

Vincent Gleviczky

**STUDY OF THE BURDEN OF INFORMAL CAREGIVERS
OF ELDERLY IN KOKKOLA**

Thesis

CENTRIA UNIVERSITY OF APPLIED SCIENCES

Degree Programme in Nursing

December 2014

ABSTRACT

Unit Unit of Kokkola-Pietarsaari	Date December 2014	Author Vincent Gleviczky
Degree programme Bachelor in Nursing		
Name of thesis Study of the burden of informal caregivers of elderly in Kokkola		
Instructor Marjo Tilus-Sandelin		Pages 49 + appendices (24)
Supervisor Anita Hollanti		
<p>The aims and objectives of this research were to assess the level of burden among informal caregivers above 65 years old in Kokkola as well as to investigate the variables correlated to the burden.</p> <p>The study was performed by using a quantitative methodology. Five questionnaires, a sociodemographic questionnaire, the Zarit Burden Interview (ZBI), the Multidimensional Scale of Perceived Social Support (MSPSS), the Lawton-Brody Index (LBI) and the Barthel Index (BI) were sent to informal caregivers of elderly. The data was analysed using the Software Package for Statistical Analysis (SPSS 18).</p> <p>The results of the study showed that the average burden level based on the ZBI was 38,52 ($\pm 14,35$) with half of the respondents were suffering from a mild to moderate burden and one third were suffering from a moderate to severe burden. The level of burden observed among informal caregivers of elderly in Kokkola was significantly correlated to multiple factors. Those factors were a lack of perceived social support for the informal caregiver, a high level of dependency of the informal care receiver, high number of years of care giving, cognitive and behavioural impairment of the informal care receiver and a reduced self rated health and happiness of the informal caregiver.</p> <p>Caregiver burden being such a complex phenomenon, future studies are needed to fully understand the process leading to burden, the burden itself and the consequences of burden on both the informal caregiver and the care receiver.</p> <p>Home nurses have a primordial role in assessing and identifying informal caregivers with high burden in order to prevent negative outcomes such as depression and improve the health of both the informal caregiver and the care receiver.</p>		

Key words

Caregiver burden, elderly, home nurse, informal care, informal caregiver, social support, ZBI

LIST OF ABBREVIATIONS

ADLs	Activities of Daily Living
ANOVA	Analysis of Variance
BI	Barthel Index
COPD	Chronic Obstructive Pulmonary Disease
IADLs	Instrumental Activities of Daily Living
KELA	Kansaeläkelaitos – Finish social security institution
LBI	Lawton-Brody Index
MSAH	Ministry of Social Affairs and Health
MSPSS	Multidimensional Scale of Perceived Social Support
RAI	Resident Assessment Instrument
SPM	Stress Process Model
SPSS	Software Package for Statistical Analysis
THL	National Research and Development Centre for Welfare and Health
ZBI	Zarit Burden Interview

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1 INTRODUCTION

Demographic aging is a current process in Europe and USA and consequently, the senior population becomes more dependent. Dependency is a state in which a person requires help from others in order to perform activities of daily living. An informal caregiver provides needed care to a care recipient, who is most often a relative, friend, or neighbour, on a long-term basis. This does not include caregivers who provide care on a voluntary basis through an organization (such as a church group) or those who provide care as a career. Long-term care often involves assisting the care receiver with personal hygiene, putting clothes on, using the bathroom or household tasks such as preparing meals. As the senior population increases and thus, their functional dependency, it is important to understand factors that influence informal caregivers' well being. Informal caregivers are the main resource for the care of care receivers and are often in need of support while having a risk of psychological morbidity. As the goal of current health policies is to reduce hospital days per stay as well as number of beds in residential care, it is expected that the relatives are more fulfilling caring obligations both in the acute and chronic phase of the patient's illness (Carretero, Garces & Rodenas 2009; Erlingsson, Magnusson & Hanson 2012; Gautun, Werner & Lurås 2011; Yeh, Wieranga & Yuan 2009.)

Caregiver burden, happening when the provided care exceeds the mental and physical capacities of the informal caregiver, is a complex phenomenon involving physical, social, financial and emotional components, as well as affecting relationships and personal strain. (Higginson, Gao, Jackson, Murray & Harding 2010; Garces, Carretero & Rodenas 2010.) The consequences of the caregiver burden can negatively affect the health of the care receiver and the informal caregiver himself as well as contributing to elder abuse. Moreover, it also affects the judgment in institutionalise the care receiver. In the scientific literature, many tools exist to screen and assess the informal care burden but one tool, the Zarit Burden Interview (ZBI), has been identified as the most useful tool. (Van Durme, Macq, Jeanmart & Gobert 2012.)

Caregiver burden assessment can be used by home nurses and social services to identify the caregiver needs and elaborate programmes and interventions in order to improve or increase the informal caregiver's skills in caring for a dependent family member (Garces et al. 2010) as well as prevent negative outcomes such as caregiver depression (Epstein-Lubow, Duncan Davis, Miller & Tremont 2008). The care giving context is highly correlated to the level of burden in informal caregivers. The main factors affecting the care giving context and thus, the burden are the medical condition of the care recipient and its outcomes, the amount of time spent in care giving, the socio-familial situation and the socio-demographic status. (Bastawrous 2013, Garces, Carretero, Rodenas & Sanjose 2009; van Exel, Morée, Koopmanschap, Schreuder Goedheijt & Brouwer 2006). Studies showed that those aged above 65 years old will represent 10% of the population by 2025. Informal care represents 80% of the total care of elderly in the European and it is very important to assess and predict the caregiver burden. (Kehusmaa, Autti-Rämö, Helenius & Rissanen 2013).

The purpose of this study was to improve informal caregiver's well-being in order to improve care receivers' quality of life and positive outcomes. This research attempted to assess the level of burden among informal caregivers of above 65 years old in Kokkola and to investigate the variables correlated to the burden and discussing the nursing implications in the informal caregiver burden. The study has been done in collaboration with the city of Kokkola which provided financial and practical support by sending the questionnaires to the members representing the target population. According to the National Institute for Health and Welfare (THL), in 2012, 291 individuals aged over 65 years old received support for informal care from the municipality of Kokkola.

2 THEORETICAL FRAMEWORK

2.1 Informal care giving

2.1.1 Definitions of informal care giving

Informal caregiver or family caregiver describes an unpaid family member, friend or neighbour whose task is to provide care to an individual suffering from an acute or chronic medical condition. The care receiver needs assistance in Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) and a multitude of other tasks such as wound care, urinary catheter hygiene, ventilator care, etc. (Reinhard, Given & Petlick 2008). ADLs consist of self-care tasks such as hygiene, dressing, eating, moving from one place to another and grooming. IADLs consist of housework, taking medication, managing finances, shopping, telephone or computer use and transportation within the community.

2.1.2 Consequences of care giving

Care giving can produce reward and satisfaction by helping another individual in need. However providing care can have numerous negatives consequences on both the caregiver and the care receiver. Due to the physically and emotionally demanding work, caregivers might suffer from serious adverse effects leading to a decline in the caregiver health. Researches claimed that caregivers possess a higher risk of developing sleep disturbances, fatigue, slower wound healing, immune system impairment, cardiovascular diseases, increase of insulin levels and altered lipid profiles. Moreover caregivers are subject to decrease their own health care by not having sufficient rest, not exercising sufficiently or forgetting their own medical care. Care giving can also negatively affect the social wellbeing by affecting relationships and appearance and the spiritual wellbeing with feelings of hopelessness. (Reinhard et al. 2008; Wittenberg-Lyles, Goldsmith, Parker Oliver, Demiris & Rankin 2012.)

Care giving can also be potentially harmful to the care recipient. A lack of knowledge and competence concerning the care giving tasks or the disease itself can lead to unintentional harm such as infection due to a lack of aseptic care, dehydration, failure in recognizing symptoms, medication errors (dose, time of administration) or failure in recognizing medication side effects. Neglect or elder abuse can also occur including restricted access to food, absence or decreased pain management, isolation, absence of emotional support, decreased hygiene, physical or verbal violence or falls. Anxiety, stress, burden and depression experienced by some informal caregivers have been linked to negative consequences such as abuse and neglect of the elderly (Lee & Kolomer 2007; Reinhard et al. 2008.)

2.1.3 Informal care giving in Finland

Until the 70's, elderly care was under the responsibility of the family members. However, in 1977, according to the Finnish law, the responsibility of elderly care didn't lie anymore with spouses and children. Elderly care became the responsibility of the Finnish social health care system, divided among municipalities, government, the Finnish social insurance institution (KELA), insurance companies and the third sector which provides multiple services such as food on wheels, education, house cleaning, rehabilitation, transportation and so on. According to the Finnish law (L937/2005), an informal caregiver is an unpaid individual responsible for taking care of another individual who can be an elderly, a physically disabled person or a chronically ill patient at the patient's home. (Juntunen & Salminen 2011; Moressi 2010).

In an economical point of view, informal care is very beneficial for the public expenditures. A Finnish study showed that the estimated yearly mean savings in public care expenditure for elderly care is 2.8 billion Euros. Moreover, informal care giving does not strongly affect labour force as the vast majority of informal caregivers are retired. However, the efficiency of informal care giving decreases as the level of disability of the informal care receiver increases. (Kehusmaa et al. 2013).

Between the years 2000 and 2010, the number of caregivers caring for elderly and receiving financial support has grown from 14355 to 24625. Two third of informal caregivers are above 65 years old. Family caregivers who are not officially recognized by KELA were estimated at 300000 in 2010. According to the same study, 4,2% of persons aged above 75 years old were recognized as care receivers by KELA. Moreover, 28% of the informal caregivers have experienced fatigue or exhaustion. (Juntunen & Salminen 2011; Vilkkö, Muuri & Finne-Soveri 2010).

According to the Ministry of Social Affairs and Health (MSAH) and its administrative sector (2007), 75% of family caregivers were women, from which 53% were of working age and 22% were above 75 years old. A report about informal care's support revealed that in the year of 2003, informal caregivers are mostly spouses (43%), children (22%) or parents (22%). In 2006, a report from the National Research and Development Centre for Welfare and Health (THL) stated that about 29500 informal caregivers were taking care of about 22000 individuals, mostly elderly and the informal carer's monthly average allowance was EUR 416. (Moressi 2010).

In 2013, the population of Finland was approximately 5,5 million inhabitants. About 19,4% of the population were above 65 years old and 8,5% above 75 years old. Among the individuals aged above 75 years old, 11,9% were institutionalized, 6,1% received a house service with 24 hours assistance and 4,6% were taken care of by officially recognized caregivers. Among the individuals aged above 65 years old, 24,6% were granted financial support for informal care. (Statistics Finland 2013).

2.2 Informal caregiver's burden

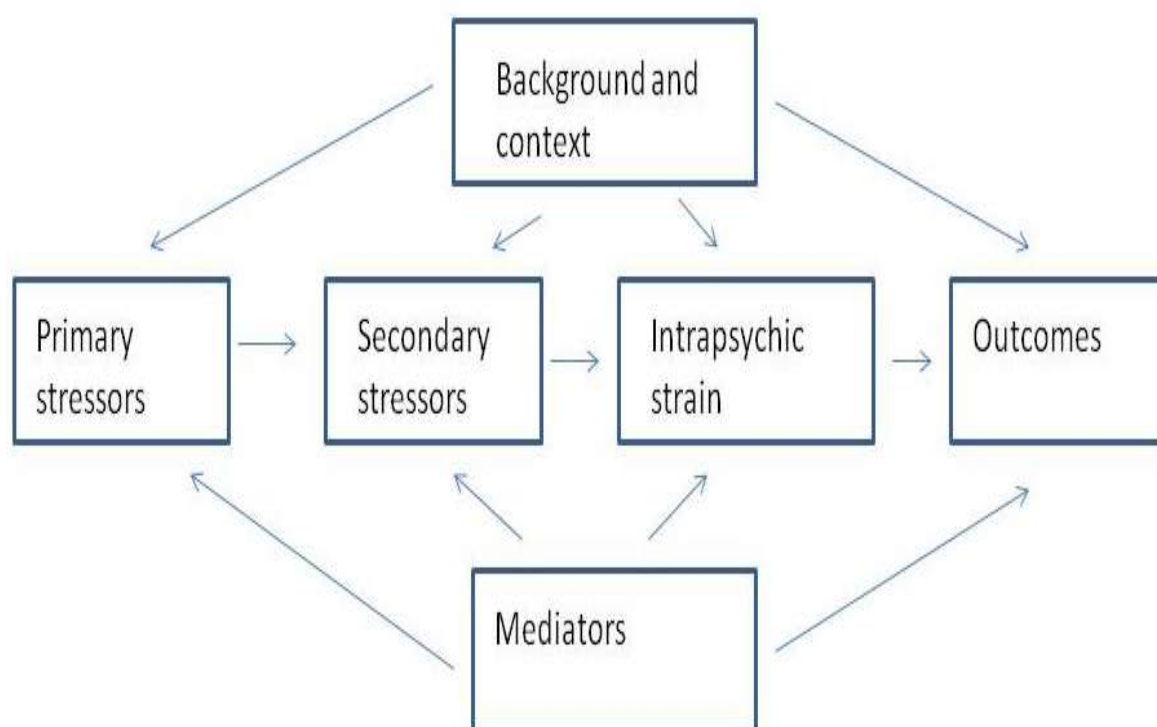
2.2.1 Definition of informal caregiver's burden

Caregiver stress is experienced when life events, chronic life strains, individual self-concepts and coping mechanisms along with the presence or absence of social supports come together to create an environment that challenges the individual's capacity to adapt to role of primary caregiver. Caregiver stress can become a chronically condition and is known as caregiver burden, which can be defined as a physical and psychological consequence of the imbalance of care demands due to intrapersonal and environmental factors, such as caregiver's personal time, social role, physical and emotional conditions of both the caregiver and care receiver, financial and formal resources. The direct and indirect effects of caregiver burden can lead to negative outcomes concerning the well being of both the informal caregiver and the person being cared for. Negative consequences on the caregiver comprise physical and mental medical conditions, such as anxiety, depression, cardiovascular problems, etc. Negative consequences for the person cared for are, among others, breakdown of care, abuse or institutionalization of the dependent person. (Carretero et al. 2009; Nelson Bialon & Coke 2012; Sherwood, Given, Given & Von Eye 2005.)

2.2.2 The Stress Process Model

The Stress Process Model (SPM) can be used to explain the burden and the stress associated to informal care giving. Pearlin (1990) stated that there are different types of stress factors which can affect the caregiver. This stress process model has been modified and adapted to the informal care giving context by Zarit & Edwards in 1996. In the SPM (Graph 1), the primary stressors are the difficulties affecting the carer related to the care receiver's condition such as loss of dependence or cognitive or physical impairment. The secondary stressors are the consequences of care giving and include among others social isolation, financial difficulties or family conflict. The intrapsychic strain describes the carer's burden or

changes in the sense of self. Mediators comprise health care professionals, social services, coping strategies, family and friends as well as the caregiver's own coping skills, self esteem, personality or care values. Those mediators can positively or negatively impact on both primary and secondary stressors, intrapsychic strain and outcomes. Outcomes comprise of negative consequences on the well being of the caregiver including depression, anxiety or physiological reactions. The background and context describes factors unrelated directly to the care giving such as the client's medical diagnosis, the relationship between the caregiver and the care receiver, age, gender and education of the caregiver as well as health, social, financial and emotional status of the caregiver, etc. As the mediators, the background and context can influence both primary and secondary stressors, intrapsychic strain and outcomes. (Carradice, Shankland & Beail 2002; Bastawrous 2013.)



GRAPH 1. Stress process model among informal caregivers adapted from Zarit & Ewards (1996).

2.2.3 Risk factors of informal caregiver burden

Due to the complexity of the SPM, caregiver burden can be caused by many different factors. Caregiver burden has been linked to the caregiver's health status, unhealthy behaviour such as smoking or alcohol consumption, high use of prescribed medication, or low personal or household income. Moreover, caregiver burden is associated with employment and marital status and relationship with the care receiver. (Nelson Bialon & Coke 2012, Reinhard et al. 2008.) Burden can occur due to factors related to care giving context such as the medical condition of the care receiver, the length of care in years or the number of hours of care per day, a lack of perceived social support or the type of care giving activities, personal care (eg. dressing, bathing) being more burdensome than instrumental care (eg. cooking, cleaning), poor or lack of sleep, physical and psychological exhaustion, fear and worry, lack of leisure time and physical activity. (Chiou, Chang, Chen & Wang 2009; Erlingsson et al. 2011, Hirano, Suzuki, Kuyuzo, Onishi, Hasegawa, Ban & Umegaki 2011; Vlachantoni, Evandrou, Falkingham & Robards 2013; Yeh et al. 2009.)

2.3 The nurse-client-informal caregiver triadic collaboration

The most important practical implication of the assessment of caregiver burden is that nurses can decrease the burden and increase the implication of the caregiver in decision-making concerning the treatment of the care receiver. Informal caregivers are an important part of the nursing care by providing information about the patient and facilitating communication with the care receiver and other family members. Nurses need to empower informal caregivers and improve their role, image and values as caregivers. Nurses can provide information to the informal caregiver, establish cost-effective treatment plans with the informal caregiver and assessing the caregiver's quality of life in the interest of the care receiver. (Wittenberg-Lyles et al. 2012.) This interaction and communication with the informal caregiver is consistent with Dalton's theory of collaborative decision-making in nursing triads, where the triad consists of the nurse, informal caregiver and patient (care receiver).

The Theory of Collaborative Decision-Making in Nursing Triads was created to describe and explain the decision-making process between care receivers, informal caregivers and nurses, and how this interaction affects the care receiver's outcomes. Dalton (2005) described three types of nursing care decision; the programme decision which focuses on goals and education, the operational control decision which focuses on the way actions are performed (such as changing dressing or administering medication for example) and the agenda decision which focuses on time and energy allocation. Dalton (2005) pointed out that client-caregiver-nurse communication increases the informal caregiver's understanding and knowledge of the care plan and reinforces relationships between the informal caregiver and the family. Moreover Dalton (2005) explained that among nursing triads (informal caregiver, client and nurse), coalitions can appear. Coalitions happen when two individuals in a triad follow an identical strategy to achieve a common goal despite an active or passive lack of cooperation of the third individual. Due to the weakness of the client (care receiver), the majority of coalitions appear between nurses and informal caregivers, pointing out the importance of the role of the informal caregiver in the nursing plan. (Dalton 2005.)

3 PREVIOUS RESEARCHES

In 2009, a Spanish study's objective was to investigate the variables associated to caregiver's burden of senior dependents found that female spouses informal caregivers with a restricted social network suffered from higher burden. The investigation used quantitative methods based and the tests were, among others, the ZBI and the Barthel Index (BI) to assess the functional capacity of the care receiver. Socio-demographic status of the informal caregiver was also investigated. This study showed that the main variables associated with informal caregiver's burden were the dependency of the care receiver and especially the mental impairment of the care receiver. (Garces et al. 2009.)

In 2013, a Turkish study investigated the relationship between caregiver burden and social support in patients with dementia. It turned out that, female informal caregivers over 50 years old had higher level of burden. The caregiver's burden was also correlated to the care receiver's dependence level (the more dependent the care receiver the higher the burden), the education of the caregiver (the lower the level of education the higher the burden), the relationship with the care receiver (married informal caregivers had a higher burden) and the perceived social support of the caregiver (the lower the perceived social support the higher the burden). The ZBI mean score was $53,09 \pm 18,19$. The study was quantitative and the tools used were the ZBI, the Multidimensional Scale of Perceived Social Support (MSPSS), the BI and the Lawton-Brody Index (LBI) for the functional dependency of the care receiver. (Yurtsever, Özge, Kara, Yandim, Kalav & Yecil 2013.)

A study among informal caregivers of Alzheimer patients during 2010 and 2011, in France, Germany and UK revealed that ZBI was between 24 and 35. This difference is due to different factors such as the relationship between the caregiver and the patient and the type of Alzheimer disease. Moreover, the results showed that while 2/3 of the informal caregivers were spouses, child caregivers suffered from a higher burden than spouses' caregivers. Patient functioning and cognitive impairment were also significantly associated with caregiver burden. (Reed,

Belger, Dell'Agnello, Wimo, Argimon, Bruno, Dodel, Haro, Jones & Vellas 2014.) In 2011, a Dutch study showed that caregivers of care recipients suffering from a combination of mental and somatic diseases experienced a higher burden compared with care recipients suffering from mental diseases or somatic diseases. In this study, informal caregivers or care recipients suffering from somatic diseases experienced the lesser burden. (Hastrup, Van Den Berg & Gyrd-Hansen 2011).

In Finland, a study of 2012 on gender differences in dementia spousal care giving showed that the average ZBI score was $37,5 \pm 14,6$ for female caregivers and $31,5 \pm 14,9$ for male caregivers. The mean age for dementia spousal caregivers was 77,0 and 78,4 for respectively male and female caregivers. The results showed that male caregivers for dementia experienced significantly less burden. (Pöysti, Laakkonen, Strandberg, Savikko, Tilvis, Eloniemi-Sulkava & Pitkälä 2012.). In Western Finland, a similar study has been conducted on the source of satisfaction of informal caregivers of older relatives. In this study, the results showed that 31% of caregivers felt highly or very highly burdened. (Kuuppelomäki, Sasaki, Yamada, Asawaka & Shimanouchi 2004.)

4 RESEARCH PROBLEMS

The purpose of this study was to improve informal caregiver's well-being in order to improve care receivers' quality of life and positive outcomes. As mentioned earlier, the consequences of the caregiver burden can negatively affect the health of the care receiver and the informal caregiver himself as well as contributing to elder abuse. Furthermore, it also affects the judgment in institutionalize the care receiver. Thus, it is essential for home care nurses to recognize the predisposing factors leading to burden in order to improve the care receiver's health. It would also be interesting to have a more specific knowledge about the burden experienced by informal caregivers in Kokkola. The predisposing factors based on the SPM in graph 1 are the primary stressors, the secondary stressors, the mediators and the background and context.

Therefore the goal of this study was to assess the burden of informal caregivers of elderly in Kokkola and study the possible variables correlated with informal caregiver's burden.

The research questions in this study were as follow:

1. What was the level of burden of informal caregivers caring for over 65 years old individuals in Kokkola?
2. What were the variables associated with informal caregiver burden?

5 RESEARCH METHODOLOGY AND DATA COLLECTION

5.1 Quantitative and correlational study

The general objective of nursing research is to answer questions or solve problems related to nursing. This study can be defined as a basic research in opposition to an applied research. Basic research is undertaken to extend the knowledge while applied research focuses on finding solutions to an existing problem. The first research question was quantitative and descriptive. Moreover, it is a cross sectional study since the data has been collected at one specific point in time.

The second research question was a correlational study. The goal of correlational research was to find out whether one or more variables can predict other variables. Correlational research allows us to find out what variables may be related. However, the fact that two factors are related or correlated does not mean there is a causal relationship. Two factors can be correlated without there being a causal relationship. (Polit & Beck 2004.)

5.2 Data collection

The collection of data has been realized by using questionnaires. The questionnaires have been sent in Finnish language. Five questionnaires including in total of 66 questions assessed the level of burden and provided information about the care giving context. The physical and mental impairment of the care receiver as consequences of the disease have been assessed using the BI (Appendix 3) and the LBI (Appendix 4), information about the socio-demographic status of the informal caregiver, the self rated health and happiness, the length of care giving in years, days per week and hours per day, the main activities of care giving, help in home care, received information and the diseases of the care receiver have been obtained using a socio-demographic questionnaire (Appendix 5), the perceived social support has been assessed using the MSPSS (Appendix 2) and the burden has been assessed using the ZBI (Appendix 1).

Although many tools exist in the literature, the 22-items ZBI is the most reliable and valid tool to assess the level of burden among informal caregivers (Higginson et al. 2010). This is mainly because it covers many aspects such as social, physical, emotional and financial burden as well as the relation to the care receiver (Van Durme et al. 2012). Each question is scored on a 5 point (0 to 4) Likert scale, ranging from - never to nearly always present. Total scores range from 0 (low burden) to 88 (high burden).

The perceived social support has been assessed using the MSPSS (Appendix 2). The MPSS was developed by Zimet (1988) and uses a Likert-type scale with 12 questions ranging from 1 (very strongly disagree) to 7 (very strongly agree). The MSPSS possesses three subscales to evaluate the perceived social support by family, friends and significant other. The MSPSS has been proven to be valid and reliable. (Yurtsever et al. 2013.)

The cognitive and physical impairment due to the disease of the care receiver have been evaluated using the BI (Appendix 3) and the LBI (Appendix 4). The BI consists of 10 questions evaluating the care receiver's daily functioning and mobility. The score ranges from 0 (fully dependent) to 100 (fully independent). The LBI consists of eight questions evaluating the care receiver's level of performing activities of daily living. The score ranges from 8 (fully dependent) to 24 (fully independent). Both indexes are valid and reliable. (Yurtsever et al. 2013.)

The socio-demographic status and additional information have been obtained using a form to fill in (Appendix 5). This form required information about the caregiver such as (sex, age, education, health, relationship with the care receiver, duration of care giving, intensity of care giving, diagnosed disease, perceived health status and happiness of the care receiver). (Garces et al. 2009, van Exel et al. 2006.)

The questionnaires have been sent by post and retrieved after two weeks.

5.3 Data analysis

The data has been analysed using the Software Package for Statistical Analysis (SPSS 18) and included multivariate statistics because of the complexity of the phenomena and the presence of multiple variables. The dependent variable was the ZBI score. Pearson's correlation was used to correlate the dependent variable with interval variables such as age of the informal caregiver, length of informal care, as well as the MSPSS score, LBI and BI. Two independent sample t-test were used to correlate the dependent variable with categorical variables possessing 2 categorical data such as gender, additional help received and sufficiency of received information. One-way Analysis of Variances (ANOVA) has been used to correlate the dependent variable with categorical variable possessing more than two categorical data such as education, employment, relationship with the care receiver, self rated health and self rated happiness.

5.4 Target population

According to the THL, 291 individuals aged above 65 years old received support from the municipality of Kokkola for informal care in 2012. Therefore, those 291 individuals represented the target population.

5.5 Ethics

It is widely agreed that nursing research is important for evidence based nursing and thus improving nursing care. However, nursing research must follow ethical considerations in order to protect the participants which are informed consent, confidentiality, data protection, right to withdraw, potential benefits and potential harms of the study. Informed consent means that the participants are fully informed of the research goals and potential benefits and harms of the study, and this information should be clearly understandable by the participants. The informed consent should be signed by the participant but in non-observational or non-therapeutic studies this is not a requirement. (Haigh & Williamson 2009).

Concerning the confidentiality, the identity of the participants should not be recognizable in research reports. Moreover, all confidential data should be stored in a locked cabinet. According to the ethics in nursing research, participants have the right to withdraw from the research at any time and are not obliged to participate in the research. Those points must also appear in the informed consent. (Haigh & Williamson 2009).

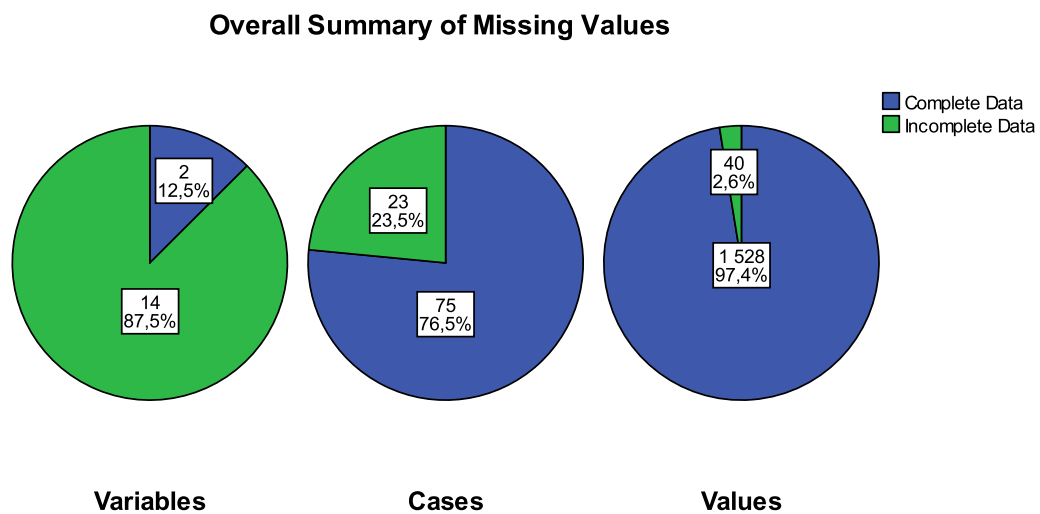
In this study, the researcher respected participants' rights by informing them about the study. The participants were well-informed so that they could choose to participate in this study and they are also allowed to withdraw from this study at any time. Their privacy right was also respected in this study since the participant chose his own time and extended time to answer the questionnaire. Moreover, the information presented from the questionnaire have not been shared in this study. To ensure the right to privacy, the questionnaire was completed anonymously, protecting the respondent's right to anonymity and confidentiality. All information has been presented in a cover letter (Appendix 8) with the questionnaire. The potential benefits of the study have been explained in the informed consent. However, the potential harms of the study, such as negative emotions while answering the questionnaire have not been précised in the cover letter.

5.6 Validity and reliability

The tools used in this study such as ZBI, BI, LBI, MSPSS as well as the sociodemographic questionnaire have been widely used in similar studies as explained in chapter 3 and 5.2. Thus, those tools are reliable and valid. However, the researcher had to translate the MSPSS and the BI into Finnish language for this study. The translations have been corrected and modified by both the supervisor teacher and the contact person at the city of Kokkola. Those questionnaires translated into Finnish language have not been tested prior to the study. Concerning the ZBI and the LBI, Finnish translations were available in the literature.

6 FINDINGS OF THE RESEARCH

A total of 213 questionnaires have been sent on the 15.12.2013 by the city of Kokkola to registered informal caregivers. One hundred questionnaires have been retrieved by the 31.1.2014, which corresponds to a response rate of 47%. From those one hundred questionnaires, two didn't present any answers and were consequently discarded. Among the 98 questionnaires left, some singular questions were sometimes not answered but those questionnaires were kept anyway because the missing data corresponded only to 2,6% of the total possible data (Graph 2) which did not impact statistical analysis. A missing value analysis done using SPSS showed us that 75 questionnaires (cases) out of the 98 possessed a complete data set (Graph 2). However, multiple linear regression has not been used in this study because of the missing information since the linear regression would have been based on 75 cases.



GRAPH 2. Summary of missing values analysis from the 98 questionnaires.

6.1 Sociodemographic data of the sample

As shown in Table 1, the informal caregiver or family caregiver in this study is often female (74,2%). Most of the informal caregivers possess a vocational school

degree (39,6%) or suspended their education after primary school (47,9%). About 6,3% pursued their studies to University of Applied Sciences while 3,1% had a degree from the university or resumed their education after gymnasium. The average age of informal caregivers is 70,73 years old, the youngest being 44 years old and the oldest 93 years old. The majority (83,5%) is retired with 8,2% working as full-time and 3,1% working as part-time respectively. Approximately 5,2% of the informal caregivers were unemployed in this study.

TABLE 1. Sociodemographic data of the sample.

Characteristics of the caregiver		N (sample size)
Age (years) mean±SD	70,73±8,73	97
median	72	
range	44-93	
	Percentage (%)	
Caregiver gender		97
Male	25,8	
Female	74,2	
Caregiver education		96
University	3,1	
University of applied sciences	6,3	
Vocational school	39,6	
Gymnasium	3,1	
Primary school	47,9	
Caregiver employment status		97
Full time	8,2	
Part time	3,1	
Unemployed	5,2	
Retired	83,5	

6.2 Characteristics of the care context

As shown in Table 2, the informal caregiver in this study consisted usually of spouse (68,4%) or child (18,4%) of the dependent person, who provides continuous care (70,2%) for a duration inferior to five years (69,7%). The majority of the informal caregivers received some additional help (57,9%) and they were satisfied with the amount of information received concerning the informal care (72,6%). About 44,9% of the caregivers considered themselves healthy while

13,3% considered themselves sick. Moreover, 32,6% of the caregivers considered themselves happy while 20% considered themselves of being sad. Approximately 33,7% and 41,1% couldn't rate their level of health and happiness respectively. About 69,7% of the informal caregivers have provided care for less than five years and 20,2% for a period of time comprised between five and 10 years. Around 1,1% of the informal caregivers have provided informal care for more than 25 years.

TABLE 2. Characteristics of the care context.

Characteristics of the care context	Percentage (%)	N (sample size)
Relationship with the care receiver		98
Husband	15,3	
Wife	55,1	
Child	18,4	
Other family member	7,1	
Other	3,1	
	1	
Caregiver self related health		98
Very sick	1	
Sick	13,3	
Can not say	33,7	
Healthy	44,9	
Very healthy	7,1	
Caregiver self related happiness		95
Very sad	4,2	
Sad	20	
Can not say	41,1	
Happy	32,6	
Very happy	2,1	
Duration of informal care in years		89
<5 years	69,7	
5-10 years	20,2	
10-15 years	2,2	
15-20 years	3,4	
20-25 years	3,4	
>25 years	1,1	
Duration of informal care in hours per day		94
<5hours	12,8	
5-10hours	12,8	
10-15hours	2,1	
15-20hours	2,1	
>20hours	70,2	
Additional help received in home care		95
Yes	42,1	
No	57,9	
Enough information received concerning informal care		95
Yes	72,6	
No	27,4	

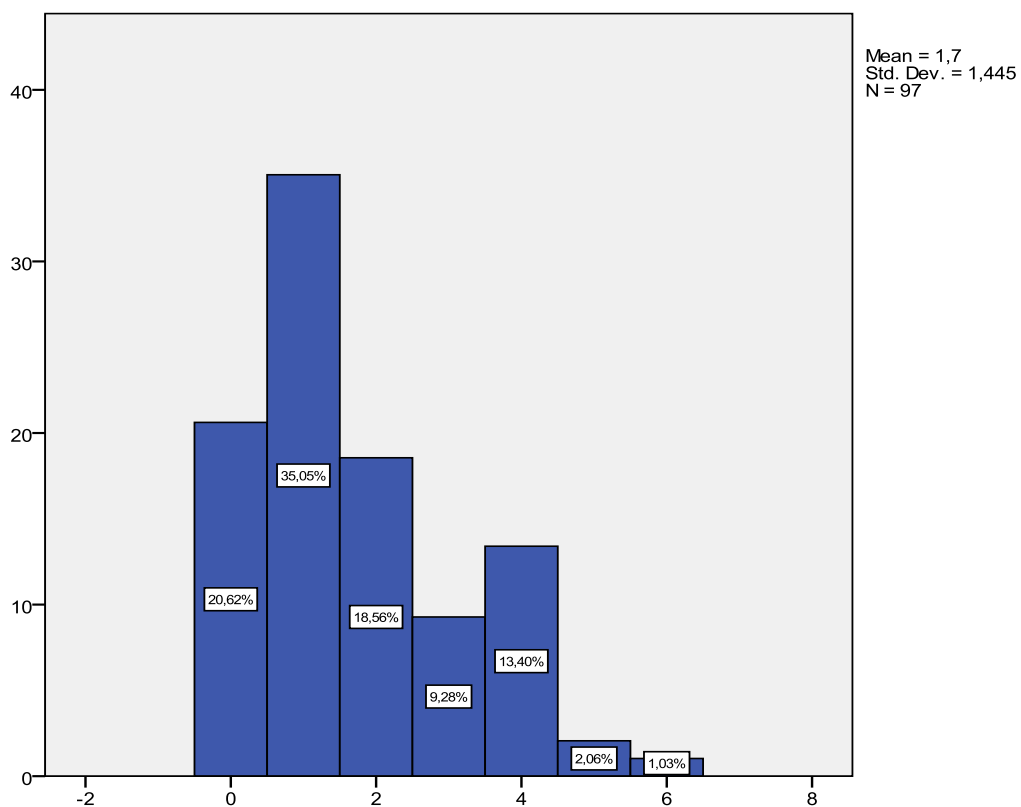
6.3 Health status of the care receiver

As shown in Table 3, the average score of the LBI, used to assess independent living skills such as telephoning, shopping, food preparation, housekeeping, laundering, use of transportation, use of medicine and financial behaviour was $1,7 \pm 1,445$, ranging from 0 to 8 with 0 meaning total dependency and 8 total independency. As shown in the Graph 3, more than one third of the care receivers scored 1 on the LBI, indicating a high level of dependency.

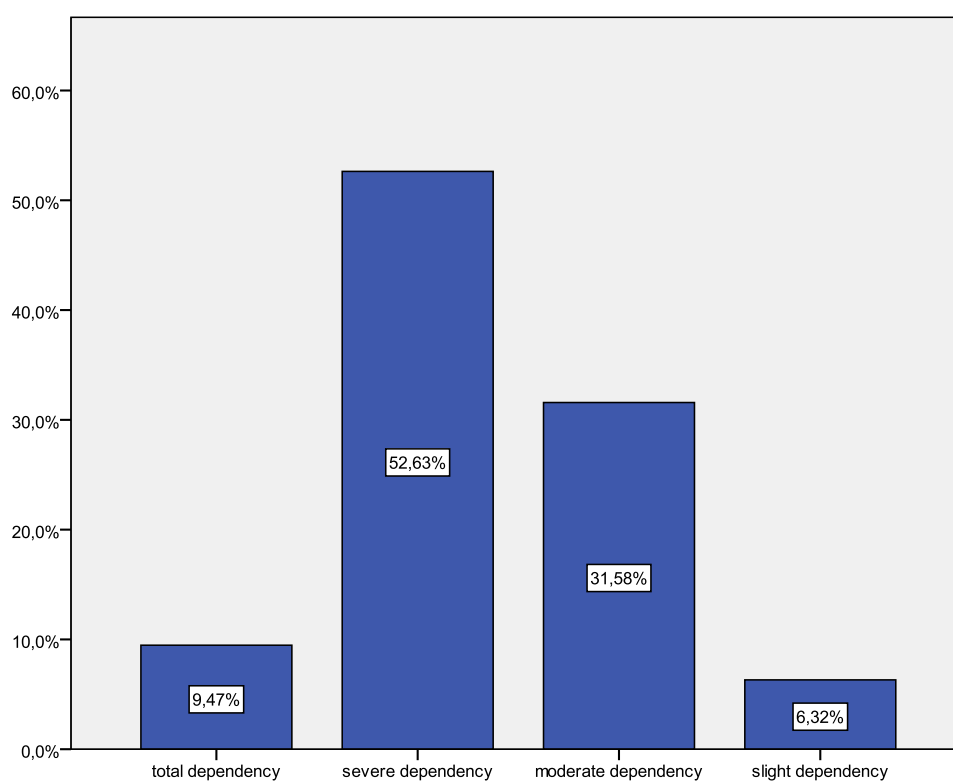
The BI measures a person's daily functioning, specifically the activities of daily living and mobility. The items include feeding, moving from wheelchair to bed and return, grooming, transferring to and from a toilet, bathing, walking on level surface, taking the stairs, dressing, continence of bowels and bladder. As shown in Table 3, the average score of the care receivers was $56,37 \pm 22,603$, ranging from 0 to 100. According to Shay (1989), the BI score can be subdivided in four categories indicating the level of dependency with total dependency ranging from 0 to 20, severe dependency from 21 to 60, moderate dependency from 61 to 90, slight dependency from 91 to 99 and total independency with a score of 100. Graph 4 shows that 52,63% of the care receivers are severely dependent and 9,47% are totally dependent while 31,58% are moderately dependent and 6,32% are slightly dependent.

TABLE 3. Characteristics of the care receiver.

Characteristics of the care receiver		N (sample size)
LBI score (0-8)		97
Mean \pm SD	1,7 \pm 1,445	
Median	1	
Range	0-6	
BI score (0-100)		95
Mean \pm SD	56,37 \pm 22,603	
Median	55	
Range	0-100	



GRAPH 3. Proportion in percentages of LBI scores of the care receivers.



GRAPH 4. Dependency of care receivers in percentage based on the BI score.

As shown in Table 4, the three main diagnosis of the care receivers were Alzheimer's disease, stroke and physical disability with respectively 28,1%, 15,3% and 12,2%. Physical disability included hemiplegic care receivers, hip reconstruction, amputated leg, blindness and other physical disabilities. Dementia, cardiovascular diseases and Parkinson had a similar proportion of 10,2%. About 6,1% of the care receivers suffered from cancer as main diagnosis while 2% suffered from multiple sclerosis. Old age (3,1%) was among the answers concerning the principal diagnosis.

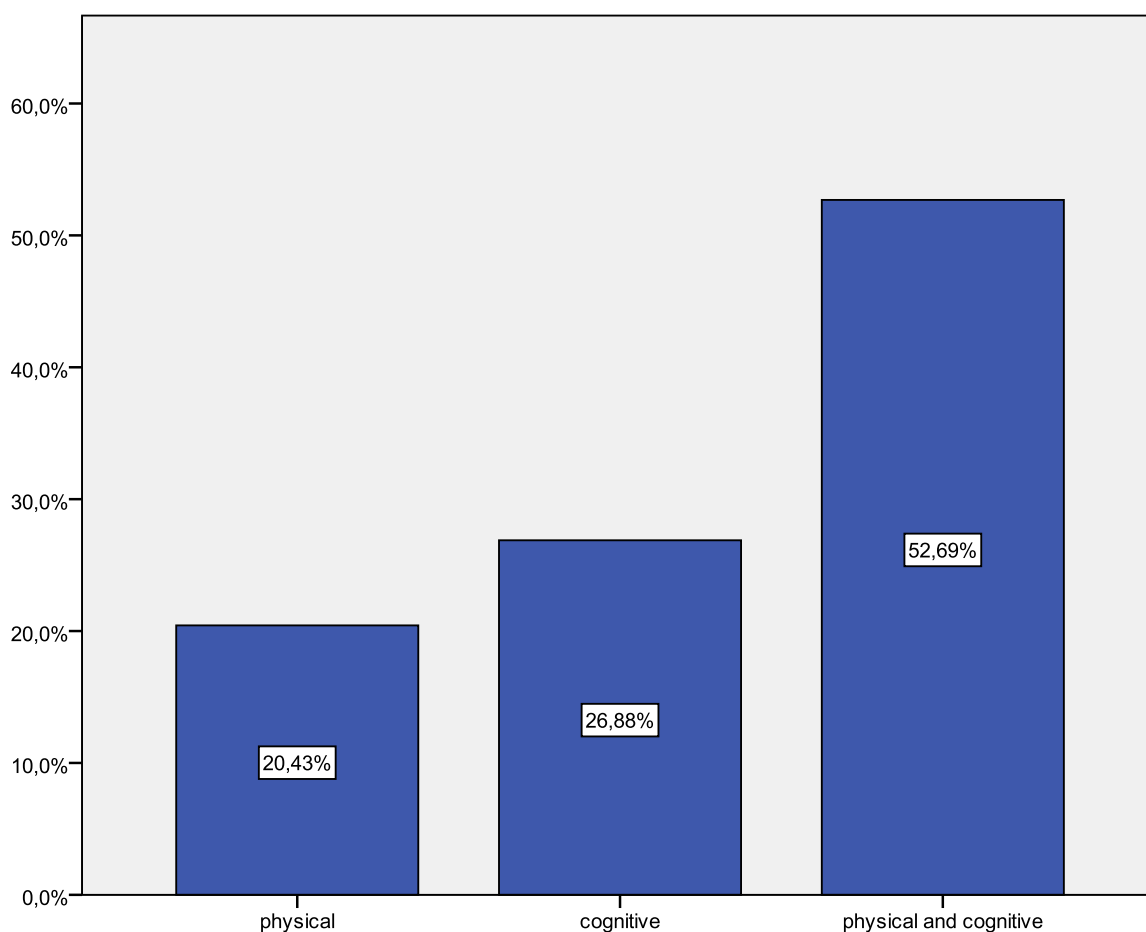
TABLE 4. Principal diagnostic of the care receiver.

Principal diagnostic	Percentage (%)	N=96
Alzheimer	28,1	
Stroke	15,3	
Physical disability	12,2	
Dementia	10,2	
Cardiovascular	10,2	
Parkinson	10,2	
Cancer	6,1	
Old age	3,1	
Multiple sclerosis	2	
Other	1	

A problem observed during reading the answers of the survey is that most of the care receivers suffered from a combination of the diseases cited. Moreover some participants wrote some other diseases in addition to the main diagnostic such as diabetes, thyroid insufficiency, memory problems, amputated leg, epilepsy, hip replacement, depression, chronic obstructive pulmonary disease (COPD), etc. It is thus difficult to analyze this variable in a statistical way in order to find a correlation between caregiver's burden and the care receiver's disease.

However, it is possible to group the different medical conditions of the informal care receiver in three distinct groups according to the symptoms which are physical impairment, cognitive impairment and a combination of physical and cognitive impairment.

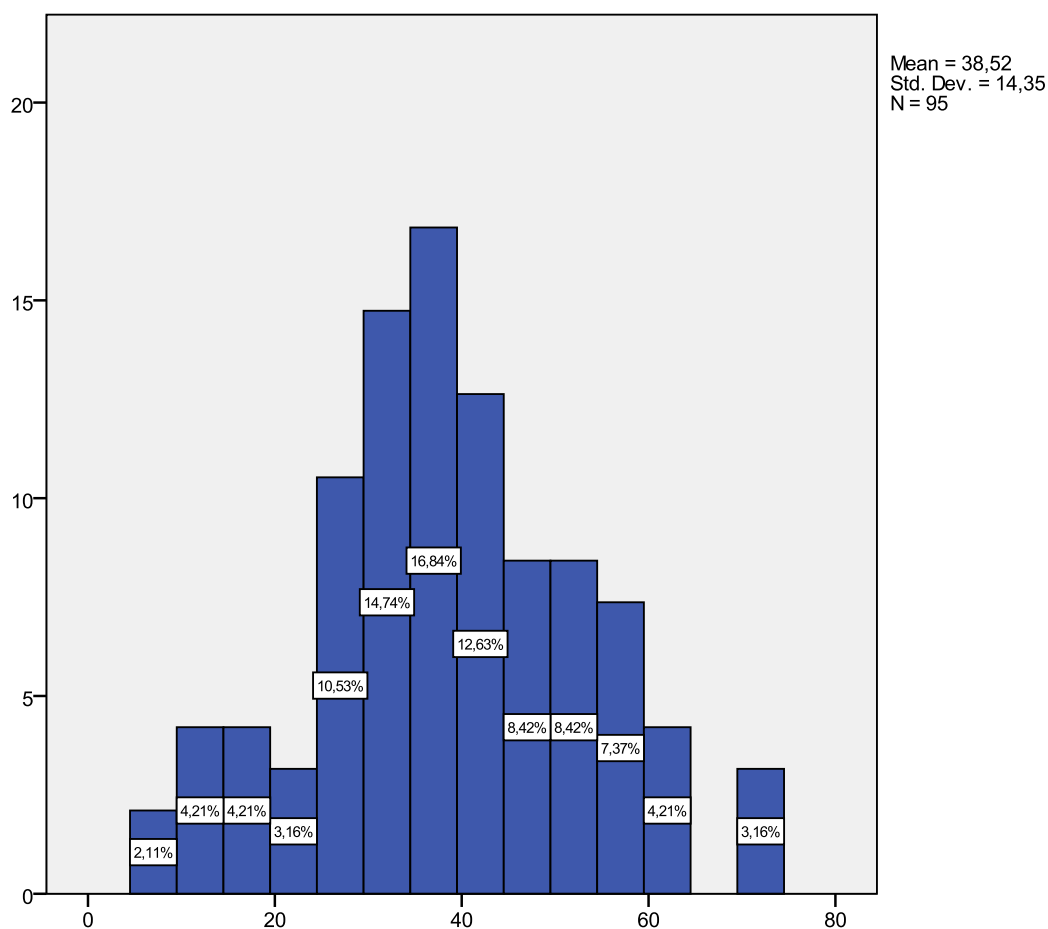
As shown in the Graph 5, more than half of the care receivers suffered from a combination of physical and cognitive impairment. Approximately 27% of the care receivers presented only cognitive symptoms and 20% suffered from a physical disease or presented only physical impairment.



GRAPH 5. Proportion in percentages of the informal care receivers diseases according to the type of symptoms (physical, cognitive or physical and cognitive).

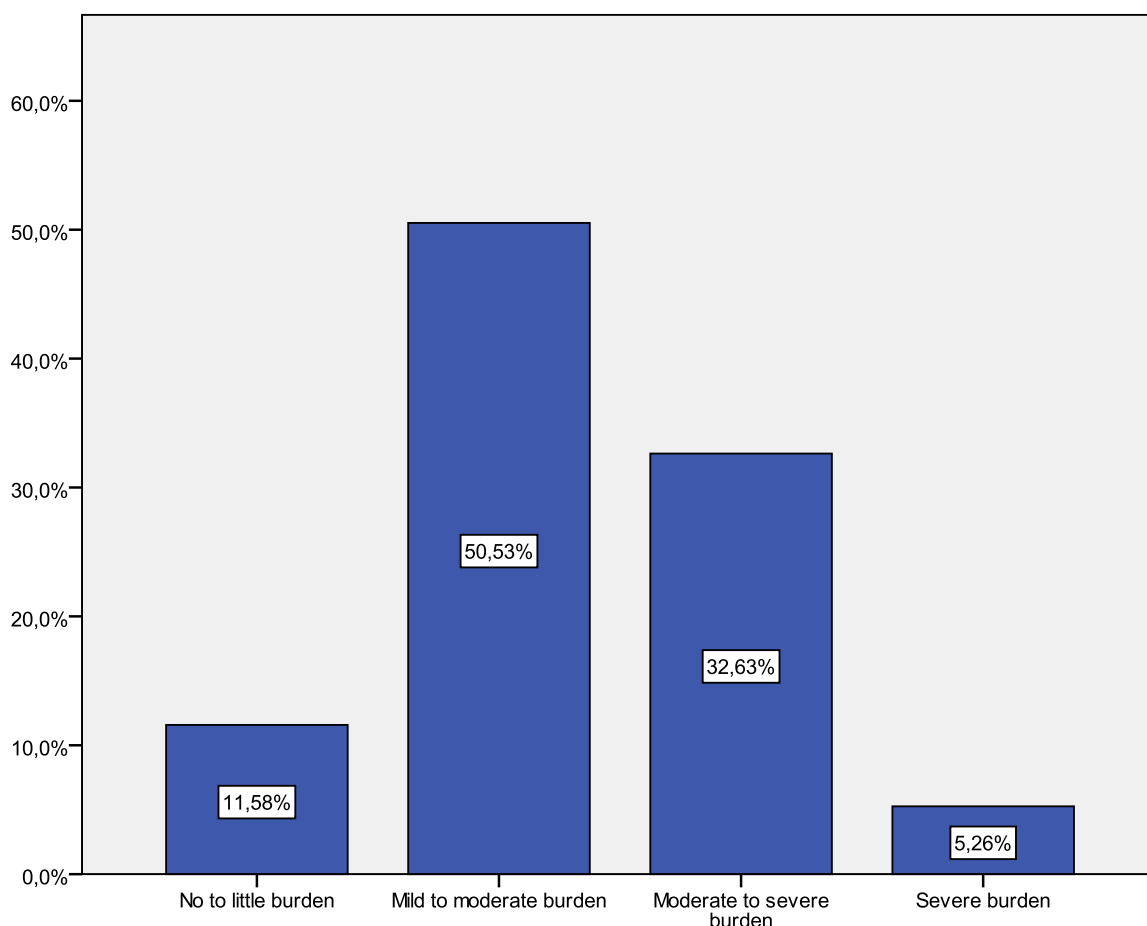
6.4 Zarit Burden Interview – Assessment of the caregiver’s burden

As shown in Graph 6, the average burden of the sample is $38,52 \pm 14,35$ and ranges from seven to 71, the maximum possible burden being 88. The burden of the sample follows a normal distribution.



GRAPH 6. Distribution of the ZBI scores of the caregivers.

The ZBI score can be divided into four categories according to the severity of the burden as shown in Graph 7; no to little burden (ZBI score from 0 to 20), mild to moderate burden (ZBI score from 21 to 40), moderate to severe burden (ZBI score from 41 to 60) and severe burden (ZBI score from 61 to 88) (Tang et al. 2013). In our study, as shown in Graph 7, half of the sample suffered from a mild to a moderate burden. Around one third of the sample suffered from a moderate to severe burden while 5,26% suffered from severe burden. 11,58% of the caregivers suffered from no to little burden.



GRAPH 7. Distribution of the ZBI scores according to level of burden.

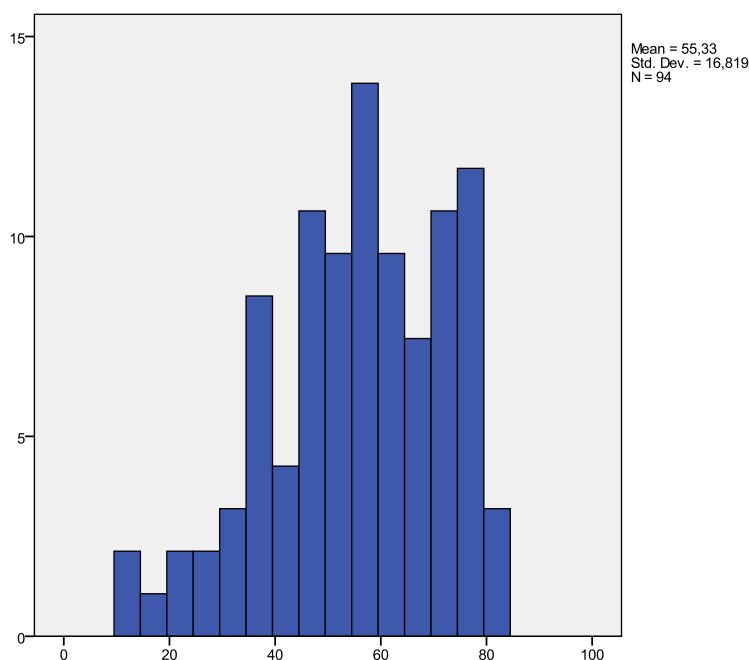
The caregiver's burden can be subdivided in five sub domains based on the questions of the ZBI. Those sub domains are burden in the relationship, emotional burden, social and family life burden, financial burden and loss of control over one's life. As seen in Table 5, the sub domain burden in the relationship represented the most important part of the burden with a mean value of 2,0667 while the financial burden was the least consequent with a mean value of 1,1474. The three other sub domains had an equivalent responsibility in the general burden with a mean value of 1,6346 for the emotional burden, 1,6868 for the social and family life burden and 1,6947 for the loss of control over one's life. Those five sub domains have been weighted in order to have a comparable mean value, ranging from 0 (no burden) to four (maximum burden).

TABLE 5. Mean and standard deviation of the five sub domains of burden of this study.

Domains of burden (0-4)	Mean±SD
Burden in relationship	2,0667±0,65837
Emotional burden	1,6346±0,69666
Social and family life burden	1,6868±0,91962
Financial burden	1,1474±1,20255
Loss of control over one's life	1,6947±0,77372

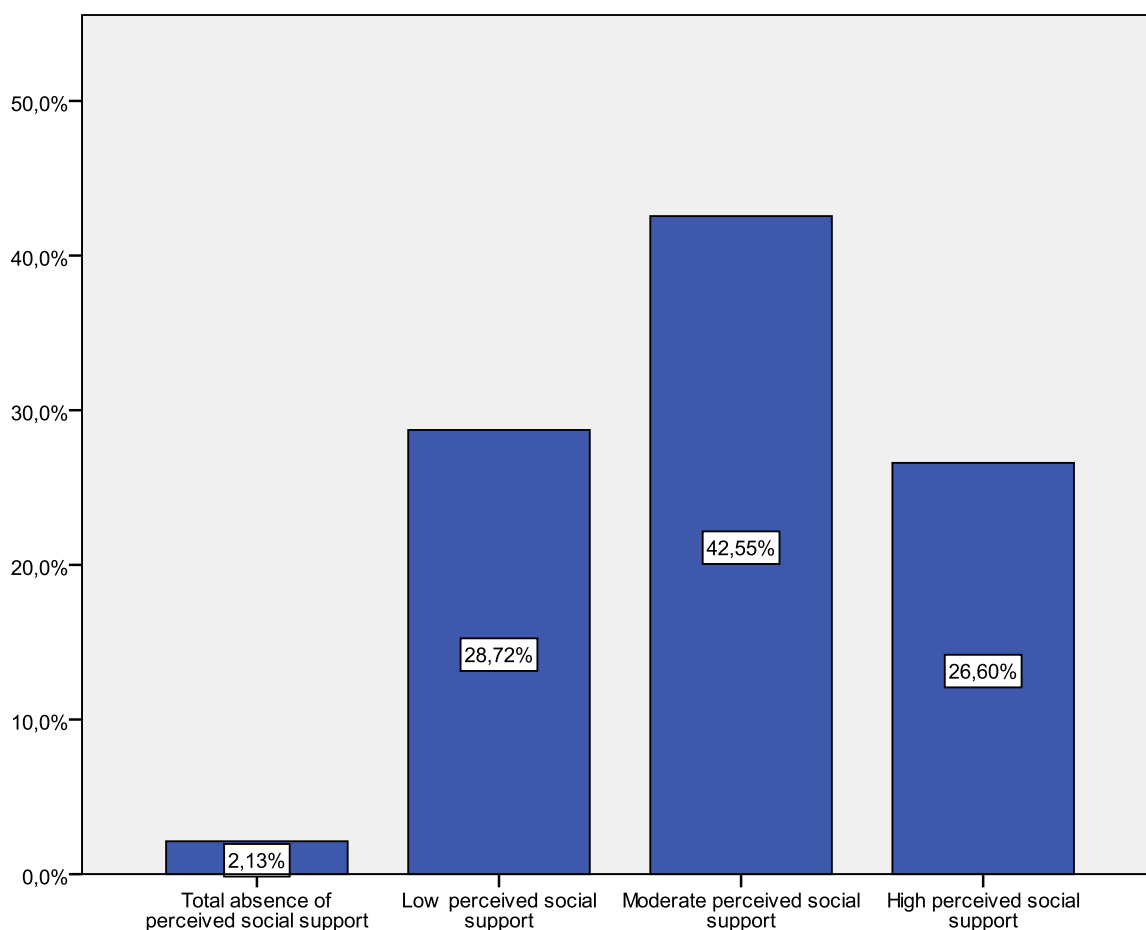
6.5 Multidimensional Scale of Perceived Social Support

Graph 8 shows the distribution of the MSPSS score. The mean score was $55,33 \pm 16,819$, seven being the minimum perceived social support and 84 being the maximum perceived social support. The perceived social support can be divided in low, moderate and high social support with scores ranging from 12 to 48, 49 to 68 and 69 to 84 respectively. A score below 11 means total absence of support. Graph 9 shows the proportion in percentages of the three different levels of perceived social support.



GRAPH 8. Distribution of the MSPSS scores of informal caregivers in percentage.

As the Graph 9 depicts, the majority of the respondents (42,55%) benefit from moderate perceived social support. Around 26,6% have a high perceived social support while 28,7% have a low perceived social support. About 2,1% of the informal caregivers do not benefit from any perceived social support.



GRAPH 9. Proportion in percentage of the level of perceived social support of the informal caregivers.

6.6 Analysis of correlation between the variables and the caregiver's burden

SPSS analyses showed that there was no correlation ($p > 0,05$) between the burden of the informal caregiver and the gender, the level of education and employment status of the informal caregiver (Table 5). Moreover, the relationship between the informal caregiver and the care receiver did not seem to have an impact on the burden. Concerning the care giving context, the number of hours per

day spent by the informal caregiver in care giving activities were not correlated to the burden ($p>0,05$).

On the other hand, the age of the caregiver was significantly negatively correlated to the burden of the caregiver ($p<0,05$). It means that the older the caregiver, the lesser the burden. The burden was also significantly less important when the informal caregiver perceived itself as healthier or happier ($p<0,01$). As indicated by the significant negative correlation with the variable MSPSS ($p<0,01$), the higher the perceived social support the lower the burden. The cognitive and physical impairment of the care receiver had also an effect on the burden. The dependency of the caregiver in activities of daily living as shown by the negative significant correlation with the Bartel Index ($p<0,05$) shows that the more dependent the care receiver was, the higher the caregiver's burden. There was no significant correlation with the LBI ($p=0,058$) but the p value was very close to being significant. Moreover, there was a positive significant correlation between the number of care giving years and the caregiver's burden ($p<0,05$), meaning that the informal caregiver's burden increases with the number of care giving years. The type of disease or type of symptoms of the care receiver was also correlated to the informal caregiver's burden ($p<0,05$).

TABLE 5. Correlation between the ZBI score and variables.

	Correlation with ZBI	p value
Age	r=-,292**	0,004
Gender	t=1,478	0,091
Education	F=0,588	0,672
Employment	F=0,956	0,417
Relationship with the care receiver	F=0,678	0,641
Self rated health	F=6,193	0,000
Self rated happiness	F=15,986	0,000
length of informal care in years	r=0,216*	0,045
Length of informal care in hours per day	r=0,005	0,963
Additional help in informal care	t=1,931	0,200
Perceived received information	t=0,715	0,342
MSPSS	r=-0,417**	0,000
LBI	r=-0,196	0,058
BI	r=-0,259*	0,012
DISEASE	F=3,718*	0,028

Note:

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Table 6 shows the details of the ANOVA analysis concerning the self rated health, self rated happiness of the informal caregiver and the type of disease or symptoms of the informal care receiver and the ZBI scores. Table 6 revealed that informal caregivers caring for a care receiver with only somatic symptoms or suffering from a somatic disease were suffering from a significant lower burden. Informal caregivers who perceived themselves as sick or sad have a higher mean burden level than the informal caregivers who perceived themselves as healthy or happy (Table 6). Only one and three informal caregivers perceived themselves as very sick and very sad respectively (Table 6). Concerning the disease component, we can clearly see that informal caregivers caring for care receivers suffering from a somatic disease or showing only somatic symptoms suffered from a lower mean

burden. Informal caregivers caring for care receivers with cognitive impairment and/or somatic symptoms presented a higher mean burden.

TABLE 6. Details of the ANOVA analyses between the ZBI and the variables type of disease, self-rated health and self-rated happiness.

Variable	ZBI mean(N)	pvalue
Self-rated health		0,000
Very sick	28 (1)	
Sick	49,17 (12)	
Can not say	43,94 (32)	
Healthy	32,21 (43)	
Very healthy	35,71 (7)	
Self-rated happiness		0,000
Very sad	64,33 (3)	
Sad	52,06 (18)	
Can not say	37,54 (39)	
Happy	31,26 (31)	
Very happy	14,50 (2)	
Type of disease		0,028
Somatic	31,21 (19)	
Cognitive	41,38 (24)	
Somatic+cognitive	40,72 (47)	

7 DISCUSSION AND CONCLUSION

7.1 Discussion of the research methods and limitations

The questionnaire was responded by 47% of official informal caregivers of elderly in the Kokkola area. This low response rate could be due to minimum allowance of time to answer (two weeks), busy period when the questionnaires were sent due to Christmas season or other factors such as mental or physical exhaustion from the informal caregivers or a rapid aggravation of the condition of the care receiver. Another problem encountered was that some respondents did not fully complete the questionnaire as shown in the Graph 2 where only 23,5% of the questionnaires retrieved were fully completed in this study. However, the low percentage of missing values (2,6%) did not have a significant on the data analysis.

As explained earlier, the variable disease of the care receiver was problematic while conducting the data analysis since the majority of the care receivers suffered from more than one disease. Grouping the diseases in physical, mental or a combination of both was also problematic as many neurodegenerative diseases for example Alzheimer's disease or Parkinson possess a somatic component and a cognitive component. Moreover care receivers having suffered from brain stroke also suffer from a combination of cognitive and physical symptoms.

In addition to the care receiver disease, another variable posed some problems during the data analysis. The question concerning the main task of care giving was answered mostly by the respondents as all the tasks proposed in the questionnaire as opposed as only one choice as asked by the researcher. Thus, the researcher decided to not take this question into consideration as it was impossible to analyze this data in order to point out a correlation with the informal caregiver's burden. This can point out the importance of a face to face interview to clarify the questions. On the other hand the researcher chose to send the questionnaires by post as it was a less intrusive method. Moreover, the researcher believes that due to the strong emotional component of some

questions, the presence of the researcher during a face to face interview might have influenced the answers.

The researcher deliberates that it is important to remember that correlation does not mean causation. Some variables can be correlated to the occurrence of an event but are not systematically the cause of this event.

Nevertheless, the researcher believes that the quantitative method used was appropriated for a preliminary assessment of the informal caregiver's burden and the possible correlated variables. However, an in-depth analysis or assessment of the informal caregiver's burden should combine quantitative and qualitative methods in order perceive to the maximum the complexity of the phenomenon. The quantitative questionnaires used have been proven valid and reliable.

7.2 Discussion of the research findings

The first goal of the research was to assess the level of burden of informal caregivers of elderly (above 65 years old) in Kokkola. The average burden level according to the ZBI was 38,52 ($\pm 14,35$) with half of the respondents suffering from a mild to moderate burden and one third suffering from a moderate to severe burden. Those results are similar with the European countries results (Soulas, Sultan, Gurruchaga, Palfi & Fenelon 2011; Jones, Romeo, Trigg, Knapp, Sato, King, Niecko & Lacey 2014; Cicek, Cicek, Kayhan, Uguz & Kaya 2013; Ozdilek & Gunal 2012; Kuuppelomäki et al. 2004; Reed et al. 2014; Pöysti et al. 2012). However, the average of informal caregiver's burden level in this study was significantly higher than in Thailand and Brazil according to some studies (Chindaprasirt, Limpawattana, Pakkaratho, Wirasorn, Sookprasert, Kongbunkiat & Sawanyawisuth 2014; Torres, Travenisk Hoff, Padovani & de Abreu Ramos-Cerqueira 2012). This difference is surely due to a cultural difference as in some cultures the role of informal caregiver is natural and thus leads to lesser burden. Moreover, in some cultures the sociofamilial network is usually important providing more practical and emotional support to the informal caregiver (Chindaprasirt et al. 2014; Otis-Green & Juarez 2012; Torres et al. 2012).

A second goal of the study was to find out the variables correlated with burden in informal caregivers. A first important finding in our study is that informal caregivers caring for elderly suffering from physical impairment (amputated member for example) had a significant lower burden than those caring for care receivers suffering from cognitive impairment (dementia for example) or a combination of cognitive and physical impairment (stroke for example). This finding is consistent with previous studies (Flyckt, Löthman, Jörgensen, Rylander & Koernig 2011; Grant, Cavanagh & Yorke 2012; Hastrup, Van Den Berg & Gyrd-Hansen 2011; Seeher, Low, Reppermund & Brodaty 2013). A suggestion for this significant difference is that caring for a care receiver suffering from a mental or neuropsychiatric disease or displaying cognitive and behavioural symptoms greatly affects the relationship between the caregiver and the care receiver leading to greater burden. Caring for a family member with, for example, dementia or Alzheimer's disease can affect the loving relationship and feelings of shame, guilt or hopelessness can arise among informal caregivers. As explained by Magliano, Fiorillo, De Rosa, Malangone & Maj (2005), cognitive and behavioural symptoms in care receivers are strong predictors of anxiety and depression in informal caregivers. Moreover, the social acceptance from the population is usually lower and the caregiver can decrease social contacts due to unpredictable or socially unacceptable behavioural symptoms. This can result in a lower social and family support leading to social isolation and increased burden. Another possible explanation is that care receivers not suffering from cognitive impairment might be more aware of their condition and be more involved in their own treatment and care plan, reducing the informal caregiver's burden.

This study found a significant correlation between the level of dependency of the care receiver and the informal caregiver's burden, especially concerning the activities of daily living ($p < 0,05$). The correlation was however not significant with the instrumental activities of daily living. Nevertheless, those results are consistent with most of the findings in the literature (Jones et al. 2014). Loss of dependency of the care receiver is linked to the symptoms of his/her disease and thus cognitive and physical impairment are responsible for the loss of dependency. We already discussed that cognitive impairment and problematic behaviour can already affect the social environment of the caregiver. Moreover, consequential loss of

dependency increase the amount and frequency of care giving activities leading to exhaustion, stress, fatigue and burden

The self perceived health and self perceived happiness are strongly related with the level of burden. Those findings are identical to other studies' findings (Andren & Elmståhl 2007). However, it is very difficult to evaluate if a low self rated health and happiness constitute a risk factor for burden or a consequence of burden as this study was a correlational study and not a risk-factor study. As mentioned in many studies, caregiver burden have negative outcomes on the physical and emotional wellbeing of the wellbeing due to for example a lack of sleep, lack of exercise, reduced social support and network, increased stress and anxiety which can lead to depression (Reinhard et al. 2008; Wittenberg-Lyles et al. 2012.) On the other hand, poor health and low emotional wellbeing can also represent risk factors of burden. For example, individuals with poor judgement or coping skills or being in poor physical health can find it very challenging physically and emotionally to engage in care giving activities, thus increasing the burden. (Nelson Bialon & Coke 2012; Reinhard et al. 2008.)

Another variable correlated to the burden is the age of the informal caregiver. This study showed a negative correlation between the age of the informal caregiver and the burden, meaning that burden decreases as the age of the informal caregiver increases. In the literature, results vary as the variable age of the informal caregiver can be positively correlated to burden (Yurtsever et al. 2013) or negatively correlated to burden (Garces et al. 2009). A first possible explanation is that usually informal caregivers of older age have been engaging in care giving activities for a high number of years. The informal caregiver could, among the years, develop new coping skills, increase his/her knowledge concerning the disease or care giving activities or finding more emotional and practical support. The informal caregiver might be in the acceptance stage of his/her new role and not anymore in denial or anger. However, this explanation is not confirmed by the fact that this study showed that burden increases with the number of years of care giving. Another possible explanation is that in Finland informal care giving is not required by law (Kehusmaa et al. 2013) and thus, caring for a family member is accomplished by will and by love. Many studies showed that caring for a family

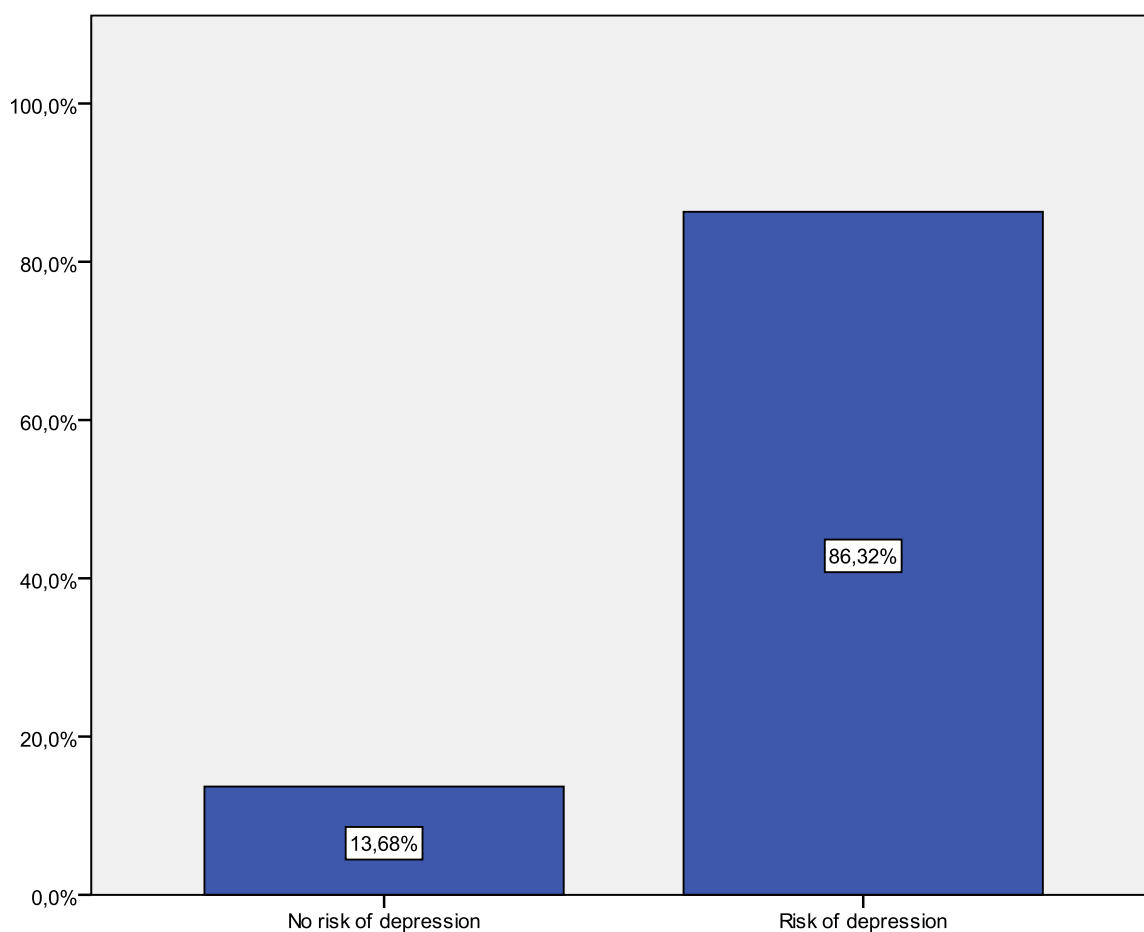
member can have positive outcomes for the informal caregiver such as providing reward and satisfaction, enhance the caregiver-care receiver relationship and consequently increase the emotional wellbeing (Reinhard et al. 2008; Wittenberg-Lyles et al. 2012.)

This study showed that burden increased with the number of years spent by the informal caregiver in care giving activities. Many explanations are possible for this phenomenon. First, as explained earlier, the behavioural and cognitive impairment can slowly negatively the social network and consequently practical and emotional support leading to an higher burden. Secondly, care giving can have negative consequences on the mental and physical health of the informal caregiver such as for example higher blood pressure, slower wound healing or fatigue. Coupled to a lack of social support and social isolation, the caregiver might not have sufficient physical and emotional strength to engage in care giving activities leading to higher burden with time. A third explanation is that new informal caregivers benefit from a lot of support in terms of psychological support, information and practical help. As a nurse, it is important to assess constantly information needs and support needs all along the care giving process.

This study didn't find any correlations between the informal caregiver's gender, the relationship with the care receiver and the level of education of the informal caregiver and the level of burden. Those findings are not consistent with the majority of the literature as most of the studies showed that, as informal caregiver, being a female, a spouse or a child of the care receiver and having a low level of education are predictable factors of burden. (Garces et al. 2009; Yurtsever et al. 2013; Reed et al. 2014; Pöysti et al. 2012.)

As briefly mentioned in the discussion earlier, depression represents a negative outcome of informal care giving burden. Depressive symptoms are the second most common negative outcomes of care giving after caregiver burden. Depression consists in a mood disturbance resulting from the stress of providing care and the consequential burden (Sherwood et al. 2005). Studies stated that elevated burden is predictive of depression symptoms among caregivers as physical, psychological, emotional, social and financial problems can lead to

elevated stress and depression (Epstein-Lubow et al. 2008). According to Schreiner, Morimoto, Arai & Zarit (2006), 64% of informal caregivers having a ZBI score of 25 and above also exhibit depressive symptoms. Thus, informal caregivers with a score equal or above 25 are at risk of developing depression. Graph 10 shows that 86,2% of the informal caregivers in this study had a ZBI score equal or above 25 with 86,2% of the respondents being at risk of developing depressive symptoms.



GRAPH 10. Risk of depression in percentage of the informal caregivers based on the ZBI score.

As mentioned earlier, informal caregivers suffered from greater burden when caring for care receivers suffering from a mental disease or displaying neuropsychiatric symptoms and/or cognitive impairment. Thus, it is expected that they are at a greater risk of developing depression. A further cross tabulation analysis of the results confirms that hypothesis. Table 7 shows that 73,7% of informal caregivers of elderly with somatic symptoms are at risk of depression while 91,7% of informal caregivers caring for elderly with cognitive impairment

present a risk of developing depression. However, there is no significant difference between the different groups concerning the risk of depression ($p>0,05$).

TABLE 7. Cross tabulation analysis results of the risk of depression among informal caregivers of elderly according to their symptoms.

	Disease type			Total
	physical	cognitive	physical and cognitive	
No risk of depression	26,3%	8,3%	10,6%	13,3%
Risk of depression	73,7%	91,7%	89,4%	86,7%
Total	100,0%	100,0%	100,0%	100,0%

Anxiety, stress, burden and depression experienced by some informal caregivers have been linked to negative consequences for the wellbeing of the care receiver. The most problematic potential negative outcome is elder abuse and neglect (Kuzuya, Enoki, Hasegawa, Izawa, Hirakawa, Shimokata & Akihisa 2011.) According to Lee & Kolomer (2007), elder abuse is significantly correlated with care giving burden and cognitive impairment and behavioural problems of the care receiver. Moreover, mentally impaired elderly being victims of abuse or neglect are not able to recognize or report it to authorities. Thus, it is essential to identify caregivers at risk of committing abuse or neglect to promote the wellbeing of the care receivers and prevent negative outcomes. Nurses and especially home care nurses represent an important tool in assessment and prevention of elderly abuse risk by informal caregivers. Tools used in this study can provide critical information concerning the risk for elderly abuse. Informal caregivers at risk of committing elderly abuse should benefit from additional psychological and practical support.

Another possible consequence of burden, anxiety and depression is institutionalization of the care receiver. Although there are many factors that can lead to a decision to institutionalize the care receiver, several studies pointed out that decreased social support of the informal caregiver, cognitive impairment and high level of dependency of the care receiver and caregiver burden are

significantly correlated to institutionalization of the elderly (Abdendroth, Lutz & Young 2012; Cohen-Mansfield & Wirtz 2011).

Due to various factors such as culture, social isolation and family conflicts, some informal caregivers are the only caregivers of the ill relative and thus, lack of emotional and practical support and have a great need of support and services (Nelson Bialon & Coke 2012; Washington, Meadows, Elliott & Koopman 2011). Psychosocial support can be defined by his quality, such as love, trust and quantity, such as accessibility and amount of time. Lack of psychosocial support has a negative effect on the caregiver's wellbeing and caregiver's mental health leading to burden and/or depression. (Steiner, Pierce, Drahuschak, Nofziger, Buchman & Szirony 2008; Yeh et al. 2009).

This study found that the lack of perceived social support is highly correlated to the informal caregiver's burden ($p < 0.001$) confirming the importance of social support for informal caregivers (Chiou et al. 2009). This finding is consistent with the majority of the literature (Chiou et al. 2009; Yeh et al. 2009; Chindaprasirt et al. 2014, Yurtsever et al. 2013; Garces et al. 2009). According to Dyck (2009), each informal caregiver's situation is unique and can depend of various factors such as the care giving context, the caregiver's values, the consequences of care giving, the skills and knowledge of the caregiver and the availability of the resources for the caregiver. Even if this study did not show a significant direct correlation between the lack of information and the level of caregiver's burden ($p > 0.05$), nurses and other health professionals have an important role in providing information and support to the informal caregiver (Washington et al. 2011).

To reduce the burden and stress at the informal caregiver's level, many different kind of support and services are available for informal caregivers. A study on elderly caregivers of Alzheimer's disease spouse in Finland found out that the most desired services are physiotherapy for the patient, financial support, house cleaning and respite care. (Raivio, Eloniemi-Sulkava, Laakkonen, Saarenheimo, Pietilä, Tilvis & Pitkälä 2007). Nurses can play an important role in reducing burden and depression in informal caregivers by providing psychological support and information. Studies showed that psychological support decrease informal

caregiver's depression and improve coping skills by providing education, counseling, information and emotional support. Psychological support can be provided individually or during group interventions. (Belgacem, Auclair, Fedor, Brugnon, Blanquet, Tournilhac & Gerbaud 2013; Lopez-Hartmann, Wens, Verhoeven & Remmen 2012).

Most of the studies about informal caregiver burden showed that caring can negatively affect the financial situation of the caregiver as he/she must cover additional care giving costs and in most of the situation the caregiver must reduce or stop working hours in order to care for the elderly (Higginson et al. 2010; Garces et al. 2010). However, other studies showed that the majority of the informal caregivers are retired and so does not belong anymore in the working life (Kushimaa et al. 2013). This is confirmed by this study as the results showed that 83% of the informal caregivers in Kokkola were retired. Moreover, the respondents in this study did not have financial difficulties as the financial component of the burden was low. This is due to the fact that all of our respondents were informal caregivers officially recognized by KELA and thus all of them received financial support and for some practical support. In 2010, the average financial allowance for informal caregivers was 416 Euro (Moressi 2010).

In 2010, there were 24625 informal caregivers receiving financial support caring for elderly. However it was estimated that 300000 informal caregivers did not receive any financial support. (Juntunen & Salminen 2011; Vilkkio et al. 2010). Based on those statistics, the results of this study are alarming since approximately 300000 informal caregivers are not receiving any financial support from KELA and possibly a lot less practical, psychological or emotional support. Moreover, it is in very difficult to assess who is an informal caregiver based on the definition of informal caregiver. Further studies are needed to evaluate the burden in those non-official caregivers and it is expected that the level of burden is higher than in this study with more dramatic consequences for both the caregiver and the care receiver. Undeniably, many existed associations provide support and services. However, as mentioned earlier, caring for an elderly can lead to stress, burden, depression and social isolation. All those negative consequences can

isolate the informal caregiver preventing him/her from both receiving support and seeking support.

7.3 Conclusion

One of the actual main challenges in public health is the ageing population and the accompanying multimorbidity. In Europe, it is estimated that 30% of individuals aged 65 years old and above are suffering from two or more chronic health conditions and need long term-care. In Finland, almost 20% of the population was 65 years old and above in 2013 and is expected to reach 25% in 2030. Due to reductions in expenditures for formal care, seniors suffering from chronic diseases are more and more expected to be taken care of at their home by informal caregivers.

However, informal care giving can be very challenging and can lead to physical and mental health problems such as burden and depression with potential negative repercussions on both the informal caregiver and the informal care receiver. This study showed that 38% of informal caregivers of elderly in Kokkola suffered from moderate to very severe burden and 86% of informal caregivers presented a risk of depression. The burden observed in informal caregivers of elderly individuals in Kokkola is significantly correlated to a lack of perceived social support for the informal caregiver, a high level of dependency of the informal care receiver, high number of years of care giving, cognitive and behavioural symptoms of the disease of the informal care receiver and a reduced self rated health and happiness of the informal caregiver.

In order to provide long term care to the elderly, their informal caregivers need support as well. The nurse role in supporting informal caregivers is psychological support in order to improve coping skills and reduce stress and burden as well as providing information. Moreover the nurse role is to assess informal caregivers at risk of developing burden. The theory of collaborative decision-making in nursing practice for triads should be the basis for the care of both the informal caregiver and the care receiver.

This study focused only on informal caregivers being officially recognized by KELA and thus, receiving financial support and other forms of support. A higher number of informal caregivers are not recognized by KELA and it is challenging to assess their level of burden and the possible negative outcomes.

7.4 Implications for nursing practice and future studies

This study seemed very important as most of the home nursing care focus mostly on the informal care receiver. The informal caregiver is not enough taken into consideration, especially concerning his or her physical, emotional and psychological well-being. However, informal caregivers have an extremely important role in the well-being of the ill elderly and thus, their well-being should also be monitored and assessed.

Caregiver burden being such a complex phenomenon, future studies are needed to fully understand the process leading to burden, the burden itself and the consequences of burden on both the informal caregiver and the care receiver. This study was a cross-sectional study meaning that the level of burden was assessed in one point of the time. Longitudinal studies are needed to understand how this burden evolves in time. Assessing depression in informal caregivers could provide additional information on burden and its relation to depression. Moreover, future studies should include qualitative methods as feelings and emotions are not represented in a quantitative study. Other studies could include the assessment of benefits of intervention strategies for informal caregivers suffering from burden such as providing additional information, psychological support or financial support.

Nurses have a primordial role in assessing and identifying informal caregivers with high burden in order to prevent negative outcomes such as depression and improve health of both the informal caregiver and the care receiver. Moreover, by understanding and knowing possible risk factors of burden, nurses, in association with social services and doctors, can focus on caregivers at risk of developing burden. Prevention can be realised by early intervention such as additional

provision of services or equipment and education. Many tools exist and are in use to assess the informal care receiver such as the Resident Assessment Instrument (RAI). Assessment of the informal caregiver is also primordial. The results of the ZBI and an assessment of the risk factors could provide useful information to increase the wellbeing of both the informal caregiver and the care receiver.

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BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

4. Do you feel embarrassed over your relative's behaviour?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

5. Do you feel angry when you are around your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

7. Are you afraid what the future holds for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

8. Do you feel your relative is dependent upon you?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

9. Do you feel strained when you are around your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

20. Do you feel you should be doing more for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

- 0. Not at all
- 1. A little
- 2. Moderately
- 3. Quite a bit
- 4. Extremely

KYSELY KOSKIEN OMAISTEN HOITOTAAKKAA

OHJEET: Seuraavat kysymykset koskevat sitä, miltä ihmisistä joskus tuntuu kun he hoitavat toista ihmistä. Merkitse jokaisen kysymyksen jälkeen, kuinka usein sinusta tuntuu siltä: ei koskaan, harvoin, joskus, aika usein tai melkein aina. Oikeita tai vääriä vastauksia ei ole.

1. Tuntuuko sinusta, että omaisesi pyytää enemmän apua kuin hän tarvitsee?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
2. Tuntuuko sinusta, ettei sinulla ole tarpeeksi aikaa itsellesi omaisesi kanssa viettämäsi ajan vuoksi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
3. Stressaako sinua se, että hoidat omaistasi ja samalla yrität vastata muihin velvollisuuksiin koskien perhettäsi tai työtäsi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
4. Tunnetko itsesi vaivautuneeksi omaisesi käytöksen vuoksi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
5. Koetko suuttumuksen tunteita ollessasi omaisesi kanssa?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
6. Tuntuuko sinusta, että omaisesi nykyään vaikuttaa kielteisesti muihin perhe- tai ystävyys-suhteisiisi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
7. Oletko huolissasi tulevaisuudesta omaisesi suhteen?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina

8. Tuntuuko sinusta, että omaisesi on sinusta riippuvainen?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
9. Tunnetko olevasi stressaantunut ollessasi omaisesi kanssa?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
10. Tunnetko terveytesi kärsineen sen vuoksi, että hoidat omaistasi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
11. Tuntuuko sinusta, että omaisesi hoitamisen takia sinulla ei ole niin paljon yksityisyyttä kuin haluaisit?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
12. Tunnetko sosiaalisen elämäsi kärsineen sen vuoksi, että hoidat omaistasi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
13. Tuntuuko sinusta omaisesi takia kiusalliselta pyytää ystäviä käymään kylässä?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
14. Tuntuuko sinusta, että omaisesi odottaa sinun huolehtivan hänestä aivan kuin olisit ainoa ihminen, johon hän voi tukeutua?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
15. Tuntuuko sinusta, ettei sinulla ole tarpeeksi rahaa omaisesi hoitamiseen muiden menojesi ohella?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina

16. Tuntuuko sinusta, ettet pysty hoitamaan omaistasi enää kauan?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
17. Tuntuuko sinusta, ettet ole pystynyt hallitsemaan omaa elämääsi omaisesi sairastumisen jälkeen?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
18. Toivoisitko, että voisit jättää omaisesi jonkun toisen henkilön hoidettavaksi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
19. Oletko epävarma siitä, miten sinun pitäisi hoitaa omaistasi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
20. Tuntuuko sinusta, että voisit tehdä enemmän omaisesi hyväksi?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
21. Tuntuuko sinusta, että pystyisit hoitamaan omaistasi paremmin?
0. Ei koskaan 1. Harvoin 2. Joskus 3. Aika usein 4. Melkein aina
22. Kuinka rasittavaksi kaiken kaikkiaan koet omaisesi hoitamisen?
0. Ei lainkaan 1. Vähän 2. Kohtalaisesti 3. Aika paljon 4. Erittäin paljon

MSPSS (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements.
Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if
you **Strongly**
Disagree Circle
the "3" if you
Mildly Disagree
Circle the "4" if
you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

TAJUNEEN SOSIAALISEN TUEN MONIULOTTEINEN ARVOASTEIKKO

Ohjeet: Olemme kiinnostuneita siitä, miten teistä tuntuu seuraavista väittämistä. Lukekaa jokainen väittämä huolellisesti. Ilmoittakaa ympyröimällä seuraavista vaihtoehdoista yksi mikä tuntuu teistä sopivammalta.

Ympyrä "1", jos olette erittäin vahvasti eri mieltä
Ympyrä "2", jos olette täysin eri mieltä
Ympyrä "3" jos olette lievästi eri mieltä
Ympyrä "4", jos olette neutraali
Ympyrä "5" jos olette lievästi samaa mieltä
Ympyrä "6" jos olette täysin samaa mieltä
Ympyrä "7" jos olette erittäin vahvasti samaa mieltä

	erittäin vahvasti eri mieltä	täysin eri mieltä	lievästi eri mieltä	neutraali	lievästi samaa mieltä	täysin samaa mieltä	erittäin vahvasti samaa mieltä
1. On olemassa erityinen henkilö, joka on lähellä, kun olen tarpeessa	1	2	3	4	5	6	7
2. On olemassa erityinen henkilö, jonka kanssa voin jakaa ilot ja surut	1	2	3	4	5	6	7
3. Koen että perheeni yrittää kovasti auttaa minua.	1	2	3	4	5	6	7
4. Saan tunteellista apua ja tukea perheestäni kun tarvitsen	1	2	3	4	5	6	7
5. Minulla on erityinen henkilö, joka on todellinen lohtu minulle	1	2	3	4	5	6	7
6. Koen että ystäväni yrittävät kovasti auttaa minua	1	2	3	4	5	6	7
7. Voin luottaa ystäväni tukeen silloin kun asiat menevät pieleen.	1	2	3	4	5	6	7
8. Voin puhua ongelmistani perheeni kanssa.	1	2	3	4	5	6	7
9. Minulla on ystäviä jonka kanssa voin jakaa ilot ja surut	1	2	3	4	5	6	7
10. On erityinen henkilö elämässäni, joka välittää tunteitani.	1	2	3	4	5	6	7
11. Perheeni on halukas auttamaan minua tekemään päätöksiä.	1	2	3	4	5	6	7
12. Voin puhua ongelmistani kavereiden kanssa.	1	2	3	4	5	6	7

Barthel Index of Activities of Daily Living

Instructions: Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning. Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation. Refer to the Guidelines section on the following page for detailed information on scoring and interpretation.

The Barthel Index

Bowels

0 = incontinent (or needs to be given enemas)
1 = occasional accident (once/week)
2 = continent

Patient's Score: _____

Bladder

0 = incontinent, or catheterized and unable to manage
1 = occasional accident (max. once per 24 hours)
2 = continent (for over 7 days)

Patient's Score: _____

Grooming

0 = needs help with personal care
1 = independent face/hair/teeth/shaving (implements provided)

Patient's Score: _____

Toilet use

0 = dependent
1 = needs some help, but can do something alone
2 = independent (on and off, dressing, wiping)

Patient's Score: _____

Feeding

0 = unable
1 = needs help cutting, spreading butter, etc.
2 = independent (food provided within reach)

Patient's Score: _____

Transfer

0 = unable – no sitting balance
1 = major help (one or two people, physical), can sit
2 = minor help (verbal or physical)
3 = independent

Patient's Score: _____

Mobility

0 = immobile
1 = wheelchair independent, including corners, etc.
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid, e.g., stick)

Patient's Score: _____

Dressing

0 = dependent
1 = needs help, but can do about half unaided
2 = independent (including buttons, zips, laces, etc.)

Patient's Score: _____

Stairs

0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent up and down

Patient's Score: _____

Bathing

0 = dependent
1 = independent (or in shower)

Patient's Score: _____

Total Score: _____

(Collin et al., 1988)

Scoring:

Sum the patient's scores for each item. Total possible scores range from 0 – 20, with lower scores indicating increased disability. If used to measure improvement after rehabilitation, changes of more than two points in the total score reflect a probable genuine change, and change on one item from fully dependent to independent is also likely to be reliable.

Sources:

- Collin C, Wade DT, Davies S, Home V. The Barthel ADL Index: a reliability study. *Int Disabil Stud.* 1988;10(2):61-63.
- Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J.* 1965;14:61-65.
- Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud.* 1988;10(2):64-67.

BARTHELIN PÄIVITTÄISTEN TOIMINTOJEN INDEKSI

Ohjeet: Valitse pisteytys pisteen lausuman, joka parhaiten vastaa hoidettavan nykyinen pätevyys kunkin seuraavan 10 tuotetta. Ilmoittakaa ympyröimällä vaihtoehto miten sinusta tuntuu sopivammalta jokaiselta väittämältä.

Suolentoiminta

- 0 = pidätyskyvytön
 1 = satunnainen vahinko (kerran viikossa)
 3 = ei ongelmia

Virtsarakko

- 0 = pidätyskyvytön tai kestokatetroinut
 1 = satunnainen onnettomuus (kerran päivässä)
 2 = pidättyväinen

Puhtaus

- 0 = tarvitsee apua henkilökohtaiseen hygieniaan
 1 = itsenäinen kasvot/hiukset/hampaat/parranajo

Vessan käyttö

- 0 = riippuvainen
 1 = tarvitse apua mutta voi tehdä jotain yksin
 2 = itsenäinen (istuminen, pukeutuminen, pyyhintä)

Ruokinta

- 0 = kyvytön
 1 = tarvitse apua (leikkaminen, levittää voita, jne)
 2 = itsenäinen (ruoka on käden ulottuvilla)

Siirtäminen

- 0 = riippuvainen – ei ole tasapainoa istuen
 1 = suuri apu (yksi tai kaksi henkilöä), osaa istua
 2 = pieni apu (sanallinen tai fyysinen)
 3 = itsenäinen

Liikkuvuus

- 0 = liikuntakyvytön
 1 = pyöratuolilla itsenäinen
 2 = kävelee yhden henkilön avustamana
 3 = itsenäinen (mutta voi käyttää tuen)

Pukeutuminen

- 0 = riippuvainen
 1 = tarvitse apua, mutta voi tehdä jotain yksin
 2 = itsenäinen

Portaat

- 0 = ei osaa
 1 = tarvitse apua (sanallinen tai fyysinen)
 2 = itsenäinen

Kylpeminen

- 0 = riippuvainen
 1 = itsenäinen

LAWTON-BRODY INDEX

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)

M.P. Lawton & E.M. Brody

A. Ability to use telephone

- | | |
|---|---|
| 1. Operates telephone on own initiative; looks up and dials numbers, etc. | 1 |
| 2. Dials a few well-known numbers | 1 |
| 3. Answers telephone but does not dial | 1 |
| 4. Does not use telephone at all. | 0 |

B. Shopping

- | | |
|---|---|
| 1. Takes care of all shopping needs independently | 1 |
| 2. Shops independently for small purchases | 0 |
| 3. Needs to be accompanied on any shopping trip. | 0 |
| 4. Completely unable to shop. | 0 |

C. Food Preparation

- | | |
|--|---|
| 1. Plans, prepares and serves adequate meals independently | 1 |
| 2. Prepares adequate meals if supplied with ingredients | 0 |
| 3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet. | 0 |
| 4. Needs to have meals prepared and served. | 0 |

D. Housekeeping

- | | |
|--|---|
| 1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") | 1 |
| 2. Performs light daily tasks such as dish-washing, bed making | 1 |
| 3. Performs light daily tasks but cannot maintain acceptable level of cleanliness. | 1 |
| 4. Needs help with all home maintenance tasks. | 1 |
| 5. Does not participate in any housekeeping tasks. | 0 |

E. Laundry

- | | |
|---|---|
| 1. Does personal laundry completely | 1 |
| 2. Launders small items; rinses stockings, etc. | 1 |
| 3. All laundry must be done by others. | 0 |

F. Mode of Transportation

- | | |
|--|---|
| 1. Travels independently on public transportation or drives own car. | 1 |
| 2. Arranges own travel via taxi, but does not otherwise use public transportation. | 1 |
| 3. Travels on public transportation when accompanied by another. | 1 |
| 4. Travel limited to taxi or automobile with assistance of another. | 0 |
| 5. Does not travel at all. | 0 |

G. Responsibility for own medications

- | | |
|--|---|
| 1. Is responsible for taking medication in correct dosages at correct time. | 1 |
| 2. Takes responsibility if medication is prepared in advance in separate dosage. | 0 |
| 3. Is not capable of dispensing own medication. | 0 |

H. Ability to Handle Finances

- | | |
|---|---|
| 1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income. | 1 |
| 2. Manages day-to-day purchases, but needs help with banking, major purchases, etc. | 1 |
| 3. Incapable if handling money. | 0 |

Source: Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." *Gerontologist* 9:179-186, (1969).

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IADL-ASTEIKKO	
1. Puhelimen käyttö	1 Käyttää puhelinta oma-aloitteisesti, etsii ja valitsee numerot
	1 Soittaa muutamiin hyvin tuntemiinsa numeroihin
	1 Vastaa puhelimeen, mutta ei soita
	0 Ei käytä puhelinta lainkaan
2. Ostosten teko	1 Huolehtii itsenäisesti kaikista ostoksistaan
	0 Tekee itsenäisesti pieniä ostoksia
	0 Tarvitsee avustajan kaikilla ostoskäynneillä
	0 Täysin kykenemätön tekemään ostoksia
3. Ruoanvalmistus	1 Suunnittelee, valmistaa ja tarjoilee asianmukaiset ateriat itsenäisesti
	0 Valmistaa asianmukaiset ateriat, jos tarveaineet on toimitettu valmiiksi
	0 Lämmittää ja tarjoilee valmiiksi tehdyt ateriat tai valmistaa ateriat, mutta ei ylläpidä riittävää ruokavaliota
	0 Tarvitsee valmiiksi tehdyt ateriat tarjoiltuna
4. Kodinhoito	1 Hoitaa kodin yksin tai ajoittaisella ulkopuolisella avustuksella (esim. raskaat työt)
	1 Tekee kevyitä päivittäisiä kotitöitä kuten tiskausta, sängynpetausta
	1 Tekee kevyitä päivittäisiä kotitöitä, mutta ei pysty ylläpitämään riittävää siisteystasoa
	1 Tarvitsee apua kaikissa kodin ylläpitoon liittyvissä töissä
	0 Ei osallistu lainkaan kodinhoitotöihin

5. Pyykinpesu	1 Pesee henkilökohtaisen pyykkinsä kokonaan itse
	1 Pesee pikkupyykin, huuhtelee sukkia, sukkahousuja jne.
	0 Kaikki pyykki on pestävä muiden toimesta
6. Liikkuminen kulkuvälineillä	1 Liikkuu itsenäisesti julkisilla liikennevälineillä tai ajaa omaa autoa
	1 Järjestää itse liikkumisen taksilla, mutta ei muuten käytä julkista liikennettä
	1 Liikkuu julkisilla liikennevälineillä, kun toinen henkilö avustaa tai on seurana
	0 Matkustaminen rajoittuu taksin tai auton käyttöön toisen henkilön avustamana
	0 Ei matkusta lainkaan
7. Vastuu omasta lääkityksestä	1 Vastaa omien lääkkeiden ottamisesta oikein annoksin oikeaan aikaan
	0 Vastaa lääkityksestään, jos lääkkeet on jaettu etukäteen valmiiksi annoksiksi
	0 Ei pysty itse hoitamaan lääkitystään
8. Kyky huolehtia raha-asioista	1 Hoitaa raha-asiat itsenäisesti (budjetti, vuokran ja laskujen maksu, pankissa käyminen)
	1 Hoitaa päivittäiset raha-asiat, mutta tarvitsee apua pankkiasioissa ja isojen menojen hoitamisessa jne.
	0 Kykenemätön käsittelemään rahaa

Lähde: Lawton MP, & Brody EM. Assessment of older people: Self-maintaining and instrumental activities of daily living. The Gerontologist. 1969;9:179-186.

Tekijänoikeudet (copyright): The Gerontological Society of America. Käyttöä ei ole rajoitettu.

Suomennoksen vastaavuus alkuperäiseen IADL-asteikkoon on tarkastettu TOIMIAssa (työryhmä Tiina Autio, Päivi Sainio ja kielenkääntäjä Jaakko Mäntyjärvi).

SOCIODEMOGRAPHIC QUESTIONNARY

Instructions: Circle the appropriate answer among the different propositions. For questions without multiple choice write the appropriate answer.

1. **Age:**
2. **Gender:** 1.Male 2.Female
3. **Education:** 1.University 2. Polytechnics 3. Junior high school 4. College 5. Primary school
4. **Employment:** 1.Full-time 2. Part-time 3. Jobless 4. Retired
5. **Relationship with the care receiver**
1. Husband 2. Wife 3. Child 4. Other family member 5. Friend 6. Neighbour 7. Other
6. **How would you assess your own health at the moment?**
1. Very sick 2. Sick 3. Can not say 4. Healthy 5. Very healthy
7. **How happy are you at the moment?**
1. Very sad 2. Sad 3. Can not say 4. Happy 5. Very happy
8. **For how long have you been an informal caregiver? (years and months)**
9. **How many days per week are you providing informal care?**
10. **How many hours per day are you providing informal care?**
11. **What are the main activities as an informal caregiver? Choose one among the three possibilities above.**

1.cleaning (laundry, dishes, house cleaning, ironing,...)
2.personal hygiene (bathing, feeding, dressing, ...)
3.daily activities (shopping, finances, transport, cooking,...)
12. **Do you receive help at home? (also including municipal help)?** 1. yes 2. no
13. **Do you think that you have enough information concerning informal care giving?**
1. yes 2. no
14. **What is the main diagnostic of the informal care receiver?**

SOSIODEMOGRAFINEN TILA KYSYMYSLOMAKE

Ohjeet: Ilmoittakaa ympäröimällä vaihtoehto miten sinusta tuntuu sopivammalta jokaiselta väittämältä.

15. **Ikä:**
16. **Sukupuoli:** 1.Mies 2.Nainen
17. **Koulutus:** 1.Yliopisto 2. ammattikorkeakoulu 3. yläaste 4. lukio 5. ala-aste
18. **Työ:** 1.kokopäivätyössä 2. osanaikatyössä 3. työtön 4. eläkkeellä
19. **Suhde hoidettavan kanssa**
 2. Aviomies 2. Vaimo 3. Lapsi 4. Muu perheenjäsen 5. Ystävä 6. Naapuri 7. Muu.
 Mikä? _____
20. **Miten arvioitte oman terveyden tällä hetkellä?**
 2. tosi sairas 2. sairas 3. ei osaa sanoa 4. terveellinen 5. tosi terveellinen
21. **Kuinka onnellinen olette tällä hetkellä?**
 2. tosi surullinen 2. surullinen 3. ei osaa sanoa 4. iloinen 5. tosi iloinen
22. **Kuinka kauan olette ollut omaishoitaja? (vuosina ja kuukausina)**
23. **Kuinka monta päivää viikossa toimitte omaishoitajana?**
24. **Kuinka monta tuntia päivässä toimitte omaishoitajana?**
25. **Mitkä ovat pääasialiset tehtäväsi omaishoitajana: Vastakaa yksi kolmesta alleivivattuista mahdollisuuksista ympäröimällä mielestänne oikea vaihtoehto.**
1.siivous (esim. pyykin pesu, astioiden pesu, silitys, siivous),
2.hoidettavan henkilökohtaisesta hygieniasta huolehtiminen (esim. avustaminen ruokailussa-, wc-käyneillä, -peseytymisessä tai pukeutumisessa)
3.käytännön asioiden huolehtiminen (esim. kaupassa käynti, taloudenpito, ruoanlaitto tai kuljetus).
26. **Saatteko kotiapua (sisältäen myös kunnallinen kotihoito)?** 1. Kyllä 2. Ei
27. **Luuletteko, että teillä on riittävästi tietoja omaishoitajantyöstä?** Kyllä vai ei?
28. **Mikä on hoidettavanne olevan henkilön sairaus?**

PERMISSION TO USE MSPSS

Hello Vincent,

You have my permission to use the MSPSS in your study. I have attached the original English version of the scale as well as a document that lists several articles that report on the psychometric properties of the MSPSS. I am unaware of either a Finnish or Swedish translation. So, you will have to translate the scale into those two languages as well. I do try to collect translated versions of the MSPSS.

So, if you are willing, please send me copies of your translated versions. That way, if someone in the future wants to administer the scale in Finnish or Swedish, I can send them copies of the scale and direct them to you.

I hope your research goes well.

Best regards,
Greg Zimet

=====
Gregory D. Zimet, PhD
Professor of Pediatrics & Clinical Psychology
Section of Adolescent Medicine
Indiana University School of Medicine
Health Information & Translational Sciences
410 W. 10th Street, HS 1001
Indianapolis, IN 46202
USA
Phone: +1-317-274-8812
Fax: +1-317-274-0133
e-mail: gzimet@iu.edu
<http://pediatrics.iu.edu/center-hpv-research/about-us/>

PERMISSION TO USE ZBI-22

Dear Vincent,

Thank you for emailing us your User Agreement. **May I take this opportunity to remind you that I must also receive the signed original version by post.**

As you are carrying out a not-funded research, I am pleased to be able to send you the requested versions of the ZBI . I have also attached the scoring manual for your analysis. Please confirm safe reception.

However unfortunately we do not have the requested versions for the BI. If you are interested in performing the translations yourself, please let me know and I will send you the Translation Agreement.

Please do not hesitate to get in touch if you have any questions.

New! It is now possible to pay your invoice online with a credit card(except for American Express) It is quick, easy and secure. Don't hesitate to ask me should you be interested.

Best regards,

Sunita Shetty

(Not in the office on Wednesday mornings)

Information Resources Specialist

PROs & ClinROs Information Support Unit

Mapi Research Trust

27 RUE DE LA VILLETTE | 69003 LYON | FRANCE

Tel.: +33 (0)4 27 44 58 61 (Direct line)| Fax: +33 (0) 4 72 13 66 82 |

sshetty@mapigroup.com

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COVER LETTER

<p style="text-align: center;">Unit of Kokkola-Pietarsaari Health Care and Social Services Study of the burden of informal caregivers of elderly in Kokkola</p>

.
Dear respondent,

This is my sincere request for your participation in my thesis research. I am a 3rd year nursing student in CENTRIA University of applied sciences. Currently, I am writing my thesis which is about the burden of informal caregivers of elderly in Kokkola

.
The purpose of this study is to evaluate the burden of informal caregivers caring for over 65 years old patients in Kokkola and find out the possible predisposing factors. The consequences of the caregiver burden can negatively affect the health of the care receiver and the informal caregiver himself thus it is essential for home care nurses to recognize the predisposing factors leading to burden in order to improve the care receiver's health.

.
The research method used in this research is quantitative. There are 67 questions which will take approximately 25-30 minutes to answer. The answered questionnaires should be sent back by the **31.1.2014**. The postage costs are pre-paid. The results of the questionnaires will be handled with utmost confidentiality and anonymity. The completed thesis will be located in the library for public use.

Your participation is voluntary; however your kind consideration in answering the questionnaires will be highly appreciated.

Thanks you in advance

In case of any questions or more information please don't hesitate to contact me on:

E-mail: vincent.gleviczky@cou.fi or on the phone number: 0458590773. More information are also available from Hanna Saarinen from the Homecare Service Centre: 0408065457.

Best regards

Vincent Gleviczky

SAATEKIRJE

**Centria Ammattikorkeakoulu – Kokkola-Pietarsaaren yksikkö – Hoitotyön
koulutusohjelma
Vanhusten omaishoitajien taakan tutkimus**

Hyvä vastaaja,

Pyydän teitä ystävällisesti osallistumaan opinnäytetyön tutkimukseeni vastaamalla oheisiin viiteen kyselyyn. Olen kolmannen vuoden sairaanhoitaja-opiskelija CENTRIA ammattikorkeakoulussa Kokkolassa. Opinnäytetyöni käsittelee omaishoitajien kokemaa taakkaa

Tutkimukseni tarkoituksena selvittää omaishoitajien kokemaa taakkaa heidän hoitaessaan sairastunutta omaistaan tai läheistään sekä selvittää mahdollisia tekijöitä jota aiheuttavat taakkaa tai lisäävät sitä. Omaishoitajan kokeman taakan seuraukset voivat vaikuttaa kielteisesti hoidettavan terveyteen ja omaishoitajaan itse. Tämän vuoksi on tärkeää, että kotisairaanhoitajat ja sosiaalityöntekijät tunnistavat omaishoitajien taakkaa aiheuttavat asiat ja voivat näin tarvittaessa tarjota tukea ja apua.

Tutkimusmenetelmänä on kyselytutkimus, joka sisältää viisi erillistä kyselyä. Tutkimuksessa on yhteensä 67 kysymystä. Vastausaika on noin 25-30 minuuttia. Vastattuanne kaikkiin kysymyksiin, pyydän Teitä lähettämään ne takaisin mukana seuraavassa kirjekuoressa 31.12.2014 mennessä. Postimaksu on valmiiksi maksettu. Kyselyjen tulokset tullaan käsitellä ehdottoman luottamuksellisesti ja kaikkien vastaajien henkilöllisyys tullaan salaamaan. Valmis opinnäytetyö on lainattavissa ammattikorkeakoulun kirjastosta ja kotihoidon palveluohjauskeskuksesta ensi vuoden lopulla.

Tähän tutkimukseen osallistuminen on vapaaehtoista, mutta toivoisin sitä kovasti. Halutessanne voitte saada minulta lisää tietoa tutkimuksesta sähköpostin kautta

vincent.gleviczky@cou.fi tai puhelinnumerosta 0458590773. Lisätietoja voi kysyä myös kotihoidon palveluohjauskeskus / Hanna Saarinen p. 0408065457.

Ystävällisin terveisin,

Vincent Gleviczky

KOKKOLAN KAUPUNKI
 Sosiaali- ja terveystoimi

 Viranhaltija ja virka-asema
 Juola Maija
 Vanhustyön palvelujohtaja

VIRANHALTIJAPÄÄTÖS
 Tutkimusluvat

 Päivämäärä / pykälä
 30.10.2013 / § 179

1

Asia	Tutkimuslupa-anomus														
Päätös ja sen perusteet	<p>Päätän myöntää Keski-Pohjanmaan ammattikorkeakoulun opiskelija Vincent Gleviczkyllle tutkimusluvan opinnäytetyön tekemistä varten aiheesta "Study of the burden of informal care givers of elderly in Kokkola"</p> <p>Tutkimuksen tarkoituksena on selvittää omaishoitajien jaksamista omaisena hoitajana Kokkolassa. Kohderyhmäksi on valittu yli 65 vuotiaiden asiakkaiden omaishoitajat. Tutkimusmenetelmänä on kvantitatiivien kyselytutkimus.</p> <p>Tutkimuksen kaikissa vaiheissa tulee noudattaa tietosuojasta ja salassapidosta annettuja ohjeita ja määräyksiä.</p> <p>Tutkimuksen valmistuttua tutkija luovuttaa yhden kappaleen työstään Kokkolan sosiaali- ja terveystoimen käyttöön.</p>														
Allekirjottus	 Vanhustyön palvelujohtaja														
Oikeusvaatimus-oikeus	Päätöksen työtymän voi tehdä kirjallisen oikeusvaatimuksen. Oikeusvaatimuksen esittäjä on, johon päätös on koettu tai jonka oikeuteen, velvollisuuteen tai etuun päätös välittömästi vaikuttaa (selauslainen) sekä kunnan jäsen.														
Oikeusvaatimusviranomaisen	Sosiaali- ja terveystoimisto														
Oikeusvaatimustaika ja sen alkaminen	Oikeusvaatimus on tehtävä 14 päivän kuluessa päätöksen tiedoksi saamisen jälkeen. Päätöksestä luetun kun pöytäkirja on saatettu yleisesti nähtäväksi. Asiantuntijan katsotaan saaneen päätöksestä tiedon, jolloin määräaika alkaa laskettuna siitä päivästä, jolloin päätös on saatettu yleisesti nähtäväksi.														
Oikeusvaatimuksen sisältö ja toimittaminen	Oikeusvaatimuksesta on käytävä ilmi vaatimus perustelut ja se on tehtävä allekirjoitettuna. Oikeusvaatimus on toimittettava oikeusvaatimusviranomaiselle ennen oikeusvaatimustajan päättämistä.														
Päätöksen nähtävöksi asettaminen	Sosiaali- ja terveystoimi, tiistai 5. 10. 2013 klo 9-16														
Tiedoksianto asianosaiselle	<table border="1"> <thead> <tr> <th></th> <th>Asiantoinen</th> </tr> </thead> <tbody> <tr> <td><input checked="" type="checkbox"/> Lähetetty tiedoksi kirjellä</td> <td></td> </tr> <tr> <td>Anneltu puolesta kuljettavaksi, pvm / tiedoksiantaja</td> <td>Vincent Gleviczky Banerinkatu 20 L 2 67100 Kokkola</td> </tr> <tr> <td><input type="checkbox"/> Luovutettu asianosaiselle</td> <td>Asiantoinen</td> </tr> <tr> <td>Päivä pvm</td> <td></td> </tr> <tr> <td>Tiedoksiantajan allekirjoitus ja virka-asema</td> <td>Vastaanottajan allekirjoitus</td> </tr> <tr> <td><input type="checkbox"/> Muulla tavoin miten</td> <td></td> </tr> </tbody> </table>		Asiantoinen	<input checked="" type="checkbox"/> Lähetetty tiedoksi kirjellä		Anneltu puolesta kuljettavaksi, pvm / tiedoksiantaja	Vincent Gleviczky Banerinkatu 20 L 2 67100 Kokkola	<input type="checkbox"/> Luovutettu asianosaiselle	Asiantoinen	Päivä pvm		Tiedoksiantajan allekirjoitus ja virka-asema	Vastaanottajan allekirjoitus	<input type="checkbox"/> Muulla tavoin miten	
	Asiantoinen														
<input checked="" type="checkbox"/> Lähetetty tiedoksi kirjellä															
Anneltu puolesta kuljettavaksi, pvm / tiedoksiantaja	Vincent Gleviczky Banerinkatu 20 L 2 67100 Kokkola														
<input type="checkbox"/> Luovutettu asianosaiselle	Asiantoinen														
Päivä pvm															
Tiedoksiantajan allekirjoitus ja virka-asema	Vastaanottajan allekirjoitus														
<input type="checkbox"/> Muulla tavoin miten															
Lisätietoja															
Liitteet															
Sisäinen jakelu	Hanna Saarinen, Kaija Keski-Rahkonen														

 Postiosoite / Postiresepti:
 PL 43 / PB 43
 67101 KOKKOLA - KARLEBY

 Käyntiosoite / Besöksadress:
 Kausungintalo / Stadshuset
 Kaupatori 5 / Salutorget 5

 Puhelin / Telefon:
 (05) 828 5111
 Fax: (05) 828 358

 S-posti / E-post:
 etunimi.suuronni@kokkola.fi
 toiminn.allenanni@kokkola.fi

 Internet:
 www.kokkola.fi

TUTKIMUSLUPA-ANOMUS

Organisaatio, jolle anomus osoitetaan KOKKOLA KAUPUNKI

Vastuhenkilö organisaatiossa JULIA MAISA

Tutkimusluvun aneja(t) GLEVICZKY VINCENT

Osoite RANERINKATU 20 L2 67100 KOKKOLA

Puhelin 0458590773

Sähköpostiosoite VINCENT.GLEVICZKY@LOU.FI

Tutkimuksen nimi Ikuiskyvän erinäköisyyden tuikka Kokkolassa
Study of the burden of informal care givers of elderly in Kokkola

Tutkimuksen tarkoitus
- omaishoitajien tuikan ~~arvio~~ ja keuhkojen arvio
- Kotihoidon kehittäminen

Tutkimuksen kohderyhmä
yli 65v erinäköisten omaishoitajat

Aineiston keruun arvioitu ajankohta 15.11.2013

Tutkimusmenetelmä kyselylomake / kvantitatiivinen

Tutkimussuunnitelma hyväksytty 21.10.2013

Tutkimuksen ohjaaja Marya Tulas-Sandela

Lupa myönnetään

paikka Kokkola aika 20.10.2013 § 179

Anomuksen mukaisesti muutosehdotuksin hylätty

Luvanmyöntäjän allekirjoitus Ulla Järvi

LIITTEET Tutkimussuunnitelma

Kysely/haastattelulomake

Muut liitteet, mikä