

SUPPORT FOR THE FAMILY CAREGIVER
OF A PERSON WITH DEMENTIA LIVING IN
A CARE HOME

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Bachelor's thesis
February 2013

Degree Programme in Nursing
Social Services, Health and Sports



Author(s) PAJALA (MIKKOLA), Annina TATARU, Gabriela Paula	Type of publication Bachelor's Thesis	Date 22.02.2013
	Pages 46	Language English
		Permission for web publication (X)
Title SUPPORT FOR THE FAMILY CAREGIVER OF A PERSON WITH DEMENTIA LIVING IN A CARE HOME		
Degree Programme Degree Programme in Nursing		
Tutor(s) PALOVAARA, Marjo GARBRAH, William		
Assigned by		
Abstract <p>The purpose of this study was to determine the family caregiver's need for information about dementia, specifically concerning their beloved ones in the care of "Akseli ja Elina-koti" care home. The research aimed at helping the family caregivers to understand the effects of dementia on their beloved ones. The results of the research were directed at facilitating a good relationship between the family caregivers and the care home staff in order to improve day by day life of the beloved with dementia living in a care home.</p> <p>The collection of the research data was carried through questionnaires which enabled the respondents to consider their answers; to ensure their possible anonymity and to avoid their embarrassment when answering the questions. The questionnaires were left with "Akseli ja Elina-koti" personnel, to be handed to the family caregivers, in June 2012 and were collected at the end of July 2012. The questions within the questionnaire were open-ended in order to give the respondent the possibility to freely express their opinions in detail without feeling pressured, and to protect the sensitivity and the complexity of the issue.</p> <p>This study found that in order for the family caregivers to be satisfied with the amount and quality of the information provided, "Akseli ja Elina-koti" care home staff is to offer more detailed and personalized information. Furthermore, as a solution for enabling a supportive relationship between the family caregivers and "Akseli ja Elina-koti" care home staff, improvement should be made in the staffs' methods of communication and providing feedback. The family caregivers' main expectation for improvement was concerning the quality of care, especially regarding personalized care reports, their involvement in the decision making of the beloved ones care, and the living environment within the care home.</p>		
Keywords Family caregiver, support, elderly care home, dementia, relationship		
Miscellaneous		



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1 INTRODUCTION

As for the purpose of this thesis it is necessary to take a detailed look at what is dementia and how it is linked to Alzheimer's and other leading dementia diseases. Alzheimer's related dementia is one of the most traumatic diseases a victim's family caregiver can experience. The beloved one loses the abilities to fulfill daily routine tasks, loses memory and finally the ability to recognize family members. From the clinical view point dementia is referred to as a syndrome and a pattern of cognitive impairments characterized by deficits in memory and at least one of the other cognitive functions: language, executive functions, and visuospatial abilities. (Sounder E. 2010) This impairment must be significant enough to impact behavior and interfere with socialization. Dementia may occur as progressive, static, or remitting as a result of neuropathology from various causes. (Bondi, M., Wierenga C. 2011) In a practical sense even the elderly suffering from mild dementia are almost unable to care for themselves at home; therefore, a family member must be always present to guide and help them day after day.

However, when the family caregiver becomes too tired, or sick, there are solutions available to offer them some time to care for themselves. A care home, where the staff's training and education provide the necessary care for the beloved one, is an excellent opportunity for the family caregiver to rest, or recuperate after being sick. However, when the family caregiver decides to place their beloved one to the care home, there are multiple aspects to be considered. These include: the relationship between the care home staff and the family caregiver, information from the care home staff to the family caregiver, and the family caregivers care expectations. Nevertheless, the family caregiver's role is sometimes difficult to manage in cooperation with the staff at a care home; this is why it is important to take a closer look at how to support this cooperative relationship.

2 DEMENTIA

2.1 Alzheimer's disease as a form of dementia

There are over 100 different types of dementia, the most common being Alzheimer's disease, vascular dementia and Lewy body dementia. These disorders all have in common the loss of brain function. (Cayton, Graham & Warner 2008, 1) The loss of brain function is caused by the death of neurological cells distinguished by the presence of beta-amyloid A β plaques and neurofibrillary tangles as in Alzheimer's Disease; ischemic injury or hemorrhagic lesions as in vascular dementia; cell loss and deposition of Lewy bodies in the brain as in dementia with Lewy bodies; and prominent frontal and temporal lobar atrophy as in frontotemporal dementia. (Sunder E. 2010) Dementia can also be found in connection with other neurological infections or metabolic conditions as in Parkinson's disease, Huntington's disease, human immunodeficiency virus or traumatic brain injury. (Bondi et al. 2011)

As mentioned in the description of dementia, Alzheimer's disease is the leading cause of dementia. Alzheimer's is known to account for about 50% of all dementia cases (Cayton et al. 2008, 19). It is an age-related degenerative brain disorder which is found to have abnormal accumulation of extracellular fibrillar amyloid deposits and intra-neuronal neurofibrillary tangles in the brain. It is a progressive pathological disease that gradually causes brain changes beginning with accumulation of A β plaques. This is followed by a variable lag time and finally neurodegeneration becoming the leading pathological process. (Bondi et al. 2011)

Alzheimer's disease patients show characteristics of forgetfulness, lose their sense of time and place, and gradually become unaware of their condition. Furthermore, they will increasingly have difficulties to perform daily tasks such as washing, eating and dressing. They become uncommunicative and aggressive and suffer from severe behavioural problems. (Cayton et al. 2008, 19) They develop a semantic memory deficit characterized by a loss of

general knowledge and impairment of language abilities as in aphasia. Alzheimer's patients usually score poorly in tests of confrontation naming, verbal fluency, and semantic categorization. They perform worse than non-demented adults in tests requiring set shifting, self-monitoring, or sequencing, but not on tests that require cue-directed attention or verbal problem solving. (Bondi et al. 2011)

The diagnosis of Alzheimer's disease is rarely absolutely sure because autopsy of brain tissue is the only method of making a medical diagnosis. However, in a clinical diagnosis, Alzheimer's disease is diagnosed on the basis of identifying that a person has symptoms of dementia, and then ruling out causes that do not lead to Alzheimer's disease. In this way physicians are able to accurately conclude whether the condition is Alzheimer's or another type of dementia. (Cayton et al. 2008, 20)

The risk Factors for Alzheimer's disease

Alzheimer's disease can affect people as young as 30, unsurprisingly age is the greatest risk factor for Alzheimer's disease. (Park, A. 2010)

In fact, the incidence of Alzheimer's increases from about 1 person in 1000 up to the age of 65, 3 people in 1000 over the age of 65, and 10 to 15 people in 1000 over the age of 80. (Cayton et al. 2008, 21)

The second greatest risk factor is genetics as Bondi et al. (2011) state:

Early-onset familial Alzheimer's Disease has been linked to the presence of mutations in one of three genes—amyloid precursor protein (APP) on chromosome 21, presenilin 1 gene on chromosome 14, or presenilin 2 gene on chromosome 1—or duplication of APP as may occur with Down Syndrome, presumably due to these genes' impact on A β .

As described above there is a well-known gene mutation linked to late-onset Alzheimer's Disease that is found in 20 percent of Caucasians which may claim as much as 50 percent of the risk for developing Alzheimer's disease. (Bondi et al. 2011)

The third risk group includes stroke, atherosclerosis, cardiovascular disease, systolic hypertension, elevated pulse pressure, elevated serum cholesterol, current smoking, obesity, and diabetes. These factors can also increase the rate of decline after diagnosis of Alzheimer's disease. Many theories have been proposed to explain the link between cerebrovascular disease risk factors and Alzheimer's disease, as described by Bondi et al. (2011) in the following part:

Vascular pathology may have an additive effect by increasing the overall burden of pathology. Another theory is that Alzheimer's and vascular diseases may interact to worsen pathologic effects. Finally, Alzheimer's disease may be conceptualized as a vascular disorder with amyloid deposition linked to a breakdown in the blood-brain barrier and alterations in brain perfusion.

This means that the eventual weakening of the circulatory system, in specific the health of the vascular components (arteries, veins and capillaries), has a major effect on the health of the brain function and may directly cause the death of brain cells. (Bondi et al. 2011)

Other significant risk factors associated with the development of Alzheimer's disease include head trauma, low education, oxidative injury, depression, never having been married, having low social support, or meeting diagnostic criteria for mild cognitive impairment. (Park, A. 2010) Mild cognitive impairment is a condition prior to dementia that is characterized by subjective and objective memory impairment occurring with preserved general cognition and functional abilities. (Bondi et al. 2011)

Symptoms

Alzheimer's disease is characterized by an increasing number and occurrence of changes in an aging person. In the early stages the person seems to be different from their usual self in ways that are difficult to define. The person may lose interest in hobbies and pastimes show loss of concentration, can be unable to make decisions, and seem to avoid taking responsibility. (Park, A. 2010) Furthermore, the manifestation of mood changes such as irritability and suspicion occurs because of the person becoming aware that there is something wrong in the body but not knowing what it is. Such changes

happen over time in the development of Alzheimer's disease and for that reason this disease is difficult to discover in the early stages. (Cayton et al. 2008, 28)

Although difficult to define as symptoms of Alzheimer's disease in the early stages the following list outlines the early stage symptoms: difficulties with language, memory loss especially short term memory loss, disorientation in time, disorientation in familiar places, difficulty in making decisions, lack of initiative and motivation, signs of depression and aggression, loss of interest in hobbies and activities. (Cayton et al. 2008, 29)

As Alzheimer's disease progresses the symptoms become more distinct and restricting. The following symptoms outline the characteristics of middle symptoms when a person begins to have difficulties with daily living: forgetting recent events and peoples' names; being unable to cook, clean, dress; become dependent on assistance with personal hygiene; increased difficulty with speech; wandering and getting lost; experience hallucinations; become suspicious and paranoid; and becoming depressed. (Park, A. 2010)

Furthermore, in the late stage of increasing dependence and inactivity, the physical side of the disease becomes more apparent. The following list outlines the symptoms of the late stage Alzheimer's disease: difficulty eating; not recognizing relatives, friends and familiar objects; difficulty interpreting events; unable to orientate around the home; difficulty walking; bladder and bowel incontinence; and confinement to a wheelchair or bed. (Cayton et al. 2008, 30)

Alzheimer's disease and other dementias may cause people to behave in abnormal ways that are difficult for their loved ones and caregivers to understand and cope with. Their capabilities and behavior can change from day to day and even many times during one day. These behavioral changes include symptoms creating annoying behavior, losing things, non-recognition, hallucinations, restlessness and agitation, anger and aggression, and sexual behavior. Annoying behavior is characterized by doing child-like actions,

appearing bewildered, or perplexed. As the dementia advances loved ones or caregivers may feel increasingly bitter and angry. (Cayton et al. 2008, 96-106)

It is inevitable that a person with dementia will lose things. This may lead to problems as they tend to place their important possessions such as wallets or keys in hiding places, which they also forget. As the memory of an Alzheimer's patient continues to worsen they become unable to recognize their family and other familiar people. They still have a good long term memory as a result of which they may remember their loved ones, but only as they were in an earlier part of their life. Even their surroundings become unfamiliar because they can no longer recognize their own home. (Cayton et al. 2008, 98, 99)

Furthermore, hallucinations are common in Alzheimer's disease in which the patient may see, hear, or sense the presence of someone or something that is not there. Hallucinations are sometimes a result of poor vision, or medications that can cause hallucinations as a side effect. (Cayton et al. 2008, 100)

Likewise, restlessness is very common in Alzheimer's patients which makes them very agitated and often leads to wandering. Sudden restlessness may be a result of pain or discomfort as a cause of toothache, digestive problems, or difficulty urinating. Boredom may also cause restlessness which can be relieved by offering activities or exercise to pass the time. Restlessness and agitation can cause anger and aggression in an Alzheimer's patients.

(Skovdahl, K., Larsson Kihlgren, A. & Kihlgren, M. 2003) To reduce anger and aggression it is best identify the causes and avoid their occurrence.

Although uncommon, people with dementia sometimes display inappropriate sexual behavior. These behaviors may include undressing in public places, fondling the genitals or touching someone in an inappropriate way. (Cayton et al. 2008, 101, 103, 106)

2.2 Treatment of dementia symptoms

Currently, there is no cure for Alzheimer's disease and most forms of dementia. However, the use of drug and non drug therapy, it help people with dementia to alleviate problems such as restlessness, depression, and in the early stages with memory loss. (Cayton et al. 2008, 176-188)

Drug therapy

Alzheimer's disease is progressive, which leads to death in between five and ten years upon diagnosis. With the use of drug therapy it is possible to slow down the progression of the symptoms of memory loss and disorientation. (Restifo, S., Lemon, V. & Waters, F. 2011) Other drugs can be useful for treating some of the changes in behavior, such as sleeplessness and agitation, which occur with dementia. The use of drugs such as sleeping pills or tranquilizers should be kept to a minimum if someone has Alzheimer's disease, as they can cause increased confusion and falls. (Cayton et al. 2008, 176-188)

Those who are diagnosed with Alzheimer's at an early stage will most likely benefit from anticholinesterase drugs. These drugs may help slow down the progress of symptoms but cannot stop the disease nor reverse the damage that has already happened. Research has found that the brains of many people with Alzheimer's disease have a low level of acetylcholine; a naturally occurring chemical in the brain which enables nerve cells in the brain to send messages to each other. This chemical is constantly being made and destroyed within the brain. The ideal solution to this problem would be to increase the amount of acetylcholine in the brain, but as research has indicated that simply administering acetylcholine to a person has no effect. (Restifo et al. 2011) Anticholinesterase drugs have been created to inhibit the breakdown of acetylcholine. These drugs include Donepezil, Galantamine and Rivastigmine. Specifically the drug Galanamine has another action within the brain that stimulates nicotinic receptors which may be involved in memory and learning. (Cayton et al. 2008, 176-188)

Some rare forms of dementia which are caused by an under-active thyroid gland, or a deficiency of vitamin B 12, can be cured, or helped considerably, by appropriate treatment. Treatment is simply taking tablets of thyroid hormone or injection of vitamin B 12. It is important to note that taking these hormone or vitamin supplements is not helpful for those dementia patients who do not have a deficiency in these substances. Inappropriate use of supplements can be harmful. (Cayton et al. 2008, 176-188)

Any drug may have unpredictable and unpleasant side effects. The main side effects associated with dementia drugs include nausea, vomiting and diarrhea. Of course side effects vary depending upon the drug and the person but usually become less troublesome within a few weeks of use. (Cayton et al. 2008, 176-188)

As earlier discussed one symptom of Alzheimer's disease is constipation which causes increased agitation and other behavioral symptoms. In the beginning, constipation can be treated by a diet containing fiber, fruits and vegetables, drinking plenty of water and regular exercise. In some cases, however, further treatment is required. A doctor may advise the use of laxatives such as ispaghula and lactulose. (Restifo et al. 2011)

3 THE ROLE OF THE FAMILY CAREGIVER

3.1 Understanding the role of the family caregiver in the life of a person with dementia living in a care home

According to Family Caregiver Alliance as FCA (2012), a caregiver can be each and every one that provides basic support for a person which is disabled, fragile, diseased, and in needs of help. Furthermore, Prabhu, L., Molinari, S. M., Lomax, V. A., James, W. (2006, 26) have stated that Feinberg and Pilisuk, (1999) defined caregiver as:

...one who provides care without pay and whose relationship to the care recipient is due to personal ties (rather than to the service system): family, friends, or neighbours, who may be primary or secondary caregivers, provide full time or part time help, and live with the person being cared for or separately.

FCA (2012) claims that the majority of people will play the role of a caregiver or of one that is in need of care, at some point in their lives. According to Prabhu et al. (2006, 26), the recognition of the caregiving phenomenon has developed over the last ten years even though human being, especially women have constantly provided care for family members and friends. In advance, the caregiver's tasks are of a wide variety including assistance and support with daily activities and medication. However, when the caregiving role falls in the care of a family member or friend, most of them do not think of themselves as being care providers; they claim that they just do what seems to be natural to them, taking care of their loved ones. In many cases, the care they provide demands months and years of emotional, financial and physical recourses. (FCA 2012)

People are different, therefore, for some of them, caregiving comes naturally but for others, it becomes a process to digest and assimilate over time. Also, the type of caregiving changes according to the situation, starting with the full-time caregiving and finishing with the part-time caregiving. However, in both cases, family members are the ones that provide it free of charge. Many family members that care for person with a cognitive impairment usually share common issues and situations, even though each disease has its own characteristics. As common causes of the cognitive impairment, Alzheimer's disease and dementia related symptoms, Parkinson disease, and brain injury are to be mentioned. (FCA 2012)

It is acknowledged that caring for person with dementia or any kind of cognitive impairment, raises challenges for the family caregivers. One of the challenges that caregivers may face is the fact that moderate to severe dementia patients need special care; in many cases they need 24-hours supervision, including help with daily living activities. In advance, the

caregivers need to possess communication skills and approach as well as the necessary patience to cope with the difficult behavior of a person with dementia. Simple acts such as normal conversation can be very difficult in the context when the loved one does not remember what has been told from a moment to another. (FCA 2012)

Alzheimer's and dementia related diseases are progressive diseases in which the patient's state of mind continuously worsens. Furthermore, part of the symptoms includes mood swings and behavioral changes, which are aspects very difficult to accommodate, if there is lack of information and knowledge. Therefore, very often, the family caregivers become confused and feel guilty for not being able to understand and help their loved ones. (FCA 2012)

When making the decision to accommodate the person with dementia into a care home, the worries and stress of the family caregiver can be significant. They are confronted with the pain caused by the process of losing their loved one while he is still alive. During this process feelings and emotions rise to the surface, such as helplessness, jealousy, denial, disbelief, guilt, loneliness and anger. These are the moments when the family caregiver needs as much help as possible. (Buijssen 2005, 143)

When the person with dementia transfers from life at home to life in a care home, the time spent at home reduces and therefore the family caregivers role changes. (Kotiranta 2008, 2) The transfer of the person to the care home it is a significant transition for both parts involved. Furthermore, the responsibility and the care in such cases does not end, but transforms into an extreme sense of responsibility towards their loved one. Likewise, the strong responsibility feeling triggers the wish of involvement in the care of the person with dementia such as a continuity of the care they provided at home. For example, some family caregivers prefer to take the person's laundry home in a regular manner or buy new clothes or other personal items for them. Also, protecting their dignity and self esteem, maintaining their individuality and helping to preserve their contact with family and friends as well as socializing with them, are proved of being important in the life of the person with dementia. (Woods, B., Keady, J., Seddon, D. 2007, 46, 69) According to

Hoffman S.B. and Platt C. A. (2000, 213), Bowers (1988) stated that the preservation of the self-esteem within the care home will prevent depression in a person with dementia.

Likewise, the family caregiver's role is unique from the point of view of the information provided to the care home staff about their loved one. Besides, the family caregivers are the right persons to be given the necessary information on the individuality and the individual needs of the person with dementia. Despite this matter, in many cases the family caregiver's fear during the post-admission period is that the care home staff would interpret their information as interference in the home care system. (Woods et al. 2007, 28) Likewise, the person with dementia's mood is translated by the family caregivers as an indicator of the quality of care offered by the care home staff, during their absence. For example, if the person with dementia is depressed, the conclusion of the family caregiver is that the care home staff behaved in the way that caused the depression of their loved one. However, often, the feelings are not communicated to the care home staff because the family caregiver fears insulting them. Therefore, it is strongly recommended for the care home staff to encourage the family caregiver to openly communicate with them. (Hoffman et al. 2000, 214)

However, many family caregivers face the difficulty of not knowing their role in the care of the loved one when the new situation arises. (Kotiranta 2008, 21) For example, the burden and guilt felt by family caregivers when visiting their loved one in the care home, and hear from them "I want to go home". Also, the confusion and the hopelessness when they take them home only to hear once again "I want to go home". Not only that their loved ones do not recognize the home that they lived in for the past 20-years but the meaning of "home" can simply mean a place where to feel love, happiness, safety and a sense of belonging. Therefore, the role of the family caregivers is to simply help their loved ones by making them feeling safe and comfortable in the place they need to live in. (Brackey 2000, 17)

There are several important matters to be clarified in order to attenuate the fears accompanying the transition to the care home. One of the most important ingredients is the communication between the family caregiver and the care home staff. Also, any misunderstandings and misconceptions should be identified and discussed and if any conflict arises, it can be solved before it escalades. For instance, discussions about the expectations, practical information given by the care home staff and answering the family caregiver's questions will reassure them they choose the right place for beloved one. (Woods et al. 2007, 15) Also, when the family caregiver and the care home staff clarify practical matters such as the frequency of physician visits, the care products used in the care home, the habits and the program, the policies, procedures and routines of the care, the communication between the parties becomes easier. Furthermore, it is of significant importance that the family caregiver trusts the care home's staff and allows them to care for their loved one. (Silin, P. S. 2001, 203) Therefore in order to enhance the family caregiver's trust, it is recommended that the care home staff introduce the care home facility to the family caregivers and their beloved one, help them with the adjustment to the new place, and offering sufficient information.. (Woods et al. 2007, 92) As will be discussed further in the thesis, the relationship between the family caregiver and the care home staff influences the well-being of the person with dementia.

One of the other concerns of the family caregiver can be related to the visiting of the care house; when and for how long, how to bear the fact that the loved one is there and not home with the family. There is no right or wrong time for visiting the loved one and there is not right way of doing it, just the right time for the family caregiver. Therefore, the caregiver's schedule, relationships and needs are to be considered when planning a visit to the care home. Also, in the situation when the family caregiver's burden becomes unbearable when visiting the care home, it is recommended to seek for professional help. Coping with the guilt and pain caused by the loss of the loved one requires special attention and professional help. Very often, the beginning of the post-admission period corresponds to a significant amount of guilt that determines the family caregiver to do what their loved one needs, forgetting about their

own limits. It is to be remembered why the family caregiver organized the care for the person with dementia in a care home, initially. The simple answer is, because of the difficulty of caring for the loved one at home. Therefore, when recognizing own limits, the adjusting process to the new situation involving the family caregiver the care home staff and the person with dementia, balances. As a result, the relationship between the parts involved is more amiable and harmonized. (Silin, P. S. 2001, 205)

3.2 Important information for the family caregiver when the person with dementia lives in a care home

According to Woods et al. (2007, 50), there are a number of aspects that are considered the most important for the family caregivers having a family member in the care home. For example, the relationship between the home care staff and the family caregiver, the quality of the care provided in the care home, family role and involvement within the care home and dementia related symptoms, causes and medication. Since the family caregiver's role had been argued above, the further discussion's focus is on the relationship between the home care staff and the family caregiver and the quality of the care provided in the care home.

There were findings according to which, the quality of care provided by the care home staff was most importantly the physical environment within the care house. Resonant with Downs (2008, 213), Brooker (2006, 13) stated the principles recognized as part of the quality care for a person with dementia. First of all, the person centered dementia care principles are recognized to be an important ingredient for high quality care. Therefore, valuing the person with dementia and the family caregiver, together with the respect for the individuality of the person and an environment in which the person with dementia experiences "relative well-being" were considered sufficient in providing high quality care. However, the principles are to be adapted and transformed in order to accommodate the individuality of different care homes.

In their book, Hoffman et al. (2000, 215) suggest that, according to McEvoy & Patterson (1986), another important aspect of the care for the family caregiver is the physical security of their loved one living in the care home. For example, finding their loved one physically injured, as a consequence of a fall, can be very upsetting. As a result, the family caregiver may have doubts about making the right decision when choosing the care home facility. However, the care home staff's role is to explain to the family caregiver that falling is not less common in the first period post-admission when the patient with dementia is disoriented and confused.

The “relationship triangle”

According to Downs (2008, 341), Robinson and Banks (2005); Werezak and Morgan (2003); Zgola (1999) have stated that relationships are of significant importance for the well-being of the person with dementia. After being admitted into a care home, the person with dementia needs plenty of support from the family members and the staff. In order to offer the best care to the person with dementia, it is important that the communication between the family caregivers and care home staff is of a high quality. However, the reality is that the relationship between them causes stress to all parts involved. Even though the relationship is not difficult in all cases, the communication gaps between family caregivers and care home staff can make it demanding. Very often, the staff's response to this matter is, “We don't have any problems with the residents – just with their relatives”. On the other hand, family caregivers complain about the difficult experiences encountered related to the care home staff and management. (Woods et al. 2007, 9)

Furthermore, the relationship between the family caregiver and the person with dementia has an impact on the “person's journey through life”; the relationship with the staff influences the person's day by day life, happiness, satisfaction and needs. Since the two sets of relationships have been established, the only missing side is the relationship between the staff and the family caregiver in order to achieve the “dementia care triangle”. (See Figure 1.) It has been proven that the relationship between the staff and the family

caregiver (triangle's third side), has the power to influence positively or negatively to the wellbeing of the person with dementia. (Woods et al. 2007, 14) However, there is sufficient evidence about the relationship triangle and how it influences the person with dementia's life but not sufficient information about how to apply the previous researches.

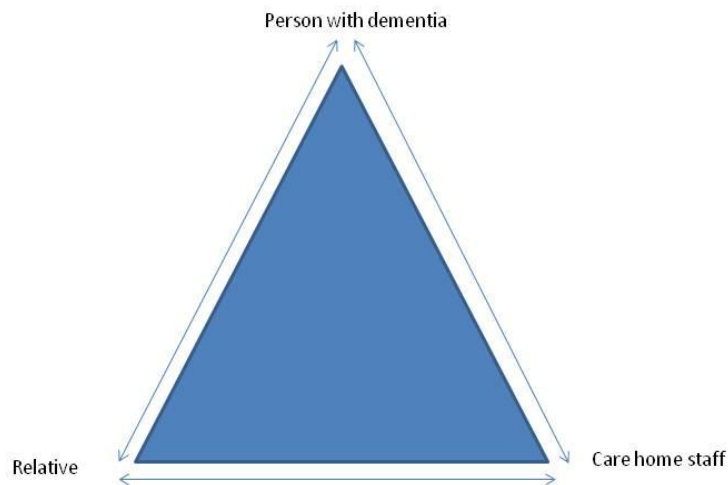


FIGURE 1. The dementia care triangle. The figure can be found in Woods et al. (2007) work

There is a need of understanding of the triangular relationship between the person with dementia, family caregivers and care home staff. In order to solve the issue, Woods et al. (2007, 15) claims that Nolan et al. (2003) suggested the “Senses Framework” as a tool in the understanding of the psychological needs of the person with dementia. The “Senses Framework” emphasized six senses. The first sense proposed was the “sense of security” that provides the person with dementia a free from harm (secure) feeling. The second was the “sense of belonging” that can be interpreted as a feeling of belonging to a place or a feeling of stability. The third sense is the “sense of continuity”, or,

the importance of the link between the past, present and future. The fourth sense is the “sense of purpose” when feeling important, having a goal or an aim, makes life worth living. The “sense of achievement” is the fifth emphasized and means making progress to achieve a goal. The sixth sense of a “Senses Framework” is the “sense of significance”, translated as the sense of feeling important.

According to Woods et al. (2007, 15), Nolan et al. (2003, 2006) argue that each of these six areas, the person with dementia, the family caregiver and the care home staff may experience differently. Furthermore, a disagreement in the understanding of any of the sense areas may influence the quality of the relationship triangle. For example, in the sense of security, the person with dementia may simply feel secure when physical needs are met and when seeing smiling and friendly people around; when on the other hand, the family caregiver feels safe when their beloved one is properly taken care of in the care home; also, the care home staff may feel safe when their work is being appreciated and is not continuously under scrutiny or physically or verbally attacked.

As a conclusion, the communication between the family caregiver and the care home staff is considered important; therefore, family caregivers must be accepted as partners in the care of the person with dementia. Also, the care home staff should actively support the integration of the family caregiver into the daily routine of their beloved one. Hence, by collaborating, communicating and working together, the care related relationship between the family caregiver and the care home staff becomes pleasant and increasingly easier. (Hoffman et al. 2000, 216)

3.3 Support for the family caregivers

According to Woods et al. (2007, 88), all human beings need support at some point of their life. For the family caregiver of a person with dementia

transferred to a care home, the support is particularly important, in order to cope with the emotional effect of their new role. One of the important types of support is emotional support. Emotional support can be often offered by the care home staff, by providing the family caregiver with opportunities to talk about their fears and encouraging them in all ways. For example, the care home staff could offer a cup of coffee and encourage the family caregiver to discuss about their feelings openly. The support offered by the care home staff is significantly important as it comforts the family caregiver's feeling.

Also, another type of support offered by the care home staff is the family caregiver's support group connections. The support groups are usually operated by health professionals including psychologists, social workers or nurses. During the group meetings, the family caregivers are encouraged to express and share their feelings, frustrations and fears related to the situation when their beloved one suffers from dementia. Likewise, within the group meetings, positive feelings are being shared, in order to comfort the participants. (Hoffman et al. 2000, 214) According to Woods et al. (2007, 65), such meetings are beneficial in the way that supports people finding themselves in similar situations and struggling with similar issues. By sharing their problems with people in similar situations, family caregivers may possibly find the right solutions or tips that suit their troublesome cases.

Besides, the family caregivers as well as the care home staff are both supported by different associations concerned with dementia and dementia related symptoms. (Hoffman et al. 2000, 214) For example, in Finland, Muistiliitto or the Alzheimer Society of Finland is a non-profit organization established in 1998 and works worldwide. The organization provides support and help to people with Alzheimer's disease, their caregivers and the health care professionals working in dementia care. The support provided is offered in various ways such as seminars and projects, trainings and rehabilitation programs in which the prevention of the dementia is emphasized.

Furthermore, The Alzheimer Society of Finland develops models and recommendations for the support of the persons with dementia and the family caregivers. (See Figure 2.)

THE MODEL OF REHABILITATION – A PERSON’S RIGHT TO A GOOD LIFE

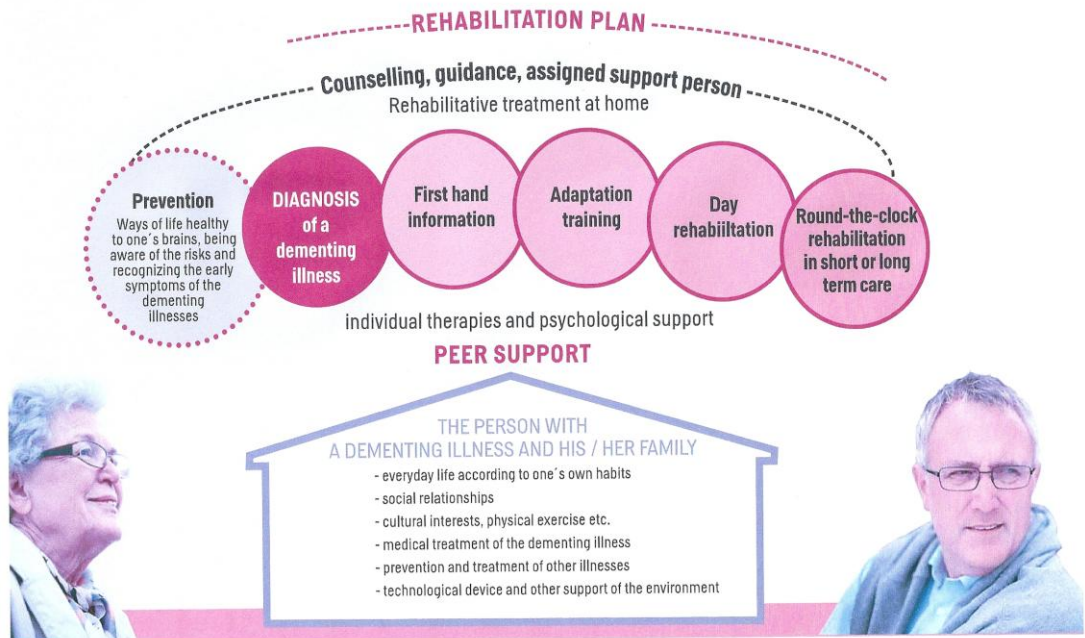


FIGURE 2. Model of rehabilitation. The figure can be found on Muistiliitto, The Alzheimer Society of Finland website.

4 THE AIM AND THE PURPOSE OF THE RESEARCH

The aim of the research was to help the family caregivers of a person with dementia living in “Akseli ja Elina-koti” understand the way dementia affects their beloved ones. The purpose of the study was to identify the need and the type of information on dementia for the family caregivers living in “Akseli ja Elina-koti”. Hence, the study results mediate a good relationship between the family caregivers and the care home staff also improving day by day life of a person with dementia living in a care home.

In order to achieve the above mentioned purpose and aim, the following research questions will be analyzed:

1. What kind of information is needed for family caregivers of a person with dementia living in a care home?
2. What is the family caregiver’s opinion on their relationship with the care home staff?
3. What are the family caregiver’s expectations in their relationship with the care home staff?

5 IMPLEMENTATION OF THE STUDY

5.1 Research settings

In order to reach the research goals, research collaboration was needed. The thesis research was in collaboration with “Akseli ja Elina-koti” care house, located in Jyväskylä. Furthermore, the research cooperation permission (See appendix 1) “Akseli ja Elina-koti” is a short term elderly care home that has 50 places to accommodate older people, mainly suffering from dementia. However, during daytime, the house also accommodates elderly living in the area, willing to meet other elderly and spend time with. It is significant to mention that the elderly that visit “Akseli ja Elina-koti” during the daytime are not suffering from dementia. The care home facility is a two level building which provides the elderly with short time housing for the period when their caregivers need a pause. There are 29 rooms, offered to be used according to a pre-agreement set between the care home staff and family caregivers; also, the accommodation periods vary from case to case according to the family caregivers needs. (Jyväskylän kaupunki 2012) Most of the elderly family caregivers are relatives such as husbands, wives, children and siblings but there are cases where the caregivers are represented by close friends.

5.2 Sampling

The target group in this study was represented by family members of elderly with dementia living in “Akseli ja Elina-koti” care home facility. The reason why this target group was chosen was to observe the need of the information within “Akseli ja Elina-koti” care home. In advance, the target group includes family members as family caregivers, but also close friends that care for the elderly with dementia.

5.3 Data collection

The data collection method when performing a research has relevance to the research results. The questionnaire is an important source of information about a person`s beliefs, feelings, and knowledge. (LoBiondo et al. 2006, 325) The research data collection was carried out through questionnaires because the method was accommodative of the respondents and no prior arrangements were needed. Furthermore, the method enabled the respondents to consider their answers; it ensured their possible anonymity and avoided their embarrassment when answering the questions. The questionnaires were left with “Akseli ja Elina-koti” personnel, to be handed to the family caregivers in June 2012, and were collected at the end of July 2012. The questions within the questionnaire were open-ended, because it gave the respondents the possibility to express freely. LoBiondo et al. (2006, 325) states that open-ended response questions allow the subjects to answer in their own words. Also, open-ended questions were used because of the controversial, sensitivity and the complexity of the issue within the questionnaire. Therefore, with this method, the respondents can freely express their opinions in detail without feeling pressured.

The family caregivers’ time to complete the questionnaire was limited, this was taken into consideration. The intention was to allow the family caregivers to have the choice to take the questionnaires home and mail them to us after completion. In order to save time and resources, the questionnaires (See appendix 2) and the letter of consent (See appendix 3) were distributed by the “Akseli ja Elina-koti” care home staff. The questionnaire was created according to the thesis’s research questions, the aim and the purpose.

5.4 Data analysis

Data collecting was completed throughout questionnaires. It is significant to remember that the whole research and analysis is based on the opinion of the

family caregivers. A number of 20 (twenty) questionnaires were delivered to “Akseli ja Elina-koti” staff for distribution. With a total of 8 completed questionnaires, the analysis was a matter of organizing the responses into the three research questions.

In this research, themes were used in order to organize and analyze data’s content as a mind map. Furthermore, the data were carefully read, and colored tabs were used to indicate which research question was answered through a response. All answers were translated into English by each of us and organized into themes and subthemes. Finally, every subtheme was separately analyzed and exemplified by phrases chosen from the data.

However, in order to achieve an accurate analysis, all data were examined individually. Nevertheless, each analysis was compared, discussed and merged. As a result, new combined mind maps for each research question were created. Furthermore, many similarities amongst the individual analysis were found; however some themes were approached from different perspectives. (See Figure 3)

Subthemes	Themes	Research Q.
Same care home staff should take care of the beloved one during each period spent in the care home	Stability within the care of the beloved one	Research Question 2: What are the family caregiver’s expectations in their relationship with the care home staff?
The beloved one should spend the periods in the same ward, every time.		
A good relationship would ensure the best possible care towards the beloved one.	Good relationship between family caregivers and care home staff	
The family caregiver to be part of the decisions to be made in relation with the care of their beloved one.		
Communication is successful, but brief.	Communication between family caregivers and care home staff	
Communication is extremely difficult		

FIGURE 3. Themes and subthemes

5.5 Ethical considerations

When distributing a research questionnaire, general principles of ethics must be considered. According to the American Nurses Association, Guidelines for nurses in clinical and other research, a research project should always take into consideration guidelines outlined as follows: the right to self-determination, the participant must be informed in writing about the nature of the activity involved in the research, and that participation is voluntary; the right to freedom from risk or harm, meaning that the researchers must ensure freedom from risk or harm by estimating the potential physical or emotional risk and benefit involved; the scope of application and the protection of human rights of all individuals, even those with limited civil freedom must be also considered. Furthermore, the responsibilities to support knowledge development in which the research must support the development of knowledge or base of nursing practice. Finally, by the informed consent, self-determination is protected when permission is obtained from the individual included in the research. (LoBiondo et al. 2006, 296)

The above mentioned guidelines provided the requirements for the letter of consent which was attached to the questionnaire. The purpose of the letter of consent was to provide ethically correct protection for the participants. Furthermore, the letter of consent included a brief introduction of the thesis, information about the researchers, and the authenticity of the research. In advance, the participants were informed about the confidentiality of their participation to the research. Also, by accepting the letter and completing the questionnaire the participant gave their consent. The research permission was sent to the City of Jyväskylä representatives for approval.

6 RESULTS

6.1 Information for the family caregiver

One of the research questions was created to determine what kind of information the family caregiver of a person with dementia living in a care home need and what kind of information they already have. The intention was to learn if the family caregivers possess general information about dementia. When analyzing the data, two themes aroused; the information on dementia and its sources, and the information related to the beloved one's care.

Information on dementia and its sources

Some of the responses to the first research question describe the sources of information about dementia. Three sources of information were identified: "Akseli ja Elina-koti" staff, an unidentified source, and an expert or professional.

The information that was most requested from the "Akseli ja Elina-koti" staff was about the beloveds' health during the stay at the ward to be given mid-stay and at the end. In advance, the most requested information from an expert or a professional included guidance, follow-up and clinical examinations of those with chronic illnesses such as dementia. One request was even for a geriatric statement or opinion about their beloveds changing health situation.

...I wish I would get more information, guiding and advice. All the given information's are welcomed.

...it would be good to get a geriatric opinion...

Most of the family care givers stated that they possess sufficient information on dementia. The theme was organized according to the following sources:

from “Akseli ja Elina-koti” staff, an unidentified source, and information from elsewhere. All answers were of the opinion that these sources have provided them with all the necessary information on dementia. Furthermore, sources of information such as magazines, books, television, and media were mentioned as being used.

...the disease has persisted for a few years already, so some amount of information has been given before coming...

I get my information from other sources...(newspapers, TV, etc...)

Yes, I have enough information. I have gotten the information from the Alzheimer’s Society of Finland, Jyväskylä branch...

Information on the beloved one’s care

The family caregivers were interested in different types of information related to care and well being of their beloved one suffering from dementia. Furthermore, most of the family caregivers suggested that more individualized information regarding the care of the beloved one during the period spent in the care home would be useful. For example, the kind of information to help the family caregiver learn about their beloved one health condition, especially when the period spent in the care home is longer than usually. Based on the individualized and detailed information, the family caregiver is able to better plan the period spent home; extra needs, eventual routine changes in the beloved ones’ behavior. Also, there were suggestions according to which, knowing the nurses that took care of the beloved one during the previews periods, would improve the information flow between the care home staff and the family caregivers.

...what to do when he/she doesn’t want to go to shower, change clothes, go outside, get off the bed (at 11 o’clock!) ...how can they be “activated”, tips, please!!!

...they are professionals... it would be useful to get more information on "where we are going"...most important areas would be general well being, eating, mobility, exercising, sleeping, bowel movement...

I would like to have information on my own case because every situation is different...

6.2 Relationship with the care home staff

The second research question targeted the relationship between the family caregiver and care home staff. In advance, the analysis of the data revealed three distinct themes; stability within the care of the beloved one, good relationship between family caregivers and care home staff, and communication between family caregivers and care home staff.

Stability within the care of the beloved one

When analyzing the stability theme, some of the family caregivers suggested that the same care home staff should take care of the beloved one during each period spent in the care home. That would enhance a better relationship between the parties and would improve the well-being of the beloved one. However, the stability was not only related to the care home staff, but also to the unit the beloved one usually spends his/her periods.

...would be good to know at least the main nurse that took care of our beloved during the previews period, this could improve the collaboration and relationship...

Nurses change so often, the family caregiver never knows who took care of my beloved during the previews period...

...now, there is only one unit where we bring our mother to, and if there are no free places there, we do not bring our mother to the care home at all.

Good relationship between family caregivers and care home staff

For all of the family caregivers, a good relationship between them and the care home staff was proven to be significant. For most of the family caregivers, the relationship was satisfactory but some of them described it as “distant”. Furthermore, some of them stated that if the relationship between the care home staff and the family caregivers is good, it would ensure the best possible care towards the beloved one. In advance, more respect and flexibility towards family caregiver’s choices related the beloved ones’ care, is desired. The family caregiver wants to take part in the decisions to be made in relation to the care of their beloved one. However, a vast majority of the answers were of a positive opinion. The caregivers’ opinion about the relationship and cooperation with the care home staff was described as good, communicative, professional, trustworthy, conversation is easy, friendly, helpful, and good even though time is a limitation.

...relationship goes well; there is openness and trust a bit distant, official but at the same time warm and understanding...and respectful

...a good personal relationship between nurses and relatives will ensure the best care possible...

...feels like the family’s opinion when choosing the long term place is dismissed and family has no right to have wishes related to...

Communication between family caregivers and care home staff

For some of the family caregivers, the communication was successful, but brief. However, there were family caregivers that considered the communication as being extremely difficult, describing “Akseli ja Elina-koti” staff as being ignorant, monotonous, not cooperative and irresponsible. Also, some confusion was expressed by the family caregivers, when trying to

understand why the care home staff is distant. In order to find a solution, a few family caregivers were ready to give the staff some advice to improve the relationship. The advice centered on the importance of open contact between the staff and the family caregiver, and the importance of proper and professional care on the outcome for the patient.

...the check-in and check-out times are so short, there is not much time left to exchange news...

...a good personal relationship between nurses and relatives will ensure the best care possible...

... they are somehow distant and reserved...is it my fault, because I am a man and we have to talk about "women's matters"?

6.3 Family caregiver's expectations in their relationship with the care home staff

The third research question directed the family caregivers' expectations towards the care home staff and "Akseli ja Elina-koti" as an institution. In advance, when analyzing the data, four themes were identified. Themes such as expectations for the organizational structure of the care, quality of care for the beloved one and care home atmosphere and environment expectations were argued. However, the fourth theme belongs to those satisfied with the care home services and has little or no expectations for the care home.

Expectations for the organizational structure of the care

When analyzing the expectations from the care home organizational point of view, family caregivers' opinions were different. Some of them wished that the same care home staff would care for their beloved ones during the periods spent in the care home; in addition, beloved ones should spend the care home periods in the same unit. That would enhance a better relationship within the

family member, elderly suffering from dementia and care home staff triangle. Furthermore, they suggested that the physician taking care of the beloved ones in the care home, should take care of them when living at home. The advantage would be that the care home physician would know the “patient” better than the Health care center physician. Also, some other family caregivers were wondering if the lack of personnel is the affecting factor in the failing organizational structure within the care home.

...would be wonderful if the “family member” could use the same unit every time and same nurses would take care of him....nurses would remember their “patient”...

...it would be good if the doctor taking care of the patient in the care home, would assist him while he is living at home too...pointless to use the Health care center doctor...he doesn't know the patient that well...

Is there sufficient personnel? ...the question crosses my mind every time I hear about the shortage of personnel...

Quality of care for the beloved one

Most of the family caregivers expected more quality care from the care home staff. Some of them were expecting that the care home staff would give them a more personalized, detailed care report when checking out from the care home. Furthermore, they suggested that more detailed discussions about the beloved one`s health condition would be helpful. For example, guidance material to take home, describing the care of the beloved one. However, some of the family caregivers considered that receiving also positive information when receiving feedback about the beloved one is significant to providing good quality care.

The care home staff`s training on dementia rehabilitation must be up-to-date, for a better understanding of the care that should be constructed in order to support the beloved ones and the family caregivers.

...would be nice to have a wider report on how it is going, wellbeing, and all the information related to this disease...

...I usually get negative information, it would be nice sometimes to get some positive information, it would make me feel better...

...has to be in a place where personnel gotten enough training in how to rehabilitate dementia patients.

Care home atmosphere and environment

Another important aspect resulting from the data analysis was related to the care home environment. Their expectations were for a more home-like environment that will promote rehabilitation, home-like patient rooms which are unlike the hospital setting.

...Room is not home-like, rather looks like a hospital room!...how to get him a bit of happiness?

...own room where to bring some personal things from home...a place where he can sleep at night, without being disturbed by the roommate that keeps noise the whole night...

Furthermore, almost all family caregivers considered the beloved ones physical activity and other relaxing activities in the care home very important. However, some of them stated the existence of some activities but suggested that more activities would keep the beloved ones' general health in better condition for example, reading materials, music and exercises.

*...once, I have noticed my granny has had her manicure done
...very nice...*

...I would like to see more activities such as reading books, newspapers, music!!, exercise...I got the information that he has spent the whole week in his room, he did not want to socialize...

Little or no expectations for the care home

The answers of the family caregivers with no expectations are to be considered and discussed. Some of the motivations were related to the good flow of information, the sufficient time spent with care home personnel and communication. However, some of the family caregivers' answers were short, with no explanations on why they have no expectations.

...Current practice is enough for me; I discuss with the nurses almost every day and at the end of the period, I get the report...

...no expectations...

6.4 Mind map

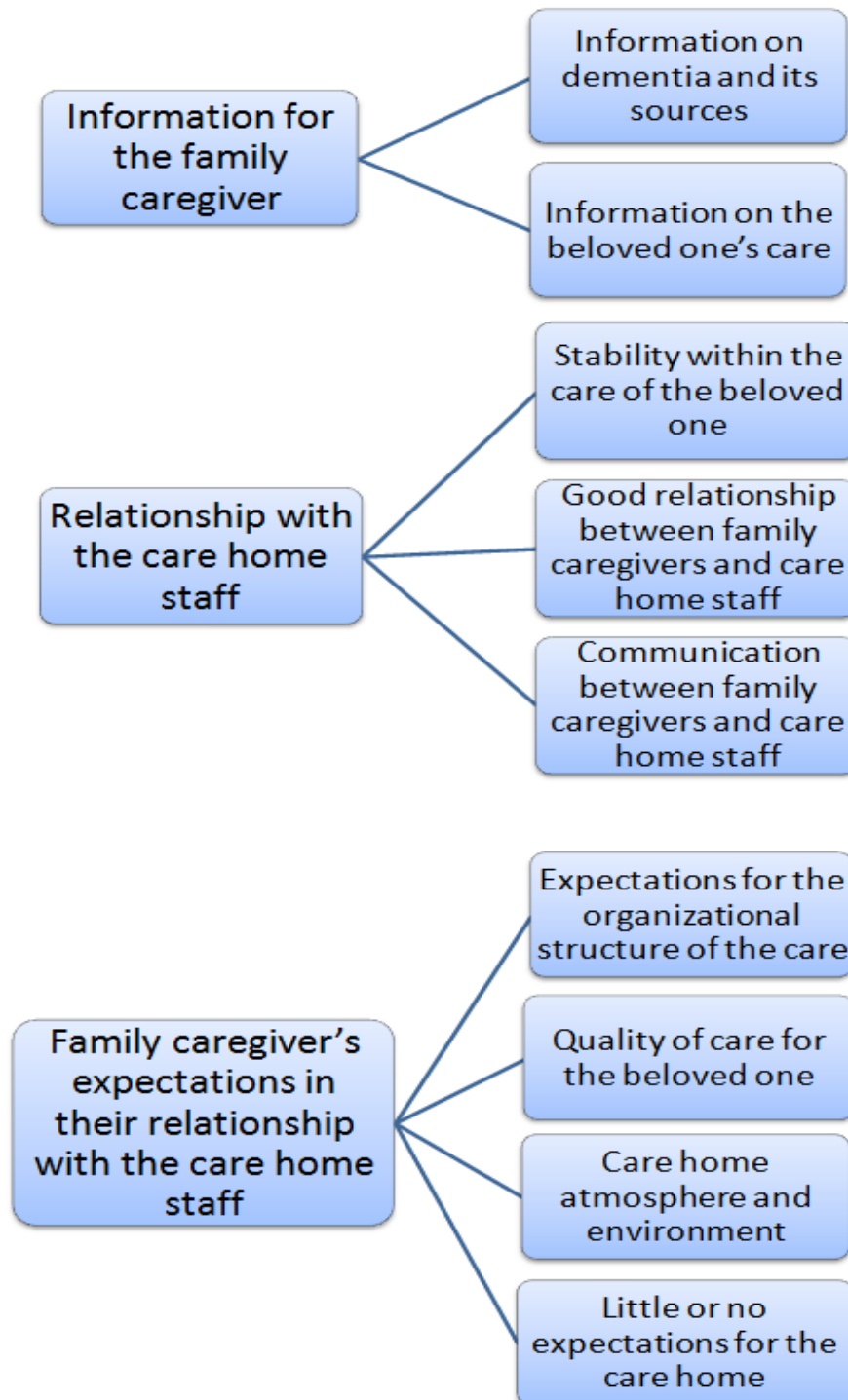


FIGURE 4. Merged mind map

7 DISCUSSION

The purpose of this study was to determine the family caregiver's need for information about dementia, specifically concerning their beloved ones in the care of "Akseli ja Elina-koti" care home. The research aimed at helping the family caregivers to understand the effects of dementia on their beloved ones. The results of the research were directed at facilitating a good relationship between the family caregivers and the care home staff in order to improve day by day life of the beloved with dementia living in a care home.

Earlier researches have shown that different family caregivers have a different perception when their beloved one becomes affected by dementia. The perception and the need for information about dementia differ from family caregiver to family caregiver. (FCA 2012) In this study, much emphasis was placed on researching the family caregiver's need of information about dementia and their beloved one's care. It was found that some family caregivers felt they had enough information, however, a majority of the respondents stated that they needed more information. Furthermore, "Akseli ja Elina-koti" care home staff was mentioned as the desired source of information when discussing about the beloved one's care. In advance, as sources of information about dementia, experts and professionals were preferred. However, the difference in the specific needs of the family caregivers further proves that individualistic attention must be directed to family caregivers by the care home staff. In conclusion, if "Akseli ja Elina-koti" care home staff were to offer more detailed information to the family caregivers, this would have a beneficial outcome for their cooperation.

According to Woods et al. (2007, 50), one of the most important aspects for the family caregiver having a member in the care home was their relationship with the care home staff. In this study the relationship mentioned above was divided into communication and good relationship between family caregivers and the care home staff. Furthermore, the communication as a mediating factor for the relationship showed a variety of experiences and perceptions. In

advance, throughout these differing experiences and perceptions it was evident that open contact, consistency within the care, and constructive feedback to and from the care home staff would facilitate a good relationship. However some family caregivers who had previous negative experiences about the relationship with the care home staff felt that more respect and flexibility towards the family caregiver would lead to an improved relationship. In the end, if “Akseli ja Elina-koti” care home staff would improve their methods of giving feedback and communication with the family caregivers, the result would be a better relationship.

Nevertheless, the relationship between the care home staff and the family caregivers may positively or negatively influence the well-being of the person suffering from dementia (Woods et al. 2007, 14). This research results indicated that the family caregivers were aware of the effects of a good relationship to the well-being of their beloved one. This gave the family caregiver motivation to participate to the decision making in the care of their beloved one. Overall, if “Akseli ja Elina-koti” care home staff would allow involvement of the family caregiver in the decision making in the care of the beloved one, this would have a positive impact on the well-being of the person suffering from dementia.

In Downs’s book (2008, 213), Brooker (2006, 13) stated that the quality of care provided by the care home staff and the physical environment within the care house were amongst the family caregivers most important expectations. Furthermore, in order to achieve high quality of care, it is significant to provide person centered dementia care. In this study, the need of personalized, detailed care reporting was found to be one of the necessary components of high quality care. Also, more detailed discussions about the beloved one’s well-being were suggested. When taking a closer look at the impact of the care home physical environment on the well-being of the person with dementia, the family caregivers expected that improvements would be made to provide a home-like environment that would promote rehabilitation. Previous studies showed that providing an environment in which the person with dementia experience a “relative well-being” would contribute to a high

quality care (Downs 2008, 213). In conclusion, if “Akseli ja Elina-koti” care home staff would prove more flexibility in decorating the living environment within the care home, the family caregivers would be more satisfied with the quality of care.

When analyzing the data, it became evident that the first question, regarding the experiences of the dementia patient living in a care home had been irrelevant to proving the aim and purpose of this study. This is motivated by the fact that the family caregivers were not able to express on behalf of their beloved one. Also, the questions responding the research question number two were insufficient as number. However, the result was successful because of the thoroughness of the analysis as well as the double analysis of the answers.

As a further recommendation following this study, a leaflet containing specific information for both, the family caregivers and the care home staff, aiming to mediate a better relationship. In addition, changing the method of data collection from questionnaires to recorded interviews may give additional information on the family caregivers’ general opinion. Overall, further research should be made within elderly care homes without limitations to elders suffering from dementia.

8 CREDIBILITY/TRANSFERABILITY

In the article written by Graneheim & Lundman, Polit and Hungler (1999) state that credibility refers to confidence in the collected data and its targeted result. This includes choosing the correct participant group(s), as well as the pretesting of the data collection method. During this study, the lack of time of the researchers and the participants banned the pre-testing of the questionnaires. In advance, in the same article of Graneheim & Lundman, Polit and Hungler (1999) state that trustworthiness is a question of transferability. This indicates the importance of a clear description of the

research context including the specific features of the study group, data collection, and analysis of the collected data. In this study, in order to increase the trustworthiness of the results, the analysis of the data was done by each researcher, individually, and the results were compared and merged. Furthermore this double analysis emphasizes the transferability of the research process to other studies in a similar context.

However, the limitation of this study was the low number of the responses that may have affected the results of the study. A number of twenty questionnaires were sent for completion and only eight responses were received. One of the reasons why the rate of the participant's responses was low could be the lack of time or the summer period when people usually travel more than during other periods of the year.

9 CONCLUSIONS

In conclusion, the results of this study indicate guidelines of how to support the family caregivers with their beloved one living in the care of "Akseli ja Elina-koti".

In order for the family caregivers to be satisfied with the amount and quality of the information provided, "Akseli ja Elina-koti" care home staff is to offer more detailed and personalized information.

As a solution for enabling a supportive relationship between the family caregivers and "Akseli ja Elina-koti" care home staff, improvement should be made in the staffs' methods of communication and providing feedback.

The family caregivers' main expectation for improvement was concerning the quality of care, especially regarding personalized care reports, their involvement in the decision making of the beloved ones care, and the living environment within the care home.

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11 APPENDICES

Appendix 1. Cooperation permission

	JYVÄSKYLÄN AMMATTIKORKEAKOULU <small>JAMK UNIVERSITY OF APPLIED SCIENCES</small>	1(2)
SOPIMUS OPINNÄYTEYHTEISTYÖSTÄ		
Sopijaosapuolet		
Toimeksiantaja	Jyväskylän Kaupunki	
Toimeksiantajan edustaja	Sirikka Karhula	
Toimeksiantajan yhteystiedot (osoite, puhelin, sähköposti)	Vapaudenkatu 28, 40100 Jyväskylä, puh. 014 266 3634, gsm 050 61591	
Jyväskylän ammattikorkeakoulu		
Opinnäytetyötä ohjaava(t) opettaja(t)	Marjo Palovaara, Puistonkatu 35, 40101, Jyväskylä, phone: 0400976746. marjo.palovaara@jamk.fi	
Yhteystiedot (osoite, puhelin, sähköposti)	William Garbrah, Puistonkatu 35, B411, 40101, Jyväskylä, phone: 040 0915305. william.garbrah@jamk.fi	
Opiskelija(t)	Tataru Gabriela Paula	
	Mikkola Annina	
Yhteystiedot (osoite, puhelin, sähköposti)	Säppitie 17, 40530, Jyväskylä, Puh. 040 553 4868, paula.tataru.snp@jamk.fi	
	Valajankatu 9A4, 40600, Jyväskylä, Puh. 044 252 2005, annina.mikkola.snp@jamk.fi	
Opinnäytetyön aihe		
	Opiskelija laatii opinnäytetyön aiheesta	
	Tietopaketti muistisairaiden asiakkaiden omaisille	
T&K		
	Opinnäytetyö täyttää opetus- ja kulttuuriministeriön 1.2.2011 antaman ohjeen mukaisesti tutkimus- ja kehitystyön ominaisuudet	
	KYLLÄ	<input checked="" type="checkbox"/> opinnäytetyö on %:sti tutkimus- ja kehitystyötä.
	EI TÄYTÄ	<input type="checkbox"/>
Ohjaus		
	Ammattikorkeakoulu vastaa opinnäytetyön ohjauksesta. Ammattikorkeakoulu ja opettaja eivät ole konsulttivastuussa työstä.	
Dokumentointi		
	Työstä laaditaan Jyväskylän ammattikorkeakoulun opinnäyteohjeen mukainen kirjallinen esitys joka luovutetaan toimeksiantajalle ja ammattikorkeakoulun kirjastoon julkaistavaksi.	
Oikeudet		
	Opinnäytetyön tekijänoikeudet kuuluvat Opiskelijalle. Toimeksiantaja saa rinnakkaisen käyttöoikeuden teokseen sen valmistuttua. Muut mahdolliset teollisoikeudet ja tekijänoikeudet ovat toimeksiantajan omaisuutta.	
Keksinnöt		
	Jos opinnäytetyön tekijä on osallisena keksintöön, joka patentoidaan, mainitaan hänet yhtenä keksijöistä. Mahdollisesta keksintökorvauksesta sovitaan erikseen noudattaen Jyväskylän ammattikorkeakoulun keksintöohjeen linjauksia.	
Työsuhte		
	Mahdollisesta työsuhteesta tai työstä maksettavasta palkkiosta toimeksiantaja ja opinnäytetyön tekijä sopivat erikseen. Opinnäytetyötä tekevät opiskelijat ovat Jyväskylän ammattikorkeakoulun tapaturmavakuutuksen piirissä, mikäli heillä ei ole työsuhdetta opinnäytetyön toimeksiantajaan.	



Opinnäytetyön julkisuus

Jyväskylän ammattikorkeakoulu noudattaa opetusministeriön suositusta, ettei opinnäytetöihin sisällytetä salassa pidettävää aineistoa ja että opinnäytteet ovat julkisia heti, kun ne on hyväksytty. Arvioitavaan opinnäytetyöhön ei sisällytetä toimeksiantajan liike- tai ammattisalaisuuksia, vaan ne jätetään työn taustaineistoon.

Luottamukselliset tiedot

Toimeksiantaja sitoutuu ohjauksellaan myötävaikuttamaan siihen, että opinnäytetyöhön ei sisällytetä luottamuksellista aineistoa. Toimeksiantajan nimeämälle edustajalle varataan mahdollisuus tutustua opinnäytetyöhön viimeistään kaksikymmentä (20) päivää ennen aiottua tarkastukseen luovuttamista. Toimeksiantajalla on oikeus vaatia muokkauksia opinnäytetyöhön, mikäli julkaiseminen vaarantaa mahdollista Toimeksiantajan patentin hakua tai muuta immateriaalioikeudellista suojaamista tai sisältää Toimeksiantajan luottamuksellisia tietoja. Kieltävä päätös tulee perustella. Opiskelijalla on oikeus saada aineisto, jonka sisällyttämiseen opinnäytetyöhön Toimeksiantaja on antanut kielteisen päätöksen, muokattavaksi yhteistyössä Toimeksiantajan kanssa ja opinnäytetyö jätettäväksi tarkastukseen sen jälkeen kun Toimeksiantajan etuja haittaavat kohdat on poistettu. Mikäli Toimeksiantaja ei edellä mainittuna määräaikaana vaadi muutoksia opinnäytetyöhön, on opiskelijalla oikeus jättää opinnäytetyö sellaisenaan tarkistukseen.

Opinnäytetyön esitys

Opinnäytetyön esitys on aina julkinen. Työn teettäjä ja tekijä määrittävät yhdessä esityksen sisällön siten, että esitys ei loukkaa salassapitosopimusta.

Salassapito

Ohjaava opettaja ja opinnäytetyön tekijä ovat velvolliset pitämään luottamuksellisia ja salassa kaikki toimeksiantajan liike- ja ammattisalaisuudet. Mikäli toimeksiantaja sitä vaatii, tehdään opinnäytetyötä koskeva erillinen salassapitosopimus.

Vastuut

Sopijaosapuolet ovat vastuussa toisilleen sopimusrikkomuksen aiheuttamista vahingoista. Vastuun ulkopuolelle on rajattu välilliset vahingot. Vastuun syntyminen edellyttää tahallaan tai törkeällä huolimattomuudella aiheutettua sopimusrikkomusta.

Tätä sopimusta on laadittu kolme (3) samasanaista kappaletta, yksi (1) kullekin sopimuksen osapuolelle. Sopimus astuu voimaan allekirjoitushetkellä.

Julkaisu

Opinnäytetyön ja sen tiivistelmän saa julkaista myös elektronisesti.

Kyllä Ei

Toimeksiantaja pidättää oikeuden päättää elektronisesta julkaisemisesta myöhemmin

Allekirjoitukset

Paikka ja aika _____

Toimeksiantajan edustaja

Opinnäytetyön tekijä

Opinnäytetyön tekijä

Ohjaava opettaja

Ohjaava opettaja

Appendix 2. Questionnaire

KYSELYLOMAKE

1. Okaa hyvä ja vastatkaa alla oleviin kysymyksiin asteikolla 1-5 mikä vastaa mielipidettänne ja tuntemuksianne omaisenne asumisesta Akseli ja Elina-kodissa.

Mielestäni omaiseni Akseli ja Elina-kodissa...	Vahvasti eri mieltä	1	2	3	4	5	Vahvasti samaa mieltä
tuntee olonsa turvalliseksi							
tuntee olonsa kotoisaksi							
tuntee yhteyden menneisyyden ja nykyisyyden välillä							
tuntee itsensä tärkeäksi							
tuntee onnistuneensa ja menneensä eteenpäin elämässään							

Kirjoittakaa vapaasti tähän mitä edellä mainittu taulukko tuo mieleenne

- Saatteko mielestänne riittävästi tietoa omaisenne hyvinvointiin liittyvistä asioista? Jos ette, millaista tietoa haluaisitte lisää?
- Saatteko mielestänne riittävästi tietoa omaisenne terveyteen liittyvistä asioista? Jos ette, millaista tietoa haluaisitte lisää?
- Onko teillä mielestänne riittävästi tietoa dementiaasta? Millaista tietoa haluaisitte saada Akseli ja Elina-kodin henkilökunnalta?
- Miten kuvailisitte Akseli ja Elina-kodin henkilökunnan ja teidän välistä yhteistyötä ja suhdetta?
- Onko teillä joitain tiettyjä odotuksia tai toivomuksia teidän ja hoitohenkilökunnan väliseen yhteistyöhön ja suhteeseen liittyen? Kuvailkaa mahdollisimman kattavasti.
- Millä keinoin kehittäisitte omaisten ja Akseli ja Elina kodin henkilökunnan välistä yhteistyötä (tiedonanto, yhteistyösuhde, materiaali jne.)?
- Tähän voitte kertoa ja kirjoittaa muuta palautetta koko tutkimusprosessiin tai omaisenne hoitoon ja vointiin liittyen.

Kiitoksia yhteistyöstänne, vastauksienne avulla pystymme kehittämään Akseli ja Elina kodin asukkaiden, heidän omaisten ja henkilökunnan välistä yhteistyötä.

Appendix 3. Letter of consent

Arvoisa omainen:

Teemme opinnäytetyötä parityönä Jyväskylän Ammattikorkeakoulun sairaanhoitajakoulutuksessa. Pyydämme teitä osallistumaan opinnäytetyömme tekemiseen vastaamalla kysymyksiin, jotka ovat seuraavalla sivulla. Vastauksenne ja mielipiteenne käsitellään anonyymisti vain meidän tutkimustamme ja opinnäytetyötämme varten. Kaikki vastauksenne hävitetään tulosten analysoinnin jälkeen. Tätä opinnäytetyötä ja tutkimusta tehdään yhteistyössä Akseli ja Elina-kodin kanssa. Tarkoituksena on saada tuloksistamme tehtyä tukimateriaalia niin hoidettavan omaisille kuin hoitohenkilökunnalle. Tukimateriaalin tarkoitus on auttaa täydentävästi yhteistyössä tehtävää hoitotyötä mm. siten, että omaisten ja hoitohenkilökunnan välille syntyy vahva yhteys ja ymmärrys. Voitte vapaasti kieltäytyä tai keskeyttää tutkimukseen osallistumisenne. Voitte myös esittää kysymyksiä opinnäytetyön tekijöille missä vaiheessa tahansa.

Kiitokset tutkimukseen osallistumisesta

Yhteyshenkilöt,

Annina Mikkola, sairaanhoitajaopiskelija

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0442522005

Paula Tataru, sairaanhoitajaopiskelija

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20.06.2012

Jyväskylä