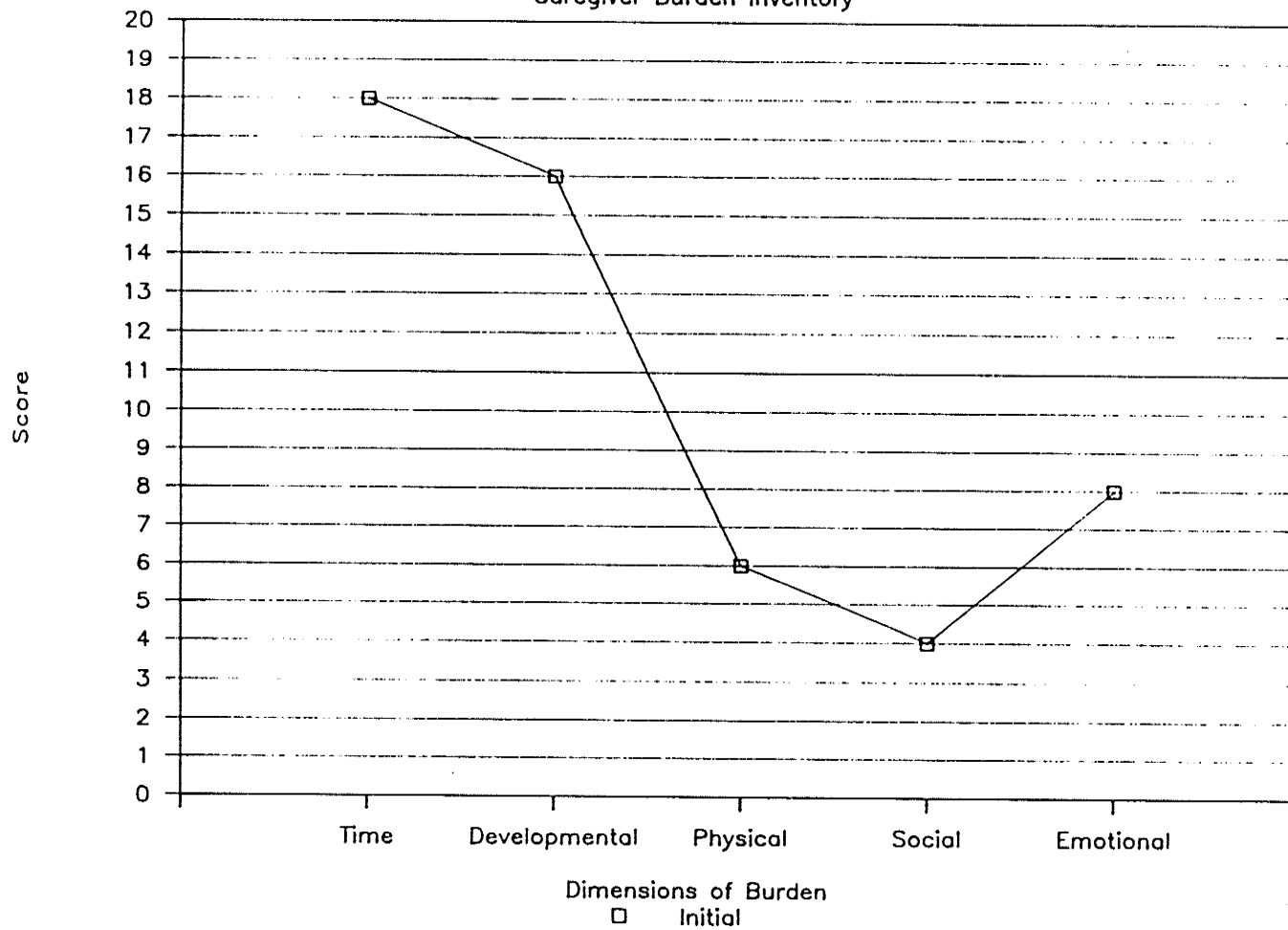
Unlike Clients # 2 and # 3, this client scored low in the Physical Burden sub-scale. This result also is not unexpected, because unlike Clients # 2 and # 3, this client was physically healthy.

This client also scored low in the Social Burden sub-scale. This woman did not expect support from her family because she was the family member who always provided support to the others.

Finally, this client's score in the Emotional Burden sub-scale may reflect the residual negative emotions she felt towards her husband, as a result of their long history of marital discord.

# Client IV, Graph A

## Caregiver Burden Inventory



Client # 7**Contact:**

Client was referred to the practicum in January, 1989. She volunteered to participate in the practicum after she heard about the practicum from an announcement made at a Family Support Group meeting. Two sessions, averaging one and one half hours in length, were completed. Follow-up contact was completed in a one hour phone conversation.

**Assessment:**

Client was a 48 year old lady caring for her 49 year old husband. Couple had been married 20 years. Client described the marital relationship prior to the onset of the symptoms as very good. She stated couple's relationship had deteriorated during the few years prior to diagnosis. During this period client had interpreted her husband's deteriorating ability to communicate and increasing forgetfulness as a marital problem and had been very frustrated and angry towards him since he had been reluctant to work on this problem. Client still had many guilt

feelings about her interactions with her husband during this period.

Client's husband was still employed in a managerial position. It appeared that co-workers were very helpful in assisting him in compensating for his deficits. Client was employed full time as a nurse. Couple lived in rural Manitoba approximately a one hour driving distance from Winnipeg.

Couple had two children, sons aged 13 and 17. The nuclear family had always been very emotionally close and supportive. Client was very concerned about the potential affect her husband's illness might have on her children. She was also concerned because she found herself crying daily in front of her children, an action she felt was inappropriate. There were some early indications that the children's performance at school was being affected by the home situation.

Client had a long history of estrangement from her parents and siblings. She had also always had a poor relationship with her mother-in-law. Her mother-in-law had not yet been advised of the diagnosis. Client did have a

close relationship with her husband's sister and her husband but they also had not been advised of the diagnosis. Couple had many friends, but because client's husband was in the early stages of the disease and still able to compensate for his deficits, these friends tended to not see the difficulties client was having, and therefore, client found them unsupportive. As a result of all of these factors client felt very socially isolated. She was especially hurt and angry at the lack of support she was receiving from her friends.

Over the last few years client had noticed progressive deterioration in her husband's memory and language skills. After extensive medical investigation by a neurologist and a psychiatrist, in September 1988 husband was diagnosed with Alzheimer's Disease. Client had never anticipated this diagnosis and was shocked by it. Husband presently appears to be in the very early phase of the Confusional stage of the disease.

As a nurse client had some basic understanding about the disease and the disease process, but she did have some difficulty applying this knowledge to the specific symptoms

exhibited by her husband. She also appeared to have good problem-solving skills and, for the most part, she was effective in managing her husband's symptoms.

**Intervention:**

I felt the intervention with this client should consist of not only a section on education, specifically examining the impact of this disease on her husband, but an exploration of her feelings and the impact her feelings were having on her life. I felt that this client was deeply grieving the loss of the relationship she previously had with her husband and she also had residual guilt feelings about how she responded to her husband's deficits in the two years prior to the diagnosis.

Client did not want to explore the emotional aspects of her life. She felt that with time her grief would abate on it's own and, as long as she got adequate sleep, she would be able to effectively cope. In accordance with her wishes our sessions were limited to some minimal education about the disease and it's impact on her husband, and some discussion of the impact the disease was having on her children.

Evaluation:

At the initial session client scored 35 (39.7%) on the BI. This placed her in the mildly to moderately burdened range. She scored 30 (31.3%) on the global CBI score. Her scores on each of the dimensions were (see Client VII, Graph A):

Time Dependence	=	5
Developmental Burden	=	8
Physical Burden	=	6
Social Burden	=	6
Emotional Burden	=	5

Client refused to complete the BI and CBI at the final session or in the follow-up session, therefore, I have no data upon which to evaluate the effectiveness of the intervention.

Simply by looking at these scores one might make the assumption that the impact of caregiving for this woman was less traumatic than on some of the other clients. Her low burden scores did initially cause me to reach the mistaken conclusion that this woman was coping well with her

situation. It was not until our follow-up conversation that I truly appreciated the emotional distress this woman was under. When I consider the scores obtained on these instruments by this client and client # 5, I wonder if these instruments are biased towards the type of burden felt by older caregivers, and caregivers caring for someone in the more advanced stages of the disease. Do these instruments fail to measure the real distress felt by younger caregivers and caregivers with individuals in the early stages of the disease? Clinically I found that it was the younger spousal caregivers that were the most distressed. Younger spousal caregivers have few social supports that understand what they are going through. They have more responsibilities (employment, child care) and often they are less financially secure. Caregivers of people in the early stages of the disease are often dealing with problems that do not have easy solutions. If a caregiver is tired because her demented spouse is up all night, we can help her/him by putting in a sitter. But, how do you support a caregiver who is worried because their family member is driving around all day and might get in an accident? These instruments can be helpful



but I feel we must be cautious in their application with younger caregivers and with caregivers of individuals in the early stages.

Client VII, Graph B demonstrates this client's ratings of the previous week stressfulness. Since the therapeutic process was so short we do not have an established baseline. As a result of not having a baseline the statistical significance of this data is unknown. The data appears to suggest that the intervention had limited affect on this client. This impression certainly correlates with my clinical impression and client's self evaluation.

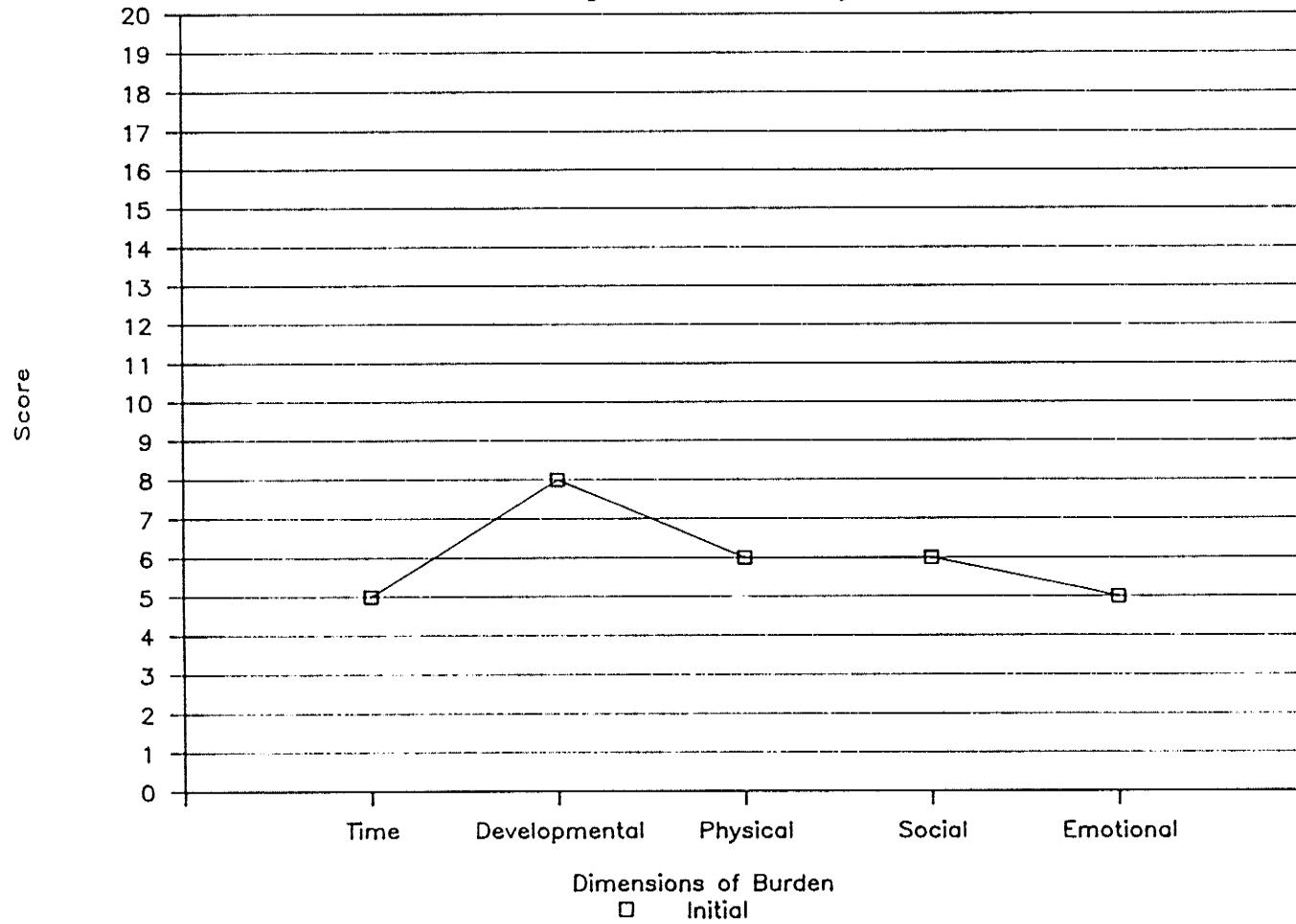
Clinically, I did not feel that our sessions were very helpful in meeting this client's needs. In our follow-up conversation client agreed with my evaluation and stated she felt that her needs had not been met through either my practicum or through the Alzheimer Support Group. This client stated that what she wanted were specific skills in how to cope with general life stress so that she would be able to control and suppress her emotional responses until they had abated on their own. What this client wanted was in direct contradiction with a basic philosophy of my practicum

and the Alzheimer Society that is, that it is beneficial for caregivers to identify and ventilate their emotions. Is our basic tenet right? Is it right for all caregivers? This is an issue that requires more research and contemplation if we are to be able to address the needs of all caregivers.

This client was very open about her evaluation about the Society's Family Support Group. She did not like the format of the group. She did not feel that just sitting around discussing problems was that helpful. She felt it would be more useful to have a informal part to the session, where caregivers could visit with each other one to one, and a formal part to the session, where specific skills would be taught. She also felt there were limitations in the composition of the group. She did not feel any bond with the older spousal caregivers present because they were not coping with working full time and having to be a single parent. She also found that caregivers have different needs at the different stages and, for her, it was not helpful to listen to the caregivers of individuals in the later stages because they were not having the same problems as she was having now.

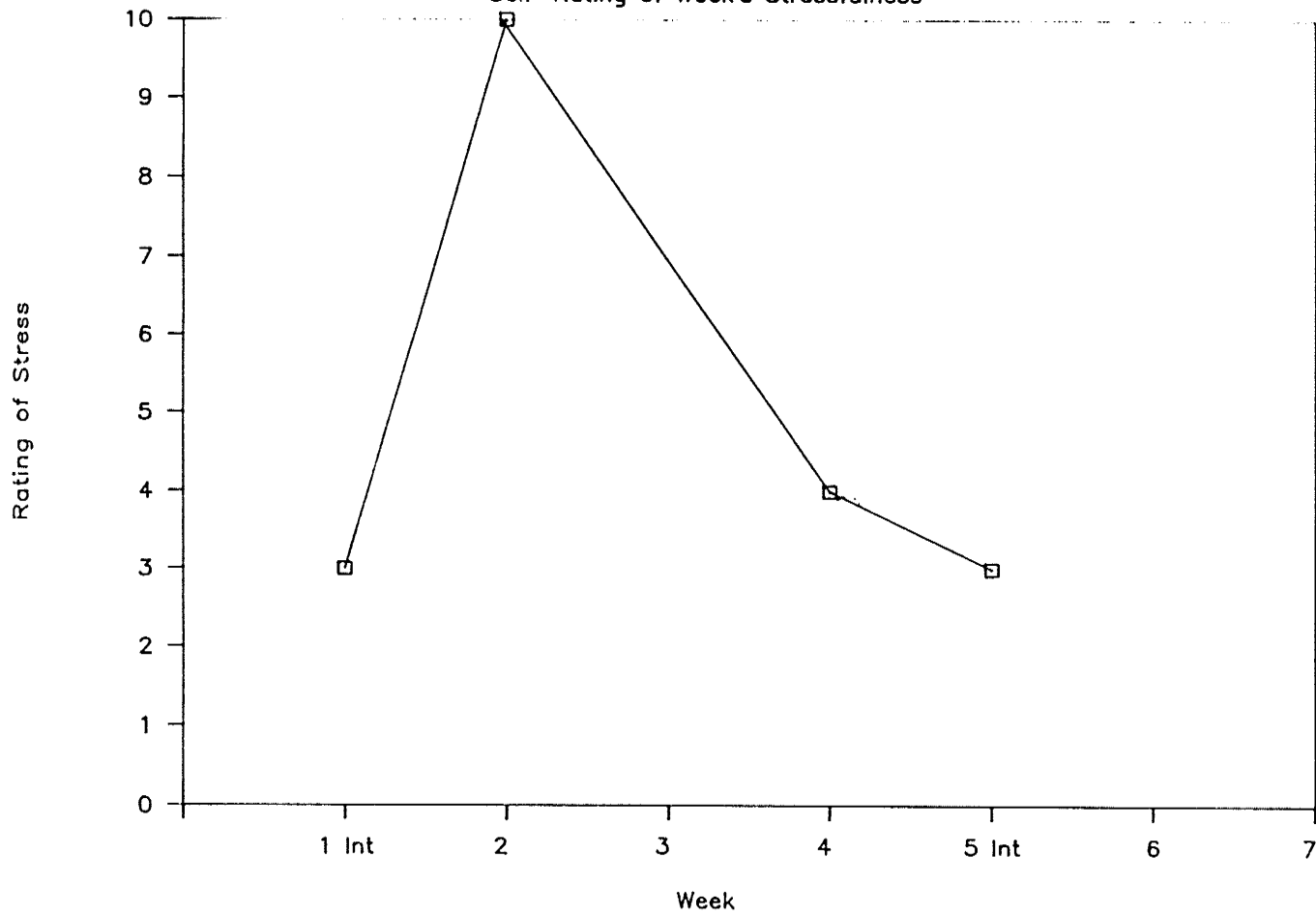
# Client VII, Graph A

## Caregiver Burden Inventory



# Client VII, Graph B

## Self-Rating of Week's Stressfulness



Client # 8

Contact:

Client was referred to practicum in January, 1989. Client volunteered to participate in the practicum after hearing about it from an announcement made at a Family Support Group meeting. Five sessions were completed averaging approximately two hours in length.

Assessment:

Client was a 53 year old lady who was caring for her 56 year old husband. Couple had been married for 30 years. Client stated couple had always had a very good relationship. Client was a nurse but she had not worked since marrying. Husband was on disability pension. Prior to his retirement he had been a pilot who held a managerial position. As a pilot her husband had been frequently away from home and it had only been in the last ten years that couple had the opportunity to be together most of the time. Client was grieving the loss of their life together and angry that this had to happen at this point of their life.

Couple had four children. Their youngest son still lived at home while he attended university. They had one son who lived in Winnipeg, a daughter that lived in rural Manitoba, and another daughter who lived in Alberta. Nuclear family had always been close and supportive. Client's parents, one sister, and one brother also lived in Winnipeg and were supportive. Husband's mother and brother lived in Winnipeg. Client stated that her mother-in-law had difficulty accepting the diagnosis and as a result contact with her were a strain. Client felt very socially isolated because she felt few of her friends really understood what she was going through.

Over the last two to four years client had noticed increasing confusion, disorientation and decreasing verbal skills in her husband. He was diagnosed with Alzheimer's Disease in October 1987 after an extensive medical evaluation. He presently appeared to be in the Confusional stage of the illness. Her major concern at this time was that her husband was still periodically driving, an activity which he no longer could safely manage. She and her children had reported him to the Motor Vehicle Department but no

action would be taken by this department until they received a medical from the doctor.

While client had a good understanding about the disease and the disease process, she had difficulty understanding and accepting the impact the disease was having on her husband's personality and behaviour. She felt responsible for her husband's moods and felt very responsible and guilty when he was moody and depressed.

**Intervention:**

The focus of my intervention with this client was to provide her with the opportunity to ventilate her emotions, to educate her about the impact this disease has on those afflicted with it, and to explore the cognitive aspects of her emotions especially those surrounding her feelings of guilt.

**Evaluation:**

Clinically, client appeared to benefit from the intervention. For example, prior to therapy when her husband became moody, client would feel she had failed as a

caregiver and feel angry and guilty. Once client realized that mood swings were an inherent feature of the disease process, she began to effectively challenge the irrational beliefs that were the basis of her anger and guilt. Client also felt she had benefited from the interventions and that the therapy had improved her ability to cope with her situation.

The data from the burden instruments is less clear about the success of the intervention. Client's initial score on the BI was 43 (48.8%) and her BI score at the final session was basically unchanged, 44 (50%). Both scores place her in the moderately to severely burdened range. In the follow-up session she scored 33 (37.5%) which placed her in the mildly to moderately burdened range. On the CBI, her initial score was 39 (40.6%). This did drop in the final session to 33 (34.4%), but the statistical significance of this change is unknown. In the follow-up session her score increased again to 40 (41.7%). The scores client obtained on the various dimensions of the CBI were (see Client VIII, Graph VIII A):



		Initial	Final	Follow-up
Time Dependence	=	8	9	8
Developmental Burden	=	14	15	15
Physical Burden	=	5	1	0
Social Burden	=	2	1	6
Emotional Burden	=	10	7	11

The significance of the changes in the different dimensions is unknown, but the Developmental Burden score was always the highest. This is not surprising considering the young age of this client.

Client's rating of the previous week's stressfulness is found in Client VIII, Graph B. Using the two standard deviation band (Shewart Charts) method of statistical analysis, no significant increase or reduction in client's stressfulness was found. A possible reason for this is that this client also appeared to be rating the stressors in her life rather than her feelings of stress.

A follow-up meeting was held with this client approximately five weeks after the termination of therapy.

She reported that her husband continued to steadily deteriorate. She was still waiting for the doctor to complete the medical so the Motor Vehicle Department would review her husband's driving licence but, as her husband was loosing interest in driving, this was no longer a major concern. She was now more concerned that her husband was loosing his ability to sign his name and her main focus now was in setting up a power of attorney.

At the follow-up meeting this client stated she continued to feel that the intervention had been instrumental in improving her ability to provide care for her husband. She felt that as a result of therapy she had a better understanding of the impact of the disease on her husband's behaviour. She also felt that, while she still felt angry and guilty at times, her emotions had less of an impact on her ability to provide care.

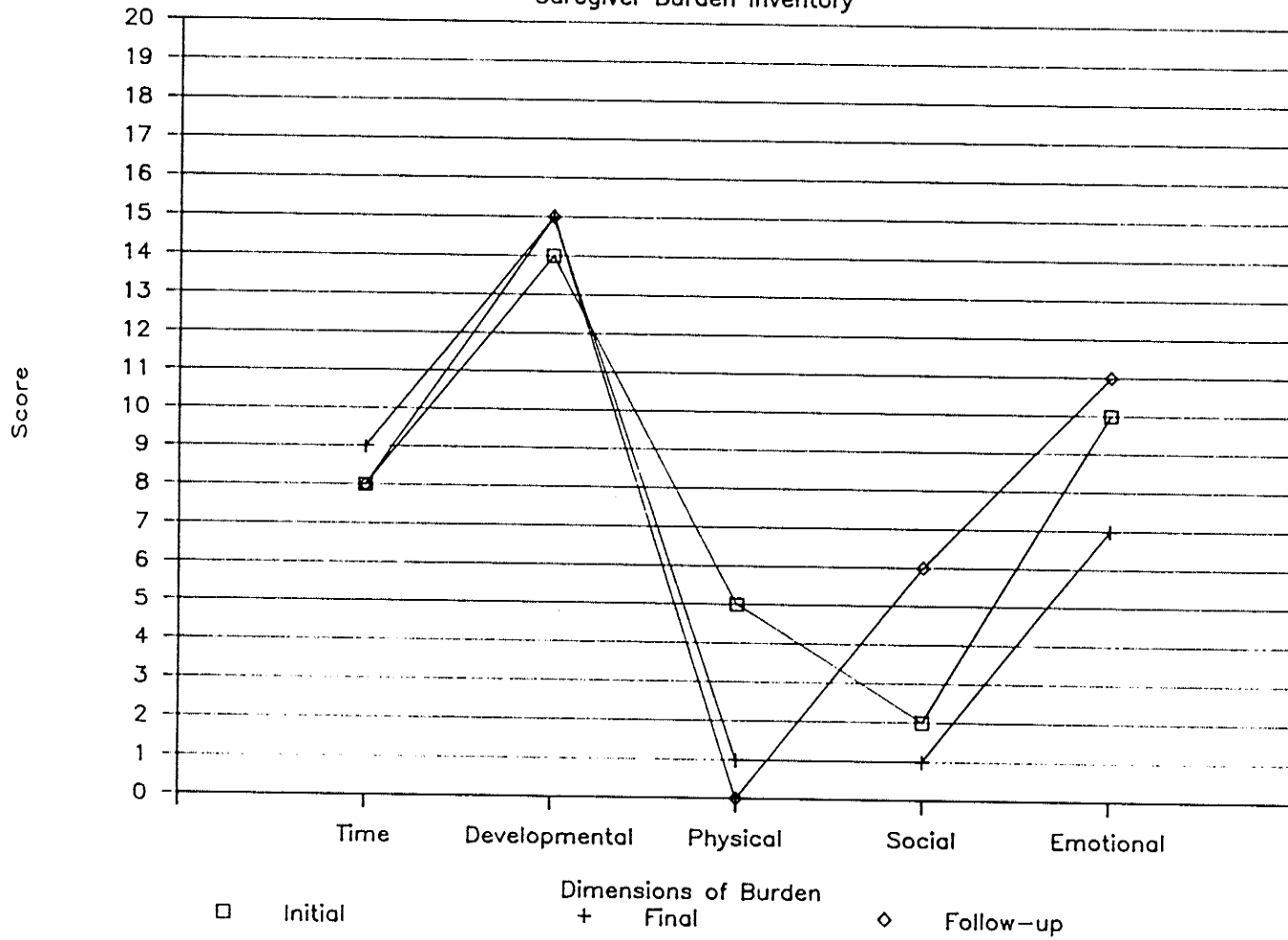
Client felt the mode of intervention, individual counselling, had been especially instrumental in her progress. This client also attended Family Support Group meetings. She felt that, while the group meeting were helpful in decreasing her sense of caregiver isolation,

individual counselling was much more effective for working on specific problems.

This client found that it was sometimes upsetting to attend support group meetings. She found that she sometimes would become very angry and resentful, especially towards the older spousal caregivers who were complaining about their husbands/wives becoming ill. She felt robbed that she and her husband had, because of the illness, been deprived of the years together that these older spousal caregivers had. This client also found that it was not always helpful to listen to caregivers caring for individuals in the later stages of the illness. She felt that support groups would be more useful if membership of the group was limited to a specific age group or at a particular stage of the illness.

# Client VIII, Graph A

## Caregiver Burden Inventory



# Client VIII, Graph B

## Self-Rating of Week's Stressfulness

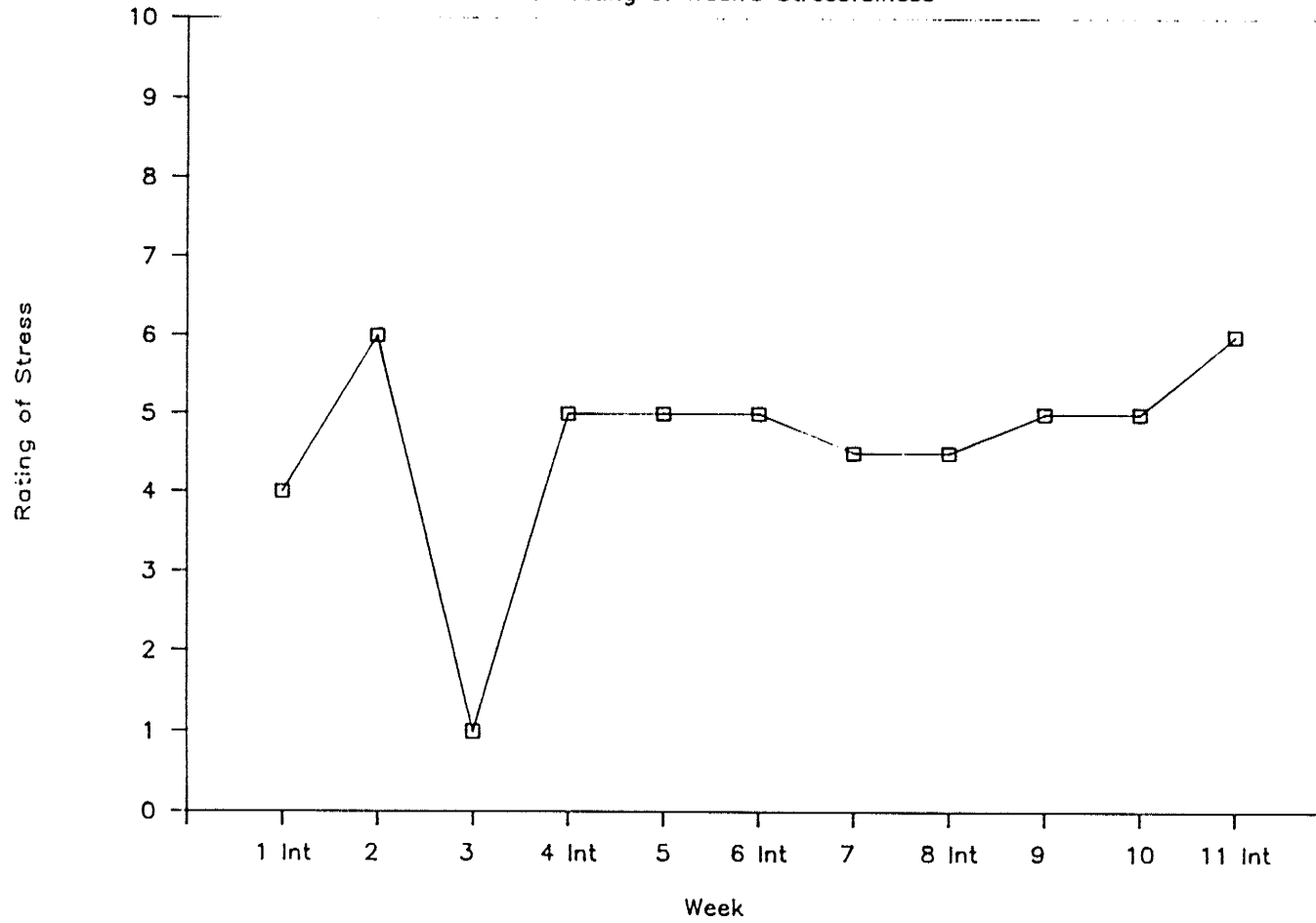


Table 1

Caregiver Burden Inventory (CBI)  
(Mean=22.14; s.d.=16.30)

<u>Factor</u>	<u>Factor Loading</u>
<u>Factor 1: Time Dependence (Mean=6.98; s.d.=5.89)</u>	
1. My carereceiver needs my help to perform many daily tasks.	.88
2. My carereceiver is dependent on me.	.77
3. I have to watch my carereceiver constantly.	.77
4. I have to help my carereceiver with many basic functions.	.71
5. I don't have a minute's break from my caregiving chores.	.66
<u>Factor 2: Developmental Burden (Mean=7.08; s.d.=5.89)</u>	
1. I feel that I am missing out on life.	.78
2. I wish I could escape from this situation.	.78
3. My social life has suffered.	.71
4. I feel emotionally drained due to caring for my carereceiver.	.65
5. I expected that things would be different at this point in my life.	.63
<u>Factor 3: Physical Burden (Mean=4.37; s.d.=4.72)</u>	
1. I'm not getting enough sleep.	.73
2. My health has suffered.	.73
3. Caregiving has made me physically sick.	.70
4. I'm physically tired.	.69
<u>Factor 4: Social Burden (Mean=2.54; s.d.=3.54)</u>	
1. I don't get along with other family members as well as I used to.	.81
2. My caregiving effort aren't appreciated by others in my family.	.79
3. I've had problems with my marriage.	.73
4. I don't do as good a job at work as I used to.	.61
5. I feel resentful of other relatives who could but do not help.	.60
<u>Factor 5: Emotional Burden (Mean=2.02; s.d.=3.04)</u>	
1. I feel embarrassed over my carereceiver's behavior.	.81
2. If feel ashamed of my carereceiver.	.74
3. I resent my carereceiver.	.64
4. I feel uncomfortable when I have friends over.	.64
5. I feel angry about my interactions with my carereceiver.	.53

## THE HIDDEN VICTIMS OF ALZHEIMER'S DISEASE

**TABLE 4.3.**  
The Burden Interview

### INSTRUCTIONS:

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way, never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
4. Do you feel embarrassed over your relative's behavior?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent upon you?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
10. Do you feel your health has suffered because of your involvement with your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like because of your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
13. Do you feel uncomfortable about having friends over because of your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

## UNDERSTANDING THE STRESS OF CAREGIVERS

**TABLE 4.3.** (Continued)

17. Do you feel you have lost control of your life since your relative's illness?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative to someone else?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
20. Do you feel you should be doing more for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
21. Do you feel you could do a better job in caring for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
22. Overall, how burdened do you feel in caring for your relative?  
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

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## THE HIDDEN VICTIMS OF ALZHEIMER'S DISEASE

**TABLE 4.1.**  
Memory and Behavior Problems Checklist

### INSTRUCTIONS TO INTERVIEWER

This checklist has two parts. Part A measures the frequency with which problems occur. Part B determines to what degree the behavior upsets the caregiver. Begin by asking if a problem has occurred and, if so, how often. When you find it has occurred, then go immediately to Part B, and determine the caregiver's reaction to that problem *when it occurs*. (In other words, do not go through the whole list for frequency, and then come back to get their reaction.)

### Instructions to Caregiver

**Part A.** "I am going to read you a list of common problems. Tell me if any of these problems have occurred during the past week. If so how often have they occurred? If not, has this problem ever occurred?" Hand the subject the card on which the frequency and reaction ratings are printed.

**Part B.** "How much does this problem bother or upset you at the time it happens. The subject indicates his/her typical reaction on the card on which the frequency and reaction ratings are printed. Reaction is how the person reacts when the problem occurs. When the caregiver's response to frequency is "7," you determine reaction by asking:

"How much does it bother or upset you when you have to supervise N to prevent that?"

### FREQUENCY RATINGS

- 0 = never occurred
- 1 = has occurred, but not in past week
- 2 = has occurred 1 or 2 times in past week
- 3 = has occurred 3 to 6 times in past week
- 4 = occurs daily or more often
- 7 = would occur, if not supervised by caregiver (eg., wandering except door is locked).
- 8 = patient never performed this activity

### REACTION RATINGS: How much does this bother or upset you when it happens?

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely

BEHAVIORS	FREQUENCY	REACTION
1. Wandering or getting lost	0 1 2 3 4 7	0 1 2 3 4
2. Asking the same question over and over again	0 1 2 3 4	0 1 2 3 4
3. Hiding things (money, jewelry, etc)	0 1 2 3 4	0 1 2 3 4
4. Being suspicious or accusative	0 1 2 3 4	0 1 2 3 4

## UNDERSTANDING THE STRESS OF CAREGIVERS

**TABLE 4.1.** (Continued)

BEHAVIORS	FREQUENCY	REACTION
5. Losing or misplacing things	0 1 2 3 4	0 1 2 3 4
6. Not recognizing familiar people	0 1 2 3 4	0 1 2 3 4
7. Forgetting what day it is	0 1 2 3 4	0 1 2 3 4
8. Starting, but not finishing things	0 1 2 3 4	0 1 2 3 4
9. Destroying property	0 1 2 3 4	0 1 2 3 4
10. Doing things that embarrass you	0 1 2 3 4	0 1 2 3 4
11. Waking you up at night	0 1 2 3 4	0 1 2 3 4
12. Being constantly restless	0 1 2 3 4	0 1 2 3 4
13. Being constantly talkative	0 1 2 3 4	0 1 2 3 4
14. Talking little or not at all	0 1 2 3 4	0 1 2 3 4
15. Engaging in behavior that is potentially dangerous to others or self	0 1 2 3 4 7	0 1 2 3 4
16. Reliving situations from the past	0 1 2 3 4	0 1 2 3 4
17. Seeing or hearing things that are not there (hallucinations or illusions)	0 1 2 3 4	0 1 2 3 4
18. Unable or unwilling to dress self (either partly or totally, or inappropriate dress compared to previous standards)	0 1 2 3 4 7	0 1 2 3 4
19. Unable or unwilling to feed self	0 1 2 3 4 7	0 1 2 3 4
20. Unable or unwilling to bathe or shower by self	0 1 2 3 4 7	0 1 2 3 4
21. Unable to put on make-up or shave by self	0 1 2 3 4 7	0 1 2 3 4
22. Incontinent of bowel or bladder	0 1 2 3 4 7	0 1 2 3 4
23. Unable to prepare meals	0 1 2 3 4 7 8	0 1 2 3 4
24. Unable to use the phone	0 1 2 3 4 7	0 1 2 3 4
25. Unable to handle money (e.g., to complete a transaction in a store; do not include being unable to manage finances)	0 1 2 3 4 7	0 1 2 3 4
26. Unable to clean house	0 1 2 3 4 7 8	0 1 2 3 4
27. Unable to shop (to pick out adequate or appropriate foods)	0 1 2 3 4 7 8	0 1 2 3 4
28. Unable to do other simple tasks which he/she used to do (e.g., put away groceries, simple repairs)	0 1 2 3 4 7	0 1 2 3 4
29. Unable to stay alone by self	0 1 2 3 4	0 1 2 3 4
30. Are there any other problems?	0 1 2 3 4	0 1 2 3 4

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Burden Questionnaire

The following are a list of statements, which reflect how people sometimes feel when taking care of another person. After each question, circle the response that best reflects your present feelings. There are no right or wrong answers.

1. My carereceiver needs my help to perform many daily tasks.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

2. Do you feel that your relative asks for more help than he/she needs?

0.	1.	2.	3.	4.
never	Rarely	Sometimes	Quite Frequently	Nearly always

3. My carereceiver is dependent on me.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

4. I have to watch my carereceiver constantly.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

5. I have to help my carereceiver with many basic functions.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

6. I don't have a minute's break from my caregiving chores.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

7. I feel that I am missing out on life.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

8. Do you feel uncomfortable about having friends over because of your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

9. Do you feel you have lost control of your life since your relative's illness ?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

10. I wish I could escape from this situation.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

11. Do you feel that because of the time you spend with your relative you don't have enough time for yourself?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

12. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

13. Do you feel that you don't have as much privacy as you would like because of your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

14. My social life has suffered.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

15. I feel emotionally drained due to caring for my carereceiver.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

16. I expected that things would be different at this point in my life.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Moderately descriptive	Quite	Very descriptive

17. Do you feel strained when you are around your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

18. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

19. I'm not getting enough sleep.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

20. My health has suffered.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

21. Caregiving has made me physically tired.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

22. I'm physically tired.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

23. I don't get along with other family members as well as I used to.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

24. My caregiving efforts aren't appreciated by others in my family.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

25. I've had problems with my marriage.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

26. I don't do as good a job at work as I used to.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

27. I feel resentful of other relatives who could but do not help.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

28. I feel embarrassed over my carereceiver's behaviour.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

29. I feel ashamed of my carereceiver.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

30. I resent my carereceiver.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

31. I feel angry about my interactions with my carereceiver.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

32. I feel uncomfortable when I have friends over.

0.	1.	2.	3.	4.
Not at all descriptive	Slightly	Sometimes descriptive	Quite	Very descriptive

33. Are you afraid of what the future holds for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

34. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

35. Do you feel that you will be unable to take care of your relative much longer?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

36. Do you wish you could just leave the care of your relative to someone else?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

37. Do you feel uncertain about what to do about your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

38. Do you feel you should be doing more for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

39. Do you feel you could do a better job in caring for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

40. Overall, how burdened do you feel in caring for your relative?

0.	1.	2.	3.	4.
Never	Rarely	Sometimes	Quite frequently	Nearly always

Appendix VII, A



THE UNIVERSITY OF MANITOBA

CONTINUING EDUCATION DIVISION

Winnipeg, Manitoba  
Canada R3T 2N2

October 4th, 1988

Ms. Elizabeth McKean  
62 Swan Lake Bay  
Winnipeg, Manitoba  
R3T 4W1

Dear Elizabeth:

You have my permission to use the Caregivers Burden Inventory in  
your practicum work.

Please let me know how your work progresses.

Sincerely

Mark Novak, Ph.D.  
Program Coordinator  
Gerontology Programs

MN/ml

Appendix VII, B

THE PENNSYLVANIA STATE UNIVERSITY  
COLLEGE OF HUMAN DEVELOPMENT  
UNIVERSITY PARK, PENNSYLVANIA 16802

Department of Individual and Family Studies  
5-110 Henderson Human Development Building

Area Code 814  
863-0241

April, 1987

Dear Colleague:

Thank you for your interest in The Memory and Behavior Problems Checklist and The Burden Interview. The enclosed booklet includes descriptions of the measures, psychometric information, and a brief bibliography. You are welcome to use these instruments or parts of them in your research and to make copies of them for that purpose, with appropriate citation of the source in any papers or reports you prepare. If you do use these measures, we would appreciate learning of your results.

Sincerely,

*Steven H. Zarit*  
Steven H. Zarit, Ph.D.  
*Judy M. Zarit*  
Judy M. Zarit, Ph.D.



Appendix VIIISummary of CBI and BI Scores

Client	CBI	BI	Percentage Difference in CBI and BI scores
#1	na	na	na
#2	39 (40.6%)	na	na
#3 f	54 (56.3%)	49 (55.7%)	.6%
#4	52 (54.2%)	48 (54.5%)	.3%
#5	43 (44.8%)	51 (57.9%)	13.1%
#6 i	73 (76%)	64 (72.7%)	3.3%
f	43 (44.8%)	42 (47.7%)	.1%
#7	30 (31.3%)	35 (39.7%)	8.4%
#8 i	39 (40.6%)	43 (48.8%)	8.2%
f	33 (34.4%)	44 (50%)	15.6%
fu	40 (41.7%)	33 (37.5%)	2.5%
#9 i	34 (35.4%)	29 (32.9%)	2.5%
f	44 (45.8%)	50 (56.8%)	11%
fu	61 (63.5%)	65 (73.9%)	10.4%

i= initial session    f= final session    fu= follow-up session

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