Alzheimer’s in Middle Age

A study of the situation of 45-65 year olds in Iceland diagnosed with Alzheimer’s

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PREFACE

Since June 2002 I have held a half-time position in the research laboratory of the Memory Clinic at LSH at Landakot in Reykjavik, Iceland. In consultation with Jón Snaedal, chief physician, it was decided that I undertake research of the group of people under 65 years of age who had been diagnosed as having Alzheimer's. Little attention had been paid to this group by the public health system in general and little was known about them. At the same time Jón Snaedal became the person responsible for the research.

I have had the help of Dr. Rannveig Traustadóttir, professor, Faculty of Social Sciences at the University of Iceland. Her assistance has been a great support for me, especially in light of the fact that I worked alone on the research.

The Science Fund of Landspítali-University Hospital, the Memorial Fund of Helga Jónsdóttir and Sigurlidi Kristjánsson and the Science Fund of the Icelandic Social Workers' Union supported this research, and I extend to them my heartfelt thanks.

Then I wish to thank Jón Snaedal and Rannveig Traustadóttir for their support and assistance. The Gerontologic Centrum of the University of Iceland and Landspítali-University Hospital (RHLÖ) provided space and equipment. I wish to thank the board of RHLÖ for their good support. Finally, I want to thank my interviewees for their very good reactions, excellent co-operation, and the invaluable information they provided. It is my sincere hope that the results of this study will play a large part in improved services and solutions for younger patients with dementia and for their families.

Reykjavík, 22nd February 2005

Hanna Lára Steinsson

INTRODUCTION

Not very long ago people were described as senile or confused when in fact they were suffering from an illness that today is defined as dementia. *Dementia* not only includes diminished short-term and long-term memory but may also involve aphasia, apraxia, impaired judgment, agnosia and impaired spatial ability. The diminished ability is evidenced in complex events such as tending to finances, purchasing, driving a car, seeing to one's medicines, washing the laundry and cleaning, cooking and using home appliances. Decreased abilities makes even the basic events of daily life difficult, such as getting dressed, keeping clean, eating, going to the toilet, and moving around indoors. The behaviour of such patients can be difficult for those who care for them as about 90% have psychiatric symptoms and behavioural difficulties at some point in the course of the disease. Psychiatric symptoms can include, depression, anxiety, distorted thinking, hallucinations and sleep problems. The behavioural difficulties can often be displayed by rambling around, restlessness, noise, aggression and indecent behaviour (Jón Snaedal, 2001; Rabins, Lyketsos and Steele, 1999).

Various diseases causes dementia, with Alzheimer's the most common or about 60% of cases. Other diseases include frontal lobe dementia, Lewy body disease and other less common diseases (Rabins, Lyketsos and Steele, 1999). Dementia reduces the life expectancy and it is felt that patients with Alzheimer's, for example, have on the average a 40% less chance of living as long as their age mates (Jón Snaedal, 1997). Common figures for the incidence of dementia in the Western countries indicate that about 1% of people younger than 65 come down with dementia, about 8% of people aged 65-75, 20% of people aged 75-85, and 35-40% of those over 85 years of age (Rabins, Lyketsos and Steele, 1999).

The diagnostic accuracy of dementia has increased and therapeutic options as well as social solutions have become more readily available. When a family member is diagnosed with dementia it affects all those who come in close contact with the patient and the burden on those such as the spouse and children continually increases. At the same time it is common for outside assistance such as home service and home nursing to increase little by little as the illness progresses. Nevertheless, it is always the closest relatives who bear the heaviest burden of care.

Selection of topic and importance of the research

The staff of the Memory Clinic at LSH at Landakot have long had an interest in mapping the number and conditions of people in Iceland who have dementia and are younger than 65. All services for patients with dementia up till now have been based on the elderly. The reason for this interest in younger and middle-aged patients is that their conditions are different to those of the elderly. Most are working full time when the symptoms first appear. Many still have children under twenty at home, even teenagers. They are socially active and most of them are physically healthy and in good shape. All support and treatment must take this into account.

No research has been carried out in Iceland on younger patients with dementia and information about this group has generally been very limited and widely distributed. It was therefore thought to be desirable to make use of the database at the Memory Clinic, which stretched back to the establishment of the Clinic in 1995.

Organization of the report

The first section of this report deals with the main studies that have been carried out in other countries on patients aged 45-65 with dementia. The second section presents the methodology of this study. The third section presents the results, divided into eight factors, and the fourth and last is general discussion.

1. BACKGROUND

Research on the group of people aged 45-65 who are diagnosed with dementia is new in the Western world. Serious interest did not begin until the 1990s in Europe and has increased considerably in recent years. The British have been the instigators and by far the greater part of the academic material available today comes from Britain. Scholarly papers and books, however, are thin on the ground as yet, though undoubtedly there will quickly be much more in the near future. Research on the conditions of younger patients is now being carried out widely with the intent of improving services for the patients and their families and to create new solutions that suit them better than those now available, as these were first and foremost developed for the elderly.

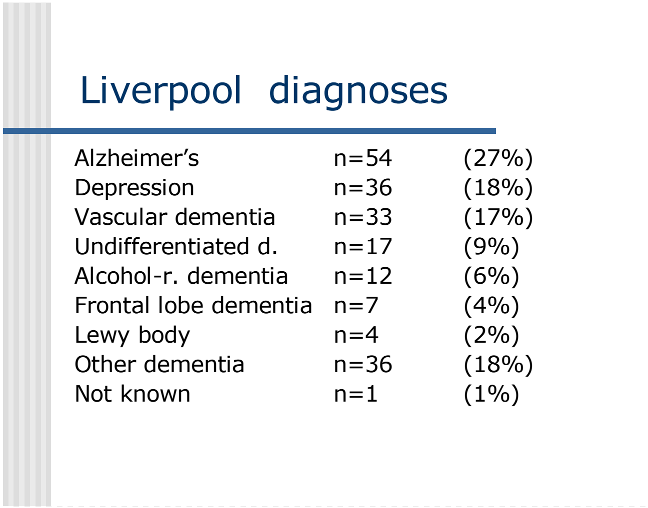
1.1. Data

Data about the prevalence of dementia among people younger than 65 is very disbursed and available in different ways, making a comparison between countries very difficult. In Denmark there are about 5,000 people younger than 65 of the total population of 5,400,000 who are thought to have dementia and about 400 to 500 new cases diagnosed there per year (Sylvest, 2002). The British periodicals show figures for the total number of cases in Britain that range from 16,700 up to 22,000. The article by Newens et al. in northern England (1993) states that in a society of 60,000 people aged 45-65 one can assume 20 patients with dementia. In his study of Britain Harvey (1998) found that for every 100,000 inhabitants there were 67.2 younger than 65 who had dementia. The Norwegian psychologist Per Kristian Haugen (2002), based on 100,000 people aged 45-65, reported that 90-120 of them had dementia and that 7-14 new cases were diagnosed annually. Some studies also indicate that more than a fourth of the patients of this age span is not correctly diagnosed (Hofman et al, 1991). No epidemiological research has been carried out on the prevalence of presenile dementia in Iceland.

1.2. Dementia in middle age

Alzheimer's disease is the commonest cause of dementia regardless of age. It is generally agreed that the progress of the disease is faster in younger patients, that they are more at risk for apraxia and aphasia, that they have worse symptoms and more extensive brain damage. Alzheimer's considerably shortens life expectancy as the average life expectancy of younger patients is expected to be about 8 years instead of the 10-12 among the older patients. The average life expectancy of those who need round-the-clock care is expected to be two years, partly because the elderly usually have to cope with more illnesses at the same time and therefore need to be institutionalized sooner. The younger patients with dementia stay at home longer with their relatives. The disease is more likely to be inherited among young patients than among older ones (La Rue, O'Hara, Matsuyama and Jarvik, 1995; Tindall and Manthorpe, 1997; Keady, 2000; Haugen, 2002; Reed, Cantley, Clarke and Stanley, 2002).

Research was carried out in 1993-1994 in Liverpool on the first 200 patients who came to the Memory Clinic and were younger than 65 years of age. Of those, 58% were men and 42% women, and it has been seen that dementia is somewhat more common among younger men than among younger women (Whalley, 1997). The diagnosis of the disease among younger patients is often inexact to begin with and as many as a third of the patients do not receive an exact diagnosis. The diagnosis was then re-examined a year later and the results may be seen in Table1.



Liverpool diagnoses

Alzheimer's	n=54	(27%)
Depression	n=36	(18%)
Vascular dementia	n=33	(17%)
Undifferentiated d.	n=17	(9%)
Alcohol-r. dementia	n=12	(6%)
Frontal lobe dementia	n=7	(4%)
Lewy body	n=4	(2%)
Other dementia	n=36	(18%)
Not known	n=1	(1%)

Table 1. Diagnoses at the Memory Clinic in Liverpool

Based on the MMSE test over half (51%) had mild dementia (MMSE more than 20 points), 40% had moderate dementia (MMSE = 11-19 points), and a few (9%) had severe dementia (MMSE 10 or fewer points). Only 7% of the patients had a family history of dementia. The main symptoms that afflicted the patients were depression, insomnia, anxiety, aggressiveness, wandering around, impaired movement and mood swings. Impaired memory was not important in the beginning. At the initial assessment 8% of the patients were already in an institution and at the re-assessment a year later 22% were institutionalized (Ferran, Wilson, Doran, Ghadiali, Cooper and McCracken, 1996).

In similar research carried out in Australia in 2000 only 11.9% were diagnosed with Alzheimer's but 19% with frontal lobe dementia and only 3.1% with vascular dementia (Panegyres, Frencham and Davies, 2002). Comparison between the countries can then be difficult because the methods used to make the diagnoses are not the same everywhere and are used by different professionals.

In Norway 30-35% of the younger patients has Alzheimer's opposed to 55-65% of those who were over 65. Frontal lobe dementia afflicts 10-15% of the younger patients but only 1-3% of those over 65 (Haugen, 2002).

In Denmark it was found that about half of the younger patients had either Alzheimer's or vascular dementia. Others had various other brain diseases, frontal lobe dementia being the most common. Frontal lobe dementia causes personality changes and changes in behaviour patterns. It is common for the patients to show complete lack of drive or very uncontrolled behaviour. Some of the patients have aphasia early and abstract reasoning is comprised. The symptoms of the disease may vary, which makes diagnosis even more difficult especially when the patient's memory is relatively preserved (Sylvest, 2002). Research shows that in general frontal lobe dementia is proportionately more common in younger patients than among the elderly.

It is assumed that medical treatment is more effective when diagnosis is made early. With present medication, however, it is not possible to expect more than 1 years delay of the progress of the disease (O'Brian and Ballard, 2001). For most, on the other hand, it does make much difference if it is possible to slow down the disease by 1-2 years. However, it is more difficult to accept the fact that someone near and dear has contracted dementia in middle age than when someone is of higher age.

Diagnosis of the disease leads to three results: Firstly it is possible to diagnose other illnesses that are conceivably possible to cure. Secondly it gives more time to tend to legal and personal matters. And thirdly the caregivers have more time to prepare for the task and to look for support. As Alzheimer's is rare in younger people it is most likely that the family physician will miss the diagnosis at first. Books that include younger patients descriptions in the course of the disease recount that professionals that were contacted were usually reluctant to the idea of dementia, especially in the beginning. The most prevalent complaints were the delay of diagnosis, that they were not told the diagnosis, that they were not given support after the diagnosis and that they did not get enough information (Keady, 2000).

Research shows that usually two to three years pass from the time that younger patients seek the doctor until they get the correct diagnosis. Doctors readily explain the first symptoms as depression, physical weakness, alcoholism, difficult conditions, stress, migraine or even the menopause (Haugen, 2002).

1.3. Telling the diagnosis

British research shows that only half of doctors tell their patients directly that they have dementia. There are three reasons for this: Firstly the diagnosis is often unclear in the beginning, secondly doctors may assume that the patient does not have enough insight to understand the diagnosis, and thirdly that the diagnosis itself would be too great a shock and could reduce the patient's initiative and activity. Most relatives were also in favour of shielding the patient from hearing the diagnosis. Nevertheless, most doctors and relatives said they would want the diagnosis revailed to them if they themselves contracted the disease (Pinner and Bouman, 2002).

Because of how inexact the diagnosis of younger patients can be in the beginning it is important that the patients and their relatives are followed up by a team of professionals and that they have access to a contact person in the team. The danger of providing the patient and his/her relatives too little information or a false sense of security is that the relatives' relations with the patient can become more complex and also that it can become more difficult for the family to make plans for the future. Doctors who are not specially trained in the area of dementia often avoid communicating the diagnosis because the illness is incurable and therefor they see no point in it. Younger patients usually feel that something is bothering them and are most often reliefed to know the diagnosis. It is common that they had been wondering whether they were psychotic or had a brain tumour. If they are told of the diagnosis in a considerate and positive way and the patient is informed of the support and solutions that are possible, their reaction will seldom be as strong as the professional expected. Often it is important to explain specific symptoms to the patient and his relatives as they will usually find it difficult to understand the changes that will take place. This information should be provided over a long period of time. After one visit to the doctor it can be expected that the client will remember half of what is said. It is therefore important that the family takes the opportunity later to talk with professionals and get answers to the questions that they have been occupied by (McKennan, 1999).

1.4. Socio - psychological effect on the patient and family

The first symptoms in younger patients are generally a feeling of insecurity and fear in doing some things, depression and increased irritability. Some individuals have distorted thinking and hallucinations. Many have difficulties at the workplace and are then readily referred to a doctor by their supervisor. They may have found it difficult to learn new working methods or had difficulties in carrying out common tasks. The reason is often attributed to stress and some are shifted to simpler projects or are let go. Diminished ability to stand the demands of the workplace can cause depression in patients (Fossey and Baker, 1995). The patient's spouses may also need to reduce their own work load or stop work altogether to take care of the patient. Financial worries may then ensue. Social isolation increases, both for the patient and for the spouse as the disease progresses. The spouse is quickly left alone with the responsibility for the family, finances and relations with people outside the family. It is often necessary to give up plans for travel and other events connected with the years after retirement (Williams, 1995; Barber, 1997; Whalley, 1997; Tindall and Manthorpe, 1997). It can be difficult for an outsider to understand that the person is ill as he/she is physically healthy and it is generally not expected that someone around fifty can have dementia. Relatives can also be at risk of meeting similar reactions from professionals and this can have a very negative effect on them (Haugen, 2002).

In 1993 research was carried out in London with interviews of fifteen relatives of younger patients with dementia. They complained most about the delay in getting the correct diagnosis and that they preferred more support and information when the diagnosis was confirmed. The solution they found most wanting was daily training for the patient. Those who had loved ones in an institution spoke about how difficult the process of institutionalization had been. Measurements showed that the relatives were undergoing a great deal of stress and that they had a strong need for emotional support (Sperlinger and Furst, 1993).

In 1997 in Australia 102 relatives of younger patients took part in a survey on the effect the diagnosis had on them and on others in the family. The study revealed that most (71%) had experienced difficulties in getting the right diagnosis. The average time from the start of seeking help until the right diagnosis was obtained was 3.4 years, and until seeking a specialist 2.8 years on average. The relatives experienced helplessness (81%) and grief (73%). The younger the spouses were, the more they had striking emotional and physical symptoms. Only 8% said that the illness had not caused difficulties for the children. Of those 65 relatives who were working outside the home 59% had reduced their work load or stopped working after the diagnosis and 89% of all the relatives had landed in financial difficulties that were linked to the illness (Luscombe, Brodaty and Freeth, 1997). Further research has shown that financial difficulties readily follow in the wake of illness of younger patients (Sperlingar and Furst, 1994; Keady and Nolan, 1997) and the research of Delany and Rosenvinge (1995) showed that more than 50% of the spouses or carers had to stop work or reduced their work load in order to take care of the patient.

There is generally little understanding of dementia in younger people and it is often difficult to get the correct diagnosis. Younger people often do not exhibit a sign of dementia on account of the fact that they usually are in good physical shape. It is common to try to ignore the symptoms in the beginning and to hide the problems that arise at work and at home. Isolation increases as the patient avoids being amongst a lot of people and many also stop their hobbies or leisure activities and thereby lose that part of their self-image. Patients can also feel left out and that they are not allowed to do things. They feel that friends and relatives do not always talk directly to them but rather ask their spouses how they are, and people do not treat the patient with the same respect as before (Sylvest, 2002).

MacNess and Baran (1996) have examined what younger patients find most difficult and the answers they obtained were:

- Being very bored and having shortage of meaningful tasks.
- Disappointment as they were not able to keep up hobbies
- Having to stop driving with the concomitant reduction in independence
- Having less money to spend
- Having a lower self-esteem

Research shows that spouses of younger patients show more stress symptoms than spouses of older patients (Sperlinger and Furst, 1994, Williams, Keady and Nolan, 1995; Harvey, Roques, Fox and Rossor, 1996; Keady and Nolan, 1997). Keady and Nolan (1997) concluded that the reason for this is that the younger patients often have more behavioural disturbances than the older ones. Harvey et al. (1996) found that if a marriage had not been good before the illness, the spouse was in even more risk of stress. Keady and Nolan (1997) noticed that spouses often felt they were stuck in the role of carer.

The illness has a strong influence on the patient's children, both on those who have moved out of the house and also those who are still at home. It is important that the parents discuss the diagnosis with the children as soon as possible. If youths are involved, they seldom understand what is going on with mum or dad. Help from professionals can be necessary in such cases. The time before the diagnosis can often be a time of arguments between the youth and the ill parent in which neither can explain what is happening. Like the parents, the children sense the insecurity in regards to the future even though the diagnosis has been made. They do not know how the disease will progress; the only thing they know is that they will lose the ill parent sooner than otherwise. They also get limited understanding from their friends and are left alone with their thoughts. Younger children find it difficult to accept the changes in personlality and their parent's strange behaviour. They try therefore to avoid contact with the ill parent. Children are also often worried whether the disease is inherited (Williams, 1995; Barber, 1997; Tindall and Manthorpe, 1997; Sylvest, 2002).

The British psychiatric nursing specialist John Keady in the 1990s held extensive interviews with 25 relatives of younger patients. He came to the conclusion that it is important to diagnose dementia early. The family was stressed living with symptoms like depression, irritation and poor concentration without an explanation. The relatives were generally dissatisfied how they were met by their family physician, who was generally the person they first went to. The doctors explained the symptoms readily as stress at work or marital difficulties. The relatives needed various types of support and their condition required support from those near and from specialists. The spouses had continually fewer interrelations with others, both friends and colleagues. They stopped little by little looking at the patient as a sexual being but rather saw themselves as caretakers. Children over 5 needed a great deal of explanation about the disease and the behavioural changes that accompany it. Information from professionals for the relatives was very limited (Keady, 2000).

1.5. Solutions for younger patients

Younger patients readily have more insight into their illness. They lose patience with themselves over their limitations more than the older patients and need good explanations from professionals. The results of the British survey in 2002 (Cordery et al., 2002) showed the need for good co-operation between the different specialists concerning younger patients. If this is not carefully seen to, the patients either get limited examination or incomplete follow-up.

Generally younger patients are more active and it is therefore important to offer special solutions for this group such as special day care centres that meet their needs for activities in addition to maintaining their self-esteem and self-image (Williams, 1995; Barber, 1997; Tindall and Manthorpe, 1997).

Dementia causes great changes in the lives of younger patients. Before the illness they worked, shouldered the responsibility of home and family, solved various projects and attended to leisure activities outside of the home. Expectations of work, home and leisure time collapse. When the patients are continuously at home without any project or leisure activity it has a very negative effect on their emotional and physical health. Their self-image nevertheless worsens if they are offered solutions that are ment for the elderly. It is therefore necessary that they are given tasks that give them the opportunity to use the knowledge that they still have. By that it is possible for them to retain their self-respect and the feeling that they can still be of use. It is therefore important to provide day care centres for younger patients. If this can not be done, the day care centres that are now in use must try to meet their different needs. Younger people have more need for physical activities and they often want to do other things, listen to different music than older people do, and even talk about different subjects. Support groups and support representatives are solutions that suit younger patients well. It can also help a great deal to share experiences with others, not least in the wake of the diagnosis (Haugen, 2002)

The study of Newens et al. (1994) showed that 57% of patients lived at home despite the impairment in their ability. They seldom saw their family physician and accepted relatively little assistance from society. Delany and Rosenvinge's study (1994) of the conditions of 27 British younger patients showed that they felt they did not get good enough advice and information after the diagnosis and that for those patients who were physically active felt a lack of suiteble solutions.

In 1983 proposals were made in Britain for services for younger people with brain damage. The proposals were based on the need for services far from large hospitals and in the outskirts. Both long-term and short-term stays were taken into account and also day or outpatient hospitals. Special emphasis was placed on facilities on the ground floor with access to gardens (Williams, 1995).

This section has reviewed the main studies that have been carried out in other countries on the conditions of dementia patients aged 45-65. It should be noted that in 2002 the Norwegians began a long-term 15 year study to map the conditions of dementia patients younger than aged 65. The objective is to determine which services these patients are accepting and also how the disease progresses with time (Haugen, 2002). The next section discusses the methods used in the present study.

2. RESEARCH METHODS AND EXECUTION

The following is a discussion of qualitative research methods in general and what methods were applied in this study, how the sample was selected, and how data collection and analyses were carried out. The main limitations of the study are discussed and then finally the research questions are presented.

2.1. Qualitative research methods

In the nineteenth century and in the first part of the twentieth century qualitative research methods made their way through in social science research. To begin with they were first and foremost used by anthropologists, but US sociologists were also quick to adopt them as well, especially those connected with the University of Chicago around 1910. The expression *qualitative research* was not generally used until the 1970s when researchers became more varied, such as researchers of women's studies and minority groups, teachers, social workers, nurses, executives, and others (Taylor and Bogdan, 1998).

There are many qualitative research methods but all have various characteristics in common. The commonest methods are participant observation and intensive interviews. The data collected describe people, places and conversations that are difficult to reduce to statistical formulas. The research questions are posed to study the research material in context, but at the same time to elicit the widest range of views as possible. The researcher knows how to develop a specific point of view at the same time as he is collecting data but he does not put forth hypothesis to be tested. He is concerned with understanding people and the phenomena he is observing on the basis of their own criteria (Bogdan and Biklen, 1998). For this reason qualitative research methods are characterized by induction and not by deduction, where the researcher continues to gain more understanding as the research progresses and he acquires a better perspective of what he is studying (Taylor and Bogdan, 1998).

2.2. Data collection and analysis

The research was carried out in 2002-2004 and covered the eight year period of 1995-2003. When the required permission had been obtained from the Data Protection Authority and the National Bioethics Committee, the Patient Register of all those who had come to the Memory Clinic during that time and were younger than 65 years of age was examined. The Register listed 87 people in all.

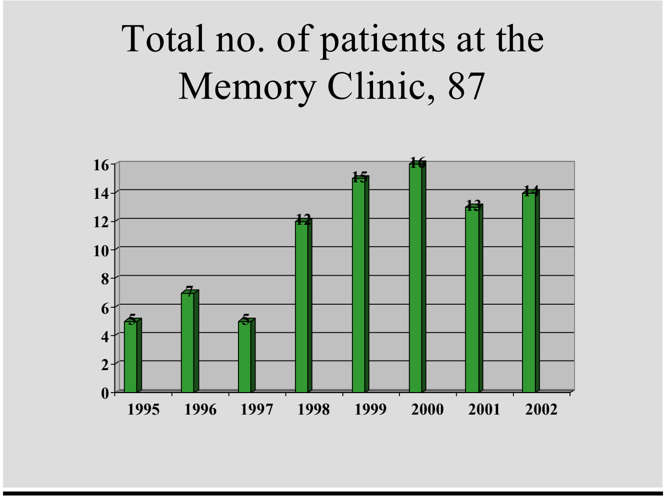


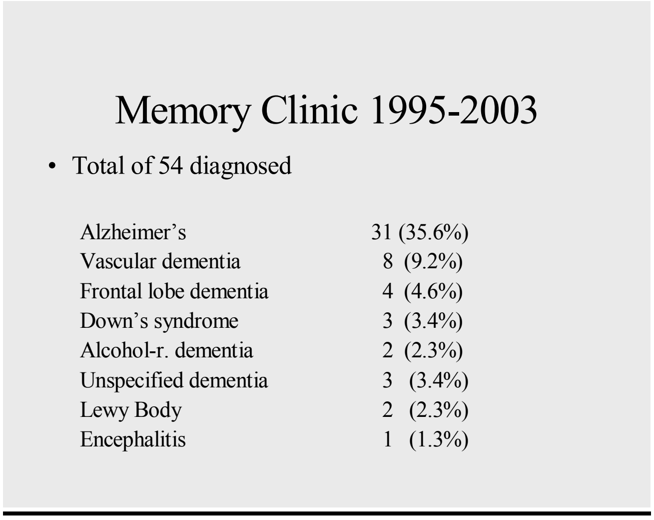
Figure 1. No. of people aged 64 and younger at the Memory Clinic

Of these 87, a total of 54 were diagnosed with some type of dementia. During the first years in 1995-1997 the Memory Clinic was located in Hátún and Jón Snaedal was the only doctor of the Clinic. When the Memory Clinic was moved to Landakot in 1997 more doctors were added and the Clinic was open every day of the week. The number of patients increased with these changes.

When work on this report began in October 2004, a total of 50 patients younger than 65 had been added to the list. The age distribution of this group was: Two younger than 45 (individuals with Down's syndrome), twelve aged 45-55, and thirty six 56-65 years old. It is thus not common that people younger than 55 attend the Memory Clinic and it appears that few patients of middle age with dementia come for diagnosis or are to be put under the supervision of professionals elsewhere. The staff of the Memory Clinic pointed this out in 2000 in a letter sent to all the psychiatrists and neurologists in the country. Few answered and none of those who replied had such a patient in their care.

2.3. The sample

Originally the intention was to include 15 people, as is common in qualitative research, but subsequently it was decided to contact relatives of all those who have been diagnosed with Alzheimer's and frontal lobe dementia, a total of 35 people.



Memory Clinic 1995-2003

- Total of 54 diagnosed

Alzheimer's	31 (35.6%)
Vascular dementia	8 (9.2%)
Frontal lobe dementia	4 (4.6%)
Down's syndrome	3 (3.4%)
Alcohol-r. dementia	2 (2.3%)
Unspecified dementia	3 (3.4%)
Lewy Body	2 (2.3%)
Encephalitis	1 (1.3%)

Table 2. Patients with a diagnosis of dementia

2.4. Dropout rate

The diagnosis of dementia is often unclear at the beginning of the course of the illness, not least for younger patients. The diagnosis can therefore change as time passes, which happened in five cases, including four in which the patients were originally diagnosed as having frontal lobe dementia. It is also interesting how few in Iceland are diagnosed with frontal lobe dementia compared to the figures in other countries. Two patients had no relatives in Iceland and the relatives of two others did not trust themselves to participate in the study. The dropouts therefore totalled nine people. Five of the nine patients had passed away and the loved ones of two of them did not trust themselves to participate. This left a final sample of 26, all relatives of patients with Alzheimer's.

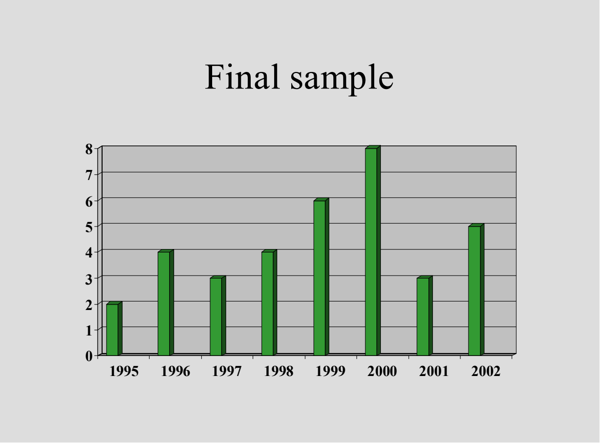


Figure 2. Final sample, 26 patients

2.5. Participants

The participants were those listed on the Patient Register as the patients' nearest relatives. The first step was to contact them by phone and then to send a follow-up letter introducing and explaining the study. Several days later they were contacted again by phone and if the person agreed to participate a place and time for the interview was established. Before the interview the interviewees read over the informed consent agreement and signed it. The interviews on the average took an hour to an hour and a half. They were recorded on tape with the interviewees' permission and then entered into a computer program. The transcribed interviews totalled 594 pages.

The interviewees were asked where they would like to meet and 13 of them opted for their own homes, 12 came to Landakot, and one interview took place at the person's workplace. Six of those interviewed lived outside the Reykjavík area, two in the north-west area, one in the town of Akureyri in the north, two on the Snaefells

Peninsula, and one in Reykjanesbaer in the south-west. Four of the patients had died before the interviews took place. Twelve of the patients were still in follow up at the Memory Clinic, eleven were or had been in day training, and ten were or had been in a nursing home. The group consisted of nine wives aged 52-64, eight husbands aged 62-72, eight daughters aged 35-45, and one son about thirty years of age.

Analysis of the research data was carried out along with data collection. In order to increase the validity of the study, five of the interviewees and another five relatives of younger patients who did **not** participate in the study were asked to read over the main results of the study and to give their opinions.

2.6. Limitations of the research

This study has several limitations which should be recognized. Most importantly, the researcher worked alone at collecting and processing the data. It is common in qualitative research that more than one person analyses the data, but not in this case. To compensate, the ten relatives, as stated above, read over and commented on the results.

The researcher had previously met most of the interviewees. She is an employee at the Memory Clinic and is involved with most aspects of the services for people with dementia. There was therefore a risk that the interviewees would not dare to express themselves openly about their experience of the service. However, this did not appear to be the case in any of the interviews. The interviewees were told that the results of the research would be used to improve service in the future and with that as a guiding light they were generally very open, both about individual staff members and about the services provided.

The sample is not large on a quantitative scale, but is rather large for qualitative research and actually very large based on how small this group in fact is.

2.7. Research questions

The main research questions that were asked were:

1. What is the difference in having dementia in middle age rather than when elderly?
2. What effect does the disease have on work, finances and performance?
3. How is the diagnostic work-up arranged?
4. What effect does the disease have on family life?
5. What services are received and what services are missing?
6. Is there a need for special solutions or is it possible to tailor services for the elderly to the needs of this group?

3. RESULTS

The results of the study are divided into eight sections. The first three sections deal with the symptoms of the disease in the beginning, when others begin to suspect that things are not all right, when the diagnosis of the disease is given, and how the patients and their relatives experience the fact that the person has Alzheimer's disease. It is then discussed how the disease generally progresses, although the progression of the disease is very much dependent on the individual. The next two sections provide descriptions of the effect of the disease on the nearest relatives, spouse and children. The sixth section deals with what services and support the patient and family received and what solutions were missing. That is followed up by a section on the main social changes that take place in the life of the patient and his spouse, and the final section deals with institutionalized living and how the families cope with the changes that occur when their loved one is transferred to a nursing home.

3.1. Early stages of the disease

When the disease first makes itself known most of the patients were 55-61 years of age. The youngest was 49 and the oldest 62, the average age 58.1.

3.1.1. Prehistory

In all cases there was some sort of prehistory before the closest relatives became aware of changes that were not possible to explain in a simple way, for example as a result of overload, depression, stress or normal ageing. Dementia or Alzheimer's is in most cases the last thing that occurs to people. The disease often sneaks in slowly in the beginning and it can be difficult for the closest relatives to understand what is going on as they simultaneously adjust to the changes. Thus a long time may pass before they seek medical help.

3.1.2. Initial symptoms

The initial symptoms are varied and differ between individuals, and relatives usually do not understand these behaviours as symptoms until much later. Typical initial symptoms are especially fear, anxiety, insecurity, suspicion, increased lack of stamina, headaches, general unexplained lack of well-being and even, at the same time, crying spells. In other words, it is not generally the loss of memory that is first evident in younger people, although that happens quickly as the disease progresses. The reason why these symptoms appear more prominently in younger patients is probably the various demands made on them. They are working, keeping house, bringing up children and in addition many of them have considerable responsibility for their own parents. Younger patients are usually in good shape physically and all this explains why it is normal not to suspect dementia at this stage. Other initial symptoms that relatives mentioned were that the patients were disturbed by noise, put things in strange places, collected things and tolerated badly any changes.

The first warning that something was abnormal most often appeared at work or in keeping house. Patients made repeated mistakes at work, even at the simplest tasks, and insecurity together with a lack of well-being increased at the same time, which also lead to a great deal of mood swings and anger. The insight of younger patients is often quite good – they know that something is wrong, but they have difficulty in finding an explanation. Purchasing supplies for the home can become complicated and generally patients buy the same products over and over. The ideal housewife suddenly stops baking for Christmas because she can’t remember what she has already added to the dough. She sometimes forgets to turn the stove off and little by little turns to cooking simple meals like boiled fish and potatoes. The patient has trouble with manual tasks and stops taking care of things that go wrong in the home. Patients readily become slower at moving and thinking and their reaction time is less than before. Apraxia usually increases quickly and difficulties in driving were apparent in the initial phase. Patients may lose their orientation to place and time and while driving or walking may lose their way, especially when dark. Aphasia is often prominent early in the course of the disease. The person either does not remember specific words, especially names, or does not finish his sentences as he forgets what he intended to say. Repetition becomes increasingly common. This causes a lot of insecurity, leading people increasingly to avoid being with others. All decision making becomes diffficult for the patient and finances become difficult to handle. In order to cope with these changes patients try to simplify their daily lives as much as possible and to stick to routine. Unexpected events, places with lots of people and trips can be difficult for them and demand a great deal of energy. Generally they wish to have relations only with their nearest and dearest and then only with one person at a time.

3.1.3. Denial

Denial is the method that both patients and relatives use almost without exception in the initial phases in reaction to the changes taking place. Usually relatives do not take note of these initial changes until a great deal later, as dementia or Alzheimer's is the last thing that occurs to most people. The children of patients readily tell themselves that these changes must be normal with age. Other explanations that are used are stress, over-tiredness, depression, alcohol consumption and poor physical condition. Knowledge about dementia is generally limited, especially linked to younger people which explains delayed suspicion. To complicate things even more, there is usually a large difference in the patient from day to day. Some days they can perform completely normally but on other days everything goes haywire. Often this is connected with stress and changes. The patients can also set themselves to it and play their role well for a short while, such as when people visit or they go to the doctor. In some cases the children are very worried about their parent but they don't bring it up for fear of causing hurt or embarrassment. The patients themselves seldom talk about their own worries because they have enough to do to keep their head up and get through the day without mishap. Spouses, on the other hand, are with the patient more or less for the entire twenty-four-hour day and become impervious to those changes that take place little by little. They readily feel that something is wrong, for example when the patient stops tending the garden, the home or her or his own appearance. On the other hand, they cannot explain the changes and therefore try to push their worries away and instead relax demands on the patient. They often automatically begin to protect the patient against outside demands, from tasks that he or she can no longer cope with, and even answer for him/her, so that others discover the symptoms late. In those cases in which a healthy spouse dies the children were astonished how little the patient could in fact take care of him- or herself. Denial, nevertheless, continues and this is explained by grief or depression after losing one's spouse.

It is common that relatives of the patient try to some extent to avoid upsetting, hurting or insulting the patient. This takes place little by little and generally continues after the diagnosis is clear.

3.1.4. Reaction of patients to the initial symptoms

Patients themselves are generally very slow to seek an explanation from a doctor for their diminished mental ability and try as hard as they can to hide their condition. They use various methods to get through the day, for example, by using notes, examining the map before they set off in a car, and even marking the route on the map. They try to avoid places where they assume they would know many persons and they devote themselves to using certain answers for various questions. Generally, when relatives look back after the diagnosis is clear, they see how the patient managed to simplify daily life by handing over tasks to others and by using various excuses which, at the time, did not seem unnatural to them.

Sometimes the patients had gone to their family doctor or a psychiatrist because of these initial symptoms, often without letting others in the family know until much later. There were also examples of seeking medical help because of physical symptoms like headache, lack of balance and disturbance of vision.

3.2. Diagnosis

Generally a long time passed from appearance of initial symptoms until the correct diagnosis was obtained. In one case ten years passed from the time the relatives began to be worried until the diagnosis was clear. At first the delay was blamed on a lack of scrupulousness on the part of the closest relatives or a disagreement as to whether something was wrong. It was also common for the patient him-/herself to see no reason to go to the doctor or was afraid to go, and others in the family found it difficult to find a way to get the person to the doctor. Usually it was difficulties at the patient's workplace together with repeated mistakes that convinced the family in the end that something was amiss.

3.2.1. Delay in getting the correct diagnosis

When finally medical help was sought there was an even longer delay before getting the correct diagnosis. Often the opinion of several doctos was sought, a maximum of nine. On average 3.8 years passed from the onset of first symptoms until the diagnosis was obtained. Most sought the advice of two to five doctors or an average of 2.9. These figures are congruent with the results of Australian research that was carried out in 1997 where an average of 3.4 years passed between the first symptoms and the diagnosis, and opinion was sought from an average of 2.8 doctors (Luscombe et al., 1997).

It should be kept in mind that the Memory Clinic was not a well known part of the public health service in Iceland during the first years of operation and it is likely that the delay in getting a correct diagnosis is somewhat shorter now than the figures presented here. In addition, the first medicine for the condition did not appear on the Icelandic market until 1997 so that before that time there was less incentive to get a diagnosis than today. Today there are many advantages to an early diagnosis of dementia. It is possible to begin medication, inform the patient and family about the illness and its effect, the family gains more time to plan the future, and there is less chance of financial disorder, road accidents or injuries.

3.2.2. Lack of understanding of professionals

In those cases where the opinions of many doctors were sought, it was common for the interviewees to complain about the unprofessional reception. The patients and their relatives often met a lack of understanding, they were not believed, and were not referred to another doctor. In one case the daughter of a patient out in the countryside had to argue both with the local doctor and with the nurse that her mother had Alzheimer's, despite the fact that the results of the diagnosis were available and that she had confirmed the diagnosis at the Memory Clinic. Both the doctor and the nurse were convinced that the stress of having a sick husband was the cause of the diminished mental ability of this 65 year old woman. In another case the daughter had wasted a lot of time in convincing her father and brothers that her mother needed medical help. When they finally went to their family doctor, he simply laughed at the woman's answers, as by that time she had considerable aphasia. The doctor's manner hurt both the patient and the family. In yet another case the relatives prepared for a long time to pull themselves together and go to their family physician with their mother/wife. When they got there the doctor picked up the phone in front of them and ordered tests for a woman who was depressed and forgetful. The family had to endure the doctor's manner and ever since have tried to help the patient to avoid such reception and to protect her from the opinions of others. It is therefore generally a sensitive matter and difficult for relatives to seek medical help with their loved one because of distorted mental ability which is nevertheless so difficult to explain.

3.2.3. Getting the diagnosis

In some cases the patients reacted with anger at hearing the diagnosis and the anger was directed either at the doctor who reveiled the fact or at the relatives who were present. Younger patients often have good insight and they can therefore imagine how things are progressing. They might wonder why they had to be struck with this disease and quite often make comparison with cancer and stroke. The same applies to the relatives; one spouse noted that if you are diagnosed with cancer you get a chance to fight it, but not Alzheimer's. It is however more common that patients are less affected by the diagnosis than other family members and even forget it before long. Almost without exception the relatives hold onto the hope for a long time that the diagnosis is not correct, especially if the diagnosis has been somewhat unclear or diffuse. The daily differences that the patient often shows underscores this weak hope. Nevertheless, it causes considerable stress, both to the patient and the relatives, if the diagnosis is very late. It is extremely important for the relatives that the doctor communicate the diagnosis to the patient as clearly as possible.

3.2.4. Importance of good information

Some of those interviewed complained about the shortage of information after the diagnosis, especially during the first years that the Memory Clinic was in operation, and felt there was a great need for both written information and access to professionals to talk to and ask questions of. Better access to specialists was considered desirable. Both patients and relatives may experience a kind of emptiness after receiving a clear diagnosis and they wonder how the disease will progress and what is the next step. Most tried to find information on the Internet, in libraries, from professionals in the family or from someone who also had a relative with Alzheimer's. Those who obtained books and pamphlets from the Memory Clinic or FAAS, the Association of Relatives of Alzheimer's Patients, found considerable information in this way. They felt that such information helped themselves, others in the family and even employees who came to take care of the patient. Many relatives said they found it important to be able to phone the Memory Clinic for direct communication with a professional who knew the patient's history. It causes considerable strain and discomfort to have to keep repeating the patient's history for each new outside helper.

Receiving a diagnosis of dementia is a blow, both for the patient and for the closest relatives, but on the other hand knowing also lightens the burden. The diagnosis provides an explanation of the various incidents that arose and that people had wondered about. It varied considerably what the patients and their families made out of the knowledge that the person had Alzheimer's. Some thought it best to tell most people about the diagnosis so that they would not make abnormal demands on the patient and have a better understanding of conditions. Others found it better to hide the diagnosis for fear of unnecessary branding which can colour people's approach to the patient. It was also the experience of many that the patient was not treated with enough respect after the diagnosis was made public. It is also difficult to set a person in the role of patient who is physically healthy and looks good.

3.3. Development of the disease

No two Alzheimer's patients display exactly the same symptoms but the disease follows the same course in every patient, with increasing symptoms. In most of the cases studied the progress of the disease was rather rapid. Often there were periods when the disease seemed to remain constant but periods of rapid progress were also common. Apraxia and aphasia increased quickly and the ability to organize dwindled, both at home and at work. The spouse gradually took over most tasks that the patient saw to before such as making purchases for the home and handling the finances. If the patient was responsible for too long for these tasks there was the risk that he or she would steadily keep buying the same foods or that the patient would lose control and be in debt. However, there are various types of tasks that people hold onto longer like washing the clothes, making the bed, ironing and tending the garden. Patients need increasing supervision as the disease progresses and also guidance on simpler tasks such as eating with a knife and fork, shaving and keeping clean, dressing, going to bed, opening a door with a key, etc. They subsequently become increasingly dependent on their spouse or others.

The patient often has considerable insight in the beginning, such that they feel very definitely that there is something wrong but cannot explain what it is. On the other hand, they have very little insight about their own capability and this often creates difficulties and tension in marital relations. Patients often are well aware of their increasing inability in the beginning of the illness and that can either cause irritation and anger over small things or they become sad and cry easily. These symptoms often improve and even disappear as the disease progresses and insight is reduced. Personality changes can occur when the disease affects the frontal lobe. Some of them can become negative while others became milder and more tolerant with progression of the disease. Commonly the behaviour that characterized the patient before illness is increased as the disease progresses.

Almost without exception difficulties in driving occur quickly in the course of the disease. It makes no difference whether or not the person was a driver by occupation. In the first place, the sense of direction is diminished so that patients find it difficult to find the way, especially if they are in a new area. In the beginning this is connected to insecurity in driving, most often in finding the way in the dark. As the disease progresses people limit their driving to specific streets and good driving conditions. In the second place, their perception of distance, streetlights and traffic signs diminishes. In the third place their sense of the speed of the vehicle is deadened so that it is common that they drive too slowly or too fast, and in the fourth place their judgement and sense of direction can be impaired, which causes the person to drive in the face of oncoming traffic or against a red light. Patients generally drive a car considerably longer than relatives think is advisable, but it can be very difficult to intrude and limit the freedom of the person by deciding that he or she is unfit to drive. Relatives begin by frequently banning children from going in the car with the person, and often the spouse or another person accompanies the patient and assists orally so that he/she can take the right street and without mishap. The study at the Memory Clinic has shown, however, that in 80% of cases the patient him- or herself made the decision to stop driving, and this research made no distinction for the age of the patient (Helga Hallgrímsdóttir and Jón Snaedal, 2000).

When the disease progresses patients continually develop less understanding of time. First they find it difficult to follow what day it is, and later they don't know what year or season is it. The error in the twelve hour day is also common, such that they find it difficult to know whether it is twelve noon or twelve midnight. When it has come to that there is always the chance that patients will dress themselves at midnight and wander out. It is also common that they become quite unable to read a clock. Many spouses therefore experience that, although they go out for just a moment, it feels like a long time to the patient and he becomes uneasy and insecure.

Delusions are often discernible and can end with thoughts of persecution that arise from insecurity and suspicion. These are especially connected with ideas that some people, particularly those who are closest to the patient, are acting behind his/her back, cooking up a plot, trying to get him into an institution or are cheating him in some way. Spouses are often accused of adultery. In many cases it is possible to control delusions with medication.

Dementia causes the patient little by little to stop recognizing people and places that they should know. First they stop remembering the names of people and places that they seldom use. The problem increases and ends with their no longer knowing the people that they should know well. This causes a great deal of insecurity in the patient and plays a part in their avoiding increasingly gatherings and prefer to be inside with their closest friends and relatives. A large part of the problem is also that, as time passes, the patient has less and less tolerance for outside stimuli; even grandchildren can suddenly cause them a great deal of stress. Patients often keep themselves going for quite a while by keeping the days routinized and avoiding all changes. The more their ability is reduced, the more they need to routinize the day and it is very common that they need to sleep more than before because of tiredness and a lack of stamina.

As the dementia worsens and becomes more all-encompassing the patients find it more difficult to understand what they hear or see and there can be a considerable amount of distorted interpretation and misunderstanding that can be difficult to correct. This dwindling understanding causes the patient subsequently to stop reading books and newspapers. They also stop understanding the news on the television, though they may perhaps watch out of habit. It is common that they cannot relax in front of the television, especially if they need to follow the story line, and the result is usually one of the following: 1. The patient watches simple material like sports, informative programmes or children's shows. 2. The patient sits with the remote control and constantly surfs the channels. 3. The patient stands up and leaves. For the same reasons, the patient at this stage has difficulty following the conversation of others and finds it best to talk quietly to one person at a time. When more people are present, the patient will most likely retire from the scene. When they themselves talk and discuss with others they continually repeat the same lines. They readily ask the same question over and over and they ask most what day it is and when they are to be at a specific meeting or go to the doctor or other event that was scheduled in advance.

3.4. Experience of spouse

The course of the disease is long and difficult and the burden steadily increases on the spouse, who is the main caretaker. Most spouses must struggle with some kind of breakdown of health that can be traced to the long-term burden of caring for the patient. On reaching middle age people often have to cope with a series of blows connected, for example, with their own health, the loss of those near and dear, illness of family members or friends, and various mishaps or accidents. This happened to many of the interviewees in this study, such that they were not only caring for their sick spouse, keeping their job up and raising children, but also coping with various other problems.

3.4.1. Relations between patient and spouse

Some patients can have difficult relations with their spouse and direct their anger or negativism chiefly against them. It often does not take much for the patient to flare up so that the spouse has to watch what he/she says. It is generally best not to protest, correct or reason with the patient. Best to steer the conversation to something else. Then there are also cases where the patient becomes milder and relations are easier.

In those cases when spouses find it difficult to discuss the disease openly with the patient and others around, all relations can be very strained and superficial. It also increased the stress and lack of well-being of the spouse. It is common that the illness was not discussed within the family of younger patients because it was more difficult for them to understand that they were ill, since they were almost always physically healthy.

The basis of discussion between the couple becomes steadily more limited and misunderstandings or misinterpretations readily arise that are often difficult to correct. This can result in a stressed environment in the home for the rest of the day. The patient then tends to ask the same questions without let-up and repeats the same sentences, which greatly tries the patience and tolerance of the people in the home, especially spouses. In some cases there are children under twenty and even of confirmation age still living at home, which causes still more stress in all family relations.

Everything that can be counted as the private life of the spouse gets more and more constricted as the disease progresses. The patient is more and more dependent on the spouse and wants him or her to be home and within sight. It is common that the spouse is followed throughout the house, has difficulty talking on the phone and even using the toilet. This tries the spouse a great deal as everyone has a need now and then for personal space.

Both spouses and children greatly fear the progress of the disease and generally want to avoid thinking about too far in the future. It is therefore rare that the family discusses the disease openly. Usually patients only have a limited knowledge of how much their ability has become diminished and spouses make use of various methods to manage things so that they keep their dignity as much as possible. There are examples of spouses talking beforehand with parties that the patients have dealings with so that they can be met with more forebearance, for example in banks and shops. Spouses often answer for the patients so that they won't feel bad when they can't answer well and they readily become assistant drivers so that the patients can continue to drive as long as possible. As the disease progresses the spouse becomes the spokesperson for the patient, especially if communication is diminished, and it is important that they are listened to as they know best the patient's wishes and needs.

Nearly all patients with dementia show signs of lack of initiative, of interest and of drive. This puts the burden on the spouse to find something to discuss and things to do to pass the time. It is often necessary to encourage the patients strongly in order to get them to go out of the house as they come up with a lot of excuses to skip going along. The burden on the spouse generally causes a great deal of long-term stress and sometimes also night "duty" because of the patient's changed sleeping habits. The patients sleep more during the day because of their lack of stamina and therefore can be awake during the night.

3.4.2. Lack of understanding of others

Spouses of patients with dementia generally encounter little understanding from the environment and outsiders keep sending them a message that the situation is not as bad as they say. This message is easily based on a short visit or phone conversation with the patient. Spouses are very hurt by this and little by little they come to understand that no one can put themselves in their shoes unless they live with a patient day and night. Spouses are also rarely asked about their own health.

Both the spouse and the children of the patients become aware of the lack of knowledge and understanding of other people about dementia. They themselves find it difficult not to know in advance how the disease progresses as it differs so with the individual.

3.4.3. Increased isolation

When the disease worsens it is common that friends and relatives visit less often and relations with others than the nearest relatives are considerably reduced. Spouses are constantly on the alert as the patient can become exposed to unexpected behaviour at any time. Generally they cannot turn to very many to talk to beside their children but it is common that they try to protect the children as much as possible and even hide from them the real situation. The isolation of the spouses can also come about because the patient refuses to accept help from an outsider who could possbile relieve the spouse of having to care for the patient at all times. Spouses therefore become very bound to the patient and can seldom if ever see to their own interests. They are often themselves slow to accept assistance, either from the children or others, as they are usually in good shape and think that they can continue to see to things the same as before. The patients are also usually physically healthy so that they usually continue to live at home with limited outside assistance until everything goes out of control. Only later do spouses think that there will come a time when they will need to put the patient in a nursing home. They try to think only about one day at a time.

3.4.4. Loss and grief

Spouses experience losing their life's companion little by little as personal characteristics disappear one after the other. They try to maintain as normal a married life as possible, despite the disease, and continue to convince themselves that that which they have to give still matters to the patient. They experience deep grief and find it very difficult to accept the changed conditions. In reality they face a marriage with an individual who is entirely different from the one they married.

The disease prevents the couple from enjoying retirement years together as they had planned, plans for trips little by little are abandoned and the patient stops doing the hobbies or leisure activities that he or she did before. Loneliness and depression are common among the spouses, which can be directly traced to the effects of the patient's dementia. The understanding of society for other illnesses like cancer is generally greater than it is for dementia.

3.5. Children's experience

Most of the children in this study were in their twenties or thirties when their parent´s symptoms first appeared. It is often one of the children who discovers the first abnormal changes in the patient, but it can take time to convince brothers and sisters or the healthy parent that it is right to seek medical help. The experience of children of a patient with dementia is in many instances similar to that which spouses experience. However, they are most often not living with the patient day and night so that the burden on them is different from the burden on the spouses.

In some cases a long time passed before the children were aware of what had happened as both the patient and the spouse helped to cover over the true condition when the children came to visit. In those cases when the healthy spouse died it was a great shock to the children to discover the patient's true state. Many children, like the spouses, were impervious to the condition, which meant that they did not take account of the changes until considerably later. In those cases when there was no spouse usually one child had to shoulder most of the responsibility. It is common that the child who sees to most of the care of the patient becomes the butt of unrealistic comments or that distorted thinking that is related to the disease. This can cause a great deal of hurt as it can be difficult to understand how much the illness has changed the parent.

3.5.1. Loss of a parent

The children experience a slow loss of the parent and deep grief, like the spouse. One daughter wrote a collection of poems about the loss of her mother who was, however, literally alive but was in a nursing home. Many described it as losing a parent over and over again. They met the same lack of understanding from others as the patients' spouses, even from their own spouses. Other outsiders have difficulty in understanding the loss and relatives often get little or no comfort from others before the patient's death, though they needed it long before.

Children are very afraid that the condition is inherited, both for themselves and for their own children. They feel pangs of anxiety if they forget something minor or become absent-minded. In eleven cases in the study it was known of others in the family who had contracted the same dementia.

3.5.2. Responsibility of the children

The children readily take on a great deal of responsibility for the patient and also for the other parent, not least if they are only children. If the patient does not have a spouse to help, the children are on duty day and night. Then it is necessary to see that the parent gets through the day without mishap, either by phoning to remind him/her of what has to be done or to visit the patient to provide assistance. The children struggle with the steady, underlying fear that something will happen to the parent, especially in the evening or at night. It is common that most of the responsibility, and therefore the burden, lands on one of the children, especially a daughter In some cases some one of the children were in complete denial for a long time which made it even more difficult for those who did see to taking care of the ill parent.

3.5.3. Having many obligations

The children of younger patients are trying to advance in their work or attend school, most have spouses and in-laws, and in addition are raising their own young children. This creates a great deal of stress and an additional burden and they need to divide their responsibilities between these various people. If the spouse of a patient is present, he or she turns especially to the children for support and advice. It makes a great deal of difference that the patient's children are well set up, both at home and at work.

Having a parent with dementia often makes huge demands on the marriage and the family life of the children. It requires a lot of understanding and patience on the part of the spouse and children that a lot of time goes to taking care of an ill parent and that emotional health can be poor. The patients' daughters- and sons-in-law in some cases have not known them when they were healthy and have difficulty understanding which behaviours are the symptoms of the disease are and which personality characteristics. This causes difficulties in relations between them and also with their own spouses.

3.5.4. Missing the parent's support

Children often miss the support of the ill parent at the same time as they very much need to relay on him or her. One daughter, for example, was carrying her first child and could not turn to her mother for the assistance she needed. Another example was the case of the handicapped boy who was dependent on his mother, both socially and financially. He had to move to a home for the disabled because of his mother's illness.

Children often find it difficult to explain to their own children what is happening to grandma and grandpa. They mind it when the grandparents' interest in the grandchildren seems to wane, though the cause is that the grandparents can no longer withstand the activities of children as well as before. When patients can no longer tell the difference between one grandchild and the other, and even between their own children, they suffer a good deal of anguish.

It also hurts the children of the patient that the possibility of doing things together with the parent subsequently diminish and likewise they stop enjoying things together. They however constantly try to find something that still brings happiness.

3.6. Services for the patient and relatives

All the interviewees were familiar with the services at the Memory Clinic, but concerning other services there was a gulf between what was offered in the capital area and in the less settled areas. No specialized solutions were available for people with dementia in the sparsely settled areas such as day wards, support groups, hospitalization to profice rest or specialized nursing wards. People in the countryside need to turn even more to the assistance of relatives. The descriptions that follow are therefore almost wholly based on the experience of people in the capital area.

3.6.1. Getting information step by step

All agreed that there was a huge need to inform both patient and family much better about practical details concerning the progress of the disease, relations with the patient, rights and services. The relatives experienced the search for information as a very complicated process at the same time as they had to adjust to the illness. It is important to have one doctor and good access to him and to have the opportunity to talk to other professionals. It is most desirable that the same professionals follow the patient through the whole course of the disease and that it is easy to get in contact with these helpers. Relatives find it very difficult to talk to the doctor in front of the patient and to have to keep repeating the history of the disease to someone new who is not acquainted with the case. The study revealed that it is important that professionals make information available to as many as possible in the family at the same time and not just one family member as he or she often has difficulty passing on the information to others in the family. The relatives also wish to be included in decisions concerning the patient, as there were many examples of when the professional offered patients various services, even including a place in a nursing home, without consulting the relatives and the necessary service was rejected. Patients generally do not have the judgement to decide what assistance they need in each stage of the illness.

3.6.2. Support groups

Eleven people had been in support groups for relatives at the Memory Clinic and generally talked favourably of them. They found it of great worth to meet others coping with the same conditions and to find that they were not alone with their problems. There was general approval of the information provided for the group and also of the opportunity to get varied reading material about the illness and what it entails. Nevertheless, it was clear that it was not good to mix younger spouses with older spouses. One woman who had been by far the youngest in her group found it just plain difficult, but another man was especially pleased that one spouse had been younger than he. It is therefore important to have a special group for younger spouses.

3.6.3. Home service

Both the patients and their spousses are generally slow to accept outside service in the beginning and to let unknown people into their home, but many said that more home service was needed to meet the needs of this group. The service of supporters or assistance where the patient gets help in running the home and doing leisure activities is extremely important when they have lost their job but are nevertheless not so ill that they need to go to a day care center. This is often a period of restlessness or complete lack of initiative where the patient no longer has the role of a provider. There are cases where the spouses were refused assistance on the grounds that the patient was not handicapped despite the fact that the patient had a valid disability certificate because of his illness. Others talked about similar experiences about how they had trouble getting service at home because the employees at Social Services felt that the spouses were not sufficiently ill. Some had, for this reason, applied to the private sector or within the family.

Spouses of younger patients usually work outside the home and even though the patient goes to a day care center there can be a need for home service assistance, especially in the afternoon to meet and be with the patient until after the spouse returns home. This service was not possible to find and caused a great deal of difficulty for several of the interviewees. Those patients who were taken care of in a nursing home lived at home until it became impossible because of the lack of assistance. Several relatives were convinced that their loved one could have lived at home longer if home service had been stronger and more flexible. One daughter said that it was necessary to raise the wages for employees in home service as they performed an invaluable job.

3.6.4. Day care centres

Almost all of those who had experience of day care centres were very pleased with the quality of work that goes on in the centres. It is a great relief for relatives to know that the patient is safe during the day and that they can work or run errands without having to worry. Nevertheless the decision to accept such day care is often difficult as they are afraid that the patient will react badly and the family feels it has failed. There were cases when the relatives avoided accepting a place in a day care center because they felt the patient was much younger than those already there. In one case the offer was rejected but the relatives saw quickly that situation at home had become very difficult. They had to wait an entire year in addition for another offer at day care. One spouse experienced the center as prison as it was closed with a digital lock. It seems as if the waiting time for day training was far too long and also that it was necessary to support the relatives better to accept such a solution when it was offered. It also was revealed that it mattered a great deal how the patient and the relatives were received during the first few days. The closest relatives wanted to impart information and the staff needed to be good listeners. To be a good listener applies to all aspects of services for patients with dementia.

Most of the patients did well in the day care centres and some relatives felt that the patient’s initiative and level of activity increased. Some began again to do things they had stopped doing. Nevertheless, the spouses sometimes had difficulty getting the patient to go every morning, especially if they themselves drove the patient there.

The most prevalent criticism was on the opening hours as most of the patients were driven home about 3.00 p.m. This is very inconvenient for spouses working outside the home and they made perfectly clear that there was a need for a longer opening hour so that they would have time to buy food or run errands before the patient returned home. In most cases the spouses could not leave the patient home alone.

Only a few emploees were criticised, both in the day care centres and in the institutions. This criticism was usually caused by poor relations with the person, that the relatives did not feel they were listened to sufficiently well or they felt a lack of respect for the patient. Good, open relations between relatives and staff were considered very important, as the relatives were the spokespersons for the patients, who generally found it difficult to express themselves and communicate their needs themselves.

In general the interviewees found the level of service high in the day care centres, staffing good, staff turnover minimal, and that a lot was done for the patients' activities. Those who also had experience of nursing homes spoke of transferring from a day care center to a nursing home as a great step backwards.

3.6.5. Respite care

Five people had experience of respite care and had different stories to tell of the experience. It is a big step for relatives to admit an individual in middle age and in good health to a closed hospital ward whith patients that are very sick and most are elderly. Relatives and especially spouses have become experts on the care of the patient and have the best knowledge of his/her feelings and are very anxious when they have to turn the care over to strangers. Nevertheless most felt that it had been necessary to accept such hospitalization in order to provide respite for the spouse, who often had to cope with the very negative behaviour of the patient or got little rest at night because of the patient. Many of the spouses needed rest, in the opinion of the researcher, but could not consider accepting hospitalization at that point in time. Most were afraid of the institutional atmosphere and many felt that three weeks was too long a time, but it is the usual length of time that is offered. Three working spouses said that they would have wished to have had the opportunity for a weekend off every now and then, or during the week and that it would be necessary to offer this in a home-like environment, outside an institution. One wife said that she thought it would be best if such admissions were offered at the day care center where her husband attended as he knew both the surroundings and the staff there. A great deal of emphasis was placed on a home-like environment where it would also be possible for relatives to be with the patient in peace and at their convenience.

In addition the main criticism of admission for respite care was the lack of leisure activities and that the patient was bored. It is very trying for relatives to visit and find how much the patient wants to go home and how insecure he feels in these strange surroundings. Some said that they would have preferred having more influence on the care provided. For example, one spouse would have preferred to help bathe the patient as it was the first time that an unknown person had seen to it and the patient struggled against it. Relatives often wanted to check on the medication and all changes in the medication given. Friendly reception by the staff, good communication between staff and family, and activities for the patients were the main points importence in the view of the interviewees.

3.7. Social changes

Dementia is a family disease. It affects everyone who comes in contact with the patient regularly and cares about him or her. Often a lot of other blows can rain down on the family during the time, such as the death of the patient's parents and spouse, accidents or other illnesses within the family. Few are familiar with dementia and its effect when it sneaks into the life of the family. Everything that is unknown causes insecurity and relations within the family become more difficult. This can become even more complicated when the patient is in his or her second or third marriage and it is common that various disagreements arise concerning support, care of relatives, finances and various other concerns, for example between spouses and the children of a former marriage. The burden of care is always heaviest on the spouse and when a breakdown in relations within the family is added, the burden can become too much. A complex family pattern can therefore in some cases add to the problem. Grandchildren are easily forgotten in the discussion of a patient with dementia and in this younger group of patients they are of all ages, even as yet unborn. Children and teenagers often find it difficult to look up to a middle-aged grandfather or grandmother with dementia and they need help in understanding what lies behind their behaviour.

Of 26 patients, a total of 22 were working outside the home and everyone lost their job. Most were let go, though others quit voluntarily. It made no difference whether the job was simple or complicated. The result was loss of income for the home, and often people lost their job before they received a diagnosis so that for a time they could lose their rights to benefits as well. In addition, extravagant spending could follow, which led to the patient's making dubious investments without control of those near. In most cases the loss of their job was very difficult for the patients, with little or no leisure amusements to pass the time. Some simply did not understand why they had lost their job. Often spouses stopped work before retirement age or decreased their work so that they could better take care of the patient. Since financial worries were added, spouses felt it important to be instructed as to their rights, as they found it insulting to have to go to the social security for help.

In some cases the spouse decided to change housing for financial reasons, in others to find more suitable housing because of the patient's limited motor ability. There were also cases where the spouse did not dare to change the large and unsuitable housing for fear that the patient's condition would worsen with the change.

The social isolation of the patient and his or her spouse usually increased rapidly after the diagnosis was clear. Many find it difficult to adjust to the changes that occur in the patient's personality and do not know a way to maintain a rewarding relationship with him or her. In most cases there are fewer visits by friends and relatives and it is subsequently less possible to take the patient out.

3.8. Institutional life

In those three cases that the relatives had had experience of their loved ones living in a home unit they were greatly pleased with this solution. It appears to suit younger patients well to live in such an invironment while in the middle stage of the disease. On the other hand, the relatives felt quite differently about the nursing homes. Only one of the ten who had experience of nursing homes was very satisfied with the service provided. His loved one had been in a special hospital ward for several months before receiving a place in a nursing home. The interviewee was pleased with the service in the hospital ward but he found the environment of the nursing home more home-like, a good environment and the staff stayed on the job well, which was especially important. Others said that they found it important that the nursing homes were home-like. Almost all had had experience of other service levels such as day care centres and home units or other stays in special hospital wards and they criticized how the service, for both patients and relatives, was considerably reduced after the patient was placed in a nursing home. The staffing and training of the employees were clearly considerably less good, with little or no emphasis on education for the employees. There were many foreigners who did not speak Icelandic and everyone was very unhappy with that as it was difficult enough for those near and dear to communicate with the patient, let alone with someone who did not speak the native language.

Very little activity is offered for patients in nursing homes in general and the main emphasis is on physical care. Service seems to be based on some low limit and relatives felt that they had to ask for everything to be done for the patient, other than daily care, for example, dental care, pedicures, physio-therapy/motor ability, even to call attention to various changes in the patient's behaviour which could indicate a broken bone or other distress, and a great deal besides. One relative complained of not being told when the patient was given a service for which a special payment is required, but instead the bill came by post afterwards, and that it was often difficult to get confirmation that the patient had indeed had such service. Many reported that they felt the staff made poor use of the time between regular tasks to build constructive relationships with the patients. Some said that often the staff simply sat down and talked to each other while the patients were arranged in front of the television, no matter what was being broadcast. The interviewees felt that general relations between patients and staff were more impersonal than they were used to at the former level of service and that the patients were treated more unfairly. They felt that more care and respect for the patients were missing and they sometimes said they were ready to teach the employees how they ought to care for the patient. Some felt there was striking use of medicines to make the patient more tractable, and one interviewee said they did everything possible to keep the patient calm and to numb the sex drive so that they could be put to bed early. Very clearly the relatives were unwilling to complain to the staff or the department head for fear that it would make things worse for the patients.

Nearly all the interviewees were well aware of the steps to save money and the shortage of staff. They saw this with their own eyes and the staff spoke a great deal about it to them when they visited. The staff apologized that there were no more activities for the patients as the burden on the staff was great and they had no extra time. Most of the relatives reacted to this by swapping visiting days with each other, taking the patients as often as possible out of the home and trying to think of new things to do that were suitable. There were complaints of little or no support for the relatives and meetings with family members to inform about the patient's progress on the ward or how things could be better handled were rare.

In general the interviewees were agreed that it would not have been excusable to wait longer before admitting the patient to a nursing home because of the long-term burden on the family. Some complained that in actuality the relatives had no choice as to where the patient was domiciled or what kind of accommodations the patient got, as when the first place is available it is necessary to take it because of the situation at home. One of the relatives who had looked at many nursing homes said that he had the feeling that they were generally badly set up for such patients. His loved one was first at an institution that the family was very dissatisfied with and he said it was an awful experience to be pushed to accept the placement. The patient did very poorly in the ward and the relatives suspected that he was physically punished by the staff. They felt the staff did not listen to them and only succeeded with great difficulty in getting the patient moved to another institution. They were pleased with the new home but still found the same shortage of activities for the patient.

In all cases the decision to institutionalize the patient was difficult. Spouses were left with a deep feeling of guilt and found it difficult to enjoy life, thinking of their spouse in the institution. One wife, who had worked very purposefully to control her feelings was, however, very determined to live her life despite the fact that her husband was in an institution after 45 years of happily living together. It is never the intent of the spouse to let the patient go away at some point and it is therefore very difficult for them to acknowledge that they can do no more.

No interviewee found it difficult to accept the fact that their loved one was considerably younger than the other inmates in the nursing home because he or she was just as ill as the others. In specialized nursing wards all the patients have dementia and although only a few contract the disease before they are aged 65 they exhibit the same symtpoms during the last stages. The most important thing for the patient is to get good care from professionals and that they are as comfortable as possible.

In the last stages of dementia the patient's motor ability and communication are generally severely impaired. Many are no longer able to recognize their nearest and dearest, which is a severe blow to those who experience this lack of recognition. It often seems that the patient's quality of life is severely reduced. Nevertheless it is usually possible to find something that pleases them and music, pretty things, little children, pets and photographs and the comforting nearness of other people can never be rated too highly.

Relatives felt that the manner of the staff that take care of the patient is most important. They have themselves a great need for an open relationship with the staff and want to keep careful track, in addition to which they can often give the staff good advice concerning care of the patient. They want to be greeted when they come to visit, that the staff turn to them and give them information about the patient without being asked all the time. It is also very important that there are not a lot of changes in the staff personnel. A great turnover causes substantial insecurity, both on the part of the patients and of the relatives. It appears that if the patient feels better, the relatives feel better and if the patient feels worse, the relatives feel worse also.

Alzheimer's

If you were robbed in a hideous way
blindfolded
your clothes torn from you
driven in a car a long way
thrown out onto a dim wasteland
you don't recognize
if then the only signs of life in that place
were vague creatures
who spoke
but you could not understand them
nor they you
how would you feel?

Without the strength you are used to
to survive evey day

Without friends

But these conditions,
though bad,
are better than the days
she struggles through

You still have your thoughts to keep you company
You are your own companion

I watch her wonderfully
warm hospitality
I remember her laughter and her song
that she was strong and positive
shining, proud
and good

I would say,
if I were to look at her now and ask:
Where are you, Mother?

This is the worst
to feel her gone

Instead this doll

That which shows her still a person
is the fear, the anguish, the trembling

But even these signs will disappear
the disease shows no mercy

I wake each day with a pang of conscience
a cold fist around my heart

I cannot take care of my mother
I have to hold her hand in mine
stop work to be with her

Why? I ask
God! I cry
grit my teeth as she always did
now she has no understanding of why the world treats her so badly
why her family is not always beside her

I know that our roles have reversed
and if I was ill
she would sacrifice everything to think of me
this is the difference between being
parent and child

Original Icelandic by the daughter of one of the patients in this study

4. CONCLUSION

Soon after this research began in the summer of 2002 a work group was appointed at the Memory Clinic to work for better service for the group of younger patients and their relatives. In addition, the internal work of the Memory Clinic was generally improved. The group has since met monthly and will continue to do so as there is a continuing need to examine and improve the services provided. The main changes that have been made up to now are:

1. Hugely improved information flow to patients and relatives. Everyone now receives an information packet on diagnosis of the illness with information on the examiniation that has been carried out, who are their contact persons at the Memory Clinic, in addition to several practical booklets. A new booklet was written and issued covering the ten most prominent symptoms of dementia and distributed throughout the country. Sales and distribution of reading material for relatives have greatly increased.

2. Family of all younger patients are invited to a special meeting with the staff after the diagnosis has been made where the diagnosis is reviewed, the progress of the disease discussed, information on services provided and the relative's questions answered.

3. There are now special support groups or courses of study for younger spouses and two such courses have already been held and received very well. The idea of holding a special course for children of younger patients is being discussed and a support group for younger patients is now being prepared.

4. As the Memory Clinic has a service contract with all those special day care centres that existed it was decided to direct all younger patients to one center, Hlídabaer. Now the majority of the patients there were born in 1940-1950.

The Icelandic government has never had a policy concerning the problems of people with dementia, let alone one concerning younger patients. There is therefore nothing for it but to let the professionals in the area do as they see fit, as possible. The only legal clause that deals with dementia is in the Act on the Elderly, Article 14, which requires that all nursing homes have special facilities for these patients. However, the requirement is continually contravened throughout the country and in fact, the lawbreakers go so far as to design and build new nursing homes without taking into account patients with dementia. Nevertheless it is estimated that the number of such patients will nearly double in the next 25 years.

While this research was in progress it was clear that the waiting list for day care centres had grown much too long and the time of waiting had reached one and a half years from the time of registering. As a result of the urging of professionals at the Memory Clinic, with articles, lectures and letters to the minister and pressure from the association of relatives, FAAS, and an extensive campaign for signatures, a special day care center was opened at Eir in March 2004. In the beginning the ward was to be general. With this the waiting list was considerably shortened and the situation is now still better after the inhabitants of Kópavogur opened their own day care center, Rodasalir, in January 2005.

In 2004 the public health authorities suddenly decided to prevent patients with dementia that were younger than 67 from being admitted to a nursing home. This was accomplished by closing the access of professionals to electronic assessment of admission for that age group and without any professional discussion of the matter. The arguments that were voiced afterwards were of two kinds: that the demand of younger people on nursing homes was a great problem and that nursing homes were designated as being for the elderly, which, according to the Act on the Elderly, are defined as those who have reached the age of 67. Examination of this demand of younger people for the year 2003, before access was limited by age, showed that a total of 19 people of 856 had been granted admission to the nursing homes in the nation under the age of 67. This sudden connection with the Act is also strange in light of the fact that the assessment of admission had been made for younger people by professionals on the aged ever since it had been enacted twelve years before. There are examples of the management of nursing homes, such as Sóltún and Hrafnista, having decided, under the protection of the Act, to deny entrance to all those who had not reached the age of 67. This is deplorable, especially in light of the fact that these two homes have especially good facilities for younger dementia patients.

It is clear that the present thinking is such that it is perfectly all right to break some legal requirements, and without taking into account the professional assessment as to whether a patient who is not yet 67 shall be counted as having a disease of the elderly and therefore needs to be assigned a nursing home bed currently reserved for the elderly.

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