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University of Applied Sciences

Degree Programme in Health Promotion

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THE EFFICIENCY OF SUPPORTING THE QUALITY OF LIFE OF FAMILY CAREGIVERS
ACCORDING TO THE FAMILY CAREGIVERS OF PERSONS WITH DEMENTIA WHO
ARE MEMBERS OF THE MEMORY ASSOCIATION OF PÄIJÄT-HÄME

Master's Thesis 2013

ABSTRACT

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KURVINEN, ANNETTA The Efficiency of Supporting the Quality of Life of Family Caregivers according to the Family Caregivers of Persons with Dementia who are Members of the Memory Association of Päijät-Häme

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In the area of Päijät-Häme live many persons with dementia with their family caregivers. A diagnosis of dementia has an impact not only on the quality of life of the person with dementia, but also on the family caregivers.

This study was commissioned by the Memory Association of Päijät-Häme. The purpose of this study was to get additional information about how the Memory Association of Päijät-Häme could more efficiently support family caregivers as well as the person with dementia and there for improve their quality of life.

The study was carried out using quantitative, semi-structured questionnaires. The basic study population consisted of 183 family caregivers who are members of the Memory Association of Päijät-Häme. The response percentage was 42%. The results of the study were analyzed using SPSS. Content analysis was applied to the open-ended questions.

The results of the study indicate that family caregivers are interested in the activities that the Memory Association of Päijät-Häme offers. Time limits prevent family members from availing of and short participation in activities. Not all family caregivers interviewed received the services of the Memory association of Päijät-Häme. The opportunity to avail oneself of some of the services is influenced by where the person with the memory disorder lived, or the travelling time involved. It is necessary for the Memory Association around the Päijät-Häme to look at itself and by making changes made to when and where activities were provided the activities of the Memory Association around the Päijät-Häme area, such as activities in evening, facilitating activities nearer to the person's home, or indeed in the family home. In this way the association supports also a better quality of life of persons with dementia and their family caregivers.

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1 INTRODUCTION

Dementia is a major disease. In Finland there are 120 000 persons with slightly weakened cognitive impairment. Within this group 35 000 persons have mild problems of dementia and 85 000 persons have moderate problems of dementia. The group of patients is growing yearly with 13 000 persons who get the dementia diagnoses. The number of people in the working age, under the 65 years old, with dementia is also growing. There are 7000–10 000 persons that have dementia still in their working age. Many persons who have dementia are currently undiagnosed. (Memory disorders: Current Care Guidelines 2010.)

The first step in the nursing part of person with dementia is that somebody, usually from the family, starts giving support and care. In the event that a loved one has dementia, preventing or minimizing the effects of the family caregiver's burden and stress is very important as well as providing the best possible support to the loved one affected. The effects of dementia impinge on the patient's quality of life and also on the quality of life of their family caregivers. Family caregivers of persons with dementia experience more stress by physical, emotional and economic pressure. (WHO Dementia fact sheet N362, 2012.)

In Europe there are about 100 million family caregivers. According to the Finnish National service there are about a million people who support other people who need more care. There are about 300 000 family caregivers in Finland but only one out of ten persons get official municipal support for family care giving. (Salanko - Vuorela 2010, 7.) In this study, all persons who act as family caregivers, both the ones with and without financial support from the municipality, are considered family caregivers of a person with dementia.

Quality of life is based on many factors, which are mostly personal. The factors can be based on lifestyle, purpose in life, personal characteristics but also on social relationships, social networks, and social support. The factors are also based on the physical condition, age and the financial status of a person. For the family

caregivers it is important that they get information about dementia, support and peer support. Nowadays, as the memory coordinator makes home visits to persons with dementia and their family caregivers, it shows that it is essential that the coordinator has the knowledge, skills and information to share with the customers so that they can use the information to their own benefit.

The Memory Association of Päijät-Häme was asked in November 2012 to undertake a research study to see how it could improve the quality of its service to family caregivers based upon scientific findings using the information provided by the caregivers of family as evidence. For this study, a quantitative, semi-structured questionnaire was used. The collected dataset was analyzed by using Statistical Package for the Social Sciences (SPSS). The data was collected from 77 family caregivers of loved ones with dementia who are registered with the Memory Association of Päijät-Häme.

The aim of this study is to use the surveys as a means to investigate how the Memory Association of Päijät-Häme should develop and enhance better service to provide by using researched best practice methodology and listening to the opinion of the family caregivers.

The questionnaires covered five specific areas. They also afforded the caregiver to cover areas which were of importance to them and which may not have been detailed in the study.

Firstly this study looks at what the association offers now, what the family caregivers currently use and what the family have requested more. Secondly this study looks at access and egress if the distance is a problem for getting service of the Memory Association of Päijät-Häme. Finally this study looks at how the information of the association is distributed.

Most family caregivers welcomed the opportunity to share their story and were pleased that the research outcome aims would result in providing a more enhanced service and support for not only persons with dementia but also the family

caregivers. After this introduction, the theoretical chapter two outlines the condition of dementia and the associated problems for a person with dementia on an information level. It also explains the concept of family caregivers and the quality of life of the family caregiver as influenced through dementia. Chapter three is about the support that can be offered to persons with dementia and their family caregivers. Chapter four and five consist of the methodologies and results part.

2 THE LITERATURE REVIEW OF THE FAMILY CAREGIVERS OF A PERSON WITH DEMENTIA

2.1 Different types of dementia

The dementia is classified as a syndrome, not a separate disease. Dementia is associated with loss of memory. This may also be associated with one or more of the following symptoms; mood changes, problems with the languages, reasoning and decisions making. Most commonly the cause of dementia is a progressive disease of the memory. Dementia causes limitations with regard to social, professional and physical activities. (Eloniemi-Sulkava, Sormunen & Topa 2008, 10; Vuori & Heimonen 2008, 8.)

According to Erkinjuntti (2010, 87) dementia has three stages; the mild stage, the medium stage and the difficult stage. In the mild stage there is reduction of work and social skills but the person is still able to manage himself. In the medium stage the person is not totally able to manage himself and in this stage a little bit help is needed. In the difficult stage, or third stage, there is a need of help all the time.

There are different kinds of dementia: **Alzheimer`s** is the most common cause of dementia. About 50-60 percent of the people with dementia have Alzheimer`s in Finland. About 20 percent have also another kind of with another name. With diagnose of Alzheimer`s it is possible to start with medication. The medication

helps to get less cognitive impairments and it decrease also the behavioral problems. For the family caregivers medicines can be helpful to let them get along with the person with Alzheimer's. It gives more time to live at home and it is a part of the overall treatment of Alzheimer's. (Juva 2007, 11-13; Sulkava, Alhainen & Viramo 2004, 5.)

The first symptoms of Alzheimer's can be shown as somatic symptoms as feeling stressed, being very tired and a little depressed. In the mild stages, the first stage, the behavioral symptoms usually are apathy, being more irritated, depression, somatic symptoms and losing weight again without any apparent reason. In the medium stage, the behavioral symptoms are restlessness, being depressed, sleeping- awake disturbances, misconceptions and hallucinations. The somatic symptoms are losing weight without a reason, difficulty in using daily objects and inflexibility. In the difficult stage of Alzheimer's, the third stage, the behavior symptoms are restlessness, depression, disturbance of sleep and not normal physical behavior. The somatic symptoms are not finding and understanding words, sucking and sticking reflex. (Juva 2007, 10-11; Memory disorders: Current Care Guidelines 2010; Sulkava, Alhainen & Viramo 2004, 7.)

The second most common form of dementia, **Vascular dementia**, is also called cerebrovascular disorder. About 15-20 percent of people with dementia get the vascular dementia. The starting of vascular dementia is usually abrupt and there can be neurological problems as strike. There are problems in walking and there are problems with holding control over losing the urine. The symptoms depend on which part of the brain is affected. Problems may appear with languages or in giving form or structure to things, or walking is slow and inflexible. (Juva 2007 13-14; Erkinjuntti, Juva & Sulkava 2007, 3; Sulkava, Alhainen & Viramo 2004, 5-6.) With vascular dementia patients are usually given medication for keeping the blood thin. Also a combination of Alzheimer's medicine seems to work well. (Juva 2007, 14).

Another form of dementia is the **Lewy Body** increase. About 10-15 percent of the people with dementia has this form of dementia. This can start in the age category of 50-80 years. There are changes in the capacity of to think logically. Also there are difficulties with physical mobility, which includes slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression, and changes in the strength and tone of the voice. If the person has Lewy Bodies, it is important to be physical as flexible as possible and to get physiotherapy. Problems also occur with falling asleep very easily by day and the nights are restless, disturbed nights with confusion, nightmares and hallucinations. Hallucinations are also experienced in the day time. (Juva 2007, 15; Erkinjuntti, Juva & Sulkava 2007, 3; Sulkava, Alhainen & Viramo 2004, 6.)

Only two percent of persons with dementia get **Frontal-temporal** diagnosis. Here the frontal-temporal lobe degeneration starts usually between 45 and 65 years. This is a genetic illness. The frontal-temporal lobe degeneration is caused by damage to the frontal lobe and/or the temporal parts of the brain. These areas are responsible for our behavior, emotional responses and language skills. The social behavior is changing at the beginning of the illness. Usually activities are hard to make by themselves. The persons with frontal-temporal diagnose are passive apathetic and unobstructed. Through all the symptoms it is difficult to manage the daily life. (Juva 2007, 16-17; Erkinjuntti, Juva & Sulkava 2007, 3; Sulkava, Alhainen & Viramo 2004, 7.)

A more rare kind of dementia is the **Parkinson** disease. In Finland there are about 3.000 persons who have Parkinson's disease. Usually if a person gets the diagnoses of Parkinson disorder they pay much attention to the physical side, as this is the first part which becomes very obvious in that carrying out everyday tasks gets more difficult. Memory loss causes one to lose the ability to think and to respond quickly. The person may also become obsessive, and there may be a loss of emotional control, with sudden outbursts of anger or distress. Visual hallucinations are also a part of the condition. The person's symptoms can seem better or worse at

different times and can change quickly. (Juva 2007, 17-18; Memory disorders: Current Care Guidelines 2010.)

Also **Korsakoff** is a kind of dementia which is not often diagnosed. Korsakoff's syndrome is a brain disorder usually associated with heavy alcohol use over a long time. People with Korsakoff's syndrome have a shortage of thiamine which affects the brain and the nerve system. There are changes in the behavior, which can result in either apathy or in hyperactive conversation. This condition may also present with the person having large gaps in his memory he may believe that his memory is functioning normally. They have difficulty in acquiring new information or learning new skills. Korsakoff is the kind of dementia that is on the increase due to high alcohol consumption. (Alzheimer's Disease International 2012; Memory disorders: Current Care Guidelines 2010.)

Ruutiainen and Sivenius (2003, 214) present the ideas of Sulkevan and Eloniemi that there are several risk factors that can explain why the family caregivers have problems with taking care of a person with memory disorder at home. There can be behavior problems, e.g sleep-wake disorder. The family caregiver is exhausted; the obligation, the responsibility for problems caused by different types of treatment alone, the stress. The reduction of the physical capacity of the person with dementia becomes visible, including walking problems, physical stiffness and the retention problems. Where short term respite care was offered following problems were noted; the person with memory disorder came home in a worse condition, this was a result of giving of wrong medicine, putting pampers on a person or they put him/her sitting in a geriatric chair. The offering temporary place for a short stay service is inflexible; the facilities are not designed for people with dementia but for the normal geriatric population. Families found it difficult if not impossible to get appropriate assistance in an acute situation. To get services the services was found to be very bureaucratic and for that reason the family caregivers got exhausted and disillusioned. The professional's support as a part of the service is not sufficient for

the families; there was reported a lack of appropriate information, a traditional schematic approach and an incorrect attitude (Ruutiainen & Sivenius 2003, 213).

2.2 Definition of concept family caregiver

The official term for family caregiver, according to the Central Association of Carers in Finland, is a person who takes care of a family member or a loved one who through illness, disability or for another reason can't manage with his or her daily activities independently. (Salanko-Vuorela 2010, 7; Central Association of Carers in Finland. 2013)

In legislation (The Act on Support for Informal Care), a caregiver means a family member or another person who is close to the care receiver, and has signed an informal care agreement with the care receiver's municipality of residence. The number of persons receiving support has increased steadily. This numbers are all family caregivers in Finland not special the family caregivers who take care of persons with dementia. It is estimated, that 13.000 persons collected support in 1994 in comparison with approximately 36.000 persons in 2010. Improvements regarding several matters, such as provisions and the right to time off have been gained over the years. The Act on Support for Informal Care came into effect in 2006. (Central Association of Carers in Finland. 2013)

2.3 The quality of life of the family caregivers influenced by dealing with dementia

There are many definitions of quality of life. The World Health Organization describes quality of life of the individual in context to the society and the culture, in which the individual will evaluate its position in relation to its aspirations, expectations, demands and concerns. They look to the person's physical health, psychological condition, a social relationship, personal believes and their position according to the environment support. (WHOQOL Group 1994.)

According to the thesaurus care and welfare quality of life are determined by physical, psychological and social factors such as personal characteristics and the quality of relationship. Also mental balance, the fulfillment of life goals, the degree of adaption to the new situation in the event of illness, disability or old age, and social participation have influence on the quality of life. (Thesauruszorgenwelzijn 2013.)

The Health-Related Quality of life (HRQoL) concepts means the physical, mental, emotional and social function of people. HRQoL is derived from the concept Quality of Life. Also related with HRQoL is the concept of wellbeing that includes positive emotions and life satisfaction (Measuring healthy days 2000, 5.)

The functioning of people physically, mentally and socially is personal. Everyone makes it in their own way. People with the same health do not necessarily have the same opinion about their quality of life. How the quality of life is experienced, is determined by the inter-action with a large number of determinants. The most important are personal stressors and lifestyles, social environmental factors, personal characteristics, psychological characteristics such as personality, needs, goals, values, attitudes, and skills, characteristics of social relationships, social networks, and social support. One factor is also how people deal with stress and are able to look for and ask for help has influence on the quality of life (Sprangers & Snijders 2009.)

The family caregivers have to accept that the relationship between their partner/friend with dementia and themselves may change. The changes can happen quickly or slowly, the personality can change, and behavioral problems appear. Also the daily activities are changing. This can cause problems for the care givers, as without support they are tired, and depression is often a part of their life. For protecting themselves it is very important that family caregivers understand why the changes are coming, how to deal with them and also to accept that. They need also look after themselves in order to survive and to cope. They have to learn to accept more help from outsiders. Peer-to-peer groups help them to get more power.

The relationship with friends or family can change and friends are very important. (Palosaari 2010, 179-195.)

Socioeconomic situation, living surroundings and the living area can have influence on the availability of nursing treatment and conveniences. These factors have effect on the stress situation of the family caregiver. Often the stress situation comes from more different factors. The hearing of the diagnose of dementia, not knowing what will happen in the future; are there showing up behavioral problems, is the decreasing physical condition, can the person with dementia manage in the every day life. (Pearlin, Mullan, Semple & Skaff 1990, 583-594.)

According to the study of Juntunen, Era & Salminen (2013, 2-12) it seems that the maintaining of friendships is very difficult. The caregiver feels that they are trapped in their roles. Most of the support they get from their own families. The lowest quality of life is got in the social part and the highest is got in the environment part care giving takes a lot of time and energy so the caregivers own physical condition will often go down.

The roles of associations are very important. They listen and have professional workers and can give many advice and guidance. The Association also supports the family caregivers and their clients for going on with the normal life. They have connections with other organizations and can offer help or opportunities in many ways show how. Making the peer groups a part of their organization and finding new organizational possibilities also between other organizations requires much work. (Viitanen & Purhonen 2010, 161-162.) According to Perren, Schmid and Wettstein (2006, 539-548) a psycho- educational group intervention can have a positive effect on the family caregivers' appraisal of behavioral problems. Peer groups are based on sharing experience, emotional, appraisal and informational support, and hope. There are many peer groups for chronic diseases like diabetes, concerning asthma and they work well (Castelein, Bruggeman, van Busschbach, van der Gaag, Stant, Knetering & Wiersma. 2008, 64.)

The common causes of the exhaustion of family caregivers are usually caused by the behavior symptoms; neuropsychiatric symptoms and the ability to function of the person with the memory disorder. The other reason is that they do not get enough information about how to support a person with a memory disorder (Ruutiainen & Sivenius 2003, 213; Wong & Wallhagen 2012, 516). The age of the family caregivers has an influence on the risk to get burnout: the younger family caregivers have bigger risk for burnout than the older ones. Also incomes are related with depression. Improvising talent is also needed with regard to the changes the dementia illness brings with it. (Tremont, Davis & Spitznagel 2005, 307-315.)

A Chinese study of NurFatimah, Rahmah, Rosnah, Ismail, Khadijah & Shezat (2013 7-13) pointed out that associated with Chinese culture, behavior problems of the patients, employment status and type of dementia the family caregivers has experiencing poor physical and mental health. They interviewed 145 primary caregivers. This was the first kind of study in China looking at the quality of life associated with the family caregivers of persons with dementia. This study was made in a local setting and according to this study a cohort study would be better off in comparison to a cross sectional study in order to identify the causal effects of the factors related to measuring the quality of life.

A coaching course for persons with dementia and their relatives has shown to be useful. But they are not organized often and the possibility to get on the course is very low. (Ruutiainen & Sivenius 2003, 213.)

Family caregivers of people with dementia experience more stress through physical, emotional and economic pressure (WHO Dementia fact sheet N362, 2012). A caregiver's burden may be associated with the loved one's behavioral problems which sometimes is a strong predictor of institutionalization. It also has financial implications for the state as funding is required to provide various forms of support. According to a Spanish study (Arigimon, Limon, Vila & Cabezas, 2004, 454-457)

especially female caregivers of persons with dementia have a decreased quality of life in comparison to their contemporaries in the general population. This was a cross-sectional study, and there were 181 family caregivers, 78 % of whom were females. Sample size was 543 individuals from the general population. They used the SF-36 questionnaires, which is a generic measure of health status.

The study of Rosness, Mjorud & Engedal (2011, 299-306) shows that the provision of domiciliary nursing care for the family caregivers has a positive effect on their depression. The study of Huang, Chang, Tang, Chiu & Weng 2008 has pointed out that it is possible that in high quality caregiver-patient relationship there is more understanding between the caregiver and the patient and caregivers views are thus closer to the patient views.

A Dutch study made by Peeters, Werkman and Francke (2012, 33-35) shows that taking care of a person with dementia is very burdensome for ten percent of the 2384 family caregivers and for a third part of the 2 384 family caregivers it is quite burdensome. The needs of activities for a person with dementia is for three quarter of the family caregivers very important and three quarter of the family caregivers make also use of the activities for persons with dementia. A temporary place for a short stay was needed by one quarter of the family caregivers.

3 SUPPORT FOR PERSONS WITH DEMENTIA AND THEIR FAMILY CARE GIVERS

Persons with dementia and their family have access to the everyday support of a variety of social forms of support. The forms of supports are social care and health care services, various benefits and allowances, as well as other forms of assistance. A large part of the social form of aid is fund allocations for these service and support from the municipal needs assessment. Right of social welfare for the client position and his rights have his own will. This law promotes focus on the client, confidentiality of customer relationship and the right of the client for a good service and treatment in social welfare. The law of patient's status and rights

provides the patient's right to good care and treatment and treatment of the patient recruitment and related with this associated policies. Also the Alzheimer's Disease International organization has given a Statement of Principles in which they highlight the demented people and their caregivers to play an active role in the life and their own decision-making rights (Mäki-Petäjä-Leinonen & Nikumaa 2012, 4-10.)

3.1 Economic support by Kela

The Social Insurance Institution of Finland is Kela. It is the provider of social security benefits for all residents of Finland. Everyone who lives permanently in Finland has a personal Kela-card. Kela offers many benefits and to get them one has to check and apply them by oneself. All applications of Kela are on the internet. The client can print them out and sent them or going with your bank identification and fill them in online and sent them by internet (Mäki-Petäjä-Leinonen & Nikumaa 2012, 10; Kela 2013.)

Partially or fully reimbursed medicines: This needs an application including a B-medical certificate. Kela makes the decision whether an applicant gets the reimbursed medicines partially or fully. Without a Kela-card it is impossible to get the reimbursed price straight from any pharmacy. There is an option that when the client needs the medication immediately, the client pays first the whole price and afterwards gets subsidized part back in exchange for a saved receipt. The reimbursement can be claimed from Kela within 6 months of the purchase. If the client out-of-pocket medicine expenses in a calendar year exceed the threshold of €700.92, the exceeding part is reimbursed in full. After this the clients pays €1.50 / medicine. Kela sends to the customer information when the deductible reached the fulfillment as well as a notification of presentation to the pharmacy (Mäki-Petäjä-Leinonen & Nikumaa 2012, 19; Kela 2013.)

Pensioners' care allowance: Support the survival of the long-term sick or disabled, and replaced the specific costs. There has to be reduced function in at least a year

and the disease causes at least the need for weekly assistance, guidance and supervision needed for personal activities or there has to be specific cost allowance amount / month. The client have to fill in the Kela application and from the receiving day Kela can pay of half a year back if they see that the situation has been for a longer time so. This support is tax-free; income does not affect the support. The amount of pensioner's care allowance is from the first of January 2013 as follow; Basic care allowance is €61.83 per month. The basic care allowance is for assistance, supervision or control, the need for personal activities at least weekly. The increased allowance is €153.91 per month. This is for assistance, guidance and control daily and regular. The highest Care Support is €325.46 per month. This is for almost 24 hours treatment and guidance needed. This applying needs an attachment C- medical certificate. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 13-14; Kela 2013.)

Pensioners' housing allowance: This can be applied from Kela. For this the income has to be low, if the client is 65 years and he has a national pension, widow's pension or less than 65 years and get a full disability pension entitles one can get the pensioner housing assistance. The housing allowance may be paid half to the spouse. Housing allowance affect the amount of the cost of housing, family relationships, the annual income and property. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 13-14; Kela 2013.)

Reimbursement of travel expenses: According to The Health Insurance Act, Kela paysthe travel expenses incurred in case there is a disease related examination and treatment. The travel expense is counted to the nearest treatment facility in accordance with the general transport costs. The travels expenses consist of the clients own part which the client must pay. This part is in 2013 €14.25 one way. The maximum limit is €242.25 after that the client will receive a card stating that he has reached the out-of-pocket maximum. When the client show this card to the driver he can travel free of charge if the transport provider has a contract with Kela. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 20; Kela 2013.)

3.2 Supporting from the Social and Health Care Group of Päijät-Häme

Care payment ceiling; it is possible to apply for this service when the payment limit covered by the amount of payments in 2013 is up to €636 per year. When the ceiling get this limit then full payment will be received for services that are free of charge until the end of the year, with the exception of short-term institutional care, which the fee is charged for €15.10 per day.

The free card application form filled by the care facility, where the ceiling is reached. The clients have to follow the payment limit by themselves and also the receipts have to be there. The receipts and the applications have to be given to the nursing place. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 22.)

Family care support; Family care support is possible to apply if the partner is an elderly, disabled or sick person at home. The family caregiver helps the person with daily life activities. The family care support consists of services provided for the affected; the premium paid to the family caregiver and the family caregiver's 3 days free per month as well as family care support services. After the application is received the home care service makes a home visit in order to make a care and service plan and contract support for family care support. They do also different tests to see in what condition the patient is. There are criteria for the patient. Here are also three kinds of levels and it depends on how many help the patient needs. The payment depends on the municipality in which one lives but by law is put out a basic tax that has to be paid. The payment is a taxable income. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 20-21.)

From 2006 there has been Family caregiver act 937/2005 that supports the family caregivers more of being a family caregiver through granting them three days free in a month, also the payment for them is a little better. Now the knowledge and respect for family caregivers have grown. In this law, the family caregiver has been defined as a person, based on a commission made by the municipality or joint

municipal board responsible for arranging care, gives in his /her home such family care as is referred to in section 25 of the Social and Welfare act (710/1 982). (Meriranta 2010, 5; Salanko-Vuorela 2010, 7; The Central Association of Carers in Finland 2013.)

Transportation Support; social welfare service of the municipality can give support for contact and leisure traveling when the age is over 65 years if a person has difficult mobility's ability to take the public transport or a call- taxi on the route. If the call-taxi is driving then it is not possible to get transportation support. The charged for the call taxi is the same as a bus tickets price. Usually by the home care they help with the application, they have an application paper and this needs also a medical certificate. This service is different in different municipalities. There are different kinds of transportation what they can offer. For example; a call taxi, a route taxi, a bus with a low go in, and also normal taxi for 8 times one way per month, or a taxi arranged by house service ones a week. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 17.)

The other possibilities is to get *transport service for disabled persons*. If the patient is difficult disabled the he has the right to use a taxi for contact and leisure times 18 times a month, in the nearest surrounding. They pay there their own part of the taxi which depends on how long the distance is. For this also an application to fill in and a medical certification is needed. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 17.)

Home care; this can be offered when there are needs to get more help when the person with dementia is still living at home. For this criteria are defined, and evaluation visits are made to definefor what the needs are. The service charge is based on the customer's income and length of service. (homecare criteria of Oiva area; homecare criteria of Aava area; homecare criteria of the town Lahti; homecare criteria of the town Heinola; (Mäki-Petäjä-Leinonen & Nikumaa 2012, 16-17.)

Support and security services; there are different kind of services; the day center activities; catering, shopping service, laundry service, sauna/washing service and the emergency phone. The emergency phone works 24 hours a day. The customers get a safety wristband and when they need help they can give alarm with. The alarm goes first to the central alarm office, where they check whether there is a real emergency or not. Usually in day time when the home service works the alarm comes to them. In night times the alarm goes to a taxi or ambulance. The first connection does not have to be homecare, taxi or ambulance, but it can also be somebody else which has a close relation with the client. For this service the client has to fill in an application and also this has its own criteria. The customer must have a landline or mobile phone. The security service rents the emergency phone and for every alarm they charge a small fee. A door alarm warning system is also possible with the same opportunities as the emergency phone. When the alarm system is turned on there is an automatic alarm to the service office. (Homecare criterion of Oiva area, 2013; homecare criterion of Aava area, 2013; homecare criterion of the city Lahti, 2013; homecare criterion of the city Heinola, 2013.)

Then there are support and security services which one can buy them selves. For example alarm services a cooking plate alarm and a special water tap alarm for somebody who tends to let the water tap open. For this there is a special website on the internet by the Alzheimer Society of Finland: http://www.muistiliitto.fi/fin/muisti_ja_muistisairaudet/muistikoti/. (Muistiliitto 2013).

Assistive and home renovation; the health care service is responsible for the medical rehabilitation of housing. Social services are related to assistive devices. Assistive device are lent free of charge to the need for judgment. Changes in the home or the purchase of equipment for the disabled have to be applied by the office for facilities for the disabled. For this there is an own law: Disability Services Act. They have their own criteria, and for using this, one have to make

the application by the disability service. Also a medical certification is needed for this. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 12.)

Care Accessories Distribution; this is based on individual requirements. For care accessories or equipment there has to be a long-term need, usually at least 3 months. Equipment and instruments are from free of charge. (Mäki-Petäjä-Leinonen & Nikumaa 2012, 21.)

In the Päijät-Häme district there are several societies and associations working which also give support for the family caregivers. Most of them have only a yearly contribution and for some trips and activities they asked a little bit support. (PalveluSantra 2013.)

3.3 The roles of the Memory Association of Päijät-Häme

This chapter describes an overview of the association, the preventing program carried by the association and the relationships with the Alzheimer society of Finland, Alzheimer of Europe and Alzheimer's International.

The office of the Memory Association of Päijät-Häme is in the center of Lahti, on the fourth floor with elevator. The memory Association of Päijät-Häme has 470 members according to the December 2012 register. The distances from the village/town to the office of the Memory Association of Päijät-Häme are variable from the center of Lahti zero kilometers and farthest destination about 80 kilometers away. The land surface ground of working area is 7295 69 km². The population on this ground is 213 40 inhabitants. The largest part of it is the town Lahti with 100 854 inhabitants. In the area of Päijät-Häme there are 6 314 persons with dementia in the age of 60-95 in the year 2010. Expected is that in 2020 there are 8741 persons with dementia. (Siltala 2012, 3-4.)

Table 1 shows the membership towns of the Memory association of Päijät-Häme and gives a look of the percentage of people per village/town of 65 years and older

(Finnish statistic from first December 2011). Here it can be seen that in the small towns such as Sysmä, Padasjoki and Hartola, there are many people older than 65 years.

Table 1. Statistics of the percentage of the people older than 65 years and the total inhabitants of the village /town (Finnish statistics 31.12.2011)

Village/Town	Percentage > 65	Inhabitant
Sysmä	32.5	4261
Padasjoki	30.7	3369
Hartola	28.5	3292
Asikkala	25	8498
Heinola	24.7	20164
Hämeenkoski.	23.7	2130
Iitti	23.8	7002
Myrskylä.	22.8	2008
Pukkila	20.4	2016
Lahti	19.7	102308
Orimattila.	19.6	16369
Kärkölä	19.6	4798
Hollola	16.9	22020
Nastola	16.6	15027

The goals of the Memory Association of Päijät-Häme are to support the life quality for memory disorder persons and their family in all phase of the memory disorder through support, advice, guidelines and by volunteers help and activities. This can be by personal contacts but also for a whole group. They are giving, in this area, prevention of memory diseases, giving information about the memory disorder and they are giving support to the persons with dementia and their families. Also the generate interest in the work of dementia, and to strengthen the role of the Memory of the Association as part of the social support. This part of supporting belongs to the program of Muistiluotsi (guiding for memory). The Memory Association of Päijät-Häme works together with the Social and Health care organization to take care of the persons with dementia and their family. Guidance and counseling are

happens through personal contacts but also by big happenings they are given guidance and counseling. (Siltala 2012, 4-8.)

The preventive programs carried out by Memory Association of Päijät-Häme started in the year 1988 and had the name of the Dementia Association of Päijät-Häme. Since 1997 it is project work. The Finnish Slot Machine Association. (RAY) finance the Alzheimer society of Finland, Muistiluotsi and the PääOma project. The PääOma project is a new project started in 2012. The PääOma project has a rehabilitation vision and sees the person with dementia as a rehabilitation person and it doesn't matter is the status of the disease is a progressive one or is a permanent status. The project has their own groups for people with memory disorder and for persons whom has dementia through brain incident. The groups are closed groups and include initial and final testing. The target groups are from the age of 50- 75 years old which got a brain infarction, brain hemorrhage or brain accident and has a status of permanent dementia or under the 75 year old whom has dementia in the beginning (Siltala 2012, 7; The Memory Association of Päijät-Häme homepage.)

There are all together five full-times employees working for this association. They have the following expertise: The project coordinator and the counselor both have social counselor education they have the responsibility for the PääOma project. The expertise of the employers of the Muistiluotsi project areas follow; a project worker with nurse education and a Bachelor of Health Sciences degree , a counselor with social counselor education and a Bachelor of Business Administration, and a relief staff who is currently studying social counselor course All have experience in the working in the field of dementia. (Reimari 2013.)

The nationwide Muistiluotsi project was set up stage over the period 2008-2011 coordinated by the Alzheimer society of Finland. The objective of the project was that in each province in Finland there would be support center for dementia, which consists of voluntary, development and service activities. Nowadays Muistiluotsi isn't anymore a project, but an official part used by all the Memory Associations.

The Alzheimer society of Finland is responsible for the local Memory Associations. (The Memory Association of Päijät-Häme homepage; Siltala 2012, 4.)

Three times a year the Memory Association arranges open coaching course for persons with dementia and the family caregivers. Peer groups (table 2.) are organized to in with for workers age, senior age and also for their family. The Memory Association organizes member meetings including the market coffee every month, as well as refreshment in its various forms as excursions, theatre visits etc. Twice a year the Memory Association of Päijät- Häme publishes their own newsletter Muistike. The Alzheimer society of Finlandand publishes a per anon newsletter which is called ”Muisti-lehti” (Siltala 2012, 4; The Memory Association of Päijät-Häme homepage.)

Table 2 Schedule of peer groups' spring 2013

Kind of group	Group	Participation	Meetings
Workers age with two different levels of groups (Lahti)	2	16	Every second week
Senior-age (Lahti)	1	12	6 x in this spring
Group of memory association of Päijät-Häme in Wanha Herra (free for everyone) (Lahti)	1	20	1 x month
Family care givers with dementia person's institutionalized or died (Lahti)	1	9	1x month
Family caregiver for spouse cg's (Lahti)	1	7	1x month
Family caregivers adults children (Lahti)	1	6	1x month
Group instructed by volunteers (Lahti and Hollola)	2	18	1x Month

There have been different kind of projects since 1997 but most of them have a focus on supporting the working age, persons under 65 years old, with dementia. With the activities of the Memory association of Päijät-Häme has got through the whole region her own memory network. A big project has been made together with the Social and Health service in the area, which the Memory Association is working. They made together Memory plan. This shows exactly how, when, where and a timetable when the people with dementia avail of his /her support. The memory Association of Päijät-Häme has a yearly contribution and all the activities are free. Only if they arrange some trip they ask a little bit support. The Memory Association is a part of the Alzheimer Society of Finland. (Siltala 2012, 7; The Memory Association of Päijät-Häme homepage.)

The Alzheimer Society of Finland started in 1988. Their task is to provide help, assistance and guide people with Alzheimer disease and their care givers now a day people with dementia. Through whole Finland there are 44 local associations. The society has more than 10.000 members. The Alzheimer society of Finland has a national office with three local branches. (Muistiliitto 2012.)

The idea and values of the Alzheimer society of Finland are to improve the quality of life of people with dementia and their caregivers. They give information and

promote the legal, economic and social rights for the people with dementia and their caregivers. For professionals in the dementia fields they organize three or four times a year seminars, staff in dementia homes can get training. For schools, associations and public occasions they give lectures. They are also active for develop the support system of people with dementia and their caregivers, to educate professionals in the health care. They influence the attitudes of the general public about all the issues related to memory problems, the supports required and also very importantly managing to influence the political decision making process. The society is a member organization of the Alzheimer's Disease International (ADI) and Alzheimer Europe. (Muistiliito 2012.)

Alzheimer Europe Alzheimer co-operate and co-ordinate between Alzheimer organizations through whole Europe. There are 34 Alzheimer organizations from 31 countries across Europe members. They have created a common European platform with awareness rising of all forms of dementia. The office of this organization is based in Luxembourg and they have a team of five persons who are also representatives in Brussels, Belgium. This is a non- governmental organization. The idea and values of the Alzheimer Europe are also to improve the quality of life of people with dementia and their caregivers. They give information and promote the legal, economic and social rights for the people with dementia and their caregivers. (Alzheimer Europe, 2012.)

Alzheimer's Disease International was founded in 1984 and they serve as a network for Alzheimer Associations around the world to share and exchange information, resources and skills. It is an international federation of 78 Alzheimer associations. Their vision is also to improve the quality of life of people with dementia and their caregivers in their respective countries. They give information and promote the legal, economic and social rights for the people with dementia and their care givers Their office is in London and in the state of Illinois USA it is registered as a non- profit organization. They have official relations with the World Health Organization. (Alzheimer Disease International, 2012.)

4 EMPIRICAL PART OF THE STUDY

4.1 Aim of the study and the research questions

The aim of this study was to use the development surveys as a means to investigate how the Memory Association of Päijät- Häme has to develop their association action for their customers with dementia, support their family and relatives based on their quality of life

The main question is:

- How should the Memory Association of Päijät-Häme change their service to improve the quality of life of the family caregivers?

Sub questions

- How can the Memory Association of Päijät-Häme help, with their activities, the family caregivers of a person with dementia?
- How can the Memory Association of Päijät-Häme make the way in which they support the family caregivers more effective?
- How much does the location of the Memory Association of Päijät-Häme affect the participation of the family caregivers?
- How effective does the information offered by the Memory Association of Päijät-Häme reach the family caregivers?

In almost all scientific studies the supposing hypotheses are given. With help of statistics it can be shown if the supposing hypotheses are correct or incorrect. (Holopainen & Pulkkinen 2002, 156.)

Hypotheses

- Peer groups and all information about dementia are very important for family caregivers
- Through spreading their activities in the whole area they can get more members and users from small villages

- The distance is for many persons of dementia and their caregiver a problem.
- The location of the office in the center of Lahti supports the members of the Association in Lahti the most.
- For persons that are already a member they get good information over the activities arranged by the Memory Association of Päijät-Häme. The attention of getting new members is more a challenge

4.2 The research method

Quantitative research examines data numerically; to explore things and to discover properties relationships are discussed in general, described by numbers. The research methods are a tool for the researcher, in order to search for an answer to the research problem. Quantitative method is often used social research and consists of developing models, theories, and hypotheses of what the researcher expects to find. For developing instruments and methods for measuring is used of data. The data is collected and after that analyzing the data and evaluate the results. (Holopainen &Pulkkinen 2002, 14-17; Vilkka 2007, 14, 89). In the data analysis stage, the researcher sees what kind of response he gets on the problems. Quantitative research results can be described numerically, verbally and graphically (Hirsjärvi et al 1998, 216; Vilkka 2007, 135).

The questionnaires (Appendix 1 and 2) were made based on the theoretical approach. Reading the theoretical literature about dementia, behavior problems, Quality of Life and family caregivers, enabled to outline the theoretical framework and explained the key concepts. The main subjects were quality of life, family caregivers and the index of the memory Association of Päijät-Häme works. The questionnaires have to be connected to each other.

The questionnaires consist of different kind of themes:

- The background information part, questions 1–6
- Quality of life –related questions 7–11

-The questionnaires about the Memory Association of Päijät-Häme in the following subjects:

-The way of how information is spreading; how to get more members and also how the association gives information to the client, questions 12, 15, and 16

-The reach ability and location of the Memory association of Päijät-Häme, questions 17–18

-At least the index of the Memory association of Päijät-Häme, what family caregivers use, what they need and are they satisfied. Questions 13, 14, 19–27.

A part of the questions are made using the Likert scale from 1 to 5. In the Likert scale there have to be two different opposites and in the middle is the neutral answer. (Vehkalahti 2008, 38–39.) It depends on the question how to put the scales in words; the scale words can be for example: disagree totally – somewhat disagree – neutral – somewhat agree – agree totally. The rest of the questions are based on the activities of the association and on facts of supporting for the persons with dementia and the family caregivers which the surrounding offers. At the end of the question there is always the possibility to put something else.

4.3 Data collection

The data was collected using the members of the Memory Association of Päijät-Häme as respondents. Only the family caregivers of a person with dementia, which are members of the Memory Association of Päijät-Häme, were sent a questionnaire.

From the Memory Association's registration the address of the family caregivers were given. When they became a member of the Memory Association they have to give information if they are a person with dementia, a family caregiver, a supporting member or a professional. There are 185 members that are in the registration signed up as family caregivers. The Memory Association of Päijät-Häme took care of the printing of the questionnaires and the cover letter

(Appendix 3). The envelope includes labels with names of the family care givers and a return envelope with post stamp and return address is also supported by the Memory Association of Päijät-Häme. Before sending the questionnaires three pre-test persons who are members of the Memory Association tested the questionnaires. Two were official family care members. According to them everything within the questionnaires was fine and no changes had to be made. From the 185 were two persons a test person so 183 questionnaires were send. From the 183 questionnaires returned 87 questionnaires. Nine questionnaires were empty and with a note that the person with dementia was deceased. One was with a note that she is not a family caregiver. The basic study population consists of seventy seven persons (N=77). So the answer response was 42 %. That is a usual number for this kind of questionnaire (Vehkalahti 2008, 44).

In January the permission of the board of directors of the Memory Association of Päijät Häme arrived. (Appendix 4) The questionnaires and cover letter were sent by post on 8 February 2013 and the response time was given to 18 February 2013. The cover letter tells about why this study is performed and how important it is to answers the questionnaires. After getting the data back the incomplete and incorrectly answered questionnaires were taken out. The questionnaires were coded and numbered and ready for using the SPSS program.

4.4 Treatment of the study

The study is carried out using quantitative, semi- structured questionnaires. The results of the study were analyzed by using Statistical Package for the Social Sciences version 21.0 for Windows (SPSS) and content analysis was applied to the open – ended questions. Using the SPSS program the results will be displayed in the form of frequencies, percentages and mean values (Tähtinen, Laakkonen & Broberg 2011, 171.) After that, cross table analysis was used. Cross tables analysis

provides information about the relationship between the variables (Holpainen & Pulkkinen 2002, 48; Vehkalahti 2008, 68).

Firstly the results of the questions based on the themes of the questionnaires were dealt with. There are questions where only one answer is possible and the results of these questions in this study are given in percentages. Then there were questions with more options and the results are giving in number of persons.

By collecting information how the family caregivers feel about their own situation, the caregivers were asked whether they agreed with a given set of statements about their situation. The possible answers ranged from completely different opinion to completely the same opinion. During the analyses some of the original questions were reversed from positively asked questions to negatively asked question and the distribution of the percentages over the answer categories changed accordingly. This was done to be able to interpret all questions in the same direction.

The questionnaires gave a lot of information for the Memory Association of Päijät-Häme. Most of the research questions answers can be used for develop their activities. However it would be good to show whether there are any relations between some of the variables. It is especially interesting whether some of the background variables or some of the quality of life questions influence how the respondents see the barriers for participating in the activities organized by Päijät-Häme. Because every possible barrier is coded in a different variable, cross tables of some explaining variables with every category of the barrier variable were made using SPSS. A Chi-Square statistical measure was also included to see whether there is a significant relationship between the variables. However, the results showed that it was very difficult to make reliable cross tables and perform reliable Chi-Square analysis because the SPSS program noticed in a lot of cases that there were too many cells with expected frequencies below 5.

By the question about the understanding of the behavior changing the mean score is based on the four possible answers (“Don’t know” - category is excluded from the calculation of the mean score)

4.5 Reliability and validity of the study

In this study the questionnaires consist of checkmark questions that are easy to fill in. There are also some open ended questions to get a wider view of the answerer’s thinking. Preparing the questionnaires it is important that one question means stay for thing. This gives a possibility to keep out wrong answered questions so the reliability is growing.

Validity and reliability together form the overall reliability of the study. According to Heikkilä and Vilkka the total reliability of the study is good, if the measurement minimizes random errors and the sample is representative of the population (Heikkilä 2004, 185 & Vilkka 2007, 152).

The addresses getting from the Memory Association of Päijät-Häme with the family caregivers was good but there were also family caregivers whose partner was already passed away. In this study the family caregivers are all together paid or not paid and also a part of them are not living in this area. They can have a different opinion then somebody who is living together with the patient.

Preparing a questionnaire does not mean that a number of people make the questionnaires and that a researcher looks at the answers before sending out the questions are critically evaluate by test persons. Test persons can check the style, needs there to make changes for the instructions how to answer the questionnaires or are the answers options clear. When the form is used to help the preparation of a pilot study, design issues can be corrected for the actual research. (Hirsjärvi, Remes & Sajavaara 1998,; Vilkka 2005, 88-89.)

The number of test persons was very low. It should have been at least five persons and in this case, the time was running out and it was impossible to get more test persons.

For the research process, it is important to think of how successfully the sample is representative of the population, which is the response percent of the study, how carefully the research information has been put in the computer and what kind of measurement errors included in the study which has influence on the validity and reliability (Vilkka 2007, 150).

In the end of many questions the participants had possibilities to insert their own answer option and they had used it very often. The answer opinions were put in excel-tables. The questionnaires were filled in with much care. Maybe too many participants wrote marks and some of them personal experience on the questionnaire. The coded answers were checked twice when they were put in the SPSS program

Validity of the study refers to if the study measures are successes of what the study is supposed to measure. Validity, therefore, tells if the researcher has been able to put the theoretical concepts in everyday language level. By arranging the questions as clearly and put it in simple forms, so to avoid any misinterpretation of the questionnaires. Validity of the study can be considered good if the researcher has not been staid at the level of concepts and has not made systematic errors. (Vilkka 2007, 150.)

By gathering the questionnaires by post there is a risk that somebody else fill the questionnaires and also the answer percent can be lower than other research methods. Ten family caregivers of the returned questionnaires told that the person with dementia deceased but that they wanted to fill the questionnaires and so support the Memory Association of Päijät-Häme to help developing their activities.

For the study permission was granted by the board of directors of the Memory Association of Päijät-Häme. All personal in the relation to this study on completion

will be shredded. At all times all questionnaires and associated issues were treated with respect. The printed paper with the addresses from the Memory Association of Päijät- Häme and an all received questionnaires are put, after making this study, in a paper shredder. All questionnaires were treated with respect.

5 RESULTS

5.1 Background information.

The section started with giving background information of the respondents. The background information includes municipality, mean ages and distribution of gender of family caregivers and the persons with dementia, and the percentage of the caregivers who are official, paid, family caregivers. Among the questionnaires answered there were ten family caregivers of persons not alive anymore. They are still in the administration of the Memory Association of Päijät-Häme as family caregivers signed in.

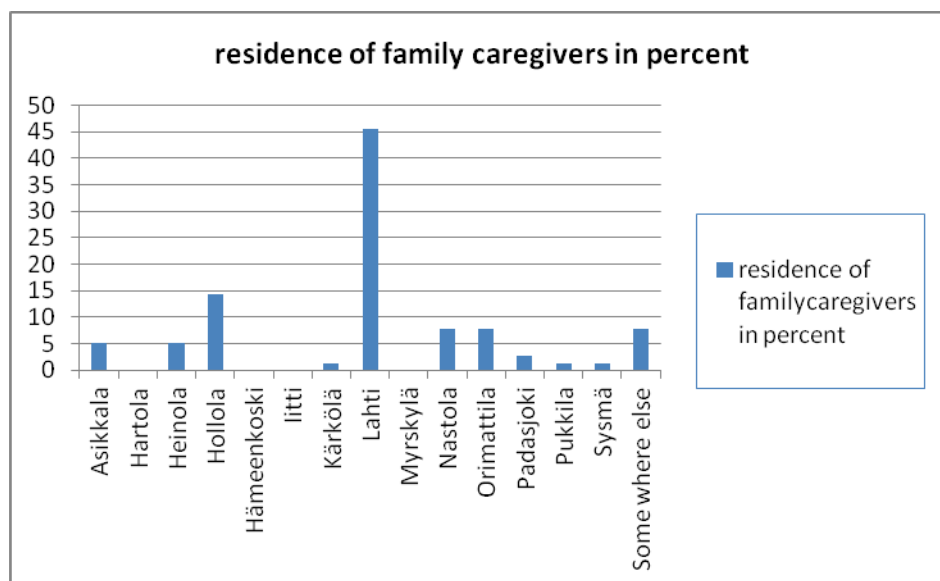


Figure 1. Residence of the family caregivers in percent N= 77.

The place of residence of the respondents is shown in Figure 1. The results for the place of residence of the respondents show that most of the family caregivers come from Lahti and Hollola. These cities are very close to the office of the Memory Association of Päijät-Häme. There were no participants from the small villages like Hartola, Hämeenkoski, Iitti, Kärkölä or Myrskylä.

The relation of the family caregivers with the patient is 59.7% a spouse taking care, 36.4% is a child taking care of a parent with dementia and 3.9 % has another relation with the person with dementia. The mean age of the family caregivers is 67.5 years ; all caregivers are between the age of 48 and 88 years old. 22.1 % of the family caregivers are male and 77.9 % are female. From the family caregivers are 26 % of the caregivers an official, paid family caregiver.

The mean age of the persons with dementia is 78.4 years. The range of the age of all patients is between 58 and 93 years old. From 10 patients the age is missing because they are not alive anymore. 48.1% of the persons with dementia are male and 51.9% are female.

26 % of the family caregivers are working officially and getting paid for their job paid, 74% of the family caregivers are not an official paid caregiver. 58.4% of the persons with dementia have this illness for more than four years. 33.8% percent of the persons with dementia have had the illness for 2–4 years. The numbers of persons diagnosed with dementia for 1–2 years are 7.8 %. None of them have had dementia for less than one year.

5.2 Quality of Life part

The impact of taking care of a patient with dementia is according to the family caregivers as following: 27.3 % of the family caregivers thinks that taking care of the patient has little effect on their own getting along. Getting along with the patient has for 40.3 % family caregivers much impact on their life and for 24,7% of

the family caregivers it has very much impact on their life. 7.8% of the family caregivers do not know the impact of taking care of the patient with dementia. Most family caregivers said that taking care of a patient has an impact on their own lives.

Family caregivers' health condition is according to 18.2% of the caregivers bad. 58.4% of the caregivers think that their own health condition is good and 5.2 %of family caregivers think that their health is very good. 18.2% of the caregivers don't know how their own health condition is. A majority of the participants seem not to suffer negatively from being a caregiver although a substantial group of 18.2% says their own health condition is bad.

The health situation of the patient of whom the family caregivers take care of is according to the family caregivers as following; the health situation of 13% of persons with dementia is very bad. The situation of 48 % persons with dementia is bad . 18.2 % of the family caregivers has the opinion that the health condition of the person with dementia they take care of is good 1.3 % of the family caregivers thinks that the heath condition of the person with dementia is very good. 20.8 % of the family caregivers report that they don't know the health condition of the person with dementia.

Only 14.3 % need 24/7 help according the answers. A little help is needed for 24.7 % persons with dementia. According to 32.5 % of the family caregivers their persons with dementia needs much help and 23.4 % needs very much help. 5.2 % of the respondents don't know how much their persons with dementia needs help. More than half of the persons with dementia needs a lot of help during the day.

The followings tables (3, 4 and 5) show how the family caregivers feel about their own situation. The caretakers were asked whether they agreed with a given set of statements about their situation. The more a respondents agree with the statement

the more positive they think about this topic. The more they disagree with the statement the more they think this topic is a real problem.

Table three (The understanding of the behavior changing) shows the results for this analysis. For all the questions in this table not a lot of persons say that they completely disagree with the statements. For the statements saying that the caregiver understands the changes in the behavior of the patient and saying that the caregiver is not worried that the number of dangerous situations increases a substantial group of respondents have completely the same opinion. Looking at the mean scores the opinions on the different statements can be compared. The lowest mean and thus the most negative score is for the statement that when the patient excludes himself from the outer world this is a problem for the caregivers. Of the mentioned topics related to the behavior of the patient this is the biggest problem for the family caregivers. The caregivers are the most positive about the statement whether they are worried about the number of dangerous situations. They seem not to worry about this.

Table 3. The understanding of the behavior changes in % and mean N = 77.

Changing of the behavior	Completely different opinion	Rather different Opinion	Rather the Same Opinion	Completely same opinion	Don't know	Mean (Don't know excluded)
I understand the changes in the behavior of the patient.	0.0%	5.2 %	53.2 %	35.1 %	6.5 %	3.32
I can deal with the patient, if he is afraid.	0.0 %	6.5%	53.2%	18.2%	22.1%	3.15
I can deal with patient, if he is angry.	2.6%	13%	39%	14.3%	31.2%	2.94
I can deal with the patient, if he is confused	2.6%	13%	40.3%	11.7%	32.5%	2.90
When the patient excludes himself from the outer world this does not give problems.	6.5%	15.6%	27.3%	15.6%	35.1%	2.80
I am not worried that the numbers of dangerous situations are increasing.	0.0%	9.1%	32.5%	41.6%	16.9%	3.39
I am not afraid that the patient will get lost.	3.9%	13.0%	35.4%	26%	20.8%	3.07

Table four (Problems for the family caregivers with the care situation) the mean scores show that the most negative to the statement that they do not feel guilty when someone else has to care for the patient. In other words, most caretakers do feel guilty when they cannot take care for the patient themselves. The most positive score here is that most caretakers agree with the statement that the caretaking is not mentally hard.

Table 4. Problems of the family caregivers with the caring situation in % and mean N = 77.

The care situation	Completely different opinion	Rather different Opinion	Rather the Same Opinion	Completely same opinion	Don't know	Mean (Don't know excluded)
I have somebody to who I can tell my problems and ask for help.	3.9%	15.6%	45.5%	26%	9.1%	3.03
I do not feel that I have to take responsibility for the patient by myself.	9.1%	16.9%	32.5%	27.3%	14.3%	2.91
I feel that I can give enough help and support to the patient	9.1%	18.2%	36.4%	7.8%	28.6%	2.60
Professionals give also attention to me.	9.1%	16.9%	35.1%	6.5%	32.5%	2.58
I do not feel that it is difficult to make decisions for the patient.	7.8%	23.4%	41.6%	9.1%	18.2%	2.64
I do not feel guilty, that someone else takes care of the patient.	36.4%	27.3%	13%	3.9%	19.5%	1.81
I do not feel guilty, if I am too tired to take care of the patient.	11.7%	13%	29.9%	11.7%	33.8%	2.63
The future is not scarring me.	3.9%	9.1%	35.1%	29.9%	22.1%	3.17
Being a caregiver of a patient is not physically hard.	14.3%	23.4%	33.8%	13%	16.9%	2.55
Being a caregiver of a patient is not mentally hard.	0.0%	6.5%	41.6%	41.6%	10.4%	3.39

The mean scores (table 5) to do not differ that much so it is difficult to make statements about differences between the opinions on the different questions.

Table 5. The social life problems of the family caregiver in percentages. N = 77

Social life	Completely different opinion	Rather different Opinion	Rather the Same Opinion	Completely same opinion	Don't know	Mean (Don't know excluded)
Keeping in touch with other family members is not hard	10.4%	28.6%	35.1%	13%	13%	2.58
Keeping in touch with my own friends is not hard	14.3%	23.4%	36.4%	13%	13%	2.55
I feel myself not lonely	16.9%	20.8%	35.1%	3.9%	23.4%	2.34
I can continue with my own hobbies	20.8%	20.8%	23.4%	19.5%	15.6%	2.49

5.3 Opinions on several aspects of the Memory Association of Päijät-Häme

The respondents of getting information about the memory association is as following

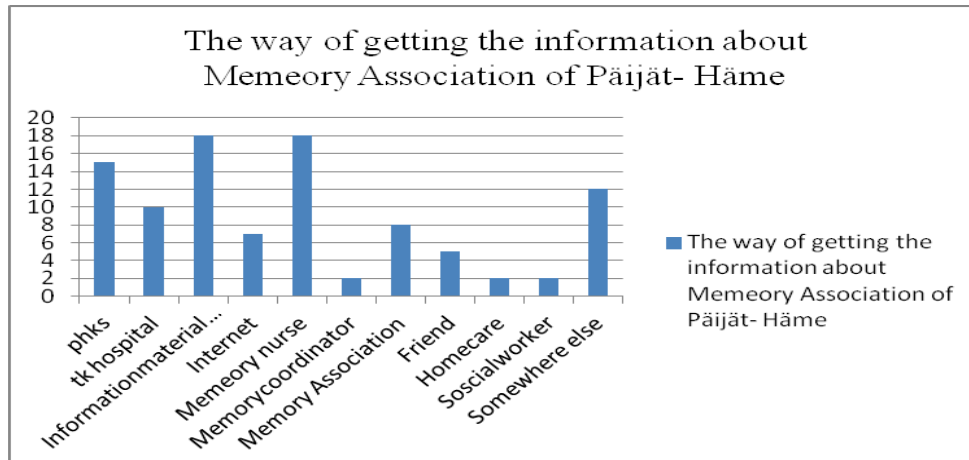


Figure 2. The information about the Memory Association of Päijät- Häme in frequencies N = 77.

Figure 2 shows that most of the family caregivers got the information from professionals. The knowledge about the Memory Association of Päijät-Häme comes from the “memory nurse” according to 18 family caregivers and also

according to 18 family caregivers they use the information material of the Memory Association. According to 15 family caregivers the information has been received from The Central Hospital (PHKS). Also health care centers give information.

Besides the channels mentioned above, 12 family caregivers gets the information Memory Association of Päijät-Häme in another way (Table 6). The guide book for elderly in the area of Päijät- Häme in which the Memory Association of Päijät-Häme works too gives also information for the family care givers.

Table 6. Getting way of information over Memory association of Päijät- Häme in another way N= 10

PalveluSantra (guide for elderly)	2 persons
Doctor of my mother	2 persons
Sister	2 persons
Memory Association of Keski-Suomi	1 person
My mother	1 person
Radio	1 person
News paper	1 person

Most of the family caregivers get the information about the activities by letter (N=41) from the organisation and by the newsletter of Memory Association of Päijät- Häme called Muistike (N=68) . Respondents could report more than one choice for this question. One family caregiver got the informing some where else; from the doctor.

The best way for getting information over the Memory Association of Päijät-Häme according to 62 family caregivers is by letter, the south finland newspaper (ESS) by 11 family caregivers and by email by 29 family caregivers. Other newspapers according to 17 family care givers wanted to have the information as in the following (Table 7).

Table 7. The other news papers to get information N = 17

Muistike	10 persons
Newspaper of Hollola	3 persons
New Lahti paper	2 persons
Kirkonseutu	1 person
Itä- Häme newspaper	1 person

5.4 The using of activities and information of the Memory Association of Päijät-Häme

The using of activities and information of the Memory Association of Päijät-Häme by family caregivers is as following:

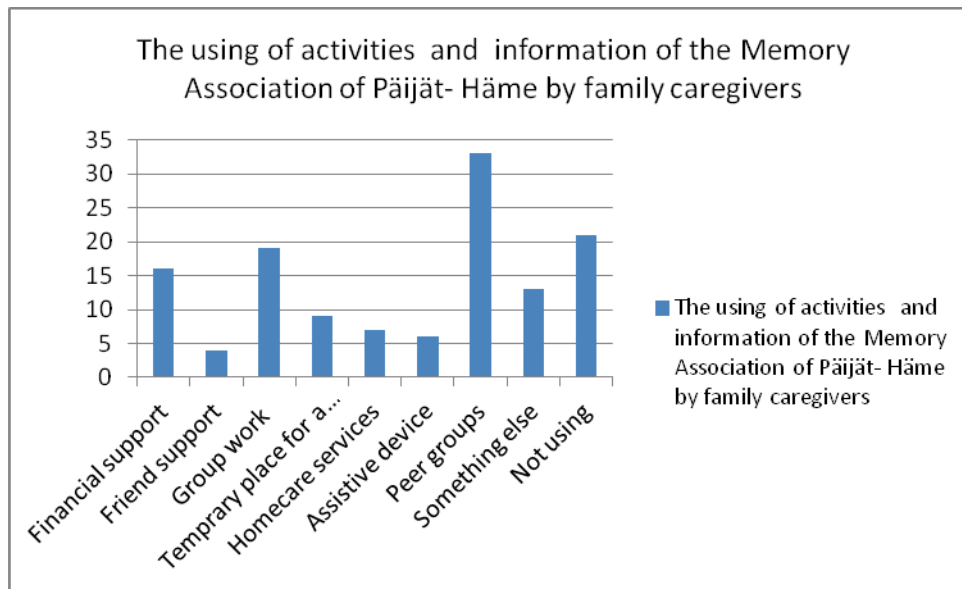


Figure 3. The using of activities and information of the Memory Association of Päijät- Häme by family caregivers in frequencies N = 77.

Figure three shows us that the main supporting and informations that is used is peer groups by 33 family caregivers, groupwork by 19 family caregivers and receiving information about the economic support by 16 family caregivers. For this question was also more than one choice possible

21 family caregivers do not use any of the Memory Association of Päijät-Häme services. The open question "something else" gives a short view of what kind of service the family caregivers also got. Advising for going in a nursing home and conversation is important but the service of the Memory association of Päijät-Häme offers a bright scale of variables according to the family caregivers. (Table 8.)

Table 8. Something else what the family caregivers use from the the Memory Association of Päijät- Häme service N = 13.

Advising given for going to a nursing home	2 persons
Conversation	2 persons
Presentations	1 person
Trips	1 person
See other people in the office	1 person
Cheap cleaning service	1 person
Therapy for myself	1 person
Research project	1 person
Getting answers on my questions	1 person
Guardianship	1 person
News letter	1 person

The kind of group activities used by the family caregiver and for the person with dementia which the Memory Association of Päijät-Häme arranged gives many options. Also in this question it is possible to give more than one choice. For family caregivers peer support groups are attractive, 27 caregivers used it. Peer support groups for the person with dementia is used by 20 family caregivers and also open coaching course for the family caregiver and the persons with dementia is used by 22 family caregivers used. Here it turned out that 26 family caregivers do not use group activity. Using something else answered 8 persons in the following way (Table 9)

Table 9. Using something else of group work arranged by the Memory Association of Lahti N = 8.

market coffee	2 persons
fitness training	2 persons
presentation	1 person
meeting of peer group	1 person
Varsa laava project	1 person
open doors	1 person

The using of the activities of the Memory Association of Päijät-Häme last year. Here also were more choices possible. (Figure 4). Trips arranged by the Memory Association of Päijät-Häme are popular according to 21 family caregivers. Other peer groups are used by 17 family caregivers. Third, the marketcoffee is important for 16 family caregivers. Also here 31 persons did not use the activities

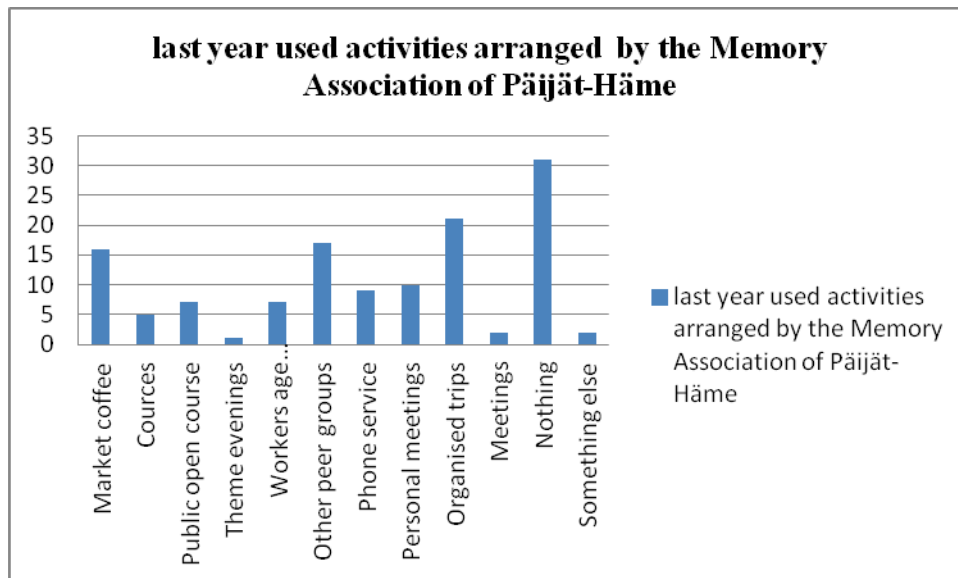


Figure 4. Last year used activities arranged by the Memory Association of Päijät-Häme N =77.

The family caregivers want to have more theme evenings and courses about the following subjects: According to 43 family caregivers it should be nice to get lectures and courses about supporting the family caregivers so that they get some

power to go on with their caregiving. Also by this question more choices were possibly. Second is rising the behavior problems, 28 family caregivers want to know more over this subject. One family caregiver want to know more about working together between the city Lahti and the Memory Association of Päijät-Häme

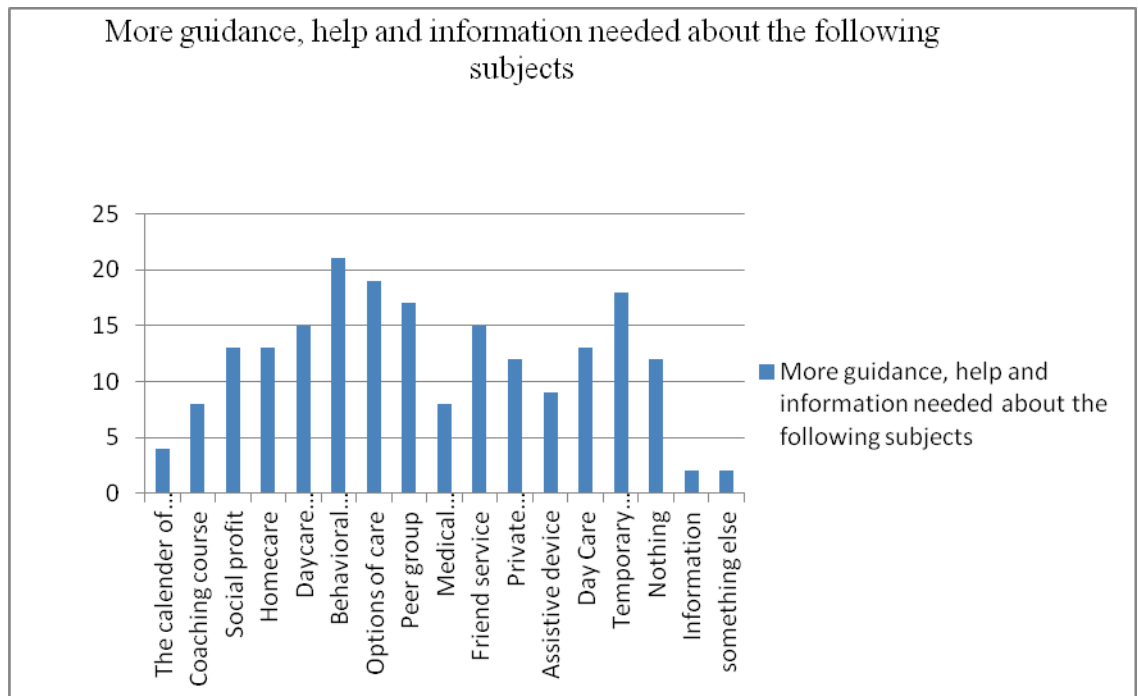


Figure 5. More help, guidance or information wanted about the following subjects in frequencies. N=77

As indicated in Figure 5, 21 family caregivers have stated that they need more help, guideness or information about behavioral problems . By this question more than one choice is possible to give. 19 family caregivers are intrested in hearing about options of the care. Also for a temporary place for a short stay 18 family caregivers want to know more about it. 17 family caregivers are interested in peer groups. 14 persons have no ideas what they want or need. Three persons answered something else, one of them want to now more of personal help at home, and the other two want to know more about physiotherapy.

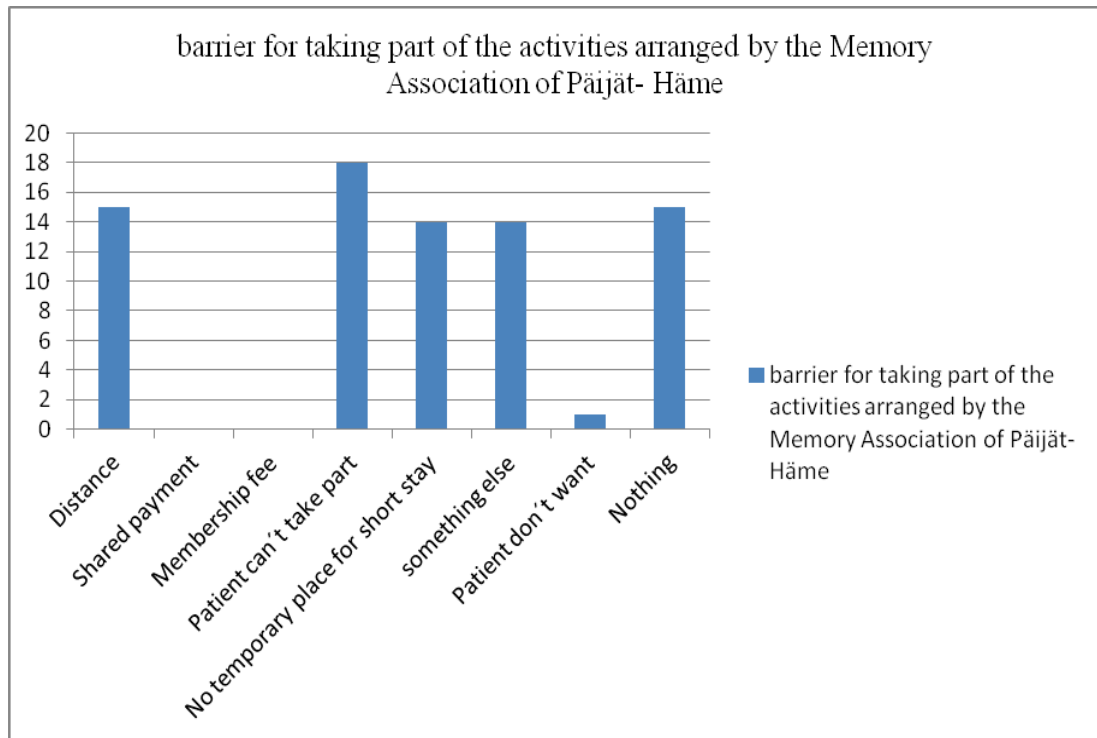


Figure 6. Barrier for taking part of the activities arranged by the memory Association of Päijät-Häme frequencies N =77.

The barriers for using the services of the Memory Association of Päijät-Häme (Figure 6) are the main reason for 18 family caregivers that the person with dementia is not able to take part of the activities. For 15 persons the distance is a problem. A temporary place for a short stay is for 14 family caregivers a problem to get. For this question more than one choice is possible. There are no problems for 15 persons at all.

Other barrier's for using the activities of the Memory Association (Table 10) shows us that for 16 family caregivers has the following reasons.

Table 10 More barriers for using the activities of the Memory Association of Päijät- Häme N = 16

Job	4 persons
Don't need	3 persons
Own disease	2 person
No time	2 persons
Going alone	1 person
Too tired	1 person
Expensive parking place	1 person
Not for working age own age group for family caregiver	1 person
Preparing house	1 person

First, the way respondents think whether the patient has an effect upon their own life influences the way which barriers they see for participating in the activities, was examined by cross table. Table 11 reports the relation between these variables. It seems that thinking that the own situation is effected by the patient does not change the opinion on seeing distance as a barrier. The Chi-Square measure is not significant. The significant score should have been below 0.05 to be significant. There is no relationship.

Table 11: Relation between thinking that the own life is affected and seeing distance as a barrier N = 77. (7 upon 23A)

		Patient has an effect upon the own situation of the caretaker		
		Very little	Little	Much
Do you think distance is a barrier for participating in activities?	Distance no barrier	14 (73.7%)	26 (83.9%)	17 (81.0%)
	Distance Barrier	5 (26.3%)	5 (16.1%)	4 (29.0%)
	Total	19 (100%)	31 (100%)	21 (100%)

Chi Square = 0.781 sig =0.667

Another relationship tested here is between the question on the effect upon the own situation and the possible barrier that there is no short place to stay near the activity. Table 12 shows that in the group of people who think that the patient has much effect on the own situation. Twenty one persons think the place to stay is a barrier while no persons at all think the place to stay is not a barrier. In the group of people who feel very little affected by the patient they see that getting a short place to stay in 31, 6% of the cases as a problem. It seems that being affected in the own situation makes the possibility of more temporary places for a short stay should be more. This relationship is significant according to the Chi-Square test. The Cramer's V indicates the strength of the relation. 0.327 means the relation is moderate.

Table 12: Relation between thinking that the own life is affected and seeing short place to stay as a barrier N = 77. (question 7 upon 23E)

		Patient has an effect upon the own situation of the caretaker		
		Very little	Little	Much
Do you think that no temporary place for a short stay is a barrier for participating in activities?	Place to stay no barrier	13 (68.4%)	23 (74.2%)	21 (100.0%)
	Place to stay barrier	6 (31.6%)	8 (25.8%)	0 (0.0%)
	Total	19 (100%)	31 (100%)	21 (100%)

Chi Square = 0.57 sig = 0.023 (Significant at the 0.05 level) Cramer's V = 0.327

An extra test (table 13) related to the barrier of the absence of temporary places to stay shows that the background condition of age also has to do with seeing the temporary place to stay as a barrier for participating in activities. The age variable

is recoded in two groups. Within the group of older people 30.2% see the getting a short places to stay as a barrier while this is only two point nine % for the younger caretakers. The test shows that there is a significant relationship.

Table 13: Effect of age on seeing temporary place to stay as a barrier N = 77

		AGE	
		Up to 65 Years old	66 years and older
Do you think that no temporary place for getting a short stay is a barrier for participating in activities?	Place to stay no barrier	33 (97.1%)	30 (69.8%)
	Place to stay barrier	1 (2.9%)	13 (30.2%)
	Total	34 (100%)	43 (100%)

Chi-Square = 8.22 Sig 0.004 (Significant at 99% level)

It was examined whether there are effects between variable 8 (own health), variable 9 (health of the patient) and variable 10 (24 hour help needed) and the question about the barriers for participation but no effects were found.

According to 33.8 % of the family caregivers the biggest value of being a member of the Association of Päijät- Häme comes from sharing the experience and have a possibility to talk to someone who understands your situation. The second big group of family caregivers is 31.2 % who are happy with all the information they got of the memory losing. For 7.8% of the family caregivers the organised trips are the the main factor of being a member.

Table 14 shows the other reasons for being a member of the Memory Association of Päijät-Häme. Four family caregivers want to support the Memory Association of Päijät-Häme by being a member. This is for them the important reasons for being a member but by being a member they support in any case the Memory Association.

Table 14. Some other reasons to be a member of the Memory Association of Päijät-Häme N = 7.

Support member	4 persons
All of the proposed possibilities	2 persons
Newsletter Muistike	1 person

63.6 % of the family caregivers thinks that. the Memeory Association of Päijät-Häme arrange enough activities. According 10.4 % family caregivers there are not enough activities and 26% of the family caregivers don't knowif the association arrange enough activities.

The following tables 15 and 16 shows that usually the participants are satisfied with the group works. Getting a place in the group for the patient and the length of the groups in hours and month according the family caregivers are facts where can be more attention to. For the groups for the family caregivers the group work in length of months can be paid attention to.

Table 15. Satisfaction of the group work for the patients N = 77

Group work for the patient	very bad	bad	moderate	good	very good	mean
Feelings after the group meeting	0.0%	5.6%	16.7%	27.8%	50.0%	4.22
The activities in the group meetings	0.0%	5.6%	11.1%	50.0%	33.6%	4.11
Getting a place in the group meetings	16.7%	0.0%	5.6%	50.0%	27.8%	3.72
The length of the group meetings in hours	0.0%	5.6%	33.3%	33.3%	27.8%	3.83
The length of the group work in month	0.0%	0.0%	27.8%	61.1%	11.1%	3.83
Professional work	0.0%	0.0%	5.6%	22.2%	72.2%	4.67
Group meeting feelings	0.0%	0.0%	11.1%	27.8%	61.1%	4.50

Table 16. Satisfaction of the peer group for the family caregivers. N =77

Peer group for family caregivers	very bad	bad	moderate	good	very good	mean
Peer group	0.0%	0.0%	20.0%	36.0%	44.0%	4.24
Listening in the peer group	0.0%	0.0%	16.0%	64.0%	20.0%	4.04
Guiding in the peer group	0.0%	0.0%	32.0%	52.0%	16.0%	3.84
Group meeting feelings	0.0%	4.0%	12.0%	52.0%	32.0%	4.12
Getting a place in the group meetings	4.0%	4.0%	12.0%	48.0%	32.0%	4.00
The length of the group meetings in hours	0.0%	4.0%	12.0%	56.0%	28.0%	4.08
The length of the group work in month	0.0%	4.0%	28.0%	52.0%	16.0%	3.80

5.5 Transport

Figure 8 (The transport ways to the the Memory Association of Päijät- Häme) shows that 43 family caregivers they use a car. The bus is used by 20 family caregivers so this give a clear few understanding of what kind of transport the family caregivers use. Eight family caregivers answered that they are not interested and six family caregivers have not at all the possibility to come. By this question are also more choices are possible.

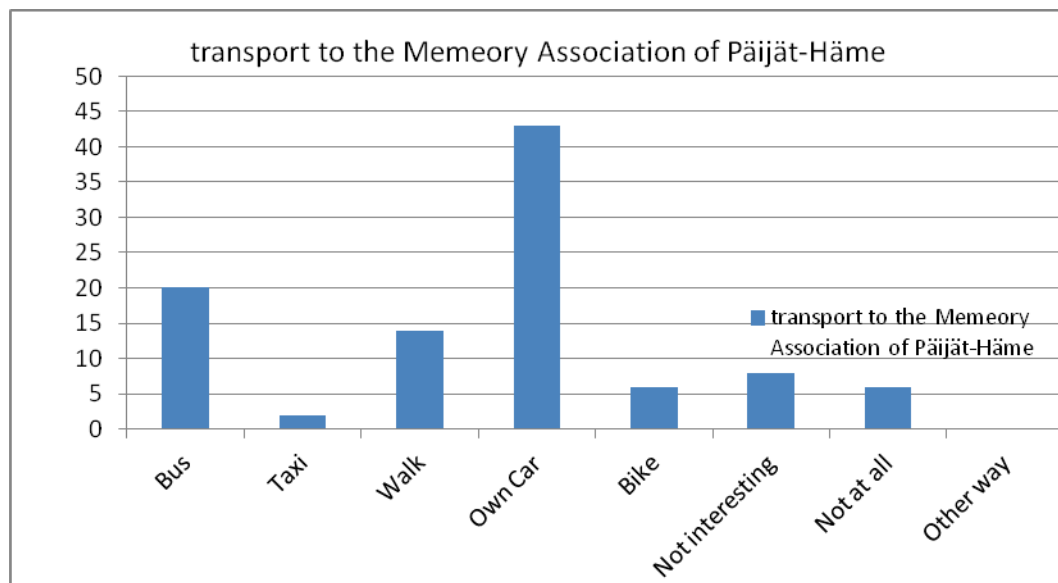


Figure 7. The transport ways to the the Memory Association of Päijät- Häme N= 77

Almost 50 % of all the family caregivers do not use the parking place, bus stop, office on the fourth floor, accessibility with wheelchairs and the space inside of the office. The parking place is according 16,9 % of the family caregivers fair and not using it is according 64.9 % of the family caregivers. The bus stop is according 31.5 % very good but 55.8 % is not using it. The office laying on the fourth floor is for 23.4 % family caregivers a good place but 49.4 % don't use it. The accessibility with wheelchair is according 22.1% family caregivers good but 53.2% don't use it. The space inside the office is for 26% family caregivers good but 48.1% of them don't use it.

According to 63.6 % family caregivers, the Memory Association of Päijät-Häme arranges enough activities. According 10.4 % family caregivers there should be more activities and 26% did not give an answer.

5.6 The satisfaction about activities, support and peer groups of the Memory Association of Päijät- Häme

There are 27.3% of the family caregivers moderately of the activities and supporting of the Memory Association of Päijät- Häme. 19.5% of the family caregivers are satisfied and nine point one % of the caregivers is very much satisfied about the activities and supporting of the Memory Association of Päijät- Häme. A little satisfied is 18.2 % of the family caregivers and very little satisfied is 13 % of the family caregivers. Thirteen percent of the family caregivers feels that they do not need the help of the Memory Association of Päijät- Häme.

The wishes for the future are activities in the evening, for the family caregivers holidays with and without the patient. The family caregivers want also attention of the Memory Association of Päijät- Häme for persons with dementia in nursinghomes. Family caregivers in the surrounding of Lahti wish to have a place of their own place and at least one times a week and half a day of activities arranged

by the Memory Association of Päijät- Häme. Regular, weekly arranged peer groups for patient and family caregivers and more organised trips.

23.4 % of the family caregivers think that peer groups are important and for 18.2 % it is very important. It is relevant for 20.8 % family caregivers. Peer groups are for six point five % of the family caregivers not at all important and for 13 % of the family caregivers not important .This are a part of the family caregivers which never used the peer group activities. There are 18.2 % of the family caregivers that have no experience with peer groups. One comment in the open end is that there are no peer support groups in Nastola.

6 CONCLUSION

According to the results of the cross table test it shows that it is difficult to get a temporary place for a short stay for the persons with dementia according the family caregivers and also that the patient has an effect upon the own situation of the caregiver. In this study the family caregivers should like to take part of the activities but also when we take a look at the condition of the person with dementia and the distance then it is logical that the possibilities to take part are low and has an impact on the quality of life of the family caregivers. Studies from Sulkevan & Eloniemi reported by Ruutiainen & Sivenius (2003) pointed out that a temporary stay for a short time is not always working, the person with dementia is more confused when he or she comes back home. On the other hand the Dutch study made by Peeters, Werkman & Francke (2012) pointed out that taking care of a person with dementia is burdensome, that peer groups and a temporary place for a short stay was needed and the needs of activities for a person with dementia and their family caregivers are high. The study of Viitanen & Purhonen (2010) pointed out that the roles of associations are very important; they give advice, guidance, and support for the family caregivers and the person with dementia for going on with the normal life.

There is obviously a need to get collected information about short-term care-places for-persons with dementia and also for the daycare possibilities arranged in the whole area. This information could be given to the family caregiver and through the information their mind calms down with this knowledge.

This study shows that most of the family caregivers have a problem in participate the peer groups. The lack of the temporary place for the person with dementia is one of the mean. The evening time is also an opportunity for the family caregivers who are working

The Memory Association of Päijät-Häme can help, with their activities, the family caregivers of a person with dementia and give them with their service more quality of life. Then if you look what they want kind of service they should like then you can make a conclusion that the family caregivers need the activities and that it supports their quality of life. This came out in the results that they want to get more information about behavior problems, option of different kind of care possibilities, peer groups and more knowing where to get a temporary place for short stays. Also what the caregivers used comes out that peer groups, market coffee and organized trips are popular. It also showed out that getting a place in a group arranged by the Memory Association is for a part of the family caregivers difficult. The needs are more than the memory association offers. For the persons under the 65 years old is according to family caregivers difficult to get an own age peer group for the family caregivers. Also the time when the family caregiver needs the support of the Memory Association of Päijät-Häme can be in a different time then when the person with dementia needs the support.

The opportunity to avail of some services was curtailed by where the person with the memory disorder lived, or the travelling time involved. Most of the members of the Memory Association of Päijät- Häme are from Lahti. This explains also why there are many family caregivers do not use the activities of Memory Association of

Päijät- Häme. The bus goes from the small towns coming to Lahti only few times a day. Then the social support for transport is usually in the place where you live so with this it is not possible to come in Lahti. Also the transport service for disabled persons is very difficult to get because there are some precedent that a person with dementia can't get the permission to use this.

The way in which the Memory Association of Päijät-Häme supports the family caregivers is inside the organization very good: by letter and by the newsletter Muistike. Almost all family caregivers got the information by that way. In the future, when more people use computers, the Memory Association of Päijät-Häme could also try using email newsletters to contact their members.

According to the family caregivers who are member of the Memory Association of Päijät- Häme they got most part of the information from professionals. There were in 2010 about 8741 persons with dementia in this area and only 470 persons are member of the Memory Association of Päijät- Häme. So every time when you are visiting the memory nurse or coordinator they have to promote the Association.

Also when peer groups and other activities are coming all around the Päijät- Häme area it is easier to get persons with dementia and their family caregivers more interested. When the person with dementia get this diagnose it can be a shock for both, the patient and the family caregiver and refuse all information but after a while when they are used with this diagnose they usually want to know more. Work closely with all relevant parties including the caregivers

In this study the type of the family caregivers difference a lot. There were family caregivers who are paid and the family caregivers that were unpaid. But it also consists of family caregivers who are still in the register of the Memory Association but the one they took care of is passed away. So next time it is important split the family caregivers in groups paid/unpaid and maybe there are better results coming out. Also my questionnaires had too different kind of questions and it was very difficult to find a good way to explain them with SPSS. There are also for the quality of life measuring many ready research questionnaires

and they are used all over the world and so many times that they give much better an indication of quality of life.

However, with these results of my questions the Memory Association can get an indication what the family caregivers and the persons with dementia have used, what they need more and on these basic can make some changes in their activities.

To support the changes needed The Memory Association of Päijät-Häme is taking stating dementia as a public health priority just as The Ministry of Social Affairs and Health in Finland (STM 2008:3, 28) prefers.

The next step is to act positively on the research outcomes and incorporate all national and indeed international guidelines. A kind of study what they make in the Netherlands should be good. All association in the country give the same questions, which are special, made for family caregivers, and with those results it is good to make conclusions and compare them. So the participants part is large and the results more reliable.

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This is a questionnaire for the members of the Memory Association of Päijät- Häme who are family caregivers. The purpose of this study is to find out how The Memory Association of Päijät- Häme can better support the quality of life of the family caregivers.

We will first ask some background information

1. What is your place of residence?

- | | |
|--------------------------------------|-------------------------------------|
| <input type="checkbox"/> Asikkala | <input type="checkbox"/> Lahti |
| <input type="checkbox"/> Hartola | <input type="checkbox"/> Myrskylä |
| <input type="checkbox"/> Heinola | <input type="checkbox"/> Nastola |
| <input type="checkbox"/> Hollola | <input type="checkbox"/> Orimattila |
| <input type="checkbox"/> Hämeenkoski | <input type="checkbox"/> Padasjoki |
| <input type="checkbox"/> Iitti | <input type="checkbox"/> Pukkila |
| <input type="checkbox"/> Kärkölä | <input type="checkbox"/> Sysmä |

2. What is your relation with the patient?

- 1 Husband
- 2 Child
- 3 Something else what _____

3. a) What is your gender?

- Male
 Female

b) What is the gender of the patient?

- Male?
 Female ?

4. a) What is your age? _____

b) What is the age of the patient? _____

5. Are you an official, paid, family caregiver?

- Yes
 No

6. How long does your patient already suffer from dementia ?

- Below a year 1-2 years

2-4 years

More than 4 years

The following questions ask how taking care of a person with dementia influences the quality of life of the family caregiver.

7. How much do you think that the situation of your patient has an effect on your own situation ?

Ring the number:

1=very little bit 2=a little bit 3= don't know 4=much 5=very much

1 2 3 4 5

8. How is your health situation? Ring the number

1=very bad 2=bad 3= don't know 4=good 5=very good

1 2 3 4 5

9. How is the health situation of your patient according to your opinion?

Ring the number:

1=very bad 2=bad 3= don't know 4=good 5=very good

1 2 3 4 5

10. How much does your patient needs your help in the 24 hour period?

Ring the number:

1=very little bit 2=a little bit 3= don't know 4=much 5=very much

1 2 3 4 5

11. What is your opinion on...

Ring the number

1 = completely different opinion 2= rather different opinion 3= don`t know 4=rather the same opinion 5 = completely same opinion

Changing of the behavior					
I understand the changes in the behavior of the patient.	1	2	3	4	5
I can deal with the patient, if he is afraid.	1	2	3	4	5
I can deal with the patient , if he is angry.	1	2	3	4	5
I can deal with the patient, if he is confused.	1	2	3	4	5
When the patient excludes himself from the outer world this gives problems.	1	2	3	4	5
I am worried that the number dangerous situations are increasing.	1	2	3	4	5
I am afraid that the patient will get lost	1	2	3	4	5

Questions about the care situation					
I have somebody to who I can tell my problems and ask for help.	1	2	3	4	5
I feel that I have to take responsibility for the patient by myself.	1	2	3	4	5
I feel that I can give enough help and support to the patient.	1	2	3	4	5
Professionals give also attention to me.	1	2	3	4	5
I feel that it is difficult to make decisions for the patient.	1	2	3	4	5
I feel guilty, that someone else takes care of the patient.	1	2	3	4	5
I feel guilty, if I am to tired to take care of the patient.	1	2	3	4	5
The future is scarring me.	1	2	3	4	5
Being a caregiver of a patient is physically hard.	1	2	3	4	5
Being a caregiver of a patient is mentally hard.	1	2	3	4	5

Social life					
Keeping in touch with other family members is hard	1	2	3	4	5
Keeping in touch with my own friends is hard.	1	2	3	4	5
I feel myself lonely.	1	2	3	4	5
I can continue with my own hobbies.	1	2	3	4	5

The activities of the memory association (MA)

12. . How did you get the information about the memory association?

- | | |
|--|---|
| <input type="checkbox"/> Central hospital of Päijät - Häme | <input type="checkbox"/> Employee of the MA |
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Information material of the MA | <input type="checkbox"/> Homecare |
| <input type="checkbox"/> Internet | <input type="checkbox"/> Social worker |
| <input type="checkbox"/> Memory nurse | <input type="checkbox"/> Somewhere else, where? _____ |
| <input type="checkbox"/> Memory coordinator | |

13. Did you use or obtain any of the following types information or services offered by the MA?

You can make more than one choices

- | | |
|--|---|
| <input type="checkbox"/> Financial support or benefit | <input type="checkbox"/> Homecare service |
| <input type="checkbox"/> Friend service activities | <input type="checkbox"/> Assistive device |
| <input type="checkbox"/> Group work possibilities | <input type="checkbox"/> Peer groups |
| <input type="checkbox"/> A temporary place for a short staying | <input type="checkbox"/> Something else _____ |

14. Have you or your patient used group services offered by the MA?

You can make more than one choice

- | | |
|---|--|
| <input type="checkbox"/> Peer support group for patients | <input type="checkbox"/> Memory club |
| <input type="checkbox"/> Peer support group for family caregivers | <input type="checkbox"/> Club arranged by volunteers |
| <input type="checkbox"/> Memory club taking place in the restaurant Wanha Herra | <input type="checkbox"/> Coaching course |
| | <input type="checkbox"/> Something else ? _____ |

15. How did you get the information about the activities arranged by the MA

- | | |
|--|---|
| <input type="checkbox"/> Post | <input type="checkbox"/> Market coffee |
| <input type="checkbox"/> Email | <input type="checkbox"/> Phone |
| <input type="checkbox"/> Internet www.menopalsta.fi | <input type="checkbox"/> Friends |
| <input type="checkbox"/> Facebook | <input type="checkbox"/> Somewhere else, where? _____ |
| <input type="checkbox"/> New Lahti -paper association column | |
| <input type="checkbox"/> Newsletter of MA | |

16. In which way do you like to get information of the activities arranged by the MA?

- | | |
|--|---|
| <input type="checkbox"/> Phone | <input type="checkbox"/> Letter |
| <input type="checkbox"/> Email | <input type="checkbox"/> Etelä-Suomen Newspaper |
| <input type="checkbox"/> Internet association side | <input type="checkbox"/> Other newspaper, where?_____ |
| <input type="checkbox"/> Face book | <input type="checkbox"/> Something else, where?_____ |

17. Which kind of transport do you use to come to the happenings and/or group works?

- | | |
|----------------------------------|---|
| <input type="checkbox"/> Bus | <input type="checkbox"/> Bike |
| <input type="checkbox"/> Taxi | <input type="checkbox"/> Nothing at all |
| <input type="checkbox"/> Walk | <input type="checkbox"/> How_____ |
| <input type="checkbox"/> Own car | |

18. We now ask you to indicate how good you think some of the facilities at the MA office and location is ? Ring the number:

1 very bad **2**= bad **3** = fair **4** = good **5** = very good

Parking place	1	2	3	4	5
Bus stop	1	2	3	4	5
Office on the 4 th. floor	1	2	3	4	5
Accecbility with wheelchairs	1	2	3	4	5
Office inside	1	2	3	4	5

Regarding the location and office; what can be better arranged: _____

19. Which of the following activities arranged by the MA did you use last year?

You can make more than one choice

- | | |
|--|--|
| <input type="checkbox"/> Market coffee | <input type="checkbox"/> Other peer groups |
| <input type="checkbox"/> Courses | <input type="checkbox"/> Phone service |
| <input type="checkbox"/> Public open courses | <input type="checkbox"/> Personal contact with employees |
| <input type="checkbox"/> Theme evenings | <input type="checkbox"/> Organised trips |
| <input type="checkbox"/> Workers age peer groups | <input type="checkbox"/> Meetings |

Something else what?_____

20. Does the MA arrange enough activities?

Yes

No

What do you want to change?_____

21. About which topic do you want that we organize theme evenings? You can make more than one choice

Diseases

Kela social service

Medication

Help of organisations

Behavior problems

Something else, what?

Support for family caregivers

Being a supervisor/guardian

22. About which topics do you want more knowledge or help? You can make more than one choice.

The calendar of events

Friend service

Coaching course

Private homecare and day care

Social profit

Assistive device

Homecare

Day care

Daycare applications

Temporary places for a short stay

Behavioral problems

Information

Options of care

Something else what?

Peer groups

Medical treatment

23. What are the barriers causing you not to take part in the activities? You can make more than one choice.

Distance

Share payment /own part

It is difficult to get a place for a short

Membership fee of the MA

stay

- Something else, what?

24. About group meetings in the MA. What about the following statements

Ring the number

1=very bad 2=bad 3= not bad/ not good 4=good 5=very good

Groupwork for the patient					
Feelings after the group meeting	1	2	3	4	5
The activities in the group meetings	1	2	3	4	5
Getting a place in the group meetings	1	2	3	4	5
The length of the group meetings in hours	1	2	3	4	5
The length of the group work in months	1	2	3	4	5
Professional work	1	2	3	4	5
Group meeting feelings	1	2	3	4	5
Peer group for family caregivers					
Peer group	1	2	3	4	5
Listening in the peer group	1	2	3	4	5
Guiding in the peer group	1	2	3	4	5
Feelings after the group meeting	1	2	3	4	5
Getting a place in the group meetings	1	2	3	4	5
The length of the group meetings in hours	1	2	3	4	5
The length of the group work in months	1	2	3	4	5

What we can do better: _____

25. What is the most important reason for being member? Only one choice.

- Discussion and experience sharing with other family caregivers
- Getting more information about dementia

- | | |
|---|---|
| <input type="checkbox"/> Advice and guidance of the employees | <input type="checkbox"/> Organised trips |
| <input type="checkbox"/> Want to help other care givers | <input type="checkbox"/> Supervisory |
| <input type="checkbox"/> MA gives support | <input type="checkbox"/> Something else, what?
_____ |

26. Do you get help and support of the MA? Ring a number.

1=very little bit 2=a little bit 3= don't know 4=much 5=very much

1 2 3 4 5

If you are not satisfied what are your wishes?

27. How important is the peer support arranged by the MA for you?

Ring a number.

1 = Not important at all, 2= not so much important, 3= a little bit important , 4=important 5 =very important

1 2 3 4 5

Thanks for answering!

Tämä tutkimuskysely tehdään Muistiyhdistyksen jäsenille, jotka ovat muistisairaana omaisia. Tutkimuksen tarkoituksena on selvittää miten Muistiyhdistys voi paremmin tukea omaisten elämänlaatua.

Taustatiedot

1. Mikä on asuinkuntasi?

- | | |
|--------------------------------------|-------------------------------------|
| <input type="checkbox"/> Asikkala | <input type="checkbox"/> Lahti |
| <input type="checkbox"/> Hartola | <input type="checkbox"/> Myrskylä |
| <input type="checkbox"/> Heinola | <input type="checkbox"/> Nastola |
| <input type="checkbox"/> Hollola | <input type="checkbox"/> Orimattila |
| <input type="checkbox"/> Hämeenkoski | <input type="checkbox"/> Padasjoki |
| <input type="checkbox"/> Iitti | <input type="checkbox"/> Pukkila |
| <input type="checkbox"/> Kärkölä | <input type="checkbox"/> Sysmä |

2. Mikä on suhteesi hoidettavaan?

- Puoliso
- Lapsi
- Muu, mikä _____

3. a) Oletko

- Mies?
- Nainen?

b) Onko hoidettava

- Mies?
- Nainen?

4. a) Minkä ikäinen olet? _____

b) Minkä ikäinen hoidettava on? _____

5. Oletko virallinen omaishoitaja?

- Kyllä
- Ei

6. Kuinka pitkään hoidettavasi on sairastanut?

- Alle vuoden
- 1-2 vuotta

2-4 vuotta

4 vuotta tai enemmän

Muistisairauden merkitys omaisten elämänlaatuun

7. Kuinka paljon koet, että hoidettavasi tilanne vaikuttaa omaan jaksamiseesi?

Ympyröi valitsemasi numero:

1=erittäin vähän **2**=vähän **3**= en osaa sanoa **4**=paljon **5**=erittäin paljon

1 2 3 4 5

8. Minkälainen on oma terveydentilasi? Ympyröi valitsemaan numero

1=erittäin huono **2**=huono **3**= en osaa sanoa **4**=hyvä **5**=erittäin hyvä

1 2 3 4 5

9. Minkälainen hoidettavasi terveydentila on sinun mielestäsi?

Ympyröi valitsemasi numero:

1=erittäin huono **2**=huono **3**= en osaa sanoa **4**=hyvä **5**=erittäin hyvä

1 2 3 4 5

10. Kuinka paljon hoidettavasi tarvitsee ympärivuorokautista apuasi?

Ympyröi valitsemasi numero:

1=erittäin vähän **2**=vähän **3**= en osaa sanoa **4**=paljon **5**=erittäin paljon

1 2 3 4 5

11. Vastaa seuraaviin väittämiin.

Ympyröi valitsemasi numero

1 = täysin eri mieltä 2= jokseenkin erimielistä 3= en osaa sanoa 4=jokseenkin samaa mieltä

5 = täysin samaa mieltä

Käytökseen liittyviä muutoksia					
Ymmärrän hoidettavan käytöksen tai käytöksen muutoksen.	1	2	3	4	5
Osaan kohdata hoidettavan, jos hän pelkää.	1	2	3	4	5
Osaan kohdata hoidettavan, jos hän on vihainen.	1	2	3	4	5
Osaan kohdata hoidettavaa, jos hän on sekava.	1	2	3	4	5
Hoidettavan sulkeutuminen tuottaa ongelmia.	1	2	3	4	5
Olen huolissani, että vaarallisten tilanteiden määrä lisääntyy ajan myötä.	1	2	3	4	5
Pelkään että hoidettavana oleva saattaa eksyä.	1	2	3	4	5

Hoitoon liittyviä kysymyksiä					
Minulla on joku, jolta voin kysyä apua tai kertoa ongelmista.	1	2	3	4	5
Tunnen olevani yksin vastuussa hoidettavana olevan hoidosta.	1	2	3	4	5
Tunnen pystyväni antamaan hoidettavalle tarpeeksi tukea ja apua.	1	2	3	4	5
Ammatti-ihmiset antavat myös minulle tarpeeksi huomiota.	1	2	3	4	5
Tunnen että, hoidettavan puolesta on vaikea tehdä päätöksiä.	1	2	3	4	5
Tunnen syyllisyyttä, jos joku muu hoitaa hoidettavaa.	1	2	3	4	5
Tunnen syyllisyyttä, jos en jaksa hoitaa hoidettavaa.	1	2	3	4	5
Tulevaisuus tuntuu pelottavalta.	1	2	3	4	5
Hoidettavan hoitaminen tuntuu fyysisesti raskaalta.	1	2	3	4	5
Hoidettavan hoitaminen tuntuu henkisesti raskaalta.	1	2	3	4	5

Kanssakäyminen					
Yhteyden pitäminen muihin sukulaisiin hoidettavan kanssa tuntuu hankalalta.	1	2	3	4	5
Yhteyden pitäminen omien ystävieni kanssa tuntuu hankalalta.	1	2	3	4	5
Tunnen itseni yksinäiseksi.	1	2	3	4	5
Pystyn jatkamaan omia harrastuksiani.	1	2	3	4	5

Yhdistystoiminta

12. Mistä sait tietoa Päijät-Hämeen Muistiyhdistyksen toiminnasta?

- | | |
|---|--|
| <input type="checkbox"/> Päijät-Hämeen keskussairaala | <input type="checkbox"/> Muistiyhdistyksen työntekijältä |
| <input type="checkbox"/> Terveyskeskuksesta | <input type="checkbox"/> Tutuilta |
| <input type="checkbox"/> Muistiyhdistyksen Info-materiaalista | <input type="checkbox"/> Kotihoidosta |
| <input type="checkbox"/> Internetistä | <input type="checkbox"/> Sosiaaliohjaajalta |
| <input type="checkbox"/> Muistihoitajalta | <input type="checkbox"/> Jostain muualta, mistä? _____ |
| <input type="checkbox"/> Muistikoordinaattorilta | |

13. Oletko käyttänyt / saanut yhdistykseltä ohjausta ja neuvontaa seuraavista palveluista?

Voit valita useamman vaihtoehdon

- | | |
|---|--|
| <input type="checkbox"/> Taloudellinen tuki- ja taloudellinen etuus | <input type="checkbox"/> Kotihoidon palvelut |
| <input type="checkbox"/> Ystäväpalvelutoiminta | <input type="checkbox"/> Apuvälineet |
| <input type="checkbox"/> Ryhmätoimintamahdollisuus | <input type="checkbox"/> Vertaistukiryhmät |
| <input type="checkbox"/> Lyhytaikaishoitopaikka | <input type="checkbox"/> Jokin muu _____ |

14. Onko jompi kumpi osallistunut seuraaviin yhdistyksen tarjoamiin ryhmätoimintoihin?

Voit valita useamman vaihtoehdon

- | | |
|---|--|
| <input type="checkbox"/> Muistisairaiden vertaistukitoiminta | <input type="checkbox"/> Muistikerhot |
| <input type="checkbox"/> Omaisten vertaistukitoiminta | <input type="checkbox"/> Vapaaehtoisten vetämät kerhot |
| <input type="checkbox"/> Muistikerho Ravintola Wanhan Herran tiloissa | <input type="checkbox"/> Sopeutumisvalmennuskurssi |
| | <input type="checkbox"/> Jokin muu _____ |

15. Miten saat tietoa tapahtumista tai ryhmätoiminnasta, joita yhdistys järjestää

- | | |
|--|--|
| <input type="checkbox"/> Kirjeitse | <input type="checkbox"/> Jäsenlehestä |
| <input type="checkbox"/> Sähköpostitse | <input type="checkbox"/> Markkinakahveilta |
| <input type="checkbox"/> Internetistä www.menopalsta.fi | <input type="checkbox"/> Puhelimitse |
| <input type="checkbox"/> Facebookista | <input type="checkbox"/> Tutuilta |
| <input type="checkbox"/> Uusi Lahti -lehden yhdistyspalstalta | <input type="checkbox"/> Jostain muualta, mistä? |

16. Mitä kautta olisi hyvä ilmoittaa tapahtumista ym?

- | | |
|--|---|
| <input type="checkbox"/> Puhelimitse | <input type="checkbox"/> Etelä-Suomen Sanomissa |
| <input type="checkbox"/> Sähköpostitse | <input type="checkbox"/> Muussa lehdessä, |
| <input type="checkbox"/> Internetissä yhdistysten sivuilla | missä? _____ |
| <input type="checkbox"/> Facebookissa | <input type="checkbox"/> Jossakin muualla, missä? |
| <input type="checkbox"/> Kirjeitse | _____ |

17. Miten pääset osallistumaan yhdistyksen tapahtumiin ja/tai ryhmätoimintaan

- | | |
|---|---|
| <input type="checkbox"/> Linja-autolla | <input type="checkbox"/> Polkupyörällä |
| <input type="checkbox"/> Taksilla | <input type="checkbox"/> En ollenkaan |
| <input type="checkbox"/> Kävelen | <input type="checkbox"/> Miten muuten _____ |
| <input type="checkbox"/> Omalla autolla | |

18. Yhdistyksen toimitilat ja sijainti ovat mielestäni Ympyröi valitsemasi numero:

1 erittäin huono 2= huono 3 = tyydyttävä 4 = hyvä 5 = erittäin hyvä

Parkkitila	1	2	3	4	5
Linja-auto pysäkki	1	2	3	4	5
Sijainti neljännessä kerroksessa	1	2	3	4	5
Esteettömyys	1	2	3	4	5
Sisätilat	1	2	3	4	5

PARANNUSEHDOTUKSIA: _____

19. Mitä järjestön toimintoja olet käyttänyt viimeisen vuoden aikana?

voit valita useamman vaihtoehdon

- | | |
|--|---|
| <input type="checkbox"/> Markkinakahvila | <input type="checkbox"/> Työkäisten vertaistukiryhmät |
| <input type="checkbox"/> Kurssit | <input type="checkbox"/> Muu vertaistukiryhmät |
| <input type="checkbox"/> Avoimet yleisötilaisuudet | <input type="checkbox"/> Puhelinpalvelu |
| <input type="checkbox"/> Teemaillat | |

- | | |
|--|--|
| <input type="checkbox"/> Henkilökohtainen tapaaminen
työntekijän kanssa | <input type="checkbox"/> Jotain muuta, mitä? _____ |
| <input type="checkbox"/> Virkistysretket | |
| <input type="checkbox"/> Kokoukset | |

20. Onko järjestöllä riittävästi toimintoja?

- KYLLÄ
 EI

Mitä muuttaisit? _____

21. Mistä aiheista haluaisit teemailtoja ja tai kursseja? Voit valita useamman vaihtoehdon

- | | |
|--|---|
| <input type="checkbox"/> Sairauksista | <input type="checkbox"/> Kelan sosiaalietuuksista |
| <input type="checkbox"/> Lääkkeistä | <input type="checkbox"/> Avun palvelujärjestelmästä |
| <input type="checkbox"/> Käyttäytymishäiriöstä | <input type="checkbox"/> Muusta, mistä?
_____ |
| <input type="checkbox"/> Omaisena jaksamisesta | |
| <input type="checkbox"/> Edunvalvonnasta | |

22. Mistä kaipaisit lisää apua ohjausta ja tai tietoa? Voit valita useamman vaihtoehdon.

- | | |
|--|---|
| <input type="checkbox"/> Tapahtumakalenterista | <input type="checkbox"/> Ystäväpalvelusta |
| <input type="checkbox"/> Sopeutumisvalmennuskursseista | <input type="checkbox"/> Yksityisestä kotihoidosta ja tai
päivätoimintaan pääsystä |
| <input type="checkbox"/> Sosiaalieduista | <input type="checkbox"/> Apuvälineistä |
| <input type="checkbox"/> Kotihoidosta | <input type="checkbox"/> Päivähoidon toiminnasta |
| <input type="checkbox"/> Päivätoimintaan pääsystä | <input type="checkbox"/> Lyhytaikaisesta hoitopaikasta |
| <input type="checkbox"/> Käyttäytymishäiriöstä | <input type="checkbox"/> Tiedottamisesta |
| <input type="checkbox"/> Hoitovaihtoehdoista | <input type="checkbox"/> Muusta, mistä?
_____ |
| <input type="checkbox"/> Vertaistuesta | |
| <input type="checkbox"/> Lääkehoidoista | |

23. Estääkö jokin sinua osallistumasta järjestön toimintaan? Voit valita useamman vaihtoehdon.

- | | |
|---------------------------------|---|
| <input type="checkbox"/> Matkat | <input type="checkbox"/> Osallistumismaksut/omavastuu |
|---------------------------------|---|

- Järjestön vuosittainen jäsenmaksu Muu, mikä? _____
- Hoidettava ei voi osallistua toimintaan
- Hoidettavalle on vaikea saada tilapäishoitopaikkaa

24. Päijät-Hämeen muistiyhdistyksen ryhmätoiminnoista. Arvioi seuraavia väittämiä

Ympyröi valitsemasi numero

1 erittäin huono 2= huono 3 = kohtalainen 4 = hyvä 5 = erittäin hyvä

Hoidettavana olevan ryhmätoiminta					
Hoidettavan olo ryhmätoiminnan jälkeen	1	2	3	4	5
Ryhmätoiminnan ohjelmasisältö	1	2	3	4	5
Pääseminen ryhmätoimintaan	1	2	3	4	5
Ryhmätoiminnan kesto	1	2	3	4	5
Ryhmätoimintajakson pituus	1	2	3	4	5
Henkilökunnan osaaminen	1	2	3	4	5
Ryhmätunnelma	1	2	3	4	5
Vertaistuki omaisille					
Vertaistukitoiminta	1	2	3	4	5
Kuunteleminen vertaistukiryhmässä	1	2	3	4	5
Ohjaus vertaistukiryhmässä	1	2	3	4	5
Oloni vertaistukiryhmän jälkeen	1	2	3	4	5
Pääseminen vertaistukiryhmään	1	2	3	4	5
Vertaistukiryhmän kesto	1	2	3	4	5
Vertaistukiryhmäjakson pituus	1	2	3	4	5

PARANNUSEHDOTUKSIA: _____

24. Mikä on tärkein syy jäsenyydellesi? Valitse yksi vaihtoehto.

- | | |
|--|--|
| <input type="checkbox"/> Keskusteleminen ja kokemuksien jakaminen muiden omaisten kanssa | <input type="checkbox"/> Halu auttaa muita omaisia |
| <input type="checkbox"/> Tiedon saanti hoidettavan sairaudesta | <input type="checkbox"/> Järjestöltä saatu tuki |
| <input type="checkbox"/> Työntekijöiltä saatu neuvonta ja tai ohjaus | <input type="checkbox"/> Virkistystoiminta |
| | <input type="checkbox"/> Edunvalvonta |
| | <input type="checkbox"/> Muu, mikä? |
-

26. Kuinka paljon koet saavasi järjestöltä apua ja tukea? Ympyröi valitsemasi numero.

1= erittäin vähän 2= vähän 3=kohtalaisesti 4=paljon 5=erittäin paljon

1 2 3 4 5

Jos et ole tyytyväinen, mitä olisit toivonut järjestöltä?

27. Kuinka tärkeäksi koet yhdistykseltä saamasi vertaistuen?

Ympyröi valitsemasi numero.

1 = ei lainkaan tärkeäksi, 2= ei kovin tärkeäksi, 3= merkitykselliseksi, 4=tärkeäksi 5 =erittäin tärkeäksi

1 2 3 4 5

KIITOS VASTAUKSISTASI!



Hyvä Päijät-Hämeen muistiyhdistys ry:n jäsen omainen

Opiskelen Kymenlaakson Ammattikorkeakoulussa ylempää ammattikorkeakoulututkintoa ja tavoitteena on valmistua englanninkieliseltä linjalta terveyden edistämisen opinnoista syksyllä 2013. Opintoja varten teen opinnäytetyötä yhteistyössä Päijät-Hämeen muistiyhdistys ry:n kanssa. Ammattikorkeakoulun lehtori Merja Laitoniemi toimii opinnäytetyöni ohjaajana ja Muistiyhdistyksestä muistiluotsiohjaaja Nina Reimari.

Opinnäytetyön tavoitteena on saada tietoa miten Päijät-Hämeen Muistiyhdistys voi entistä paremmin kehittää toimintaansa ja tukea muistisairaiden ja heidän omaistensa elämänlaatua.

Olen kiinnostunut Teidän mielipiteestänne hoidettavan omaisen näkökulmasta katsottuna. Haluan selvittää miten yhdistystoimintaa tulisi parantaa, jotta se voisi vielä paremmin tukea ja helpottaa teidän elämäntilannettanne. Ohessa on kyselylomake, johon vastaamalla autatte kehittämään Päijät-Hämeen muistiyhdistys ry:n toimintaa. Vastausaikaa kyselylomakkeelle on perjantaihin 18.2.2013 saakka, jolloin viimeistään toivon kyselylomakkeen postitusta ohessa olevaan kirjekuoreen suljettuna Päijät-Hämeen Muistiyhdistys ry:lle.

Kyselyn vastaukset käsitellään luottamuksellisesti. Täytetyn kyselylomakkeen voi sulkea ohessa olevaan postimerkillä varustettuun kuoreen ja palauttaa nimettömänä. Opinnäytetyöni valmistuttua kyselylomakkeet hävitetään asianmukaisesti.

Yhteistyöstä kiittäen

Geronomi AMK Degree Programme in Health Promotion opiskelija

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TUTKIMUSLUPA-HAKEMUS 08.12.2012

Päijät- Hämeen muistiyhdistys ry:n hallitus

Olen Annetta Kurvinen ja opiskelen Kymenlaakson Ammattikorkeakoulussa ylempään ammattikorkeakoulututkintoa ja tavoitteenani on valmistua ylempään ammattikorkeakoulun Geronomiksi englanninkieliseltä terveyden edistämisen linjalta syksyllä 2013.

Tällä hakemuksella pyydänkin lupaa toteuttaa opinnäytetyötäni varten tutkimus Päijät- Häme Muistiyhdistys ry:ssä. Opinnäytetyöni tarkoituksena on kerätä tietoa järjestön omaisjäsenistöä ja selvittää heidän mielipiteensä sitä, miten Päijät-Hämeen Muistiyhdistys voisi vielä paremmin kehittää toimintaansa ja tukea muistisairaiden sekä omaisten elämänlaatua.

Tutkimus toteutetaan määrällisenä tutkimuksena, jossa lähetetään järjestön omaisjäsenille kyselylomake helmikuussa 2013. Tutkimuksen tuloksia analysoidaan kevään 2013 aikana. Opinnäytetyötä tehdessäni minulla on täysi vaitiolovelvollisuus. Tämä tarkoittaa, että käsittelen tutkimuksesta esiin tulleita tietoja täysin luottamuksellisesti. Kyselyihin vastanneiden henkilöllisyydet eivät tule esille opinnäytetyössäni. Ammattikorkeakoulun lehtori Merja Laitoniemi ja Muistiyhdistyksen puolelta muistiluotsiohjaaja Nina Reimari toimivat opinnäytetyöni ohjaajina.

Terveisin


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Lupa tutkimuksen tekemiseen hyväksytty /hylätty

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Jouni Helén

3 / 1 / 2012

Allekirjoitus ja nimenselvennys