

A NEEDS ASSESSMENT FOR THE USE OF A
MEMORY DISORDER CLINIC FOR ALZHEIMER
CARE, RELATED DISORDERS AND RESEARCH

BY
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A Practicum Report
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF SOCIAL WORK

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial
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ABSTRACT

Critical to providing care for the increasing number of individuals with dementia is an early diagnosis of Alzheimer disease or related dementia. In order to address this issue physicians in Manitoba were asked to respond to a mail survey designed to examine the service utilization of a Memory Disorder Clinic at Lions Manor for assessment/diagnosis, family support and education and research into the dementias.

There is a dearth of knowledge relating to which intervention best supports individuals with Alzheimer disease and their families. To assist in the planning and development of support services at the Memory Disorder Clinic at Lions Manor, a subgroup of physicians, geriatric social workers and nurses, and families were asked to respond to a mail survey requesting the evaluation of a service model for family support used at the Memory Disorder Clinic, Duke University, Durham, North Carolina.

The findings from this study suggest that physicians will find the clinic very valuable to their practice and will refer patients. The findings also suggest that barriers exist for families accessing support services. Even when families desire available services and claim to need them, services remain underutilized. Interventions which best support caregivers must be based on an adequate assessment of their needs, and an understanding of family attitudes, values and beliefs about accessing formal and informal help.

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A heartfelt thank you to Lisa Gwyther, my mentor, for her generous hospitality in assisting me with this project and providing me with a vision of excellence in care management for individuals with AD and their families.

I would like to dedicate this report to my parents, George and Helen, for their lifelong unconditional love and support, even in the most challenging of times.

“When it gets dark enough, you can see the stars.”

Lee Salk

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1.0 INTRODUCTION

Alzheimer disease (AD), a progressive degenerative irreversible disease of the brain is the most common cause of dementia (i.e. memory loss). In Manitoba, estimates for 1990 indicate that approximately 15,000 Manitobans had an Alzheimer type dementia. By the year 2021, it is estimated that the numbers will more than double to reach 35,000 Manitobans with the disease (Alzheimer Society of Manitoba, 1995). It is commonly recognized that AD is unique and varied in its impact on patients and families when compared to other common illnesses affecting people in late life. The slow insidious onset of AD means even symptom recognition and diagnosis is difficult. Often times, AD is written off as normal aging or mistaken for a treatable condition such as medication interaction. From research carried out at the Memory Disorders Clinic of the Joseph and Kathleen Bryan Alzheimer Disease Research Centre at Duke University Medical Center, it appears evident that even when facilities for diagnosis are available, families typically need special help interpreting the nature of a clinical diagnosis like Alzheimer disease (Gwyther, 1987). Their findings go on to indicate that families need even more help in managing the prominent behavioural, mood and personality manifestations typical of the illness. Family physicians often feel as helpless as the family caregivers in managing variable and somewhat unpredictable symptoms (Gwyther, 1987). In fact, it is suggested that general practitioners as a whole fail to diagnose dementia at an early stage and so miss the opportunity to mobilize the support that is so vital for the person with dementia and their caregivers (Connell et al, 1996) or regard it as normal for elderly people to become forgetful (Grob, 1993).

Memory Clinics are common and well established in North America where they are usually linked to Alzheimer Disease Centres (Osvaldo et al, 1992). They have an important role to play in investigating the cause of memory impairment and the detection of early causes of dementia (Bennett, 1987). As well, the clinics have been able to provide physicians, other professionals and caregivers with advice on general principles of memory management and highly motivated subjects for research in Alzheimer disease and related dementias (Osvaldo et al, 1993).

The Lions Club of Winnipeg Housing Centres and The St. Boniface Hospital Research Centre have formed a partnership to develop a Clinical Research Centre at Lions Manor for the study of Alzheimer disease and related dementias. A critical component of the research unit will be a Memory Disorder Clinic. This outpatient clinic will be designed to investigate causes of memory impairment and help in early detection of AD dementia. An early diagnosis will enable the development of a clear plan of care to support the individual with AD and their family.

Gwyther et al (1990) found that Alzheimer families are more likely to seek physician services first, before checking into other support options. In their opinion, an adequate interpretation of a "possible" or "probable" diagnosis of AD is the first hurdle for families. It is well documented in current research that AD and similar dementias with an insidious nature result in huge costs to our health care system (Gubrium, 1986). More importantly, decisions with respect to coping with care issues are often overwhelming for families. As a result, families often choose early institutionalization rather than trying to maintain a relative in the community for as long as possible.

The purpose of this practicum study is to explore the need and/or use of the proposed Memory Disorder Clinic at Lions Manor. This examination will assist with the planning of the next phase of the project - the development of the functional program. Critical to that next step is support from physicians in Manitoba for the project. As well, the clinic will specialize in Family Support and Education. This practicum report will establish recommendations for Family Support and Education based on the evaluation of successful existing models and a review of current research trends in Alzheimer disease, related dementia and research.

1.1 Learning Objectives

I have endeavored to accomplish the following intervention, research, and learning objectives through the development and implementation of this practicum study.

1. To conduct a survey of physicians in Manitoba.
2. To document the clinical value of a Memory Disorder Clinic for the use of the early diagnosis and treatment of Alzheimer disease and related dementias by evaluating a brief questionnaire mailed to four groups of physicians in Manitoba (questionnaire #1).
3. To design and evaluate a survey questionnaire based on the social work approach of providing family support and education used at the Memory Disorder Clinic at Duke University.
4. To make recommendations for a social work intervention to be used at Lions Manor Memory Disorder Clinic based on an evaluation of the responses from questionnaire #2 and current research trends.
5. To develop an understanding of Memory Disorder Clinics.
6. To develop knowledge and skill in analysis and evaluating questionnaires.

1.2 Definitions

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

Alzheimer Disease

Alzheimer disease (AD) is a progressive, degenerative disease that attacks the brain and results in impaired memory thinking and behavior. AD has a gradual onset. The rate of progression varies from person to person. The time of onset of symptoms to death ranges from 3 to 20 years. The average is 8 years. Most people diagnosed with AD are older than 65, however, AD can occur in people in their 40's and 50's (National Institute on Aging, 1996).

The person with AD also may experience confusion, personality change, behavior change, impaired judgment and difficult finding words, finishing thoughts, or following directions. An absolute diagnosis can only be made upon examination of brain tissue, usually at autopsy. On microscopic examination at autopsy, AD brains show senile plaques and neurofibrillary tangles in those areas of the brain responsible for memory and intellectual functions. (Alzheimer's Disease and Related Disorders Association, Inc. 1991).

Most people who work with patients and families think of the disease in three phases: mild, moderate and severe. These three stages may overlap and the appearance and progression of symptoms will vary from one individual to the next (Gwyther, 1985).

Mild Symptoms

Confusion and memory loss
Disorientation; getting lost in familiar surroundings
Problems with routine tasks
Changes in personality and judgment

Moderate Symptoms

Difficulty with activities of daily living, such as feeding and bathing
Anxiety, suspiciousness, agitation
Sleep disturbances
Wandering, pacing
Difficulty recognizing family and friends

Severe Symptoms

Loss of speech
Loss of appetite; weight loss
Loss of bladder and bowel control
Total dependence on caregiver

Related Dementia

Dementia is a loss of intellectual functioning (such as thinking, remembering, and reasoning) of sufficient severity to interfere with an individual's daily functioning. Dementia is not a disease itself, but rather a group of symptoms which may accompany certain diseases or conditions. The three most common causes of related dementias are Alzheimer disease which accounts for at least 50% of persons with dementia. Multiple small strokes, known as multi-infarct Dementia or MID (20%). AD and MID together are responsible for another 15% - 20%. Third, Acquired Immune Deficiency Syndrome, AIDS (percent unavailable). (The Arizona Long Term Care Gerontology Center, 1992, Alzheimer's Disease and Related Disorders Association Inc., 1991).

Memory Disorder Clinic

Memory Disorders Clinic investigate causes of memory impairment and help in the early detection of dementia. The multi-disciplinary clinic staff work closely with the patient's personal physician to determine if a cause for the problem can be identified and

if any treatment is possible. Services are available on an outpatient basis. Those services usually include an assessment of the current problem, a complete diagnostic evaluation, an interview with a social worker and a follow up evaluation. Patients and their families may volunteer to participate in research studies investigating the causes of memory loss and evaluating drug treatment (Duke University Medical Center, 1994).

Needs Assessment

A needs assessment is a “formal systematic attempt to determine and close the more important gaps between “what is and what should be” . . . the determination of documentable and important gaps between current outcomes and desired outcomes, and the placing of those gaps in priority order for closure” (Kaufman and English, 1979). A needs assessment is most useful when there is a good likelihood that it will influence program decisions, when there is both opportunity and commitment to change, and when resources are available to do an adequate job (Feather, McGowan, and Moore, 1994).

1.3 Organization of the Practicum Report

The organization of the practicum report has been divided into five chapters. Chapter one has provided the introduction to the report, and has described both the purpose of the study and the student learning objectives.

Chapter two briefly describes Memory Disorder Clinics. A more detailed overview of Alzheimer disease and related dementia from a biological clinical and social perspective are reviewed. Current research progress on Alzheimer disease and future directions are discussed. This section also includes a brief review of interventions for

caregivers including the social work role in the Individualized Barriers Focused Model at Duke University Memory Disorder Clinic. Finally, the proposed Memory Disorder Clinic at Lions Manor is introduced.

Chapter three describes the methods used for the study including the general aim and design of the two questionnaires. The respondent and sample selection are detailed as well as the method of analysis and limitations to the study.

Questionnaire results are shown in chapter 4 as well as implication for service development. A series of recommendations for assessment and diagnosis, family support and education, and research at the Memory Disorder Clinic at Lions Manor are included in the final chapter.

2.0 LITERATURE REVIEW

2.1 Memory Disorder Clinics

The demand for the assessment of newly diagnosed dementing illness and memory disorders is growing (O'Neill, Surmond, Wilcock, 1992) as dementia and its implications for sufferers, caregivers and society are gaining greater public support (Bennett, 1987). The purpose of memory clinics is to investigate causes of memory impairment and help in early detection of dementia (Osvaldo et al, 1993, Bayer et al, 1987, Bennett, 1987). An early diagnosis enables the development of a clear plan of care, existing drug treatment can be rationalized and appropriate treatment started at a stage when it is potentially most valuable (Bayer, Patny, Twining, 1987).

Bennett (1987) describes the important role that memory clinics have to play in investigating the causes of memory impairment and in detecting early cases of dementia. He also suggests that the clinic should also function as a district "resource centre" with educational and research functions. This specialist multidisciplinary centre could offer early referral and assessment as the first stage of a spectrum of available resources. Other resources could be counseling and information, day care, relative and volunteer support groups, day and night setting and, later, intermittent respite care and if necessary a permanent home in hospital or a community setting.

A review of the literature on memory disorder clinics support the three functions of the Memory Clinic at the University hospital of Wales in Cardiff. This clinic acts as a practical resource for doctors, patients, and relatives, Using a multi-disciplinary approach, an early diagnosis and an individual care package is planned. A second

function has an educational focus on countering negative attitudes and supporting elective decisions rather than crisis intervention. A third function is to develop new research methods and investigate prospects for treatment (Bayer, Patny, Twining, 1987).

Van der Cammen et al (1987) found that although the professionals at a memory clinic varied, there appeared to be a standard "core" at most clinics. This included a clinical psychologist, a physician, and a psychiatrist. This team usually assessed individuals collaborating their data to form a cumulative profile of the patient concerned. Social Work input is extremely helpful (Bennett, 1987).

In describing the important role that memory clinics have to play in investigating the cause of memory impairment and in detecting early causes of dementia Bennett (1987) describes the general assessment process:

- The clinical psychologist has to ascertain whether or not a memory deficit is present. Numerous tests are available such as the cerebral function test, where naming, vocabulary and spatial skills are investigated. Increasingly, more sophisticated tests are being used involving computerized assessment.
- The physician needs to look for and rule out the treatable causes of memory loss (Table 1). A good history and full examination are necessary. As well, the physician needs to subclassify those people suffering from the symptoms of dementia into disease entity, for instance senile dementia of the Alzheimer type, or a multi-infarct dementia (or indeed others). To help do this, the Hachinski score (table 2) is used, a score of seven or more indicating the probability of the condition being vascularly induced.
- The psychiatrist assesses the mental state looking at the clinical severity of any dementia found, and as importantly, ruling out affective disorders such as depression.

The results of a study done at The Maudsley Memory Clinic shed some light on the demographic of 418 patients attending the clinic. Patients were referred by family doctors and by other hospitals. Interestingly enough, they found an absence or

Table 1: Some potential treatable causes of memory loss

- **Metabolic**
 - Hypothyroidism
 - Hypopituitarism
 - Hypercalcaemia
 - Cushing's disease
 - Renal failure & dialysis "dementia"
 - Hepatic encephalopathy
 - **Infective**
 - Brain abscess
 - Neurosyphilis
 - **Deficiency problems**
 - Vitamin B₁₂
 - Folic acid
 - Thiamine (Wernicke Korsakoff's syndrome)
 - **Traumatic**
 - Subdural haematoma
 - **Other causes**
 - Normal pressure hydrocephalus
 - Depression
 - Drug toxicity
-

Table 2: Hachinski score

	Symptoms and signs	Score
	Abrupt onset	2
	Stepwise deterioration	1
	Fluctuating course	2
	Nocturnal confusion	1
	Preserved personality	1
	Depression	1
	Somatic complaints	1
	Emotional incontinence	1
	Hypertension (history of)	1
	History of strokes	2
	Associated atherosclerosis	1
	Focal neurological symptoms	2
	Focal neurological signs	2
7 or more:	cause is probably ischaemic (i.e. multi-infarct)	
4 or less:	cause is probably non-ischaemic (i.e. Alzheimer's type)	
5 - 6:	Intermediate	

potentially reversible conditions of dementia. Alzheimer disease was the most frequent diagnosis (57%) followed by a group of patients complaining of memory problems with no obvious neuropsychiatric diagnosis (24%). In a similar study of 100 patients, Bayer et al (1987) also reported a high number of patients diagnosed with Alzheimer disease (44). Forty-three patients had other previously unrecognized but treatable medical conditions.

The memory clinic approach appears to be a relatively efficient way of detecting early and mild cases of dementia, particularly Alzheimer disease (Philpot, Levy, 1987). Memory clinics will increasingly become more sophisticated and by the time neurochemical manipulation is possible (drug trials) the clinic may well be the best source of patients for treatment (Bennett, 1987). A comprehensive assessment performed in a memory clinic assists in planning for the management of patients with dementia. Future research will be directed at improving the accuracy of diagnostic instruments in this clinic setting and evaluating the efficacy of the family conference (Ames, Flicker, Helme, 1992).

2.2 Alzheimer Disease and Related Dementia

Alzheimer disease is one of the most common causes of the loss of mental functioning known broadly as dementia. This type of dementia proceeds in stages, gradually destroying memory, reason, judgment, language and eventually the ability to carry out even the very simplest of tasks (National Institute on Aging, 1996). Similarly, dementia can usually be sub-classified into senile dementia of the Alzheimer type

(SDAT) and the less common multi-infarct dementia. In Alzheimer disease there is a progressive and seemingly relentless deterioration of memory intellect and personality. There is a blunting of emotions, a reduction of initiative, and a loss of insight as the patient seems unaware of the memory impairment (Grob, 1993).

In multi-farct non-Alzheimer dementia associated with an underlying organic disease there is a deterioration of memory intellect and personality but it is "not relentless". There is emotional incontinence but insight is preserved. This dementia is not progressive in the same way as AD. It has a remitted and fluctuating course. AD rarely responds to treatment if ever, where multi-infarct dementia may well respond (Grob, 1993).

While AD is a form of dementia, dementia is not necessarily AD. There are various forms of dementia, some causes of dementia are listed in Table 3.

AD is the most common cause of dementia in North America and Europe. The prevalence of the disease increases with increasing age. Approximately 10% of all persons over the age of 70 have significant memory loss and more than half of these individuals have AD. The prevalence of dementia in individuals over the age of 85 is estimated to be 25 to 45% of that population. Because the elderly represent an expanding age group, the occurrence of AD represents a tremendous medical economic and social problem (Ebby et al, 1994, Max. 1993).

Recent epidemiology reports from the Canadian Study of Health and Aging (1994) provide estimates of the prevalence of dementia in the Canadian population. The prevalence results suggest that 252,600 (8%) of all Canadians aged 65 and over met the

Table 3

Causes of Dementia

Degenerative Disorders - Alzheimer disease, Diffuse Lewy Body dementia and Lewy Body Variant, Frontal and Frontal-temporal lobe dementias, Down syndrome.

Strokes - Vascular or Multi-infarct dementia, Heart disease producing emboli or reduced perfusion.

Trauma - Head trauma

Toxic or Metabolic Disease - Depressed pseudodementia, Alcohol, B₁₂ deficiency. Folate deficiency.

Immunologic Diseases - Multiple Sclerosis, Chronic Fatigue Syndrome.

Infections - Acquired Immunodeficiency Syndrome (AIDS).

Rarer Causes of Dementia include the following:

Degenerative Disorder Amoy's lateral sclerosis (ALS) and other Frontal Lobe Dementias, Pick's disease and other frontal temporal lobe dementias, Creutzfeldt-Jakob Disease, Primary Progressive Aphasia, Parkinson's disease, Parkinson's Plus diseases, Huntington's Chorea, White matter diseases (Leukodystrophies).

Ventricular Disorders - Normal Pressure Hydrocephalus Obstructive or Non-communicating Hydrocephalus, Non-obstructive or Communicating Hydrocephalus.

Vascular Diseases - Binswanger's Disease, Subarachnoid Hemorrhage. Chronic Subdural Hematoma, Vasculitis or Small Vessel Disease.

Immunologic Diseases - Immunoglobulin deficiencies.

Systemic or Metabolic Diseases - Alcoholism Liver Diseases, Kidney Disease, Lung Disease, Diabetes, Wilson's Disease.

Convulsive Disorder - Epilepsy, Transient Global Amnesia.

Cancer - Brain and Metastatic Tumors

Infections - Acquired Immunodeficiency Syndrome (AIDS), Chronic Encephalitis, Neurosyphilis.

(National Institute on Aging, 1996).

criteria for dementia (95% confidence interval). They were divided equally between community and institutional samples; the female male ratio was 2:1. The age standardization rate ranged from 2.4% among the 65 - 74 years, to 34.5% among those aged 85 and over. The corresponding figures for Alzheimer disease were 5.1% overall, ranging from 1.0% to 26.0%; for vascular dementia (MID) it was 1.5% overall ranging

from 0.6% to 4.8%. If the prevalence estimates remain constant, the number of Canadians with dementia will rise to 592,000 by 2021 (Canadian Medical Association Journal 1994; 15(6)).

2.3 Alzheimer Disease: Biological, Clinical, and Social Perspectives

2.3.1 Biological Perspective

Alzheimer disease is by no means a new disease. Ancient Greek and Roman writers describe symptoms similar to those of AD. These characteristic symptoms were named in 1906 by Alois Alzheimer, a German physician who described the signs of the disease during the brain autopsy of a 50 year old patient who had died. The autopsy revealed dense deposits, now called neurotic plaques outside and around the nerve cells in her brain. Inside the cells were twisted strands of fiber, or neuro-fibrillary tangles. (National Institute on Aging, 1996). Although structural changes in the brain are also found in older persons without dementia, it is the density of plaques and tangles that distinguishes Alzheimer disease from normal aging (Cohen and Eisdorfer, 1986). Today a definite diagnosis of Alzheimer disease is still only possible when an autopsy reveal these “hallmarks” of the disease (National Institute on Aging, 1996).

The structural changes in the brain cortex affect thinking, judgment, reasoning, speech and language which are referred to as higher brain functions. In addition, structural changes in the hippocampus and other parts of the limbic system (which lie deep below the cerebral cortex) disrupt attention and memory and also account for

changes in emotional control and in personality that occur in Alzheimer disease afflicted persons. (Burns and Buckwalter, 1988; Cohen and Eisdorfer 1986, Reisberg, 1983).

Even though the disease is fairly well defined microscopically, there is as yet no known cure, and no single test to diagnose (Wright, 1993). Intense biomedical research currently focuses on the accumulation of beta amyloid protein deposits that form the neuritic plaques. Beta-amyloid is a protein fragment clipped from a larger protein (amyloid precursor protein) during metabolism. However, researchers don't know whether amyloid plaques cause AD or result from it (National Institute on Aging, 1995).

Although early and accurate diagnosis of AD is difficult, a reliable diagnosis with 80 to 90 percent accuracy (when compared to autopsy findings) can be obtained in many specialized centres (National Institute on Aging, 1995).

Although AD is diagnosed by excluding other causes, an 85 - 95% diagnostic accuracy can be achieved by using the NINDS-ADRDA criteria (Diagnostic Standard - Alzheimer Disease Related Dementia Assessment). These criteria require the presence of the dementia syndrome and a pattern of progressive decline in short term memory (the earliest symptom), followed by impairments in comprehension, naming, visual and spatial abilities, judgment, insight, and organizational skills, and the ability to perform complex sequences of tasks (Institute For Brain Aging, 1996).

According to the Alzheimer Disease Education and Research Center (1996), Doctors make a diagnosis of "probable" AD after reviewing a person's symptoms using the following format. A complete medical history is requested often with assistance of a person's family or friends to get more information. Basic medical tests are conducted to

rule out other possible causes or diseases. Neuropsychological testing of memory, problem solving, attention, counting and language help pinpoint specific problems. Brain scans focus on brain abnormalities and are also used to diagnose AD. There are several types of brain scans including a computerized tomography (CT) scan, a magnetic resonance imaging (MRI) scan, and a position emission tomography (PET) scan.

Age and family history are the strongest risk factors for AD (Graves et al, 1990). Approximately 25% of individuals with AD have one other first or second degree relative with dementia (Bird, 1996). Research has clearly determined that AD can be divided into several subgroups on a genetic basis as described in Table 4 by Bird (1995).

2.3.2 Clinical Perspective

Clinically AD typically begins with subtle and poorly recognized failure of memory. Slowly, over a period of years, the memory loss becomes more severe and eventually incapacitating. Other common symptoms include confusion, language disturbance, poor judgment, withdrawal, agitation and hallucinations. Some patients may develop seizures, Parkinsonian features, increased muscle tone, myoclonus, incontinence and mutism (Risse et al, 1990). Death usually results from general inanition, malnutrition and pneumonia. The typical clinical duration of the disease is 8 - 10 years with a wide range of 1 - 25 years (Bird, 1996).

More detailed clinical phases have been identified and summarized by Reisberg (1983) with the Global Deterioration Scale (GDS). This scale lists seven stages and

Table 4

Alzheimer Subgroups

1. Sporadic AD: Most patients with AD have a negative family history, and, therefore are considered to have sporadic AD. Onset can be anytime in adulthood. The exact pathogenesis of the disease is unknown, but as in all forms of AD there are deficits of cholinergic neurotransmitter systems and accumulation of A Beta amyloid peptide (in neuritic plaques) and abnormally phosphorylated tau protein (in neurofibrillary tangles). There is an association of AD with the e4 allele of apolipoprotein E (Apo E). A common hypothesis is that sporadic AD is multifactorial and results from a combination of aging, genetic predisposition and exposure to one or more environmental agents such as head trauma, viruses and/or toxins. Such environmental agents have not yet been proven to be directly involved in the pathogenesis of AD.
2. AD associated with Down syndrome: Essentially all persons with trisomy 21 develop the neuropathological hallmarks of AD after 40 years. More than half such individuals also develop clinical evidence of cognitive decline if carefully observed or tested [Brugge et al, 1994]. The reason for this association is presumably the presence of the amyloid precursor protein (APP) gene which maps to chromosome 21q21.3-22 and the resultant chronic overproduction of Ab amyloid in the brains of persons with Down syndrome who are trisomic for this gene.
3. Early onset familial Alzheimer's disease (EOFAD): There are uncommon but important families that have AD occurring as a Mendelian autosomal dominant disorder [Bird et al, 1989]. In the early onset type of FAD the mean age of onset in each family is before the age of 65. Children of affected persons are at 50% risk. There are at least three subtypes of early onset FAD.
4. Late onset familial Alzheimer's disease: Many families have multiple affected members all of whom have onset of dementia after the age of 65 or 70. No chromosomal assignment for a gene or genes directly responsible for this form of AD has yet been discovered. However, there is clear and well-documented association of late onset FAD with the e4 allele of Apolipoprotein E whose gene locus is chromosome 19q13.2 (Corder et al, 1993). Apo Ee4, by unknown mechanisms, appears to modify age of onset and shift the onset curve toward an earlier age.

corresponding phases. Stage one is considered to be normal with no cognitive decline. Stage two evidences very mild cognitive decline and is characterized by forgetfulness of such things as where has placed familiar objects. Stage three, the early confusional stage, is characterized by getting lost in familiar places, co-workers becoming aware of poor performance, forgetting names, and misplacing objects, mild and moderate anxiety tends to present. Stage four, the late confusional phase is characterized by decreased knowledge of current and recent events, decreased concentration, decreased ability to travel and manage finances. Denial is a common defense mechanism at this time. In stage five, the early dementia phase, the afflicted person can no longer service alone, some disorientation to time and place occur and the person may be unable to name close family members. In stage six, the middle dementia phase, afflicted persons still know their own name but occasionally forget the caregivers. Knowledge of the past is sketchy, they require travel assistance. Personally and emotional changes occur. Stage seven, the final late dementia phase, is characterized by loss of all verbal abilities, the afflicted person is unable to walk, is incontinent of urine, and requires assistance with toileting and feeding (Wright, 1993).

The Global Deterioration Scale correlates significantly with other psychometric measurements and with computerized tomography and metabolic changes in Alzheimer patients and is therefore a useful clinical tool (Ferris et al, 1980, Riesberg, 1983). Another commonly used scale to evaluate cognitive performance is the Mini-Mental State exam, which assesses orientation, registration, attention and calculation, recall and language (Folstein, Folstein and McHugh, 1975). The Maximum obtainable score is 30,

a score of 24 or below is considered to be an indication of cognitive impairment (Wright, 1993).

2.3.3 Social Perspective

It is estimated that 80% of care for individuals with Alzheimer disease is provided in the home by the family (Drew, 1995, Olsen, 1995). Family care provided in the familiar surroundings of one's home is the families' preferred choice (Morris and Murphy, 1995). However, care in the home offers a number of challenges to the caregiver as well as the afflicted person. Daniel tries to empathize with his wife, Norah, and her situation in the late stage of Alzheimer disease as she tries to "find home" (Heinrichs, 1996).

Imagine yourself in Norah's predicament. She no longer recognized her surroundings, her husband, or her friends. She had no sense of the time of day or night. She had no idea what to wear, or how to dress.

She knew she had to hide her pills, her glasses, her wallet, and all her credit cards. Why? Who knows? She knew she had to go to the toilet sometimes, but didn't know where it was or what it looked like.

She did remember the Globe and Mail newspaper which had always been important to her.

Home? She had lived in many places in her life and they had all vanished from her memory. The desire "to go home" is innate to the human being, but Norah had no home...

Yes, we've had the odd problem or contention in our wedded life states Daniel. But when Norah was diagnosed with Alzheimer disease the happiness of married life began to sour. He describes a situation when she "had him in a crisis."

She began to turn our thermostats up to 80, and if I tried to reason with her she turned them up as far as they would go. As well, she put on winter underclothing and two woolen sweaters. If I remarked that she might be too hot she put on her fur coat, woolen toque and mitts, as well. Was this my wife?

The ability of family caregivers to cope successfully is essential not only in the preservation of their own health, but also the prevention of inappropriate or premature nursing home placement (Mittelman et al, 1994). Schulz and Williamson (1994) report that the most frequently studied symptoms among caregivers are those indicating depression and demoralization. They go on to say that care for a demented individual is often extremely distressing although "it has been difficult to distinguish between the stress associated with providing care from the distress that results from witnessing the decline of the loved one."

In their book Broken Connections, Souren and Franssen (1994) argue that caregivers adjust their care in stages to adjust to the nature and degree of loss of functions of the person with AD. With each successive stage the caregiver's involvement in the activity of daily life increases from supervision and stimulation in the first stage to a total take-over of activity in the final stage.

Given the intensity of the care required by Alzheimer patients through the progression of the disease, we might expect that family caregivers would frequently use community services (Collins et al, 1993). However, a consistent finding of family research has been that individuals in the caregiving roles make little use of community services (Caserta et al 1987, Stone et al, 1987).

Possible explanations for low rates of service use are that families cannot locate services, afford those services that are available, or find available services unacceptable (Collins et al, 1994). Several studies have documented a high prevalence of clinical depression and anger two distinct, but interrelated negative emotions in family caregivers (Gallagher-Thompson, 1994). This author goes on to say that a considerable body of research has shown that depression is associated with certain kinds of deficits in social support such as a smaller informal social support network, less satisfaction with various kinds of support, and more conflicted relationships.

A consistent finding of research over the past decade is that family members of Alzheimer patients experience a great deal of stress. Collins et al (1994) in an article titled When Is a Service of Service? state the following:

In the absence of a cure for Alzheimer disease, a key health policy question is what service delivery model will best assist the family so that patient functioning can be maximized, the disruptive aspects of Alzheimer disease on the family can be minimized, and the quality of life can be enhanced for both patient and family.

2.4 Research Progress on Alzheimer Disease

Research on basic, clinical, and epidemiological studies of the etiology (cause), diagnosis and treatment of Alzheimer's disease and other dementias and treatable brain disorders fall into four areas. Basic research which deals with the cause of Alzheimer disease and other age-related neurodegenerative disorders including biomedical molecular genetic studies into inheritance and abnormal structures found in brains of people with Alzheimer disease. Population studies focus on the epidemiology of

Alzheimer disease and models for large area registries for Alzheimer disease and other dementing diseases of late life. Clinical studies focus on diagnosis, treatment and management of patients with AD. Research into treatment and management of AD includes developing the knowledge base required to interrupt the course of the disease, managing behavior and ultimately preventing AD. Research Centres (ADRC). The program at the Research Centers are designed to support the multifaceted approach to Alzheimer disease including clinic and basic research, professional and public information and educational activities (Alzheimer Disease Education and Referral Center, 1996).

Several recent genetic discoveries have shed new light on researchers' understanding of the cause and development of AD, leading them to believe that genetics could have a much larger role in the disorder than previously suspected. Based on this information, scientists have determined that there are several forms of AD (Department of Health and Human Services, 1994). Dr. Alan Roses (1994) refers to them as "The Alzheimer Diseases". Variations have been identified at four distinct chromosomal locations (chromosome 1, 21, 14 and 19) that appear to be responsible for different forms of the disease).

Although it is true that genetics play an important role in the development of AD, it is really a very complex disorder. Attempts to associate AD with environmental toxins, viruses, or lifestyles have met with little success (vs. Department of Health 1994). Risk factors for AD based on data from the Canadian Study of Health and Aging (1994) were studied, and supported a number of previously reported risk factors but provided little support for others. A new finding was an increased risk for those with occupational

exposure to glues as well as pesticides and fertilizer. The study supported the following previously reported risk factors of family history of dementia, lower education level, and history of head injury. Other factors that have been implicated as having a protection effect include postmenopausal estrogen replacement therapy, long term use of anti-inflammatory drugs and cigarette smoking (National Institute on Aging, 1995).

To date, only one drug has been approved for treatment of AD. In 1993, the Food and Drug Administration approved Tacrine hydrochloride (Cognex), however, its overall cognitive benefits are small and limited to a minority of patients (Schaum-Resau, 1995), and side effects require vigilance in monitoring (Schneider and Tariot 1994).

New research constantly changes our thinking about the diagnosis and management of AD (Weksler, 1994). There are several approaches to treatment or management of the disease. One approach is to treat the behavioural symptoms such as agitation, aggression, psychosis, depression, anxiety, apathy, and sleep or appetite disturbance. A second approach attempts to treat the primary symptom of the illness such as memory, language, praxis, attention orientation and knowledge. A third approach attempts to slow the rate of the illness. A fourth approach is to delay the time of onset of illness (Schneider and Tariot, 1994).

Patients often are referred to centres conducting clinical drug trials as soon as diagnosis of AD is confirmed. Although hopes for some recovery of symptoms are raised, they are seldom realized. It is more likely that researchers will come up with something that will slow the progress of the disease and that means people will be needing care at lower levels (Whitehouse and Voice, 1995).

Proceedings from a research planning workshop held in Washington, DC, 1994, resulted in a commitment to accelerate research on Alzheimer Disease over the next 10 years. The research document entitled "The Five-Five, Ten-Ten Plan for Alzheimer disease was a call to arms intended to rally the Federal Government, academia, pharmaceutical industry, general public and family support groups behind an integrated plan aimed to discover treatments for Alzheimer disease (Khachaturian, 1994).

Scientists have learned a great deal about AD over the past year. Projects in 1995 - 96 will seek to identify the gene on chromosome 14 responsible for one form of early onset AD. Scientists will also look for ways to enhance imaging techniques, especially MRI (Magnetic Resonance Imaging), as early diagnostic or predictive tools of AD. PET scans eventually may detect changes in brain metabolism that precede AD onset by as much as 20 years (National Institute on Aging, 1995). Some of the most current research projects at Alzheimer Disease Centers include the following basic and clinical projects. Researchers at Duke University MDC in Durham, North Carolina, are exploring the way that different apolipoprotein (apo E) alleles bind with tau, a protein associated with AD, to determine how the binding affects the neurofibrillary tangles a often found in AD brains. Scientists at Harvard Medical School/Massachusetts Hospital ADC in Cambridge, Massachusetts, are using strategies to isolate and identify familial (FAD) gene mutation on chromosome 14. Investigators at Case-Western University ADC in Cleveland, Ohio are examining how ethical and policy issues raised by both apo E testing and FAD testing affect families (Alzheimer Disease Education and Referral Centre, 1996).

Another important area of research in the next few years will focus on behavior intervention for patients and training programs for caregivers (National Institute on Aging, 1995). Behavior intervention will include preserving function and reduce excess disability, including research on wandering, insomnia, pacing, agitation, feeding and dressing difficulties, and urinary and fecal incontinence (Alzheimer's Disease Education and Referral Service, 1996).

Alzheimer Disease Research Center Clinics tend to follow research study participants over time, "enhancing the access to and potential efficacy of a sustained patient care and research" (Gwyther, Ballard, Hinman-Smith, 1990). These authors claim that the research setting builds upon family hopes and successful outcomes. In addition, the pro-active nature of the research centers buffer many families' feeling of helplessness by normalizing and dignifying services in the content of the longer term search for treatment or cure.

2.5 Interventions for Caregivers

"Unfortunately, as Alzheimer's Disease progresses, the family often bears a heavy burden. I only wish there was some way I could spare Nancy from this painful experience." Ronald Reagan, November 5, 1994.

If there is only one thing that caregivers, clinicians, and researchers can all agree on, it is that the stresses of caregiving can adversely affect family members (Bourgeois, 1995). The comprehensive nature of Alzheimer disease makes caregiving for these individuals one of the most demanding of all caregiving situations (Alzheimer

Association of Canada, 1992). The unrelenting social, emotional, and financial burdens of caregiving places caregivers at risk for psychiatric and physical illness (Schulz, O'Brien, Brookwala and Fleissner, 1995). To further complicate matters, caregiving families rarely have "one voice". That is to say, conflict in caregiving families often results in long-term imbalance in reciprocity, solidarity and role obligation (Gwyther, 1995). Another interesting point about caregivers is that families experiencing stress often resist using community services (George, Clipp, 1995). It goes without saying that planning for and providing supportive services that families will "use" to ease the burden of caregiving offers some interesting challenges.

Caregiving interventions reflect a wide diversity of approaches ranging from general educational programs, support groups, individualized counseling and multi-component outpatient or home-based approaches (Bourgeois, Schultz, and Burgio, 1995).

Historically, professionals felt that if caregivers received more knowledge about the disease they could manage patients better. Educational programs, workshops and telephone hotlines proliferated (Bourgeois, 1995). Support groups arose out of the perceived need of caregivers to express and share common feelings, experiences, and practical problem solving solutions. Although the information sharing and support were found to be helpful from support groups, personal needs of individual caregivers who had unresolved feelings of guilt, anger, and fear of their future relationship with the patient were inadequately addressed in a group setting (Gonya, 1989).

Individual and family counseling programs available through outpatient clinics have been the traditional vehicle for providing information and ancillary psychiatric social and nursing services to individuals and family caregivers of AD living in the community. Unfortunately, claims Bourgeois (1995), the social stigma associated with seeking psychological help is a major barrier to effective use of these services. Programs that attract families for their medical and diagnostic services components claim to increase the likelihood of enrollment in other counseling services once a trusting relationship between the family and agency has been developed (Gywther, Ballard, and Hinman-Smith, 1990).

Outpatient clinics can offer comprehensive multi-faceted intervention programs that address the changing needs of caregivers throughout their caregiving career. These programs largely blanket caregivers with a diversity of services - a more is "better" approach (Bourgeois, 1995). Gray (1983) found that caregivers who are offered too much at once may become overwhelmed and unable to decide where to direct their efforts. Although there is some evidence to suggest the more is better approach is helpful, what is lacking is a clear understanding of the relationships of various single components of the program to specific needs of individual caregivers (Bourgeois, 1995). Although Ferris and colleagues (1987) found that intensive individualized attention to caregivers in the form of family meetings, home visits, telephone consultations, support groups and referrals created a significant reduction in caregiver depression, anger, anxiety and patient institutionalization, it would be helpful to know which component or combination of components would be most effective. In today's age of diminishing

resources if we are not sure if more is better, the cost is too high to support these kinds of intensive intervention programs for caregivers (Bourgeois, 1995).

Caregivers of persons with Alzheimer disease can access family support services in Manitoba through the Alzheimer Association of Manitoba (ASM). The ASM began in 1982 with family support goals to (1) educate families about the disease, effective management and coping skills and community resources and (2) provide emotional support. The ASM mission statement is as follows:

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.

The program components are as follows:

- (1) Information and Educational Services
Information and Referral, Family Information Kits, Resource Library, Public Information and Caregiver Workshops.
- (2) Family Support Groups
- (3) Individual/Family Counseling
- (4) Other Programs
 - (a) Wanderers' Registry
 - (b) Brain Tissue Recovery Program
 - (c) Familial Alzheimer Disease Registry
 - (d) Annual Family Pot Luck Dinner

A Program Evaluation of Family Support Services for Caregivers of Persons with Alzheimer Disease was conducted by Pam Robb (1992). The overall purpose of the study was to increase the responsiveness of the ASM in addressing needs of caregivers

adjusting programs if necessary, to assist in priority planning, and to increase the knowledge and understanding of caregiving families.

A questionnaire consisting of 79 questions was returned by the sample population (which was comparable to other studies) and composed of 76 family members that lived in Winnipeg and used ASM services within the past 24 months. Respondents ranged in age from 26 to 82 years, with a mean age of 54.9 years. Most participants were women, most quite well educated and most had adequate income. Racial and ethnic distribution of this group of consumers did not represent the multi-cultural nature of our current society. Of the female group (77.3%), 19.7% were wives, 50.0% were daughter or daughter-in-law, 1.3% were sisters and 2.6% were nieces. The male group was 14.5% husbands and 11.8% sons.

The key developmental issues that were identified by this evaluation were in the implementation, specifically in the assessment of client needs, and subsequent referral to ASM and other services. Strategies addressing those issues were the basis of the following evaluation recommendations to the Alzheimer Society of Manitoba.

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 practice must be better explored and adapted, and models developed. It is suggested both prevention and intervention models be explored.

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

5. Winnipeg programs, currently staffed by one full 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 where identified.
7. Additional training modules related to volunteer training should be considered and developed to ensure that volunteers can expand their knowledge base and increase their skill level to meet clients' needs.

In conclusion, the key "developmental issue" according to the evaluator is providing adequate and timely assessment and ongoing service for family caregivers.

2.5.1 An Individualized Barriers Focused Model Intervention

Strategies to provide adequate and timely individualized assessments and intervention for family caregivers was developed and implemented by geriatric social workers at the Memory Disorders Clinic of the Joseph and Kathleen Bryan Alzheimer's Disease Research Centre at Duke University Medical Center. Each family was followed for eighteen months from the time of their relative's first visit to the clinic (Gwyther, Ballard, Hinman-Smith, 1990).

The Duke Model for Family Care was designed and implemented as a professional intervention to overcome some of the barriers to the use of formal and

informal services by families caring for individuals with AD. Previous research that included a survey to 50 family caregivers at Duke University identified three categories of barriers, mainly (1) personal and family (2) agency based, and (3) policy based. This model "highlights personal and family barriers to acceptance and use of help because these barriers are most amenable to clinical intervention". (Gwyther, Ballard, Hinman-Smith, 1990).

The setting for the out patient clinical intervention for families is the Memory Disorders Clinic which is the clinical core of one of the fifteen National Institute on Aging Alzheimer's Disease Research Centers in United States. The Memory Disorders Clinic is the clinical arm of the Joseph and Kathleen Bryan Alzheimer Disease Research Center (ADRC), Division of Neurology at Duke University Medical Center in Durham, North Carolina.

Alzheimer Disease Research Center Clinics tend to follow research study participants over time, "enhancing the access to and potential efficacy of a sustained patient care and research" (Gwyther, Ballard, Hinman-Smith, 1990). These authors claim that the research setting builds upon family hopes and successful outcomes. In addition, the pro-active nature of the research centers buffer many families' feeling of helplessness by normalizing and dignifying services in the context of the longer term search for treatment or cure.

2.5.2 The Social Work Role at Duke Memory Clinic

The Memory Disorders Clinic at Duke Medical Center is open five days a week and located in a physically separate, handicapped accessible building one mile from the Duke Medical Center hospitals (Appendix A). It is a small manageable unimposing one storey building that was originally an insurance office. It offers the security of a major medical center's expertise and credibility, without unduly frightening vulnerable patients and families by exposure to crowds of very sick people in one place" (Gywther, Ballard and Hinman-Smith).

The first hurdle for families facing Alzheimer care is seeking a diagnosis and an adequate interpretation of "probable" or "possible" Alzheimer disease. The social work intervention at Duke is designed to reach families at this critical point. Their hypothesis was that "the timing of information about services is the active ingredient in determining use and efficacy of these strategies. The diagnostic visit is a turning point for many families."

The author's claim that the written service plan (Appendix C) serves a number of purposes in assisting families to overcome barriers to service use. First, it is a concrete reminder of what the family has already initiated and what is recommended. Second, it should assist in reinforcing successful family coping strategies. For example, if the primary caregiver is already receiving informal respite from his/her children, this can be acknowledged on the plan as "continue to encourage your daughter to take her mother shopping and out to lunch on Saturday." The third purpose is to give the family some time to incorporate the normalizing aspect to overcoming barriers as well as time to calm

down from the diagnostic crisis and think about their options. The service plan is reinforced and revised for the family member in a clinic visit, over the telephone or by letter from either the physician or worker.

The intervention relies heavily on the use of non-traditional clinical skills - brief, non-pathologically focused assessment skills, telephone counseling, educational interventions, interpretive skills, and close links with local service providers. It is somewhat like case management, but it keeps the family caregiver in the driver seat."

It teaches the family how to enhance their own care management. It supports the family caregiver's preferred level of involvement in care, and it does not encourage the use of specific services or the use of formal over informal services. It relies heavily on the "borrowed" legitimacy of health services patient-centered services, as well as less traditional communication by telephone, letter and client advocacy with local community agencies (Gwyther, Ballard and Hinman-Smith, 1990).

The Social Work Service Plan

After the initial diagnosis, the physician encourages the family to see the social worker for immediate concrete information. All families are routinely introduced to the social worker as part of the treatment team. At a suitable time, arrangements are made with the primary caregiver for an initial baseline structured assessment interview with the social worker. Following the assessment with its "subtle attention to addressing potential barriers," a more structured service plan can be developed (Gwyther et al, 1990).

2.5.3 Social Work Role - A Systems Perspective

Systems theory offers a conceptual framework that supports the purpose of the social work profession by shifting attention from either the person in the environment to problems in the interaction. Systems theory link people to their interactions with other

systems and relationships therefore it provides a framework for gaining an appreciation of the entire range of elements that bear on social problems including the social units involved, their interrelationships and the implications of change in one as it affects all. The systems perspective also places the agency as a social system and the social worker and client in the same transactional field. Social workers, then, are a social system and involved as components of a clients' social system network (Compton and Galaway, 1989).

The role of the social worker at the Memory Disorders Clinic at Duke is to act as "care manager" for the family unit. Professional feedback remains goal directed, flexible and involves the client's participation. This concept fits well with Systems Theory that sees people as active personality systems capable of self-initiating behavior and thus able to contribute and alter their behaviour or even create new environments (Compton and Galaway, 1989).

The potential value of using systems theory as an organizing framework for social workers is that it allows for problems of dysfunctioning to be logged in the transactions and lack of fit between the individual and the various social systems of which he/she is a part (Compton and Galaway, 1989). The systems framework for the individualized strategies to assist Alzheimer family caregivers at Duke's Memory Disorder Clinic are based on the following Social Work goals.

There are four major goals guiding the individualized strategies to overcome barriers to service use among Alzheimer family caregivers.

1. To decrease the negative consequences of caregiving on the physical, mental, social and financial resources of the family.

2. To reduce or prevent potential family conflict which may diminish the availability of emotional support and practical informal help from secondary family caregivers.
3. To enhance the equitable sharing of responsibilities for care within a family unit and between family and other informal and formal services. This does not imply that equal division of responsibility is desirable or realistic.
4. To increase the effectiveness and quality of family care and to enhance the confidence and satisfaction of the family with its capacity to maintain preferred levels of involvement in caregiving.

According to the authors, the objectives suggest an initial reliance on educational and interpretive strategies, case management, client advocacy and family conflict resolution. Counseling was relatively focused on enhancing caregiver coping effectiveness to encourage appropriate use of relevant local help (Gwyther et al, 1990).

The individualized service plan is developed with the caregiver at the patient's second clinic visit, usually a month after the first one.

2.5.4 The Internet and Family Support

The internet is a powerful way for people with shared interests to communicate. In the past, people suffering from disease and disabilities, and their caregivers could rely only on published information and support groups, if they existed and were accessible. Today, they can join a virtual community on the internet to communicate with others experiencing similar problems. The benefits of such virtual communities are just beginning to be seen and the potential is huge. The immediate communication between patient/caregiver groups and the medical community is sure to contribute to future developments in disease management and treatment (Alzheimers Association and University Hospital of Cleveland, 1995).

An innovative computer pilot project called CHESS (The Comprehensive Health Enhancement Support System) has been developed to meet the informational, social and decisional support needs of individuals and families facing a diagnosis of AD. CHESS is designed to integrate patient, doctors, and technology in order to remove or reduce the barriers to the information and support needed. Used in the home, CHESS can be convenient, comprehensible, timely user-controlled (Wackerbarth, 1996).

Another similar program is offered by the Alzheimer's Disease Support Center (ADSC) on the Cleveland Free-Net. Families caring for Alzheimer patients do not participate in traditional support groups or education programs because they are overwhelmed by the responsibility of caring for the patient (ADSC). In Cleveland, these families can participate in meetings, share their thoughts and obtain advice from experts - all without leaving home. The ADSC provides access to personal computers, modems, and the Internet to local families and health and social service professionals who care for persons with AD and related dementias. The supply network offers 24 hour-a-day e-mail, a "Caregiver Forum" bulletin board monitored by professionals, a question and answer forum staffed by clinical experts from the University Alzheimer Center and numerous informational resources. ADSC users, ranging in age from teens to people in their eighties have formed a "computer family" and meet for monthly support luncheons. ADSC "breaks the boundaries faced by many Alzheimer families and provides a full circle link from caregiver to professional and back." It is an example of the virtual community that exists on the internet and how others facing similar problems can find

through the information highway. (Alzheimer's Association and University Hospital of Cleveland, 1995).

2.6 The Memory Disorder Clinic at Lions Manor

The St. Boniface General Hospital Research Foundation recently made a commitment to set up a Clinical Research Centre, specializing in the senile dementias at Lions Manor. An important component of this Centre will be a Memory Disorder Clinic.

Lions Housing Centres are building a new 102 bed Personal Care Centre at Lions Manor. Included in the plan is a 24 bed unit on the fourth floor specializing in care for individuals with Alzheimer disease and related dementias. Along side of this unit, a 6,000 square foot area will be developed by St. Boniface Research Centre for clinical research purposes. Also, to be developed on the fourth floor north tower will be a day/evening program for individuals with Alzheimer dementia, and respite care for overnight weekend or vacation relief. In effect, the total fourth floor will be available for possible research purposes as it will provide a continuum of care options for individuals with Alzheimer dementia and their families.

Dr. John Foerster, Director of Research, St. Boniface Hospital Research Centre, describes the partnership with Lions Housing for the Clinical Research Unit at Lions Manor as follows:

The Lions Manor satellite will act as the outreach arm of the Centre of Health Research For The Elderly to be developed on the fourth floor of the Research Centre. The Centre development will encompass 20,000 sq. ft. of new laboratory space and over 100 new scientific personnel actively engaged in the basic and clinical research associated with the "aging brain". In general terms, the Lions Manor clinical research unit will be involved in studies dealing with clinical behavioral

manifestations, psychometrics, diagnostic criteria, prognostic factors, epidemiology and clinical genetics, and metabolic studies in support of basic science research. In addition, and perhaps more importantly, the unit should foster and support scientifically designed clinical trials involving medications or other therapeutic interventions and should function as the clinical arm of the molecular, genetic and biochemical studies, both in familial and sporadic forms of the disease.

The Research Foundation believes that the Lions Manor Research Centre will be an excellent first step towards realizing the goal of establishing a Centre of Health Research For The Elderly. Since most dementia patients are cared for in outpatient and day programs or in institutions other than acute care hospitals, it is crucial that the St. Boniface Hospital establish alternate ways to access these patients. In partnership with Lions Manor, we believe that a major step towards becoming a centre of excellence in the senile dementias can be established in Winnipeg.

An analysis of the results of the two questionnaires used in the needs assessment for the use of a Memory Disorder Clinic at Lions Manor will initially be used to develop the Functional Program for the clinic. In other words, the recommendations from this practicum report will be critical to the development of not only the architectural design of the facility but the intervention model of family support as well.

A draft of the architectural plan for the clinical research space has been developed (Appendix B). What remains undeveloped is the area to be used for the Memory Disorder Clinic. Our aim for both spaces is to create a friendly, warm unique homey environment which is non threatening for patients and families. Because of the multidisciplinary nature of the clinic we expect students from many different professional disciplines. We also expect to partner in a student/professional exchange program with Duke University. Scientists from the clinical research centre will be participating

members of a consortium of international researches, during collaborative studies (i.e. drug trials).

The scientific team will include a clinical director, neurologist, neuropsychologist, nurse and social worker. A draft of the space requirements for The St. Boniface Hospital Research Centre scientists includes five dry labs for clinical research, space for 6 students, a conference room, an observation room, a reception area, and an office area. In an attempt to understand how to best design the clinic area, it was important to understand two things. First, what type of activity would likely take place at the clinic, and second, how and by whom would patient referrals be made. At this point it was anticipated that the project would be supported by physicians, professionals, and the community, due to the perceived need for such a specialized operation. This need being perceived by recent demographic indications of the tremendous increase in the aging population to be affected by the disease in the very near future.

In keeping with the goal of creating a "centre of excellence" it was important to research a successful model. With a leadership reputation of excellence and a "proven" track record in dementia family support and research, the Memory Disorder Clinic, Duke University, was selected as a possible model. Arrangements were made to tour the facility and speak to the people in charge. This was arranged during the 9th Annual Alzheimer Research Centre Conference, February 1995 in Durham, North Carolina. Our gracious tour organizer also arranged a special luncheon so that we were able to meet the conference presenters and ask questions first hand. Many of the conference presenters played an integral role in setting up and on working at the clinic. It was at

this luncheon I met my “mentor to be” and co-author of the book Overcoming Barriers To Appropriate Service Use, Liza Gwyther, Director of Education, Duke University, Centre on Aging. I have subsequently met with Liza and she has reviewed my second questionnaire. The family support intervention model used for the second questionnaire was based on her “overcoming barriers” approach.

Although there are a variety of referral options at the MDC at Duke, most patients are referred by their family physician. Therefore, it seems clear that the successful outcome of our clinic will in part depend on a referral base of physicians in Manitoba who see the clinic as valuable to their practise. It is important to know what group of physicians will support the clinic, how many referrals they will make in a year, and how they feel about the importance of assessment and diagnosis, family support and education and research as it relates to their practice. Those questions form the basis for the first questionnaire of the needs assessment.

According to Kaufman (1979) a needs assessment “attempts to determine and close the gaps between what is and what should be.” Furthermore, three elements are involved, (1) the notion of formal, planned investigation, (2) the focus on discrepancy between current reality and some desired state, and (3) the inclusion of a process of setting priorities among potentially competing needs.

Needs assessment should be used to guide policy and program development. It provides information on which to base funding allocations. The general needs assessment is sometimes called an external needs assessment because it focuses on the health problem or gap itself, with no assumption about any organization's role or mandate to close the gap. There are no preconceived notions about solutions.

In contrast, the service specific needs assessment assumes the perspective of the service providing agency, and tries to demonstrate need for new and modified approaches to service delivery by that agency. There are more preconditions or constraints on the scope of the assessment; it assumes a set of boundaries on the solutions and focuses on how to bring those solutions about (Feather, McGowan, and Moore, 1994).

The needs assessment for the use of a Memory Disorder Clinic would fit into a service-specific needs assessment as it attempts to demonstrate the need for a new approach to service delivery for individuals with memory problems and their family caregivers.

3.0 METHODOLOGY

3.1 General Aims and Design

A mail survey design was chosen as the method of assessing the need for the Memory Disorder Clinic. The survey included two questionnaires, each containing an introductory letter describing the purpose of the study and requesting clients' participation. Survey research questionnaires have a number of advantages. First they can be used to gather data more inexpensively and quickly than interviews. Second, mailed questionnaires enable one to collect data from a sample that is geographically dispensed. Third, with questions of a personal or sensitive nature, mailed questionnaires may possibly provide more accurate answers than interviews. Finally, mailed questionnaires eliminate the problems of interviewer bias (Monette, Sullivan, and Dejong, 1986). In addition, Rublin and Babbie (1993) state that questionnaires are a method of collecting data by asking questions that people can agree or disagree with.

The two survey research questionnaires sent to respondents consisted of closed-ended questions using the Likert scale and open-ended questions asking for respondents' comments. A five-point Likert scale was used to increase the sensitivity of the survey instrument and show wider variation in responses. Also sent was a covering letter indicating data confidentiality, the purpose of the study, who is doing it, the anticipated benefits of the research being conducted, and a deadline for returning the questionnaire. A self-addressed stamped envelope was supplied for returning the questionnaire.

3.1.1 Questionnaire One

The purpose of the first questionnaire was to attempt to determine how and if physicians in Manitoba will use the clinic. It consisted of an introductory letter (Appendix D), a brief summary of memory disorder clinics (Appendix E), and a brief "four questions" survey (Appendix F). The questionnaire was mailed to a sample population of psychiatrists, neurologists, family physicians, and physicians specializing in internal medicine in Manitoba.

A diskette containing all fully registered physicians in Manitoba (with specialty codes) was obtained from the College of Physicians and Surgeons of Manitoba. A systematic stratified sampling of four coded groups of physicians was used for the first mailed questionnaire. Systematic sampling ensures a degree of representativeness and permits an estimate of the error present. A stratified sampling is a method for obtaining a "greater" degree of representativeness - for decreasing the probable sampling error. Also, stratified sampling is based on a second factor in sampling theory. "Rather than selection your sample from the total population, appropriate numbers of elements are drawn from homogeneous subgroups." (Rubin and Babbie, 1993). More specifically, Cochran (1977) argued that stratified sampling is useful when

1. the population is made up of different types or subjects for each type of what you wish to know things individually
2. you have a good system for distinguishing one group from another, and
3. the questions you are asking will likely show a difference in overall responses by group.

Because we were interested in finding out if there were difference in response rates between the four groups, a systematic sampling framework was developed. With the desired sample size of 200 physicians, the following stratum sample size was calculated. The total population of the four groups was 1247. They were broken down as follows:

$N = 1247$ - total number of doctors

$N_1 = 988$ = # of Family Physicians

$N_2 = 126$ = # of Internal Medicine Specialists

$N_3 = 117$ = # of Psychiatrists

$N_4 = 16$ = # of Neurologists

Table 5 Physician Sample Size				
$N = 1247$	Stratum I	Stratum II	Stratum III	Stratum IV
	FP's	Int. Med.	Psych.	Neuro
	$N(1) = 988$	$N(2) = 126$	$N(3) = 117$	$N(4) = 16$

The weighted desired sample size $N = 200$ calculates as follows:

Desired Sample Size $n = 200$

$$n_1 = \frac{N_1}{N} n = \frac{988}{1247} (200) = 158.5 \text{ Take } n_1 = 159 = \text{sample of 159 Family Physicians}$$

$$n_2 = \frac{N_2}{N} n = \frac{126}{1247} (200) = 20.2 \text{ Take } n_2 = 21 = \text{sample of 21 Internal Medicine Specialists}$$

$$n_3 = \frac{N_3}{N} n = \frac{117}{1247} (200) = 18.8 \text{ Take } n_3 = 19 = \text{sample of 19 Psychiatrists}$$

$$n_4 = \frac{N_4}{N} n = \frac{16}{1247} (200) = 2.6 \text{ Take } n_4 \geq 3 = \text{sample of at least 3 Neurologists}$$

The formula used to calculate the stratum sample sizes assumes the cost of every observation is the same and the variance is the same for all strata. It is also based on $p = 0.5$, which is the worst case scenario (table 5) i.e. the actual error bound may be better than calculated before the experiment is carried out (Natalie Edwards, Statistical Services, University of Manitoba, 1996).

Bound on Error of Estimation (Neurologists)

$$2 \frac{1}{N^2} \sum_{i=1}^4 N_i^2 \left(\frac{N_i - n_i}{N_i} \right) \left(\frac{p_i q_i}{n_i - 1} \right) = 0.06508 \quad \text{when } n_4 = 3$$

$$= 0.0647 \quad \text{when } n_4 = 8$$

$$= 0.0646 \quad \text{when } n_4 = 16$$

(all 16 neurologists were surveyed as there was no significant difference to the error bound).

Table 6

Stratum Sample Size $n(1) - n(4)$ with 6 sample sizes (n) and related error bound (B).

FIXED n

N	n(1)	n(2)	n(3)	n(4)	B ($p = .5$)	B ($p = .25$)	B ($p = .10$)
200	159	21	19	3	0.06508	0.05636	0.03905
250	199	26	24	4	0.05658	0.04900	0.03395
300	238	31	29	4	0.05085	0.04369	0.03027
350	278	36	33	5	0.04542	0.03933	0.02725
400	317	41	38	6	0.04126	0.03573	0.02500
450	357	46	43	6	0.03773	0.03267	0.02264

Questionnaire one was mailed by Manor Custom Mail, 260 St. Mary Avenue, Winnipeg, to 235 potential respondents on April 4, 1996, with a return request date of April 26, 1996. A systematic random sampling with a random start was made from the coded physician list. Each component of the questionnaire was given a number for easier

data entry when the surveys were returned (i.e. 1a, 1b, 1c, 1d). A computer data base software program, Access, was used to analyze the coded data. The questionnaires were numbered so that a subgroup for the second questionnaire could easily be identified.

3.1.2 Questionnaire Two

The purpose of the second questionnaire was to assist in planning for a social work role in providing family support and education at the clinic at Lions Manor. An introductory letter (Appendix G) and questionnaire (Appendix H) was mailed to the following four groups of people. First, a subgroup of physicians interested in the family support and education component of the clinic (those who responded to question #4 from questionnaire #1). Second, 10 families whose relative has Alzheimer disease and live in Meadowood Personal Care Home. Third, 10 geriatric social workers. Fourth, 10 geriatric nurses (belonging to the Manitoba Association on Gerontology).

This questionnaire requested that respondents evaluate the social work role at the memory disorder clinic, Duke University, as to its appropriateness for use at Lions Manor. The focus of the Duke model is an individualized service plan based on recommendations for timed and dosed informal and formal assistance for the family unit (Appendix C). Respondents were also requested to make recommendations for the enhancement of the social work role in providing family support and education at Lions Manor. A special introductory letter along with the questionnaire was mailed to the subgroup of physicians (Appendix I).

As previously stated the rapid pace of research on Alzheimer disease over the past 20 years has opened numerous pathways that ultimately will lead to effective treatment for the disease. Treatment research falls into two general categories. First neuroscientists have turned up an array of substances in the brain that seem to be related to the disease and these are potential targets for biomedical treatments. From a clinical perspective, a second group of studies focuses on management of the disease. This area of research is looking for ways to treat the symptoms of Alzheimer disease and slow its progress, either through drugs or behavioral approaches (McNeil, 1995).

Memory clinics have an important role in investigating the cause of memory impairment, and in detecting early cases of dementia. These specialized clinics therefore provide a service for physicians, caregivers, and patients. They also provide opportunities for families to assist with investigating treatments. Neuroscientists will be located at St. Boniface Hospital Research Centre, 4th floor, researching biomedical treatments. Clinical scientists will be located at the Clinical Research Centre at Lions Manor also on the 4th floor. The purpose of the MDC at Lions Manor which is part of the clinical research center will be to assess and diagnose individuals with dementia, to provide support for families, and to assist in the selection of appropriate individuals for treatment research.

3.2 Method

3.2.1 Questionnaire One

An important first step in planning for a Memory Disorder Clinic that intends to provide service to support physicians practice is to survey physicians requesting their

feedback on the plan. After consultation with Dr. John Foerster, Director of Research for St. Boniface Hospital Research Centre, I chose a brief physician questionnaire. The questionnaire was limited to 3 - 4 very specific central questions to ensure response rate. The aim of the first question was to categorize the most likely groups of physicians making referrals (1) family physicians, (2) neurologists, (3) psychiatrists, and (4) specialists in internal medicine. The next two questions would identify if the clinic would be of value to their practice and if so how many referrals they expect to make in one year. The final question was designed to assist me in selecting a physician subgroup to send the second questionnaire to. The question asked physician to rate the importance of the clinical components of the MDC as they related to their practice on a scale of 1 - 3. The components being, assessment/diagnosis, family support and education, and research. The physician subgroup was identified on the basis of a high positive rating (most important) given to the family support and education component.

I would like to acknowledge the contribution of several individuals that I consulted with on the design of the questionnaire. Natalie Edwards, my advisor from Statistical Services, University of Manitoba, and Linda Scholcz, Manager of Manor Custom Mail, pretested both questionnaires and offered valuable suggestions to the design and wording. I also consulted with Dr. Ken Brown, Registrar, College of Physicians and Surgeons.

A personal letter of support from Dr. Foerster was included to give the study credibility and increase the likelihood of a response from physicians. Dr. John Foerster co-signed the introductory letter which was also printed on the Research Centre

letterhead. Along with the letter and questionnaire, was a one page information summary sheet on the Memory Disorder Clinic at Duke. All three were marked with a stamped self addressed envelope to The Memory Disorder Clinic, Lions Manor, Attention Judie Velnes.

Responses were forwarded to Manor Custom Mail for data entry.

3.2.2 Questionnaire Two

According to Gwyther et al (1990) research findings of Alzheimer caregivers' reluctance to use services or their underutilization or inappropriate use of needed and desired service has major implications for social work practice. Furthermore, they suggest knowledge of a service and its benefits, need for the service, desire for the service do not insure appropriate timely use." Group education, outreach and publicity address the knowledge barriers only. There is obviously some breakdown between family knowledge, desire or need for a service and family capacity to use it." (Gwyther, Ballard, Hinman-Smith, 1990).

These findings provide the rationale for the second questionnaire which first examines how people feel about existing Alzheimer Care Services. That is to say, are there barriers for families, if so what are they? Five of the eight barriers were identified by Gwyther et al (1990) in their book Overcoming Barriers to Appropriate Service Use. They include government policy, government funding, family pressure, lack of knowledge and financial. From my experience of working with family caregivers seeking appropriate services I would often hear - there is just too much red tape. For an

exhausted caregiver the fragmented complicated help system is often overwhelming and a barrier to service use. The final two barriers, lack of training of Alzheimer service providers and continuity of care (staff) were barriers suggested by Liza Gwyther (Barriers author) in revising the questionnaire with me.

From my personal experience social work support for families caring for individuals with Alzheimer disease begins with developing a genuine trusting and honest relationship together. That relationship forms the basis for helping families to either take "one day at a time" or move ahead in care planning for the future. According to The Arc's Family Support Program (1995) the goals of good family support include the following:

- To keep families together
- To improve the caregiving ability of families and to improve their ability to meet the many needs of the family member with a disability
- To respect cultural, economic, social and spiritual differences
- To help families find and use available support

The individualized service plan approach to family support used at the MDC at Duke was specifically designed for out-patient centres. The intervention plan forms the basis of question 3 and 4 of questionnaire two. The very brief introduction includes the comment that Social Workers at the Memory Disorders Clinic at Duke University Medical Centre was a preventative barriers focused strategy to reach families before crisis develop (Appendix C). They work with physicians before and after diagnostic evaluation is complete. Question three asked respondents to indicate whether they

strongly disagree (SD), agree (A), disagree (D), strongly disagree (SD), or don't know (DK) to the following components of the individualized strategy

- a) contact with the social worker on the initial visit to the clinic
- b) family assessment of barriers at the MDC on the return visit for the medical evaluation one month after the initial visit
- c) development of a one page written "service plan" with concrete recommendations for use of informal services (voluntary), formal services, products, gadgets, literature and
- d) a three month follow up by phone to review the service plan. Respondents were asked if they would recommend this model at the MDC at Lions Manor in question 4. Questions asked respondents "how could we enhance the social work role of providing family support and education?"

3.3 Limitations of the Study

3.3.1 Questionnaire One

In an attempt to keep the survey length to one page, only a limited amount of information was received from respondents. Clearly a disadvantage to questionnaires is that there is no opportunity to probe for more information or evaluate nonverbal behavior of the respondent (Monette et al, 1986). Although adequate, a response rate of 41% may not be representative of the study population. Rubin and Babbie (1993) argue that the chief criterion of the quality of the sample is the degree to which it is representative the extent to which the characteristics of the sample are the same of those of the selected study population.

There are also other potential influencing factors that could place limits on this study. Since all questionnaires face the problem of non-response bias (Monette, 1986) these factors are worthy of consideration. First and foremost is the current political climate of health care reform in Manitoba and its effects on physicians' practice. The closure of hospital beds, emergency services in some hospitals, centralizing of rural health services and the careful scrutiny to physician billing could negatively influence physicians' attitudes to any new health care initiative. There is also the issue of the Memory Disorder Clinic being located in Winnipeg only. The questionnaire was mailed to a sample of physicians in Manitoba. Access therefore, could present as a barrier to rural practice referrals when travel, transportation and cost become real issues for patients and families. There is the perception by two physicians that the MDC would duplicate current available psychogeriatric assessment units. On the other hand, judging from other responses, there seems to be a general "lack of knowledge" on the part of many physicians about Alzheimer disease related dementias, the need for early diagnosis and the value of research. In my opinion it would be very difficult to estimate the number of referrals to such a clinic in one year. Some physicians may feel intimidated by the concept of someone offering help to their practice, as is "they can't take care of their own patients." In addition, another important thing to keep in mind is the change in status of physicians since the data was coded. Some physicians may have moved, retired, changed specially or decreased.

3.3.2 Questionnaire Two

I found it challenging to summarize the Duke Model of Family Support into 4 very specific questions that were to be inclusive of all vital components of the model. As Rubin and Babbie (1993) empathized “often you can become so deeply involved in the topic under examination that opinions and perspectives are clear to you but not be clear to your respondents.” With respect to the subgroup of physicians sampled, I have a couple of comments. First, physicians may not have reacted well to receiving a second, longer questionnaire. Also, some physicians may not be familiar with an integrated social medical model approach to support. Perhaps there simply was not enough information in the questionnaire to grasp the notion of operationalizing the model well enough to make an informed decision. There tends to be some overlap in the nursing and social work role related to family support and education. Clearly this intervention as described is based on a bias toward social work. However, social workers do not have exclusive rights to providing family support and education. Nurses responding to the questionnaire may have felt sensitive to this issue. The ten families surveyed had relatives placed in a personal care home. The questionnaire could have contained too much social work “jargon”. Simply put, the questionnaire content was so unfamiliar that families might have found it to overwhelming to fill out.

4.0 SURVEY FINDINGS

The findings from the surveys are presented in this chapter. The information collected from the respondents in the study was analyzed using descriptive, comparative and quantitative methodologies. The first section deals with descriptive findings from questionnaire one followed by a discussion of the implications of the findings on future service use. The second section deals with descriptive findings from questionnaire two followed by a discussion of the implications of the findings. As well, current research trends on future service use are reviewed.

4.1 Questionnaire One

There was an overall response rate of 41% from questionnaire one. A description of the subgroup comparison is presented in Table 7.

TABLE 7
Response by Specialty Area
(n = 95)

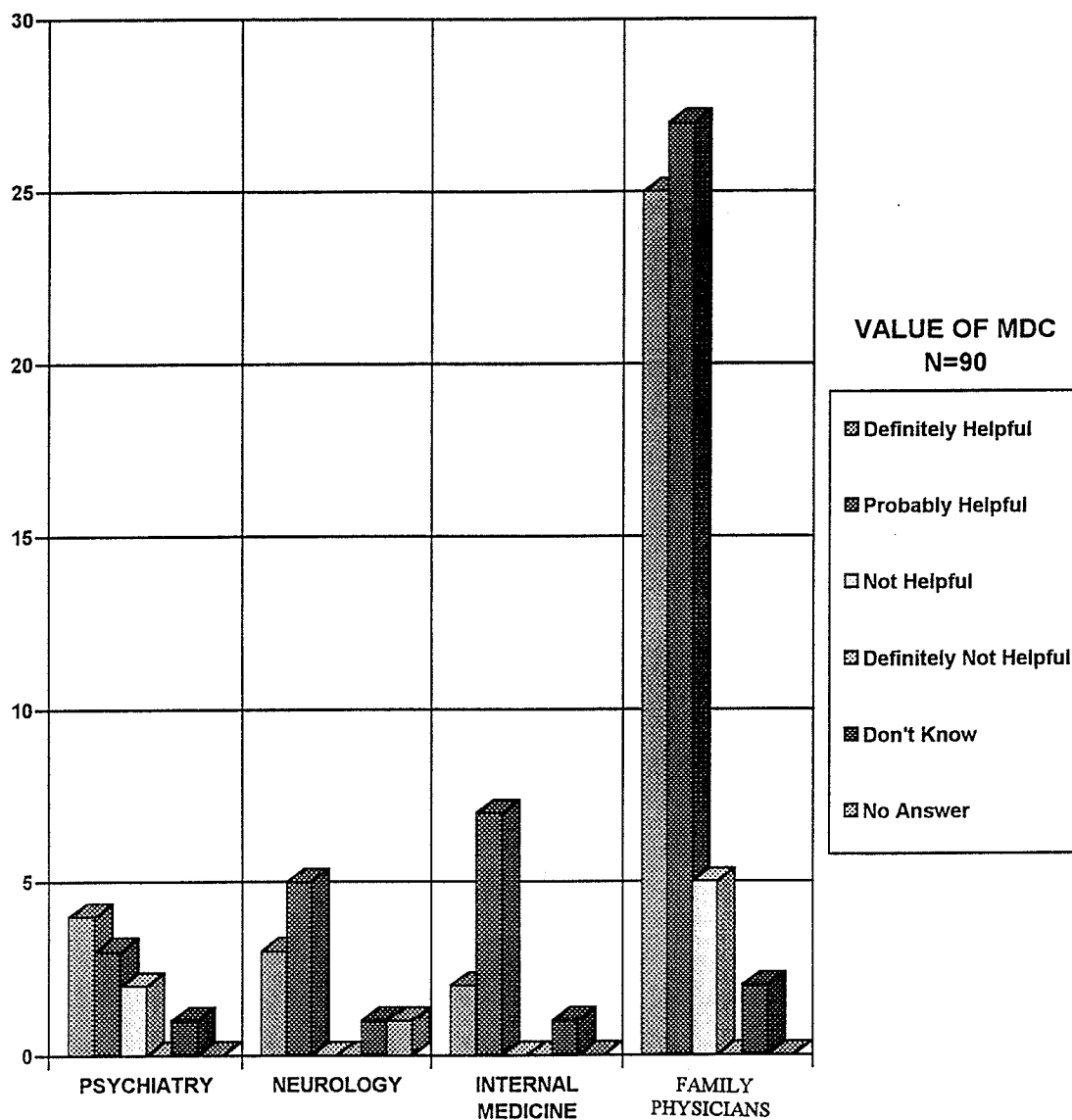
<u>Type of Specialty</u>	<u>No.</u>	<u>% of Responses</u>
Psychiatry	11	12
Neurology	10	11
Family Physicians	59	61
Internal Medicine	10	11
None of the Above	<u>5</u>	<u>5</u>
	95	100

An opportunity was given to respond to "none of the above" to provide flexibility in the event the category did not "fit". The five physicians that responded to that

category included an anesthesiologist, ophthalmologist, pediatrician, and emergency room physician, and one respondent who did not identify an area of specialty.

An estimate of the weighted average of the survey respondents indicating a MDC would be helpful (Definitely Helpful and Probably Helpful) is 81% ($\pm 8\%$ with 95% confidence). In other words, the 81% response supporting the clinic can be generalized to the total population of physicians with 95% confidence that it is representative \pm or -8% ($.73 < p < .89$). This percentage however, ignores non-response and other non-sampling error. A comparison of physician responses is graphically presented in figure 1. Generally the graph indicates how the 81% support for the clinic (definitely helpful, probably helpful) is represented in the four physician groupings. Different shading is used for responses to questions indicating the 5 categories of the Likert scale as well as a no answer category. The highest bars in each physician grouping represent the positive response to the Clinic.

Physicians in Manitoba feel the Memory Disorder Clinic at Lions Manor will be valuable to their practice. As one physician pointed out "I work in Emergency Medicine, there are patients we see who are a diagnostic dilemma and/or need family support education and/or support. A memory disorder clinic would be helpful." Another wrote "this is a relatively neglected area in our province, despite its utmost utility." Psychogeriatric programs are available in Manitoba and one physician felt that the MDC would serve a similar purpose. Three physicians were concerned that a Winnipeg location only would limit rural referral. One respondent felt that the majority of cases of



PSYCHIATRYSAMPLE SIZE 11
 NEUROLOGYSAMPLE SIZE 10
 INTERNAL MEDICINE.....SAMPLE SIZE 10
 FAMILY PHYSICIANSSAMPLE SIZE 59
 TOTAL 90

FIGURE 1. VALUE OF THE MEMORY DISORDER CLINIC AT LIONS MANOR AS IT RELATES TO PHYSICIAN PRACTICE
 (Questionnaire One)

dementia did not need a formal Memory Disorder Clinic evaluation. "The issue is not usually diagnosis but what can be done about it."

Although there is overwhelming agreement by physicians in Manitoba (81%) that the Memory Disorder Clinic will be of value to their practice, there appears to be some confusion as to the overall purpose of the various components of the clinic.

Physicians who answered definitely helpful or probably helpful to the clinical need/value of a MDC were asked to assess the number of patient/referrals that they anticipated making in the period of one year. A total of 77% of physicians responded to a specific number as described in Table 8.

TABLE 8
Number of Patient Referrals to MDC
at Lions Manor in One Year
(n = 95)

<u>Physician number</u>	<u>Patient Referrals</u>
51	1 - 9 per year
21	10 - 29 per year
1	50 - 69
5	Don't know
1	0
<u>16</u>	No answer
95	

Note: The approximate average number of referrals per physician in a year is 10 patients.

$$\frac{(1)(0) + (51)(5) + (21)(120) + (1)(60)}{74} = 9.9 \text{ ref/phy.}$$

Several physicians made comments with respect to the number of patient referrals that they would anticipate making in one year. Again the issue of rural accessibility was

raised. Referral to Winnipeg would be limited because of "travel problems" for rural families. Generally, physicians felt that the number of referrals would increase once the service became more familiar to physicians and the public became more aware of the benefits of the MDC at Lions Manor.

Physicians were asked to rate the importance of the clinical components of the MDC as they related to their practice on a scale of one to three (1 being most important, 2 being important and 3 being least important). Assessment/diagnosis was important to 82% of physicians. Family Support and Education was important to 81% of physicians. Research was important to 33% of physicians. In the analysis of subgroup comparisons, family support and education was most important for neurologists (80%) and family physicians (95%). A descriptive analysis of the clinical components is presented in Table 9.

TABLE 9
Clinical Components of MDC
(n = 95)

<u>Components</u>	<u>Importance %</u>			% A	Total
	Most Imp.	Imp.	Least Imp.		
Assessment/Diagnosis	42%	40%	12%	6%	100%
Family Support and Education	54%	27%	13%	6%	100%
Research	26%	34%	29%	11%	100%

Physician comments to this question again emphasized the problem for rural access which would "inhibit the centres usefulness for patients." This problem could be addressed with "outreach clinics" suggested one physician. There seemed to be a

general consensus that all aspects of the clinic were important to “address this major health issue.”

4.1.1 Implication of Findings on Future Service Planning - Questionnaire One

There is overwhelming support by Physicians in Manitoba for a Memory Disorder Clinic at Lions Manor (81%). Overall, family support and education was rated as most important to 57% of physicians, assessment and diagnosis was rated as most important to 44% of physicians and research was rated as most important to 27% of physicians. Neurologists represented the subgroup with the largest response rate at 63%. This is an interesting finding as Neurologists were reported to be the most frequently consulted specialist for a diagnosis of AD by family members in a Winnipeg study (Robb, 1992).

Findings also indicate that physicians intend to refer patients to the Memory Disorder Clinic. Although 23% of physicians did not know how many referrals they would make, the average per physician was 10 patients or 950 patients per year ($n = 95$).

A comparison of subgroups indicates the strongest support for a Memory Disorder Clinic from Family Physicians. Other findings suggest these physicians will make the most number of patient referrals (Table 9). Family support and education is also reported to be most important to general practitioners and research least important. On the other hand, psychiatrists report assessment and diagnosis most important and family support and education least important. Neurologist and physicians specializing in

internal medicine indicate no significant difference in rating the important components of the clinic.

TABLE 10 Number of Patient Referrals by **Family Physicians (F.P.)**
in One Year n = 59

No. F.P. selection to each category		
38	A	1 - 9 patients
13	B	10 - 29 patients
	C	30 - 49 patients
1	D	50 - 69 patients
	E	70 - 99 patients
	F	100 + patients
6	G	Don't know
1	H	Zero

Total n = 59

There is a general feeling that the kind of specialized clinic at Lions Manor will be extremely valuable to physicians in Manitoba. The acknowledgment by many physicians for more education is significant. In a recent study on Alzheimer dementia services caregivers from 11 focus groups suggested that most local physicians were inadequately prepared to respond to people with dementia due to lack of knowledge of information and referral services and lack of training about dementing illness (Connell et al, 1996). Physicians also report a real concern for rural patient referral. Again Connell et al (1996) reports "access to transportation is another major problem in rural areas, especially for older adults who may be unable to drive for reasons of health or poverty."

In summary, implications from this survey suggest that the improved knowledge of the clinical symptoms of the disease and the somewhat predictable course of AD is not

widely known to many physicians. Knowing the functional progression of AD and related dementias would help physicians appreciate the changing management needs of the individual with AD.

4.2 Questionnaire Two

A total of 81 surveys were mailed. The four subgroups included 51 physicians identifying family support and education as most important in question 4 of questionnaire one, 10 geriatric social workers, 10 geriatric nurses and 10 family members whose relative had AD and resided in Meadowood Manor Personal Care Home. Of the 81 surveyed 36 (44.4%) participated in the study.

The questionnaire was titled Alzheimer Care Support Services. The brief introduction to the questionnaire stated that "Some families report difficulties in getting the help they need to manage Alzheimer care. These difficulties can act as barriers to appropriate timely use of services. In this first section we are interested in learning how you feel about Alzheimer Care Services."

The first question study participants were asked was did they feel there were barriers (difficulties) to accessing service use experienced by some families (yes or no)? and the second point of the question asked respondents to check one or more of the listed barriers. Included in the list were government policy, government funding, family pressures, lack of knowledge, too much red tape, financial, lack of training of Alzheimer service providers, continuity of care (staff) and nothing. The responses to question one are summarized in Table 11A. Table 11B ranks the responses to the second part of question one indicating the barriers selected.

Respondents reported that there were barriers to accessing service use for Alzheimer care (81%). Lack of knowledge was identified as the strongest barrier for families accessing help (80%). However, most respondents selected at least three barriers indicating a combination of factors could be involved in the decision to access service.

Two respondents added barriers (write-ins). The first respondent added “stubbornness of the patient in not allowing others into the home” and “lack of awareness of the need for services.” A second respondent wrote “fears of mental illness (i.e. keep issues in closet, i.e. abuse)” and “cultural insensitivity.”

From my experience in working with families, I feel that often families do not know how to access the help they need (even if they know what they need). Often families are referred to the Alzheimer Society and/or Continuing Care from a physician but the red tape involved in accessing the right person to speak to is often overwhelming. A person inquiring about services possibly speaks to three or four individuals prior to obtaining the information they need. By then they are often very confused, angry, and tired.

TABLE 11A - PERCEPTION OF BARRIERS
(physicians, social workers, nurses, families response)

Accumulated Responses	(n = 36)	Percentage
Yes there are barriers	29	81%
No there are not barriers	4	11%
No Answer	<u>3</u>	<u>8%</u>
Total	36	100%

TABLE 11B

RANK ORDER OF BARRIERS TO ALZHEIMER CARE SUPPORT SERVICES
(multiple responses by physicians, social workers, nurses, families response)

	(N = 36)
Lack of knowledge	29
Family pressure	14
Lack of training	14
Continuity of care	13
Financial	11
Too much red tape	10
Government funding	8
Government policy	6
Nothing	2

In the second question, respondents were asked how they felt about three statements on service use and families. The statements were (a) families delay seeking service, (b) families inappropriately use services, and (c) families underutilize services. Respondents agreed (80%) that families delay seeking services and underutilize service (78%). However, only 14% of respondents feel that families use service inappropriately. The responses to question two are presented in Table 12.

TABLE 12 - FAMILY USE OF ALZHEIMER SERVICES
(Physicians, social workers, nurses, families response)

	Delay Seeking Services %	Inappropriate Use of Service %	Underutilized Service %
	N = 36	N = 36	N = 36
Strongly Agree	28	0	39
Agree	52	14	39
Disagree	11	33	11
Strongly Disagree	3	22	5
Don't Know	3	25	3
No Answer	<u>3</u>	<u>6</u>	<u>3</u>
Total N = 36	100%	100%	100%

The positive response to the first and second question of the questionnaire relating to barriers and family patterns of use support previous research findings by Gwyther et al (1990). In fact, their findings related to barriers provide what they describe as the "rationale" for developing their social work assessment and intervention strategies used in the manual Overcoming Barriers to Appropriate Service Use: Effective Individualized Strategies for Alzheimer Care. Evaluation of this Duke Model forms the basis of the second part of questionnaire two.

In the brief introduction to the second part of the questionnaire, the respondents are told that Social Workers at the Memory Disorder Clinic at Duke University Medical Centre use a preventative barriers focused strategy to reach families before crisis

develop. They work with physicians before and after the diagnostic evaluation is complete.

Respondents are asked the following in question three. Listed below are the components of the individualized strategy used by the Social Worker for overcoming barriers to appropriate use for Alzheimer Care. Beside each statement, please indicate which you strongly agree (SA), agree (A), disagree (D), strongly disagree (SD), or don't know how you feel (DK).

- a. contact with the Social Worker on the initial visit to the clinic and comments
- b. family assessment of barriers at the Memory Clinic on the return visit for the medical evaluation one month after the initial visit and comments
- c. development of a one page written "service plan" with concrete recommendations for use of informal services (voluntary), formal services, and products, gadgets, literature
- d. a three month follow-up by phone to review the service plan

Contact by the social worker on the initial visit to the clinic (part a) was supported by 92% of the respondents. Two respondents felt that other disciplines could provide similar input. There is a concern from one respondent as to exactly what would occur on the first visit. As well, two respondents felt that there may be too much information for families to absorb when meeting with a social worker on the initial visit.

The physician's introduction of the family to the social worker sets the tone for professional work with the family claims Gwyther et al (1990). "If immediate concrete information can be provided at the initial meeting many of the potential problems can be eliminated. Perhaps the help could be in assisting to calm a restless patient. Further

findings suggest that families are more easily engaged by offering concrete help immediately. The information packet they receive would provide reminders and additional answers to common questions when family members had time and interest to review it.”

The responses to part b, family assessment of barriers on the return visit one month after the initial visit (part b) was supported by 83% of the respondents. However, three respondents were concerned that setting a return visit of one month would not allow for flexibility in meeting individual needs. For some a respondent wrote “it may be too long a wait.”

The intention of meeting with families on the return visit for a diagnostic evaluation according to Gwyther et al (1990) is that it usually takes time to gather the information for an adequate interpretation of a “possible” or “probable” Alzheimer diagnosis. Gwyther et al suggest that diagnosis is the first hurdle for families facing Alzheimer care. The individualized intervention was designed to reach families at the critical point of diagnosis. Their hypothesis was that the “timing of information about services was the active ingredient in determining use and efficacy of the strategies.” In their opinion the diagnostic visit was a turning point for many families as most families are reluctant to see physician, and many patients are not aware of the extent of their disability. Families often fear the impact of the diagnosis on the patient and on an independent future. They go on to say that many families struggle to get the patient to a diagnostic center and it could be the only time that patients and family member are together and amenable to professional intervention. Also it is an ideal time to introduce

the family to available educational and support services and the potential for professional guidance as the disease progresses.

I agree with the family assessment on the return visit after the diagnosis is made. Although it may be a long wait for some families, it is important to receive all results from tests to ensure reversible conditions do not exist.

The development of a service plan with concrete recommendations (part C) was supported by 92% of the respondents. Several respondents commented on the service plan component. One excellent suggestion was to incorporate an “abilities enhancement approach” developed with and for the family and client. This respondent commented “Why a barriers focus?” Although Gwyther et al (1990) used a barriers concept, their approach did focus on building on existing family strengths. Another individual suggested that the service plan be short, easy to understand, and take into consideration that not all patients are English or French speaking. It was suggested there must be appropriate follow through of the plan. That is to say, services must be in place to meet expectations engendered by the recommendations. He/she also suggested financial implications be discussed “openly” and options for subsidies provided.

Gwyther et al (1990) acknowledge the many purposes of the service plan in overcoming barriers to service use. First, they suggest it is a concrete reminder of what the family has already initiated and what is recommended. First service plans should “reinforce successful family coping strategies.” For example, if the primary caregiver is already receiving informal respite from his/her children, this can be acknowledged on the plan as “continue to encourage your son/daughter to take mother shopping and out to

lunch on Saturday.” This type of service would fall under informal or unpaid help that may, according to the authors, be more predictive of enhanced caregiver well being than any formal plan. It gives the family some time to incorporate the normalizing approach to overcoming barriers that were introduced in the assessment interview. The family may need time to talk to each other, calm down from the diagnostic crisis, and think about options.

The month lead time between assessment and the development of a service plan has two major advantages. The first is the opportunity to consult or brainstorm with the other social work staff at the weekly peer supervision session held at the MDC, Duke University. The clinical assistance in resolving family conflicts about care was often the first step in service planning. It became apparent over the course of the three year action/demonstration at Duke that some of the most troublesome issues for Alzheimer caregivers are the changes in sexuality, intimacy, and sexual behavior of patients and the impact of these changes on family and paid caregivers.

The month lead time for service planning gives the professional a chance to investigate local formal and informal services. All too often families are too overwhelmed and lack the energy to search for available services and to even investigate eligibility requirements. If the social worker can talk with local service providers in advance, she or he can smooth the way for successful referrals.

The wording of recommendations is also critical in overcoming barriers. Many families want to retain control or decision making. The recommendations to “explore, visit or call” leaves the ultimate decision to the family. Gwyther et al (1990) suggest

families resist recommendations to “use day care three times a week”, but they may accept an initial recommendations to “visit the Life Centre and talk with Jane Jones about what the program can offer your husband.”

The final section of the service plan according to the author is to include recommendations for reading, preserving valued routines, and environmental adaptations. This section has an “awareness” value in just raising family consciousness about other coping strategies and low tech innovations. This provides further opportunities to individualize recommendations. For example, very religious family caregivers may respond well to spiritual books or explanations. Others may need encouragement to continue routines that are familiar and pleasant for the patient and/or caregiver such as walks in the park (Gwyther et al, 1990).

In summary the authors suggest the written service plan provides a common focus for the social worker, primary caregiver and secondary caregiver. It also validates and reinforces successful family coping, makes realistic, concrete and immediately relevant individualized suggestions. It encourages exploration of options without demanding compliance. Most important, it is not written in stone or handed down from an authority to a subordinate client. It is simply a reminder and/or memory jogger of a joint family/professional alliance to support family care.

In evaluating the service plan, I feel a short section should be added that includes input from the individual with AD. If the individual has any requests, special needs, interests or concerns, they should be recorded on the service plan. Families may not think to ask these questions on underestimate the significance of small concerns or fears

that a person with AD may have. I also feel it would be helpful to record possible tasks that individuals can feel successful with at home such as cleaning the table or taking out the garbage. From my experience, individuals with AD want to contribute and want to be busy. However, I feel family don't always think to include them in household chores or are often too critical if the job/task takes longer than they would like.

The three month follow up by phone to review the service plan (part d) was supported by 89% of the respondents. Two respondents felt that a home visit should be made instead of a phone call. One individual felt it would be necessary to "clarify the length of time of the phone call" and to "clarify what is to be accomplished by the phone call." Another individual felt the family should be agreeable to the follow-up phone call in advance.

Some systematic follow up of Alzheimer's patients and their families is generally helpful suggests Gwyther et al (1990). These authors claim families will often call in a crisis, but a true preventative and individualized service should anticipate and head off potential crises with regular dosing of information and monitoring of successful compliance of recommendations. They further add that regular monitoring is probably preferable to suggestions for the family to call "as needed". From their experience many families are not use to requesting professional help. They fear rejection if they "bother" professionals unnecessarily. Others may be afraid that it will get worse, and they don't want to call until "they can't take it anymore." A barriers-focused approach is not well suited to crisis requests. Yet other families indicated that they had "thoughts about

calling” but they weren’t sure it was justified. Other families were reluctant to acknowledge that they hadn’t followed through on service recommendations.

Once the service plan has been revised, immediate reinforcement and follow-up are again necessary. Sometimes the physician’s authority is needed to convince unwilling secondary caregivers that it is time to step in. Whether the social worker and/or the physician reinforces the plan, the timeliness of follow-up and reinforcement is critical. “There are many unanticipated contingencies of even the most benign recommendations.” Gwyther et al (1990).

Question four asked respondents if they would recommend the Duke Model for use at Lions Manor Memory Disorder Clinic. The Duke Model for use at Lions Manor Memory Disorder Clinic was supported by 86% of respondents. One respondent commented that the personalized plan enhances and complements medical information in a “one stop shopping model”, making good use of appropriate professional support.” Another suggested “the model outline was good but there should be an outreach component, i.e. home visit as most candidates for the program and possibly their caregivers have mobility and transportation problems. They also function poorly in unfamiliar settings.” Another respondent felt a multidisciplinary approach was necessary. Four individuals did not have enough information to say “yes”. Two others indicated a concern about who would be financing this “elaborate plan.”

The Duke Model was developed by the authors based on earlier findings of reluctant, delayed, inappropriate and underutilized services among Alzheimer’s families. They report that earlier studies indicated group education, outreach, and publicity don’t

go far enough in helping families relate their needs and preferences to available service options. A strength of this approach is its capacity to address person/familiar barriers to service use.

Reinforcement calls and care plan revision offered additional opportunities to identify and address barriers to service use. A significant weakness of this intervention is the limited capacity of any single, brief and intermittent service to significantly affect the long term consequences of a degenerative illness upon a primary family caregiver. The authors go on to say that caregiver well being or burden is more sensitive to personal or social context than to formal or professional interventions (Gwyther et al, 1990).

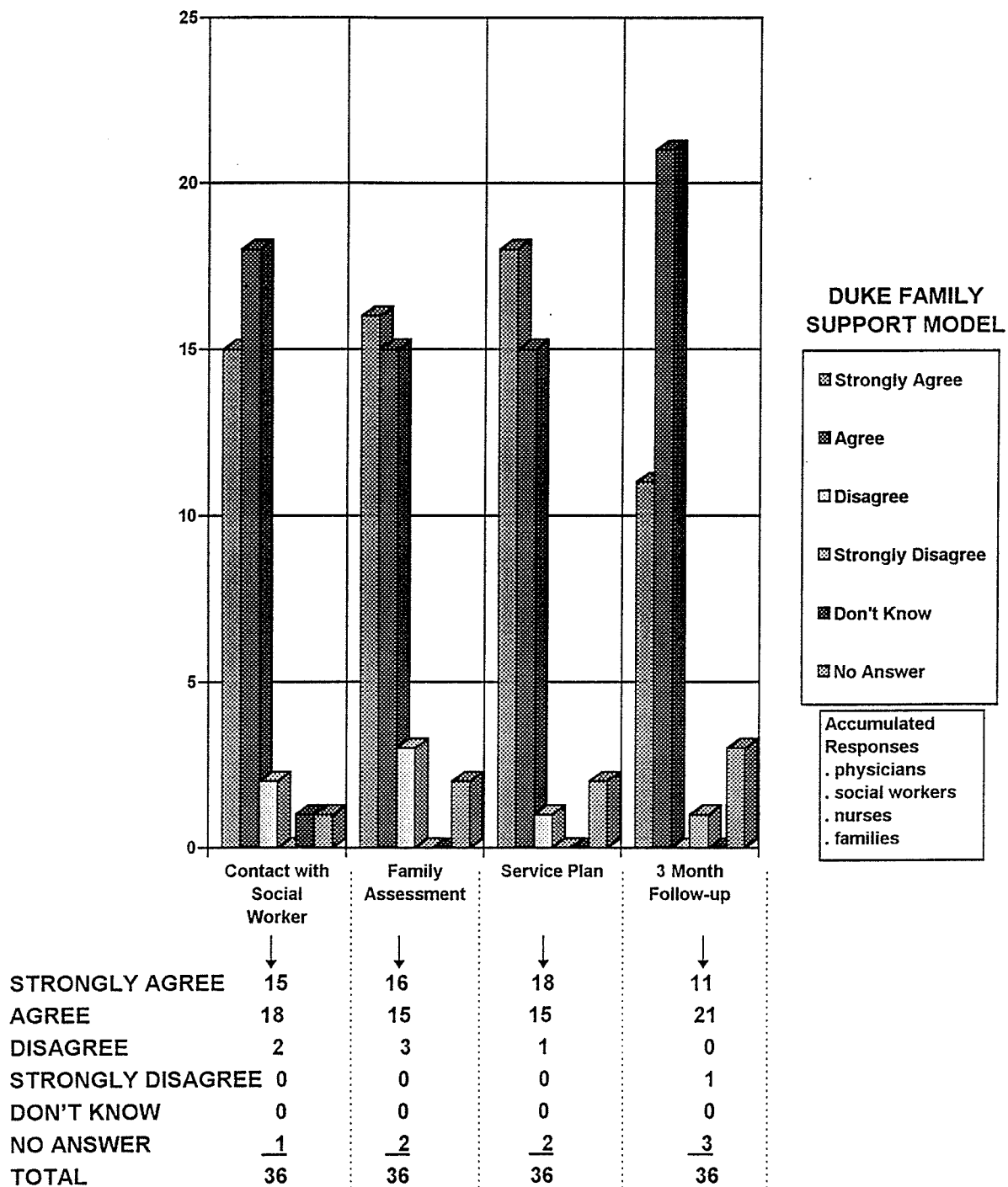
In question 5 respondents were asked how the social work role of providing family support and education could be enhanced. Generally, there is agreement that education through public awareness campaigns is essential to advertise the services of the MDC. As one physician pointed out "ensure that the Memory Clinic is widely publicized to general practitioners in the province so that families caring for members with AD come into contact with a social worker". Another recurring comment was in the area of training. Physicians, families, and professionals reported a need for more training in the "Alzheimer area". An important issue for one respondent was that social workers use a crisis intervention model initially with families. "This will help reduce stress to a tolerable level that then allows caregivers to act." He/she also reminded the worker not to assume feelings/problems will ever go away but only become more manageable with time. Using an interdisciplinary team approach to problem solving, a strong peer/social support component for families and promoting the trust relationship

by establishing ongoing contact and monitoring of the service plan, are additional recommendations to enhance the social work role.

The social work role can also be enhanced by following some basic assumptions about Alzheimer family care that the Duke intervention was based on. Gwyther et al (1990) suggest that professionals working with Alzheimer families should resist the temptation to overly romanticize or pathologize family care. The eleven assumptions of a helpful attitude include such things as the family in and of itself is not necessarily the problem, there is no one right way for families to respond, there is no right place for a person with Alzheimer disease to live or receive care, there are no perfect family caregivers, there is rarely a fair equitable sharing of family responsibilities, and finally although a primary caregiver may be efficient and preferred, "no one can do it alone" (Appendix K).

I feel that the social work role at the Memory Disorder Clinic at Lions Manor can be further enhanced and expanded from the Duke Model by reviewing current research and future trends in Alzheimer Care. It is also important to know if this model is still being used at Duke Memory Disorder Clinic and if any changes have been made since the introduction of the intervention.

In summary, a description of an analysis of the evaluation of the Duke Model is presented in Figure 2. This figure indicates that 86% of respondents (n = 36) which include physicians, geriatric social workers, nurses, and families who have relatives in a personal care home with Alzheimer disease agree with the Duke Model for family support. Furthermore, these findings from question two indicate strong community



**FIGURE 2. ANALYSIS OF INDIVIDUALIZED FAMILY SUPPORT MODEL
 USED AT THE MEMORY DISORDER CLINIC, DUKE UNIVERSITY
 (Questionnaire Two)**

support from professional people who understand the current issues and challenges of caring for individuals with AD.

4.2.1 Implications for Future Service Use - Questionnaire Two

Lack of knowledge was reported most often by respondents (81%) as the major barrier to access support services for families. The majority of respondents agreed that families delay seeking services (80%), underutilize services (78%) but don't agree that families inappropriately use service. A recent study by Connell et al (1996) on attitudes about Alzheimer disease and the dementia service delivery network among family caregivers and service providers in rural Michigan sheds some new light on an old problem. The predominant themes identified in the study included myths and misconceptions about dementia, barriers to effective service delivery, and community strengths.

The study confirms that dementia shares a stigma with mental illness and people with dementia are often seen as "crazy". There is confusion about the cause and nature of dementia. Because these beliefs may prevent or delay utilization of services including a comprehensive diagnosis and assessment, efforts to increase "public awareness of dementia are extremely important (Connell et al, 1996)."

The barriers to effective service use identified in this study were lack of coordination of health and social service agencies, the prohibitive cost of service, and the lack of available services, especially diagnostic and assessment services and respite. Attitudinal barriers included denial of symptoms, belief that family members should be

self-reliant, ageism and misconceptions about dementia among health care professionals reduce the likelihood that people will receive adequate information and referral to needed services. Additionally people fear a diagnosis of a dementing illness with hereditary tendency that take such a devastating toll on the patient and the family (Connell et al, 1996).

Individualized family centered care planning is overwhelmingly supported by the respondents in questionnaire two. The significant omission to the approach at Duke in my opinion is the exclusion of the desires, strengths and needs of the "individual with Alzheimer disease." I feel that all too often these individuals are left sitting in a room full of people deciding their future without ever consulting with them as to how they feel about the plans being prepared for them. I feel that we underestimate their ability to comprehend what is happening because they are often unable to articulate their feeling - but their feelings are there. The real tragedy of Alzheimer disease is its devastating effect on the individual with the disease. It has been described to me as "a terrifying feeling of loss of self", a "feeling of a sense of uselessness." Prior to a presentation I was making on Alzheimer disease, I asked Gordon, a gentleman in our Pacesetter Program (dementia day care), what it was like to have Alzheimer disease.

Gordon describes AD as "absence of orderly thoughts" or a "repetition of disaster in your thinking." I feel no continuity of thought, seconds later you forget 2 - 3 things - the more you try to remember, the harder it is. I get disgusted with myself. Sometimes I know the answers but I can't formulate them or isolate the points. A frustrating feeling comes over me when things like remembering what you were going to do at any time is lost. I feel "trapped" when asked the simplest questions I can know I can't make sense for answers.

I also asked Gordon if there was anything good about having Alzheimer disease. "Yes, he said, I am physically healthy and I don't have a serious problem like heart trouble. Also, I hope I won't get worse, they might find a cure soon."

Research for the intervention model by Gwyther et al (1990) was carried out in the 1980's when the emphasis was on caregivers. There is a greater shift in the 90's on the individual with dementia (Bell and Troxel, 1995). It is important to understand this new trend prior to planning support services for families in the 90's and beyond the year 2000.

Bell and Troxel (1995) offer suggestions of future trends in Alzheimer care. The focus of service providers will be in providing services and therapeutic interventions to the individual with dementia. They also predict that new drug therapies will allow individuals with AD to remain in earlier stages of the illness much longer. Ethical issues will become more complex as individuals with early stage dementia are able to play a greater role in decision-making. These decisions at times may differ from family wishes and professional recommendations. Also, greater number of people with dementia, at all stages, will place new demands and pressures on health care, senior service and long term care providers. These authors propose a 12 point Alzheimer disease Bill of Rights due in part to these trends. They argue that the Bill of Rights will serve as a "touchstone for providers to see if they are meeting client needs." Table 13 provides a brief overview of an Alzheimer disease Bill of Rights.

An excellent point from a psychological perspective has been raised by Kirkwood's (1995) article In the New Culture of Dementia Care. He outlines ten

differences between the old and new cultures of dementia care. The emphasis is on positive beliefs and attitudes. Behind these lie the organizations, with their power structures and their patterns of status and control. His “new culture concept” is literally the creation of a new paradigm in conceptualizing dementia care. The old paradigm (culture) primarily was concerned with negative beliefs and attitudes such as gloom, apathy, fear, alienation and estrangement. The new culture, one in which the person comes first, is one of hope, confidence in our power to know, to discover, to give, to create, to love. “It enables not only the recipient of care, but also the giver of it, to be more relaxed and free.”

This new culture concept supports many comments from individual respondents in questionnaire two. One comment was to use “an abilities enhanced” model not

Table 13

Alzheimer Disease Bill of Rights

Every person with Alzheimer disease or related disorder deserves:

- To be informed of one’s diagnosis
 - To have appropriate, ongoing medical care
 - To be productive in work and play as long as possible
 - To be treated like an adult, not like a child
 - To have expressed feelings taken seriously
 - To be free from psychotropic medications if at all possible
 - To live in a safe, structured and predictable environment
 - To enjoy meaningful activities to fill each day
 - To be out of doors on a regular basis
 - To have physical contact including hugging, caressing, and hand-holding
 - To be with persons who know one’s life story, including cultural and religious traditions
 - To be cared for by individuals well trained in dementia care
-

“barriers” model for family care. Several individuals made the comment to include the “individual” with AD in family planning for care and support. From my experience, planning information is often held back from individuals with AD and/or they are often not consulted as to what they would find helpful.

Fazio (1995) echoes similar sentiments around the issue of negative language used to describe Alzheimer disease. Words such as “victim”, “stranger”, and “burden” shape our opinion and, as a result dehumanize people who have the disease. The result? People see Alzheimer solely as a debilitating depressing illness that needs to be controlled. This claim Fazio shapes how we care for the person with Alzheimers.

Families and individuals with Alzheimer disease are continually bombarded with press releases and breakthrough research news on AD that depicts the disease in negative terms, i.e. “the never-ending funeral”, “the worst disease of the century”. Individuals with AD are seen as helpless, hopeless, deviant creatures. It is no wonder that families delay seeking service and do not always use available services as reported in questionnaire two. They may want to deny the diagnosis and hide from the truth to same face (public embarrassment) for as long as possible.

Collins et al (1994) have conceptualized an untested service delivery model to assist the family so that patient functioning can be maximized and quality of life for patient and family enhanced. This model focuses on the social-psychological experience of the family caregiver and how components of this experience influence the caregivers’ intent to seek community based services. This model builds on previous research that reports underutilization of services by families caring for relative with AD even when

services are available and acceptable to families. They argue that three categories of caregiver attitudes and values act as barriers to service use. (1) the caregivers' need to remain independent, (2) caregivers' fears such as relinquishment of family control to strangers, and (3) caregivers' reluctance to make decisions about service use that override the expressed preference of their relative with AD. These authors conclude that service use appears to depend on factors related to the health and behavior status of the patient, the services available in the community and the knowledge and appraisals of the caregiver as indicated in figure 3.

"Family pressure" has been identified as a barrier to service use by some families in questionnaire two. An adequate family assessment of attitudes and values related to making decisions about use of service would assist social workers with recommendations for families.

4.2.2 Enhancing the Social Work Role

I spoke with Lisa Gwyther (February, 1996), co-author of the Duke Model used in questionnaire two and asked her if she could identify how/if the social work role could be enhanced at the MDC at Lions Manor using her model. She suggested that families receive a booklet in advance of their first visit that answers a list of most commonly asked questions. For example, "What's going to happen to me when I come to the MDC?" A follow up phone call addressing the most pressing questions will help identify what type of information will be appropriate. A small dose of culturally appropriate information at the right time will be most manageable for families. She suggested that

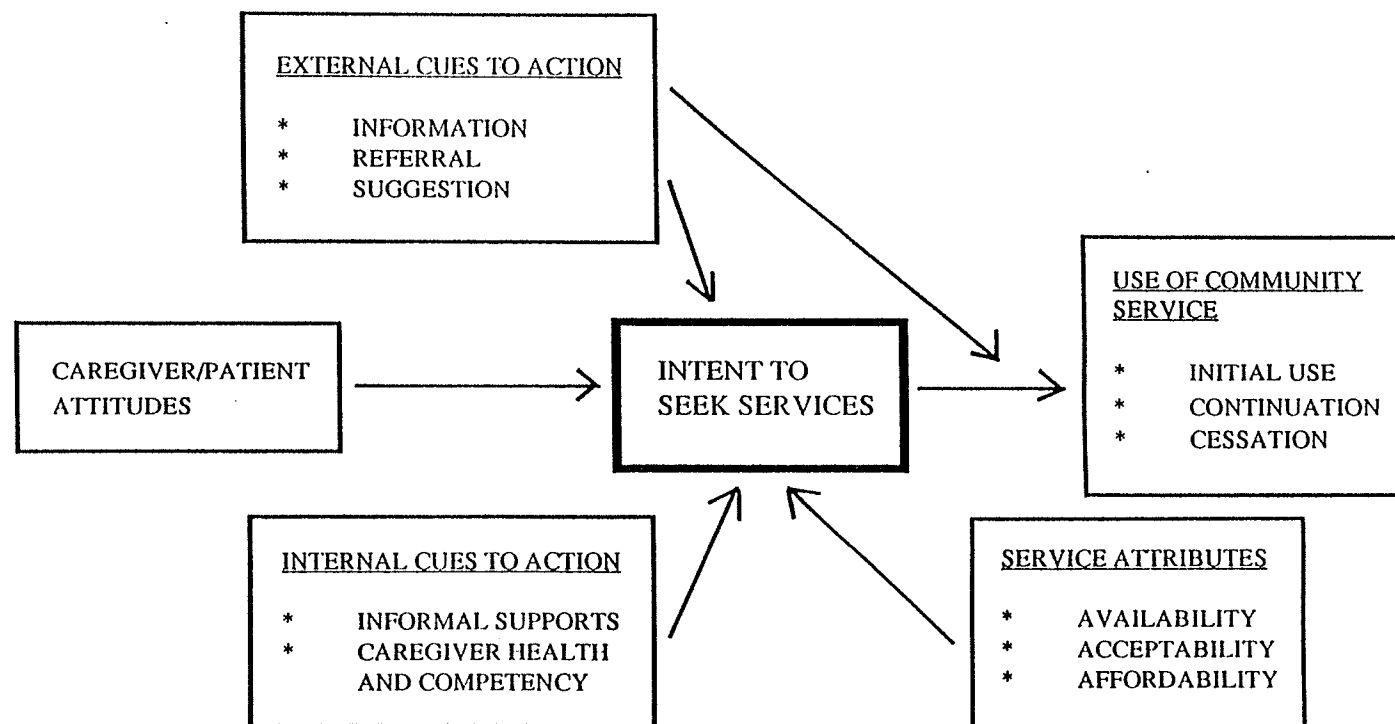


Figure 3 Factors influencing community service use among family caregivers of Alzheimer's patients (Collins et al 1994).

specialized support groups were the “wave of the future.” Support groups for couples, and husbands and sons are absolutely necessary.

Lisa goes on to say that, families’ trust the legitimacy of the health facility connection the MDC has to Duke Medical Centre. “It adds a great deal of dignity and credibility particularly when it comes to clinical drug trials. Families are very enthusiastic to support any research if they believe they might help make a difference.” Finally, with a word of caution she adds, “it is often necessary to convince physicians that you are not stealing their patients and you are not competing for patients/families with other service providers.”

In summary, findings from this chapter indicate a need for more education in the area of Alzheimer disease and related dementia and research for physicians in Manitoba. Lack of knowledge is also an issue for caregivers as it relates to service use. The questionnaire findings support previous research indicating families’ delay seeking services and underutilize available services. What needs further exploration is how attitudes, values, and beliefs about service use influence caregivers’ decision to access services. Current trends in Alzheimer care support a more positive approach to the language used to describe the disease. Emphasis is now placed on the interaction between the person with AD and their environment and less on the person as the “problem” in the environment.

Approximately 950 referrals to the MDC will be made by our sample population of physicians in one year ($n = 95$). Hypothetically, if the 1247 physicians representing the four subgroups of physicians in the province were to make an equal number of

referrals in one year, we could expect 12,470 patient referrals to the Memory Disorder Clinic in one year.

The social work role as it relates to family support and education is seen as very valuable to respondents. The concept of developing a service plan with the family unit that includes the individual with Alzheimer disease is critical according to professionals working in the gerontology field.

4.2.3 The Memory Disorder Clinic at Lions Manor

Implications for Social Work Service

A major focus of the Memory Disorder Clinic at Lions Manor will be to provide family support and education using a multidisciplinary team approach. Initially the social worker will act as a committee member involved in the planning and design development of the clinic. Once the clinic is operational, the social worker will act as clinic manager and the liaison person between the St. Boniface Hospital Research Centre and The Lions Club of Winnipeg Housing Centres. Recommendations from this report will be used by the social worker to develop the functional program and strategic plan for the clinic.

Social workers will also act as care managers for the family and individuals with Alzheimer disease or related dementia. The care manager will be responsible for crisis management, family assessment, development of a service plan, counseling, referrals and follow-up. Specialized support groups will be developed and facilitated by social work staff. A computerized peer support family resource centre will be developed.

The multidisciplinary team will develop and deliver educational information on an outreach basis to rural Manitoba. As well, the team will be involved with collaborative

research projects and planning an educational and research update conference to be held annually in Winnipeg.

In summary, there will be three major areas for social work practice at the Memory Disorder Clinic as highlighted below.

1. Social Worker as Manager

Areas of Responsibility

- Clinic Manager
- Functional Program
- Strategic Plan
- Policy and Procedure
- Marketing and Public Relation
- Job Descriptions
- Admin. Support System
- Staff Selection Committee
- Referral System

2. Care Manager

Areas of Responsibility

- Initial Screening
- Crisis Management
- Family Assessment
- Referral
- Follow-Up
- Counseling
- Education
- Support Group Facilitator

3. Social Research

Areas of Responsibility

- Independent Research
- Collaborative Studies
- Student Supervision

5.0 RECOMMENDATIONS AND CONCLUSIONS

The positive response from the two questionnaires developed for this study have demonstrated the need for a Memory Disorder Clinic at Lions Manor. It appears that this specialized centre for Alzheimer care and related dementia will become the first of its kind in Manitoba. To ensure a “centre of excellence” the following recommendations will be presented to the planning and development committee for consideration.

The following recommendations are based on the analysis of both questionnaires used to assess the use of the Memory Disorder Clinic at Lions Manor. As well additional recommendations are added based on current research trends in Alzheimer disease related dementia and research. Separate recommendations are made for the three components of the clinic, (1) assessment and diagnosis, (2) family support and education and (3) research. An overview of the components are presented in figure 4.

5.1 Recommendations for Assessment and Diagnosis

1. Assessment and Diagnosis should include formal testing and diagnostic services procedures that include generally accepted guidelines.

Although Alzheimer disease is diagnosed by excluding causes, an 85 - 95% diagnostic accuracy can be achieved using the NINDS-ADRDA criteria (appendix J, Institute for Brain Aging, 1995).

2. Student, Resident, and Fellow educational training programs related to Alzheimer disease, related dementia and research should be developed.

Grobb, (1993) suggest that early diagnosis is important if patients suffering from dementia and their careers are to be successfully helped. "The condition is often missed because some doctors regard it as normal for elderly people to become forgetful. Thus, before a definite diagnosis of dementia is made alternative conditions should be excluded."

3. Outreach components of the clinic should be considered for rural Manitoba patients and their families.

The recommendations for the Family Support and Education component of the Memory Disorder Clinic are based on an ability focused approach to providing support for the individual with AD and their families. The following enhancements to the Duke Model are recommended thus creating more of a proactive/preventative enabling model of care/support.

5.2 Recommendations for Family Support and Education

4. The individualized service plan based on the "family unit" needs/wishes developed at the Memory Disorder Clinic Duke University be utilized by Social Workers. The social work role will be that of a "care manager".

The care management role calls for documenting and implementing a treatment strategy appropriate to each stage of the disease. General principles of care management include (1) helping the person preserve and maximize function, (2) using intervention and supports that are appropriate to the stage of the disease, and

(3) conducting care planning that is multidisciplinary and which involves information from multiple sources (Heller et al, 1995).

The following are suggested enhancements to the Duke Model

4.1 Use of the Alzheimer Bill of Rights to assist in meeting client/patient needs (table 13).

4.2 Develop a one page fact sheet on what to expect on a visit/appointment to the MDC.

4.3 The Social Work family assessment should include the social-psychological experiences of the family (figure 3).

4.4 All educational and written material for distribution to physicians, health care professionals and families contain the language of the "new culture of care" (hope, positive language).

5. Peer Support Services should be established by trained volunteers to assist others who are presently meeting the challenges of managing the issues and needs of someone with Alzheimer disease or related dementia.

The training program for peers would effectively prepare individuals who have had experience in living with and/or caring for a loved one with Alzheimer disease to offer support. The peer could provide individualized guidance for effective management of day to day living, offer sympathy and personalized support, assist in constructive problem solving and be a referral service.

6. Establish specialized support groups, i.e. sons and husbands, couples, and support seminar groups for early stage dementia and their families

A support seminar for people with early stage dementia and their families could include information about coping with memory problems, daily living, self-esteem, relationships, health, legal and financial concerns. The group format would help participants see the positive aspects of their situation, options in coping response, and survival defenses (Alzheimer Disease Education and Referral Center, 1996).

7. Establish a Genetic Counseling Service.

The genetic counselor would be trained in neuro-degenerative disorders. As well, he/she would have knowledge of privacy and confidentiality policies to genetic information and AD.

Information about genetic susceptibility is particularly complex in the case of apo E (susceptibility gene for late onset AD). It is recommended that families receive genetic counseling before and after testing. Through counseling, families can learn about the genetics of AD, the tests themselves, and possible meanings of the results. This information may help families decide whether or not to take part in research. A primary goal of genetic counseling is to explore the consequences of such knowledge for people with AD and their families (Alzheimer's Disease Education and Referral Center, 1996).

8. Develop educational modules and videos related to Alzheimer disease, related dementia and research for professionals and families to increase their knowledge and skill level to meet patient and family needs.

MEMORY DISORDER CLINIC AT LIONS MANOR

Needs Assessment Recommendations

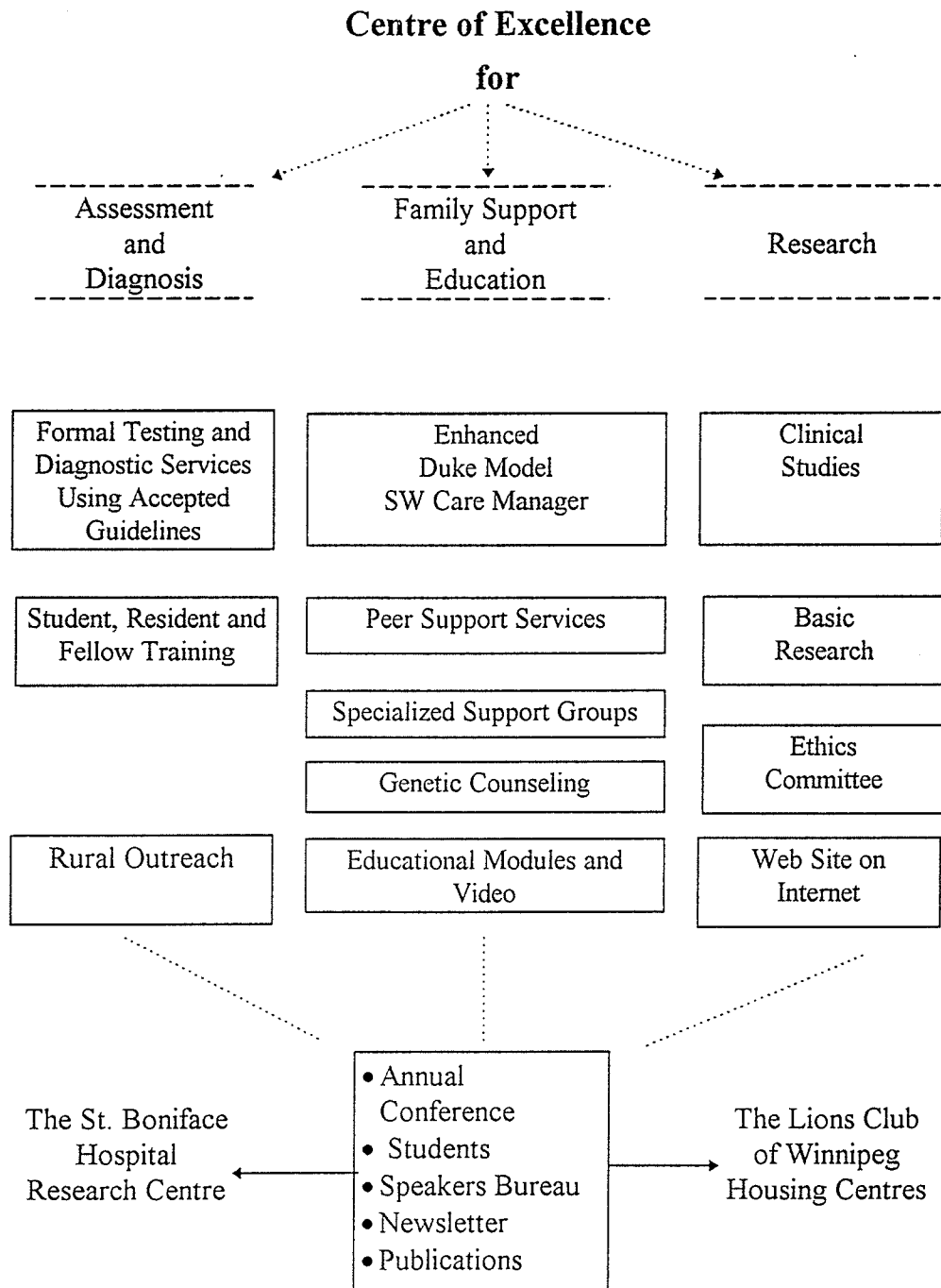


FIGURE 4. NEEDS ASSESSMENT RECOMMENDATION FOR THE USE OF A MEMORY DISORDER CLINIC

5.3 Recommendations for Research

9. Provide opportunities for clinical studies.

10. Provide opportunities for basic research.

11. Obtain relevant Ethics Committee approval for research

Policies and procedures related to information access, genetic testing and drug trials raise ethical, legal, and social questions that need to be addressed on an ongoing basis to ensure the rights of individuals with AD and their families are maintained.

12. Establish a web site on the internet.

Snyder (1996) suggests creating a web site requires assembling a team with four unique talents and settling design and management issues up front. The four team members Snyder refers to are first, an overall architect and designer, the team leader, Next a programming person who understands HTML and whatever programming interface (CGI, Java, AP's, etc.) is used to give life to your site. The third member of the team is a graphic designer as custom graphers will "always be part of the big picture." The fourth member is the organizational representative to provide the content and guidance to package the information and work with the hired team.

5.4 Conclusion

The overall objective of this practicum study was to design, implement and evaluate two surveys, then to make recommendations based on the surveys as well as current

research. The recommendations will be presented to the planning committee for consideration in the development of the Memory Disorder Clinic at Lions Manor for Alzheimer Disease and related disorders and research. A review of this report demonstrates that the overall objective of this practicum have been achieved.

I found the experience of developing and interpreting the surveys was very valuable both in terms of increasing my social work research skills and increasing my knowledge of the value of the social work role in a Memory Disorder Clinic. I also gained a great deal of knowledge in the area of Alzheimer disease and research into that disease. I have become much more aware of the need for policy development with respect to ethical issues in treatment and research procedures for individuals with Alzheimer disease and related dementia.

A great deal of the current literature research focuses on a need to better understand caregivers' attitudes, beliefs, and values with respect to use of support services. There is also a need to incorporate a paradigm shift in the language we use to describe AD and caregiving experiences. A more positive use of language such as hope, opportunity, enabling and building on strengths should replace the old negative language of victim, burden, crazy and barriers. This shift in language use will positively influence caregiver attitude to seek appropriate services as negative stereotyping is replaced with the concept of hope. Socially acceptable care and support services will be easier to provide when the services are believed to be of value and family caregiving seen in more positive terms.

In summary, this study has identified an urgent need for expertise in the early diagnosis of Alzheimer disease and related dementia. The study also reinforces the need for culturally sensitive treatment options that ensure the maintenance of dignity for the individual with Alzheimer disease. Finally, our hope lies in research breakthroughs that will one day very soon shed new light on the challenges of Alzheimer disease.

BIBLIOGRAPHY

Alzheimer's Disease and Related Disorders and Dementia Inc. (1991). A Description of the Dementias - Suspect Symptoms Brochure. Chicago, IL.

Alzheimer Society of Manitoba (1995) Centre on Aging. Spring Symposium. Report on Alternate Housing. Winnipeg, MB.

Alzheimer's Disease Education and Referral Center (1996). Connections, 5 (1).

Alzheimer Canada (1992). Guidelines For Care. Toronto: The Alzheimer Society of Canada.

Alzheimer's Disease Education and Referral Centre (1996). Connections, 5 (1), 1-11.

ADEAR Center (1995) Alzheimer's Disease Education and Referral Center, P. O. Box 8250, Silver Springs, Maryland.

Bayer, A., Patny, J., and Twinning, C. (1987). The Memory Clinic. A new approach to the detection of early dementia. Drugs, 33 (2), 84-89.

Bell, V., Troxel, D. (1994). Alzheimer Disease Bill of Rights. American Journal of Alzheimer Care and Related Disorders and Research. September/October.

Bennett, G. (1987). Memory Clinics. Geriatric Nursing and Home Care, June 15-16.

Bird, T. D., Lampe, T. H., Nemens, E. J., et al (1988). Familial Alzheimer's disease in American descendants of the Volga Germans: Probable genetic founder effect. Ann Neurology, 23, 25-31.

Bourgeois, M. (1995). Interventions for caregivers: Skills training. In The Changing Face of Alzheimer Care. Chicago. The Fourth National Alzheimer's Disease Educational Conference.

Bourgeois, M., Schulz, R., and Burgio, L. (in press). Interventions for caregivers of patients with Alzheimer Disease: A Review and analysis of content process and outcomes. The International Journal of Aging and Human Development.

Brugge, K. L., Nichols, S., Salmon, D., et al (1994). Cognitive impairment in adults with Down's syndrome: Similarities to early cognitive changes in Alzheimer's disease. Neurology, 44, 232-238.

Burns, E. and Buckwatter, K. (1988). Pathophysiology of Alzheimer's disease. Nursing Clinics of North America, 23, 11-29.

- Canadian Study of Health and Aging (1994). Study methods and prevalence of dementia. Canadian Medical Association Journal, 150 (6), 899-913.
- Caserta, M., Lund, D., Wright, S., and Redburn, P. (1987). Caregivers to dementia patients: Use of community service. The Gerontologist, 27 (2), 201-213.
- Cochran, W. (1977). Sampling Techniques. New York: John Wiley and Sons Inc.
- Cohen, D. and Eisdorfer, C. (1986). The Loss of Self. New York: Penguin.
- Collins, C., King, S., Given, C., and Given, B. (1994). When is a service of service? Understanding community service use among family caregivers. In E. Light, G. Niedereke and D. Lebowitz (Eds). Stress Effects on Family Caregivers of Alzheimer's Patients. New York: Springer Publication, 316-327.
- Compton, B. R., and Galaway, B. (1989). Social Work Processes. California: Wadworth Inc.
- Connell, C., Kole, S., Avey, H., Benedict, C., and Gilman, S. (1996). Attitudes about Alzheimer's disease and the dementia service delivery network among family caregivers and service providers in rural Michigan. American Journal of Alzheimer's Disease, 11 (3), 15-25.
- Corder, E., Saunders, A., Strittmatter, W., et al (1993). Gene dose of Apolipoprotein E type 4 allele and the risk of Alzheimer's disease in late onset families. Science, 261, 921-923.
- Drew, J. C. (1995). Cultural variations in dementia experiences. In the Alzheimer Association (Ed). The Changing Face of Alzheimer Care. Chicago: The Fourth National Alzheimer Disease Educational Conference.
- Duke University Medical Centre (1994). Memory Disorders Clinic. Brochure. Durham, NC: Division of Neurology.
- Ebby, E. M., Parkad, I., Hogan, D. B. et al (1994). Prevalence and types of dementia in the very old: Results from the Canadian Study of Health and Aging. Neurology, 44 1593-1600.
- Fazio, S. (1995). How we describe Alzheimer disease: Finding the right words. In The Alzheimer's Association (Ed.), The Changing Face of Alzheimer Care. Chicago: The Fourth National Alzheimer Disease Education Conference.

Feather, J., McGowan, V., and Moore, M. (1994). Planning Health Needs Assessment: The Basic Choices. University of Saskatchewan: Prairie Region Health Promotion Research Centre.

Ferris, G., deLeon, M., Wolf, A., et al (1980). Position tomography in the study of aging and senile dementia. Neurology of Aging 1 127-131

Folstein, M. F., Folstein, S. E., and McHugh, P. R. (1975). Mini-Mental State. Journal of Psychiatric Research, 12, 189-198.

Gallagher-Thompson, D. (1994). Clinical intervention strategies for distressed caregivers: Rationale and development of psychoeducational approaches. In E. Light, G. Niedeiehe, B. Lebowitz (Eds.), Stress Effects on Family Caregivers of Alzheimer's Patients. New York: Springer Publishing Company.

George, L., Clipp, E. (1995). Caregiving in Alzheimer Disease. Progress In Alzheimer's Disease, Spring Durham, NC: Duke University.

Gonyea, J. G. (1989). Alzheimer disease support groups: An analysis of their structure format and perceived benefits. Social Work in Health Care, 14, 61-72.

Graves, A., White, E., Koepsell, T., et al (1990). A Case-control study of Alzheimer's disease. Ann Neurology, 28, 766-774.

Gray, V. K. (1983). Providing support for home caregivers. In M. Smyer and M. Gatz (Eds.), Mental Health and Aging. Beverly Hills Ca: Sage.

Grob, P. (1993). Practical aspects of diagnosis and early recognition of Alzheimer's Disease. In G. Wilcock (Ed.), The Management of Alzheimer's Disease, Petersfield, UK: Wrighton Biomedical Publishing Ltd., 21-36.

Gubrium, J. F. (1986). Oldtimers and Alzheimer's: The Descriptive Organization of Senility. Greenwich, Connecticut: J. A. Press Inc.

Gwyther, L. (1987). The Duke Aging Centre Family Support Program. Advances In Research, 11 (2), 1-9.

Gwyther, L., Ballard, E., and Hinman-Smith, E. (1990). Overcoming Barriers To Appropriate Service Use: Effective Individualized Strategies for Alzheimer Care, Durham, NC: Centre for the Study of Aging and Human Development, Duke University Medical Centre.

Gwyther, L. (1993). In the Spotlight Connections. Bethesda MD: Alzheimer Disease Education and Referral Centre, National Institute on Aging.

Gwyther, L. (1995). When "the family is not one voice": Conflict in caregiving families. Journal of Case Management, 4 (4). 150-155.

Heinricks, D. (1996). Caring For Norah. Winnipeg, Photolitho Printing.

Heller, J., Seltzer, G. and Hogg, J. Practice Guidelines for the clinical assessment and care management of Alzheimer and other dementias among adults with mental retardation. In Alzheimer Association The Changing Face of Alzheimer Care. Chicago: The Fourth National Alzheimer's Disease Education Conference.

Iliffe, S. (1994). Why GP's have a bad reputation. BJ General Practice.

Institute For Brain Aging (1996) <http://www.Alz.vcl.edc/diagns/html>

Khachaturian, Z. (1994). Scientific opportunities for developing treatments for Alzheimer's Disease: Proceedings of Research Planning Workshop 1. Neurobiology of Aging, 15 (2), 11-15.

Kitwood, T. (1995). Dementia care psychology: Analyzing your caregiving commitment. In The Alzheimer Association (Ed.), The Changing Face of Alzheimer Care. Chicago: The Fourth National Alzheimer Disease Educational Conference.

Knapp, J., Knopman, D., Solomon, P., et al (1994). A 30-week randomized controlled trial of high-dose Tacrine in patients with Alzheimer's disease. Journal of American Medical Association, 271, 985-991.

Max, W. (1993). The economic impact of Alzheimer's disease. Neurology, 43 (4), 36-51.

McNeil, C. (1995). Alzheimer's Disease. Unraveling The Mystery. US National Institute on Aging.

Mittleman, M., Ferris, S., Schulman, E., Steinberg, G., Mackell, J. and Ambinder, A. (1994). Efficacy of multicomponent individualized treatment to improve the well-being of Alzheimer caregivers. In E. Light, G. Niedereche, B. Lebowitz, (Eds.), Stress Effects on Family Caregivers of Alzheimer's Patients. New York: Springer Publishing Company.

Monette, D. R., Sullivan, T. J., and Dejong, C. (1986). Applied Social Research. New York: CBS College Publishing.

Morris, J., Murphy, K. (1995). The role of the family in special care: A family partnership program. In The Alzheimer's Association, (Eds.). The Changing Face of

Alzheimer Care, Chicago: The Fourth National Alzheimer Disease Educational Conference.

National Institute on Aging (1995). U.S. Department of Health and Human Services. <http://www.nih.gov/nia/>

O'Neill, D., Surmond, J., and Wilcock, G. K. (1992). Longitudinal diagnosis of memory disorder. Age and Aging, 21, 393-397.

Osvaldo, P., Almedia, Hill, K., and Howard, R. (1993). Demographics and features of patients attending a Memory Clinic. International Journal of Geriatric Psychiatry, 8, 497-501.

Reisberg, B. (1983). Clinical presentation, diagnosis and symptomatology of age associated cognitive decline of Alzheimer disease. In B. Reisberg, (Ed.), Alzheimer's Disease: The Standard Reference, New York: Free Press, 173-187.

Risse, S., Lampe, T., Bird, T., et al (1990). Myoclonus seizures, and paratonia in Alzheimer disease. Alzheimer Disease and Related Disorders, 4, 214-225.

Robb, P. (1992). A Program Evaluation of Family Support for Caregivers of Persons With Alzheimer Disease. Winnipeg: University of Manitoba Faculty of Graduate Studies.

Roses, A. D. (1994). The Alzheimer Diseases. Current Neurology, 14, 111-141.

Rubin, A., and Babbie, E. (1993). Research Methods for Social Work. Second Ed. Pacific Grove, Ca: Brooks/Cole

Schaeffer, R. (1990). Elementary Survey Sampling. Boston: PWS-Kent Publishing Co.

Schaum-Resau, L. (1995). Update: Drugs being developed for Alzheimer's Disease. In Alzheimer's Association (Ed.). The Changing Face of Alzheimer Care. Chicago: The Fourth National Alzheimer's Disease Educational Conference.

Schneider, L., Tariot, P. (1994). Emergency drugs for Alzheimer Disease. Alzheimer and Related Dementias, 78 (4), 911-934.

Schulz, R., O'Brien, A. T., Bookwala, J., and Fleissner, K. (in Press). Psychiatric and physical morbidity effects of Alzheimer Disease and Related Dementia caregiving. Prevalence, correlates, and causes. Journal of Gerontology.

Schulz, R. and Williamson, G. (1994). Health effects of caregiving: Prevalence of mental and physical illness in Alzheimer caregivers. In E. Light, G. Niedereche, B.

Lebowitz (Eds.). Stress Effects on Family Caregivers of Alzheimer Patients. New York: Springer Publishing, 38-59.

Snyder, J. (1996). Web lessons learned. Internet World, 7 (4), 96-97.

Souren, L., and Franssen, E. (1994). Broken Connections. Netherlands: E. Swets and Zertlinger, B. V. Lisse.

Stone, R., Cafferata, G., and Sangle, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27 (5), 616-626.

The Alzheimer's Disease Support Centre (1995). Alzheimer Association and University Hospital of Cleveland/Cas Western Reserve. Media Contact Eileen Korey.

The Arc's (Alzheimer's Disease Resource Center) Family Support Checklist Quality Indicators (1990). National Headquarters Arlington, Texas.

The Arizona Long Term Care Gerontology Centre (1992). Alzheimer's Disease Pieces of the Puzzle. Instructors Manuals, Arizona Health Science Centre. University of Arizona.

The Canadian Study of Health and Aging (1994). Risk factors for Alzheimer's disease in Canada. Neurology, 44, 2073-2080.

Van Der Cammen, T., Simpon, J., Fraser, R., Dreker, A., and Exton-Smith, A. (1987). The Memory Clinic. A new approach to the detection of dementia. British Journal of Psychiatry, 150, 359-364.

Wackerbarth, S. (1996). Alzheimer's chess: A Computer-based support system. International Forum on Early Dementia, 2 (2), 1-3.

Weksler, M. (1994). Alzheimer's disease. How research is changing primary care management. Geriatrics, 49 (7), 47-51.

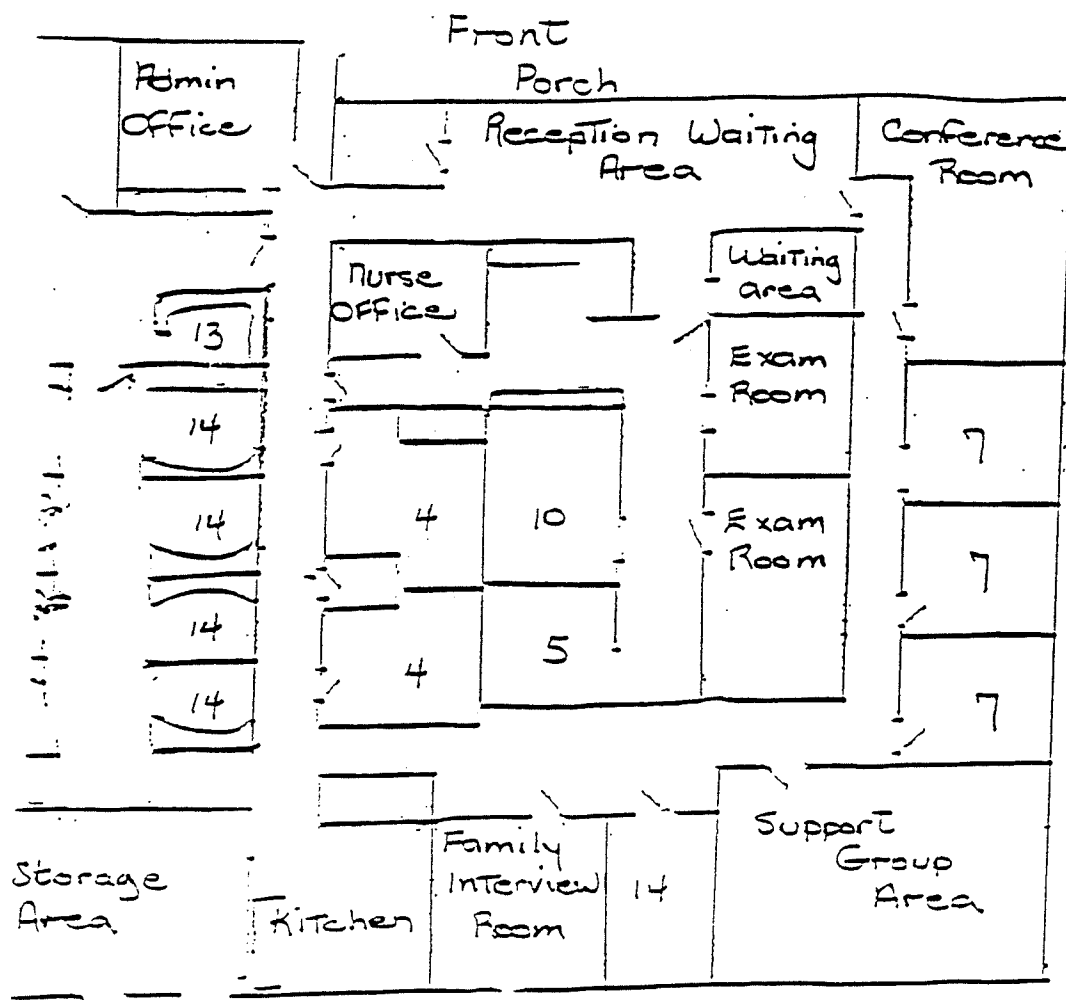
Whitehouse, P. and Voice, J. (1995). Tacrine Update and future treatment opportunities. In Alzheimer Association (Ed.), The Changing Face of Alzheimer Care, Chicago: The Fourth National Alzheimer Disease Educational Conference.

Wright, L. K. (1993). Alzheimer Disease and Marriage. Newbury, Ca: Sage Publications.

Yale, R. (1996). International Forum on Early Dementia, 2, 1-3.

Appendix A

MEMORY DISORDER CLINIC DUKE UNIVERSITY



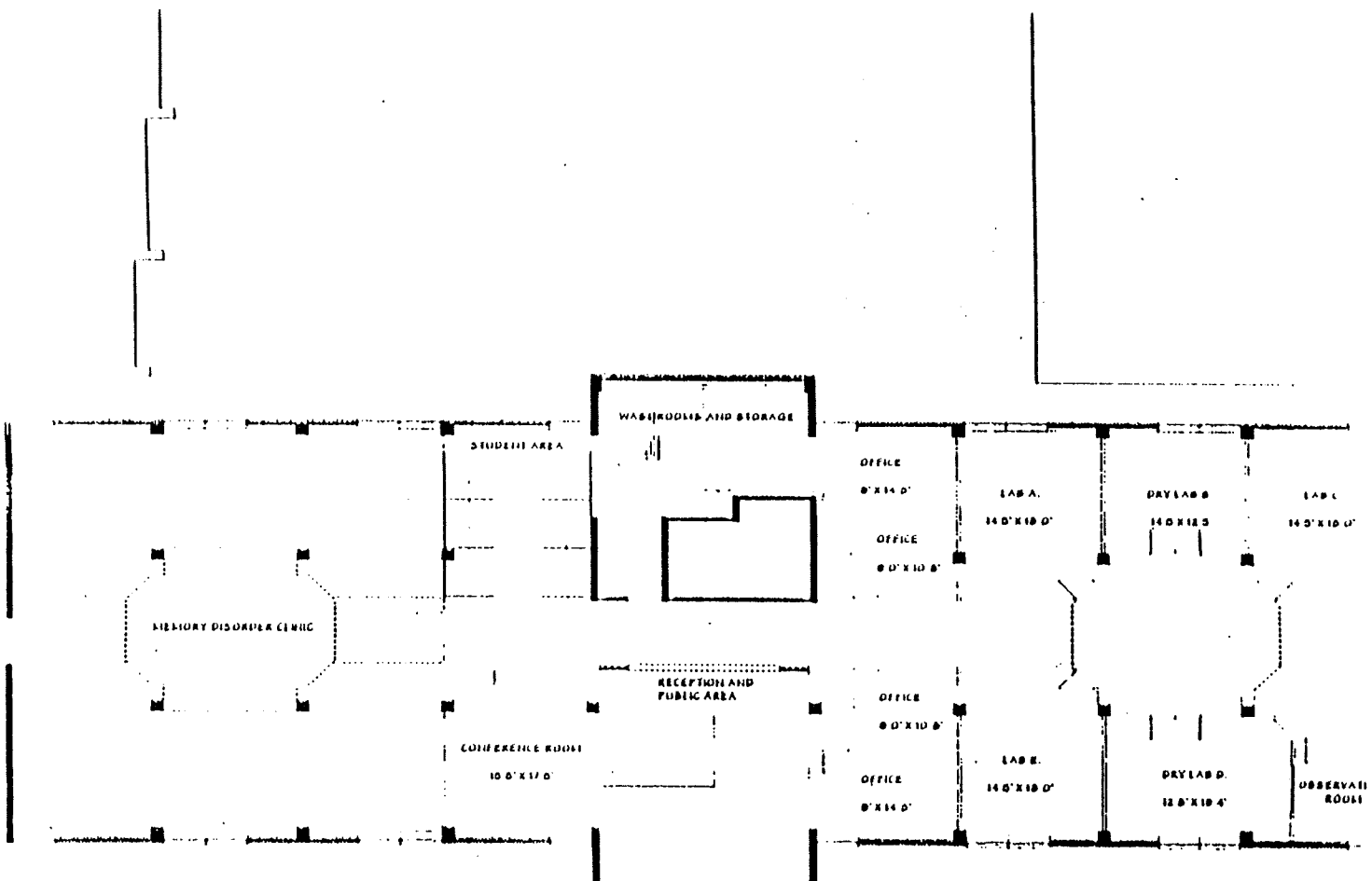
DUKE UNIVERSITY - MEMORY DISORDER CLINIC OFFICE AREA

Key		Units	Key		Units
1	Nurse Managers Office	1	12	Administration Office	1
2	Reception Waiting Areas	2	13	Secretarial Stations	3
3	Examination Rooms	2	14	Work Stations/Areas	6
4	Staff REstrooms	2		Social Worker	
5	Patient Restroom	1		Records Coordinator	
6	Conference Room	1		Graduate Students	
7	Physicians Offices	3		Pysc Tech	
8	Support Group Area	1		Clinical Fellow	
9	Patient Lab Area	1		ALPN	
10	Neuropsychiatry Test Room	1	15	Kitchen/Staff Lounge	1
11	Family Interview Room	1			

MEMORY DISORDER CLINIC LIONS MANOR

Appendix B

100



INDIVIDUALIZED SERVICE PLAN FOR THE FAMILY UNIT

SOCIAL WORKER: _____ FOR: _____ ID _____

PHONE NO.: _____

DATE: _____ PREFERRED DAY PHONE _____

SERVICE PLAN # _____ PREFERRED TIME TO CALL _____

RECOMMENDED INFORMAL (VOLUNTEER) SERVICES

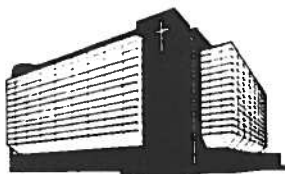
1. _____
2. _____
3. _____
4. _____
5. _____

RECOMMENDED FORMAL (PAID OR AGENCY) SERVICES

1. _____
2. _____
3. _____
4. _____
5. _____

RECOMMENDED PROJECTS, GADGETS, LITERATURE, OTHER SUGGESTIONS

1. _____
2. _____
3. _____
4. _____
5. _____



Appendix D

St. Boniface General Hospital Research Centre Hôpital Général St. Boniface Centre de Recherche

April 9, 1996

Dear Physician:

The St. Boniface Hospital Research Centre and The Lions Club of Winnipeg Housing Centres encourage you to participate in a study which examines a question of great importance for all physicians concerned with Alzheimer disease related dementias, and research into these disorders.

Recently, the St. Boniface Research Centre and The Lions Club of Winnipeg Housing Centres made a commitment to develop a **Clinical Research Centre** at Lions Manor specializing in the senile dementias. An important component of this centre will be a Memory Disorder Clinic (see attached).

My name is Judie Velnes. I am employed by The Lions Club of Winnipeg Housing Centres as Director of Adult Day Programs and I am also completing my Masters in Social Work degree at the University of Manitoba. In addition to providing important information for the planning of the St. Boniface Hospital/Lions Club project, the needs assessment will also be part of my masters thesis.

With your help the information collected from the attached brief questionnaire will be used in the planning project of the Memory Disorder Clinic.

You may be assured of complete confidentiality. The questionnaire has an identification number so that we may check your name off the mailing list when your questionnaire is returned. Your name will never be placed on the questionnaire. Please understand that you are not obligated to complete the questionnaire. Your participation is strictly voluntary.

If you do agree to participate, please complete the questionnaire and return it in the enclosed self addressed envelope by **April 30, 1996**.

Thank you for your cooperation.

Sincerely,

Sincerely,

J
Judie Velnes, BSW
Director, Adult Day Programs
Lions Club of Winnipeg Housing Centres

John Foerster, MD, FRCPC
Director of Research
St. Boniface Hospital Research Centre

Enclosure

351 Taché Avenue, Winnipeg, Manitoba R2H2A6; Telephone: (204) 235-3206

MEMORY DISORDER CLINICS

Alzheimer Disease Research Centres are often associated with satellite "Memory Disorder Clinics" designed to investigate causes of memory impairment and help in early detection of dementia. An early diagnosis enables the development of a clear plan of care.

One such clinic with an excellent reputation is the **Memory Disorders Clinic** which is part of the **Joseph and Kathleen Bryan Alzheimer Disease Research Center at Duke University Medical Center**, Durham, North Carolina. The clinic provides a thorough evaluation of memory impairment, mental confusion, changes in behavior and intellectual decline. The clinic staff work closely with the patients personal physician to determine if a cause for the problem can be identified and if any treatment is possible. Return visits may be scheduled as needed.

SERVICES AVAILABLE

The clinic is staffed by senior Duke neurologists, or geropsychiatrists, neuropsychologist, physician assistants, a social worker, a registered nurse and experienced clinical support staff.

The following services are available:

- Brief assessment of the current problem
- Complete diagnostic evaluation
- Social worker interviews and/or counseling
- Follow up evaluation are available for all patients

Patients and their families may volunteer to participate in research studies investigating the cause of memory loss and evaluating drug treatments.

A STUDY OF THE CLINICAL VALUE OF A MEMORY DISORDER CLINIC

General Instructions: Please indicate your answer to each question by placing a check (✓) in the box beside the appropriate answer or by briefly writing the answer when asked to do so. Please ignore the numbers beside the question and answers; they are for computer tabulation only.

1. What is your area of specialty?

- ☐ Psychiatry ☐ Neurology ☐ General Practice
☐ Internal Medicine ☐ None of the above

2. How would you characterize the clinical value/need of a Memory Disorder Clinic for assessment, treatment, and research of senile dementia as it relates to your practice?

- ☐ Definitely Helpful ☐ Probably Helpful ☐ Not Helpful
☐ Definitely Not Helpful ☐ Don't Know

Comments: _____

3. If you answered "Definitely helpful" or "Probably Helpful", please assess the number of patients/referrals that you anticipate making to the Memory Disorder Clinic in the period of one year

- ☐ 1 - 9 ☐ 10 - 29 ☐ 30 - 49 ☐ 50 - 69
☐ 70 - 99 ☐ 100+ ☐ Don't know

Comments: _____

4. Please rate the importance of the clinical components of the Memory Disorder Clinic as they relate to your practice on a scale of 1 - 3 for each of the parameters listed below.

1 being Most Important, 2 being Important, and 3 being Least Important

- | 1 (Most Important) | 2 (Important) | 3 (Least Important) |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> Assessment/Diagnosis |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> Family Support and Education |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> Research |

Comments: _____

Thank you for your valuable time.

May 7, 1996

Dear Family Member:

RE: ALZHEIMER CARE SUPPORT SERVICES

The St. Boniface Hospital Research Foundation will be developing a Clinical Research Centre at Lions Manor in the near future to study Alzheimer disease and related dementias. An important component of the development will be a Memory Disorder Clinic. The purpose of the clinic will be to provide diagnostic evaluations, family support and education and an opportunity for research.

My name is Judie Velnes. I am employed by The Lions Club of Winnipeg Housing Centres as Director of Adult Day Programs. In addition to my work at Lions Housing Centres, I am studying to complete my Masters in Social Work degree at the University of Manitoba. The final step in qualifying for the degree is the completion of a practicum. The project I have chosen to research is a needs assessment for the use of the Memory Disorder Clinic at Lions Manor. My particular interest is in providing recommendations for the Family Support and Education component of the clinic.

I am excited with the model of Family Support and Education used at the Memory Disorder Clinic at Duke University Medical Centre at Durham, North Carolina. I would appreciate your feedback on the various components of that model.

With your help, the information collected from the attached questionnaire will be used to plan services for families at the Memory Disorder Clinic.

The information collected for this study will be treated confidentially through the use of code numbers for mailing purposes only. This is so that we may check your name off the mailing list when your questionnaire is returned. Please understand that you are not obligated to complete the questionnaire, your participation is strictly voluntary.

If you agree to participate, please complete the questionnaire and return it in the enclosed self addressed envelope by **May 28, 1996**.

Thank you very much for assisting me with this project. I really look forward to hearing from you.

Sincerely,

Judie Velnes
Director
Day Club Programs

May 7, 1996

Dear MAG Member:

RE: ALZHEIMER CARE SUPPORT SERVICES

The St. Boniface Hospital Research Foundation will be developing a Clinical Research Centre at Lions Manor in the near future to study Alzheimer disease and related dementias. An important component of the development will be a Memory Disorder Clinic. The purpose of the clinic will be to provide diagnostic evaluations, family support and education and an opportunity for research.

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If you agree to participate, please complete the questionnaire and return it in the enclosed self addressed envelope by **May 28, 1996**.

Thank you very much for assisting me with this project. I really look forward to hearing from you.

Sincerely,

Judie Velnes
Director
Day Club Programs

ALZHEIMER CARE SUPPORT SERVICES

Some families report difficulties in getting the help they need to manage Alzheimer care. These difficulties can act as barriers to appropriate timely use of services. In this first section we are interested in learning how you feel about Alzheimer Care Services.

General Instructions

Please indicate your answer to each question by placing a check mark (✓) in the box beside the appropriate answer or by briefly writing in the answer when asked to do so. Please ignore the numbers beside the questions and answers; they are for machine tabulation only (to be added later). **Please return this form by MAY 28, 1996.**

1. Are there barriers (difficulties) to accessing service use experienced by some families?

Yes ☐ No ☐

If yes, what are they (check one or more).

- ☐ Government policy
- ☐ Government funding
- ☐ Family pressures
- ☐ Lack of knowledge
- ☐ Too much red tape
- ☐ Financial
- ☐ Lack of training of Alzheimer service providers
- ☐ Continuity of care (staff)

2. Listed below are statements about Alzheimer Care family patterns of use. Beside each statement, please indicate if you strongly agree (SA), agree (A), disagree (D), strongly disagree (SD), or don't know (DK).

	<u>SA</u>	<u>A</u>	<u>D</u>	<u>SD</u>	<u>DK</u>
a. families delay seeking service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. families inappropriately use service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. families underutilize service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix H(2)

Memory Disorders Clinic - Duke University Medical Centre

Social Workers at the Memory Disorders Clinic at Duke University Medical Centres use a preventative barriers focused strategy to reach families before crisis develop. They work with the physicians before and after the diagnostic evaluation is complete.

3. Listed below are the components of the individualized strategy used by the Social Worker for overcoming barriers to appropriate service use for Alzheimer Care. Beside each statement, please indicate whether you strongly agree (SA), agree (A), disagree (D), strongly disagree (SD), or don't know how you feel (DK).

	<u>SA</u>	<u>A</u>	<u>D</u>	<u>SD</u>	<u>DK</u>
a. contact with the Social Worker on the initial visit to the clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments _____

	<u>SA</u>	<u>A</u>	<u>D</u>	<u>SD</u>	<u>DK</u>
b. family assessment of barriers at Memory Clinic on the return visit for the medical evaluation one month after initial visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments _____

	<u>SA</u>	<u>A</u>	<u>D</u>	<u>SD</u>	<u>DK</u>
c. development of a one page written "service plan" with concrete recommendations for use of - informal services (voluntary) - formal services - products, gadgets, literature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments _____

	<u>SA</u>	<u>A</u>	<u>D</u>	<u>SD</u>	<u>DK</u>
d. a three month follow up by phone to review service plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments _____

Appendix H(3)

4. Would you recommend this Duke Model for use at Lions Manor Memory Disorder Clinic?

Yes _____

Comments _____

No _____

Comments _____

5. How could we enhance the social work role of providing family support and education?

Comments _____

Thank you for your valuable time.

Appendix I

May 7, 1996

Dear Physician:

Thank you for returning the questionnaire on the clinical value to your practice of a Memory Disorder Clinic at Lions Manor. A brief second questionnaire has been sent to you because you had identified family support and education as a valuable component to the clinic.

My name is Judie Velnes. I am employed by The Lions Club of Winnipeg Housing Centres as Director of Adult Day Programs. In addition to my work at Lions Housing Centres, I am studying to complete my Masters in Social Work degree at the University of Manitoba. The final step in qualifying for the degree is the completion of a practicum. The project I have chosen to research is a needs assessment for the use of the Memory Disorder Clinic at Lions Manor. My particular interest is in providing recommendations for the Family Support and Education component of the clinic.

I am excited with the model of Family Support and Education used at the Memory Disorder Clinic at Duke University Medical Centre at Durham, North Carolina. I would appreciate your feedback on the various components of that model.

With your help, the information collected from the attached questionnaire will be used to plan services for families at the Memory Disorder Clinic.

The information collected for this study will be treated confidentially through the use of code numbers for mailing purposes only. This is so that we may check your name off the mailing list when your questionnaire is returned. Please understand that you are not obligated to complete the questionnaire, your participation is strictly voluntary.

If you agree to participate, please complete the questionnaire and return it in the enclosed self addressed envelope by **May 28, 1996**.

Thank you very much for assisting me with this project. I really look forward to hearing from you.

Sincerely,

Judie Velnes
Director
Day Club Programs

National Practice Guidelines for Physicians Diagnosing Alzheimer's and Other Causes of Dementia - NINDS-ADRDA criteria

Recommended Lab Tests

Blood Tests

- Apolipoprotein E genotype for determining AD risk
- B12 and folate levels for deficiencies
- T4, TSH, Free Thyroxine Index for thyroid dysfunction
- Chemistry-18 panel for metabolic disorders (Na, K, Cl, HCO₃, Ca, Phos, ALT, AST enzymes, glucose, total protein, albumin, BUN, Cr, Uric Acid, Total Bilirubin)
- MHA-Tp for neurosyphilis
- Complete Blood Count with differential for evidence of anemias, clotting disorders, infection, and cancer
- Erythrocyte Sedimentation Rate, ANA titer, RF titer for evidence of possible small blood vessel disease

Other Routine Tests

- Magnetic Resonance Image of the Brain with Axial, Sagittal and Coronal Views to look for strokes, hippocampal atrophy, and masses
- Electrocardiogram for evidence of arrhythmiae or heart attack
- Chest X-ray for evidence of heart or lung disease
- Urinalysis for evidence of renal or systemic diseases or infection

Optional Tests

- Cardiological consultation if suspect heart disease producing reduced cardiac output or embolic sources of stroke
- Blood karyotyping for Huntington's chorea
- NPH Nuc Med Scan
- Tests for Leukodystrophies
- HIV if risk factors of multiple sexual partners, iv drug use, or multiple blood transfusions
- Fasting lipid panel if suspect strokes
- Prothrombin Time if suspect strokes
- Anticardiolipin Antibodies if suspect strokes
- Sleep-deprived Electroencephalogram if history of episodic cognitive disturbances or suspect Creutzfeld-Jakob Disease
- Epstein-Barr, Cytomegalovirus, Human Herpes VI titers if suspect Chronic Fatigue Syndrome
- Cerebrospinal fluid for MS panel (IgG, Albumin, Myelin Basic Protein, Oligoclonal bands) if suspect Multiple Sclerosis

- Cerebrospinal fluid for cell counts and cultures if suspect central nervous system infection
- Cerebrospinal fluid for cell counts if suspect subarachnoid hemorrhage

Key Points of Medical History

- Course
- Risk Factors
- Vascular Risk Factors
- Medical Illnesses
- Medications
- Family History of Alzheimer's
- Alcohol use
- Tobacco use

Course

- Abrupt or Rapid Onset
- Slow development and Progressive course
- Episodes of Impairment lasting up to a day
- Slow development, progressive course with periods (months) of little change

Key Features of General Physical and Neurological Exam

General Physical Exam Signs of Potential Significance

- Absent Venous Pulses
- Retinal Vascular Disease
- Hypertension
- Hypotension
- Arrhythmiae
- Heart Murmurs
- Carotoid Bruits
- Signs of Peripheral Vascular Disease (Distal Extremity Hair Loss and Skin changes)
- Enlarged Thyroid
- Lymphadenopathy or other Palpable Masses
- Enlarged Liver
- Chronic Lung Disease
- Arthritic Joint Changes
- Delayed Capillary Nailbed Refilling
- Periorbital Rash and Purple Hue (Heliotropic)
- Multiple Bruises not related to Medication or Injury

Neurological Exam Findings of Potential Significance

- Focal Neurological Signs
- Early onset of Gait disturbance, Psychosis or Extrapyrarnidal Signs not including Resting Tremor
- Cerebellar signs with or without spinal cord signs
- Peripheral Neuropathy
- Upper and Lower Motor Neuron Signs
- Paralysis of Upward Gaze
- Kayser-Fleischer Ring in Iris
- Papilledema
- Early Appearance of Extrapyrarnidal Signs including Resting Tremor
- Myoclonus
- Alien Hand (Partial Unawareness of Limb Belonging to the Patient)
- Dementia, Ataxia, and Incontinence
- Extrapyrarnidal Signs plus Autonomic Dysfunction
- Optic Atrophy
- Personality Change + Multiple Primitive Reflexes

Key Features of Cognitive Impairment

- Impaired Delayed Free Recall and Delayed Recognition Memory
- Impaired Delayed Free Recall with Preserved Delayed Recognition Memory
- Impaired Drawings of Simple Figures
- Predominantly impaired Language Skills
- Predominantly impaired Frontal Lobe Skills (Execution of Sequences of Movements, Generation of Words from a Category, Judgment, Personality Changes, Mood Changes, Shifting Attention Between Different Tasks and Correctly Performing Them)

Diagnosing the Syndrome of Dementia

Diagnosis of the syndrome of dementia requires demonstration of multiple areas of cognitive impairment, one of which is almost always memory, in the absence of an altered level of consciousness. A number of screening tests have been developed for this purpose, many of which are based on abbreviations of the Folstein Mini-Mental State Exam (MMSE). A short test that has good correlation with the full MMSE is the 8-item Short MMSE (Galasko et. al., 1990).

- The 8-item Short MMSE

Another short test is the 6-item Blessed Orientation-Memory-Concentration (BOMC) Test (Katzman et. al., 1983), which was developed from the longer (26-item) Blessed Information-Memory-Concentration (BIMC) Test (Blessed et. al., 1968).

- The 6-item BOMC

Other dementia exams include the following:

- Mini Mental State Exam
- Clinical Dementia Rating Scale
- Functional Activities Questionnaire
- Informant Questionnaire of Cognitive Decline in the Elderly
- Confusion Assessment Method
- Cornell Scale for Depression in Dementia

These Short Dementia Screening Tests can be used on-line.

Helpful Professional Attitudes About Alzheimer's Care

Professionals working with Alzheimer's families should resist the temptation to overly romanticize or pathologize family care. Family caregiving is not always "natural", fragile or off-limits to clinical tinkering. The reverse is certainly true as well. Many families cope and adapt quite well to the demands of care without reading three books and consulting umpteen geriatric or dementia specialists. This intervention was based on the following professional assumptions about Alzheimer's family care:

1. Families facing Alzheimer's care have an adaptational challenge. The family in and of itself is not necessarily the problem.
2. Given the heterogeneity of families affected by Alzheimer's, there is no one right way for families to respond.
3. There is no right place for a person with Alzheimer's to live or to receive care. Care in one's own home is not always the best alternative.
4. There are no perfect family caregivers. Most people lose their patience at some point. There is more underreporting of stress and burden and underutilization of services among family caregivers than the reverse.
5. There is rarely a fair, equal division of family caregiving responsibility. That does not mean that more equitable sharing of family responsibility is not a desirable goal.
6. There are no bad defense mechanisms. There are only defenses that don't work for the caregiver in a given circumstance. Although professionals may be quick to label an individual caregiver's response as "unhealthy denial," many family caregivers

provide high quality care only by remaining hopeful that their relative will respond and improve. Acceptance of the prognosis is not a prerequisite for effective family care.

7. There is no perfect control of an Alzheimer's patient's care nor risk-free environment for family care. Even in the safest, most stimulating and nurturing environments with the most informed, well-meaning families, some behavioral disturbances and consequent risks for the patient and others are inevitable. Even in ideal family care situations, contingency plans are necessary and wise.
8. Although a primary caregiver may be efficient and preferred, no one can do it alone. Primary caregivers need breaks, backup people and emotional support. Outside help supplements or complements personalized care and enhances the capacity of the family to sustain preferred levels of involvement.
9. Few incentives (financial, religious or motivational) will make an unwilling family assume care for an Alzheimer's relative. Few, if any, disincentives will keep a determined family or family member from honoring a commitment to care.
10. Coping skills for handling acute crises don't transfer well to the prolonged loss, grief and demands of Alzheimer's care. The critical variable is a family's flexibility in modifying and adjusting expectations of themselves and the patient to fit realistic dependency needs and the limits of family capacity. There are must less "learned helplessness and manipulation" by Alzheimer's patients than there are unmet realistic dependency needs of Alzheimer's patients. These patients rarely exaggerate their deficits.

11. Successful coping with dementia care usually involves a combination of strategies to change what can be changed and palliative strategies directed toward coping with one's reactions. Successful survivors of Alzheimer's family care often summarize their experience with statements like, "I got by with a sense of humor, the grace of God, a good family, friends and old fashioned ingenuity." Research findings on caregiver stress and coping tend to document the validity of this folk wisdom.