

Psychological Well-being of Spouse Caregivers of Dementia Patients and Their Coping Strategies

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<p>Abstract:</p> <p>The aim of this study is to contribute to a better understanding of challenges of family caregivers of dementia patients resulting in adverse effects on their psychological well-being and their coping strategies. The limitation is having to use only free full text articles which hindered from fully accessing best available articles. Studies Research questions are ; What are factors affecting psychological well-being of spouse caregivers of patients with dementia ? How do the caregivers cope in the situation? Method used is literature review. Ten research articles were revised using qualitative content analysis method. Both inductive and deductive approaches were used. The theoretical framework applied in this study is stress-coping theory of Lazarus and his colleagues. The findings in relation to factors affecting psychological well-being of family caregivers are demographic factor such as gender, educational status, and income; caregivers situation such as relationship with care recipient, care recipient's poor health, being a care giver, living with the caregiver, low social support, high conflict with family and friends and using more of emotion-focused coping style; and symptom/severity of the care recipient's disease, which consists of problem behavior and ADL impairment. Findings in relation to family caregivers coping style showed that, caregivers used both emotion-focused and problem-focused strategies.</p> <p>Conclusion: In order improve working conditions, living conditions and social inclusions of family caregivers and receivers by creating different services and interventions ,it is very important to gain deep understanding about factors affecting well-being of family caregivers and coping strategies used by caregivers. Fainally Its equally important to plan the services and interventions for family caregivers as much as possible because each caregivers use different coping strategies and has different resources and constraints.</p>	
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OPINNÄYTE	
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<p>Tiivistelmä:</p> <p>Tämän lopputyön tavoite on auttaa ymmärtämään paremmin omaishoitajien haasteita dementia potilaiden hoidossa sekä ymmärtämään psykologisia vaikutuksia omaishoitajien hyvinvointiin ja heidän selviytymis-strategioitaan. Vaikeuksia aiheutti vain ilmaisten artikkelien käyttäminen ja hyvien artikkelien löytäminen. Tutkimuskysymykset ovat seuraavat; Mitkä tekijät vaikuttavat dementiaasta kärsivän potilaan omaishoitajan psyykkiseen hyvinvointiin? Miten omaishoitajat pärjäävät tällaisessa tilanteessa? Käytetty metodi on kirjallisuusanalyysi. Kymmentä artikkelia käytettiin käyttäen kvalitatiivista analyysiä. Myös induktiivista ja deduktiivista näkökulmaa käytettiin. Teoreettinen näkökulma tässä lopputyössä on Lazaruksen ja kollegoiden käyttämä ”stress-coping”-teoria. Tutkimukset osoittavat, että sukupuoli, koulutus, tulot, suhde hoidettavan kanssa, hoidettavan huono kunto, asuminen hoidettavan kanssa, huono sosiaalinen tukiverkko, konfliktit hoidettavan perheen tai ystävien kanssa johtavat tunnepohjaiseen pärjäämistyyliin. Löydöt osoittavat, että omaishoitajat käyttävät sekä tunnepohjaista, sekä ongelmiin keskittyneitä strategioita. Päätelmä: Jotta työoloja, elinoloja, ja sosiaalisia suhteita voidaan parantaa omaishoitajien ja hoidettavien keskuudessa, pitää pystyä luomaan erilaisia palveluita. On tärkeää, että omaishoitajien hyvinvointia huomioitaisiin enemmän ja että erilaisia selviytymis-strategioita käytettäisiin. On erittäin tärkeää, että jokaiselle räätälöitäisiin hoito-ohjelmat ja palvelut henkilökohtaisesti, koska jokainen omaishoitaja omaa erilaisia strategioita, resursseja ja rajoituksia.</p>	
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Abbreviations

SUFACARE - Supporting Family Caregivers and Care Receivers in Finland and Estonia

WHO – World Health Organization

CG- Caregiver

CR- Care recipient

IADL- Instrumental Activities of Daily Living

ADL- Activities of Daily Living

1 INTRODUCTION

It is evident that increase in aging population will lead to an increase in cases of age related diseases for instance dementia, which is a leading cause of disability and dependency among older people worldwide. Though the majority of dementia patients are old people, dementia is not a normal part of aging. According to WHO (2012) statistics 35.6 million people were estimated to be living with dementia worldwide. 7.7 million dementia cases are added every year, meaning, somewhere in the world, there is a new case of dementia every four seconds .

In this rapid increase of dementia cases worldwide, family caregivers are fundamental bases for the care provision process. According to WHO (2012), and Schulz and Sherwood (2008) caregivers of older adults with dementia are usually spouses. Schulz and Sherwood further explain that in the absence of the spouse e.g due to death, sickness or unavailability for assistance, adult children commonly become the caregiver. Daughters and daughter-in-laws and then sons and son-in-laws are more likely to be the care providers.

Due to this, family caregivers are of foremost importance for their elderly relatives with dementia since by providing day to day care and emotional support they help the elderly to stay in their homes, where they want to spend the rest of their lives. Family caregivers are also important for the government or for the healthcare system since by providing care for their loved ones at home they contribute to cutting a huge amount of costs.

Assisting spouse caregivers and care receivers achieve better quality of life enables dementia patients to age at home as long as possible. For this Purpose it is important to understand caregivers and the challenges they face in everyday care giving processes . It is also important to assess the caregiver's physical and psychological well-being and their coping style to know their needs and enhance their care giving capability. Understanding the caregivers situation will help to create practical services, for instance services such as providing information about the disease, how to care and alike . It is of utmost importance to address family caregivers' needs in order to keep caregivers well-being and assure aging in place for the elderly patients.

Therefore the author is interested in and strongly believes, that researching to understand the challenges and needs of spousal caregivers has an important input in the creation of new services and the upgrading of the existing ones.

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This study focuses on literatures written about spouse and older adult family caregivers of elderly people with dementia, Alzheimer disease and cognitive impairment . In this study caregiver, family caregiver and spouse caregiver are used interchangeably .

2 AIM AND RESEARCH QUESTION

The aim of this study is to contribute to better understanding of challenges of spouse caregivers of dementia patients resulting adverse effect on their psychological well-being and their coping strategies. This study also meant to contribute in providing background knowledge about spousal caregivers of Dementia patients for SUFACARE- project. In its process of creating educational courses for family caregivers and designing effective and efficient model for home care system.

Research questions of this study are :

- 1.What are factors affecting psychological well-being of spouse caregivers of patients with dementia ?
2. How are caregivers coping in the situation?

3 BACKGROUND

Schulz and Martire (2008) describes the load and responsibility of family care giving as:

.....it involves the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Care giving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.

Numerous researches prove that due to it's time consuming nature and it's emotionally and physically demanding responsibility, caregivers psychological well-being is prone to be affected. Schulz and Martire (2004) confirm that, there is a wide spread consensus that care giving of an elderly person with disability is taxing and stressful for many family caregivers which in turn contributes to psychiatric morbidity in the form of higher prevalence and incidence of depressive and anxiety disorders .

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Hayslip et al., (2008) adds, that the odds of experiencing social, emotional, and physical stress and burden, on family members providing care for patients with Alzheimer's disease, is very high. It is also reported that family caregivers face multiple adverse outcomes such as depression, anxiety, emotional and physical burden, social isolation, and/or physical health problems.

Joling et al., (2010) on their study, about incidences of depression and anxiety in spouses of patients with dementia, reported that participant spouses of dementia patients had four times higher risk of diagnosis of incident depression when compared with matched spouses of non demented persons during an average follow-up of almost five years. These spouses also had twofold risk for prescription of antidepressants.

It is stated above that family caregivers serve the healthcare system and their family member with dementia at the cost of their physical and mental well-being. Projects like SUFACARE plays an important role in betterment of the service for family caregivers.

3.1 SUFACARE Project

SUFACARE – project done by partnership between Arcada University of Applied Science and Tallinn University in Estonia. The project work to improve working conditions, living conditions and social inclusions of family caregivers and receivers in Finland and Estonia.

The aim of project is to create courses for families and create effective and efficient home care model in order to promote the mental and physical well-being, and social inclusion of family caregivers. After the efficiency and effective of the model is evaluated and compared with the existing home care system in Finland and Estonia the model should then implemented in five different municipalities (SUFACARE-project, 2011)

3.2 Definitions

Stress is defined as a relationship between the person and the environment, which takes in to account characteristics of the person on the one hand, and the nature of the environment event on the other. Psychological stress is the relationship between the person and the environment

that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus and Folkman, 1984).

Caregiver burden – According to Novak and Guest the concept of caregiver's burden explained as many dimensions contributing to a caregiver's feeling of distress, such as feeling of overburden, hopelessness and inability to cope (see Roopalekha Jathanna et al., 2010).

Additionally Given et al., (1992) Caregivers burden is explained as alterations in caregivers' emotional and physical health, which can occur when care demands outweigh available resources (See Honea et al., 2008). According to Zarit, Reeve, & Bach-Peterson (1980) The extent to which caregivers feel that their emotional or physical health, social life, and financial status have suffered as a result of caring for their relatives (See Honea et al., 2008).

Coping is defined as constantly changing cognitive behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman, 1984 p.141) .

4 THEORETICAL FRAMEWORK

Stress and Coping theory of Lazarus and his colleagues is used as theoretical frame work of this study. The theory denotes two processes, cognitive appraisal and coping, as key factor of stressful person-environment interaction and their immediate and long-range outcomes highly dependent on the persons.

Cognitive appraisal is a process in which a person evaluates the significance of an encounter environment for his or her well-being. There are three kinds of cognitive appraisal primary appraisal, secondary appraisal and reappraisal. primary appraisal is when a person evaluate if the particular encounter is irrelevant, beneficial or stressful , secondary appraisal is when a person evaluate what coping strategies to use to overcome the stressful encounter or to make best out of the benefit, and reappraisal is a changed appraisal depending on new information from the environment and/or person (Lazarus and Folkman 1984 p. 53 f ; Folkman et al., 1986 p. 992 f).

According to (Lazarus and Folkman, 1984 p.141), Coping is defined as constantly changing cognitive behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.

(Folkman et al., 1986 p.993) explain the three key features of the definition as follows.:

First, process oriented, meaning that it focuses on what the person actually thinks and does in a specific stressful encounter, and how this changes as the encounter unfolds. Our concern with the process of coping contrasts with trait approach, which are concerned with what the person usually does, and hence emphasize stability rather than change. Second, we view coping as contextual, that is, influenced by the person's appraisal of the actual demands in the encounter and resources for managing them. The emphasis on context means that particular person and situation variables together shape coping efforts. Third, we make no prior assumptions about what constitutes good or bad coping; coping is defined simply as a person's effort to manage demands, whether or not the efforts are successful.

There are two types of coping strategies, Emotional focused coping to ease stressful emotion and problem focused coping to solve the problem causing the distress.

There are different means of coping. According to Lazarus and Folkman, (1984 p. 178 f) the way a person copes is determined in part by his or her resources such as health and energy; Existential Beliefs eg. about God or about control; Commitments, which may help to continue coping; problem solving skill; social skill; social support; and material skill. It is also determined by constraints that hinder from using the resources. There are two types of constraints personal and environmental. Personal constraint is internalized cultural value, beliefs and psychological deficits that limit certain way of behaving. Environmental constraint can be demands that compete for the same Resources. Constraint can also be high levels of threat that hinders from using the available resources.

Explaining cognitive appraisal and coping strategies of an individual, Folkman et al., (1986 p. 992) also discuss the immediate outcome of an encounter as it is

The immediate outcome of an encounter refers to the person's judgment of the extent to which the encounter was resolved. The overall judgment is based on the individual's value and goal.

Meaning, Even though the encounter causing the distress is not resolved, the person may feel the encounter was managed as well as could be expected as a result the outcome can be considered as positive. On the other hand Or even though the person resolve the encounter causing distress and he or she feel the encounter have not been managed as well as could be,

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and/or the resolution is not consistent with other values or goals the outcome may be considered as unfavorable .

Stress and coping model of Lazarus and Folkman, shown in Figure 1,

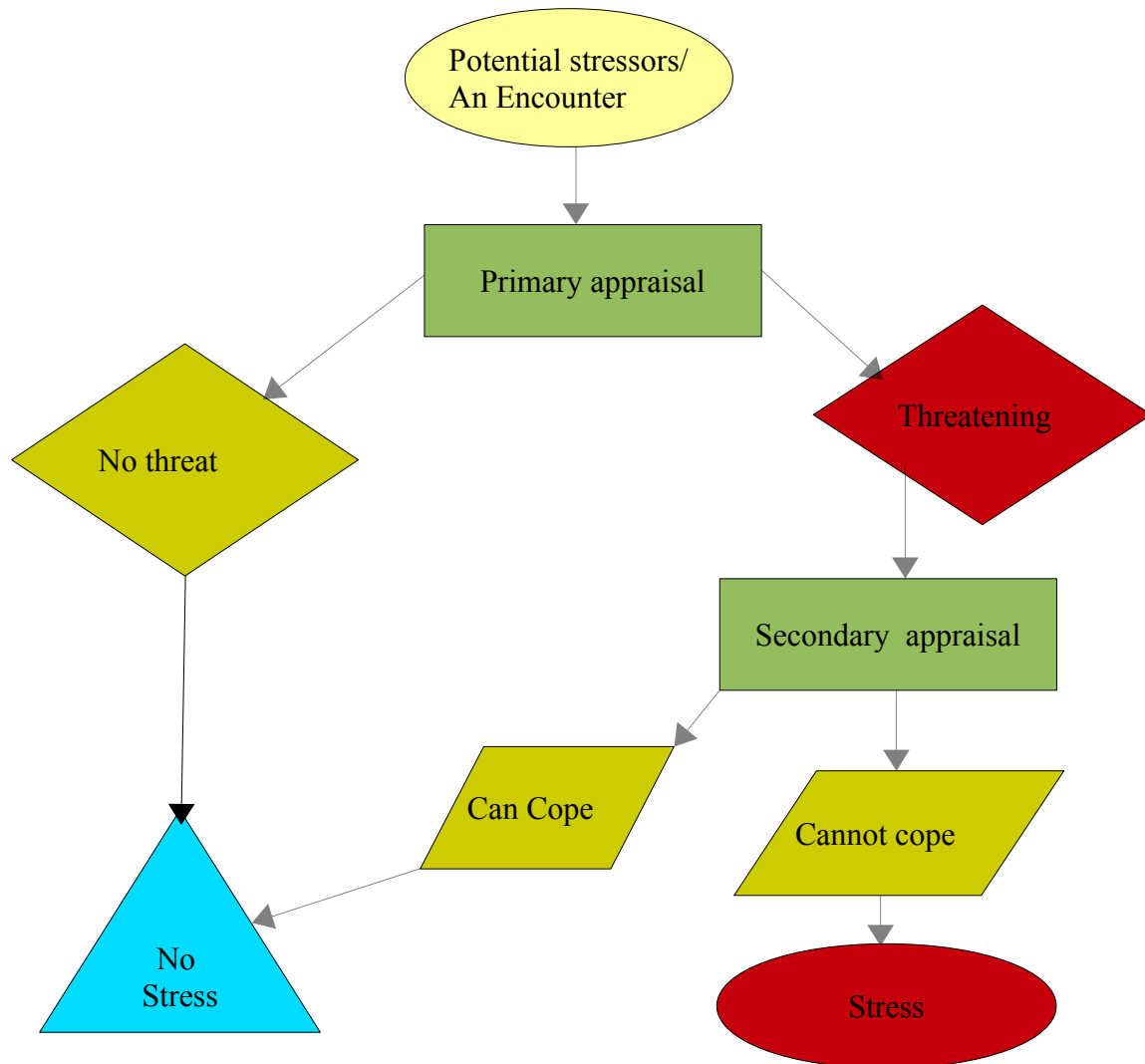


Figure 1. Stress and coping model of Lazarus and Folkman Adopted from (Taylor, 2008). *Potential stressor/ an encounter is appraised (primary appraisal) to distinguish if threatening or not. If an encounter found to be threatening then secondary appraisal process leads to a sort of action to cope successfully or not.*

5 METHOD

The methodology used in this study is literature review within the subject area of this research topic. The vast search for lecturers is made with the aim of selecting relevant, reliable, and best quality researches. After reading through selected literatures in the subject area, an argument is extracted which lead the study to analyzing the literature in order to answer the research questions.

According to Cronin et al. (2010), Literature review is defined as the critical analysis and objective summary of relevant scientific researches on the topic of interest. Literature review must provide the readers with up-to-date information on the topic being discussed with the goal of being basis for specific research line. Moreover, it should gather information from different sources, and should contain clear search and selection strategy (Cronin et al., 2010).

In the following chapter the author clearly explains the process of literature search strategies employed in this study.

5.1 Data Collection

The articles used in this study were gathered through database search. The data collection process was done systematically to make sure that the best articles are chosen from the available resource.

EBSCO and Google Scholar where used in the process of data collection. Search terms used were : family caregivers AND coping; informal caregivers AND dementia AND depression; caregiver AND burden AND alzheimer ; spouse AND caregiver AND burden; depression AND family caregivers AND alzheimer's disease; stress burden AND informal caregiving AND dementia.

Though; searching from the database resulted in thousands of hits and the majority were only abstracts, it was possible to find a few full text articles from the first couple of pages. A number of articles used in content analysis and more articles and books used in other parts of this study were accessed from Google Scholar.

The database, search terms, corresponding amount of hits , filtered articles, and chosen articles are stated in table 1.

Table 1 . Data gathering process

Data base	Key words	Hits	Limitation	Articles retrieved	Articles used
EBSCO	FAMILY CAREGIVERS AND COPING	880	244	14	5
EBSCO	INFORMAL CAREGIVERS AND DEMENTIA AND DEPRESSION	167	62	8	1
EBSCO	CAREGIVER AND BURDEN AND ALZHEIMER		79	4	1
EBSCO	SPOUSE AND CAREGIVER AND BURDEN	381	86	4	1
Google Scholar	DEPRESSION AND FAMILY CAREGIVERS AND ALZHEIMER'S DISEASE	16300	11,700	2	1
Google Scholar	STRESS BURDEN AND INFORMAL CAREGIVING AND DEMENTIA	11,000	8690	3	1

The aim of this study was to analyze challenges of spouse caregivers of dementia patients resulting in adverse effects on their psychological well-being and their coping strategies. This study based on eleven research articles gathered from EBSCO host and Google Scholar databases. These eleven articles are listed in the appendix 1 along with their aim, method, and result. In the process of searching the articles some inclusion and exclusion criteria are used . The criteria are shown in table 2.

Table 2 . Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> - Studies written in English. - Studies which were published after 2000. - Studies with an abstract. - Scientifically written articles. - Full text version of the study of interest. - Studies which focuses on caregivers of Dementia Patients. - Studies which mainly focus on spouse caregivers and family caregivers 	<ul style="list-style-type: none"> - Studies that were not conducted in English. - Studies published before 2000. - Not scientifically written articles. - Studies where it was not possible to access the full text version.

5.2 Analysis of data

In this study qualitative content analysis is applied. In order to answer the first research question of this study, researches was conducted in inductive approach and second research question the research was conducted in deductive approach.

Content analysis is research technique for making replicable and valid inferences from texts, works of art. images, maps, sounds, signs, symbols and even numerical data to the context of
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their use (Krippendorff, 2004). In nursing, content analysis, research method is mostly applied in psychiatry, gerontological and public health studies .

As a technique, content analysis involves specialized procedures. Its learnable and divorceable from the personal authority of the researcher. As research technique, content analysis provides new insights, increases the researchers understanding of particular phenomena, or informs practical action (Krippendorff, 2004).

According to Krippendorff Content analysis techniques are expected to be reliable. The same results should be produced from the researches which have been done at different points of time and conditions when when same method is applied to the same data .

Krippendorff also adds, : As scientific research , content analysis research should be able to produce a valid result. In the sense that the research work is open for reading, careful examination and it to be carried on being available ground in a given subject matter.

The aim of content analysis process is to analyze multiple meaningful references and produce a condensed broad description of phenomenon. The result of the analysis is categories and subcategories describing the phenomenon (Elo and Kyngäs, 2008).

5.3 Ethical Consideration

("Declaration of Helsinki," 2004) and (von Herten et al., 2009, Arcadas Thesis Guide)were carefully read before starting work on this thesis with the aim of avoiding plagiarism and with the intention of doing academically well written thesis.

In this study the reference materials such as research articles and books are quoted and cited properly and all corresponding references are listed specifically according to Arcada thesis guide 2009.

Additionally, all steps applied on data collection and methods applied to content analysis is explained by in text form, diagram or table so that, if a researcher could do the same process again it would be possible to come up with the same results. This is possible because the study is conducted by following complete scientific research writing methods.

6 RESULT

In this chapter findings related to the first research question; what are factors affecting the psychological well-being of spouse caregivers of patients with dementia ? the second research question; how are the caregivers coping in the situation? will be discussed.

During analyzing the eleven articles author applied both inductive and deductive approach and listed multiple words, phrases and sentences that are found to be main findings from each articles. Then the author produced a category matrix to be able to group those words, phrases and sentences found in suitable categories and sub categories. Category matrixes of the first and the second research questions are found in appendix two and appendix three.

In the process of answering the first research question, the author used inductive approach. came up with three categories. The first category is caregivers demographic factor under which gender, educational status, and income is listed as sub-categories. The second category is caregivers situation , relationship with CR (care recipient), poor health, being CG, living with CR, low social support, high conflict and coping styles are listed as sub-categories. The third category , symptom and or severity of the disease on the care receiver , consists of problem behavior and ADL impairment .

When it comes to answering the second research question the process resulted in two categories and seven sub categories . The first category is problem-focused coping strategy and the sub category under it, is defining the problem , weighing it in terms of the cost and benefit and finding a solution . The second category is emotion-focused coping strategy and the sub categories are, avoidance and/or escape, seeking social support , wishful thinking, acceptance, focusing on the positive, and guilt. In this process the author used deductive approach by inheriting the two main categories , problem-focused and emotion-focused coping strategies from stress-coping theory of Lazarus and his colleagues . And sub categories under each category is found form research materials used in this study. The categories and sub categories are shown in the table 1 .

Table 3 . Content analysis

CR= Care Recipient

CG= Caregivers

ADL= Activity of daily living

Main Category	Category	Subcategory
What are factors affecting psychological well-being of spouse caregivers of patients with dementia	Caregiver's Demographic factor	Sex Educational status Income
	Caregiver's situation	Relationship with CR Poor health Being CG living with CR Low social support High conflict Coping styles
	Symptom and or severity of the disease on the care receiver	ADL impairment Problem behavior
How are the caregivers coping in the situation?	Problem-focused strategies	Defining the problem , weighing it in terms of the cost and benefit and finding a solution

	Emotion - focused strategies	<ul style="list-style-type: none"> - Avoidance and or escape -Seeking social support -Wishful thinking Acceptance Focusing on the positive Guilt
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6.1 What are factors affecting psychological well-being of spouse caregivers of patients with dementia ?

Factors affecting psychological well-being of spouse caregivers are divided in three categories and eleven sub categories. The categories and respective sub categories are discussed below.

6.1.1 Caregivers Demographic factors

Many researches showed that female caregivers are more depressed and anxious than men caregivers. Researches in the study point out being female is significant factor contributing for depression, anxiety and caregivers burden (Mahoney et al., 2005; Papastavrou et al., 2007; Butterworth et al., 2010; Akpınar et al., 2011). Akpınar et al. gave further explanation that, female caregivers also found to be experiencing significantly high level of time dependency burden, developmental burden, physical burden, and social burden than their male counterparts.

Level of education and Income also believed to contribute for caregivers psychological well-being (Papastavrou et al., 2007; Butterworth et al., 2010). while Butterworth et al reports having lower levels of educational attainment independently associated with depression and anxiety, Papastavrou et al. States higher levels of education resulting better remuneration and

lower levels of burden. (Ferrara et al., 2008) also states as caregivers low income and patients age being less < 65 contributes for caregivers depression.

6.1.2 Caregiver's situation

Caregivers having poor quality relationship with the care recipient, caregivers having poor health and having perception of their health as being poor negatively affects psychological well-being of the caregiver (Mahoney et al., 2005; Ferrara et al., 2008; Butterworth et al., 2010). Additionally Mahoney et al., (2005) discusses that living with care recipient is a factor that contribute to caregivers mental well-being.

Getting low social support from and experiencing high levels of conflict with family and relatives are also mentioned as factors influencing psychological well-being of caregivers (Butterworth et al., 2010).

Finally using specific coping styles is also found to be a factor altering well-being of family caregivers. Using emotional focused strategies has positive correlation with caregiver's burden (Ekwall and Hallberg, 2006; Papastavrou et al., 2007). Papastavrou et al. Showed that participants who score higher on burden scale used emotional coping strategies. Ekwall and Hallberg (2006) also revealed that the participants who are less satisfied in the care giving duty happen to use emotion-Focused coping strategies while satisfied participants used problem focused-coping strategies .

6.1.3 Symptom and or severity of the disease on the caregiver

Frequency or severity of Problem behavior such as irritability, apathy, being suspicious, making accusations and becoming angry, talking in an aggressive or threatening manner, Anger, and or verbal aggressiveness significantly are of the primary factor which adversely affect psychological well-being of caregivers. Due to this, caregivers are at high risk of or are experiencing stress, depression, anxiety, and burden (Samuelsson et al., 2001; Mahoney et al., 2005; Papastavrou et al., 2007; Ferrara et al., 2008; Butterworth et al., 2010; Savundranayagam et al., 2010)

Savundranayagam et al., specify that the role of assisting the care recipient with activities of daily living (ADL) is associated with objective burden on family caregivers. Severity of ADL impairment also found to be of primary factor affecting psychological well-being of caregivers (Mahoney et al., 2005; Ferrara et al., 2008).

6.2 How are the caregivers coping in the situation

In the process of answering the second research question how caregivers cope in the situation? The study came up with two categories and seven sub categories.

Stress-coping theory of Lazarus and his colleagues states, different person cope in different way depending on the resources, and constraints at the spot. In this study, the author, after analyzing the research articles, found out there are multiple ways of coping strategies differing from person to person. Even if there are a lot of ways of coping majority of them can be categorized as problem focused and emotion focused coping strategies.

6.2.1 Problem-Focused Coping Strategies

According to (Chambers et al., 2001; Samuelsson et al., 2001; Ekwall et al., 2007; Papastavrou et al., 2007) family caregiver participants on each literature used multiple methods of defining the problem , weighing it in terms of the cost and benefit and finding a solution. The methods mentioned as follows:

- Taking practical action.
- Establishing priorities and concentrating on them.
- Taking one day at a time.
- Contacting the authorities to arrange examinations, transportation, daycare, and alike .
- Taking increased responsibilities of housekeeping.
- Trying to explain things and correct the care recipient when there is misunderstanding.
- Trying to make changes slowly and carefully.

- Helping the care recipient to post office, shopping and moving to the care recipients house to assist.

6.2.2 Emotion-Focused Coping Strategies

During literature analysis it is also evident, in (Chambers et al., 2001; Samuelsson et al., 2001; Ekwall et al., 2007; Papastavrou et al., 2007) work, that participant caregivers also practiced emotion focused-coping strategies. The strategies are categorized under six sub categories listed as follows:

Avoidance and or escape

- Trying to relax with a cup of tea and think how positive things were before the dementia.
- Taking a moment in the garden.
- Walking to the next room
- let it steam off , for example to go to the garden and scream
- When neighbors call to complain about the care recipient's disturbing behavior the caregiver escaped from answering

Seeking social support

- talking to other caregivers

Wishful thinking

Acceptance

Focusing on the positive

- realizing that there is worse off than the caregiver him/her selves .
- remembering good times the caregiver had with the care recipient .

Guilt

- The caregiver has great feeling of guilt for not doing enough for the care recipient. This resulting the care giver to give priority to the care recipient over his family.

7 CRITICAL REVIEW

In this study the research, questions raised in the beginning of the thesis are answered. The first research question was, What are factors affecting psychological well-being of spouse caregivers of patients with dementia? And the second was, How do caregivers cope in the situation. Regarding the finding of the first question, this study shows that multiple factors, such as caregivers demographic factor, caregivers situation factor, and care receivers symptom and severity of dementia factor contribute to family caregivers experiencing psychological well-being issues. The findings in relation to the second question show that, the family caregivers used different kinds of coping strategies in order to either relieve their stress or give a solution to the problem on the spot.

Looking on to the findings conducted in this study, which is to contribute to a better understanding of challenges of spouse caregivers of dementia patients and its adverse effects on their psychological well-being and their coping strategies, we can therefore conclude that the aim of this study has been accomplished.

The author found it manageable, after reading the reference materials, to derive categories and sub categories for the first research question which was done inductively. As a result of caregivers using many kinds of coping styles such as, realizing that the care giver is worse off than themselves, talking to other caregivers, taking one day at a time and many more the author found it difficult to categorize the themes and sub themes found under the second research question. But finally the author, based on stress-coping theory of Lazarus and his colleagues, was able to categorize the sub themes under Problem-focused and Emotion-Focused coping strategies.

7.1 Limitations of the study

The primary constraint of this study is limited availability of full text research articles that could be accessed free of charge. In many cases, after the author read the abstracts, saw the importance of the article, and gained interest in getting the full text version for detail reading, it was not possible to access the full text version, especially in the case of recently published articles. This hindered from fully accessing full text versions of up to date and best available reference materials needed for this study.

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Additional constraint is that the majority of articles used in this study are conducted in quantitative research method even though this study was based on quantitative content analysis method.

7.2 Validity and reliability of the study

The result is valid and reliable because the result of this study matches with the studies of of (Mattei et al., 2008; Schulz and Sherwood, 2008; WHO, 2012)

Schulz and Sherwood (2008) states factors affecting psychological wellbeing of caregivers as , caregiver's sex (with females caregivers being more affected), the care recipient's behavior problems, the care recipient's functional disabilities, and the relationship between caregiver and care recipient. These factors are similar with the findings of this study. Duration and amount of care provided, the care recipient's cognitive impairment, and caregiver's age (with older caregivers being more affected) are additional factors which are mentioned on findings of Schulz and Sherwood which are not found on this study . Even if one of the factors affecting the psychological well-being listed in this study is relationship between caregiver and care recipient Schulz and Sherwood specifies that the spousal relationship contributes for having a greater effect.

Majority of findings of WHO (2012) are also similar with this study when it comes to factors that are contributing to psychological wellbeing of the caregivers. These factors are gender (female caregivers being more affected), living with the care recipient, caregivers with low income, Problem behavior, poor quality relationship with the care recipient and coping style (Emotional-focused coping style). Factors, which findings of WHO adds, are being spouse caregiver, caregivers personality, caregivers perception and experience of caregiving role, dementia type Frontotemporal dementia and low levels of past intimacy.

The result of this research regarding the second question i.e How caregivers cope in their situation also matches with the findings of (Mattei et al., 2008). The findings of this study shows that family caregivers used both emotion-focused coping and problem-focused coping strategies. Similarly Mattei et al. also showed that the participant of the study used both emotion-focused and problem-focused strategies. The findings of this study is also supported

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by the theoretical frame work of this study i.e stress-coping theory of Lazarus and his colleagues in which it describes emotion-Focused and problem-focused strategies as two main categories of ways coping.

8 DISCUSSION AND CONCLUSION

In this chapter the author, in the process of conducting this research , discusses factors that are found to be overwhelmingly agreed up on by majority of researches studied about well-being of family caregivers of dementia patients. This is because the author believes that these factors can be areas of focus even more than the other factors in order to tackle family caregivers challenges. In this case, factors refer to factors contributing to the psychological well-being of family caregivers.

Caregivers Gender

Majority of the researches in this study agree except one (Samuelson A.M et al. 2000) disagree that being female is one of the main factors affecting caregivers psychological well-being. Female family caregivers were found to be more depressed , anxious, and burdened than their male counterparts. On Ekwall et al. 2005's result about percentage of the men and women helping with ADL ,IADL and frequency of provided help, its showed that caregiving activities such as helping with cooking, eating, putting clothes or shoes, oral and medical care were done in higher frequency than by men caregivers. And no caring activities were done more by men than women. As a result, this study explains the intensity of care provided by the female caregivers might be a contributing reason for experiencing higher levels of depression , anxiety and burden.

Quality relationship with care recipient

Quality relationship with the carer recipient is a factor that the majority of the researches agree up on as a significant factor contributing to mental well-being of family caregivers. But most of those researches came up with this result by measuring the current quality relationship of the care recipient and their caregivers. None of the researches except one (Samuelson A.M et al. 2000) used in this study directly addressed the previous quality of

relationship as a factor affecting the caregivers well-being which may be a factor contributing to poor quality relationship during caregiving.

For the purpose of showing the importance of understanding the correlation between the quality of caregivers relationship before the patient being diagnosed with dementia and the caregivers psychological well-being, the author shortly presents Samuelson A.M et al. (2000) 's work . From eight family caregiver participants, two husbands were in close relationships in the marriage , two sons and a daughter had good relationship during childhood and later on, and a daughter-in-law had a great relationship quality with the care recipient. When it comes to the result the participants who had had bad relationship reflected emotional withdrawal and ambivalence . As a result, this study implies that it is important for future research direction to investigate the previous quality relationship between caregivers and care recipient and its correlation to the issue of the caregivers psychological well-being issue .

Care recipient's Problem behavior and ADL impairment

Frequency Care recipients problem behavior such as aggressiveness and irritability also is also agreed as being significant factors contributing to psychological well-being of family caregivers. The same is true for the caregivers ADL impairment. One of the explanations ,with regard to ADL impairment and its correlation to caregivers wellbeing, can be based up on Ekwall et al. (2005) mentioned above . The extent to which care recipients can help with activities activities such as cooking, eating, putting clothes or shoes, oral care, medical care and many more are a kind of activities which show the severity of the diseases and increasing need of the caregiver to invest a great deal of time and endeavor.

According to stress-coping theory of Lazarus and his colleagues, which is a framework of this study, a person has to manage an stressful encounter and cope successfully in order not to be stressed. There are no specific ways of coping that are listed as successful or vice versa. It all depends on the person coping, his or her resources and constraints. But on Lazarus and Folkman 1984, Ekwall and Hallberg, 2006, and Papastavrou et al., 2007 it is explained that, using more of Emotional-focused coping strategies is related to burden and stress.

8.1 Conclusion

This study discussed factors affecting psychological well-being of family caregivers and in a way caregivers prevalence for different psychological well-being issues such as depression, anxiety and burden. This study also showed family caregivers used different coping strategies. As a result the author concludes that, in order improve working conditions, living conditions and social inclusions of family caregivers and receivers it is very important to to gain deep understand of the factors affecting well-being of family caregivers and and caregivers coping styles. It is equally important to individualize the services for family caregivers as much as possible. Due to the fact that is shown in this study, even if it doesn't mean that the family caregivers coped successfully, the way the cope differs from person to person.

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APPENDIX

Appendix 1

Table 4 Articles used in content analysis

NO		Title	Aim	Methods	Results
	Butterworth et al.	Factors that explain the poorer mental health of caregivers: results from a community survey of older australians	To contrast the level of anxiety and depression reported by older australians providing assistance to someone who is ill, disabled or elderly with that of non-caregivers; and to identify secondary stressors and mediating factors which explain caregivers' poorer mental health.	2,222 adults aged 64–69 years conducted in canberra and queanbeyan, australia. Mental health was assessed using the goldberg depression and anxiety scales.	Caregivers reported significantly poorer mental health than non-caregivers, and also reported poorer physical health, greater financial stress, greater responsibility for household tasks, and more conflict and less social support from their family and spouse. Mediation analysis showed that the poorer mental health of caregivers reflected elevated rates of their own physical impairment, a lack of social support and greater conflict.
	Mahoney R. et al	Anxiety and depression in family caregivers of people	To report the prevalence of anxiety and depression in a perspective sample of family	153 people with ad and their caregivers were interviewed as a part of a	23% of caregivers scored at or above caseness level for anxiety and 10.5% for depression. Care recipient (cr) adl

2005	with Alzheimer disease (ad): the laser-ad study	caregivers of Alzheimer's disease and to compare the characteristics of those that did or did not have those conditions	larger representative study of ad	impairment, being a caregiver living with cr, being a female caregiver, reporting a poorer quality of relationship with the cr and caregivers reporting their health as being poor predicted anxiety disorder. Cr irritability, caregivers reporting poor health and a poorer quality of relationship with cr predicted depression
Papastavrou et al. 2007	Caring for a relative with dementia: family caregiver burden	This paper is a report of part of a study to investigate the burden experienced by families giving care to a relative with dementia, the consequences of care for the mental health of the primary caregiver and the strategies families use to cope with the care giving stressors.	A volunteer sample of 172 caregiver/care recipient dyads participated in the study in cyprus in 2004–2005. Data were collected using the memory and behavior problem checklist, burden interview, center for epidemiological studies-depression scale and ways of coping questionnaire.	The results showed that 68.02% of caregivers were highly burdened and 65% exhibited depressive symptoms. Burden was related to patient psychopathology and caregiver sex, income and level of education. High scores in the burden scale were associated with use of emotional-focused coping strategies, while less burdened relatives used more problem-solving approaches to care-giving demands. .

<p>Samuel sson A.M et al 2000</p>	<p>Burden of responsibility experienced by family caregivers of elderly dementia sufferers</p>	<p>To gain a deeper understanding of the caregiver's burden and the experience of giving care to a relative suffering from dementia</p>	<p>Eight family caregivers of dementia sufferers participated in in-depth interviews regarding their experience of caregiving.</p>	<p>All caregivers felt a heavy burden especially early in dementia process. The husbands sustained the heaviest burden ; they expressed anger, worry, weariness, guilt, distress and isolation. Caregivers used different problem- and emotion- Focused strategies to cope in their situation.</p>
<p>Chamb ers M. et al 2000</p>	<p>Exploring the emotional support needs & coping strategies of family carers</p>	<p>Explores the emotional support needs & coping strategies of family carers divided in to two focus groups</p>	<p>Interview to investigate family carers needs and experiences and the paper focuses on emotional support needs and coping strategies identified by the group</p>	<p>Emotional impact of caring Focuses of specifically on emotional support needs .Coping strategies from the caregivers point of views there are both negative & positive ways of coping Acceptance (accept the disabilities & the resultant changes on to their), taking practical action and simple behavioral intervention - to walk to next room when the Cr is being difficult real eg. To go to the garden and scream, to have a cup of tea and think about the good</p>

					<p>things past</p> <ul style="list-style-type: none"> - carers find difficulty on antisocial behavior, mood swings or aggression carers thought inadequately supported often not know to who to turn to or having to wait to professional support
Ekwall and Hallberg, 2006	Older caregivers' coping strategies and sense of coherence in relation to quality of life	This paper reports a study to investigate coping strategies and sense of coherence in relation to gender, the extent of care, caregiving activities and health-related quality of life in a population-based sample of caregivers aged 75 and over.	A postal survey was carried out in 2001 with 171 informal caregivers, aged 75 or older. The response rate was 47%. The questionnaire included the Short-Form 12, Carer's Assessment of Managing Index, and Sense of Coherence instrument.	Almost 70% of caregivers provided help every day. Higher health-related quality of life was predicted by using self-sustaining coping strategies and by high sense of coherence. Poor economic situation and demanding social and practical support predicted low scores.	
Ekwall et al. 2007	Caregiver depression is associated with a low sense of	Objective is to examine the sense of coherence (soc) of spouse caregivers. The aim	170 patient-spouse caregiver dyads in which the patient has recently	Male caregivers' soc was significantly higher than female caregivers. The main predictor for low soc was depression, with	

		coherence and health-related quality of life.	was further investigate the association of soc, health-related quality of life (hrqol), depressive symptoms, distress and how severity of alzheimer's disease (ad) affects soc.	diagnosed mild ad. Caregivers completed soc scale (soc-29), hrqol (15d), beck depression and general health questionnaire scale.	37% of spousal caregivers reporting depressive symptoms. Women reported more depressive symptoms and distress.
Burcu Akpınar et al. 2011	Effects of Gender on Burden Among Caregivers of Alzheimer's patients	Conducted to determine the effects of gender on caregiver burden among caregivers of persons with Alzheimer's disease.	Comparative descriptive study. The sample consisted of 120 female and 72 male caregivers of patients with Alzheimer's disease. Data were collected from patients by means of the MMSE and demographic variables, and data from the Caregiver Burden Inventory [CBI] and NPI were obtained from caregivers, as well as	Female caregivers had significantly higher scores for caregiver burden than their male counterparts (p = .002). Subscale analysis on the CSI revealed that female caregivers had significantly higher scores for caregiver burden than male caregivers on time dependence (p = .040), developmental (p = .002), physical (p = .001), and social burdens (p = .045). No difference was found with respect to emotional burden (p = .718).	

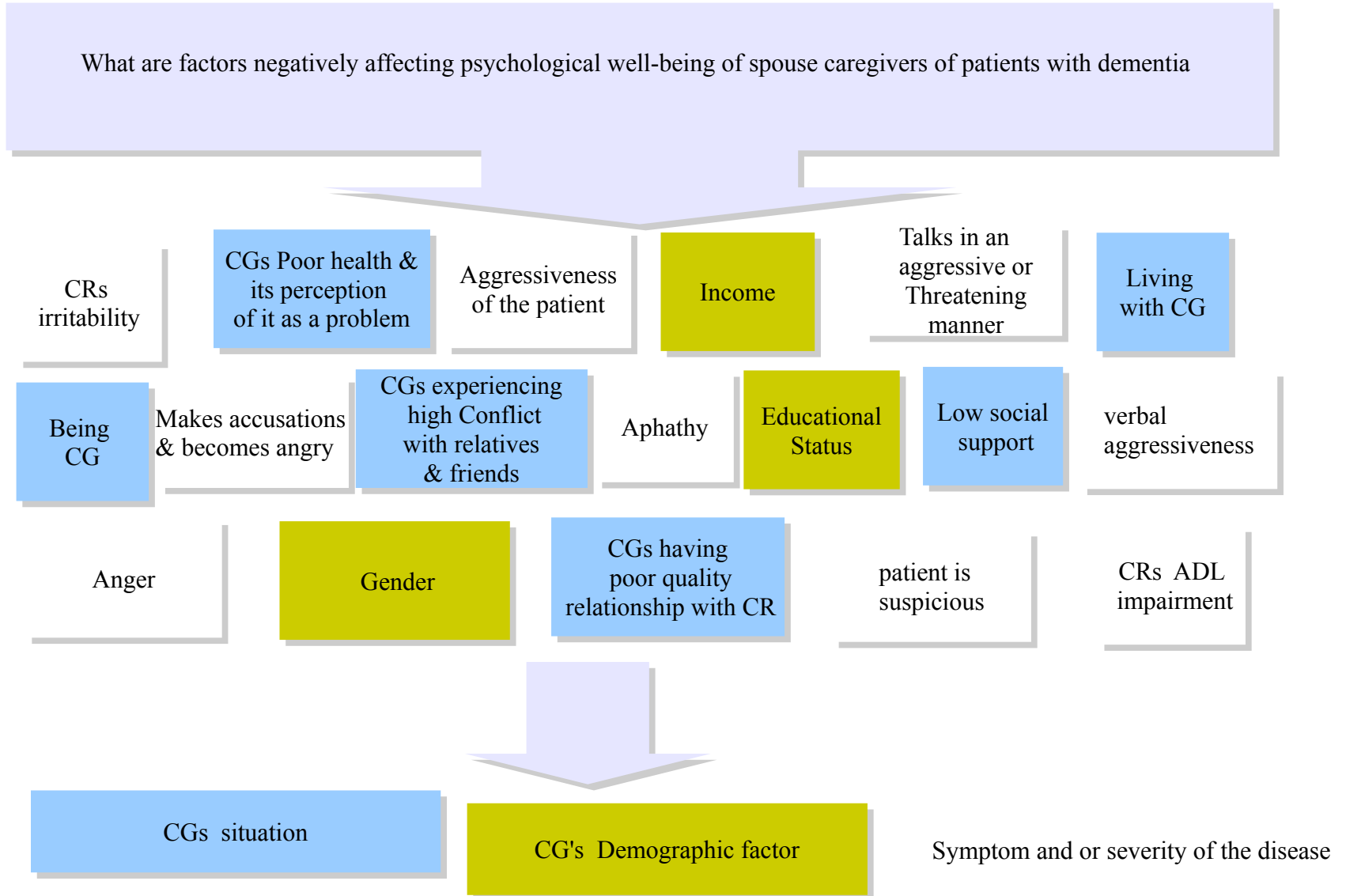
				<p>from face- to-face interviews using a questionnaire.</p> <p>Descriptive statistics and t-tests were used to describe and analyze data.</p>	
Savun drana yaga m et al. 2010	<p>A dimensional analysis of caregiver burden among spouse and adult children</p>	<p>To asses a) whether the dimensions of burden were the same for caregiving spouses and adult children, (b) the role of assisting with problem behaviors (PBs) and activities of daily living (ADLs) on each dimension of burden, and (c) the role of each dimension of burden on self-rated health and intention to institutionalize the care receiver.</p>	<p>This study included 280 spouse/ partner and 243 adult child caregivers of persons with chronic illnesses.</p>	<p>Analysis using 2-group structural equation modeling showed that the factor structure of burden was equivalent for spouses and adult children. For both groups, assist- ing with ADLs was directly related with objective burden, whereas PBs were directly related to all dimensions of burden. For both groups, stress bur- den was the only predictor of self-rated health, whereas PB s were significantly linked with intention to institutionalize. However, stress burden among spouses and relationship burden among adult c hildren were significantly linked with</p>	

					intention to institutionalize.
Papastavrou et al.	The association between caregiving satisfaction, difficulties and coping among older family caregivers	The aim was to study the association between gender, extent and content of care, satisfaction, coping and difficulties in the caregiving situation among older (75+) caregivers and to identify clusters of caregivers. The aim was also to explore psychometrically two instruments assessing satisfaction and difficulties in family caregivers.	Cross-sectional. The sample for this study consisted of 171 informal caregivers aged 75 and over, identified from an age-stratified sample in a postal survey among older people in the southern part of Sweden.	Male caregivers proved to be more satisfied than female caregivers; caregiving had seemingly widened their horizon and had helped them to grow as persons. Based on satisfaction scores, those satisfied had a higher proportion of male caregivers and a significantly higher amount of caregiving hours per week. They used other coping strategies than the respondents in the other cluster, i.e. less satisfied in using more problem-solving strategies.	
Maria Ferrara et al. 2008	Prevalence of stress, anxiety and depression in with Alzheimer caregivers	To investigate stress, anxiety and depression in caregivers.	Data on 200 caregivers and their patients were collected using a specific form to assess cognitive, behavioral, functional patient (MMSE, and ADL-IAD) and caregiver stress (CBI). The	The caregivers are usually female (64%), mean age of 56.1 years, daughters (70.5%), pensioners and housewives (30%), who care for the sick at home (79%). Of these, 53% had little time for themselves, 55% observed worsening of health, 56% are tired, 51% are not getting enough sleep. Overall, 55% have	

				<p>relationship between stress, depression and disease has been assessed by means of a linear regression, logistic analysis which reveals the relationship between anxiety, stress and depression and cognitive problems, age, the patient's income.</p>	<p>problems with the patient's family and/or their own family, 57% at work. Furthermore, 29% feel they are failing to cope with the situation as they wish to move away from home. The increase in the degree of anxiety and depression is directly proportional to the severity of the illness, affecting the patient ($r = 0.3$ stress and depression $r = 0.4$ related to CBI score). The memory disorders (OR = 8.4), engine problems (OR = 2.6), perception disorders (OR = 1.9) sick of the patient with Alzheimer's disease are predictive of caregiver stress, depression is associated with the presence of other disorders, mainly behavioural (OR = 5.2), low income (OR = 3.4), patients < 65 years of age (OR = 2.9).</p>
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Appendix 2

Figure 2 category matrix for the first research question.



Appendix 3

Figure 3. category matrix for the second research question

