

# Social Support Promoting Coping for Caregivers Caring of People with Alzheimer's disease

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| <p>Abstract</p> <p>The purpose of this thesis was to study the different forms of social support for caregivers who care for a next of kin suffering from Alzheimer's disease. The thesis focused on how these social support forms affect the coping of the caregiver. The thesis was conducted as a literature review by collecting relevant information and by analyzing and synthesizing the collected information and research results. The data was collected from the CINAHL database and Medic database as well as Linda and EBSCO Academic Search Elite databases with the inclusion of the publication years of 2000-2013, and eight studies were chosen for this review based on the relevance on the research question presented in this thesis.</p> <p>The theory part of the thesis has information on Alzheimer's disease; what kinds of symptoms it causes, how these symptoms and behavioral changes affect the coping of the caregiver and what possible threats are being placed on the coping of the caregiver. The theory part also has a review on the concepts of "social support" and "caregiver". It deals with the meaning of these concepts mean and discusses the kinds of social support forms that are available in Finland as, for example, municipal services.</p> <p>According to the literature review, the studies conducted in this field of research are often controversial and inconclusive. This would prevent the making of universal conclusions on which social support forms are the most effective. Nevertheless, there were similarities in the results: for example, interventions and group meetings seemed to be concluded to be beneficial in supporting the coping of a caregiver. The studies also raised the issue that caregivers often find it important that they are provided with up-dated information about the social support forms there are available, information about the illness itself and peer support.</p> |   |  |
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| <p>Tiivistelmä</p> <p>Opinnäytteen tarkoitus on tutkia erilaisia sosiaalisen tukemisen muotoja, joita Alzheimer potilaan omaishoitajalle on tarjolla, sekä näiden tukemismuotojen vaikutusta omaishoitajan jaksamiseen. Opinnäytetyö on toteutettu kirjallisuuskatsauksen muodossa, kooten aiheeseen liittyvää tietoa ja tehden siihen, sekä aikaisempiin tutkimustuloksiin pohjautuen analyysia ja synteesiä. Aineisto on koottu CINAHL, Medic database, Linda ja EBSCO Academic Search Elite tietokannoista 2000-2013 julkaisuvuosilta. Yhteensä kahdeksan tutkimusta on otettu kirjallisuuskatsaukseen mukaan perustuen tutkitun aiheen oleellisuuteen liittyen tässä opinnäytteessä esitettyyn tutkimuskysymykseen.</p> <p>Opinnäytetyön teoriaosuus käsittelee Alzheimerin tautia ja sen aiheuttamien oireiden vaikutusta potilaan käyttöön ja näin ollen käytöksen vaikutusta omaishoitajan jaksamiseen ja millaiset asiat luovat mahdollisia uhkia koskien omaishoitajan jaksamista. Teoriaosuudessa myös tarkastellaan käsitteitä "sosiaalinen tuki", sekä "omaishoitaja"; mitä näillä konsepteilla tässä opinnäytteessä tarkoitetaan ja millaisia tukemismuotoja Suomessa on tarjolla esimerkiksi kunnallisina palveluina.</p> <p>Kirjallisuuskatsauksessa selvisi, että usein tällä saralla saadut tutkimustulokset ovat keskenään ristiriitaisia, sekä epä johdonmukaisia ja tämän vuoksi ei ole mahdollista tehdä yleispäteviä johtopäätöksiä koskien sitä, mikä tukemismuodoista on havaittu tehokkaimmaksi. Kuitenkin samankaltaisuuksia tuloksissa on ja esimerkiksi interventiot ja ryhmätapaamiset ovat havaittu olevan omaishoitajia hyödyntäviä sosiaalisen tukemisen keinoja. Tutkimuksissa myös nousi esiin, että omaishoitajille on usein tärkeää saada tietoa koskien saatavilla olevia palveluita, sekä tietoa koskien itse sairautta, sekä vertaistukea.</p> |                                |  |
| Avainsanat (asiasanat)  |                                |  |
| Sosiaalinen tuki, omaishoitaja, Alzheimerin tauti   |                                |  |

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# 1 INTRODUCTION

The need for health and elderly care services is on the rise due to the aging of the population in Finland (Hjerppe, Kangasharju & Vuorento 2003, 11).

Approximately one million Finnish citizens' care for a next of kin and 300 000 of them offer their help daily. Out of this number approximately 30 000 people are officially considered to be a caregiver by the Finnish law and are eligible for the financial services provided by the municipality and the Government of Finland. The daily living of a caregiver is often physically and mentally challenging. Many times the most important social support form for a caregiver is the family and the close related party of the person and often a caregiver needs to cope without the official services provided by the society. It is considered as important by the caregivers that they are provided with current information related to the illness itself and with information on the social services, support- and help forms for which they are warranted. Providing a caregiver with this information may remove unnecessary fears and promote coping at home. (Järnsted, Kaivolainen, Laakso & Salanko-Vuorela 2009 5-7,134)

Alzheimer's disease and dementia do not only affect the memory and the performance of the patient. Often the problems which relatives have to face are caused by the non-cognitive symptoms caused by the disease. The non-cognitive symptoms mean changes in the behavior such as mood swings, aggressiveness and restlessness. These symptoms can be recognized in 90% of demented patients in some stage of the illness and the symptoms lower the quality of life of the caregiver and may reflect as mental health issues of the caregiver. (Erkinjuntti & Huovinen 2001, 177-179)

This study is a literature review on previous studies published in this field of research. The purpose of this study is to investigate the social support which promotes coping available for caregivers whom care for a next of kin suffering from Alzheimer's disease. The aim of this study is to provide knowledge which can be used to improve the services which are provided for the caregivers.

## 2 ALZHEIMER'S DISEASE

### 2.1 Overlook on Alzheimer's disease

The most common illness leading to dementia is Alzheimer's disease with the prevalence of 65-70% of the cases. 20% of the demented patients suffer from vascular dementia. Alzheimer's disease usually affects the elderly population and is caused by the degeneration of the brain matter. The prior symptom of this illness is difficulty in learning and this is followed by problems in functional guidance, difficulties in spoken expression and in characterizing. Later on when the illness progresses the behavioral disorders increase and the coping in the daily activities of living deteriorates. This may lead into a situation in which inpatient care is required. There is no cure for Alzheimer's disease. It is often arduous for the relatives when in the progressed stage of dementia the patient loses his/hers capability to recognize people. (Erkinjuntti & Huovinen 2001, 60-68)

Dementia is a symptom of Alzheimer's disease. Dementia is caused by a progressive illness which damages the brain and which is either permanent or transient. This leads to a premature deterioration of mental performance. Symptoms of dementia include memory problems, difficulty in learning and difficulties in memorizing. (Erkinjuntti et al. 2001, 54-55)

The occurrence of patients diagnosed with moderate to severe dementia in Finland: 65 year old 0,3% 65-74 year old 4% 75-84 year old 11% and people over the age of 85: 35% In Finland patients with memory problems are hospitalized more than in other European countries and the annual cost of treating patients with dementia is 1,7billion Euros. Out of the 1,7billion approximately 70% of the cost is created by inpatient care. Studies have shown that with the right kind of support mechanisms the home care of the patient could be prolonged by approximately a year. Annually this would create the savings of 16 million Euros ([www.suomenmuistiasiantuntijat.fi](http://www.suomenmuistiasiantuntijat.fi)). Supporting the caregiver is a common benefit of the patient him/herself, of the caretaker and of the society. The occurrence of dementia is estimated to be

the same in Finland as in other European countries and in the United States of America. (Dementiamailma, 1999, 30)

## 2.2 Symptoms

Due to the degeneration of the brain matter, Alzheimer's disease causes behavioral problems and problems in the emotional life of the person. Often these problems may occur before the actual memory problem has been diagnosed. When the illness progresses it causes a lack of concentration, restlessness and person may lose the ability of self-control. A person suffering from Alzheimer's may wander outside and start asking a lot of questions. Because Alzheimer's disease decreases the linguistic skills and the skills to understand the person may try to express him/herself physically and may use language not characterized by the persons' normal personality. Also aggressiveness and delusional behavior may occur. (Telaranta 2001, 53-87)

The changes in behavior may give the impression that the patients' entire personality has changed. A person suffering from Alzheimer's disease may have hallucinations, such as fallacies, optical illusions, and sensations. The person may interpret these hallucinations as scary or pleasant depending on the hallucinations and on the person. Sleeping problems are also common in some stage of the illness. Some patients spend most of the time in bed, while on the other hand some lose the need of sleep hence the home caregiver may feel like she/he cannot have a break from the care work. Also when the patient loses the concept of night and day it may burden the caregiver. (Telaranta 2001, 53-87)

## 2.3 Behavioral changes

The behavioral issues and changes are often difficult for the close relatives and for the caregiver to cope with and this places a possible threat on the coping. These behavioral issues may be permanent or short term and can be such as lack of inhibition; changes in sexual behavior, aggression and

restlessness. Often these behavioral changes occur for a reason and may worsen as the illness itself progresses. The cause of these behavioral changes may be related to somatic problems e.g. to the deterioration in hearing or eye sight and the person may be incapable to adequately express emotions. The caregiver should seek help for this sort of problems immediately when they occur in order to prevent them from worsening. The issues can be treated with medication or by providing the caregiver with instructions on how to handle the situation at home. Guiding the patient, supporting patients' participation in daily activities of living, positive reinforcement, giving the person time, touch, humor and other positive ways of handling the person may bring relief into the situation. These behavioral issues can tire the caregiver and in some cases the only possible solution is inpatient care. If inpatient care is required the caregiver should not have a guilty conscience because of it. The caregiver should try to recognize his/hers own feelings and by reflecting on the emotions she/he has it is possible to cope better. It is important to accept the fact that negative feelings are also a normal part of the feelings which the situation arises. The behavioral issues may also evoke a sense of shame and guilt in the caregiver. (Järnsted, et al. 2009, 120-130)

## 2.4 Treatment

Despite the fact that the medical treatments develop constantly a cure for Alzheimer's disease has not been found. Three different kinds of medications are being used in Finland. All three of the medications affect the brain in a similar way by increasing the levels of acetylcholine. (Dementiamailma, 1999. Publication number 1/1999, p.23) Medication is used to treat the symptoms and not to cure the illness itself. The medication cannot repair the damage which has already been taking part in the brain nor can it stop the progress of the illness but with the adequate medical treatment the inpatient care can be postponed by approximately one year and the behavioral problems may be easier to avoid to some extent. The medication may improve the quality of life of the patient and the caregiver. The medication is most commonly used in the



mild to moderate stage of the illness and often when the illness has progressed to the stage in which inpatient care is required the medication is usually quit. (Telaranta 2001, 25-26)

## 3 CAREGIVER

### 3.1 Definition of a caregiver

Person is legally defined as a caregiver after she/he has made an agreement with the municipality in order for him/her to be warranted to the caregiver benefit, approximately 30 000 Finns are warranted with this benefit.

The Finnish caregiver network defines a person as a caregiver if the person takes care of the next of kin who cannot cope with everyday life due to an injury, illness or due to some other need of care. It has been estimated that there are approximately 300 000 people in Finland unofficially caring of the next of kin at home and out of this number approximately 60 000 people would be in inpatient care unless the next of kin would act as a caregiver. (Järnsted et al. 2009,7-12)

### 3.2 Coping of a caregiver

Caregiving places a big challenge not only for the caregiver him/herself but for the entire family. Multiple factors affect the coping of a caregiver, such as responsibility for the daily tasks of living, varying demands and worry for the next of kin. Even though caregiving can be rewarding it can also cause fatigue. A situation may lead into fatigue especially if the situation is such in which the caregiver feels as if she/he has more demands in life than recourses. (Järnsted et al. 2009, 132)

Despite of the fact that the task of a caregiver can often be burdensome with low income and little leisure, most of the caregivers aim to care for their next

of kin at home for the longest possible period of time and avoid the inpatient care. In a study executed by the Tampere University Of Health Sciences in 1999 caregivers of demented patients were interviewed and it was established that the main motive for one's desire to become a caregiver was the sense of responsibility for one's next of kin, the sense of emotional closeness, the lack of other choices, the expectations of the parent and the opprobrium of other close people. Often there is more than one factor affecting the decision to become a caregiver. (Lipponen 2007, 75-78)

Many caregivers get a sense of strength from the feelings related to closeness, affection and love. Joined achievements and memories can often help one to cope. The mental and concrete support offered by the close relatives, friends, officials, volunteers, and by other caregivers often help the family to cope. Many times a caregiver may feel that the knowledge related to the illness is important. Caregivers also may feel that it promotes coping if they are provided with current information on matters related on the treatment, on the forms of support and information on the services and help which they are granted for. Many caregivers feel that it is important that they get recognition and appreciation for the work which they perform as caregivers on day to day bases. This appreciation is usually wished to be from their family and from the healthcare professionals and this positive feedback improves the coping of the caregiver. (Järnsted et al. 2009, 132)

Despite the fact that a caregiver may not rank his/hers own coping as a main priority in life the coping and taking care of one's own well-being is a mutual benefit of the caregiver and of the person who is being cared for. Coping both mentally and physically is the prerequisite for the caregiving. When a caregiver is taking care of him/herself it enables coping at home and hence this allows the person who is being cared for to be able to live at home for the longest time possible. It is important for the caregiver to recognize what recourses she/he has and what are the limitations. The caregiver should reflect on the tasks faced in day-to-day living and possibly make a list of the responsibilities and reflect on which are the tasks that he/she needs the most help with. This helps to perceive the need for help and the caregiver should always remember that asking for help is rather a sign of strength rather than of weakness. (Järnsted, et al. 2009, 132-134)

The caregiver needs to actively seek for help if feeling as if she/he has been left to cope alone; it is not always easy for an outsider to recognize the loneliness. If the person has the stamina to seek new hobbies it can be a good way to have a break from the day-to-day living at home with the cared one and this may prove to be a good way to make new friends and hence ease the loneliness. Home nursing services can provide either a long- or short term help and these visits also enable for the caregiver to use the situation to also express his/her feelings and to be able to talk about the situation to an outsider. Home nurses may prove useful in solving how to ease negative feelings. If the home nursing services do not seem adequate enough then it is good to discuss the possibility of sharing the responsibility of the care with i.e. adult children of the family in a situation in which the spouse is the caregiver. (Lappalainen & Turpeinen 1999, 16-18)

### 3.2.1 Potential risks affecting the coping

If the next of kin has become a caregiver by the expectations placed by other people on him/her, and if the relationship between the caregiver and the cared one has already previously been poor, the risk of stress is great (Lipponen 2007, 78).

When a person's next of kin falls ill it usually happens suddenly and often leads into a crisis. The crisis is often being described as being hard and difficult. Each person experiences the feelings in his/hers own personal way. Also the person who falls ill needs to go through his/hers feelings such as fear and anxiety related to the illness and may take these feelings out on the next of kin. Especially in the case of Alzheimer's disease, due to the fact that it most commonly progresses slowly the person will have a lot of time to ponder around the subject before the illness starts to affect the person's daily activities of living. (Lappalainen et al. 1999, 10)

Often negative feelings may reflect to the patients next of kin's by manifesting itself by demands, suspicions, and as guilt blaming. It is common that the patient and the next of kin try to act in such a manner that other people would

not recognize the symptoms and problems. This may lead to isolation which affects the coping and possibly prevents seeking for help. When a next of kin notices changes in the behavior of the patient prior to the diagnosis, he/she often feels as if it is difficult to get help and to have the required examinations executed. This may be due to the patient him/herself or due to the fact that the healthcare professionals sometimes may dismiss the requests for examinations and investigations. When the examinations have been implemented it may bring a sense of relief when the cause of the changes has been solved but the diagnosis may also be difficult to comprehend. This is because the person needs to face the fact of what is yet to come and the realization of what the family needs to get prepared for. (Lappalainen et al. 1999, 10)

Not only the amount of help which the caregiver needs to provide for the cared one affects the well-being of the caregiver. If the caregiver feels as if she/he needs to perform over the resources which she/he, both financially and mentally has, it may cause problems in the well-being and hence difficulties in coping. It may be difficult to recognize Alzheimer's disease due to the fact that the symptoms appear gradually. This may cause feuds in the family. Family members can often disagree on the diagnosis and on the amount of help which the relative needs. Also determining whether the relative needs outside help can cause arguments within the family. Even if the caregiver would want to continue the caregiving at home, the other close family may demand inpatient care. At its best home caregiving can be performed by the entire family and hence not one individual will feel overly burdened by the responsibilities. (Lipponen 2007, 78-88)

It is not always easy to recognize the fatigue by the caregiver him/herself and the fatigue may manifest itself by sleeping disorders, anxiety, cynicism, by lowering of one's self-esteem and/or by multiple different kinds of physical symptoms. When a person experiences fatigue the positive thoughts can vanish and be taken over by worry. This worry can make the future seem insurmountable and the caregiving may start to seem more of a responsibility and the person may feel as if she/he is running out of recourses. It is important for the coping of the caregiver that she/he is provided with adequate mental support. (Järnsted et al. 2009, 132)

Even though a caregiver is not physically alone it does not mean that he/she would not sense the feelings of loneliness. To some people this feeling may not be an issue but in some people this may lead to depression. At its worse the loneliness may cause constant anxiety which leads to thoughts of self-destruction. When the disease progresses it can cause a situation in which it is no longer possible to communicate with the cared one and hence increasing the sense of loneliness.

If short term care is planned for the cared one, it places a possible threat in which the patient may not be willing to go to the planned treatment place or he/she is not willing to accept care from anyone else other than from the caregiver. Also if the person's capability to function is being deteriorated during hospital care to the extent in which it will take a long period of time before the capability to function is being returned to its prior state. The caregiver may not be able to enjoy the time off due to the constant worry for the cared one. (Lappalainen et al. 1999, 14-19)

It is especially difficult for the caregiver to cope in situations in which the next of kin's personality has changed drastically. These situations can be such in which the person has become aggressive, depressed or the patient acts in a manner which is difficult to handle. The effect of this kind of situations is great on the coping of the caregiver. The best way to seek for help is to turn to a healthcare professional. (Lappalainen et al. 1999, 14-19) Especially people suffering of Alzheimer's may experience these behavioral changes and disorders (Telaranta 2001, 53).

## 4 SOCIAL SUPPORT

### 4.1 Definition of social support

Social support is communication which can take place either verbally or non-verbally between the provider and the recipient of the support. Social support works to reduce uncertainty in a situation and to enhance the person's perceptions on life control. Social support can contain features such as financial, psychological and physiological help. A network and providing information are considered as social support and also tangible help is a form of social support. These different forms of social support have been linked to helping people to cope in difficult situations and hence improving health, both psychological and physiological and the well-being of a person. (Junker & Shutterstock, 2011, 181-190)

### 4.2 Social support services provided by the municipalities In Finland

The financial benefit meant for caregivers is granted by the municipality in order to support and to ensure the home care. The benefit can also include services, which are defined in the care and service plan. This plan is made individually for each person. The benefit is applied from the municipality's service manager. The person who has been granted the caregiver benefit has a right to have three days off each month if she/he is working full time as a caregiver and the caregiving is noticeably binding. ([www.jyvaskyla.fi](http://www.jyvaskyla.fi))

The municipalities social- and health services are obligated to provide services which support the coping at home, such as required renovations at home, medical equipments and aids. The need for these services is evaluated on a home visit from the municipalities social services worker. When the evaluation has been executed a care- and service plan is being drafted together with the patient and the caregiver. The care- and service plan works

as a tool for the municipalities employee and as proof of the services planned for the caregiver and for the patient. The care- and the service plan itself does not work as a guarantee for the services. A decision is made individually for each service stated in the plan. When the support has been granted the municipality makes an agreement with the caregiver. The agreement states the amount of the fee which the municipality grants as a financial aid, the days off which the caregiver is granted to have and the way in which these days off will be organized. Starting from 1.1.2012 the minimum amount of the benefit is 364,35 Euros per month. If the required care is especially burdensome the amount paid is a minimum of 728,69 Euros per month. (Kuntainfo 9/2011)

In Finland the services provided by the municipality are planned in such manner in which each individual when required is granted the usage of these services despite the financial status of the person. The fees are set to enable this. The municipalities service fees vary depending on the service provided. Guidance, services promoting and maintaining performance and social services are free of charge. (Lappalainen et al. 1999, 107-108)

#### 4.3 Care- and service plan

Care- and service plan states multiple factors concerning the care; i.e. the quantity and the quality of the care provided by the caregiver and the services which the patient will require i.e. home nursing services and support services. These may include services such as meal service, bathing service and transportation services. It also needs to be stated in the plan the possible need for short and long term interval care and the need for required aids. The care- and service plan contains a description of the services which the caregiver needs as a support for his/her work. The municipality is required to provide the caregiver with guidance and education and this is achieved by assigning a contact person for the caregiver whom she/he can contact. It is also possible to state in the plan the possible need for services for the caregiver such as possibilities to take part in instructed exercise lessons or in caregiver group meetings. It also needs to be stated how the treatment of the patient is being organized when short-term care is needed. These situations

can be such as when the caregiver is on a holiday or when she/he cannot work as a caregiver due to reasons related to health. (Järnsted et al. 2009, 10-12)

It is recommended that the care- and service plan contains information on the functionality and the safety of the nursing environment, in this case referring to the home. Information on the ability of functioning of the patient and of the possible recourses which the caregiver has and what is the state of health of the caregiver. Common aims and goals of the treatment should be set. The care- and service plan should be updated annually and when the caregiver requires an update. The plan should also be updated when the situation at home has changed. The services stated in the plan should match the services which the caregiver and the patient require. (Järnsted et al. 2009, 10-12)

#### 4.3.1 Assistance services

There are multiple assistance services available in Finland for a person who is being cared for at home. A volunteer worker can e.g. take the patient out for walks and support and assist in hobbies. The volunteer workers help enables the caregiver to have a break of the care work and this may prove to be a big help as it allows the caregiver to have some time on his/her own. One may inquire about these services directly from the organizations providing the service and the home nursing can also provide the customer with information on where to seek for assistance services. (Lappalainen et al. 1999, 96)

#### 4.3.2 Diaconal and volunteer work

Parishes in Finland provide diaconal work. It can provide the people living in the parishes' area with guidance, support and discussion help. If requested the diaconal worker can also come and visit at home. The parishes may organize support groups in which the caregivers can meet and are able to have peer support. Parishes also organize camps and other activities. Next of



kin- and patient organizations offer guidance and education. (Lappalainen et al. 1999, 97-102)

It is important to provide the caregiver with information. Information is vital for the caregiver in order for him/her to be able to understand the behavior of a person with Alzheimer's disease and this may promote coping at home. (Telaranta et al. 2001, 1)

#### 4.3.3 Home- and support services provided by the municipalities

Home service can provide help with nurture and care with short- or long term services. These home services are provided by the municipality but also the private sector provides these services. The support services can include services such as cleaning-, meal-, bathing-, and emergency phone services. Often these services are aimed for people who live alone and need help in day to day living but the caregivers everyday living can be especially burdening and binding, hence in some municipalities they are considered to be in the same category as people living alone are. By providing these services the municipality can significantly support the coping at home. Home nursing is provided by the persons own healthcare centre and can either be regular or occasional. These home nursing visits are also possible during night time, on weekends and on evenings if required. Transportation services may be offered if the person has difficulties in mobility. (Lappalainen et al. 1999, 99-104)

## 5 PURPOSE, AIM AND RESEARCH QUESTIONS

The purpose of this study is to investigate the social support promoting coping available for caregivers whom care for people suffering from Alzheimer's disease. The aim of this study is to provide knowledge which can be utilized to improve the services which are provided for the caregivers.

Research question is: *“What kind of social support promoting coping exist for a caregiver caring of a person suffering from Alzheimer's disease?”*

## 6 CONDUCTING A LITERATURE REVIEW

### 6.1 Principles of a literature review

A literature review requires a precise scientific approach and the conduction of the review needs to be documented in such a manner that it enables the replication of the search process (Metsämuuronen 2003, 16-17). The purpose of a literature review is to answer and to seek for information for the set study question. Studies and information resources which have already been previously conducted are being used whilst conducting a literature review. (Kääriäinen & Lahtinen 2006, 39) In evidence based research i.e. a literature review the researcher needs to analyze the content of the researches and combine the results in order to create a synthesis (Kylmä, Rissanen, Laukkanen, Nikkonen, Juvakka & Isola 2008, 23-24).

### 6.2 Literature search

The data was collected, sorted and analyzed in a structured manner in order for it to provide an overview on the topic. The execution of the study was conducted in the fall of 2012.

Inclusion criteria; scientific research articles only from reliable and recognized publications which answered the set study question. Publication language either Finnish or English. Publication year between 2000-2013. The articles available as full-text and containing the references and abstract. The articles were required to contain information on either Alzheimer's or dementia and on caregivers and social support; the form of social support was not specified.

Exclusion criteria; if the article did not have relevant information and was off topic, had information on too precise situations or small groups of people. The article had information on the social support for the patient and not for the caregiver. The study was conducted on caregivers and not precisely on

caregivers of demented people or of one's suffering from Alzheimer's disease. The study did not have a clear result or a conclusion.

The search for researches and studies was started at the Jyväskylä University of Applied Sciences library website. The NELLI portal was used in order to access the database CINAHL. In CINAHL the search keyword "*support, psychosocial*" was run as the major concept and the search was limited by choosing options of full text and research articles only. The publication year was set in between 2000-2013. The search was also limited by choosing the options that the results must have references and the abstracts available. The search gave all together 533 results. The limitation of results was increased by adding the keyword "*caregivers*". The keyword "*caregiver*" on its own generated 599 results but when combining the two major concepts of "*caregivers*" AND "*support, psychosocial*" 17 results was generated. Out of these 17 studies five was chosen for closer inspection based on the abstract and the headline of the study.

The key word "*Alzheimer's disease*" generated 91 results when applying the same limitations as was applied previously. Combining this search with the keyword "*Caregiver*" 26 studies meeting these limitations was found. Out of these studies six were chosen for closer review.

Combining the keywords of "*Caregiver*", "*Alzheimer's disease*" and "*Support, psychosocial*" gave one result and this study was included in the review.

Key words "*Support, psychosocial*" and "*Alzheimer's disease*" were combined with the result of 2 studies. One was chosen to be read thoroughly.

Due to the reason that the main symptom of Alzheimer's disease is dementia also the searches were run with the keyword "*Dementia*" instead of "*Alzheimer's disease*". "*Dementia*" generated 384 results. When combined with major concept of "*Caregivers*" and "*Support psychosocial*" it gave one result. When combining "*Dementia*" with "*Caregiver*" the result was 66 studies. Out of the 66 studies 15 was chosen to be reviewed.

Out of the searches conducted in CINAHL 29 studies were read through and the most relevant studies were chosen as a part of the literature review. In the process of choosing which studies will be included in this literature review the

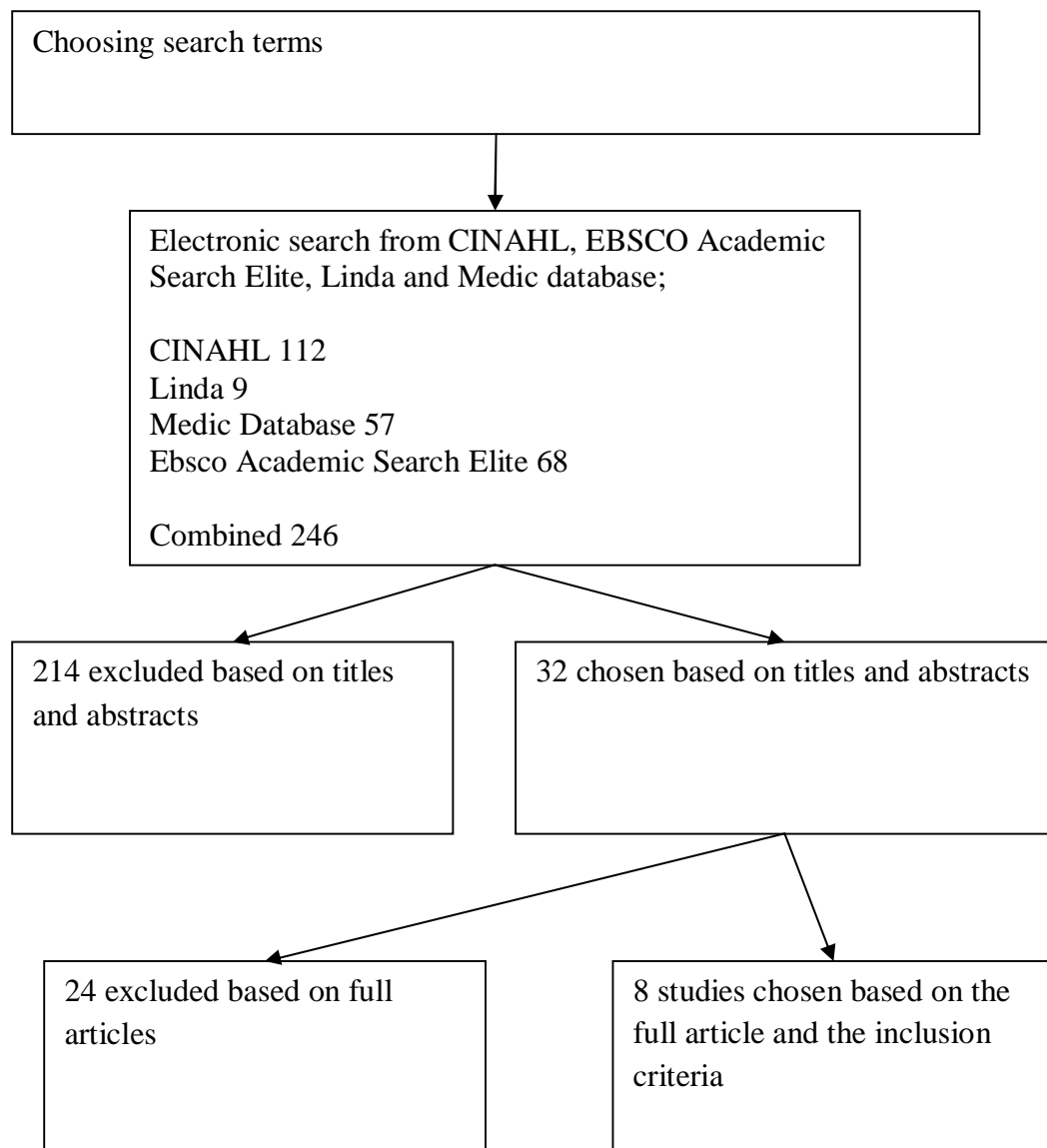
quality and the quantity of relevant information was considered as the main criteria, studies which were not relevant or from a resource which could not be proved as reliable were left out. Six studies which were found by conducting the previously explained search process were chosen to be included in the literature review.

A second search was conducted in order to include Finnish studies into the review. From NELLI portal it was possible to gain access to the Medic database. In the Medic database a simple search was conducted with the keyword "*omaishoit\**" generating 57 results. The results were investigated by reading the headlines and abstracts and one study was chosen.

A third search was conducted in the database "Linda", which is a database to Finnish universities libraries. The search was run with words "*Alzheimer's*" and "*caregivers*" and 9 results were found. Out of the nine results one study was chosen based on the relevance on the subject but was later dismissed as irrelevant to the review.

A fourth search was run in EBSCO Academic search elite. Keywords "*Alzheimer's*", "*Caregivers*" and "*Support*" were run linked to full text and publication year between 2000 and 2013. 68 results were recovered. Out of these one was chosen.

The chosen articles and studies were read and studied and based on the relevance all together eight studies were included in the review.



### 6.3 Data analysis

Content analysis is a method of research, which allows to objectively and systematically analyze documents and studies. The information can be presented in such a manner that the topic being researched can be conceptualized. The aim of a content analysis is to produce concept categories, models, or mind maps. Prior to the analysis it needs to be determinate whether the analysis contains only facts which are being clearly represented or is hidden information also being analyzed. The content

analysis can be divided into two categories; in the inductive method the data is in abstracts, concepts and divisions are being presented. The deductive method bases the analysis of the data on a framework. (Kyngäs & Vanhanen 1999, 3-5) In this study the deductive method was applied.

After the researches and articles were chosen for the review the content was analyzed. The analysis process started by reading the chosen material thoroughly and in this stage the information which was off topic was dismissed as irrelevant and the information and results found relevant and useful for this literature review were highlighted and a description of the studies was executed. After reading the materials chosen it was processed to find out how the information in hand answered the set study question. When the data which gave an answer for the study question was narrowed down to the most relevant information this data was sorted into categories. Each article was analyzed individually and the most relevant information according to the research question was chosen. A chart of the chosen articles was made including the most important result related to this study; see the appendix. The results were divided into five categories of; "peer and emotional support and group meetings", "psychosocial interventions", "homecare, healthcare and public services", "providing information" and "early intervention".

## 7 RESULTS

### 7.1 Peer and emotional support and group meetings

A caregiver may undergo a huge amount of stress whilst caring for a person who is cognitively impaired. E.g. the households in Taiwan with lower incomes and who cared for a patient with more behavioral problems had more depressive symptoms. Also caregivers who are older and cared for a person with a lot of behavioral problems have more depressive symptoms. Caregivers who received more emotional support had less depressive symptoms. When comparing the caregivers of stroke patients and Alzheimer's disease patients

it can be concluded that caregivers of Alzheimer's patients have more depressive symptoms and worse general health. (Huang, Sousa, Perng, Hwang, Tsai, Huang & Yao 2009, 502-511)

The only factor correlating with lesser depressive symptoms and the household incomes was the emotional support which the caregiver received. The caregivers who had lower income but were provided with social support had less depressive symptoms. The studies made in USA and Taiwan have been inconsistent when studying whether social support buffers the effects which stress has on home caregivers health. In the study conducted in Taiwan the social support was defined as informational, emotional and tangible support and help. When compared the amount of social support received by the caretaker the caregivers whom cared for a person with a stroke received much more social support than a caregiver caring of a person with Alzheimer's. (Huang et al, 2009 502-511).

In the study conducted by Huang Y et al. in Taiwan, 2009, it was discovered that caregivers who received emotional support had less depressive symptoms. If the household had lower incomes but was still provided with social support they experienced less depressive symptoms.

In China a bi-weekly support group programme lasting for 12 sessions for caregivers caring of a person with dementia mainly caused by Alzheimer's, was offered. When comparing the impact which the programme had to the social support services which are commonly provided for caregivers it was concluded that distress levels lowered and quality of life improved by these mutual support group meetings. The meetings had educational, supportive and mental healthcare factors included. The participants were provided with information, discussion and psychological support. The amount of social support correlated with the caregiving families' perception on the quality of life. These group sessions also enabled the development of a social support networks when meeting other caregivers in the same life situation. The possibility to discuss and to have peer-support and positive re-enforcement lessened the distress, embarrassment, guilt and discomfort. By achieving these positive results the coping of the caregiver could possibly be promoted. (Wang, Chien & Lee 2012 210-224)

By providing the caregiver with information and a conversation group the caregivers experienced an increase in satisfaction and fewer negative feelings such as sense of strain (Andren & Elmståhl 2008, 98-109). Often spousal caregivers benefit the most of different forms of social support due to the age and emotional aspects (Sussman & Regehr 2009 30-39). Often support groups together with providing information and guidance result in positive outcomes in the coping of the caregiver (Hyvärinen, Saarenheimo, Pitkälä & Tilvis 2003, 119).

In five out of the eight studies reviewed it emerged that a form of group meeting which can contain peer support or an opportunity to discuss positively affects the caregiver and hence promotes the coping by lessening negative feelings. This may improve the quality of life and may promote the coping at home.

## 7.2 Psychosocial interventions

When undergoing a five week program and a three month conversation group as a psychosocial intervention, the caregivers had significantly less feelings of strain and disappointment and these results lasted for minimum of 12 months. The caregivers also experienced increase in satisfaction. These results were achieved by providing the caregiver with information and with an access to a conversation group. (Andren et al. 2008, 98-109)

The best results in the supporting of the coping of a caregiver have been achieved by interventions in which the caregivers situation has been individually evaluated. (Hyvärinen et al. 2003) Two of the studies which were reviewed in this study showed that an intervention is a form of social support which has proved positive outcomes and the positive results can also last for a longer period of time.

Often the results have not been significant when studying the subject of which support form conclude in positive outcomes (Hyvärinen et al. 2003). The strongest evidence in this review has been concluded to be from intervention type of social support.



### 7.3 Homecare, healthcare and public services

The common aim of the society is that as many people as possible could stay at home for the longest possible time. There has been studies executed on the development and on the support which decreases the burden which the caregiver experiences but the results have often been controversial and there has not been enough evidence on the postponement of institutionalization. The home caregiving is demanding and hence the social support services need to be planned well. What has been proved is that a caregiver often experiences stress which affects the mental and psychical well-being of the caregiver. Not enough studies have been made on this field of research on the formal services in Finland in order to make universal conclusions. (Hyvärinen et al. 2003, 119)

When comparing the community-based service usage and the selected social and psychological characteristics of a caregiver it was concluded that if the caregiver had a positive attitude towards the services provided by the society the more services she/he used. The families of demented people used fewer services than of those whom had a next of kin to be cared for with the same functional capability. Neither the behavioral problems of the cared one nor the functionality affected the service usage. (Roelands et al. 2008, 42-53)

It has been widely studied and concluded that caregivers have a big influence on maintaining the person with Alzheimer's disease in the community and the need of care increases whilst the illness progresses. Hence health and human services need to be provided in order to support the caregivers efforts. Interventions which promote the services available seem to be required due to the reason that it has been reported that caregivers of people with dementia tend have a low level of service usage. The health of a caregiver can often be poor and they may experience a great sense of burden and strain. The need for further assistance has been documented. (McCallion, Tosenland & Banks 2004, 441-450) In the study conducted by McCallion et al. it was concluded that 51% of the caregivers who attended the survey estimated that the state of their health limited the ability to provide care and 25% felt as if the caregiving

had a negative effect on their health, also 25% of the caregivers in the study had reported to be physically abused by the person with dementia.

The more positive attitude the caregiver has towards the community based services the more services they use. The families of demented people used fewer services than the families of those whom cared for a next of kin with the same functional capability (Roelands et al. 2008).

In Finland the patients who are being taken care of by their spouse need fewer visits to the doctors than of those who are being taken care of by some other family member, doctors visits were the most used public service used by people with Alzheimer's disease in Eronen's study. Other services which were recorded of being used were visits to the dementia advisor, visits to the emergency polyclinic and treatment in healthcare centre hospital. As a form of financial aid over 1/3 of the interviewed individuals in the study conducted by Eronen were receiving pensioners caregiving allowance. It was concluded that doctors and dementia advisors play a big part in providing the caregiver and the patient with adequate information on the services available and on the illness itself. The information is important due to the reason that it enables the demented person getting adequate care. (Eronen 2010, 20)

Home services often fail to reduce the sense of burden which caregivers of demented patients experience and caregivers often experience stress related to the public services. Adult day programs have been concluded to be the most effective form of help. Often spousal caregivers benefit more from different forms of social support due to age and emotional aspects. The more stress the caregiver experiences due to the service system the more distress the caregiver has. The behavioral issues of the cared one place a burden on the caregiver. The cut-backs in healthcare services influence the caregiver by creating feelings of depression and anxiety. Early intervention is vital. The more the cared one attends day programs the less stress does the next of kin caring experiences. By supporting the patient and the caregiver institutional care can ultimately be avoided. (Sussman et al. 2009 30-39)

## 7.4 Providing information

In the study conducted by McCallion et al. 2006, it emerged that by providing the caregivers with adequate information the usage of human services amongst the caregivers increased but the usage of health services did not. Eronen, 2010 concluded that if doctors and other health care professionals, such as dementia advisors, play a big part in providing the patient and the caregiver with adequate information on the services available it would enable the person to get into care and have easier access to the public health services.

Providing information was also a part of the study where the influence of an intervention was studied and this study had a result that together with providing information and group meetings the satisfaction can be increased and negative feelings such as disappointment can be lessened. (Andre S, et al, 2008) If the awareness of these services is increased this may lead to positive attitudes and enable the usage of appropriate and adequate services and hence postpone institution care. The more help is being received the less burden the behavioral problems place on the caregiver. (Roelands et al. 2008, 42-53)

Positive outcomes have been achieved when combining support groups with providing the caregiver with guidance and information. (Hyvärinen et al. 2003)

Five studies out of the eight reviewed stressed the fact that providing the caregiver with guidance and information together with other forms of support is one of the most effective ways of offering social support. Providing the caregiver with information has a proven positive impact on the caregiver.

## 7.5 Early intervention

The society often fails to help the caregiver in time and the help may be provided when the situation has met its crisis point. The help is not always distributed equally and at times it is difficult for the caregiver to accept the services provided. (Hyvärinen et al. 2003, 119) It may be difficult for a person

to accept the social support available in the later stage of dementia the services should be offered in an early stage of the illness and hence this will have a positive effect on the caregiver. (Andre et al. 2008) Early intervention has been concluded to be vital and by providing the patient and the caregiver with support the institutional care can ultimately be avoided (Sussman et al. 2009).

The studies conducted in Finland have been inconclusive and inconsistent and it cannot be proved whether it is possible to postpone the institutional care by early intervention (Hyvärinen et al. 2003). Caregivers of demented patients can be less active when it comes to seeking help (MaCallion et al. 2004).

## 8 DISCUSSION

### 8.1. Reliability of the study and ethical issues

There needs to be an adequate and comprehensive sample of researches in order for the review to be reliable (Kääriäinen et al. 2006, 39). Mistakes may occur in any stage whilst conducting a literature review, it is a time consuming and demanding method of research. The validity is possible to be determined by focusing on whether the data being collected answers the research question, how representative the data is and how the data has been collected. By having multiple researchers whom evaluate the original research materials quality it would increase the validity of the review. (Nieminen 1997, 215-216)

The aim of the review was to get a description on the subject being studied; in this case of social support promoting coping for caregivers caring of next of kin diagnosed with Alzheimer's disease. The studies executed in eastern countries may be culture related and hence the study results cannot be directly applied to western countries, nevertheless some universal conclusions can be made between social support and the well-being of the caregiver due to the reason that similar results have been achieved in western countries. Because the term "caregiver" may have different meanings in different studies

it may also have an effect on the conclusions, in some research the term “caregiver” means only the spouse and in some studies it may also mean some other family member/close family nevertheless the term “caregiver” does refer to a person who is at home caring for a next of kin. Also the severity of the symptoms may vary in different stages of the illness and often the progress of the disease is very individual, this may also have some affect on the results. The take of eight studies does not give result which could be generalized but it gives an overlook on the topic. Also the broad meaning of the concept social support affects the results. Having only one person conducting this study also affects the reliability in a negative way. The results of this analysis can be considered as directional and may prove to be a good tool to assess the need for further studies.

Whilst conducting a literature review the researcher needs to meet the ethical requirements set. These requirements are such as precision, honesty and the execution needs to be conducted with care starting from the beginning until the end of the review. The review cannot mislead nor can the research results be distorted. (Hirsijärvi, Remes & Sajavaara 2000, 27-29)

The studies reviewed in this study have been searched from reliable databases. The publications in which the articles and researches have been published in are being recognized and can be considered trustworthy. The results have not been modified nor have they been presented in a form in which they could be misleading. The author of this study has practiced self-evaluation throughout the research process and has conducted the study in an honest and precise manner.

## 8.2 Conclusions

It is important to find a way to reach the caregivers and also the individuals who normally would not be actively seeking for help and provide them with information (McCallion et al. 2004, 441-450). At times the social support available is not being used due to the fact that healthcare professionals fail to provide the adequate information (Eronen J 2010, 20). Home caregivers of

demented people need to be provided with information on the services which they are granted for in order to create positive attitudes and hence promote coping at home (Roelands et al. 2008, 42-53). If the knowledge of the services available is promoted it may be easier for the caregiver to seek for further assistance and hence lower the bridge to accept help.

During e.g. nursing interventions it could be possible to give guidance and hence possibly promote the caregiver to seek for further assistance and help both from human- and health services. The healthcare professionals should pay attention on providing the customer with information. On regular visits it should also be noted whether the patient is acting as a caregiver.

Emotional support is important for the caregiver, by preventing the depressive symptoms the coping of the caregiver can be promoted and this can be achieved by providing the caregiver with emotional support. Due to the effects that Alzheimer's has on a patient, especially the behavioral problems, it is often very burdensome for the caregiver to cope at home and it can have negative effects on the caregivers health. (Huang et. al 2009, 502-511)

This could possibly be avoided by providing the caregiver with knowledge, training and recourses by nurses, other family members or other healthcare professionals.

As a form of social support group meetings have been discovered to be beneficial and hence these meetings may promote the coping by lowering the sense of distress in the caregiver (Wang et. al, 2012 210-224). Andre et al 2008, concluded that that conversation groups and information re-enforces positive feelings in caregivers of demented people. The most evidence has emerged from the benefits of an intervention and from the effectiveness of providing the caregivers with information. (Hyvärinen et al. 2003) Caregivers should have access to similar sessions in which they are able to have peer support and hence lower the sense of emotional burden.

The ongoing savings made from social support services may cause more stress in caregivers. Social services provided do not always promote the coping of the caretaker. Not only can the tangible help be considered to ease the strain on the caregiver. (Sussman et al. 2009 30-39) The outcomes of the

services ought to be studied more hence if the support is targeted in an adequate way the caregiving period at home can be prolonged. The services should be planned in such manner that it does not influence the caregiver in a negative way. If the social services promoting coping of the caregiver will be researched more it could be possible to find the most affective services and by targeting these services right it can have a positive impact on the caretaker, the patient and on the strain on the public healthcare services. A healthcare professional cannot dismiss the fact that the emotional support which the caregiver receives also often may influence on the well-being of the caregiver and hence providing discussion help and emotional support could easily be applied within the care work i.e. be provided by the home nursing services.

The best results were achieved when the intervention was made in the early stage of dementia. The social support should be offered for the family caregiver in an early stage in order to prevent problems in coping. (Andren et al. 2008, 98-109) Also Hyvärinen et. al concluded that the help often is offered when the situation has met its crisis point.

These support forms should be practiced and developed more. Interventions could be executed for example by the home nursing services together with multi-professional team which could have representatives from services such as social services, healthcare services, psychological assistance and from the provider of the tangible help and hence the caregivers situation could be individually be evaluated. Hence the caregiver could be provided with adequate assistance and services and this could possibly prolong the time which the person with Alzheimer's disease could spend at home. This intervention should be executed in an early stage of the illness before the situation has met its crisis point. At the same time the healthcare professionals should be actively providing the person with information on each contact which the caregiver has to the healthcare system and promote the services available. Also the possibilities for group meetings and peer support meetings should be promoted and the caregiver should be granted the possibility to be able to participate in such meetings

Even though it has not been conclusively proved that it is possible to postpone the inpatient care or for it to be avoided (Hyvärinen et al. 2003) the social

support has been proved to improve the quality of life of the caregiver (Wang et al. 2012) and hence the different forms of social support should be applied to care work.

By offering the right services and in an early stage of the illness the burdening of the caregiver may possibly be avoided. Not only the tangible services avoid the fatigue of the caregiver but also the emotional and psychological services together with peer support. By providing this emotional and tangible social support the negative feelings and fatigue may be avoided and the institutionalized care can possibly be postponed. When providing the home caregivers with adequate information on the illness and on the services available it can lessen the negative feelings related to the care. This information may include information on the services available or information on the illness itself and of the symptoms which Alzheimer's creates. The issues concerning the coping of the caregiver have been widely reported in studies in many countries around the world. The results on affective support systems have often been inconsistent and hence no universal conclusions can be made, nevertheless some similarities can be seen in some of the studies and it can be concluded that when providing the caregiver with the right kind of social support it promotes the physical and mental well-being of the caretaker.

Coping and well-being of caregivers can be promoted by targeting adequate services in an early stage of Alzheimer's disease and hence this may possibly postpone the need for institution care. Depending on the study multiple different forms of social support have been concluded to promote the well-being of the caregiver, such support forms are i.e. the information provided, interventions, peer support, tangible support, support provided by the social- and health services and support provided by the family. Due to the aging of the population in many western countries and the high expectancy of living this field of research should be investigated more. It may prove to be a good topic for further studies and hence lead to better services and forms of social support. Not only is it important to improve the quality of life of the caregiver but the well-being of the caregiver may also positively reflect on the person suffering from Alzheimer's disease.



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| <p>10 APPENDIX</p> <p>List of the articles included in the review</p>  |  |   |   |
|--|--|---|---|
| Title, Authors   | Purpose/aim  | Study methods   | Results/findings  |
| <p><i>“An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China”</i> 2012<br/>         Authors: Li-Qun Wang, Wai-Tong Chien and Isalebba YM Lee.</p> | <p>Investigate the effectiveness of a bi-weekly support group program lasting for 12 sessions for caregivers caring of a person with dementia.</p> | <p>An experimental study including a pre-test and a post-test. Researched by a questionnaire and by collecting demographic data.<br/>         N=78, 39 in experimental and 39 in control group.</p> | <p>Distress levels lowered and quality of life improved by mutual support group meetings. The meetings had educational, supportive and community mental health care factors included by providing the participants with information and discussion and psychological support. The amount of social support correlates with the care giving families perception of quality of life. The possibility to discuss and have peer-support and positive re-enforcement lessened the distress, embarrassment, guilt and discomfort.</p> |
| <p><i>“Lievää Alzheimerin tautia sairastavien henkilöiden ja heidän omaishoitajensa sosiaali- ja terveyspalveluiden käyttö ja siihen yhteydessä olevat tekijät”</i> 2010<br/>         Author: Johanna Eronen</p>                     | <p>Factors influencing the usage of the social and health services required by the caregiver and by the patient him/herself.</p>                   | <p>Structured questionnaire was conducted by an interview.<br/>         N=241 of which a total of 170 were spousal caregivers and 71 other family caregivers.</p>                                   | <p>Patients whom were being taken care of by their spouse needed less visits to the doctors than of those whom were taken care of some other family caregiver. This was the most used service used and other services which were recorded of being used were visits to the dementia advisor, visits to the emergency polyclinic and treatment in a health care centre hospital.<br/>         Doctors and dementia advisors play a</p>   |

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|   |  |   | big part in providing the caregiver and the patient with adequate information on the services available and on the illness itself.   |
| <p><i>"Perspectives of patients and family carers; Stressors, social support, depressive symptoms and general health status of Taiwanese caregivers of persons with stroke or Alzheimer's disease"</i> 2009</p> <p>Authors: Chiung-Yu Huang, Valmi D Sousa, Shao-Jen Perng, Mei-Yi Hwang, Chun-Ching Tsai, Mei-Huang Huang and Shu-Yin Yao.</p> | How social support, stressors, depressive symptoms and the general health status relate to caregivers whom care for the next of kin suffering of Alzheimer's or has had a stroke.  | Descriptive, cross-sectional and correlational design examining the relationships. Conducted by two different sorts of questionnaires. N=92 | Households with lower incomes caring for a patient with more behavioral problems had more depressive symptoms. Also caregivers whom were older and cared for a person with a lot of behavioral problems had more depressive symptoms. The study concluded that if the caregivers had more emotional support had less depressive symptoms occurred. When the study compared the caregivers of stroke patients and Alzheimer's disease patients it was concluded that caregivers of Alzheimer's patients had more depressive symptoms and worse general health. Only factor correlating with lesser depressive symptoms and the household incomes was the emotional support which the caregiver received the caregivers who had lower income but were provided with social support had less depressive symptoms. |
| <p><i>"The Influence of Community-Based Services on the Burden of Spouses Caring for Their Partners with Dementia"</i> 2009</p> <p>Authors: Tamara Sussman and Cheryl Regehr.</p>   | Community services effect on the spousal caregivers, whom care for a next of kin suffering of Alzheimer's, stress process and how tangible and emotional support effects the caregiver when the support has been provided by family, friends and formal service. | Study conducted by a survey in Canada. N=85   | Home services often fail to reduce the burden which caregivers of demented patients experience and that the caregivers often experience stress related to the services. Adult day programs were concluded to be the most effective form of help. The more  |

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|  |  |  | stress the caregiver was experiencing due to the service system the more distress the caregiver had. The reducing of health care services provided influences the caregivers experiences of depression and anxiety. The more the cared one attends day programs the less stress does the next of kin caring experience. Homemaking services and the in-home did not lessen the sense of burden. |
| <p><i>“Service use in family caregivers of persons with dementia in Belgium: psychological and social factors”</i> 2008<br/>         Authors: Marc Roelands, Paulette Van Oost ad AnneMarie Depoorter.</p>                   | <p>Investigate the relationship between community-based service usage and with the selected social and psychological characteristics of a family caregiver</p>           | <p>A structured questionnaire was filled by an interview, data analyzed with multiple regression analysis.<br/>         N=168</p>  | <p>If the caregiver had a positive attitude towards these services provided by the society the more services they used. The families of demented people used fewer services than of those whom had a next of kin to be cared for with the same fictional capability. The behavioral problems of the cared one nor the functionality did not affect the service usage.</p>                       |
| <p><i>Psychosocial intervention for family caregivers of people with dementia reduces caregiver’s burden: development and effect after 6 and 12 months”</i>. 2008<br/>         Authors: Signe Andren and Sölve Elmståhl.</p> | <p>Investigate how undergoing a five week program and a three month conversation group as a psychosocial intervention affect the caregivers of people with dementia.</p> | <p>Quasiexperimental study. Outcomes measured with reliable and valid instruments.<br/>         N=2721, 308 caregivers participated, 153 participated in the intervention and 155 were in the control group.</p> | <p>Caregivers whom participated the program had significantly less feelings of strain and disappointment and these results lasted for the 12 months, they also experienced increase in satisfaction these results were achieved by providing the family caregiver with information and a conversation group.</p>  |

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| <p><i>“Increasing the Use of Formal Services by Careivers of People with Dementia”</i>. 2004,<br/>         Authors: Philip McCallion, Ronald W Tosenland, and Steven Banks.</p> | <p>Impact of information and information which is aimed to help caregivers to attain health and human services.</p> | <p>Qualitative research conducted by a survey. N=608 caregivers in USA, 203 attended the study.</p> | <p>Predictors of service usage were the perceptions on the service offered, marital status and education. When referral help and information was provided it increased the usage of human services and it did not influence the usage of health services.</p>  |
| <p><i>Vanhusten omaishoitajat ja tukitoimet”</i> 2003<br/>         Author: Maritta Hyvärinen, Marja Saarenheimo, Kaisu Pitkälä and Reijo Tilvis</p>                             | <p>An article of the caregivers of elderly people and the support systems provided.</p>                             | <p>An article reviewing previous studies.</p>   | <p>The studies executed on the development and on the support which decreases the burden which the caregiver experiences have been controversial and there had not been enough evidence on the postponement of institutionalization. Care giving is demanding and hence the support services need to be planned well. What has been proved is that home caregivers often experience stress which affects the mental and psychical well-being of the caretaker. The society often fails to help the caregiver in time and the help is provided when the caregiver experiences a crisis situation and the help is not distributed equally and at times it is difficult for the caregiver to accept the services offered.</p> |