A PROGRAM EVALUATION OF

FAMILY SUPPORT SERVICES FOR

CAREGIVERS OF PERSONS WITH ALZHEIMER DISEASE

A PRACTICUM REPORT

SUBMITTED TO

THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILMENT

OF THE REQUIREMENT

FOR THE DEGREE

MASTER OF SOCIAL WORK

BY

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AUGUST 1992

ISBN 0-315-77859-8

Canada

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

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ABSTRACT

Interventions which best support caregivers of persons with Alzheimer disease have not been fully explored. In order to address this issue clients of an Alzheimer Society were asked to respond to a mail survey designed to examine caregiver characteristics, service utilization and an evaluation of services used by caregivers.

This study identifies specific ways clients are helped in individual counselling, volunteer support and family support groups. The findings suggest professionals help more with emotional coping and resolving family conflicts, while family support groups help more with issues related to institutionalization.

This study also suggests that when family caregivers are helped to understand Alzheimer disease and related behaviours, they may use this information to assist them in educating other family members, resolving family conflict, and in making the decision to institutionalize.

Interventions with caregivers must be based on adequate assessment of their needs, an understanding of their goals and effective implementation of interventions to successfully match clients with services that will meet their individual needs.

ACKNOWLEDGEMENT

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Chapter One

INTRODUCTION

There is no cure or palliative treatment for Alzheimer disease, or other related dementias. Therefore the response to the problem extends beyond the health system to the social and community service sector, with an overall focus on maximizing the quality of people's lives throughout the course of the disease. As the dementing person is rarely cognizant of the extent of his or her own decreasing abilities, their quality of life becomes dependent primarily on other family members. Programs typically have emerged to assist and support family caregivers whose own quality of life is threatened by the burdens of caregiving, and an indirect positive effect of assisting the Alzheimer sufferer is often assumed.

Models for service delivery to family caregivers across the continuum of the disease are very much in the formative stages of research, and the issue of what interventions best support caregivers is of great interest.

It is the purpose of this paper to consider this issue through a review of the literature, and design and analysis of an exploratory research survey.

Specifically, the family support programs of the Alzheimer Society of Manitoba will be evaluated. The overall purpose of the study is to increase the responsiveness of the ASM in addressing needs of caregivers by adjusting programs if necessary, to assist in priority planning, and to increase the knowledge and understanding of caregiving families. The objectives of this study are:

(1) to examine who, in reality is being served. What are the characteristics of users, and their ill relatives?

(2) to examine service utilization. What services are being used? Are there barriers to service?

(3) to examine how clients of the Society evaluate services they have used.

As this study was undertaken as a Practicum, there are further objectives related to student learning goals within the M.S.W. program of study. In completing this Practicum, student goals include acquiring knowledge and skills in evaluation research, and gaining a greater understanding of promoting and utilizing the results of research in a social agency. The specific skills of interest are:

(1) an ability to apply evaluation techniques to a family support program for caregiving relatives of people with Alzheimer disease or a related dementia;

(2) skills necessary for data collection (developing a research instrument) and data analysis;

(3) an ability to evaluate the results in a meaningful and accurate way;

(4) an increased understanding of caregiving families and their needs throughout the course of the disease.

Organization of the Practicum Report

Chapter one has provided the introduction to the report, and has developed both the purpose of the study, and the student learning objectives.

Chapter two briefly describes Alzheimer disease, its characteristics, current epidemiological and diagnostic information. This section also includes something of the experience of the family and the identified patient during the assessment process. This area is often not included in discussions about family caregivers. I believe, however, that this review provides a better appreciation of the caregiving role in relation to the needs of AD sufferers. I also found it useful for my own learning to consolidate the current psychological information concerning persons with AD.

Chapters three and four review conceptualizations of caregiving, characteristics of family caregivers and the effects of caregiving on this group. Service needs and developments in interventions are covered in Chapter four.

The Alzheimer Society of Manitoba, and its family support programs are discussed in Chapter five, and the rationale for the study is introduced.

Chapter six describes the methods used for the study including the design, sample, research instrument, and methods of analysis.

Results are shown in Chapter seven, and implications for programs are discussed in the final chapter, including a series of recommendations for program adjustment and continued program monitoring.

Chapter Two

ALZHEIMER DISEASE - THE EROSION OF SELF

Alzheimer Disease

Alzheimer disease is pathologically determined by plaques of the cortex and neocortex, tangles appearing in the cortex and hippocampus, and neurotransmitter abnormalities resulting in gross cerebral atrophy. It is the most common cause of dementia, a clinical syndrome of progressive cognitive deterioration that eventually causes functional impairment. The disease develops over months or years, and progresses anywhere from eight to over twenty years. Deficits occur in memory, intelligence, affect, judgement, orientation and visuospatial skills, and eventually involve all facets of cognition (Clarfield, 1989).

Although bio-medical research flourishes on many fronts (neurotransmitter deficiency, viral theories, genetics, aluminum), there is no known cause for Alzheimer disease. Clinical drug trials are currently being undertaken in hopes of discovering a palliative remedy by slowing the effects of functional deterioration (tetrahydroaminoacridine, alzene). Nothing to date has been proven effective.

The progression of Alzheimer disease has been described

in stages, although it is recognized that individual

experiences are not specifically predictable. Some stages

are conceptualized by clusters of symptoms (Reisberg, 1979),

or by levels of cognitive impairment (Burnside, 1979), or by

levels of functional abilities (Hall, 1988). This study

will recognize categories of severity of dementia, namely

mild, moderate and severe dementia as descriptive

categories. This criteria focuses on dependence and

independence issues, and corresponds well to comparative

levels of care required.

(1) Mild Dementia: Although work or social activities are
significantly impaired, the capacity for independent living
remains, with adequate personal hygiene and relatively
intact judgement.

(2) Moderate Dementia: Independent living is hazardous, and
some degree of supervision is required.

(3) Severe Dementia: Activities of daily living are so
impaired that continual supervision is required. There is
no ability to maintain minimal personal hygiene, and persons
are largely incoherent or mute. (Clarfield, 1989).

Epidemiology

Most of the published work on the prevalence of

dementia is based on cross-sectional surveys in which

problems of definition and sampling exist. There are few

estimates of incidence or case fatality, and mortality

statistics are unreliable due to problems of diagnosis and

coding the underlying cause of death.

Canadian studies have estimated the prevalence of

dementia as 3.5% and 4.4% of the overall population (Bland,

1988; Jeans, 1987). One of the most thorough reviews, by Jorms (1987), examined 47 community based American and Canadian studies and concluded the overall prevalence of moderate or severe dementia was 7.8%, in the community 4.2%, and in institutions 53.7%. If mild dementia is also included, the overall prevalence is probably at least 10% among those over age 65, suggesting that there are at present more than 250,000 demented people in Canada.

Data on the incidence of dementia has been reviewed by Mortimer, who concluded that dementia develops in approximately 1% of the elderly population each year. This would translate into at least 25,000 newly affected elderly persons per year in Canada (Mortimer, 1983).

Assessment and Diagnosis

Due to the fact that there have been few soundly designed studies of the causes or reversibility of dementia, there are no universally accepted guidelines on the exact composition of the dementia assessment.

The Canadian Consensus Conference on the Assessment of Dementia recognized that Canadian primary care physicians would benefit from sound and practical guidelines. Evidence shows major deficits in the recognition of this problem by family physicians and other physicians (Rubin, 1987). The Conference recommends the following procedure. Physicians should review evidence of impairment in short-term and long-

term memory, abstract thinking, judgement, constructional
ability and social relationships. Disturbances of higher
cortical functions are to be examined such as aphasia,
apraxia, agnosia, and personality. The diagnosis is made if
there is evidence from the history, physical examinations or
laboratory tests of specific organic factors judged to be
etiological. In the absence of such evidence, the diagnosis
can be assumed if the disturbance cannot be accounted for by
any other organic or non organic disorder (Clarfield, 1989).

Because autopsy (tissue diagnosis) remains the
definitive standard of diagnosis, autopsy should be obtained
whenever possible. It is particularly important in cases in
which clinical diagnosis is not resolved beyond reasonable
doubt, in atypical cases, in cases with a family history of
AD or in cases where the family initiates a request for
autopsy (Clarfield, 1989).

Alzheimer disease is insidious in nature, and the
beginnings of the disease process are not cause for alarm.
Periodic forgetfulness and lack of spontaneity are ordinary
occurrences for most people during the course of their
lives. Very often, the disease goes unrecognized until some
event calls attention to the problem such as getting lost in
a familiar environment, having a car accident or having
trouble doing mathematics (U.S. Congress, OTA,1989).
Symptoms that once seemed to be isolated incidents of
strange behaviour eventually create a picture of a serious

problem that can no longer be ignored.

For the most part, family members are the first to seek help (85%), while 15% of demented individuals initiate the process (Chenoweth and Spencer, 1986).

Families report several difficulties with obtaining a diagnosis. They have difficulty articulating subtle changes to their physicians, and convincing physicians that something is seriously wrong. Others struggle with demented relatives who do not understand or agree that medical consultation is necessary. Families report feeling overwhelmed by physicians who offer little explanation or information when the diagnosis is made, especially when the physician focuses on the hopeless nature of dementia (Chenoweth & Spencer, 1986).

The most urgent need expressed to physicians by individuals who are experiencing initial symptoms of dementia is for a definite diagnosis. As discussed earlier, this process involves a great deal of testing, over a period of time. Anxiety levels naturally increase. Individuals ask about the cure, or available treatments. They ask about the degree of disability, and they ask if they will be in pain (Clarfield, 1989).

Individuals in the early stages express many fears. They are afraid of being a burden to their family, of losing control in decision-making, of losing physical functions. Individuals express extreme fear of loss of dignity and

status, and of being institutionalized. There are many

reports of individuals extracting promises from family

members, with the doctor present, <u>never</u> to resort to this.

Individuals do not want others to know their diagnosis (U.S.

Congress, OTA, 1990; Clarfield, 1989; Mace, 1990).

<u>Effects On the Individual - The Erosion of Self</u>

> "It's hard to be in a world of strangers,
> especially when the chief stranger is me."
>
> "Every few months I sense that another piece
> of my self is missing."
>
> "Most people expect to die sometime, but who
> .ever expected to lost their self first."
>   (Quotes by Persons with Alzheimer Disease)

Alzheimer disease is fundamentally the erosion of self,

its victim requiring increasing support and understanding as

their intending and adapting self fades (Gilleard, 1983).

Research efforts have produced comprehensive

information about symptoms and deficits reflecting the

progression of the disease, or put another way, the

deterioration of the individual. Reisberg's Global

Deterioration Scale outlines clinical phases and

characteristics from a normal presentation through to late

dementia (APPENDIX I, Reisberg, 1983). A great deal of

emphasis has been placed on the symptoms of the disease; few

researchers have explored the subjective experience of the

disease.

The experience of Alzheimer disease, both for the

individual and for family members is much more complex than
a medical model that deals primarily with symptoms of a
disease. Central to the distress of family caregivers is
concern for the emotional well-being of their ill relative.
Those of us delivering programs to help family caregivers
must understand the experience of the entire family,
including the ill family member, in order to establish
credibility, build trust, provide accurate empathy, better
interpret family dynamics and suggest care interventions
(Farran et al.,1991; Robb, 1991).

People respond to their problems in different ways, and
past coping mechanisms may be predictive of what to expect
in an individual's ability to cope with the dementing
process. Some people become skilful at compensating for
their difficulties by avoiding difficult situations. Some
deny anything is wrong. Others are cheerful and positive.
Depressive reactions are common, and should be treated.
Eighty five percent of treated depressed demented patients
reviewed by Reifler et al. (1986) had significantly improved
in mood, vegetative signs and activities of daily living.

The mildly demented individual will have trouble
following conversations, will become confused by new points
of discussion, and responses may make less sense and not be
well related to the topic of conversation. Keys, wallets
and mail are misplaced. Appointments are missed.
Initiative, energy and drive are negatively affected. Most

become upset easily, anxious and sometimes angry and suspicious. Most retain some level of awareness of their limitations. Emotional and physical withdrawal is common, and persons in this stage are very high risk for severe depressive reactions (Gruetzner, 1988).

As the disease progresses, persons with AD will forget their forgetfulness and be unaware they are ill. They will try to do what they have always done, and consequently experience failure, loss of self-esteem and humiliation. Finally, they will not know who they are, or who others are, and they will be unable to interpret others' behaviour or their environments. Many have been observed to exhibit extreme and ongoing terror. They will cling to anything or anyone who seems remotely familiar (U.S. Congress, OTA, 1987).

These individuals live with chronic anxiety and fear, and their security and comfort needs are great.

Many behaviours are associated with Alzheimer disease, which some researchers label as difficult or problem behaviours and others as expected or normal behaviours within the context of the disease. While it is beyond the scope of this presentation to discuss appropriate interventions in depth, suffice it to say there are appropriate care techniques, clinical treatments, pharmacological and environmental interventions which can be introduced to maximize functioning and emotional well being

(Mace, 1990; Fabiano, 1987; Rabins, 1989).

Personality changes associated with the disease are often misinterpreted as the development of a different, or new personality. While there is a clear lack of ability to control or restrain behaviour or interpret interactive cues, many researchers believe in the continuation of personality. The expression of emotion may be blocked, but the ability to experience or feel emotion is not, even into the very late stages of the disease (Mace,1990; U.S. Congress, OTA, 1987).

At the end of the disease the person apparently has no recent or remote memory or cognitive functioning. Their ability to communicate through speech is limited, and they appear to be very easily agitated. However, case examples exist which suggest some communication is possible very late in the disease process. The key to engage the individual in meaningful communication is finding the correct stimulus.

> "Bill was fetally frozen, and had not spoken
> in three months. In the patient's room, the
> doctor was complaining of car problems as the
> reason he was late for rounds. Bill named the
> part of the engine that was later confirmed as
> the problem. Motor oil was spread on Bill's hands
> and face, and mechanic's tools were placed in his
> hands. Bill became significantly more communicative
> until his death" (Skelton, 1991).

If death is not caused by a secondary infection or disease process, coma is likely, and failure will occur in a vital central function like respiration (Hall, 1988).

Individuals with Alzheimer disease have extensive brain

damage. It is not possible to reverse the damage, therefore it is not possible to stop the symptoms. Scientific knowledge, though cannot fully explain the subjective experience of the disease, especially after communicating abilities appear to be lost. It is only possible to look beyond the symptoms to what is left of the person, and provide a quality of life.

Chapter Three

THE FAMILY CAREGIVERS

Conceptualizing Caregiving

Some effort to conceptualize the caregiving experience is evident in the literature and by and large has been based on identifying and grouping caregiving tasks. Archbold (1983) defines two main roles of the family caregiver. The first is as care-provider to meet physical and psychosocial needs. In the second role, that of care-manager, the family caregiver determines what assistance is required, then organizes others, both informal and formal caregivers to meet their needs. Pringle (1988) also identified roles associated with caregiving - diagnostition, dietician, nurse, recreationalist and social coach. Both Archbold and Pringle use tasks and functions to define roles.

Other researchers, Clark and Rakowski (1983) specifically view caregiving as a series of tasks according to whether they involve direct assistance to the elder (direct care) or caregiver adaptation to the personal challenges associated with caregiving (self-care tasks).

Despite the reality of the tasks and functions defined above, caregiving clearly involves a great deal more than supporting functional limitations like "just being with my

mother" or "coping with mood swings" (Brody, 1990). In addition to specific care tasks, the caregiver must deal with turmoil caused by restrictions on their personal life, and sadness at witnessing the deterioration of their loved one. (Gilleard, 1984).

Albert (1991) argues that the validity of researcher-imposed task distinctions should be questioned, and that caregiver task distinctions might provide greater insight.

The research of Bowers (1987), for instance, provides a more unique perspective of caregiving. Fifty caregivers discussed the purpose of caregiving, and five main themes clearly emerged. They are (1) protecting my family member (2) preventing illness and injuries (3) arranging for care (4) providing care and (5) "just-in-case" planning (anticipatory care). The most significant theme to families is protective caregiving. Families felt the most important, and the most difficult task was maintaining the emotional well being of their family member. Protective caregiving involves protecting the individual from the recognition they are deteriorating in their ability to function without making it apparent they are being protected. For example, when the ill father became disoriented in his own back yard, his son kidded him "you never did have a sense of direction". This type of caregiving creates additional stress as the caregiver is constantly "ready" to interpret or explain behaviour to the ill relative and to others.

Albert (1983) investigated the distinctions caregivers use in thinking about caregiving tasks in their own terms, and concluded caregivers have an organized lay, or folk understanding of what they do. Caregivers structured their tasks in 3 main ways (1) "this is what I have to do" (tasks related to physical impairment), (2) "this is what I have to deal with" (tasks responding to cognitive-emotional impairment), and (3) "this is what I do all the time anyway" (combination of tasks like shopping, banking, housework). Caregivers in Albert's study think about the tasks with certain sets of distinctions - the type of impairment giving rise to the task, where the task is performed and whether the task enhances autonomy or responds to incompetence.

Albert suggests that caregivers' understanding of what they do may or may not coincide with research initiatives. In his study, caregivers do not make a distinction between cognitive impairment and emotional condition, but put the two together, as opposed to physical impairment. It is interesting to note that burden is not a central dimension thought of by caregivers in either the Albert or the Bowers work, although they report burden when asked. While caregivers express burden in other ways, the use of the term "burden" may have little meaning for lay persons. Distinctions between care providing and care managing do emerge which suggest that, at times anyway, caregiver judgements and professional understanding do coincide.

There are other problems in providing a clear
conception of the caregiving process. Missing from the
literature is a systematic study of family experiences and
problems throughout the course of the disease (Chenoweth &
Spencer, 1986). Barer and Johnson (1990) cite
methodological problems such as confusing definitions of
caregivers (for example, spousal verses child or primary
verses secondary), an overrepresentation of self-selected
samples, and lack of attention to the total support network
of the carereceiver as major reasons practitioners and
researchers lack clarity in describing the caregiving
process.

Our understanding of the caregiver experience and the
caregiver process through the course of the disease may be
improved if research focused on caregiver generated issues
rather than professional generated issues.

Caregiver Characteristics

A study by Sommers (1985) found that the bulk of
caregiving is provided by women - wives, daughters, sisters,
daughters-in-law and female friends. The U.S. National
Institute on Aging (1985) states that the care principally
falls on one single caregiver, usually a female spouse or
child. Similar findings have been reported by others
(Chenoweth & Spencer, 1986; Morycz, 1985). Allan (1983)
argues that most caregiving arises from the activities of

one or more close relatives, usually female, and that these caregivers are not, in reality, part of a caring network, but individuals struggling on their own with providing care.

The importance of family support to the primary caregiver is unclear. Zarit et al. (1980), George and Gwyther (1986) and Morycz (1985) found that levels of burden and other caregiver well-being indicators related to the frequency or perceived need for more social support. However, Zarit et al. (1986) found the availability of social supports was not a factor in the decision to institutionalize, and Gilhooly (1984) found frequency of contacts was not related to mental health rating of caregivers. There are, however, few studies examining the impact on family members who are not directly providing care which might explain the dynamics of social supports more fully.

Colerick and George (1986) found that spousal caregivers, many of whom are old and frail themselves, are the last to relinquish care to professionals, and have lower levels of well-being than children or other relatives who are providing care. Zarit (1983) found that overall, husbands report less burden and have higher morale. Wagner (1984) discovered higher levels of burden in female caregivers, in spouses, and in caregivers whose dependents were male and younger than the average age of persons with AD.

Effects of Caregiving on Caregivers

Caregivers experience the difficulty of grieving for the loss of their "dead" companion who is still physically present, but slowly deteriorating (Barnes et al.,1981), and sadness at witnessing the deterioration of mind and manners in a partner or parent (Gilleard, 1984).

Many families describe the early years of the disease, prior to diagnosis, as confusing and puzzling. Uncharacteristic behaviours are sometimes viewed as evidence of marital problems or rejection and help offered to the demented relative is often interpreted by them as interfering. Many family members become guilt-ridden and remorseful after the diagnosis is made due to previous expressions of anger and resentment to their ill relative (Chenoweth & Spencer, 1986).

As the disease progresses, both supportive "hand-on" caregiving, and supervision/monitoring of potentially hazardous behaviours is necessary. This requires the caregiver to interfere with the dementing person's behaviours, at the point in the disease when insight into their decline in functioning and need for help is lost. There is often reluctance and refusal to accept assistance. In providing help, the caregiver becomes representative of the dementing person's growing incompetence, and intense emotional interactions are common. The protective caregiver is caught in a dilemma between trying to maintain their

relative's self esteem and remaining abilities, and
controlling potentially dangerous activity like driving or
wandering away (Gilleard, 1984; Mace, 1981).

Researchers unanimously report the enormous and
prolonged demands placed on family caregivers, and document
adverse effects.

Physical and mental health suffers. Caregivers report
illnesses resulting from exhaustion and stress as well as
injuries resulting from the physical tasks of caregiving.
Male caregivers tend to die prematurely of stress-related
disease (George & Gwyther, 1986). Studies report high
levels of depression among caregivers, especially wives
(Fitting et al., 1986), and that many caregivers feel angry,
guilty and are grieving. Caregivers show three times as
many stress symptoms as non caregiving matched peers, and
report lower life satisfaction. They use more psychotropic
drugs, and alcohol (George & Gwyther, 1986; Rabins et
al.,1982).

Closely related to mental health is time spent in
recreation and social activity. Caregivers lose friends,
give up hobbies and become isolated. These losses become
critical over time and have direct implications for higher
burden (Rabins et al., 1982).

It is estimated that between 25%-28% of nonworking
female caregivers had quit their jobs in order to care for a
demented relative (Brody et al., 1983; U.S. Congress, OTA,

1987). Significant work disruptions (lateness, absenteeism and decreased performance) were found to be associated with caregiver strain, the most important predictors being the more impaired carereceiver and perceived inadequate support to the caregiver (Schariach et al., 1991).

There is little documentation about abuse in these caregiver-carereceiver relationships, but there is a growing concern among practitioners. Joslin (1990) studied this issue by surveying family callers to an Alzheimer hot-line. Of 340 respondents, 11.9% reported they engaged in abuse while providing care, and 33% said they were abused by their carereceiver. Abuse was associated with more years of caregiving, lower patient functional state, higher caregiver depression, and premorbid history.

In very human terms, Novak and Guest (1988) summarized their findings of a caregiver burden survey. "Caregivers want to live like other people they know. They want to go for a walk, go to the hairdresser, socialize, do volunteer work....." They do not want to go out more with their ill spouse, or have friends in more. They want to do normal activities.

Chapter Four

SERVICES AND PROGRAMS

Service Needs

Many caregivers fulfil their role for years without the value of outside information, services or support. Fortunately, a growing number of services is now available for caregivers of persons with Alzheimer disease, such as support groups, in-home respite care, specialized adult day care, and information and referral services (Fortinsky & Hathaway, 1990). However, given the documented underutilization of formal services by these caregivers (George & Gwyther, 1986; Caserta et al., 1987), the task of better understanding service needs is great. The literature suggests the following program considerations for caregiving families:

(1) Caregivers need to understand the disease and its impact in order to increase their ability to problem-solve caregiving situations (Cohen & Eisdorfer, 1986; Zarit, Orr & Zarit, 1985; Mace and Rabins, 1981; Marples, 1986).

(2) Counselling and support groups may decrease feelings of loneliness and being misunderstood, and help caregivers better adapt to the demands of caregiving (Gwyther & Blazer, 1984; Harel & Townsend, 1985; Scott, Roberto & Hutton et al., 1986).

(3) Families and respite care staff both report that respite from caregiving plays a vital role in reducing family stress (Zarit, Todd & Zarit, 1986).

Caregivers experience stress either when they cannot manage the impaired person's behaviour, or when they feel isolated and unsupported (Zarit et al., 1985).

When Stephens et al. (1991) compared 'hassles' experienced by family caregivers of demented persons in home to those continuing to provide care in the nursing home, they reported the 10 hassles most frequently listed by both in home and nursing home family caregivers. Five involved care recipients' cognitive limitations (confusion, forgetfulness, mental decline, agitation and lack of cooperation), three involved providing assistance with activities of daily living, and two involved care recipients' behaviour problems. Thus it appears that the hassles associated with confusion and disorientation of dementia are salient features of the caregiving experience.

Smith et al. (1991) identified pressing problems of caregivers from a survey of 51 family members recruited through media and agency campaigns. Of 134 problems listed, the most pressing problems are summarized.

(1) Coping skills: time management, especially giving up social/recreation activities for caregiving; dealing with stress and anxiety and trying to find personal coping mechanisms.

(2) Family issues: lack of time, and conflict with other family relationships, especially husbands, siblings and their own children.

(3) Elder's Care Needs: emotional/behavioral, especially elder's affect, cognitive problems, and their elder's relationship with others; physical and safety concerns; and legal/financial concerns.

Fortinsky and Hathaway (1990) were interested in understanding if needs change through the course of the disease. One group of caregivers were asked to think about the time period when their relatives were diagnosed and consider what information or services they would rate as helpful to them at that time. They then asked current home caregivers to rank the information or services most important to them. Previous caregivers stated that early in the disease they priorized written material about AD, AD support groups, personal or family counselling, training workshops, education videos and training of non physician professionals as their main needs. Current caregivers reported their first priority need was for in-home respite care, followed by personal or family counselling, training workshops, overnight respite care, telephone hotline and specialized adult day care for the impaired person. It was found, quite clearly, that the perceived needs of caregivers changed through the caregiving experience.

There are special issues for the demented person living

alone. Caregivers, mostly adult children, provide an average of 15.3 hours per week providing or arranging care. Their primary concerns for their parents include inadequate dietary habits, unsafe and/or inappropriate behaviour, driving, using appliances, and allowing strangers into their homes (Ebbitt et al.,1991).

Legal issues compound the difficulties of caring for a mentally impaired person (Cole et al., 1986; Mace & Rabins, 1981). Persons with Alzheimer disease will become mentally incompetent and if a Power of Attorney with an enduring power is not obtained while the person is still competent, family members must apply to the courts for private committeeship. Not only is there significant expense involved, but the committee must present financial accounts to the courts annually. Many families are intimidated by the legal system. Even then, a private committee has no authority or "guardianship" of the "person", only the estate. Family members, then, have no legal right to make health care decisions on behalf of their demented elder.

Being a relative of an institutionalized resident is a new role for most family members, and they may need help coping with it. Placement in a personal care home is a difficult decision and it takes time to make; often families have tried everything else first. Some families feel sadness and grief, or have mixed feelings of relief, and guilt for wanting relief. Others feel angry that there is

no other choice. Family members may disagree on the need for this step. Then as family members witness the impaired person trying to adjust to their new life, there are often intense feelings of sadness and anxiety (Hayter, 1982; Mace & Rabins, 1981).

Interventions

Group interventions constitute the primary method of service for family support programs (Clark & Rakowski, 1983; Gallagher, 1985; Toseland & Rossiter, 1989). Most programs offer some combination of emotional support, information about the disease, and caregiving strategies, but program goals and methods vary considerably.

Greene & Monahan (1989) studied caregiver support groups and found that the caregivers with the greatest amount of burden and stress prior to entering the program experienced the greatest improvements.

Toseland and associates (1989) compared caregivers in professionally led groups, peer led groups and those not attending support groups, and found group interventions helpful. All participants were satisfied and showed improvements compared to those not in groups. Group caregivers showed improvement with their relationship with carereceivers, increased informal support networks, increased knowledge of community services, and improved self-appraisal of changes in handling caregiving demands.

They also showed fewer psychological problems, and more support from family members. Similar results were produced by Kahan et al.(1985).

These researchers did not find any differences in burden measures, even though other measures showed significant benefit. They argue that the benefits of these programs will not be proven by focusing on standardized global measures of psychological status, but rather on "micro" outcomes.

Groups for the purpose of education and training may be preferred by male caregivers and professional daughter caregivers (Davies et al., 1986; Mathew et al., 1990; Wasow, 1990). Robinson (1991) and Whitlatch (1990) found there were benefits to family caregivers who had training such as reduced anxiety and depression, more time to themselves and more time for friends and relatives. According to Cole and associates (1986), family education groups which focus on management techniques can be a valuable asset to individual problem-solving.

Evaluations of family support services to individual caregivers are reported much less frequently. Montgomery & Borgatta (1989) found relatively few differences when comparing the impact of five treatment formats, including individual and group formats. Goodman and Pynoos (1990) randomly assigned subjects to either a peer telephone network, or a taped telephone lecture series. Participants

showed information gain and increased perceived social support regardless of which treatment they received.

Zarit et al. (1986) and Cole et al. (1986) agree that individual counselling is important. Caregivers need their immediate questions addressed, and an opportunity to express their feelings of frustration, grief, anger and resentment. Individual counselling assists in decision-making, problem-solving and long term care planning. Zarit regards individual counselling as a necessary first step to be followed by family meetings (to restore balance to the system), and support groups (to share experiences and suggestions for coping and care). Zarit recommends, rather than focusing on dementia as a disease that cannot be cured, that interventions stress those aspects which are manageable.

Social Interventions

The need for relief from constant supervision is consistently expressed by caregivers. The request for in-home respite care is one of the most frequently requested services (Heagerty et al., 1988; Gilleard, 1984). Families are not confident, however, that in-home workers provide appropriate care, and have particular concern related to the ability of the service provider to understand and accommodate the needs of the dementia patient (U.S. Congress, OTA, 1987, 1990). Caregivers complain of poor

continuity of care due to high worker turnover and/or many different home care staff for the demented person to relate to and trust. Caregivers also state that when workers are there, they often provide no real care, but 'sit and watch the demented person doing nothing'. They also report theft, neglect and lack of dependability as problems with home care staff. Wallace found evidence of racial prejudice towards home care staff from family caregivers as another dissatisfaction with home care staff (Wallace, 1990; U.S. Congress, OTA, 1987). Families may also be concerned that the acceptance of in-home help means relinquishing family control to strangers (Gwyther, 1989).

In a study which examined caregiver evaluations of respite care provided out of the home compared with in-home respite, Berry et al.(1991) found they prefer in-home care. For day care respite, time spent caregiving was increased by having to get the person ready to go out and re-orienting them back home. This is in addition to routine tasks. Time spent caregiving was reduced for those who had in-home respite, when the worker substituted by providing the routine care the family member would otherwise provide.

The present challenges are to link caregivers with available services to preserve their own health and well being, as well as to continue to develop appropriate services for caregivers and persons with Alzheimer disease.

The issue of what interventions best support and assist

caregivers is of great interest. The research in this area is very much in the formative stage, and models for service delivery across the continuum of the disease have not yet emerged. Although research has begun to identify whether "caregiver stages" in level of burden are discernable (Chenoweth & Spencer, 1986; Novak and Guest, 1989; Stoller & Pugliesi, 1989), the longitudinal perspective has not been pursued adequately. There is a lack of understanding of caregivers' formal information and service needs and utilization through the course of the disease.

We still may be limited in understanding effective interventions to assist caregivers. First, studies have emphasized identifying problems associated with this group as a necessary beginning to developing interventions based on caregiver needs. Secondly, those in the middle or late stages who are in a program are most commonly studied, and needs associated with those attending a group may be different from the needs of families in the early stages.

However, all that we know about caregivers presents a picture of difficulties in providing care. In light of the absence of a cure or an effective treatment of the disease, the costs of providing care, and the apparent willingness of families to continue to provide care, service providers must seek answers to the current questions about which services, and therapeutic modalities are best suited to caregivers.

Chapter Five

THE ALZHEIMER SOCIETY OF MANITOBA

The Alzheimer Society of Manitoba began in 1982 as a
self-help group, and became an incorporated organization in
the same year. The following mission statement was adopted:

> "The Societe Alzheimer Society Manitoba Inc.
> exists to promote support, education, advocacy
> and research among Manitobans in order to alleviate
> and eradicate the effects of Alzheimer disease
> and related disorders."

As a result of obtaining 3 year block funding from
Health and Welfare Canada in 1984 (Health Promotions
Directorate), the first Canadian Alzheimer Family Resource
Centre was established as a demonstration project. The
project staff were the program coordinator, volunteer
coordinator and a support staff, and their activities
supported the mission by establishing family support groups,
information packages and public awareness campaigns. The
demonstration project was positively evaluated and a Board
decision to continue and expand the Resource Centre ensured
ongoing support to families.

Today, the Provincial staff consists of the Executive
Director, Directors of Programs and Fund Development, an
assistant to fund development, 2 support staff, and
bookeeping support. Two regions have Regional Directors

(part-time), and Winnipeg has 1 Program Coordinator (part-time).

ASM is governed by a Board of Directors with representation by family members, health care and legal professionals, and business and industry. There are two regional boards which oversee the staff activities in Westman region (Brandon), and South Central region (Winkler). Standing committees of the board include Executive, Nominating, Program, Research, Advocacy and Fund Development. ASM is affiliated with the Alzheimer Society of Canada.

ASM is funded primarily by funds raised through its own efforts. A small sustaining grant ($25,000) from the Manitoba government, and project funding from governments, foundations and service clubs comprise the only additional revenue in the $ 450,000 yearly operating budget.

ASM Family Support Programs

Description

The overall goals of the family support programs were established for the initial demonstration project, and have not changed. The goals consist of (1) educating families about the disease, effective management and coping skills, and community resources, and (2) providing emotional support. It is assumed that by promoting the health of caregiving families, people with Alzheimer disease would

also benefit indirectly (Shell, 1986). The program components are as follows.

(1) Information and Education Services

Information and Referral, Family Information Kits, Resource Library, Public Information Meetings and Caregiver Workshops.

These services were developed to provide accurate information about Alzheimer disease and its impact, and available resources to promote increased understanding among family members.

Public Meetings often attract family members previously not known to the Society, and provide an entry point for new clients to other Society services.

Caregiver workshops focus on specific topics or issues related to family caregiving. Specialists in the field provide education and specific skill teaching, for example, in stress management, managing behaviour and legal issues.

(2) Family Support Groups

The objectives of family support groups are to increase members' knowledge of the disease, and its impact on their relatives, to provide emotional support, and to provide opportunities for family members to share experiences and learn from one another. The groups allow members to be "helpers" as well as to receive help. Many individuals form new friendships, and have continuing relationships.

Groups are typically co-led by a trained volunteer and a volunteer, or staff who has professional background (social work, geriatric nursing). Groups are open-ended, and meet once or twice each month as decided by the group.

There are five groups in Winnipeg, meeting at different locations around the city, and approximately 80-100 family members are involved. It is unclear to Society staff why family support groups appear to be underutilized, meaning very few families known to ASM use groups (under 10%).

(3) Individual/Family Counselling

While family support groups have always been available to families in Winnipeg, relatively few known clients participate. Four years ago, staff began to focus on developing more organized and systemized work with individuals and families in order to expand options to families who, for some reason, were not attending groups. Client records were established to try to provide some continuity of support to families, and, in a very informal study, 60 families were provided follow-up telephone calls. Nearly all of these families desired closer contact with the Society, and over one third were assessed by staff to be very depressed, trying to manage moderately demented persons with little or no relief, and not knowing how to get more help. Based on these findings, follow-up and individual and family counselling began to be offerred.

Staff view this program as very important, but it has been one beseiged with difficulty due, primarily, to lack of resources. While intake has remained fairly stable at approximately 400 new families per year in Winnipeg (for the past 4 years), due to the progressive and long-term nature of the disease, families require ongoing help and needs and demands for services have an accumulating effect on service demands.

Currently, the Winnipeg program is staffed by 1 part-time social worker, who supervises 3 volunteer family callers. The program, therefore, does not provide ongoing counselling and training, but focuses on providing information, referral and limited supportive counselling. At present, there are 245 families in Winnipeg who require follow-up, which will be delayed for several months.

A further difficulty in this program is an inability to articulate clearly theoretically based practices used, or models of intervention for this target group. As a result, specific intervention goals of clients are not formulated.

(4) Other Programs

(a) Wanderer's Registry: Families and personal care home staff register impaired persons with local police (municipal or RCMP) to avoid the 24 hour waiting period to declare an individual missing, and to begin searching immediately.

(b) <u>Brain Tissue Recovery Program</u>: To assist families to participate in bio-medical research, and confirm the diagnosis.

(c) <u>Familial Alzheimer Disease Registry</u>: To assist families to participate in research where the disease appears very closely related to genetics.

(d) <u>Annual Family Pot Luck Dinner</u>: A social evening for families and their impaired relative. This event has not been well attended for 2 years and may be discontinued.

<u>Clients</u>

Clients of the support programs are defined as primary caregivers and family members of people with Alzheimer disease. The Society categorizes clients according to their relationship to the impaired person, and their role - primary caregiver or other family member. It is thought that the experiences and difficulties may be somewhat different for different relationships and roles.

Perhaps 10 to 20 individuals per year who may have, or who are diagnosed with Alzheimer disease contact the agency for information and assistance. To date, victim services are not generally offered, although few, if any, services exist for mildly demented persons. The Society is presently strategizing how best to serve this group.

<u>Records</u>

In Winnipeg, basic client files are kept. These record the relationship of the caregiver to the impaired person,

the nature of the contact, services used and collateral
contacts.   The filing system is manual, including flagging
follow-up contacts and schedules.   All file entries are
hand-written, and may or may not be very accurate, in that
all contacts are not necessarily recorded, especially if the
client talks with a support staff.

An information system is currently being developed to
provide program costs on a regional basis, but at the moment
it is not possible to identify program costs for Winnipeg.

Likewise, the Society has limited capacity to produce
program statistics on an ongoing basis, and data collection
is done manually.   Annual reports are compiled based on
numbers served, and services provided.   Missing is
information about usage patterns, and client profiles.

Implementation

It is believed that clients are typically self-
referred, and requesting information about the disease, and
resources and/or are in crisis and feeling desperate for
help.   A staff person, or volunteer begin information and
referral services immediately.   Usually, this initial
contact is followed up with written informational materials -
the Family Information Kit.   Other services are discussed,
particularly the family support group and caregiver
workshops, or they are invited to an individual or family
session with the Social Worker.   These families are followed
in 3-4 weeks (ideally), and, if appropriate,

regular contacts may be arranged.

When professional staff are unavailable, support staff may make case disposition decisions. Differences in recording is noticed, and differences in what is done is noticed. Support staff send the caller written material about Alzheimer disease, while professional staff respond to immediate questions, and assess needs. If required, services are started immediately followed by providing written material.

Staff report that clients express concern about gaps in service, particularly victim services. Clients are concerned about inadequete services like receiving proper medical assessments and diagnoses, helpful legal advice, and trained home care staff. Clients are also concerned about waiting periods for services like community and home care services and Society services.

Evaluability of the Program

Definition of Program Evaluation

Program evaluation research is an effective means of collecting and summarizing information for the purpose(s) of policy development and implementation, program planning and service delivery.

Rossi and Freeman (1989) view evaluation research as collecting, analyzing and interpreting information to

understand the need for, implementation of and impact of interventions to improve social conditions and community life. Rutman (1977) presents evaluation research as a process linking inputs to outcomes using reliable and valid scientific methodology. Yet another dimension is outlined by Weiss (1973) and Hasenfeld (1983) which conceptualizes evaluation research as an operation which takes place within a polictical and economic context. Evaluation research, then, has important elements in that it is purposeful, has a value base, applies scientific procedures, occurs within a context and is a means of producing change.

Foci of Evaluation

The nature of evaluation is determined, in part, by its focus. Programs are evaluated, not necessarily in terms of their service area, but according to the stage of practice or program development (Rossi & Freeman, 1982; Tripodi, 1983). Neilson and Turner (1983) adopt an evolutionary process which implies that as programs and their contexts evolve, so should the evaluation design. Rossi and Freeman (1989) identify three classes of evaluation research:

> "analysis related to the conceptualization
> and design of interventions, monitoring of
> program implementation and assessment of
> program utility" (p.33).

In the early stages of program development, evaluative efforts are devoted to describing the causal, intervention and action hypothesis, the target population and the

delivery system design (Rossi & Freeman, 1989). Program
monitoring, the second class of research discussed by Rossi
and Freeman includes focusing on program coverage, bias or
differential participation in programs (Dutton, 1978),
process studies (Thorner, 1979), and examinations of
delivery systems elements like accessibility (Lebow, 1983).
Program monitoring is an important means of examining
established programs (Rossi & Freeman, 1989).

The assessment of program utility encompasses summative
or outcome models: the evaluation of program effectiveness
and program efficiency. A clearly articulated program
should connect the intervention to its purpose to determine
if the services are having the desired effects.

Evaluable Program Model for ASM

It is premature to conduct an impact evaluation of the
interventions within the components of the family support
program. According to Rossi and Freeman, and Tripodi, a
major prerequisite for assessing impacts is that the program
be sufficiently well implemented to ascertain that the
important elements of the program have been delivered to
appropriate targets. The Alzheimer Society does not have
enough information about who is served, and what services
are utilized to justify this effort.

As a result of the above, a formative evaluation is
utilized for this practicum, and defined as a dynamic

process where information is added and organized systematically, and analyzed. This process provides the basis for deciding whether to continue, terminate, modify, refocus efforts or link phases of the program differently (Carter & Wharf, 1973). This is useful for shaping and developing the program. Monitoring is a vital part of program evaluation activities, and failure to monitor adequately may jeopardize programs when they are put in place on a larger scale (Rossi & Freeman, 1989).

As Patti (1983) suggests, there is a tendency among human service professionals to foreclose on the types of services provided while outcomes are relegated to secondary importance. There is a danger that client needs become defined in terms of services provided rather than the reverse. Researchers have documented the underutilization of formal services by family caregivers (George & Gwyther, 1986; Caserta et al., 1987). Therefore, the client survey in this study was designed to measure both awareness of service and client utilization of service. Clearly, client awareness effects client utilization of service. Group interventions, in particular, constitute the primary method of service for family support programs but appear underutilized (Clark & Rakowski, 1983). This survey examined reasons why clients do not participate in groups to better understand this issue.

As suggested further by Rossi & Freeman (1989), no

matter how well planned programs may be, unexpected results and unwanted side effects often surface. Changes should be made as soon as possible if and when this is realized.

This evaluation also examined characteristics of caregivers and carereceivers to determine how ASM clients compared to caregivers studied in previous research, most of which is American. ASM relies heavily on the literature to shape programs and interventions, therefore it was important to confirm that the primary consumers of service were indeed similar to other studies - primarily caregivers were white, female and had adequate income and education.

ASM has few resources to provide family support programs. As a result, establishing priorities for casework is demanded, and identifying those caregivers in high risk situations is important. The literature discusses variables which suggest caregiver vulnerability and high stress. For example, the importance of social supports may be related to levels of burden and other well-being indicators (Zarit et al., 1980; George & Gwyther, 1986; Moryez, 1985; Gilhooly, 1984). Physical and mental health may be affected by the level of direct care provided by the caregiver to the carereceiver (Colerick & George, 1986; Zarit, 1983; Wagner, 1984).

Based on the reasons stated above, "vulnerability" or "stress" variables were identified including physical health, mental health, perceived burden, relatives' help,

friends' support, how care was managed (level of direct care provided), and the length of time the carereceiver had been ill. Survey questions were developed to determine caregivers' social support network and to determine levels of other well-being indicators.

While the role of the caregiver is described in the literature (Archbold, 1983; Pringle, 1988; Bowers, 1987), how caregivers perceive their role is rarely mentioned. I wondered if caregivers perceived their role as important or valued by others and developed two survey items to begin to explore this issue. My assumption was that if caregivers felt their role was important and valued, they would have a more positive caregiving experience.

The survey also includes a series of very specific questions designed to determine how clients of ASM were helped. The items were based on very specific issues outlined throughout the literature, for example, difficulty in obtaining a medical assessment and feeling confident with physicians (Chenoweth & Spencer, 1986), and the need of caregivers to understand the disease and its impact (Zarit et al., 1985; Mace & Rabins, 1981). These "help items" also represent the goals of the ASM family support program.

The evaluation of the ASM family support program were not comprehensive, and examined particular elements of the program only. Omitted from evaluation were comparisons of sites. The programs in Westman and South Central Regions

are just being developed and cannot be considered
established. Differences in conditions for rural
populations would also have to be considered. Costs
associated with the program cannot be calculated and
therefore were not included in the study.

Evaluation Users

The study was primarily for internal agency use, and
was welcomed by the Executive Director, the Program
Committee and the Board of Directors. The results will be
considered in future strategic planning. Results of the
evaluation will be presented to the Program Committee, and
any formal recommendations will be taken forth to the Board,
where any final program policy decisions will be made. Any
decisions concerning implementation procedures and practices
are made by the Executive Director, usually in consultation
with staff.

It is thought that the Office of Continuing Care, close
collateral colleagues, will be interested in the results of
the evaluation, as well as government funders. The
evaluation will be particulary relevant to other Alzheimer
Societies in Canada, who look to Manitoba for leadership in
this area as it is, for having established the first service
program to families in Canada. Any research participants
who wish to be informed will be provided with a summary
report of the findings.

Chapter Six

METHODS

Introduction

Models for service delivery to family caregivers are in the formative stages of research, and ASM programs are no exception. The purpose of this study is to increase the responsiveness of the ASM in addressing the needs of caregivers. An exploratory research survey provided descriptive data about who is being served by ASM, what services are being used, and how clients evaluated the services they used.

Sample

Subjects were relatives of persons with Alzheimer disease or a related dementia, or suspected of having an irreversible dementing illness. They lived in the city of Winnipeg, and used ASM services within the past 24 months. Because one purpose of the study was to determine program coverage, no further limiting criteria were used.

Subjects were identified through a systematic sampling approach; every third client of a sampling frame of 225 of the current active client list of ASM was included.

Design and Procedure

A mail survey design was chosen for the following

reasons:

(1) a larger sample could be reached compared to using face to-face interviews, given the available human resources;

(2) if respondents were active caregivers, they could choose their own time to complete the questionnaire;

(3) again, in deference to active caregivers, it is often the case that the ill relative reacts adversely to questions about them being asked in their presence. Also, caregivers often find it difficult to arrange substitute care in order to leave the home for all but essential tasks.

An introductory letter describing the purpose of the study and requesting clients' participation (Appendix II), accompanied the questionnaire (Appendix III). A stamped, return addressed envelope was also included in the mailing.

An error of omission was failure to provide a time frame for completion of the survey, which resulted in several being returned too late to be included in the study.

Another design limitation was observed. For three clients, the survey was overwhelming, or confusing. This was handled by meeting with these clients and providing assistance to complete the questionnaire. One client was visually impaired, and his responses were given over the telephone. On the whole, clients were very interested in participating in the study, and several included very supportive and positive comments on their returns. Two clients even phoned to thank me for "choosing" them to be in the study. Sixty percent are interested in receiving a report of the findings.

Research Instrument

The survey instrument included five sections. The first section elicited demographic and descriptive information about the impaired relative including sex, age, education, living location and accommodation, diagnosis and length of time ill.

The second section and the final section asked about the client including demographic information, and questions about the caregiving experience. Variables associated with the caregiving experience included how care was managed, physical and mental health, relatives' help, friends' support, feeling burdened, and how they felt their role as a caregiver was regarded.

The third section focused on questions related to ASM, how they learned about the Society, their initial contact, services they were aware of and services used, and suggestions for improving services. Clients' satisfaction with each service was rated for effectiveness, importance and frequency from 1 (low) to 5 (high). Clients were also asked about other community services used.

In section four, clients were asked to respond to 23 questions about specific ways they felt they had been helped. This section was developed for two reasons. First, it was important, and useful, to operationalize the goals of the family support program to determine clearly if the Society is providing the help intended. Secondly, it was an

attempt to avoid the more global measures recently criticized in the literature (Zarit and Malone Beach, 1986), and the "usual vague considerations of needs" (Barer and Johnson, 1990).

Questions were open ended, multiple choice or formatted to be used with a five-point Likert scale. A five-point Likert was used to increase sensitivity of the instrument and show wider variation in responses.

Due to the fact that many of the key stakeholders are previous consumers, or initiators and creators of current services, I requested the Program Committee guide the process. Their perspectives were helpful in clarifying and describing program intents and objectives, and their experience helped refine the research instrument. It was also thought that by some ownership in the project as it unfolded, that any service related recommendations resulting from the evaluation would be utilized.

This process helped in establishing face validity of the instrument. Conceptualizations of the items were well grounded in the literature, and items were constructed based on the expertise and clinical experiences of myself and experts in the field. Content validity was also established by having eight former caregivers complete the questionnaire, and modifications were made as a result of this process.

Consumer Satisfaction/Consumer Feedback

The survey instrument in this study included questions which requested clients to rate their level of satisfaction of ASM services they have used. It is acknowledged there are difficulties associated with consumer satisfaction surveys. The lack of standardized satisfaction scales prevents establishing baselines and making comparisons between programs or within programs (Larson et al., 1979). Many researchers have also found an overly high reporting of client satisfaction (Kaufman et al., 1979; Denner and Halprin, 1974). Gutek (1978) explains this by suggesting that individuals tend to rate their own life experiences more highly than they rate the experiences of others.

Locker and Dunt (1978) suggest that respondents tend to be more critical when asked specific questions about the service they have received, and suggest the use of a multi-dimensional scale rather than a dichotomous (satisfied-dissatisfied) scale. In this study, this principle was utilized. Also, respondents were asked if they were helped in specific ways rather than asked if they were satisfied with a certain service. This may have assisted respondents better understand the relevance of the items and focus more on their experience.

I also focused on specific items which I felt were important to caregivers, which, according to Kaufman and associates (1979) encourages real involvement in evaluating

the services they have received. The findings in this study show good variation in responses, particularly in the "help items" section.

According to Lebow (1983) and Marin (1980) consumer feedback is useful to identify service delivery problems including the continuity, availability and accessibility of services. Consumer feedback is also used to better understand the adequacy of services, the surrounding milieu, and reactions to the quality and helpfulness of services. The findings of consumer feedback surveys can assist program planners to identify unsatisfactory programs which may be discontinued, and to identify needed programs which may require maintenance or adjustment. Resulting decisions to discontinue unsatisfactory programs have an additonal benefit of improving cost efficiency.

ASM recognizes family members as the key caregivers of persons with AD, and consumer feedback reinforces the premise that ASM is accountable to these caregivers to provide useful and meaningful services.

When survey items are related to concrete aspects of service delivery and caution is employed in developing response categories, consumer satisfaction feedback provides highly relevant information for program planning.

Limitations

ASM strives to provide services to clients throughout the course of the disease, therefore a longitudinal study

based on prospective data would be preferred for this conceptual approach. This study provided data about caregivers and services around the time of diagnosis and at the time of the survey resulting in conclusions being drawn from cross-sectional and retrospective data.

As is common in caregiving research, the sample for this study is self-selected, primarily white and middle class, and all are living in an urban setting, which limits generalizability of the findings. Even though a random sample of ASM clients was used, it is not possible to identify the population of people with AD. Family members may not seek Society services, and those in the very early stages may not be identified as ill. Clients of ASM have actively sought information and services which cannot be assumed to be random behaviour.

The "caregiver" has been defined very broadly, even though it is acknowledged that caregivers are not a homogeneous group. This flexibility is tolerated in this study due to its formative nature. One main purpose is to describe client characteristics.

While the study examined social supports, and items of help in providing care, the responses were solely from the client point of view. Persons in their social network were not consulted to confirm clients' perceptions, nor were carereceivers studied to determine their subjective experiences, or to determine if help received by the

caregiver met the carereceiver's needs.

Analysis

Within the above noted constraints, the following analysis was conducted.

Descriptive statistics were used extensively to produce information on caregiver and carereceiver characteristics, and use and satisfaction of services received.

As underutilization of family support groups was a question, in addition to asking why client did not attend groups, further exploration was done to try to gain some sense of who did attend groups. Variables thought to be associated with vulnerability or stress (accommodation of carereceiver, how care is managed, physical and mental health, feeling burdened and relatives' help and friends' support) were examined in relation to attending a group. Chi-square analysis was used when making comparisons between nominal variables.

The "help items" were analysed by describing the overall help received by clients, and by comparing if there were differences when the help was provided by a professional staff, a volunteer, or a family support group. Mean scores were calculated for each item, however, it became important to also calculate and report the mode as a further indicator of help received.

The "help items" were further analyzed to determine any

associations between the vulnerability or stress variables,
and among the "help items". Pearson product moment
correlations were used.

Chapter Seven

RESULTS OF ASM REVIEW OF SERVICES

Introduction

The program evaluation examined areas related to family
support programs of ASM including caregiver demographic
information and issues associated with the caregiving
experience, demographic and descriptive information about
their impaired relative, clients' awareness and use of ASM
services and their evaluation of the services used, and
information on how clients were specifically helped. Major
findings of the survey are reported and discussed in this
chapter.

Sample

A total of 203 surveys were mailed to clients of ASM in
Winnipeg of which 10 (4.9%) were returned as present address
unknown. Not included in the study were 2 (.9%) which were
returned but not completed, 1 (.4%) where the client tried
to describe two carereceivers in the survey, 1 (.4%) where
the client tried to describe two caregivers on the survey,
and an additional 17 (8.4%) who returned the survey after
the report was written. Of the 203 surveys mailed, 46.7%
did not respond, and 76 (37.4%) participated in the study.

A separate review of the 17 surveys returned after the

report was written was completed to determine if the responses from this group effected the overall results of the study. Of the 17 reviewed in this group 13 (76%) were female and 4 (24%) were male. Their ages ranged from 42 - 73 years with a mean age of 53.6 years. Further demographic information was examined and were compared to the sample group. No significant differences were found between this group and the sample group.

The "stress" variables were reviewed and overall frequency of reported physical and mental health difficulties would have been somewhat higher if this group were included. The health profiles of men and women were the same as the sample group.

Further similarities between this group and the sample group were found. In both "services aware of" and "services used", the four services most frequently reported were the same as those reported by the sample group. Based on this analysis, it was determined that the responses of this group would have no significant effects on the overall results of this study.

Caregivers

The sample was composed of 76 family members. Respondents ranged in age from 26 to 82 years, with a mean age of 54.9 years (sd=14.14). Spouses mean age is 69.8 (sd=8.66) and 46.0 mean years (sd=8.76) for adult children. Further demographic variables for caregivers are presented

in Table 1, which shows the participants in this study are comparable to other studies. Most participants are women, most are quite well educated and most have adequate income. Racial and ethnic distribution of this group of consumers does not appear representative of the multi-cultural nature of our current society.

Of the female group (77.3%), 19.7% are wives, 50.0% are daughters or daughters-in-law, 1.3% are sisters and 2.6% are nieces. The male group is 14.5% husbands and 11.8% sons. Where the ASM client is not the spouse of the ill person, the spouse is deceased in 63.2% of situations, or unable to provide care due to ill health (10.2%). In 26.5% of situations, the spouse is providing care which suggests that adult children may have roles like negotiating with agencies and/or seeking information and help on behalf of spousal caregivers. Of the total group, 22.7% report providing no caregiving tasks (male = 11.8%; female = 88.2%); 40.0% provide some direct care (male = 36.7%; female = 63.3%); 18.7% provide most of the care (male = 7.1%; female = 92.9%).

Table 1. Demographic Variables for Caregivers (n=76)	
Variable	Value
Age (M years)	54.9
Gender (%)	
Male	22.7
Female	77.3
Group Identification (%) (5 most reported)	
Canadian	65.8
British/English	12.3
Russian/Ukrainian	4.1
French	2.7
Asia/Oceanic	2.7
Education (%)	
Less than highschool	5.3
Some or all highschool	29.3
Post secondary	65.3
Post graduate	6.7
Family Income (%)	
Under $20,000	18.8
$21,000 - $40,000	32.8
$41,000 - $79,000	48.5
Over $80,000	12.5
Employment (%)	
Employed outside home	45.3
Not employed	54.7
Employed part/full time (%) n=33	
Part time	27.3
Full time	72.7
Religious Services (%)	
Attend on regular basis	43.1
Do not attend	56.9

Those who reported providing all of the direct care were 18.7% of the total group (male = 42.9%; female = 57.1%).

Physical health problems as a result of caregiving were reported by 65.8% of respondents, and primarily were stress related ailments like high blood pressure and more infections resulting in flues, colds and pneumonias (76.0%), followed by a worsening of existing medical problems (14.0%)

and chronic fatigue (6.0%). Spouses reported more medical health problems than children, and men more than women.

Mental health problems were reported as much as physical health problems (63.5%), with 100.0% reporting depressive symptoms like feeling depressed, anxious, crying more and suffering from insomnia. When compared to spouses, children reported more depression (66.0%) and women (70.2%) much more than men (27.7%).

Very few reported they did not feel burdened (19.2%), and most felt somewhat burdened, burdened and very burdened (80.8%). Men reported feeling the least and women and children the most burdened.

Physical and Mental Health of Caregivers

I was interested in understanding if there were variables associated with physical and mental health, two key indicators of the stress of caregiving.

The results of cross tabulation did not support a relationship between physical health of the caregiver and accommodation of the carereceiver, or between physical health of the caregiver and the level of help received from relatives, or the level of support received from friends. A relationship was found between physical health and how care was managed (ChiSq.=20.05, p.<.01, gamma=.563). The more direct care provided, the more physical health problems were experienced by the caregiver. While the literature suggests physical injuries are also commonly reported by caregivers

providing direct care, this was not reported in this study. Further, those who experienced physical health problems were also likely to experience mental health problems (ChiSq.=16.431, p.<.01, gamma=.814). Providing direct care to a person with dementia puts the caregiver in a higher risk category for physical health and mental health problems. Assisting the caregiver to decrease the amount of time spent in direct care would seem an appropriate intervention goal in these cases.

Length of Time Ill

In this study persons with Alzheimer disease had been ill anywhere from 1 to 14 years representing the full process of the disease in most cases. It was thought that physical health and mental health, how care was managed and the accomodation of the carereceiver would change as the disease progressed. However, when cross tabulations were run for the above noted variables and length of time ill, no relationships were found. Some caregivers maintained their physical and mental health regardless of how long their relative had been ill and, presumedly regardless of how long they had been providing care. Some caregivers provide care at home very late into the disease while others place within the first few years of the disease. Further, there was no evidence of a pattern developing in terms of caregivers increasing their direct care as the disease progressed.

Social Network Support

More than half (52.2%) found their relatives helpful to some extent (27.4% somewhat helpful, 15.1% helpful and 13.7% very helpful), but 43.8% did not find other relatives helpful. Friends, in comparison, are described as somewhat supportive, supportive and very supportive by 85.3% of respondents. Only 14.7% found their friends not to be supportive. This finding was higher than expected as the literature stresses the social isolation experienced by most caregivers. While friends do not necessarily provide direct care to the person with AD, they may assist the caregiver normalize the milieu of the situation by participating in social/recreational activity. Close friends can provide social peer support, and remind the caregiver of his or her identity beyond the role of caregiver.

Even though over half of the clients found their relatives helpful, 59.1% wanted more help from relatives. Of this group, 72.5% would not feel comfortable asking for more help. In 27.5% of situations there were no other relatives, or relatives lived too great a distance away to be of much help. Several reasons were given to explain clients' discomfort in asking for more help. Many felt relatives were too busy with their own families and other responsibilities (30.0%). In some cases, clients had requested help, but had received none (20.0%), and felt they would not ask again. A few (7.5%) felt they should not have

to ask for help; help should be offered. 15.0% felt the care of their ill relative is their responsibility, and that other family members should not be burdened.

Some reasons for the stated discomfort of clients in asking their relatives for more help may include issues of family conflict and/or the quality of pre-morbid relationships among family members. Some reasons may relate to dependency and control issues between parents and children, or among children. There may be very practical reasons. Families in the extended family system may well be experiencing unrelated stresses which prevent them from being involved in the caregiving or support role. In assisting the primary caregiver assemble the necessary and desired supports, issues of the extended family system must be explored and understood. Interventions designed to incude the family system should be applied whenever possible.

Attitudes of Caregivers Towards Caregiving

Clients were asked to respond to two general statements about caregiving to better understand how they perceived their role as caregivers. Almost half (42.4%) did not agree that the role of caregiver is regarded by others as important, or as having prestige and status, and 34.2% agreed somewhat. Only 23.2% agreed that the role had positive attributes in the eyes of others. Almost all clients agreed that the job of caregiving required knowledge

and experience to be done well, but most perceive the caregiving role as not being highly valued by others. The extent to which this relatively negative role perception can be interpreted is limited in this study. Overall self-esteem and motivation to continue to provide care may be negatively effected. At the very least, it must be very discouraging to be involved in the difficult situation of providing care to a demented person feeling no one really appreciates your efforts.

Carereceivers

Of the 76 carereceivers, 36.8% were male and 63.2% female. Their ages ranged from 50 to 91 years with a mean age of 76.2 years (sd=7.72). Demographic variables for carereceivers are presented in Table 2.

Level of education has recently presented some interesting questions in research. Several studies have begun to correlate less education with AD incidence (Clarfield, 1991; Katzman, 1992). The theory being developed postulates that persons with higher levels of formal education may experience a strengthening of synapse activity which may provide some defence to the disease process. While still inconclusive, researchers suggest that as education levels increase, incidence decreases. In this study, there was less representation from the highly educated group.

Variable	Value
Age (M years)	76.2
Gender (%)	
Male	36.8
Female	63.2
Education (%)	
Less than highschool	36.0
Some or all highschool	32.0
Post secondary	30.7
Post graduate	1.3
Living Situation (%)	
Winnipeg	92.1
Manitoba, not Winnipeg	5.3
Other	2.6
Accommodation (%)	
Living alone	13.2
Living with spouse	38.2
Living with another relative	3.9
Living in an institution	44.7
Accommodation prior to institution (%) (n=34)	
Lived alone	13.3
Lived with spouse	14.7
Lived with another relative	3.9
Hospital	10.7
Diagnosis (%)	
Diagnosis with AD/dementia	90.8
Not diagnosed	9.2
Age at onset of disease (%)	
41 - 50 years	2.8
51 - 60 years	9.9
61 - 70 years	23.0
71 - 80 years	51.9
81 - 90 years	10.0

Table 2. Demographic Variables for Carereceivers (n=76)

Diagnosis

Nearly all (90.8%) had received a diagnosis of AD or a dementia. A new variable "length of time ill at diagnosis" was computed, and shows that 65.7% had received a diagnosis within three years of the family first noticing symptoms. Others (26.5%) were diagnosed from 4 - 6 years after

symptoms, and 7.9% later in the disease process anywhere from 7 - 14 years.

Clients were asked who they consulted to obtain the diagnosis. General physician practitioners were consulted by 52.6% of clients, neurologists by 38.2% of clients, geriatricians by 1.1%, and psychiatrists by 13.2%. The average response for this question was 1.3 responses per person.

Services

Intake Services

It was thought that most clients were self-referred, and, in fact, 67.6% found out about ASM through media coverage, and their social network of family and friends. The remainder (28.4%) were referred by health care professionals, the highest referring group being physicians (16.2%).

Over one third (36.6%) were in contact pre-diagnosis. They had noticed changes in their family member, and wanted information and direction on what to do next. Of the 64.5% who initially contacted ASM post-diagnosis most (46.1%) initially wanted information about the disease and 18.4% wanted help in coping with their feelings.

Clients were asked to rate their level of satisfaction with their initial contact, and 10.5% reported being very unsatisfied. Most of those very unsatisfied had contact with a professional staff verses a receptionist or

volunteer. The fact that the most complex and/or crisis calls are referred to staff by support staff and volunteers may provide one explanation for this finding. As later findings suggest, though, staff must improve their assessment of client needs at intake. Most clients were satisfied and very satisfied (82.9%), whether they had a professional staff contact or receptionist or volunteer contact. Table 3 represents these findings.

Table 3. Client Satisfaction With Initial Contact			
	Total n=58 %	Staff n=26 %	Rec./Volunteer n=32 %
Very Unsat. Unsatisfied	10.5	19.2	9.4
Somewhat Satisfied	6.6	0.0	9.4
Satisfied Very Sat.	82.9	80.7	81.3

Most clients (73.3%) contacted ASM by telephone or came to the office (10.5%). The next most frequent first contact was at an educational meeting (5.3%).

Information Services

Information about client awareness and use of ASM services are presented in Table 4, and shows the general awareness by clients of services is low compared to an ideal awareness level of one hundred percent.

Table 4. Comparison of Service Awareness and Service Use				
Service	# Used	% Used	# Aware	% Aware
Family Kit	63	82.9	66	86.8
Phone Sup/Vol	36	47.4	41	53.9
Phone Sup/Staff	31	40.8	42	55.3
FSG	30	39.5	51	53.3
Wand. Reg.	23	30.3	40	52.6
Workshops	17	32	32	42.1
Lib. Books	15	19.7	42	55.3
Office Int.Staff	13	17.1	30	39.5
Videos	7	9.2	33	43.4
Pot Luck Dinner	4	5.3	24	31.6
BTRP	4	5.3	8	10.5
FAD Reg.	3	3.9	9	11.8

Note. N = 76; Responses = 418.

The goal of ASM is that clients are provided with a thorough knowledge about services, and this is clearly not happening.

The Brain Tissue Recovery Program was, in fact, very recently discontinued due to an oversupply of pathological brain tissue, and will not be discussed further beyond the observation that very few people were aware of the program while it was in operation.

The information presented concerning awareness and use of the Family Alzheimer Disease Registry is probably appropriate and can be explained by the fact that thus far, information about the FAD registry is only provided to families who are eligible to register. The criteria for becoming registered includes having a very high family incidence in at least two generations of living persons.

Client Rating of Services

Information services - information kits, books, videos and workshops - were rated as somewhat useful, useful and very useful by 90.0% of users.

Of those listed with the Wanderer's Registry, 62.5% have not had to use the service. Some (9.4%) have had police assistance over 3 times, and 28.1% have involved the police 2 - 3 times to locate their missing relative.

The Family Pot Luck Dinner has not been well attended in recent years, and two thirds who have attended would not attend again. A very low number, though, report being aware of the event.

Family Support Groups

30.2% of clients attended a family support group for approximately one year (8 - 10 sessions), or more than 10 sessions. Clients who did not attend groups, or who attended only once or twice did so for a variety of reasons: 18.4% had no need for ongoing support; 18.4% did not want to spend their free time discussing Alzheimer related problems; 17.1% found the time or the location of the group inconvenient; 13.2% do not like receiving help in a group setting; 10.5% cannot leave their ill relative alone to attend; 9.2% find listening to others' problems depressing; 7.9% have health problems which prevent them from attending; 3.9% feel too uncomfortable meeting a group of strangers by themselves; 2.6% were unable to arrange transportation.

15.8% had other reasons for not attending such as
employment, not being ready to accept the reality of AD,
other family members attended and kept the client informed,
and being reluctant to attend without the primary caregiver.
Each respondent had an average of 1.2 responses.

In an effort to understand who uses groups, cross
tabulations were run for attendance at family support groups
and accommodation of the carereceiver, how care was managed,
physical health, mental health, feeling burdened, relatives'
help and friends' support. No relationships were found.
While no association was found between those attending group
and the accommodation of the carereceiver, a visual
inspection of the table revealed that most caregivers in
family support groups had placed their ill relative in an
institution.

There may be solutions which ASM could assist with for
those (20.8%) with practical problems of transportation,
sitter services and inconvenient time or location.

All but 3.1% rated the effectiveness of group
leadership as somewhat effective, effective and very
effective, with the most giving a very effective rating.
Most felt the groups were frequent enough (78.1%) although
12.5% said they were infrequent. Most felt the groups were
important, but one quarter only felt somewhat so.

Individual Support

Individual support is judged to be both effective and

important whether it is provided by a staff or a volunteer
as is suggested in Table 5. However, when clients were
asked to rate the program for frequency, 45.8% said the
contacts were not frequent enough for both groups. This
corresponds to the assessment by staff of this program.

Table 5. Comparison (%) of Volunteer and Staff Individual Support. (Likert 1-5)				
	Effective n = 50		Important n = 49	
	Vol.	Staff	Vol.	Staff
1	0.0	0.0	4.1	3.8
2	4.0	0.0	8.2	1.9
3	20.0	12.2	46.9	25.0
4	44.0	32.7	24.5	30.8
5	32.0	55.1	16.3	38.5

Help Items - Staff, Volunteer, Family Support Groups

Comparisons of staff help, volunteer help and family
support group help were made in relation to the specific
help items and are presented in Table 6. It should be noted
from my approach that there is no real concept developed for
ideal help, therefore, these findings should be considered
areas for improvement in service verses fundamental
dissatisfaction with service.

Consumers reported receiving the least help by
volunteers overall, but volunteers provide help well in
certain areas like stress management and emotional coping,
understanding AD and the behaviour associated with it, and

in helping caregivers educate other family members. It is
clear though, that if the Society wishes volunteers to
expand their helping repertoire, additional training is
indicated.

Table 6.Client Perceived Help by Agency Service Provider						
Item	Staff n=38		Volunteer n=15		FSG n=19	
	$\bar{x}$	Mode	$\bar{x}$	Mode	$\bar{x}$	Mode
Awareness/Access Community Services						
Med. Assess.	2.90	1	2.00	1	2.36	1
Conf.Phys.	3.40	5	2.55	1	3.25	1
Obt.Home Care	4.08	5	2.00	1	4.07	5
Legal Issues	3.72	5	2.50	1	4.00	4
Conf.Lawyers	2.84	1,5	2.00	1	4.00	5
Aware Com.Res.	3.55	5	2.50	multi	3.71	5
Access Com.Res.	3.48	5	2.25	1,3	3.75	5
Advocacy	2.26	1	1.57	1	2.50	1
Conf.PCH Staff	2.72	1	2.17	1,2	4.22	5
Family Relationships						
Educ.Family	3.73	5	3.18	5	3.94	4
Res.Conflict	3.17	5	2.00	2	2.44	1
Plan Soc.Act.	3.00	5	2.00	2	2.80	2
Understanding/Managing AD						
Understand AD	4.28	5	3.62	3,5	4.61	5
Understand Beh.	4.30	5	3.30	3,4	4.27	5
Manage Beh.	3.71	5	3.00	3	3.55	5
Home Safety	3.35	4	2.86	3	3.55	5
Self - Care						
Emot.Coping	3.87	5	3.18	3,4	3.80	3
Stress Mgmt.	3.47	3	3.09	4	3.75	5
Future Plans	3.30	5	2.89	3	4.08	5
Plan Time Off	3.30	5	1.50	1	3.60	5
Dec'n To Place	2.69	1	2.25	1	3.27	5
Pers.Supp.ASM	4.00	5	2.75	3	3.75	5
Ask for Help	3.04	5	2.63	multi	3.91	5

It is noted that families do not feel they were helped in knowing how to obtain a medical assessment, regardless of the means of receiving service. The other area that families do not feel helped is in the area of personal advocacy (Item number 69 on survey: "becoming involved with other community organizations when I had trouble getting what I needed from them").

When mean scores of those helped by staff and those helped by family support groups are compared, there are few differences, both apparently offering a good level of help. The differences which do occur, though, are important.

Those in family support groups were helped with issues related to institutionalization - the decision to place and confidence communicating with personal care home staff, while those in the staff group were not helped as much. Families were also helped more by family support groups in managing their stress.

Staff, on the other hand, provided help in the area of family relationships, particularly in helping to resolve family conflicts. The other area in which staff helped more was in building confidence in communicating with physicians.

Help Items - Associations

Pearson product moment correlations were done among all help items and the variables length of time ill, how care is managed, physical health, mental health and feeling burdened. No associations were found.

When Pearson product moment correlations were done among the help items, some interesting associations were found.

The variables "understanding AD" and "educating the family" were found to be associated ($r=.934$, $p.< .001$). Once the disease is understood by the family member receiving service, the information they have gained can be shared with the rest of the family.

The variable "understanding AD behaviour" was found to be associated with "resolving family conflict" ($r=.413$, $p.< .001$) and "feeling confident with physicians" ($r=.415$, $p.< .001$). Family members who are unable to interpret or explain the behaviour of the person who is demented often attach a rational motive or purpose to their behaviour. This can result in some family members recognizing the disease process, and some not. Planning and making decisions from two points of view often result in conflict. This dynamic may also be present between the family member and the physician. When the concerned family member can interpret the disease related behaviour to the physician, the physician is provided the necessary information to begin assessment or treatment.

This finding suggests then, that when family members are helped to understand AD, and associated behaviours, they are also helped in other ways, namely, educating the rest of the family, resolving family conflict and feeling more

confident with physicians.

The correlations among educating the family and planning for the future (r=.403,p<.001), making the decision to place (r=.416, p<.001) and asking for help needed (r=.418, p<.001) were significant. When the family is educated they are helped in other ways which have to do with self-care issues including planning for the future, making the decision to institutionalize, and asking for the type of help they feel they need.

Those who had readily available support from ASM were also helped in managing stress (r=.426, p< .001) and managing AD behaviour (r=.426, p<.001), and those who were helped to manage behaviour were also more confident with personal care home staff (r=.434, p<.001) as were those who were helped to manage stress (r=.426, p<.001).

Table 7. Other Resources Used Since Relative Became Ill.		
Resource	Number	Percent
Home Care	51	67.1
Home Care (Respite)	12	15.8
Family Physician	48	63.2
Personal Care Home	28	36.8
Day Care	23	30.3
Legal Services	19	25.0
Institutional Respite	18	23.7
Police	16	21.2
Acute Care	12	15.8
Meals on Wheels	10	13.2
Day Hospital	10	13.2
Private Nurse/Companion	8	10.5
Personal Counselling	3	3.9
Public Trustee	2	2.6
Grief Counselling	2	2.6

Note. N = 76; Responses = 262.

Other Community Resources

Clients are involved with other community resources as presented in Table 7. ASM has been appropriate in targeting home care, physicians and institutional staff as primary collateral contacts.

Future Contacts

Clients were asked how comfortable they would be in initiating contact with ASM in the future if they had questions or problems. Most clients said they would feel comfortable and 85.1% felt they would contact the Society. There are, however, 14.9% who would not be comfortable.

Advice on Improving Services

Very few clients (28) offered comments or advice on improving family support programs. The three main themes families discussed were to increase family contacts (35.7%), expand information and education services (17.9%) especially to home care workers and social workers in the community and in institutions, and initiate or increase activity in the area of advocacy. Clients were concerned primarily with care services for their relative with AD, while others felt there were too few staff at the ASM, even though (many commented) they were appreciative of the help received.

Organization Affiliation

Of this client group, 52.1% were members and donors of ASM. Members are entitled to the newsletter, and 97% rated the publication as somewhat interesting, interesting and very interesting.

Chapter Eight

IMPLICATIONS OF FINDINGS ON FUTURE SERVICE PLANNING

Clients, as expected, were over two thirds self-
referred, and over one third were in contact pre-diagnosis
probably prior to coming into contact with other health care
professionals. According to this study clients had been
caregiving from anywhere from one to fourteen years which
represents the full course of the disease in the vast
majority of situations.

Most carereceivers had received a diagnosis of AD or
dementia within three years of the family first noticing
symptoms, and specialist physicians were consulted in just
over half of the situations. Geriatricians, however, were
very rarely consulted which was an unexpected finding, given
their area of specialty and their public interest in
dementing illnesses. Neurologists, the most frequently
consulted specialist, should be considered by ASM as a
special target group to become more involved with the
organization.

The sample in this study was, for the most part, white
and middle class, as is typical throughout the caregiving
literature. ASM has been unsuccessful to date in locating
and serving different racial and socioeconomic groups. An
ASM outreach project conducted in 1990 made contact with the

major identified ethnic groups, including seniors' groups,
their leaders, and health clinics in Winnipeg to discuss AD,
and any associated problems. At that time, AD was not
identified as a problem in the communities. This effort,
however, should be repeated. The results of the current
Canadian epidemiological study, as well as a separate North
American study examining AD and Aboriginal groups (who
appear to have a very low incidence of AD) will prove
helpful reference points for further outreach projects.

Previous studies point to the importance of social
support in maintaining or improving caregiver well-being,
and Gilhooly (1986) found relatives' help was significantly
correlated with mental health ratings of caregivers. This
study did not support this finding.

Over half of the caregivers in this study wanted more
help from their relatives, but very few felt comfortable
asking them. The reasons for this reluctance, like
requesting help and receiving none, and waiting for help to
be offered might suggest areas of family conflict which
could possibly be resolved through family (or multi-family)
counselling.

The fact that most caregivers in this study perceived
the caregiving role as not being highly regarded by others
is very unfortunate, and may be explained by feelings of
depression and burden, and experiencing few rewards for
their hard work. There may be other explanations. Most

public information and educational materials stress the sadness, hopelessness and difficulties associated with the disease, as does fundraising material. It is possible that this media environment only reinforces negativity to these caregivers, who also need the opposite message. The ASM could be a leader in developing materials acknowledging and encouraging the positive and essential role of family caregiving.

Caregivers of persons with dementia are not a homogeneous group. Differences have been noted, for example, between spouse and child caregivers, male and female caregivers, and employed and not employed caregivers (Brody, 1985; Montgomery, 1988; Stone et al., 1987; Lang and Brody, 1983). Similar differences were found in this study. Spouses and men reported more medical problems than children. Children and women had more depression and felt more burdened than men. To recognize the heterogeneity among caregivers is to recognize that programs providing services for caregivers must be flexible enough to individualize strategies and approaches. According to Chappell (1989), this is especially true for caregivers of persons with AD.

The ASM has expanded the more traditional Alzheimer society service offerings by providing a wider range of options including public meetings, caregiver workshops, family support groups and individual and family education

and counselling. This means clients have some choice in
addressing their needs, whether they are information or
education, skill acquisition and/or emotional support, or
whether they prefer group or individual services or a
combination of both. There is agreement in the literature
that this service mix is appropriate (Chappell, 1989; Zarit
et al., 1986), and ASM is one of the only Canadian societies
providing the individual component. The range of service
options is a real strength of the program.

Weaknesses were found in implementation, however.

The general awareness by clients of available services
is relatively low, which makes drawing firm conclusions
about utilization patterns difficult. Even though clients
are generally satisfied with services received, it is
important to develop better methods to disseminate
information, and perhaps most important to ensure clients
receive and understand the information. During the initial
contact, clients have many immediate issues to address,
especially understanding the disease and resulting
behaviours, and perhaps cannot make use of all the
information provided. Family information kits provide a
great deal of information addressing many issues. From a
purely logistic rationale, kits are standardized. This
should be re-evaluated, and effort made to individualize the
information to some extent. A full review of contents of
the kits is in order. Initial and follow-up telephone

contacts also provide the opportunity to review service options on an ongoing basis, and staff and volunteers need to be sensitized to the issue of the need for increased awareness of clients for program information.

Individual Support

Adequate and accurate assessment is critical if clients are to be matched with appropriate services of ASM and/or external resources. Specific intervention objectives must be consistent with the needs of clients, or interventions will not be successful. The intervention objectives must also be consistent with the goals clients have for themselves. Many clients initially report they have no need for ongoing support, and this is currently being taken at face value, and these clients become lower priority cases for follow-up. Closer examination is necessary as initial low reports of distress may in fact indicate an inadequate assessment of their problems and concerns. Particularly in the area of dementia, clients may need to be informed of issues which most families face before they can accurately perform self-evaluation. This is not to say that the assessment process should talk clients into problems they do not have; rather, it should raise the issues and specifics about coping with dementia which are still held primarily in the professional journals, and have not reached the popular press. Further, the process of assessment overlaps with

beginning intervention, resulting, quite often, in the beginning intervention helping the client feel more free about expressing stress levels and issues of concern.

The issue of assessment is, in my opinion, the key developmental issue for ASM. At present, there are obstacles and limitations in providing appropriate assessment.

Limited staff resources for Winnipeg programs is a major obstacle in providing adequate and timely assessment, as well as ongoing services. Expansion of the Winnipeg program is indicated. In addition to increasing staff time creative strategies will have to be employed, such as developing fundable research/developmental projects, increasing the skill levels of volunteer workers, encouraging more student involvement from appropriate disciplines, and continuing to recruit volunteers who are professionals to assist the effort.

Missing is an articulated theoretical approach to practise, and a well developed service model. The Stress Management and Problem Solving Model offered by Zarit or Ellis's Rational-Emotive Therapy would be worthy of consideration.

For clients who are not in distress following assessment, a program model based on prevention may prove beneficial. A "Course in Family Caregiving" would be an example.

Conversely, interventions designed for highly distressed clients must meet their needs. This study identified caregivers who provided the most direct care as being more at risk for health problems. This is the type of information which would suggest the client is at risk and would require more intensive help. Closer monitoring of police assistance via the Wanderers' Registry might also identify more high risk caregivers, and caregivers having real difficulty managing behaviour. As this study suggests, staff have an important role in helping with emotional coping and resolving family conflict. The availability of ongoing support to the caregiver was also shown to assist in managing stress and managing AD behaviour.

Family caregivers provide the most care to persons with dementia over long periods of time, and are considered at risk for physical and mental health problems. Often, the decision to relinquish care is made only when the health of the caregiver is in serious jeopardy. In some situations, clients must be helped to set appropriate boundaries, and in some cases, abandon the caregiving role. Selig et al. (1991) introduced the very complex issues of moral obligation and ethical issues as further dimensions of the caregiving experience. Clients may need help identifying and coming to terms with their ethical convictions and moral obligations toward the caregiving role and their impaired relative (Selig et al., 1991). Children of an impaired parent, in

particular, may feel bound by their basic value system to provide care, while experiencing conflict with the caregiving role when it interferes with other life goals and circumstances. Ethical and moral issues related to caregiving have not been tested as a counselling strategy and is an area to be explored more fully.

Analysis of the "help items", is limited as the study lacks the rigor of a quasi-experimental or experimental design, and this lead me to interpret these findings with caution. While not establishing any cause-effect relationships, some tentative logical conclusions were drawn.

As discussed earlier, family support groups offer a good level of help, most successfully in institutional related issues. Volunteers provide adequate help in the areas their training has covered. Staff are shown to help in unique ways, compared to groups and volunteers. Clients generally do not feel they have been helped much in the area of obtaining a medical assessment, or by advocacy activities. One explanation may be that negotiating the system is frustrating regardless of third party interventions, or that accessing medical services, or other community services acknowledges serious problems and/or further deterioration of their ill family member. The other explanation represents the need for staff to expand their brokerage and advocacy role. This may also relate to

inadequate assessments; clients are thought to be able to independently cope with situations, when, in fact, they require additional support.

The educational component to service cannot be underestimated. Help with understanding AD and AD behaviour may help with educating other family members, and resolving family conflict. Likewise when family members are educated and informed, planning for the future, and even the difficult decision to institutionalize can be shared from a common perspective based on sound information. This in turn, as this study suggests, may help reduce barriers for caregivers in asking for the type of help they feel they need.

A well developed service model based clearly on a theoretical approach to practice should be established in ASM. The model should include a thorough assessment of client needs and goals and incorporate both a prevention and intervention component. Both components should have a strong educational aspect to them, as education of AD and AD behaviour helps clients in other important ways like educating other family members, resolving family conflict, planning for the future and making the decision to institutionalize.

Family Support Groups

This study's findings provide highly useful information on the strengths and limitations of family support groups.

The majority of persons attending groups were caring for relatives in the later stages of the disease, and groups were shown to provide the best help in making the decision to place, and in building confidence to interact with personal care home staff. This corresponds to Gonyea's findings (1989), as does the fact that groups are not very successful in addressing the caregiver's own emotional needs, and issues related to the family system. This study demonstrated groups had less success in the "help items" resolving family conflict, planning family social events, and to some extent emotional coping. The strengths are in providing information about the disease, community resources, stress management, and providing peer support.

It stands to reason, then, that newer caregivers, who may be experiencing higher levels of reactive anxiety and family disequilibrium, may not get their needs met in family support groups. As is suggested by Zarit et al. (1985), individual and family counselling should be followed by family support group involvement.

Other reasons for clients not using groups were well explained in this study as described in the previous chapter. Reasons associated with preference are accepted and supported. Those who found groups depressing might be better served in individual counselling. A "buddy" system may assist new caregivers who are too shy to enter the group. Strategies like assisting with transportation or

respite may be plausible solutions for those with practical problems which prevent them from attending a group.

Future Research

I fully concur with Selig and associates in their concern that the experiences and needs of the carereceiver are rarely specified or used in the analysis of caregiving research, particularly as our understanding of the individual with dementia increases. "It is somewhat ironic that when we discovered the family caregiver we seemed to forget about the older person as a recipient of care." (Horowitz, 1985). In order to individualize services to caregivers, it seems logical to understand their needs in relation to the needs and circumstances of the carereceiver, and incorporate this dimension in future research.

Farran and associates (1991) introduced to the caregiving literature the idea of finding meaning through caregiving, and they provide an alternative paradigm based on an existential framework for understanding the caregiving experience. Reference was made earlier to the work of Selig et al. (1991) who discusses the moral and ethical context of family relationships. The extent to which these highly complex concepts of finding meaning, moral responsibilities, ethics, value systems and spiritual or religious beliefs influence the caregiving experience, or the healing process is unknown. This is only beginning to be explored

conceptually in the literature. Based on the finding that caregivers do not perceive their role as being valued by others may influence how caregivers themselves regard their role and estimate their value. Further research in these areas would seem important. I think it is important that caregiving be seen as more than a checklist of tasks guided by a stress/coping paradigm.

The exploratory-descriptive nature of the design of this study, plus difficulties in program implementation as identified allowed limited interpretation of the "help items". The conceptualization, though, in my opinion, is a sound premise for future experimental research of interventions designed to help this population. Particularly for service providers in Canadian Alzheimer societies, where theoretical program models do not yet exist, the development of such a research construct would be beneficial in developing, monitoring and measuring the effectiveness of interventions. This is an area I believe should be pursued, and, actually, one that I would like to pursue.

Chapter Nine

CONCLUSIONS AND RECOMMENDATIONS

During the past ten years, ASM has evolved from a
family support group based on self-help to an organization
which provides a range of services delivered by professional
staff and volunteers.

The response of family caregivers to family support
programs in Winnipeg has demonstrated a vital and ongoing
need for the program, and clients of ASM are generally
satisfied with the help they receive.

The objectives of the study, I believe, were met. This
program evaluation has provided important descriptive
information about who is being served directly (caregivers)
and indirectly (carereceivers), something of the context of
their caregiving activity, how clients are being served, and
how clients are being helped. Service utilization and
underutilization is better explained, implementation
problems identified, and realistic directions for
development provided.

The ASM program is assessed to have many strengths.
First, ASM has demonstrated flexibility, commitment and
responsiveness to clients by adjusting and adding program
components as needs were identified. This is exemplified by

the introduction of caregiver workshops, and individual and family counselling. Staff have acquired the necessary expertise to help clients, and to develop a volunteer corp who can assist clients. This study has identified more clearly the particular contributions of both groups, which is essential in planning further training, and matching clients to the most useful program. Overall the functions provided by staff and volunteers, whether through individual or group interventions, appear to be appropriate.

Volunteers performed well in assisting clients according to the content and level of their training course. Volunteers help clients with understanding AD and AD behaviour, stress management and emotional coping. These findings reinforce a premise of ASM staff, that lay persons, with training provide effective support to caregivers. The ASM method of training volunteers has proven to be effective, and additional training modules would allow volunteers to increase their expertise in helping clients, and meet a wider range of client needs. Staff with professional expertise should focus on assessment and providing interventions in more complex client situations.

Clients' provided clear evaluations of the specific help they received. Their level of relative satisfaction and dissatisfaction with services they used were identified. This information provided the basis for recommending improvements in services areas, particulary in making

clients more aware of services available to them. Also
identified was the need for staff and volunteers to improve
intervention techniques.

The ASM has recognized the importance of other
community services to clients, particularly home support
services, physician and police services, and institutional
services, and has developed useful collateral contacts. A
similar strategy could now be used to build closer
relationships with the legal profession and the acute care
sector.

The key developmental issue identified was in
implementation, specifically in the area of assessment of
client needs and subsequent referral to ASM and other
services. Strategies addressing this issue are the basis
for the following recommendations to the ASM.

Recommendations

1. Efforts should be continued to service different racial
    and socioeconomic groups.

2. Future promotional and educational material relating to
    the family caregiving role should convey a more positive
    message stressing concepts like importance, status,
    respect, and skill and knowledge, for example.

3. Better methods of informing clients of available
    services must be found. Staff and volunteers must
    become sensitized to this issue. Kits must be re-
    evaluated and attempts at individualizing information
    according to the needs of the client should be made.

4. Theoretical approaches to practise must be better
    explored and adopted, and models developed. It is
    suggested both prevention and intervention models be
    explored.

Adequate and accurate assessments of client needs and clients' goals should be carried out prior to recommending programs. This implementation requires additional resources and strategies should be developed to meet this goal.

A research/demonstration project may be a method of establishing viability and effectiveness.

5. Winnipeg programs, currently staffed by one part-time worker, require additional professional staff. In addition to family support, volunteer management, education programs and community liaison are other key functions.

6. Records relating to client services should be revised in order that important data can be recorded for ongoing program monitoring purposes. A computerized information system would assist in providing information for program adjustments when identified.

7. Additional training modules related to volunteer training should be considered and developed to that volunteers can expand their knowledge base and increase and increase their skill level to meet client needs.

The practicum provided me with the opportunity to develop social work skills in the following areas: the conduct of an evaluability assessment, evaluation research for program monitoring, including development of a research instrument, and better methods of working within the organizational context to promote utilization of evaluation research outcomes.

Given that the fields of evaluation research and Alzheimer disease are evolving rapidly, it will be a continuing challenge to keep current with innovations in these areas.

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Table 2-2.—The Global Deterioration Scale (GDS) for Age-Associated Cognitive Decline and Alzheimer's Disease

GDS stage	Clinical phase	Clinical characteristic
1 No cognitive decline	Normal	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline	Forgetfulness	Subjective complaints of memory deficit, most frequently in following areas: a) forgetting where one has placed familiar objects; b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline	Early confusional	Earliest clear-cut deficits. Manifestations in more than one of the following areas: a) patient may have gotten lost when traveling to an unfamiliar location; b) co-workers become aware of patient's relatively poor performance; c) word and name finding deficits become evident to intimates; d) patient may read a passage or a book and retain relatively little material; e) patient may demonstrate decreased facility in remembering names upon introduction to new people; f) patient may have lost or misplaced an object of value; g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline	Late confusional	Clear-cut deficit on careful clinical interview. Deficits manifest in following areas: a) decreased knowledge of current and recent events; b) may exhibit some deficit in memory of personal history; c) concentration deficit elicited on serial subtractions; d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: a) orientation to time and person; b) recognition of familiar persons and faces; c) ability to travel to familiar areas. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.
5 Moderately severe decline	Early dementia	Patients can no longer survive without some assistance. Patients are unable during interview to recall a major relevant aspect of their current lives: e.g., the names of close members of their family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouse's and children's names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear.
6 Severe cognitive decline	Middle dementia	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives, but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and sometimes forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance, but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.
7 Very severe cognitive decline	Late dementia	All verbal abilities are lost. Frequently there is no speech at all—only grunting. Incontinent of urine; requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.

SOURCE: B. Reisberg, "Clinical Presentation, Diagnosis, and Symptomatology of Age-Associated Cognitive Decline and Alzheimer's Disease," *Alzheimer's Disease: The Standard Reference* (New York: Free Press, 1983), pp. 173-187.

Alzheimer

Société

Manitoba Inc.

Society

For those of you who I have not yet met, either in person, or over the telephone, I would like to introduce myself. My name is Pam Robb and I have been the Director of Programs of the Alzheimer Society of Manitoba for the past five years.

In addition to my work here at the Society, I am studying towards a Masters Degree in Social Work at the University of Manitoba. The final step in qualifying for this degree is completing what is called a Practicum. The project I have chosen is to evaluate the services the Society offers to family caregivers of a relative with Alzheimer disease or some type of dementia.

Because I know how difficult it is for many of you to schedule time for a lengthy interview, I have prepared a series of questions concerning information about you, your ill relative, and the current services of the Society for you to fill in at home. I hope you find the questionnaire interesting and easy to complete.

The information collected for this study will be treated confidentially, and also anonymously through the use of code numbers. Your name, or the name of your ill relative will not appear in any research report. Please understand also, that your participation is strictly voluntary. You are under no obligation to complete this questionnaire.

The information from the study will be used to plan services which are the most useful and helpful to you, and to new caregivers who can so greatly benefit from your experience.

If your agree to participate, please complete the questionnaire, and return it to me in the enclosed self addressed envelope.

Thank you so much for helping me out with this project. I am really looking forward to hearing from you.

Sincerely,

Pam Robb
Director of Programs

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CHARITABLE REGISTRATION NO. 0666420-11

ALZHEIMER SOCIETY REVIEW OF SERVICES

The first few questions are to better understand the person in your family who is ill with Alzheimer disease or a dementia. Please circle your responses.

1. Is your ill relative male or female?

    1 - Male
    2 - Female

2. What is the year of birth of your ill relative?

    _____.

3. What is the education level of your ill relative?
    Choose the highest.

    1 - Completed less than high school
    2 - Completed some high school
    3 - Completed high school
    4 - Completed some trade school or community
        college
    5 - Completed trade school or community college
    6 - Completed some university
    7 - Completed university
    8 - Completed some post graduate
    9 - Completed post graduate

4. Where does your ill relative live?

    1 - In Winnipeg
    2 - In Manitoba, but not in Winnipeg
    3 - In another province
    4 - In another country

5. What is the present living arrangement of your ill
    relative?

    1 - Living alone
    2 - Living with a spouse
    3 - Living with a relative
    4 - Living with a friend
    5 - Living in a personal care home

6. If your ill relative now lives in a personal care
    home, where did they live immediately before?

        1 - Lived alone
        2 - Lived with a spouse
        3 - Lived with a relative
        4 - Lived in with a friend
        5 - Cared for in hospital
        6 - Not applicable

7. What is your relationship to your ill relative?

        01 - Husband
        02 - Wife
        03 - Son
        04 - Daughter
        05 - Son-in-law
        06 - Daughter-in-law
        07 - Brother
        08 - Sister
        09 - Niece
        10 - Nephew
        11 - Granddaughter
        12 - Grandson
        13 - Other. _____ .

8. IF YOU ARE NOT THE SPOUSE OF THE PERSON WHO IS ILL,
   what is the current status of the person's spouse?

        1 - Providing care
        2 - Unable to provide care because of ill health
        3 - Deceased
        4 - Other. Please explain._____

   _____ .

**The next questions are to better understand the caregiving
experience. Please circle your response.**

9. Choose one statement that best describes the way you
    manage the care of your relative.

        1 - I don't provide any of the direct caregiving
            tasks
        2 - I provide some of the direct caregiving tasks
        3 - I provide most of the direct caregiving tasks
        4 - I provide all of the direct caregiving tasks

10. Do you think your physical health has been affected by caring for your relative?

       1 - No
       2 - Yes

11. IF YOU ANSWERED YES TO QUESTION 10, please give examples

_____

_____

12. Do you think your mental health has been affected by caring for your relative?

       1 - No
       2 - Yes

13. IF YOU ANSWERED YES TO QUESTION 12, please give examples

_____

_____

14. Some people who provide care to ill relatives have reported they feel burdened by care. Please indicate one statement which best describes you.

       1 - I feel very burdened
       2 - I feel burdened
       3 - I feel somewhat burdened
       4 - I don't feel burdened
       5 - I don't feel burdened at all

15. How helpful are other relatives to you in providing care?

       1 - Not at all helpful
       2 - Not very helpful
       3 - Somewhat helpful
       4 - Helpful
       5 - Very helpful

16. Would you like more help from other relatives in providing care?

       1 - No
       2 - Yes

17. IF YOU ANSWERED YES TO QUESTION 16, do you feel
    comfortable asking other relatives for more help?

          1 - No
          2 - Yes

18. Please explain your answer to question 17_____

    _____

    _____.

19. How supportive have your friends been during the illness
    of your relative?

          1 - Not supportive at all
          2 - Not very supportive
          3 - Somewhat supportive
          4 - Supportive
          5 - Very supportive

**Listed below are two general statements about family
caregiving. Please indicate how much you agree with each
statement.**

20. The job of family caregiving has status and prestige;
    that is, other people look up to it and think it is
    important.

          1 - Strongly disagree
          2 - Disagree
          3 - Somewhat agree
          4 - Agree
          5 - Strongly agree

21. It takes knowledge and experience to do the job well.

          1 - Strongly disagree
          2 - Disagree
          3 - Somewhat agree
          4 - Agree
          5 - Strongly agree

**The following questions are to better understand the
experience in obtaining a diagnosis of the person you care
for. Please circle your response.**

22. Has your relative been diagnosed with Alzheimer disease or a dementia?

      1 - No
      2 - Yes

IF YOUR RELATIVE HAS A DIAGNOSIS OF ALZHEIMER DISEASE OR A DEMENTIA, please answer the following questions.

23. When was the diagnosis made?

      _____ years ago.

24. Who made the diagnosis?

      1 - Family doctor
      2 - Neurologist
      3 - Psychiatrist
      4 - Geriatrician

25. Now that you know your relative's diagnosis, and you think back on earlier symptoms, how long do you think your relative may have been ill?

      _____ years.

The following questions ask you about the Alzheimer Society.

26. How did you first learn about the Alzheimer Society?

      1 - Television or radio or newspaper
      2 - Telephone directory
      3 - Family member
      4 - Friend
      5 - Physician
      6 - Professional, other than a physician
      7 - Other. Please specify._____

27. How did you first have contact with the Society?

      1 - Telephone
      2 - Office visit
      3 - Education meeting
      4 - Family support group
      5 - Other. Please specify._____

28. Who was your first contact at the Society?

        1 - Receptionist
        2 - Professional staff
        3 - Volunteer
        4 - Family support group
        5 - I don't know
        6 - Other. Please specify._____

29. There appear to be many reasons why family members first contact the Society. Some possible reasons are listed. Please circle the primary reason you first contacted the Society.

        1 - My family member was not yet diagnosed, but I noticed changes and wanted to know if the problems could be caused by Alzheimer disease.
        2 - My family member was diagnosed, and I wanted information about the disease and available services.
        3 - My family member was diagnosed, and I wanted to talk about how I was coping and feeling.
        4 - Other. Please explain._____

        _____.

30. How satisfied were you with the initial service you received from the Society?

        1 - Very unsatisfied
        2 - Unsatisfied
        3 - Somewhat satisfied
        4 - Satisfied
        5 - Very satisfied

31. Please circle <u>all</u> Alzheimer Society services which you are aware of.

> 01 - Family Information Kit
> 02 - Library Books for Loan
> 03 - Video Tapes for Loan
> 04 - Telephone support with a volunteer
> 05 - Telephone support with a professional staff
> 06 - Office interviews for families with a professional staff
> 07 - Family Caregiver Workshop Series
> 08 - Annual Family Pot Luck Dinner
> 09 - Wanderer's Registry
> 10 - Family Support Group
> 11 - Brain Tissue Recovery Research Program
> 12 - Familial Alzheimer Disease Registry

32. Please circle <u>all</u> Alzheimer Society services which you have used.

> 01 - Family Information Kit
> 02 - Library Books for Loan
> 03 - Video Tapes for Loan
> 04 - Telephone support with a volunteer
> 05 - Telephone support with a professional staff
> 06 - Office interviews for families with a professional staff
> 07 - Family Caregiver Workshop Series
> 08 - Annual Family Pot Luck Dinner
> 09 - Wanderer's Registry
> 10 - Family Support Group
> 11 - Brain Tissue Recovery Research Program
> 12 - Familial Alzheimer Disease Registry

The following series of questions is to better understand how you would rate the services you have used. Please circle your response according to the following scale.

> 1 - Not useful at all
> 2 - Not useful
> 3 - Somewhat useful
> 4 - Useful
> 5 - Very useful

33. IF YOU RECEIVED A FAMILY INFORMATION KIT, please rate how useful it was to you.

> 1   2   3   4   5

34. IF YOU USED LIBRARY BOOKS, please rate how useful the material was to you.

    1   2   3   4   5

35. IF YOU USED VIDEO TAPES, please rate how useful they were to you.

    1   2   3   4   5

36. IF YOU ATTENDED ANY FAMILY CAREGIVER WORKSHOPS, please rate how useful they were to you.

    1   2   3   4   5

37. IF THE PERSON YOU CARE FOR IS REGISTERED WITH THE WANDERER'S REGISTRY, how many times, if any, have you contacted the Winnipeg Police for assistance in searching for you lost relative?

    1 - Never
    2 - 2-3 times
    3 - Over 3 times

38. IF YOU ATTENDED THE ANNUAL FAMILY POT LUCK DINNER, would you attend this event again?

    1 - No
    2 - Yes

39. Have you ever attended any Alzheimer family support group sessions?

    1 - Never
    2 - 1-2 sessions
    3 - 8-10 sessions
    4 - More than 10 sessions

40. If you HAVE ATTENDED any family support group sessions, which group did you attend?

    1 - Alzheimer Society office 205 Edmonton Street
    2 - Deer Lodge Centre
    3 - St. Joseph's Residence
    4 - Regents Park United Church
    5 - Tuxedo Villa

41. If you have NEVER ATTENDED or if you HAVE ATTENDED
    1-2 SESSIONS, please give your main reasons for never
    attending or for only attending 1-2 times. Circle as
    as many responses as apply to you.

    01 - I have health problems which prevent me from
         attending
    02 - I do not like to receive services in a group
         setting
    03 - My ill relative cannot be left alone, and I
         am unable to arrange alternate care
    04 - I have no need for ongoing support
    05 - When I have "free" time, or time to myself
         without care responsibilities, I do not want
         to talk about Alzheimer disease
    06 - Listening to other people's problems makes me
         feel depressed
    07 - I am unable to arrange transportation
    08 - The location and/or the time of the group is
         inconvenient for me
    09 - I am uncomfortable meeting a group of
         strangers by myself
    10 - Other. Please explain._____

    _____

42. How effective is the leadership of the family support
    group you attend?

    1 - Not effective at all
    2 - Not effective
    3 - Somewhat effective
    4 - Effective
    5 - Very effective

43. How would you rate the frequency of the family support
    group sessions?

    1 - Very infrequent
    2 - Infrequent
    3 - Frequent enough
    4 - Very frequent

44. How would you rate the importance of the family
    support group to you?

    1 - Not important at all
    2 - Not important
    3 - Somewhat important
    4 - Important
    5 - Very important

45. IF YOU HAVE HAD TELEPHONE CALLS FROM A SOCIETY
    VOLUNTEER, do you think the volunteer who contacted you
    was effective in providing support and information to
    you?

            1 - Not effective at all
            2 - Not effective
            3 - Somewhat effective
            4 - Effective
            5 - Very effective

46. How would you rate the frequency of volunteer calls?

            1 - Very infrequent
            2 - Infrequent
            3 - Frequent enough
            4 - Very frequent

47. How would you rate the importance of volunteer calls
    to you?

            1 - Not important at all
            2 - Not important
            3 - Somewhat important
            4 - Important
            5 - Very important

48. IF YOU HAD TELEPHONE CALLS FROM A PROFESSIONAL STAFF,
    do you think the staff person who contacted you was
    effective in providing support and information?

            1 - Not effective at all
            2 - Not effective
            3 - Somewhat effective
            4 - Effective
            5 - Very effective

49. How would you rate the frequency of staff calls?

            1 - Very infrequent
            2 - Infrequent
            3 - Frequent enough
            4 - Very frequent

50. How would you rate the importance of staff calls
    to you?

            1 - Not important at all
            2 - Not important
            3 - Somewhat important
            4 - Important
            5 - Very important

The following series of questions asks you more specific questions about how much help you have received from the Society. Please circle the appropriate answer according to the following scale.

> 1 - Not helped at all
> 2 - Not helped
> 3 - Helped somewhat
> 4 - Helped
> 5 - Helped a great deal
> 6 - Not applicable to me or my situation

51. To know how to arrange a medical assessment for my ill relative.

    1   2   3   4   5   6

52. To better understand Alzheimer disease.

    1   2   3   4   5   6

53. To feel more confident talking with physicians.

    1   2   3   4   5   6

54. To educate other family members about Alzheimer disease.

    1   2   3   4   5   6

55. To help resolve conflicts among family members.

    1   2   3   4   5   6

56. To better cope with my emotions.

    1   2   3   4   5   6

57. To know how to obtain Home Care services.

    1   2   3   4   5   6

58. To better understand why my ill relative behaves in certain ways.

    1   2   3   4   5   6

59. To better manage my stress.

    1   2   3   4   5   6

60. To learn skills to better manage my relative's behaviour.

      1   2   3   4   5   6

61. To know how to make my home safe for my ill relative.

      1   2   3   4   5   6

62. To plan realistically for the future.

      1   2   3   4   5   6

63. To know about possible legal issues and problems.

      1   2   3   4   5   6

64. To feel more confident talking with lawyers.

      1   2   3   4   5   6

65. To know about other resources in the community that could help me.

      1   2   3   4   5   6

66. To plan regular time away from caregiving.

      1   2   3   4   5   6

67. To better understand what social activities to plan with my ill relative.

      1   2   3   4   5   6

68. To contact other community resources.

      1   2   3   4   5   6

69. Society staff became involved with other community organizations when I had trouble getting what I needed from them

      1   2   3   4   5   6

70. To make the decision to place my ill relative in a personal care home.

      1   2   3   4   5   6

71. To feel more confident talking with staff in the personal care home.

        1   2   3   4   5   6

72. Someone from the Society was available to talk with me when I needed to talk things over.

        1   2   3   4   5   6

73. To learn to ask for the type of help I felt I needed.

        1   2   3   4   5   6

The following questions are a few general questions about the Alzheimer Society. Please circle your answer.

74. Who have you had the <u>most</u> contact with at the Society?

      1 - Staff
      2 - Volunteer
      3 - Family support group

75. Do you feel comfortable initiating contact with the Society if you have a problem or question?

      1 - Very uncomfortable
      2 - Uncomfortable
      3 - Somewhat comfortable
      4 - Comfortable
      5 - Very comfortable

76. Do you have any advice for the Society about how services to families could be improved? Please comment.

_____

_____

_____ .

77. Are you a Member of the Alzheimer Society of Manitoba?

      1 - No
      2 - Yes

78. IF YOU ANSWERED YES TO QUESTION 77, please rate how interesting you find the Newsletter "Reflects".

> 1 - Very uninteresting
> 2 - Uninteresting
> 3 - Somewhat interesting
> 4 - Interesting
> 5 - Very interesting

79. There are many other resources caregivers use in providing care to their relative. Please indicate which services, if any, you have used since your relative became ill. Please circle those resources you have used.

> 01 - Legal services
> 02 - Public Trustee
> 03 - Home Care
> 04 - Day Hospital
> 05 - Day Care Program
> 06 - Active Treatment Hospital
> 07 - Private Nurse/Companion
> 08 - Meals on Wheels
> 09 - Personal Counselling Service
> 10 - Respite Care (Home)
> 11 - Respite Care (Institutional)
> 12 - Police
> 13 - Family Physician
> 14 - Personal Care Home
> 15 - Grief Counselling

This final set of questions will provide information to us about the characteristics of the different types of caregivers who are served by the Society. Please circle your answer.

80. Which group do you identify with?

>01 - Canadian
>02 - British or English
>03 - American
>04 - French
>05 - German
>06 - Norwegian/Danish/Swedish/Icelandic
>07 - Dutch/Belgian
>08 - Polish
>09 - Russian/Ukrainian
>10 - Other European/Middle East
>   (Italian, Spanish, Portuguese, Greek etc)
>11 - Asia Oceanic
>   (Chinese, Japanese, Polynesian, East Indian)
>12 - Aboriginal
>13 - Jewish
>99 - No comment

81. What languages do you speak? Please list them.

>1 - English
>2 - French
>3 - Other. Please specify_____

82. What language do you prefer to speak?

>1 - English
>2 - French
>3 - Other _____

83. What is your education level? Choose the highest.

>1 - Completed less than high school
>2 - Completed some high school
>3 - Completed high school
>4 - Completed some trade school or community
>   college
>5 - Completed trade school or community college
>6 - Completed some university
>7 - Completed university
>8 - Completed some post graduate
>9 - Completed post graduate

84. Are you employed outside your home?

       1 - No
       2 - Yes

85. IF YOU ANSWERED YES TO QUESTION 85, do you work..?

       1 - Part-time
       2 - Full time

86. Please select the appropriate range of your family income, before taxes?

       1 - Under 10,000
       2 - 10,000 - 20,000
       3 - 21,000 - 30,000
       4 - 31,000 - 40,000
       5 - 41,000 - 50,000
       6 - 51,000 - 60,000
       7 - 61,000 - 70,000
       8 - 71,000 - 80,000
       9 - Over 80,000

87. Do you attend religious services on a regular basis?

       1 - No
       2 - Yes

88. IF YOU ANSWERED YES TO QUESTION 87, what religious denomination are you?

       _____

89. Where do you live?

       1 - House
       2 - Apartment
       3 - Other   _____ .

90. Are you male or female?

       1 - Male
       2 - Female

91. How old are you?   _____years.

      Thankyou for completing this survey.
      Please indicate if you would like a
      copy of the summary of this report.

      _____ Yes