Cyprus
University of
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Faculty of Health Sciences

Department of Nursing

Doctoral Dissertation

THE ASSOCIATION OF HEALTH LITERACY AND E-HEALTH LITERACY WITH CARING CONCEPTS AMONG CARERS OF PEOPLE WITH DEMENTIA

Areti Christina Efthymiou

Limassol, JANUARY, 2020

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Approval Form

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Cyprus University of Technology
Limassol, JANUARY, 2020

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To Marika Efthymiou, in memoriam
To all friends and family who supported me during these 4 years of hard work

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ABSTRACT

During these two last decades, there is an increase in health technological advances. Making them accessible to groups with vulnerability is a priority for educators and health care professionals. Access to web-based services could facilitate the informal carers of PwD in their everyday life. Carers of PwD are facing the consequences of the burden of care, feelings of anxiety, depression, guilt, make higher use of antidepressants and are more vulnerable to infections than the general population. Web-based services for informal carers may include training platforms and disease-specific websites, forums, social networks and other interactive services, telehealth, telemedicine, applications for support and cognitive rehabilitation. The offer and demand for these services are differentiated among European countries. They are influenced by the digital skills and attitudes of the population towards technology. Health Literacy (HL) and eHealth literacy (eHL) are two concepts that can facilitate carers to search, find, assess and apply information related to dementia-specific issues from different resources (friends, family, neighbours, health professionals, internet).

This study investigates the level of HL and eHL and the associations with other caregiving variables.

The study used a descriptive correlational study design and the methodology followed 5 phases. Initially, two scoping and two literature reviews organised to identify available research. Secondly, tools not available in Greek or for the specific population of carers were validated. The third phase included the consensus meeting on the terminology of eHealth Literacy and Health Literacy. Then, the pilot and the full-scale study followed. In total, 174 primary carers of PwD, (76% women, n=132) and 67 secondary carers (family, friend or neighbour who provide support to the primary carer and to the care-recipient), participated in a descriptive correlational study. Primary carers completed a face to face survey for the level of HL, eHL, internet use, dementia-specific internet use, caregiving self-efficacy (SE), coping strategies, caregiving perceptions and social support. Secondary carers completed the survey for HL, eHL and demographics.

In this study, primary carers report a high level of eHL (29.21/40, SD=4.8) and HL (13.64/16, SD=1.92). The above is also the case for the secondary carers (eHL=30.54/40, SD=4.34 and HL=13.09, SD=2.05).

The cluster analysis presented with 3 carers' profiles: 1) carer with High HL, eHL and SE 2) carers with problematic coping and negative caregiving attitudes 3) carers with High HL, eHL and a strong Social Network. Carers with higher HL were more likely to report higher score of eHL, SE-OR and SE-BM. Carers with higher eHL were more likely to report higher score of positive perceptions towards caring and emotion-focused coping.

Carers of PwD in this sample, report an adequate level of HL and eHL, as they may act on behalf of the care-recipient. Services designed to meet the needs of a population with this HL and eHL profile could assist in the sustainability of the web-based services. Furthermore, nurses and other health care professionals if they obtain the tools to identify informal carers with low HL, could provide more tailored services according to carers' needs and enhance their HL skills.

Keywords: eHealth, dementia, Health Literacy, self-efficacy, carers, coping, social support

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LIST OF ABBREVIATIONS

PwD: PwD
ADI: Alzheimer Disease International
ADL: Activities of Daily Living
B: Beta
BPSD: Behavioural and Psychological Symptoms of Dementia
CFA: Confirmatory Factor Analysis
CHERRIES: Checklist for Reporting Results of Internet e-Surveys
COPE-index: Carers of Older People in Europe-index
COREQ: Consolidated Criteria for Reporting Qualitative Research
CVI: Content Validity index
CUT: Cyprus University of Technology
DSM-5: Diagnostic Statistical Manual-5
EFA: Exploratory Factor Analysis
eHeals: eHealth Literacy Scale
eHL: eHealth Literacy
eLILY: eHealth Literacy Learning Skills among Carers of Older People and PwD
GP: General Practioner
HL: Health Literacy
HLS-EU-Q: Health Literacy Survey- European Union-Questionnaire
HLS-EU: European Health Literacy Survey
I-CVI: Item level Content Validity index
ICT: Information and Communications Technology
IHME: Institute for Health Metrics and Evaluation
LTC: Long-Term Care
MSPSS-FA: The Multidimensional Scale of Perceived Social Support- the Family dimension
MSPSS-FR: The Multidimensional Scale of Perceived Social Support- the Friends dimension
MSPSS-SO: The Multidimensional Scale of Perceived Social Support- the Significant Other dimension
MSPSS: The Multidimensional Scale of Perceived Social Support
NIA: National Institute of Aging

NINCDS-ADRDA: National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association
NVS: Newest Vital Sign
OECD: Organisation for economic Co-operation and Development
P: p-value
PRISMA-ScR: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for. Scoping Reviews
People with Dementia: PwD
QoL: Quality of Life
REALM: Rapid Estimate of Adult Learning in Medicine
RSCSE: The Revised Scale of Caregiving Self-Efficacy
S-CVI/Ave: Scale Level-Content Validity Index Average
SAHL S and E: Short Assessment of Health Literacy in Spanish and English
SD: Standard Deviation
SE-BM: Self-Efficacy Behaviour Management
SE-OR: Self-Efficacy Obtain Respite
SE-TC: Self-Efficacy Controlling Upsetting Thoughts
SES: Socioeconomic Status
SILS: Single Item Literacy Screening
Std: Standard
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology Statement
TOFHLA: Test of Functional Health Literacy in Adults
WAD: World Alzheimer's Day
WHO: World Health Organisation
WRAT: Wide Range Achievement Test
α: Cronbach's alpha

PART I

1. Chapter

1.1.Introduction

Informal care consists of a large part of Long-Term Care (LTC) in Europe. As life expectancy increases, more and more people face the need for support due to the increase of later life noncommunicable diseases. In Europe, there are different LTC systems and not all of them are adequate to provide services meeting the needs of frail older people or PwD (PwD). Families and friends fill this gap, and their contribution to the national health systems could be considered as lifesaving on the one hand, but on the other informal carers suffer from physical and mental health problems due to the care they provide. A recent definition of the situation that carers of PwD are experiencing is "*a high level of physical, psychological, emotional, behavioural and financial burden that experienced by informal caregivers who provide care to PwD*" (Chiao, Wu, Hsiao, & Hsiao, 2015, p.341). Caregiving has been strongly associated with chronic stress and anxiety, depression, social exclusion, lower rates of employment and a higher risk of poverty, higher rates of infections and morbidity (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Mark, 2016; Oliveira, Sousa, & Orrell, 2019).

According to a recent survey by the European Quality of Life Survey (Eurofound, 2017), the prevalence of informal care, including carers of older people, people with disabilities and children, in Europe is estimated in a range10-30% of the general population. The lowest percentage is met in Romania and the highest in Greece. In Cyprus, 15% of the total population self-reports caring for another person. Due to several carers definitions, it is difficult to present this percentage with precision (Zigante, 2018).

According to Bettio & Plantenga, (2004), there are five informal care models in Europe according to the role that family plays in the LTC systems. In case of Cyprus and Greece, there is the so-called familial model, where there is low involvement of public services in the care of the person with a chronic condition and carers most of the times undertake this role without even realising it. As carers age, more men undertake this role in the ages above 75 years old (Colombo et al., 2011) In a recent, report by the Alzheimer Disease International and the Karolinska institute on the hours of caregiving, they estimate that in 2015 globally, carers spent 82 billion hours of care, which is more than the hours of 40 million full-time workers and this number will increase (Wimo, Gauthier, & Prince, 2018). In this report, they confirm that usually, women provide the most significant percentage of hours of care, either spouses or daughters.

In a recent scoping review describing the informal carers' needs, the most common needs reported in almost more than half of the studies, are the emotional health, formal and informal help and information about dementia and caregiving. Informal carers need information about dementia, caregiving, professional support and available services as well as for legal issues (Queluz et al., 2019).

In this study, we focus on the importance of the information that carers search, evaluate and apply either from health care professionals, family, and friends or they search on the internet. Nowadays, health-related information can be obtained in several ways, and patients and families are more and more involved in the decision-making process related to their health. The benefits of being health literate are related to higher self-efficacy in managing health problems and as a consequence lower health-care utilisation and better self-care management (Palumbo, Annarumma, Adinolfi, & Musella, 2016). World Health Organisation has adopted the work done by a European project team, that is presented in detail in the following chapters, the Health Literacy Survey-EU, and provided a report on the definition, the benefits, the involved stakeholders (World Health Organization, 2013). High Health Literacy benefits the society, is a lifelong process and involves the person, the environment and the professionals.

The use of the web-based tool in searching, finding and evaluating information is also part of this problem, as people use the internet for health-related information.
Is this also the case for the informal carers of PwD? The truth is that Health Literacy and eHealth Literacy among carers of PwD is a new area and not well documented.

Carers may be the children, spouses, other relatives or friends of a person with dementia, not always well supported by the social network or public services. PwD need 24/7 care, especially in the moderate to severe stages. Due to the lack of respite services in Greece and Cyprus and other South-Eastern European countries, carers are usually the core caring unit of the national health systems. They need to stay at home, caring for their relatives and experiencing social exclusion, as their social network is gradually decreasing. The use of web-based services could be valuable for carers due to all the above reasons (bound at home, social exclusion, lack of dementia-specific services and respite services). Older adults, especially in Greece and Cyprus, may encounter difficulty with the use of the internet and, with the use of mobile devices. Even so, dementia-related internet use could be considered more complicated than personal internet use and may not be so strongly related to age.

Furthermore, nurses and other health care professionals could be assisted in their communication with this target group if they are aware of users' Health and eHealth Literacy skills. From related research, it is known that the perceptions of nurses regarding these two concepts and their health outcomes among patients is limited and not well identified. The knowledge and understanding of Health Literacy and eHealth Literacy may change the communication between health care professionals and carers of PwD and identify those carers who need assistance in navigating with Health System services and medical information. Patients with low Health Literacy are not likely to follow treatment plans, visit frequently the emergency room, have higher risk for hospitalisation, do not understand the reading materials provided or do not know how to complete a medical form. Moreover, nurses, even if they are the largest group of health care providers, are less likely to have received official training regarding Health Literacy and eHealth Literacy (MacAbasco-O'Connell & Fry-Bowers, 2011) The comfort talk and education of family and the patients, according to related research in 12 European countries, were among the five top tasks left unfinished (Jones, Hamilton, & Murry, 2015). Unfinished Nursing Care (UNC) is considered a problem due to time scarcity with impact on many actors, starting from patients, nurses and expanding to the organisations and society, requiring a multidisciplinary scientific approach as a solution (Jones, Willis, Amorim-Lopes, & Drach-Zahavy, 2019). Nurses have the closest contact with patients and relatives at the hospital settings as well as the community and they are considered as the best target for increasing the carers' skills in e-health literacy and consequently improving patients' health.

In general, searching for information and being trained could facilitate the caregiving role, by increasing caregiving self-efficacy and positive aspects of caring. Until now, we know the role of self-efficacy on the selection of coping strategies and social support may influence self-efficacy. We also understand how health literacy may influence self-efficacy, but we do not know how all these concepts are combined for this target group. In the first introductory part of this dissertation, the concepts and theoretical frameworks are presented, starting with Health Literacy and eHealth Literacy, followed by Dementia, Alzheimer's Disease, carers and their needs. Then the available evidence on this topic until today is reported. Three reviews are presented firstly on the internet use made by carers, secondly on the relation of Health Literacy and eHealth Literacy with self-efficacy, coping strategies and social support and thirdly the review in relation with the eHealth literacy scale validations. The second part of the dissertation presents the full-scale study, including the methods, the findings and discussion.

2. Chapter - Concept definitions and theoretical frameworks I

In this first part of concept definitions and theoretical frameworks I, the concepts of Health Literacy, eHealth literacy, theoretical frameworks of these two concepts and existing ways to measure them are presented. For eHealth literacy, older frameworks are presented, and the theoretical progress is discussed until the present day, starting from the first model in literature in 2006. mHealth is mentioned briefly as one of the most recent dimensions of eHealth. Finally, these concepts among older people and carers of older people are reviewed.

2.1.Health Literacy

Health literacy has drawn the attention of researchers in the past three decades as it influences the self-management of patients with chronic diseases and as a consequence the quality and the cost of care of chronic disease (Howard, Gazmararian, & Parker, 2005; Reisi et al., 2014). This is the case if we search the available research in cancer, heart failure and diabetes. In cancer research, high Health Literacy could benefit communication among health care users, professionals and policymakers (Rudd, 2019). In diabetes research, there are evidence related to self-management. People with diabetes with low Health Literacy misunderstand self-management, are passive, and they do not access information easily (Kim, Song, Park, & Utz, 2019).

Moreover, heart failure patients with high Health Literacy were more likely to have a higher knowledge of heart failure and better self-care than people with lower Health Literacy with fewer hospital admissions (64%) and higher heart failure quality of life (Cajita, Cajita, & Han, 2016)

Low Health Literacy seems to be connected with a longer stay in hospitals, GP home consultations, ambulance transportation, psychiatric consultations and more admissions to a 1-day clinic (Vandenbosch et al., 2016). Low Health Literacy seems to have negative consequences in the quality of care. People with low Health Literacy levels are involved in fewer preventive strategies, are not so willing to follow medical instructions, make higher utilisation of health care services (Doyle, Gibney, Quan, Martensen, & Schillinger, 2017; Howard et al., 2005)**.** On the other hand, high health literacy is associated with higher self-efficacy, better self-care management and lower health-care utilization and overall benefits society due to more cost-effective practices (health promotion and prevention strategies) employed by health literate people (Palumbo et al., 2016; World Health Organization, 2013).

One of the main problems in Health Literacy research is the lack of consensus regarding the concept and in some cases, as regards the terminology as well, since there are many different definitions of this term that combine several dimensions to explain the concept. In cancer and diabetes, focused research is found on Health Literacy issues (e.g. self-care management, self-efficacy, knowledge of the disease medication adherence, glycemic control, genomic control in the framework of family health history, cancer screening and medical advice) in comparison with other chronic diseases. One of the most frequently-used definitions is the one proposed by Ratzan & Parker (Institute of Medicine, 2004, p.32):

“***The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”.***

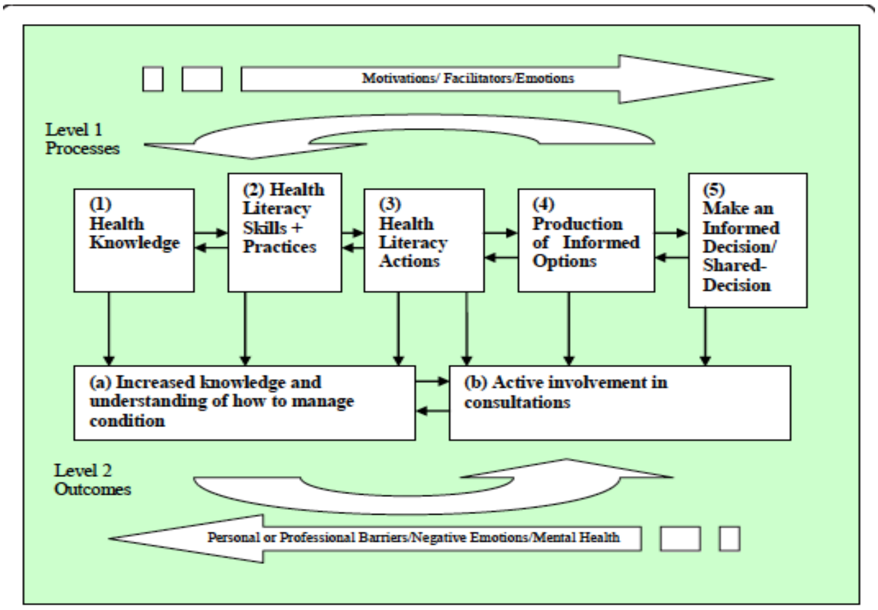
Nowadays, people with chronic diseases often encounter challenges to understand health-related material and take decisions on how to use it properly. Another widely used definition of health literacy discriminates in 3 types of literacy:

- functional literacy (reading and writing skills),
- communicative literacy (cognitive and literacy skills that facilitate social participation)
- and critical literacy (cognitive skills that facilitate critical thinking) (Nutbeam, 2000)

In 2012, Edwards, Wood, Davies, & Edwards, (2012) published the 5-stage **Health Literacy Pathway Model**:

1) building health knowledge which includes the basic knowledge someone has for one’s own health,
2) develop health literacy skills and practices, including literacy skills and self-management skills,
3) Health Literacy in actions, where the person is actively involved in one’s own health, asks and communicates with health care professionals,
4) production of therapeutic options, where people can conclude in therapeutic choices with the assistance of care professionals and
5) make an informed decision by selecting a therapeutic choice.

Figure 2-1Health Literacy Pathway Model by Edwards et al (2012)

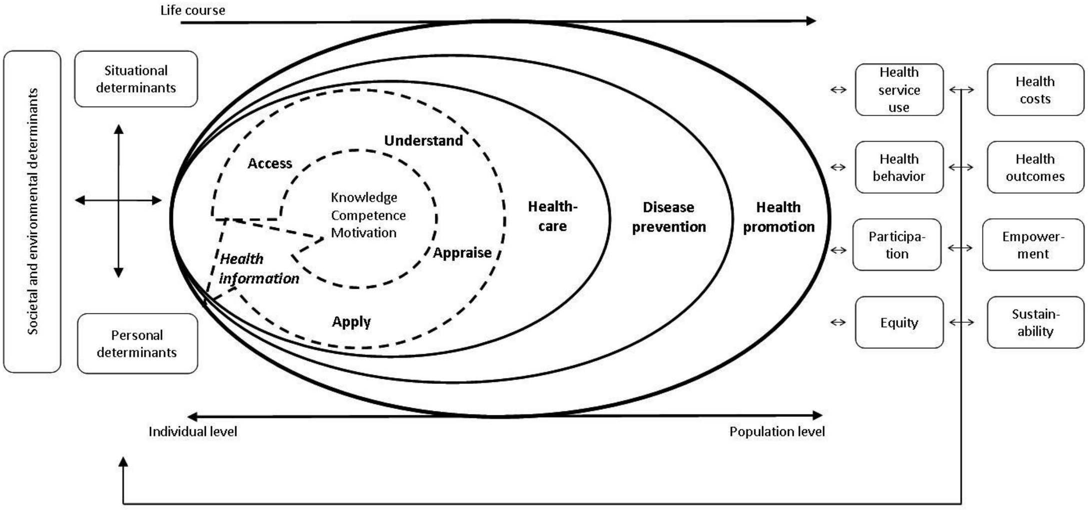


In a recent survey, the European Health Literacy Survey (HLS-EU), 8000 people were asked Health Literacy topics from 8 countries: Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland, and Spain. The HLS-EU consortium has developed a conceptual framework on health literacy:

"***Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course***"

and they have developed below a figure to describe the multiple variables that influence health literacy (Soerensen, K., et al., 2012, p.3):

Figure 2-2 The integrated model of Health Literacy (Soerensen et al, 2012)



Based on the above model, 12 sub-dimensions consist the Health Literacy concept. The concepts: access, understand, appraise, apply in combination with Health Care, Disease Prevention and Health Promotion were the basis for the development of the 47 items HLS-EU Questionnaire. ***Access, comprehension, appraisal, and implementation represent cognitive dimensions***, and according to the authors, the three (3) types of Health Literacy proposed by Nutbeam are integrated into these processes (Nutbeam, 2000). As a consequence, knowledge, and skills are developed through the above process, making people capable of deciding on questions related to their health in the health disease spectrum: as a patient in the healthcare system, at home, a person with risk factors as part of disease prevention and in the framework of public health as a citizen in disease prevention. The above model could be considered as the most recent definition trying to combine all previous definitions. In the Health Literacy report developed by WHO (World Health

Organization, 2013), the Health Literacy Survey and the related definition is the core part in presenting the concept.

Health Literacy might be challenging to be translated in national languages, and this was initially discussed by Sorensen and Brand (Sørensen & Brand, 2014), with the paper "Health Literacy Lost in Translation?". This paper is a European Health Literacy Glossary focusing on the translations available for this term. Sorensen and Brand report that in the Western world there is a rapid increase in this topic, but in Europe there is a delay due to the fact that this English term has many different translations, complicating research. Taking the above into consideration, and avoiding replication of the abovementioned situation, in Cyprus, a consensus meeting was held between the two teams working on this topic. In the case of Greece, two members of the Health Literacy Survey attended the event. The methodology and the results of the consensus meeting are presented in Chapter 6, section 6.3

2.2. Health Literacy Tools

Many different Health Literacy tools aim to measure different dimensions of Health Literacy. Between 2012 and 2014, 3 systematic reviews were published providing information on the specific variety of Health Literacy tools. In some cases, as O'Neill, Gonçalves, Ricci-Cabello, Ziebland, & Valderas, (2014) analysed, there are generic and condition-specific tools and (Altin, Finke, Kautz-Freimuth, & Stock, 2014) discriminated the tools in objectives and subjective. Subjective measurement investigates patient-provider encounter, interaction with the health care system, rights and responsibilities, health information-seeking, understanding, processing and using health care information, communication and objective measurement assesses print literacy, oral literacy, and numeracy. Furthermore, Altin et al., (2014) discussed the existing trend towards mixed measurement (objective and subjective) approach and pointed out that scholars did not justify the use of specific measures.

In total 46 generic and condition, specific tools were developed according to these three systematic reviews without including the validation to other languages of the primary tool (Altin et al., 2014; Collins, Currie, Bakken, Vawdrey, & Stone, 2012; O'Neill et al., 2014). In a recent systematic review by (Okan et al., 2018) on generic health literacy tools for children and adolescents, they identified ten (10) more tools (7 for children and/or adults).

The most widely used tools are Test of Functional Health Literacy in adults (TOFHLA), S-TOFHLA (short version of TOFHLA), and Rapid Estimate of Adult Learning in Medicine (REALM), which are only available in English and Spanish. TOFHLA was developed based on actual hospital material including hospital material for preparation for an upper gastrointestinal series, an insurance application and hospital consent form and used readability formula of Gunning Fog index, an index correlating education with text reading comprehension skills (Parker, Baker, Willia, & Nurss, 1995). The authors of TOFHLA were interested in numeracy as they consider it a critical aspect of Health Literacy. The words used in REALM are derived from actual medical material (medical forms, educational material). As in the case of TOFHLA, this test associated the score with a reading level. Other tools have been developed based on TOFHLA and REALM, and in other cases, researchers have approached the health literacy concept in different ways.

TOFHLA is a measure of functional Health Literacy, which discriminates people in three categories: adequate, marginal and inadequate literacy with high internal consistency (Cronbach a=.98) and concurrent validity tested with REALM (r=.084) and Wide Range Achievement Test (WRAT-K, r=.074)(Parker et al., 1995). It has 17 numeracy items and 3 prose passages, and the time of administration is up to 22 minutes. S-TOFHLA is an abbreviated version with 4 numeracy items and 2 reading passages and takes up to 12 minutes to administer. TOFHLA and S-TOFHLA have a good internal consistency and correlate well with the REALM.

REALM assesses the ability to read health-related words and consists of 66 words, there is also the REALM-R (short version of REALM) with 8 items and only 2 minutes to administer and high concurrent validity with Peabody Individual Achievement Test-Revised Reading recognition section (r=0.97), the Wide Range of Achievement Test-Revised (r=0.88) and Slosson Oral Reading Test-Revised (r=0.96) (Davis et al., 1993). REALM uses health-related words that progressively become harder to pronounce. The transferability in other languages is questionable and for that reason, Lee, Stucky, Lee, Rozier, & Bender, (2010) have developed the Short Assessment of Health Literacy in Spanish and English (SAHL S&E). The difference between REALM and SAHL S & E is that the user should select the word between two choices that correlate best with the word in the list.

Another widely used instrument is the Newest Vital Sign (NVS), which was developed with the funding of a pharmaceutical company and includes 6 items to assess reading and comprehension of an ice cream nutrition tab, administration time is about 6 minutes. Another measure that is widely discussed in all three systematic reviews is the three assessment questions and the Single

Item Literacy Screening (Altin et al., 2014; Collins et al., 2012; O'Neill et al., 2014). Chew & Boyko, (2004) initially developed 16 questions based on 6 themes that were derived from a qualitative study. Of these questions, three appeared to detect between people with high and inadequate Health Literacy:

1)"*How often do you have someone help you read hospital materials*",

2)"*How confident are you filling out medical forms by yourself*" and

3)"*How often do you have problems learning about your medical condition because of difficulty understanding written information*".

The difficulty with the selected questions was that they could not discriminate between inadequate and marginal literacy. Out of the three questions, the question: "How often do you have someone help you read hospital materials" seems to better detect inadequate literacy. Morris et al. (Morris, MacLean, Chew, & Littenberg, 2006) tested the Single Item Literacy Screening (SILS) "*How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy*". The SILS can predict S-TOFHLA and performs better in discriminating the inadequate level of Health Literacy.

Table 2-1 Systematic reviews of health literacy tools

Authors, Year	Aim of the Review	number of articles	tools assessed
Collins et al (2012).	Analyzing health literacy tool, that could be used as computer-based tools	28	TOFHLA, REALM, S-TOFHLA, REALM-R, NVS, HLSQMs[1], eHEALS
O'Neill et al (2014).	administration characteristics and validity of 35 health literacy measures, aims to assist selection of an appropriate index	35 (27 original instruments and 8 derivative instruments). Most of them from United States, Australia, Japan	• General HL tools:3 questions, NAAL HL[2], SILS, CCHL[3], CHC[4], HLSI[5], METER[6], Talking touchscreen, graph literacy, health LiTT[7], TAIMI[8], MHLS[9], Canadian high school student measure, HLSI short form, SDPI-HH HL[10], Massey 2012 measure, CAHPS Item Set[11], AAHLS[12], HeLMS[13], HLQ[14], • Dental: HelD[15], Harper 2014 measure, Diabetes: FCCHL[16], • Cancer: SIRACT[17], CMLT-L/CMLT-R[18], Mental Health: Reavley 2014 measure, • Nutrition: FlanKK[19], NLAI[20], Hospital: HCAHPS Item Set, HIV: HIV-HL[21], Medication: MedLitRxSE[22], • Colon cancer: ACCL[23], • Intellectual disability: ILDS[24], • eHealth: eHeals[25]
Altin et al,(2014).	identifying generic health literacy tools Objective and subjective measurement:	17	• Only 3 instruments included the communication skills. • Tools with objective approach: METER[6], REALM, SAHL S&E, Health and financial literacy test with 9 items, Critical health competencies test consist of 72 items (4 scenarios), Talking touchscreen: prose document and quantitative literacy. • Self-report (subjective) approach: MAHL[26], HELMS[13] (8 scales of 4-5 items), MHLS-50[9], HLS-CH[27], AAHLS[12] (14 items). • Mixed approach: HLSI[5] and HLSI -SF[5] (short form) 25/10 items tools: addressing print, oral quantitative and internet based info seeking skills., The European Health Literacy Survey (HLS-EU) carried out in 8 European countries, measuring functional HL with NVS, and a self-report with 47 items, SNS[28] and SLS[29] (11 item instrument), SDPI-HH-PL[10] (diabetes) , HL of Canadian high school students, Canadian exploratory study There is a trend towards mixed measurement (objective and subjective) approach. Scholars do not explain why they are using a specific type of measurement
(Okan et al., 2018)	Identifying generic health literacy tools for children and adolescents	15	• REALM-teen • Kidshealth Kids Poll of Health Literacy • HLQ[14] • AAHLS[12]Health Quiz

	• Instrument based on Health Education Assessment Project • CHC[4] • TOFHLA for Adolescents • HLQ[14] for Children and the version for High School • GeKoKids	• MaHeLI [30] • HLS-EU 47 & 16 • MHL[31] • NVS

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[1] Health Literacy Screening Question Methodologies, [2] National Assessment of Adult Literacy, Health Literacy, [3] Communicative and Critical Health Literacy Scale [4] Critical Health Competence Test, [5] Health Literacy Skills Instrument, [6] Medical Term Recognition Test, [7] Health Literacy Assessment Using Talking Touchscreen Technology, [8] Test for Ability to Interpret Medical Information, [9] Mandarin Health Literacy Scale, [10] Special Diabetes Program for Indians Healthy Heart Health Literacy, [11] Consumer Assessment of Healthcare Providers and Systems Hospital Survey, [12] All Aspects of Health Literacy Scale,[13] Health Literacy Management Scale, [14]Health Literacy Questionnaire, [15] Health Literacy in Dentistry, [16] Functional, Communicative, Critical Health Literacy Scale, [17] Stieglitz Informal Reading Assessment of Cancer Text, [18] Cancer Message Literacy Test-Listening; Cancer Message Literacy Test-Reading, [19] Food Label Literacy for Applied Nutrition Knowledge, [20] Nutrition Literacy Assessment Instrument, [21] HIV-Related Health Literacy Scale, [22] Medication Literacy Assessment in Spanish and English, [23] Assessment of Colon Cancer Literacy, [24] Intellectual Disability Literacy Scale, [25]eHealth Literacy Scale, [26] Multidimensional Measure of Adolescent Health Literacy, [27] 127 item Swiss Health Literacy Survey, [28] the brief subjective measure of numeracy, [29] general health literacy, [30] Multidimensional health literacy instrument, [31] Maternal Health Literacy

2.3. eHealth

Along with the development of technology, new terms are taking over, and researchers are interested in terms of eHealth literacy and mHealth literacy. eHealth is defined according to (Eng, 2002) as ”*the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care*”. mHealth is a component of eHealth and WHO (World Health Organization, 2011b) defines mHealth as “medical and public health practice supported by mobile devices, such as mobile phones, patients monitoring devices, personal digital assistants (PDAs) and other wireless devices. eHealth literacy term has been identified in parallel with the progress of new technologies in Health. Available technologies provided to people with chronic diseases are often misused or people are not interested in using them. In 2006, Norman & Skinner, (2006b, p.3) presented the lily model as an attempt to describe the different dimensions of eHealth literacy and defined eHealth literacy as :**“*The ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem*”**

2.4. Theoretical framework of eHealth Literacy: The Lily model

The Lily model includes 6 basic types of eHealth literacy and categorises them into two categories of skills: analytic and context-specific. In analytic category, it includes:

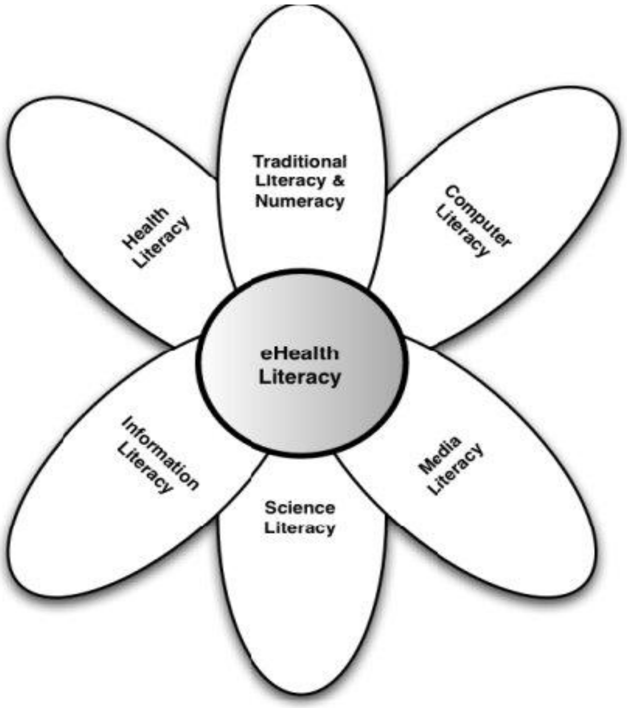
Traditional literacy, which includes basic skills to read, understand, write and speak language.

Information literacy, which describes the skills needed of a person to find, select and use the information available of any type.

Media Literacy, which is defined as a process of metacognitive strategies, to place information in a social and political context.

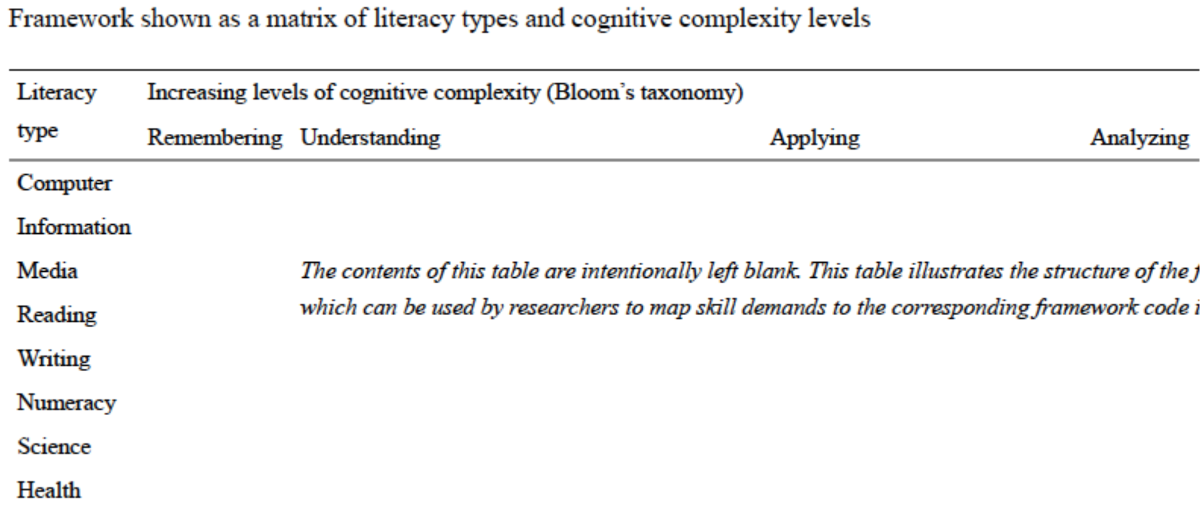
In context-specific information, Norman and Skinner included the **Health Literacy**, which is the ability to find, select and understand health-related information, **Computer literacy**, the ability to use computers and **scientific literacy**, the skill to understand the aims, methods, implementation, limitations, and politics of creating knowledge.

Figure 2-3 Health Literacy, Lily model by (Norman & Skinner, 2006b)



As a consequence, Norman & Skinner, (2006a) proceeded to the development of eHealth Literacy Scale (eHeals), an 8-items scale of eHealth literacy with a total score ranging from 8 to 40 as a way to measure the skills and knowledge of eHealth literacy. The scale was tested in 664 adolescents aged 13 to 21 years old and showed good metric properties. The scale has been translated and used in many different languages. Researchers especially in the last 5 years discuss the number of factors that the tool includes. Chan & Kaufman, (2011) have proposed a methodological and theoretical framework on how eHealth literacy can be analysed, measured and quantified. Until today eHealth tools seem to be quite generic without taking into consideration different user groups. Their model is based on Norman's and Skinner's Lily model for eHealth and Bloom's taxonomy of educational objectives. Bloom's taxonomy describes the cognitive dimensions that are prerequisite for any type of literacy and includes: remembering, understanding, applying knowledge, analysing, evaluating and creating a coherent meaning. Bloom's taxonomy constitutes the framework that eHealth can be built. Furthermore, Chan & Kaufmann separated traditional literacy into 3 types: reading, writing and numeracy. In this way, they have formed a model of 36 categories. They have found that the use of reading, information and computer literacy are the most used types when completing a task.

Figure 2-4 Framework of Chan & Kaufmann, 2011



Framework shown as a matrix of literacy types and cognitive complexity levels

Literacy type	Increasing levels of cognitive complexity (Bloom's taxonomy)			
	Remembering	Understanding	Applying	Analyzing
Computer				
Information				
Media		*The contents of this table are intentionally left blank. This table illustrates the structure of the*		
Reading		*which can be used by researchers to map skill demands to the corresponding framework code*		
Writing				
Numeracy				
Science				
Health				

Norman, (2011) has discussed the need for eHealth literacy to be revised taking into account the latest progress in internet tools and Web 2.0 and the use of social media and mobile internet. Norman discusses that the eHeals scale had a good correlation with Web 1.0 and was tested with youth and youth workers, who were frequent users during that period 1990-2000. In 2011, the study of Van Der Vaart et al., (2011) made the first critique of the model and the weak correlation between eHeals and Web 2.0, suggesting revision. After this revision of the Lily model, that included the cognitive factors of users, additional attempts to expand the model have taken place (Gilstad, 2014; Koopman, Petroski, Canfield, Stuppy, & Mehr, 2014). Gilstad (2014, p.69) redefined eHealth literacy:

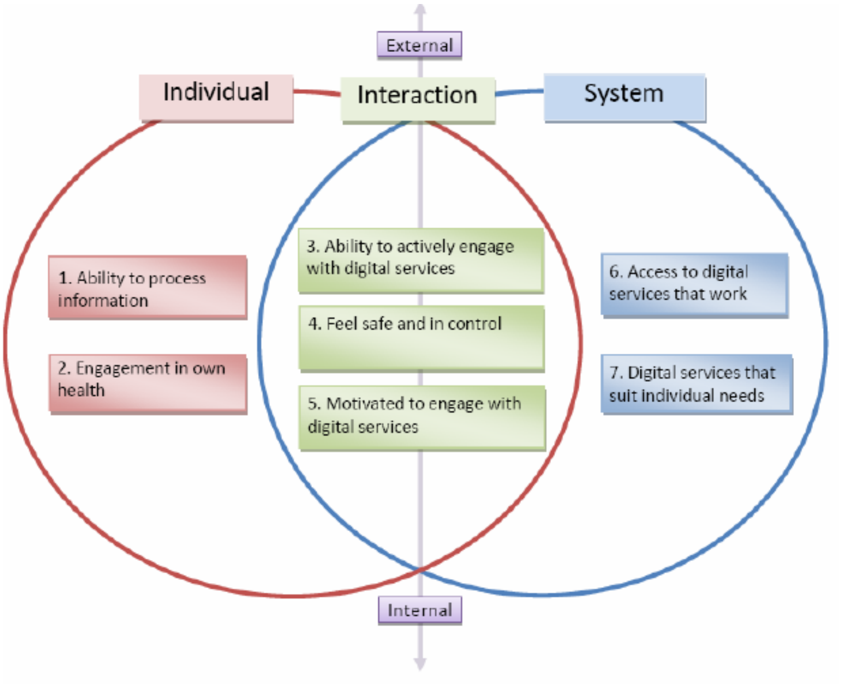
> “*eHealth literacy is the ability to* ***identify*** *and* ***define*** *a health problem, to* ***communicate****, seek, understand, appraise and apply eHealth information and welfare technologies in the cultural, social and situational frame and to use the knowledge critically in order to solve the health problem»*

and included 4 new dimensions to the Lily Model: **bodily experience** (the ability to identify health problem, procedural literacy (“how” dimension of Knowledge**), contextual and cultural literacy** (cultural background knowledge), **communicative expertise** (the ability to convey personal health issues). Additionally, Koopman et al., (2014) considered the Lily model and the eHeals questionnaire of Norman and Skinner as a model tested only on young adults, so they have tried to include dimensions that are relevant for older adults. They have developed the PRE-HIT instrument to measure eHealth literacy of older adults. A more recent suggestion is the one proposed by Norgaard, Kayser, Osborne, & Norgaard, (2015), who have used concept mapping workshops with all relevant stakeholders: IT users, non-users, patients, health care providers, IT experts to update the dimensions that consist the eHealth literacy framework. Based on this framework, Kayser et al., (2018) developed an eHealth literacy questionnaire in Danish and English with 35 items including the above 7 dimensions.

Core dimensions that have been identified are:

1. The ability to process information
2. Engagement in one's own health
3. Ability to actively engage with the digital services
4. Feel safe and in control
5. Motivated to engage with digital services
6. Access to digital services that work
7. Digital services that suit individual needs

Figure 2-5 Nordgaard et al, 2015. eHealth Literacy Framework



Bautista (2015, p.43) tried to redefine eHealth literacy as a term that

> "...*involves the interplay of individual and social factors in the use of digital technologies to search, acquire, comprehend, appraise, communicate and apply health information in all contexts of healthcare with the goal of maintaining or improving the quality of life throughout the lifespan*."

In a recent work by Paige et al., (2018, p.8), a new attempt to present a conceptual framework has been presented and a new definition proposed

“*The ability to locate, understand, exchange, and evaluate health information from online environments in the presence of dynamic contextual factors and to apply the knowledge gained across ecological levels for the purposes of maintaining or improving health*”.

The Transactional Model of Communication by Paige et al. (2018) consists of the basic framework where they have built upon and integrated the interpersonal computer-mediated communication with the use of technology. In this respect, the noise dimensions that influence this type of communication could be usability issues, stress about the disease, other limitations related to the illness. The proposed framework distinguishes 3 dimensions: 1) contextual factors (task-oriented and user-oriented factors) 2) the interpersonal skill of eHealth Literacy 3) patient engagement. Noise factors are derived from the interaction between task and user-oriented factors.

2.5. mHealth and mHealth literacy

As Health and eHealth Literacy progress new concepts make their appearance. A new term that describes the mobile technologies, that appeared almost 6 years ago is mHealth or mobile Health, defined by the **Global Observatory for eHealth** as

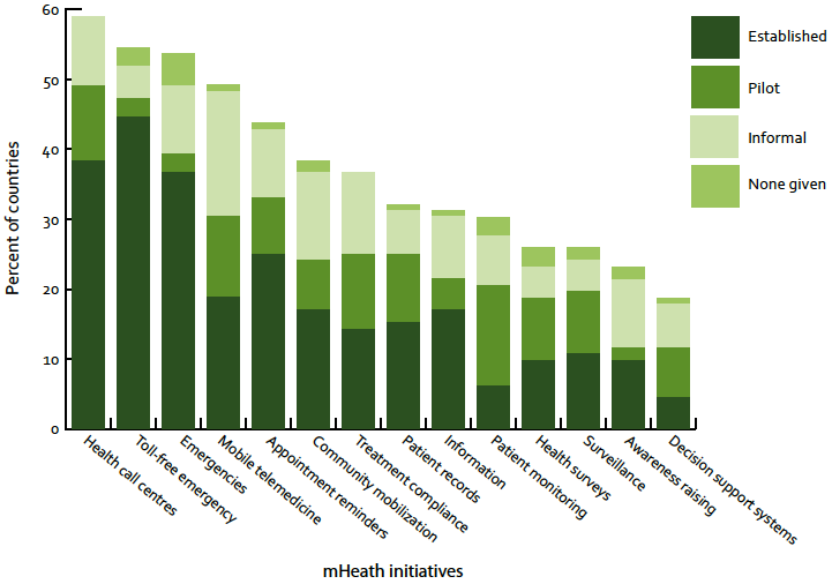
“*the medical and public health practice supported by mobile devices such as mobile phones, patients monitoring devices, personal digital assistance and other wireless devices*”

According to **WHO report on mHealth in 2011** (World Health Organization, 2011b, p.6), which was based on the findings of the second global survey on eHealth, the most commonly used mHealth technologies are health call centres/ helplines (59%), emergency toll-free telephone services (55%), emergencies (54%) and mobile telemedicine (49%). On the other hand, the initiatives that were least reported were health surveys (26%), surveillance (26%), awareness-raising (23%) and decision support systems (19%) (figure 2.6).In recent years, the mHealth network published national mHealth strategies to facilitate developers and the issue of privacy, quality standards, public consultation are only a few of the issues that were included in the related report (mHeatlh Network, 2016).

Only in 2017, do we find the first reference on the concept of mHealth literacy, as part of a dissertation (Ahmed, 2017) mHealth literacy could be described as 15 skills, essential for app users and differentiate this concept with eHealth literacy. App users need to acquire the 15 skills below to full experience mHealth apps:

1) Smartphone literacy (basic use of a smartphone), 2) App literacy (knowledge of availability, basic functions, purchasing and evaluating an app, 3) English (or national language) literacy, 4) Numeracy, 5) Understand the app health goals, 6) Information literacy, 7) Graph literacy (optional skill), 8) Computer literacy (optional skill), 9) Web literacy, 10) Data privacy, 11) App evaluation skills, 12) Technology adoption (no fear of using technology), 13) Motivation to use the technology, 14) Consistency (frequency and commitment of mHealth app use) 15) Judgment skills of consulting the doctor when necessary (willingness)

Figure 2-6 Adoption of mHealth initiatives around the world (WHO, 2011)



2.6. Internet use, eHealth literacy and older adults

Older adults and more specifically baby boomers appear to be the population with the most difficulty in using new technology (Tennant et al., 2015). How this problem will proceed in future generations, and if this research and community problem will still trouble us in the same way that it does now remain unknown. There is always the assumption that people will be more adaptive to new technology, and eHealth literacy will be part of their everyday lives, but this remains to be seen.

Many researchers tried to investigate the relationship between older people and eHealth literacy, internet use, and to describe possible predictors and associated variable.

In this section 20 relevant studies are included (Table 2.2) as part of a first literature review (1) on this topic, 10 of which confirmed age and 9 education as good predictors of eHealth literacy and internet use, giving the advantage to younger people and more educated (Agree, King, Castro, Wiley, & Borzekowski, 2015; Bonner et al., 2018; Choi & Dinitto, 2013; Ghweeba et al., 2017; Gordon & Hornbrook, 2018; Halwas, Griebel, & Huebner, 2017; Howard et al., 2005; Kummervold et al., 2008; Levy, Janke, & Langa, 2015; Noblin & Rutherford, 2017; Paige et al., 2018; Tennant et al., 2015; Van Deursen & Van Dijk, 2011). The survey in 6 cases has been delivered on-site or at home (Arcury et al., 2018; Bonner et al., 2018; Currie, Philip, & Roberts, 2015; Holden, Kulanthaivel, Purkayastha, Goggins, & Kirpalani, 2017; Noblin & Rutherford, 2017; Richtering et al., 2017), in 5 cases online (Agree et al., 2015; Ghweeba et al., 2017; Paige, David Miller, et al., 2018; Sheng & Simpson, 2013; Xesfingi & Vozikis, 2016). In 3 studies, researchers used performance tests (Agree et al., 2015; Van Der Vaart, Drossaert, De Heus, Taal, & Van De Laar, 2013; Van Deursen & Van Dijk, 2011) and in 4 studies used the telephone strategy to collect the sample (Choi & Dinitto, 2013; Kummervold et al., 2008; Neter & Brainin, 2012; Tennant et al., 2015).

Performed eHealth literacy and perceived eHealth literacy were positively correlated, but not accurately as a related study of Neter, Brainin, & Baron-Epel, (2017) of a sample of 82 Israeli people aged over 50 years old reported. Participants with low performed eHealth literacy had lower scores in perceived eHealth literacy and needed more help with the digital aspects of the tasks. Access and appraise factors of perceived eHealth literacy were low to moderately correlated with the performed factors (access, understand, appraise and apply) of the eHealth literacy.

eHeals scale has been used in 10 studies as a measure of eHealth Literacy levels usually combined with sociodemographic data and in some cases related to other measures of computer literacy and functional health literacy (Arcury et al., 2018; Choi & Dinitto, 2013; Halwas et al., 2017; Neter & Brainin, 2012; Noblin & Rutherford, 2017; Paige, Krieger, Stellefson, & Alber, 2017; Richtering et al., 2017; Sheng & Simpson, 2013; Tennant et al., 2015; Xesfingi & Vozikis, 2016). Researchers usually used additional questions to investigate internet usage, web-based health information seeking strategies, health status, health information resources, frequency of internet use and time spent to using the internet (Arcury et al., 2018; Bonner et al., 2018; Ghweeba et al., 2017; Halwas et al., 2017; Noblin & Rutherford, 2017; Paige, David Miller, et al., 2018). Other measurements included Short Test of Functional Health Literacy in adults (Levy et al., 2015), Attitudes Toward Computer/Internet Questionnaire (Tennant et al., 2015), Computer-assisted telephone interviews (Kummervold et al., 2008), Rapid Estimate of Adult Literacy in Medicine (Agree et al., 2015;

Levy et al., 2015), Newest Vital Sign and Single Items Literacy Screening (Noblin & Rutherford, 2017)

The number of electronic devices seemed to be a predictor of internet use (Arcury et al., 2018; Gordon & Hornbrook, 2018; Tennant et al., 2015). Low income, low socioeconomic status and racial/ethnic minorities are considered predictors of internet non-use (Arcury et al., 2018; Choi & Dinitto, 2013). Additionally, in the age group over 75 years old, low Health Literacy was influenced by low scores in cognitive measures (Levy et al., 2014). Direct communication with Health Professionals instead of web-based health information seeking was also a topic that was discussed in 3 studies (Bonner et al., 2018; Gordon & Hornbrook, 2018; Kummervold et al., 2008).

We can distinguish 4 core categories of internet skills: ***basic skills, formal skills (navigation, orientation), finding information and strategic skills (using the information for personal benefit)*** (Van Deursen et al (2011). Lack of skills when navigating on the internet was the most common problem identified within a sample of people with rheumatic diseases, including the difficulty in operating the computer and internet browser, navigating and orientating, utilising search strategies, evaluating relevance and reliability, adding personal content to the web and protecting and respecting privacy (Van der Vaart et al., 2013). Older users did not take advantage of the services that they found on the internet, and not all people searched for health information and even fewer people used social networks (Choi & Dinitto, 2013).

People who have never used the internet, were positive in starting to, older adults were less confident than younger ones in the use of the internet. According to the most popular activity of older people when using the internet included sending and receiving emails (Choi & Dinitto, 2013). In rural areas, where there was a close relationship between patient and care professionals, people accepted eHealth just as a supplement of the care they received and not as the only care management. Men were more positive toward eHealth in comparison with women in rural areas, and that may be due to the different social networks of men and women. Women with larger social networks might not be so willing to leave them and make space for eHealth technology (Currie et al, 2015).

Table 2-2 eHealth Literacy, internet use and older adults

Paper	Countries	Aim	Design	Sample	measures	Related outcomes
(Kummervold et al., 2008)	Denmark, Germany, Greece, Latvia, Poland, Portugal, Norway	To investigate trends of the European health-related internet use	non-experiment (single shot telephone survey) Measurements in 2005 and 2007	14956 people from seven countries.	CATI (Computer assisted telephone interviews), one item to measure internet use	the percentage that used the internet in 2007 has increased in comparison with 2005. Lowest use in **Greece** and Portugal in 2007. Highest use in Denmark. For the age group of 66-80, 22% men used the internet for health purposes and 9.9% of women. Direct contact with health professionals was considered as the most important source of health information in 73%. **In Greece, internet was considered the least important source of health info.**
(Van Deursen & Van Dijk, 2011)	Netherlands	Readiness of the population for eHealth	Performance test (2 assignments of 8 tasks each)	88 participants, randomly selected by telephone directory, 18-24: 27%, 30-39: 21%, 40-54: 26%, 55-80: 26%	demographic characteristics, performance tests	the study distinguishes between **operational**, **formal**, **information** and **strategic** skills measured in an actual performance test. **Age** was an important factor for the operational and formal but not for information and strategic skills. Younger need also to improve information and strategic skills when considering health information.
(Sheng & Simpson, 2013)	USA (South Texas)	Relationship of Health Information Orientation, eHealth literacy and Internet Knowledge with the Internet use for Health Information	non-experiment (single shot online and by post survey)	771 people among them: winter migrants, generally retired seniors, 50 years and older	Health Information Orientation (HIO): 9 items by Basu and Dutta, Internet Knowledge (IK): 5 items, 4 of them adapted by Bart et al, eHeals, health information measured by a single item	HIO, IK and eHealth literacy influence the likelihood to use Internet for health information. HIO and IK indirectly influence health search through eHealth literacy.
(Choi & Dinitto, 2013)	United States	Internet use patterns, eHealth literacy and attitudes towards computers among low-income homebound individuals aged 60 and older in comparison with younger counterparts	non-experiment (single shot telephone survey)	980 recipients of home - delivered meals in central Texas, 78% of 60 years and older and 22% under 60	eHeals, Attitudes Toward Computer/Internet Questionnaire, items on internet use, socio-demographics, health, mental health and disability by ADL and IADL	60% had never used the internet, 20% had used it before and 20% currently using it. Internet use differs by age, with a higher rate for younger people. Low income, being black or Hispanic, and being older was associated with **no use**. 75% of the younger group reported health related information searches and 55% of the older group. Most popular activity was sending and receiving emails, followed by research of non-health and health related info. Having chronic conditions is related with higher internet use

(Van Der Vaart et al., 2013)	Germany (Utrecht)	eHealth literacy of people with rheumatic diseases and problems they encounter when using the internet	Performance test with convenient sample	Study 1: 15 people out of 146 patients (convenient sample), mean age 56.4 Study 2: 17 of 45 patients of the outpatient dpt of rheumatology clinic of University of Medical centre Utrecht, mean age 48.6	Demographic information, internet experience (amount of internet use, years of internet experience, self-perceived internet skills, usage of health-related application on the internet	90% of the total sample searched for online disease-related info, only 13% used Health 2.0 application as support forum or posting a health care review. Study 1 observed problems: operating the computer and internet browser, navigating and orientating, using search strategies, evaluating relevance and reliability of the content. In study 2, participants encounter the same problems as study 1 plus difficulty in adding content, using capital letters and punctuation marks, spelling, using headers and sender info, formulating a question and also security issues.
(Levy et al., 2015)	USA (Michigan)	Relationship of health literacy and internet use among Americans, aged 65 and older	retrospective analysis of 2009 and 2010 data from the Health and retirement study, a longitudinal survey	2010: 1168 respondents aged 65 and older randomly drawn for the study. Final sample 824 and 2009: 1584 older over 65 provided a valid response	Internet use: single item question, health literacy with REALM and S-TOFHLA, cognitive function tests, single item measuring self-reported health, ADLs and IADL, demographic and socioeconomic characteristics	Internet users were younger, more educated and with better mental and physical health than the general population. People with adequate health literacy were 3 times more likely to use the internet. Over 75 years, less educated than high school and low scores in cognitive measures were associated with low health literacy.
(Currie et al., 2015)	UK (Scotland)	Examine opportunities and challenges of eHealth in relationship to chronic pain in rural areas	non-experiment (single shot survey)- Postal and home visits	168 respondents	questionnaire developed by the authors	people who are old and live alone are more likely to use technology.
(Tennant et al., 2015)	USA	Relationship of sociodemographic, social determinants and electronic device use on eHealth literacy, Web 2.0 among baby boomers and older adults	cross sectional, telephone survey	283 of baby boomers and older adults, mean age 67,46	sociodemographic and social determinant variables, eHeals, items from the Health Information National Trends Survey	35.7% use the internet to locate and share health information, users of web 2.0 and social media reported greater eHealth literacy. Significant predictors of eHeals age, education, number of electronic devices use to seek information
(Agree et al., 2015)	USA	explore associated factors with health information search	online survey and performance task	346 people over 35 years old (mean age 55)/ convenient sample	REALM, Witkin Group Embedded Figures Test, Practice search task	Predictors for online health information: age (younger vs older), daily internet use, College education or more and health literacy score and cognitive style

Ghweeba et al, 2017	Egypt	find association between demographics and web-based health information seeking	web and interview-based data	Convenience sample 1064 (majority of the sample 25-39) and 163 people over 55	sociodemographic information, health status questions, questions on health information seeking behavior	Predictors: gender (with female searching more frequently the internet), age (younger people make more frequent use of the internet), people with higher educational level spend more time in searching for health info
Halwas et al, 2017	Germany	attitudes towards eHealth, eHealth literacy on decision making	email survey	490 participants mean age 36.8/ convenience sample	Demographic info, general internet use, eHealth use questions, eHealth literacy, SILS, frequency of using health info resources, satisfaction with lecture	Age (younger people use the internet more frequent, no relation with gender and education with eHealth literacy
Holden et al, 2017	USA	develop biophsychosocial profiles of older patients' with Heart failure eHealth use	N/A	142 cancer patients and their relatives	VICS survey and Caring Hearts study instrument	6 clusters: medical, functional, psychological, technological, social, healthcare system health behaviors
Neter & Braining, 2017	Israel	search of association between perceived and performed eHealth literacy	standardized surveys and info from medical records)/ secondary analysis of survey data	30 patients with Heart Failure, mean age 72/ convenience sample	eHeals, 15 computerised simulation tasks and demographics	perceived and performed eHealth literacy are associated moderately
Noblin and Rutherford, 2017	USA	confidence in finding and interpreting health info online and the association with HL and eHL	telephone survey and face to face computer exercise	random digital number sampling: 82 participants	eHeals, singe item question on medical forms, NVS	Education, internet usage, confidence in completing medical forms is associated with higher likelihood to engage in health-related IT Usage. People with high health literacy are more likely to know where to find helpful health info on the internet. Adequate NVS score is associated with confidence in completing medical forms
Richtering et al, 2017	AUSTRALIA	predictors of eHealth literacy among people with medium to high Cardiovascular risk	survey on site	181 older adults, 71-75 age range/ convenience sample/ Learning Institute for Elders (LIFE) group	sociodemographic info, eHeals, HLQ	Lower eHealth literacy associated with time spend on the internet, positive relationship between HLQ and eHeals

(Xesfingi & Vozikis, 2016)	Greece	assess eHealth Literacy and contributing factors level of Greek citizens using eHeals	Face to face survey/part of larger study CONNECT	453 participants, 67 yo/ RANDOMISED	eHeals and demographics	Predictors: Age, education and physical exercise
Arcury et al,2018	USA	internet use and eHealth literacy among older adults	interview face to face	200 older participants, mean age 55+, patients at clinics of low income population/ convenience sample	eHeals, demographics and computer characteristics, social support, health knowledge and attitudes, NVS, SF-12V2, PCS subscale and Charlos index	eHealth literacy is associated with e-devices, computer stress, health knowledge and attitudes. Internet use didn't differ by gender. People with more than 12 years of education and greater income than 200% of poverty were more likely to use the internet. Less likely to use the internet if you have inadequate health literacy or rely on doctor's knowledge. Those who used internet had an average of 3.4 health information resource
Bonner et al, 2018	Australia	technology use in self-management	cross-sectional design/self-report survey onsite	708 participants/ convenience sample (18-71+)	38 item survey	Internet use: age below 60, employed, from non-indigenous background and with higher level of education. Less than 25% were aware of disease related websites and the majority preferred communication with health care professionals of their team
Gordon & Hornbrook, 2018	Canada	how age, race/ethnicity may affect the ability to engage with health information online	mailed survey	2602 people aged 65 to 79yo (African-American, Hispanic/Latino, Filipino, Chinese, Hispanic/white/ STRATIFIED RANDOM SAMPLE	sociodemographics, health info, access and use to digital technology, perceive ability to perform tasks using technology, interest in technology	Access to e-devices declined by age. Lower in African American, Latinos and Filipinos, 1/3 of the sample had smartphones. Internet use declined with age and by race with white and Chinese to be more likely users. Ability to read health information online, watch video, streamed video or webinar declined with age. People with chronic condition may adopt difficult health education and advice and mHealth technologies. Interest to talk to someone rather receive email, or health newsletter
Paige et a, 2018	USA	assess perceived eHealth literacy across life span of US adults	online survey	411 young (18-48) and 419 old (49-84)adults	eHeals , demographics and internet use for Health	Baby Boomers and Silent generation report lower eHealth Literacy scores than Millennian and Generation x

2.7.Health literacy among carers and carers of PwD

Health literacy levels of informal carers of adults care-recipients have been studied among carers of older people with memory problems, with Heart Failure, oncology patients, palliative care patients and patients with diabetes (Della Pelle, Orsatti, Cipollone, & Cicolini, 2018; Garcia, Espinoza, Lichtenstein, & Hazuda, 2013; Jiang, Sereika, Lingler, Tamres, & Erien, 2018; Levin, Peterson, Dolansky, & Boxer, 2014; Metin, Demirci, & Metin, 2019). The majority of this type of studies use small samples and found an adequate level of Health literacy among carers and a different level of Health literacy among carers and patients, with carers usually reporting higher level of literacy (de Almeida et al., 2019; Della Pelle et al., 2018; Garcia et al., 2013; Jiang et al., 2018; Levin et al., 2014).

Researchers use different instruments for measuring Health literacy, including NVS, 3 Health Literacy questions, S-TOHFLA making comparisons among studies more difficult as we need also to consider functional and perceived literacy levels and not only the use of different functional measures. Age and carers' relationship are frequently related to Health literacy level, but this is not always the case for education. Interestingly these outcomes depend primarily on the way that researchers use their variables (as categories or metric).

Based on the findings of a recent scoping review of 12 related papers during the period 2003 to 2015 on the Health literacy levels of informal carers of adult care-recipients, studies mainly used different ways of scoring Health literacy, either using levels, comparison of two measures or average scores. In 6 out of 12 studies using levels as the scoring method, the low Health literacy ranged from 0% to 42.9% and in 5 studies using the average score, carers participated in these studies considered having adequate levels of Health literacy. Finally, in one study comparing formal and informal carers, no statistical differences were observed in Health literacy scores (Yuen, Knight, Ricciardelli, & Burney, 2018).

Type of relationship among carers with people with Alzheimer's disease, influences the perceived Health Literacy level on a specific symptom of dementia (incontinence). Daughters are more troubled by their role of carer to the parent of the opposite sex and wives may avoid talking to health care professionals on this issue unless they cannot manage on their own (Mullins, Bliss, Rolnick, Henre, & Jackson, 2016). In another study with carers of people with memory loss, older age, lower cognitive functioning and working memory, the level of education seems to predict low Health Literacy (Jiang et al., 2018)

2.8.Summary

Through this first chapter "the core concepts and theoretical frameworks I", the concepts of Health Literacy, eHealth, eHealth literacy, mHealth and mHealth literacy were defined. The tools for the measurement of Health Literacy and eHealth Literacy (TOFHLA, REALM, NVS, eHeals) and the scoring for the eHealth Literacy Scale were discussed.

Furthermore, since there is a lack of available literature of eHealth literacy for carers, the internet use and eHealth literacy among older adults and the available research of carers and Health Literacy research are presented.

Now a more detailed presentation of this population follows, the carers of PwD, and the essential caregiving concepts that play an important role in this study are discussed.

3. Chapter – Concept definitions and theoretical frameworks II

In this chapter, the disease progression, the most frequent symptoms, neuropsychiatric symptoms and prevalence are discussed and carers' definition, needs, and information on the caregiving variables of interest: social support, caregiving self-efficacy, coping strategies and stress process model are introduced. In the final sections of this chapter, dementia status in Greece and Cyprus in policy and healthcare service level is presented.

3.1. Dementia and Alzheimer’s Disease

It is well known that the world population is ageing and the non-communicable diseases including dementia are increasing. Dementia is considered a syndrome which affects the cognitive functions (memory, thinking, orientation, understanding, calculation, learning, language and judgement), behaviour and everyday living activities. The term dementia declares a progressive neurodegenerative condition. There are cases of conditions that are stable, as in the case after a stroke or reversible as in depression or use of specific medications (World Health Organization, 2012). According to the new diagnostic criteria of DSM-5, dementia has been renamed to Major Neurocognitive disorder and includes a decline in 6 domains: in complex attention, executive function, learning and memory, language, social cognition and perceptual-motor function. The neurocognitive disorders are subdivided in delirium, mild and major neurocognitive disorder. In the case of major neurocognitive disorder, the deficit in one domain is the core criterion, and memory disorder is not mandatory to set the diagnosis. Moreover, the social cognition (social inappropriate behaviour) could be only present to set the diagnosis as in the case of frontotemporal dementia (Sachdev et al., 2014).

The most frequent type of dementia is Alzheimer’s disease and the core symptoms are a gradual decline of the cognitive function, everyday living skills. According to DSM-IV-TR, Alzheimer’s disease describes the syndrome with multiple cognitive deficits, with memory decline as primary symptom and at least one of the following: aphasia, apraxia, agnosia and executive functions. The symptoms result in behavioural disorders and gradual loss of the person’s personality (APA, 2000). The National Institute of Aging (NIA) and American Alzheimer Association updated the criteria NINCDS-ADRDA for dementia and Alzheimer’s disease after 27 years. The appearance of deficits in memory and/or to other cognitive functions such as language, visuospatial skills, executive function is important to set the diagnosis and added the biomarkers of cerebrospinal fluid and imaging techniques in the case of on-time diagnosis (McKhann et al., 2011).

The lifespan of a person with probable Alzheimer’s disease is 8-10 years and, in some cases, could reach 15 years. The progress of the disease is differentiated according to the individual, the primary symptoms appearance, the medication adherence and the care provision. The comorbidity is also a factor influencing the progress of the disease (stroke, diabetes, cardiological and respiratory diseases) (Papanikolaou, 2006).

3.2.Neuropsychiatric symptoms of dementia

Behavioural and Psychological Symptoms of Dementia (BPSD), also known and as neuropsychiatric symptoms are present in dementia and Alzheimer's disease. The most common neuropsychiatric symptoms are:

- Behavioural: wandering- restlessness, agitation, socially inappropriate behaviour, sexual disinhibition, hoarding, sleep disorders, aggressiveness, screaming and cursing
- Psychological symptoms: anxiety, depressive mood, apathy, hallucinations and delusions

The pathology of the symptoms is multidimensional. For example, in some cases, the disease affects areas of the brain responsible for emotional state, perception and behaviour. In other cases, the symptoms are a consequence of the cognitive decline. Moreover, the symptoms can be part of psychiatric comorbidities or other medical conditions (Rabins, Lyketsos, & Steele, 2014). Multiple factors contribute to the development of BPSD biological and psychosocial ones (Tible, Riese, Savaskan, & Von Gunten, 2017). It is estimated that 90% of PwD will be affected by BPSD and are also connected with caregivers' burden, long-term hospitalisation, medication overuse and higher health costs (Carejeira, Lagarto, & Mukaetova-Ladinska, 2012)

Even if, in some types of dementia, we encounter specific behavioural disorders, in the majority of dementia types, there is a great variety, depending always by the stage of the disease and the individual. For example, in Vascular dementia, we may encounter a higher prevalence of depression and anxiety, less agitated motor behaviour. It is also known that in dementia with Lewy Body, it is much more likely for the patients to report visual hallucinations and delusions. In Frontotemporal disorder, one of the first symptoms includes behaviour changes instead of memory decline, such as socially inappropriate behaviour, loss of basic emotions, food cramming and pacing. Furthermore, apart from the type of dementia, there are also demographic related factors, such as gender and age that are connected with specific behavioural disorders (Carejeira et al., 2012).

BPSD gained attention in the '80s and researchers tried to understand the pathophysiology behind the symptoms. Several scales have been developed to assess the severity of the symptoms as well as the families burden derived from the specific symptoms (IPA, 2002):

- "Cohen-Mansfield Agitation Inventory" (1986)
- "The Behavioral Pathologic Rating Scale for Alzheimer's Disease" (1987)
- "The Neuropsychiatric Inventory (1994)
- "The Consortium to Establish a registry in AD Behavioral Scale (1995)

In the last decade, the role of non-pharmacological interventions is suggested as the more effective therapeutic solution for BPSD in comparison with pharmacological therapies. The treatment should focus both on the carer and the patient. In this area, there are plenty of interventions with conflict evidence, nevertheless, the clinicians provide more positive feedback that has taken into consideration in treatment options (Tible et al., 2017). Such treatments include psychosocial interventions, psychoeducation single or group session, need-driven dementia-compromised behaviour model, physical activity, sensory stimulation and music therapy, reality orientation and cognitive stimulation, validation therapy, reminiscence therapy, psychotherapeutic interventions for mild to moderate dementia, light therapy (Tible et al., 2017).

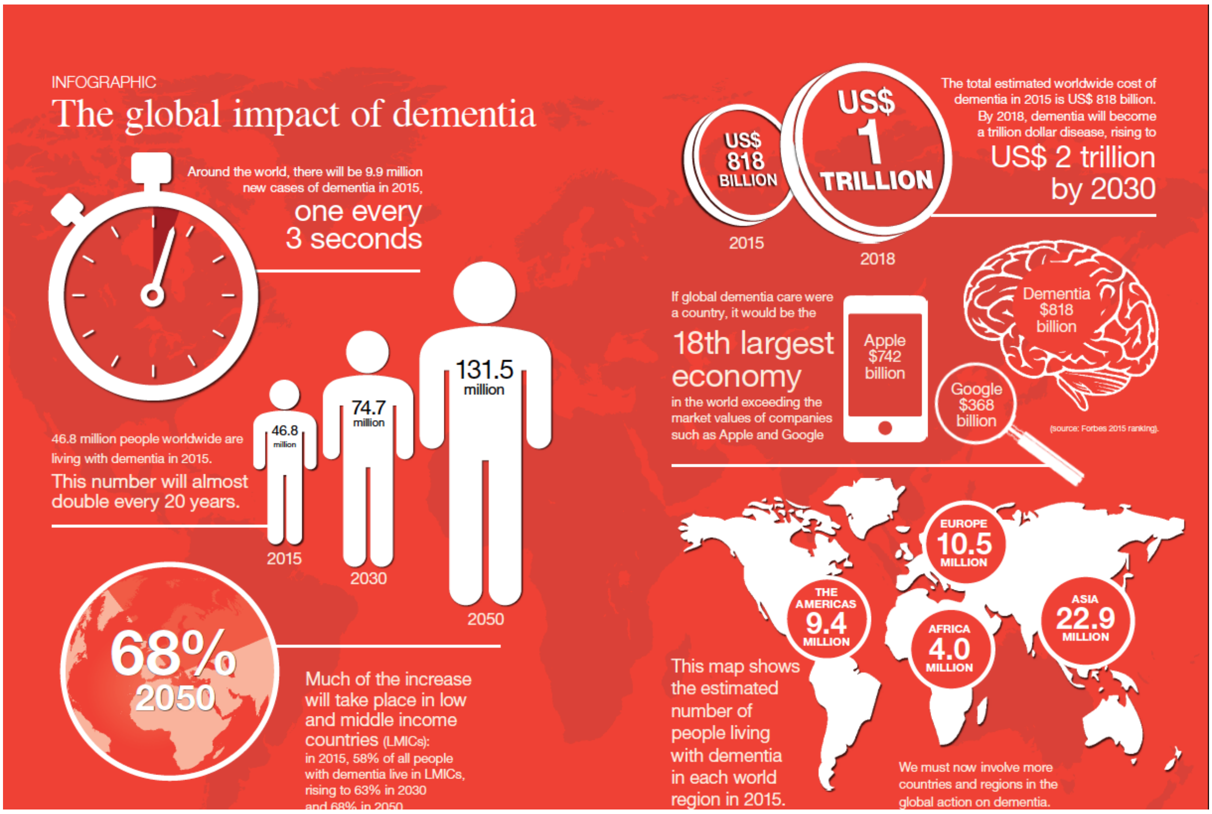
3.3. Prevalence of dementia

The increase of life expectancy in developed countries has as a consequence the increase of ageing population. People over 65 years reached 524 million worldwide in 2010 (8% of the total population) and is expected to triple till 2050 (World Health Organization, 2011a).

Prevalence of dementia is differentiated from country to country and that might be due to several reasons such as the methodology followed, diagnostic criteria adopted and the socio-economic and cultural framework of every country. According to the Global burden of the disease, dementia is third most common disease that affects everyday life and has an effect on the quality of life (IHME, 2013).

Incidence of dementia increase from 2-3% in the age group 70-75 into 20-25% for people over 85 years old (Ferri et al., 2005). According to the International Alzheimer Association report (2015), 46.5 million people suffer from dementia globally, 10,5 million in Europe and this number is estimated to double in 20 years, reaching in 2050, 131.5 million with a higher burden in the mild –low-income countries (Prince et al., 2015).

Figure 3-1 Impact of Dementia globally (Prince et al., 2015)



According to a systematic review by the World Health Organisation, incidence of dementia doubles every 5.8 years with 3.4/1000 every year to 202.2/1000 and being higher in countries with high socio-economic impact in comparison with countries with middle and low. Moreover, 7.7 million new cases are reported every 4.1 seconds (World Health Organization, 2012). In 2015, Alzheimer Disease International added 12 more studies in this review and proceeded in a metanalysis for the incidence of 46 studies. According to this data of the metanalysis, the incidence becomes 3.9/1000 every year and 124.9/1000 for high-income countries and 5.2/1000 and 58/1000 for middle and low-income countries (Prince et al., 2015).

3.4. Who are the informal carers of PwD?

As the population ages, old age diseases are increasing, with more and more people needing long-term care. In many countries, family and friends usually undertake the role of the carer replacing the lack of services that is a common phenomenon in the Mediterranean and Eastern European regions (Triantafillou et al., 2010).

Many different associations and researchers have defined the informal carer:

- World Health Organisation defines the informal carer as a person who is related to the person with dementia, living together or separately and providing regular or occasional care (World Health Organisation, 2015).
- In Interlinks project, we find the definition of the informal carer as a family, close relative, friend or neighbour, who is nonprofessional, not trained, has no contract, is not paid with no limits to hours of care and with a wide range of tasks (Triantafillou et al., 2010).
- Eurocarers defines informal carer as a person who provides - usually - unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework"(EUROCARERS, 2009).
- OECD in the related book "Help Wanted? Providing and Paying for Long-Term Care defines carer as "a person, family or friend that provides mostly unpaid care to frail seniors"(OECD, 2011). Core dimensions in these definitions are the unpaid care provision and the relationship with the patient.

The most recent epidemiological data for carers of older people are provided by EUROFAMCARE (2006). This study was realized in Germany, Italy, Poland, Greece, Sweden and the UK. Main findings describe the profile of carers and care receivers. According to these findings, carers provide care to older people for domestic needs, emotional, psychological/social need, mobility needs, financial management, organizing care support, health care needs, such as assistance with medication, treatment and rehabilitation, activities of daily living and financial support. Family carers of older people are mostly women (76%) of mean age 55 years and spent a mean of 45.6 hours of care weekly. The negative impact of caring is related to behavioural disorders, the dependency of the older person, support networks and formal support. Interestingly in this report, social networks were associated with lower stress and burden (EUROFAMCARE 2006). It seems that the most prominent age group that provides care at least once or twice per week is the one between 50 - 64 years old, followed by the 35-49 age group according to the Third European Quality of Life Survey – Quality of life in Europe : Trends, (2014).

Family friends and neighbors may provide support to the primary carer or even share equally caring tasks. More than one people usually care for the person with dementia. There is a term that we find infrequently in research "secondary carers" and refers to the people who support the primary carer and the PwD. There is not an agreed definition regarding the secondary carers. Secondary carer is frequently used in law and is defined as the current partner of the primary carer (https://www.lawinsider.com/dictionary/secondary-caregiver) . We find the use of the term in research by Perlesz, Kinsella, & Crowe, (1999), discussing the outcomes of carer's burden of people with Traumatic Brain Injury. Perlesz et al., identified the secondary carer by asking the families “ *who in the family takes most responsibility for caring for the person with the head injury, and who takes next most responsibility*” (Perlesz, Kinsella, & Crowe, 2000,p.912)

In a recent study by Ludecke et al., (2018), researchers analysed 3348 data from EUROFAMCARE study to identify the factors that could predict outcomes of informal care. Being a spouse or a partner, caring for more hours could be a predictor of caring for the same person over the 1-year. Caring for fewer hours, for a parent of a parent in law and caring for a person with dementia was a predictor for changing the status of care or being in a nursing home. Carers- patient relationship is an important factor predicting if the carer remains the same over a period or of being at a care home or at home (Ludecke et al., 2018).

3.5. Caring needs of PwD

According to a recent report by Alzheimer Disease International (ADI) in collaboration with the Karolinska Institute (Wimo et al., 2018), 84% of PwD are cared for at home and 16% in nursing homes. It is difficult to estimate the economic impact of informal care and based on the report of ADI (2018), costs for dementia are calculated in 1 trillion today with 40% informal care costs, 40% social care sector and 20% medical sector. The estimated global number of informal care hours is 6 hours per day. Furthermore, women are providing 71% of the annual informal care hours. Informal carers are experiencing more stress than the general population and they report higher levels in the use of antidepressants, are more susceptible in infections, cognitive decline and have high mortality rates (Colombo et al., 2011; Oliveira et al., 2019; Vitaliano, Murphy, Young, Echeverria, & Borson, 2011).

The needs of carers are always changing and depend on the type and stage of the disease, carers’ knowledge, skills and attitudes towards caregiving and available support (social network, services). Becoming a carer is influenced by the reason for undertaking this role: duty, love or no other choice. Reported needs of a carer of a person with dementia could be the financial and social support, the access to counselling, the preservation of identity, the establishment of a partnership with the patient and the health professionals and the access of confidential information for the cared-for person (Nuffield Council of Bioethics, 2009).

In a survey monitoring the needs of Greek carers of PwD, carers report that they would need support in different domains as financial support, daycare services and training to cope with their tasks, long-term units, trained paid carers, home care services, every day support in caregiving and peer support groups (Dimakopoulou, Efthymiou, Sakka, & Karydaki, 2015).

Considering the White Paper by Eurocarers (EUROCARERS, 2013), carers need actions in relation to awareness, recognition and support as well as practical actions :

- Recognizing the caregiving role and promoting the well-being of carers
- Raising awareness of the general public for carers issues and burden
- Provide training
- Allowances
- Develop support services (respite services, daycare)
- Promote research on caregiving issues

3.6. The outcomes of care for the informal carers and stress process model by Pearlin

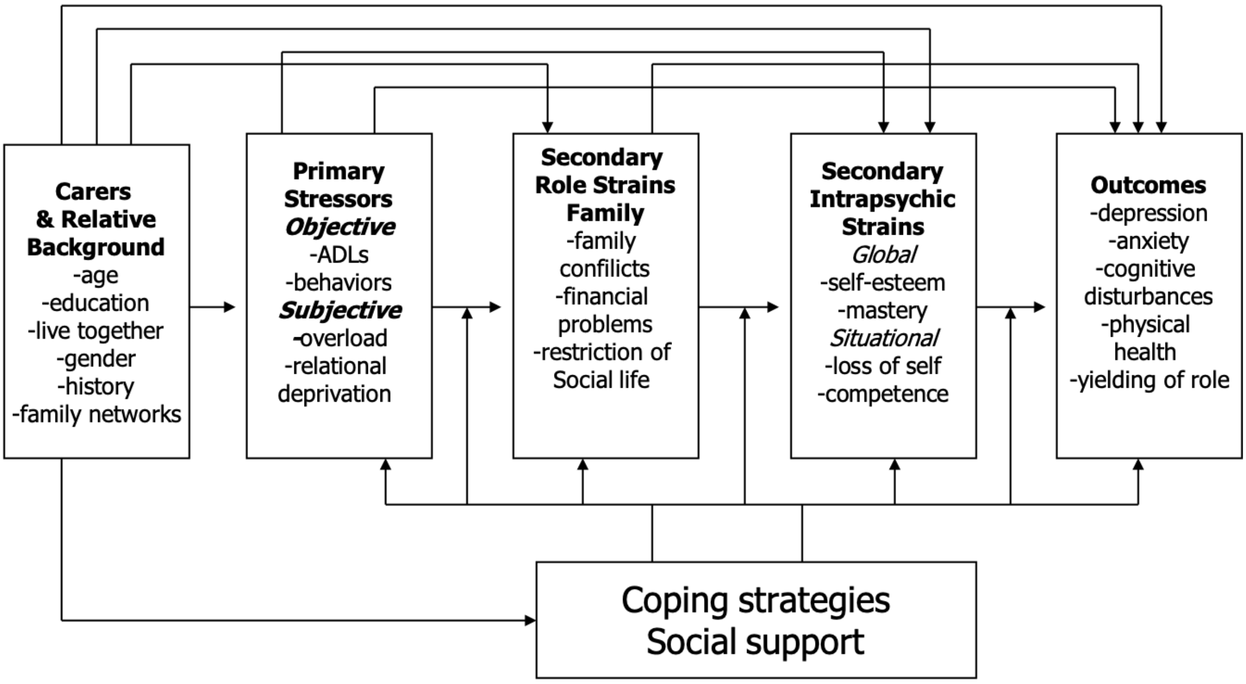
The term burden of dementia is a common term used to describe the physical, psychological, social and financial difficulties rising from informal care (George & Gwyther, 1986; Zarit, Todd, & Zarit, 1987). Activities of Daily living are strongly related to the burden of care (Reinhard, Given, Petlick, & Bemis, 2008). The first appearance of the term was made by Peter Townsend in 1950, discussing the strain of illness, and later in 1960 researchers studied the caregiving burden discriminating subjective from objective burden and everyday care activities from emotions (Hoffmann & Mitchell, 2005). One of the first references of the term as the family burden was made by Grad & Sainsbury, (1966) in the field of psychiatry. According to this study, authors measured several factors affected by care: employment, income, relations with neighbours, the health of family and other social aspects. After that, research has focused on a different dimension of burden and especially distinguishing objective and subjective burden of family care, as well as in family care burden in different chronic disease (Hoenig & Hamilton, 1966; Montgomery, Goneya, & Hooyman, 1985; Platt & Hirsch, 1981). Functional status of the PwD, prevalence of behavioural and psychological problems, the severity of the disease, type of dementia-Frontotemporal dementia and long duration were one of the most important factors related to carers burden. Carers characteristics such as income, gender, education level, cohabitation status and ethnicity were the most frequent related factors, followed by psychological health, perceived well-being, depressive symptoms, low religious coping skills, self-sufficiency, anxiety, aggressiveness and authoritarianism. In many studies, age and relationship of the carers were important predictive factors Chiao et al., (2015).

An important model developed in the early ‘90s explaining the consequences of caring was the Stress Process model (Pearlin et al, 1990), which included the core dimensions that influence carers’ well-being, mental and physical health, including:

- Carers’ background and context: personality and characteristics of carers such as age, education, living conditions, gender, personal and family history
  Stressors are distinguished in 3 types:
- primary stressors: objective as the severity of the disease, behavioural disorders and subjective, as the perceived burden as a consequence of carer’s daily tasks (maintenance tasks, instrumental tasks)
- secondary role strains as family conflicts, financial problems, restrictions of a social role (employment status, leisure activities, network relations)
- Secondary Intrapsychic strains are distinguished in global as self-esteem, mastery and situational as competence and loss of self. According to Pearlin et al., (1981)**,** self-esteem is influenced by 4 dimensions: role captivity, loss of self, competence and gain. In caregiving, competence is referred to the sense that the person can cope with the caregiving demands and gain is referred to the satisfaction that the carer receives from caregiving tasks.

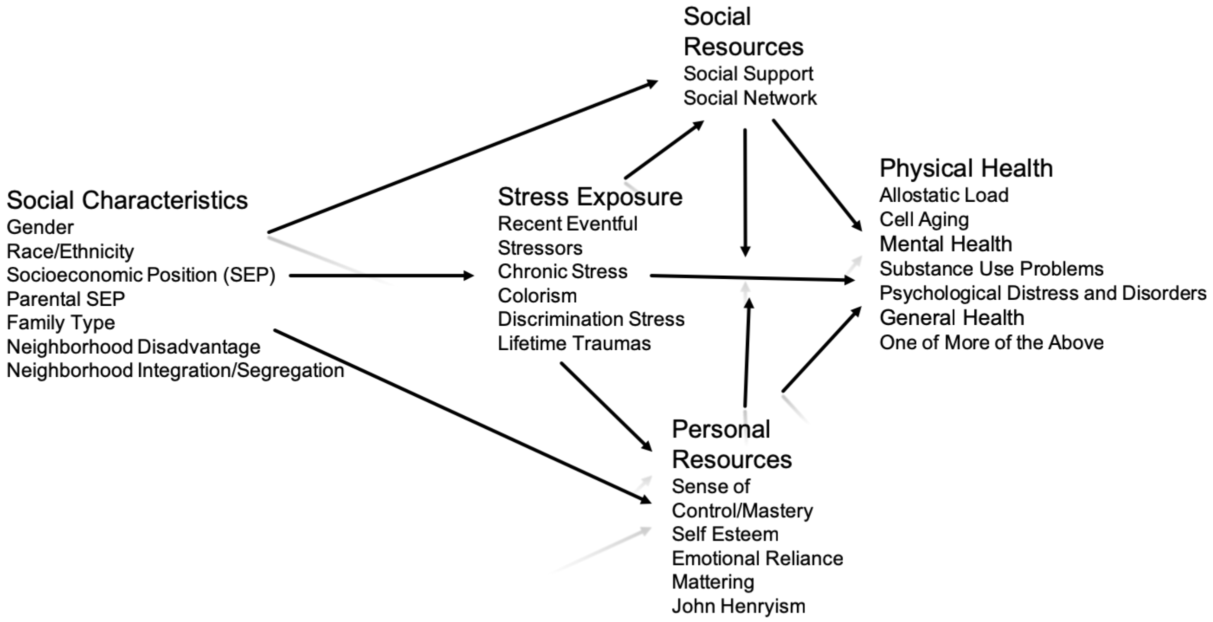
Finally, the coping strategies that a person adapts and the social support of the carer in combination with different type of the stressors, according to the model, influence the mental and physical health of the carer.

Figure 3-2 Pearlin's stress process model (1991)



Stress Process Model has been adapted by Perlin and colleagues in the following years. Pearlin perceived stress as a dynamic process, which is not usual and has its origins in the social world. He also stated that economic and social status, race as well as the neighbourhood context, plays a crucial role in justifying the stress process model. In 2005, Pearlin investigated stress across the life course and gave attention to economic status, discriminatory experience and stress proliferation (Avison., et al, 2010)**.** In Figure 3.3, the adapted model of the stress process is presented. In the health outcomes of stress exposure, allostatic load and cell ageing provide the evidence of biological consequences of stress. In the case of mediators/moderators, Pearlin distinguishes in social resources and personal resources. Optimism, mattering, mastery, self-esteem, emotional reliance and Jonh Henryism influence the reaction to stress exposure. Optimism is a coping strategy that is associated with immune function and physical and mental health. Mattering refers to a person's belief that matters to others and is associated with mastery and self-esteem, even if not the same. Emotional reliance concept is associated with vulnerability, and John Henryism refers to the behavioural predisposition to cope efficiently with everyday stressors. This final coping behaviour takes its name from John Henry Martin, an African-American who was interviewed by James in 1970, and who had adopted superhuman performance to overcame disparities (Avison., et al, 2010).

Figure 3-3 Stress process model adapted version by in Avison., Aneshensel, C.S., Schieman, S. , Wheaton, 2010)



3.7. Social relationships and carers

We already know that people's relationships play an important role in their wellbeing. As Antonucci, (2001) has discussed in the relevant chapter "*Social relations: An examination*" we know the existence of social network and social support and relations. In the case of social support, we distinguish tangible support, emotional support or affirmation. Concerning the social networks, Antonucci presented the Convoy model and discusses the importance of relationships through the lifetime of a person and personal and situational factors that influence these relationships. Our social network is a protective net that promotes our health (physical and mentally) and changes as the person grows and changes, involving or excluding people based on the circumstances. The convoy model has an objective (the structure of the network) and subjective dimension (function and quality). As a person ages, the closest relationships of a person's social ties remain the same, even if the total number of relationships decreases. Furthermore, women seem to build more intimate relationships than men and men use the social network of their spouses. The socioeconomic position also relates to social networks and support. The lower level of the socioeconomic position may be translated to a smaller number of social networks. In the case of older people, this association may not be the same, because occupation and educational status were not always associated as they are in our time. Moreover, women's health and wellbeing are highly related to the perceived social network. Feelings of control and self-efficacy can be stimulated by perceived social support (Antonucci, 2001). The association of social support with health is well documented (Johnson, Turner, & Link, 2014). Depression, reduced immunological function, coronary heart disease, blood pressure, biological ageing, substance abuse have been documented to be related to low levels of social support. Social support acts protectively to the life-threatening events in the course of our life-time, as moderates the effects according to Cobb (Cobb, 1976). According to Thoits the type of support affects the health outcomes: tangible support and emotional support (love, care, sympathy) seem to be most effective for our health (Thoits, 2011).

Concerning people of older age, their social networks tend to focus on close family members and friends. Older people select the most satisfying relationships, or they even regulate their networks as an effort to regulate emotions due to limited time. In this respect, researchers have distinguished four types on social networks, diverse (friends and family), friend-focused, family-focused and restricted networks. In any case, even if we may find similar structures among older individuals, they differ in quality and function (Fiori, Smith, & Antonucci, 2007). Restricted type of network is more common in oldest-old. Fiori et al identified new types of restricted networks in relation to existing literature: restricted-nonfriends-unsatisfied and restricted-nonfamily-unsatisfied network. The restricted-nonfriends-unsatisfied cluster included unmarried people, with small networks and not frequent communication with friends. The restricted-nonfamily-unsatisfied cluster included unmarried people, with no frequent family contacts and small networks. They hypothesised that the people in the restricted non friends are more disappointed due their inability to increase their emotional support in their networks in relation to nonfamily restricted network, wherein this case people may have chosen to build this type of network from earlier in their life.

People with more extensive social networks have higher chances to receive home care at a later age. According to Fernandez-Carro & Vlachantoni, the structure, access and availability of the members in the network can be a predictor for potential carers and is differentiated from northern-western to southern-eastern European countries based on the familial model (Fernández-Carro & Vlachantoni, 2019). For example, in Eastern countries, an extended family network can predict the informal care provision, but in the case of Northern countries, only the close partner is a predictor of informal care. Fernandez-Carro & Vlachantoni identified the role of social networks taking into consideration the three models of Care: Scandinavian, Continental and Mediterranean (Pommer, Woittiez, & Stevens, 2007). In another study from Spain representing the Mediterranean Care model, by Serra et al., resilience and social support are protective factors of abuse to PwD and confirmed the mediating role of the burden for the association of social support and abuse.

(Serra et al., 2018). In a cross-sectional study among Chinese carers of people with Alzheimer's Disease, social support seems to have a moderator effect on the way patient's cognitive impairment and depression associated with carers' burden. Carers with low social support express higher levels of burden due to the effect of disease progression and depression (Wang et al., 2018). The social network, received support and negative interactions are associated with self-rated health among carers, and carers' burden acts as mediator in this relationship (Xian & Xu, 2019)

Carers are experiencing social exclusion due to their caregiving tasks. Levitas et al define social exclusion as *"... a complex and multi-dimensional process. It involves the lack or the denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole."*(Levitas et al., 1974). The dimensions influencing social exclusion among carers are not well researched and available studies did not strictly define and measure social exclusion. Mostly they included difficulties in the quality of relationships, leisure time and work and care balance (Nan Greenwood, Mezey, & Smith, 2018).

3.8. Self-efficacy and carers

In Perlin's Stress Process model, the concepts of mastery and self-esteem as part of the secondary intrapsychic strains that are connected with the concepts of competence/ self-efficacy are encountered (Au et al., 2010). Bandura has discussed self-efficacy and the role of this concept in everyday living and how perceived mastery can impact directly people's selected coping styles (Bandura, 1978). This concept seems to influence the behaviour of a person and the effort that someone will put on a task. People with a high level of perceived self-efficacy will sustain their effort to cope with difficult tasks in comparison to people with a low level of perceived self-efficacy. On the other hand, a high level of perceived self-efficacy does not guarantee success if the capabilities do not support the action. Another important element of the social learning theory is the appraisal of the action. In the case, that a person perceives success due to external factors it is more possible not to take credit for the success and when a person perceives failure due to his/her ability has also greater impact on self-efficacy. The amount of effort to succeed plays a role in the perceived self-efficacy. Success after a high amount of effort does not add to the perceived self - efficacy in the way that a low amount of effort does. Operative self- efficacy is "*a generative capability in which multiple subskills must be continuously improvised to manage ever-changing* *circumstances, individuals with the same subskills may perform differently….depending on their self-belief of self-efficacy.*"(Bandura & Wood, 1989, p.805). Social learning theory of Bandura focuses on the self-regulatory mechanisms that interact with external factors. Motivation plays an important role in the specific model excluding the mere behavioristic approach of external reinforcement effect. People may act based on "anticipating consequences". Perceived self-efficacy influences motivation and action and is influenced by previously successful experiences (mastery), experiences through observation of others (vicarious), social influence (verbal persuasion) and physical and emotional states (Bandura, 1986). The previous experiences that we have lived, influence our level of self-efficacy, the observation of others in a task that we are considering challenging also plays role in how possible we may consider success over the specific task. Feelings of stress, anxiety or other negative emotions during a task provide negative cues for a person's self-efficacy. Avoidance behaviour is associated with anticipatory fear and feelings of self-inefficacy (Bandura, 1986). In motivation, we may distinguish 3 types: "causal attribution, outcome expectancies and goals". If a person has a high perception over one's own skills, a failure may be attributed to insufficient effort. The belief of what one can do and the challenging goals together with the causal attribution determine a self- belief of efficacy.

In a systematic review on the role of self-efficacy on the health-related quality of life among informal carers of PwD 22 studies are included (Crellin, Orrell, McDermott, & Charlesworth, 2014). Self-efficacy among carers seems to be associated with the health-related quality of life with a low to medium effect size in 8 out of 11 studies. In 9 studies, higher self-efficacy is associated with more positive aspects of caring. Positive aspects of caring include different outcomes such as gain, satisfaction, rewards, mastery. Kramer has defined gain as "*the extent to which the caregiving role is appraised to enhance an individuals' life space and be enriching*" (Kramer, 1997, p.219). Positive outcomes have also been categorised through qualitative research in spiritual growth and closer relationship with God, closer relationship with the care-recipient and opportunity to give back, re-evaluation of life goals and discovery of inner strength and personal growth, mastery and personal accomplishments and new caregiving skills (Peacock et al., 2010; Sanders & Corley, 2003). Religion could also provide motivation and meaning in caring (Quinn, Clare, & Woods, 2010). Higher self-efficacy of controlling upsetting thoughts and on managing behavioural disorders in dementia is related to the positive aspects of caregiving. Optimism and self-efficacy on maintaining the relationship to the care-recipient are strongly related to self-efficacy. Optimism is a stronger predictor for carers' mental health in comparison with coping and self-efficacy (Gottlieb & Rooney, 2004).Low self-efficacy of obtaining respite is associated with burden and depression(Cheng, Lam, Kwok, Ng, & Fung, 2013).

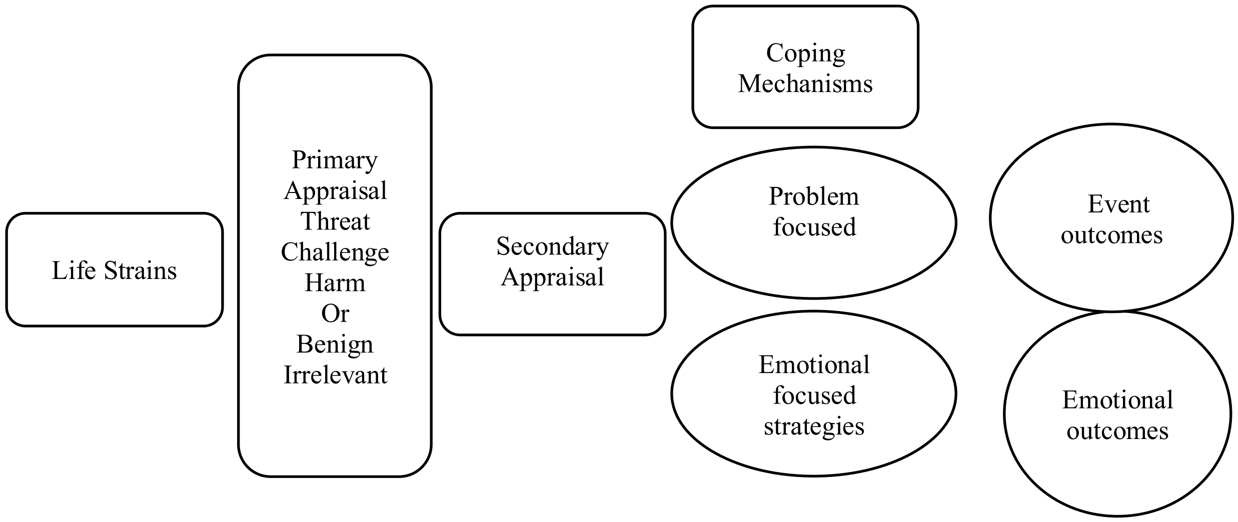
Symptom management self-efficacy acts as a mediator in the relationship between neuropsychiatric symptoms of dementia, burden and depression and predicts the carer's burden and depression (Gallagher et al., 2011). Mastery and self-efficacy mediate in the association of stress levels among a sample of carers and depression (Mausbach et al., 2012).

3.9. Coping strategies and carers

Researchers through the years have developed models to interpret people' coping behaviours. In the case of Perlin's model (1991) and as part of the personal resources apart from social support, there are also 3 types of coping strategies: problem-focused, emotion-focused and meaning-focused. According to Pearlin & Schooler, (1978, p.2 -3) coping is defined as *"the things that people do to avoid being harmed by life-strains…any response to external life strains that serves to prevent, avoid or control emotional distress"* and the coping process is multidimensional, includes "*behaviors, cognitions, perceptions*" and has 3 functions "management of the situation, management of the meaning and management of stress symptoms". Perlin and Schooler discuss the coping efficacy meaning how effective the selection of a person's coping strategies is on the stress that derives from a situation. "*Effective coper*" is the person that feels no stress even in the most severe life situations. When a person has control over a role (e.g. family role), it is more effective to follow a problem-focused strategy. In the case where personal control over a role is lower (work, finances), the person may adopt emotion-focused or meaning -focused strategies, where reappraises the situation. In some cases, there are the so-called compensatory coping, when after reappraisal, the person may proceed to a problem-focused strategy to reinvest (Thoits in Avison et al 2010).

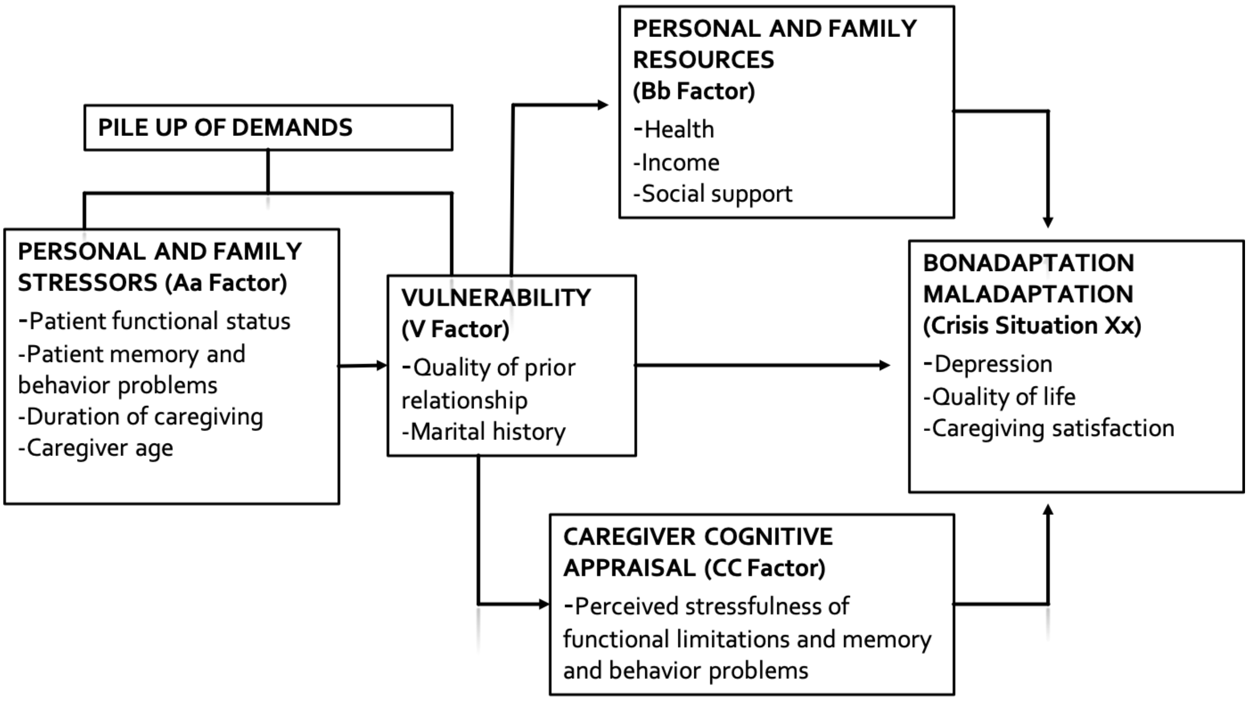
Additionally, Lazarus & Folkman, (1984) distinguish between the coping processes and coping styles. Coping processes concern the current states, the relationship between person and environment and the coping styles, which are the traits, inherent characteristics of the person. Part of the transactional framework is the appraisal theory**.** There are two types of appraisal: primary and secondary. In primary appraisal, the person concentrates on the magnitude of the event even if it is irrelevant to one's own well-being, benign positive or stressful. In the secondary appraisal, we encounter the contextual factor and the ability of the person to cope with the stressor.

Figure 3-4 Lazarus and Folkman Coping model



Another proposed framework of Kramer, (1993) includes the personal and family stressors, the vulnerability effect (prior relationship and marital history), the importance of personal and family resources, followed by the cognitive appraisal made by the caregiver and resulting in adaptation or not to the situation, resulting either in depression, influencing quality of life and the level of caregiving satisfaction. Kramer's model is relied to the ABCX model by Hill (1949) on bonadaptation to maladaptation continuum when a crisis (X) occurs. The model was developed as a consequence of the war-torn families of World War II. Stressful events (A), capabilities of resources (B) and appraisal of the event situation (C) are the 3 essential dimensions that drive to Crisis (X). V factor (vulnerability) is the quality of the family's interpersonal dynamic (Kramer, 1993)

Figure 3-5 Kramer's carers model of adaptation to caregiving



Coping strategies are organised in primary dimensions e.g. problem solving, cognitive restructuring, express emotion, social support, avoidance, wishful thinking and more. These dimensions are further organised to higher-order categories, which according to Lazarus and Folkman we find: problem-solving or emotional strategies. We may easily identify the primary dimensions of these 2 categories in the coping strategy inventory the "Ways of Coping" developed by the aforementioned authors. Another categorisation has been proposed by Moos et al (Powers, Gallagher-Thompson, & Kraemer, 2002) including active cognitive, behavioural coping and avoidance.

Carver, Scheier, & Weintraub, (1989) consider the ways of coping oversimplified tool as many more factors derive from that questionnaire and they developed another inventory to measure coping strategies including 14 dimensions: *Active coping, planning, suppression of competing activities, restraint coping, tangible support, emotional support, focus on and venting of emotions, behavioural disengagement, mental disengagement, alcohol-drug disengagement, positive reinterpretation and growth, denial, acceptance, religion*

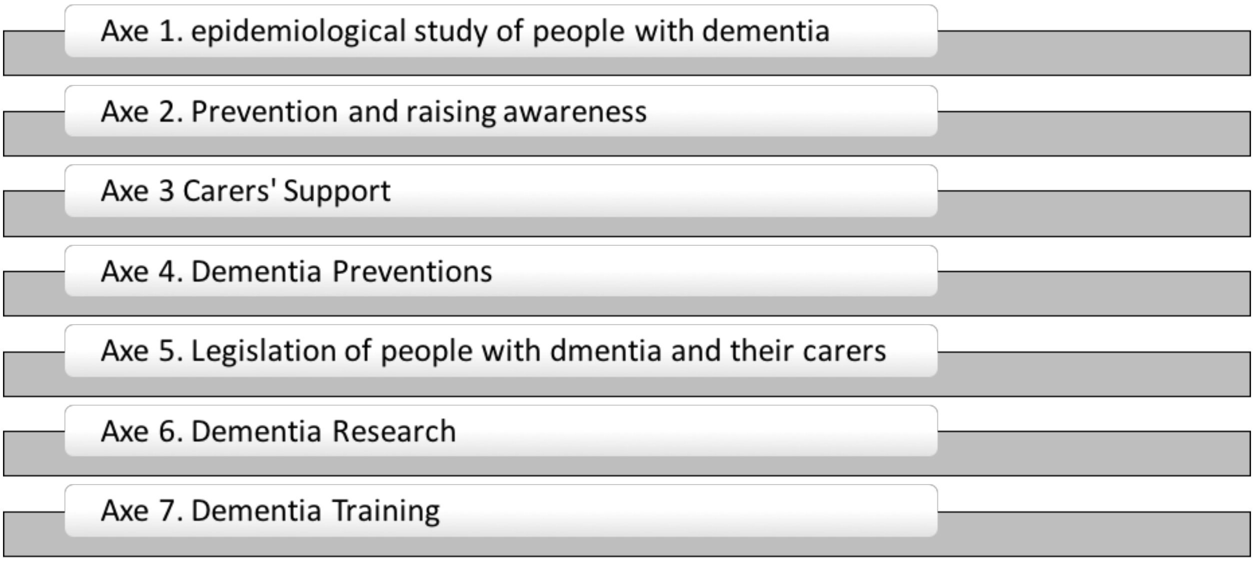
Coping strategies adopted by carers have been associated with anxiety and depression (García-Alberca et al., 2012). According to this study of a small sample of Spanish carers, following the framework by Tobin (engagement and disengagement strategies), problem avoidance, wishful thinking, self-criticism and social withdrawal are associated with depression and anxiety among carers. There are conflicting findings on the role of emotion-focused and problem-focused coping in caregiving. Studies provide both findings as protective from anxiety (Cooper, Katona, Orrell, & Livingston, 2008; Lavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). A possible explanation is that problem-focused coping may be adapted by carers with high anxiety or the combination may be a successful recipe that carers find helpful. Helpful stress strategies for carers include setting priorities, believing in oneself, taking one step at a time, searching for positive aspects, relying on carer's expertise and experience, accepting, keeping the patient active, altering home environment to facilitate everyday for the care recipient, planning and taking mind off things in some way (Kuuppelomäki, Sasaki., Yamada., Asakawa., & Shimanouchi., 2004). These strategies are part of the Carer's Assessment of Managing index by Nolan, including 38 coping mechanisms and 3 categories, based on Lazarus and Folkman stress-coping theory. Another explanation for the conflicting findings may be that studies samples are small in number and may not depict the realistic profile of carers.

In research usually, we find 3 types of coping strategies among spouses of carers of PwD: problem-focused, emotion-focused and dysfunctional and are usually mediators between the carer and the caregiving variables (including avoidance, substance use, denial, emotional discharge) (Roche, MacCann, & Croot, 2016). Potential predictors of coping behaviour included: ethnicity, age, education, employment, duration of caregiving, health, personality, self-efficacy, carers knowledge, premorbid relationship, emotional support, diagnosis, behavioural disorders and activities of daily living. Carers "*for longer periods, with poorer health, non-white and with poorer premorbid relationships, less emotional support, not attending support groups, coping with behavioural disorders would be most possible to adopt dysfunctional coping strategie*s" (Roche et al., 2016, p.87). Gender on the other hand provides contradictory findings. Greater self-efficacy was associated with problem-focused and emotional focused strategies and not with dysfunctional coping. Solution-based coping is related to higher education. Moreover, carers with people more dependant on them seem to use more emotional -focused coping. Carers who face behavioural disorders, select more frequent dysfunctional coping strategies and are more prone to depression (Roche et al., 2016)

3.10. Dementia in Greece

In Greece, 200.000 people are estimated to suffer from dementia, which can be translated to more than 400.000 carers, bringing dementia into the spotlight, as it influences a large percentage of people directly and indirectly. In 2014, the Working Group for Dementia, established by the Minister of Health (ΔΥ1δ/Γ.Π.οικ.108620) launched the Greek Dementia Action Plan with key priorities: public and professional awareness, early diagnosis and intervention, improvement of quality of life of PwD and their carers (Sakka et al., 2005). The Dementia Plan 2015-2020 consists of seven (7) core axis:

Figure 3-6 Greek Dementia Plan Axis



In the same year, the Greek Parliament enacted a law to ensure the implementation of the Dementia Plan by supporting the establishment of the National Observatory for Dementia. The Dementia care services in Greece are quite limited, based in metropolitan cities and mainly in Athens (Braoudakis et al., 2015). The existing dementia care services include dementia daycare centres, help at home programmes, memory clinics, short-term respite centres developed and coordinated by non-profit associations, funded and supervised by the Ministry of Health as part of the mental health reform “Psychargos” (Braoudakis et al., 2015).

In Greece, until recently there was no accurate data about the prevalence and incidence of dementia. Using prevalence rates by the EuroCode and EuroDEM projects, Alzheimer Europe produced estimates for EU-28 and another 5 countries (Jersey, Iceland, Norway, Switzerland, Turkey). According to these data, the prevalence of Dementia in Greece is calculated 201.767 people, which accounts for 1.71 of the population (Reynish et al., 2006; Rocca et al., 1991). Only recently, we obtained national epidemiological data from the "Hellenic Longitudinal Investigation of Aging and Diet-HELIAD" (Kosmidis et al., 2018). According to this study, the prevalence of dementia is estimated at 5.0% of people over 65 years old with the majority of the cases to being diagnosed with Alzheimer's Disease (75%). Age, education and APOE-e4 allele were predisposing factors for dementia. Older people with lower education and at least one APOE-e4 allele were more likely to receive a dementia diagnosis.

In Greece, there is limited research among carers of PwD and we may find small samples or development phases of small scale funded projects (Konerding et al., 2018; Protopappas et al., 2016; Torkamani, Katsanou, Jahanshahi, & ALADDIN-COLLABORATIVE-GROUP, 2014; Vlachogianni, Efthymiou, Potamianou, Sakka, & Orgeta, 2015; Zafeiridi et al., 2018). Research topics of interest include burden, quality of life, integration of carer after the end of caring period and scales validation in Greek language (Dimakopoulou et al., 2015; Mougias et al., 2015; Mougias, Politis, Lyketsos, & Mavreas, 2011; Vlachogianni et al., 2015). In a recent survey, the researchers assessed health-related quality of life and its association with depressive symptomatology in a sample of 155 carers, of mean age 58 years, 48% children, mostly married, with secondary education (Andreakou, Papadopoulos, Panagiotakos, & Niakas, 2016). In another study, by Mougias et al., (2015), we find a sample of 161 carers, of mean age 59, mostly married, equally children or spouses, with 12 years of education. Younger carers, behavioural disorders and carers' depression considered factors associated with carers' burden among Greek carers of PwD according to this study.

3.11. Dementia in Cyprus

In Cyprus, available estimation is derived by the Alzheimer Europe calculations, with 11250 people suffering from dementia, which equals 1.07% of the total population for the year 2012 (Reynish et al., 2006; Rocca et al., 1991).

The multidisciplinary committee for dementia established by the Minister of Health has developed the National Dementia Action Plan, including below key points:

- action for primary care,
- treatment options,
- community care,
- dementia centres,
- socializing opportunities for carers,
- dementia management counsellors,

- home care,
- carers' education,
- short-term and long-term care,
- new technologies and dementia,
- memory clinics,
- public awareness campaigns,
- integration of volunteers,
- patients and families,
- National legislation on dementia and modification of the existing laws,
- development of dementia commissioner office,
- health care professionals training,
- implementation of services' quality improvement,
- health monitoring in the community,
- research and volunteerism promotion in dementia (Multidisciplinary-Committee-Dementia, 2012).

In Cyprus, we encounter focused research on carers of PwD on the topics of burden, quality of care, coping strategies and the role of community participation on burden (Papastavrou, Andreou, Middleton, Papacostas, & Georgiou, 2014; Papastavrou, Andreou, Middleton, Tsangari, & Papacostas, 2015; Papastavrou et al., 2007; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2011; Papastavrou et al., 2011). According to the aforementioned research, Cypriot carers of PwD report a high level of burden (68%) and depressive symptomatology (65%) according to a sample of 172 carers, of mean age 56,8 years, mainly daughters of patients. The burden is associated with patient's behavioural disorder's (e.g. aggression), social capital, education, income, gender and coping strategies. Low perceptions of social capital "*norms and networks that facilitate a collective action*" and gender (female carers) are associated with higher levels of burden. Higher education and income were associated with lower levels of burden. Emotional instability and destructive disorder of the person with dementia were associated with depression, stress and low level of carers' well-being. Selection of positive coping strategies was associated with less burden in comparison with emotional coping strategies (Papastavrou et al., 2007, 2011,2015).

3.12. Summary

In this third chapter, dementia or major neurocognitive disorder symptomatology, the role of behavioural and psychological symptoms or neuropsychiatric symptoms in dementia, as well as the prevalence of dementia were discussed.

Major neurocognitive disorder includes a decline in 6 domains: in complex attention, executive function, learning and memory, language, social cognition and perceptual-motor function.

The most common neuropsychiatric symptoms are:

- Behavioural: wandering- restlessness, agitation, socially inappropriate behaviour, sexual disinhibition, hoarding, sleep disorders, aggressiveness, screaming and cursing
- Psychological symptoms: anxiety, depressive mood, apathy, hallucinations and delusions

Furthermore, in Greece, according to recent results, 5% of people over 65 years old are estimated to suffer from dementia. In Cyprus, this number is available as part of Alzheimer Europe calculations, with 11250 people suffering from dementia, which equals 1.07% of the total population for the year 2012.

Carers were defined based on the existing definitions by WHO, EUROCARERS, INTERLINKS and OECD and the role of stress was discussed (Pearlin's stress process model), coping strategies, social support (and social network) in the carers' lives.

Next chapter combine the concepts of chapter 2 and 3 through a systematic scoping review and become the link for the final part of the overall introduction to the chapter on the conceptualisation.

4. Chapter. Evidence regarding Internet use, Health Literacy and eHealth literacy

This chapter present the available research of internet use among carers of PwD, of Health Literacy and eHealth literacy with self-efficacy, coping strategies and social support and the eHeals validations. Then the Erasmus+ eLILY project realised in five European countries is described. The scoping review aims to identify all available research on internet use for the specific population. Main topics presented in the results are the origin and sample characteristics, how carers use the internet, what they post online, and what their need is regarding internet use. Existing literature specifically on eHealth Literacy and carers has only been available by 2019. The second review is an attempt to understand the association of Health Literacy and eHealth literacy with the caring concepts, and finally, the eHeals validations follow as this was part of our methodology for the adaptation of the eHeals for carers.

4.1.Carers and Internet use: A systematic scoping review (1)

In the literature, there was no available information on the research on the level of carers' eHealth literacy until 2019 (Soleimaninejad, Valizadeh-Haghi, & Rahmatizadeh, 2019). There is much information on the type of internet use that informal carers of different chronic diseases make without any further recommendation regarding the level of eHealth literacy. People usually search for information on their suggested treatment, questions that doctors have not replied to and information on healthy habits and the majority of users consider the information on the internet to be of good quality. There is a classification of 3 question categories search by carers online: the questions of fact, of policy/action and value. The use of interactive services usually used in the case of policy question. Carers may search the websites to receive information on fact and value questions (Kanthawala, Vermeesch, Given, & Huh, 2016).

Apart from the descriptive information of the way carers use the internet, there are several, effectiveness and usability studies of web-based support programmes, such as online communities, forum, psychoeducational programmes (Lee, 2015). Systematic reviews of studies on the internet use made by carers also provide a concrete presentation of the current status of carers' internet use (Boots, Vugt, Knippenberg, Kempen, & Verhey, 2014; Christie et al., 2018; Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016; Hopwood et al., 2018). In the systematic review of Chi et al (2015), 65 papers were analysed: 19 randomised control trials and 33 other study designs as pilot, feasibility, comparison and quasi-experimental studies, pre and post-test designs, case and evaluation studies. Half of the studies included family carers of adults and older adults. The majority of the studies included less than 100 participants and only 20 studies included over 100 carers as a sample. Technology tools used were videoconferencing tools (40%), phone-based technology (31%), web-based info (18%), remote monitoring and telemetry (11%). The technology-based interventions for carers were categorised as follows:

1) education using mainly telephone-based, web-based and video interventions (37%),
2) consultation: using videoconferencing (37%),
3) psychosocial/ CBT intervention: using the telephone and videoconferencing tools (35%),
4) social support: using videoconferencing tools (23%),
5) data collection/ monitoring: including response centre, sensors, fall detectors (20%) and
6) clinical care delivery: using videoconferences (11%) (Chi et al., 2015).

In the systematic review of Dam, et al (2016)**,** 39 papers were selected. The interventions reported were befriending and peer support intervention, family support and social network interventions, support group and remote interventions. In another systematic review by Boots, et al (2014)**,** 12 studies were identified, that included carers interventions: websites with information and support, websites with additional caregiving strategies, websites combined with telephone support, websites with additional email support, websites with a combination of individual work and exchange with other caregivers online. Additionally, Christie et al., (2018) identified determinants of eHealth interventions including the characteristics of the eHealth applications, the informal carer of the person with dementia, the implementing organisations and the wider context (such as support by the health insurance authorities, Broadbent availability).

The outcomes of these systematic reviews were contradictory. The limitations of the included studies were spotted on the methodology: sample size (samples from 11-700), eligibility criteria, measures, study design (no information on the duration of the intervention, no information on the time spent online), follow up and focus on a specific sample (carers of PwD) (Wasilewski, Stinson, & Cameron, 2017; Hopwood et al., 2018). Results provided positive outcomes of the use of the web-based interventions for carers as the improvement in psychological health, well-being (measured with depression measures), sense of competence, decision-making confidence, self-efficacy satisfaction, knowledge, QoL, social support, problem-solving skills communication with providers, cost-saving and physical health. On the other hand, results shows that internet interventions did not affect depression, anxiety, burden, QoL, social isolation (Chi et al., 2015; Dam, et al.,2016; Boots, et al (2014) The outcomes had qualitative results on sharing, companionship and improved relationships but there were not any quantitative results supporting this (Dam, et al.,2016). In the case of randomized trials, mental health has improved (Hopwood et al., 2018). Videoconferencing and online psychological support were promising, providing results of enhanced satisfaction, on self-efficacy, reduced burden, distress and depression (Dam, et al.,2016; Hopwood et al., 2018))**.**

There is a growing research field discussing the type, impact, quality and implementation of web-based interventions of carers of PwD to understand the factors that may influence carers characteristics and needs that would facilitate the internet-based intervention use. On the other hand, there were not many reviews on the type of internet (health-related and dementia-specific) use made by carers. The current scoping review aimed to identify the available literature of the health-related internet use made by carers of PwD, older people with disabilities or chronic diseases focusing on the type of use that carers make and the characteristics that may influence this use.

4.1.1. Summary of the Scoping Review (1) Methodology (Appendix I.A)

The methodology followed the Preferred Reporting Items for Systematic Reviews and Meta-analysis for scoping reviews (Tricco et al., 2018) as well as the five stages of Arksey & O'Malley, (2005) on scoping reviews. As part of the research questions we searched for the characteristics of the carers that may predict the internet use and dementia-specific internet use; the way that carers use the internet; available theoretical frameworks for dementia-specific internet use and the needs of carers with dementia when using the internet. In the second stage, we identified all relevant studies by searching all available resources: electronic databases, conference proceedings and grey literature. Inclusion criteria and detailed methodology of this scoping review are described in detail in the Appendix I.A. We have included studies with carers in general and of older people and PwD, as in this way, we broaden our search and it was possible to find related information on our topic that was important for us to understand the phenomenon. Based on this, we also included interventional studies, even if not related directly with internet use, as this type of research is an indicator of online service use and we were also interested in mapping the existing research on online use and services. Additionally, usually in the interventional studies, there is always the usability issue and how ready and friendly the carers consider this type of technology, which was a question of interest in our research. Studies were excluded if the language was not English and if there was no full paper available. Systematic reviews of the relevant topic were also identified but not included. No type of study design was excluded as the area is new and we were interested in identifying all possible aspects.

The search resulted in 1223 Papers and after reading the titles we included 208 papers. Through abstracts reading, we included 101 papers and after full-text reading, we concluded 13 papers. Another 6 articles were included by the snowball effect. The final number of included papers raised to 19 full texts (Appendix I.A.3). The reviewer also included a quality appraisal section in the same section for the selected papers used for qualitative studies (interviews and focus groups), the Consolidated Criteria for Reporting Qualitative research (COREQ), for the observational study Strengthening the Reporting of Observational Studies in Epidemiology Statement (STROBE) and for the online surveys, the Checklist for Reporting Results of Internet E-Surveys (Cherries).

4.1.2. Results of Scoping Review (1)

In the analysis, 9 qualitative studies and 10 quantitative studies (including 2 reports and 1 dissertation) were included (Table 4.1). In the case of the qualitative studies, 3 of them analysed and discussed the findings from the text that was already uploaded on the internet by the carers of older people through related websites or open online support groups as ALZConnected.org and other blogs. In the majority of the qualitative studies, the authors did not provide information on the personal characteristics of the interviewers or moderators or the relationship that was established during and before the study. Information regarding methodology orientation, sampling, and data collection as well as the consistency of data and findings and presentation of major and minor themes were always included. On the other hand, authors usually did not provide information on data saturation, setting of data collection, involvement of the participants in the transcription and findings and non- participation rates.

The 3 papers that used online posted material and messages was the most difficult to be assessed as in COREQ the majority of items were not related as in the case of the relationship with participants, non-participation, method of approach, presence of non-participants, setting, interview guide, duration, transcription. In this case, we used items 1 to 5 regarding the characteristics of the coders, theoretical framework, participant (posts) selection, description of the sample, data collection, analysis and findings items. Only in one case, did the authors discuss this regarding the terminology of posts and if posts considered being handled as "participants" (Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017)

In six of the seven studies, the assessment of the observational studies was high with minimum score 16/22 and maximum 19/22. Only in one study, did we find a low score of STROBE 5/22 including only items 3, 5, 13, 14 and 18. In this study, the topic discussed the use of the internet and NHS telephone line from people with cognitive disorders and was the first study that we included chronologically in the area, followed by Blackburn (Blackburn, Read, & Hughes, 2005; Larner, 2003). The majority of the internet use research among carers was based in the United States, with 11 out of 19 papers developed in the United States. Other countries of research were the UK (4), China (2), Australia (1) and South Korea (1). The total number of the studies sample were 10091, with 5 papers using a sample under 50 carers (Chiu & Eysenbach, 2010, 2011; Lucero et al., 2018; Ruggiano et al., 2018; Werner et al., 2017). Furthermore, 3 research papers analysed 3393 posts on social media and forums to understand how carers of PwD post online (Anderson et al., 2017; Scharett et al., 2017; Yoo, Jang, & Choi, 2010). The majority of the papers focused on carers of PwD (13). In other cases, the research focused on carers of older people (3), carers of adults (1), carers without defining (1) and carers of adults of mental and physical diseases (1).

In the year 2018, we found the majority of published papers (4). In all other years apart from 2010, the usual number of publications on this specific topic fluctuated from one to two papers. And in many cases, there was no related publication. This revealed the tendency during this last year.

In 9 out of the 19 papers, a theoretical framework supported the findings. In total 9 theories were presented:

- "*Andersen's Behavioral Model of Health Service use: Model explaining service use including 3 main dimensions, predisposing, enabling and needs factors"*
- "*Venkatesh's unified theory of acceptance and use of technology: intention to use information technology with 4 core dimensions: performance and effort expectancy, social influence and facilitators"*
- "*Chatman's and Wilson's information behaviour theories: dynamic relation among the user, information system and information resources"*
- "Stress Process model" by Pearlin
- *"System Engineering Initiative for Patient Safety: sociotechnical system model"*
- "*Lazarus coping strategies: primary and secondary appraisal, coping processes and coping styles: problem-focused and emotion-focused"*
- *"Law of Attrition" by Eysenbach – stages of use: consideration, initiation of use, attrition or continuation of use and outcomes"*
- *"Chronic disease self-management programme framework: improvements in health status and outcomes are a result of an individual's knowledge, ability and confidence in practising self-management"*
- *"Linguistic inquiry and word count system (to analyse the emotional level of posts online)"*

Carers' characteristics that affect the use of the internet for health – related or caregiving topics

Internet access and use by carers seemed to be influenced by socioeconomic factors. The age of the carer and the age of the person cared for, gender, employment status, living conditions and hours of care are factors associated with internet access and frequency of use. Being over 55 years old and with more hours of care was related to limited internet access and less frequent use. Being not in paid employment was also connected with not having use the internet. Being a female also was the strongest predictor for using the internet less than once a week. (Blackburn, Read, & Hughes, 2005).

The health-related internet use was also related with sociodemographic characteristics of carers, such as age, education, income, hours of caregiving and relationship with the cared-for person, age of care recipient and IADL level of dependency, chronic condition and having a recent crisis in health. More specifically, younger carers (children and grandchildren), more educated, with higher income, more financial hardships and fewer hours of caregiving were most likely to be health-related internet users (Kim, 2015; Fox & Brenner, 2012). Dementia-specific internet use was also associated with being a carer or not (Fox & Brenner, 2012). Internet use was associated with better mental health after adjusting for confounders such as the age of the carer, being a primary carer and caring for a disabled person were significant (Lam & Lam, 2009). The frequency of internet searches for caregiving information was related to the carers' service needs, being or not a primary carer, carers' strain and health status. The higher the service needs for carers, being a secondary carer, reporting better health status and higher caregiving strain, the more likely it was for carers to search the internet (Li, 2015).

The percentages of internet use and access differed according to the study. Blackburn, Read, & Hughes, (2005) found that 61% were frequent users and almost half had internet access and Kim, (2015), that 59% of the carers used the internet for health-related reasons and caregiving information.

How do carers use the internet?

Carers of older people visiting a caregiving website mostly looked for health information, practical issues, legal and financial issues (Kernisan, et al, 2010)**.** These preferences were directed from the type of caregiving. Carers also searched online to communicate and receive support by other carers, health professionals and eHealth solutions. Kernisan, et al (2010) categorized replies in 4 categories: caring for a parent, caring for themselves only, other caregiving situations and unknown caregiving situations. In the case of the carer of older people, practical issues were the most frequently searched.

According to Lam & Lam, (2009) the most common use of the internet among carers in Australia included chat sites and emails. This was connected with the carers needs to communicate. Furthermore, carers used the internet for information and also for accessing government services, to pay bills. Carers who used the internet 12 months before the study had better mental health in comparison with the carers who had not used the internet during that period. In another study by Li, (2015) using secondary data of 812 carers from the US Caregivers survey, carers searched for disease-specific information (77.2%), services for the patients (52,7%) and only 11% searched for information for themselves. In the report by Pew Research Center "Family Caregivers Online" (Fox & Brenner, 2012), 860 carers participated in the survey about internet use among carers in the United States. The majority of the sample, 79% used the internet at home, 88% searched for health information online and 55% had a laptop or another mobile device. Carers were more likely to search for health information for someone else, use social media for communication and read clinicians, medical facilities and drugs reviews. They also considered the internet as useful when searching for health- related issues.

In other research on information-seeking among the family of PwD, 171 out of 214 carers replied that they were searching for information mainly through dementia association websites (82%) and that 38% rated the information that they found on the internet about dementia as low quality(Allen, Cain, & Meyer, 2018). The internet together with newspapers and television were considered as passive information sources and the internet was considered the most accessible source (86%) and was the first source of the search for information followed by the health professionals. Carers also considered access to online sources as important for the knowledge and skills of health self-management (Lucero et al., 2018). Carers considered technology use as important for networking and personalized care, being most useful for information management (Ruggiano et al., 2018). In the same study, spouses made less frequent use than children who cared for a parent with dementia and only 3 carers used applications for caregiving.

What do carers post online?

In this scoping review (1), 3 papers analysed posts and messages of carers. In the case of the research by Anderson et al., (2017), 2345 posts were analysed by 9 websites and were categorized in 4 categories: social support – communication and inclusion, the search for information, the sharing of memories with the person with dementia, information to other carers and advocacy.In another study by Yoo et al., (2010), 798 messages were analysed by carers from South Korea and they found that carers expressed mostly negative feelings in comparison with carers in the United States and they looked for emotional support to online communities. More recently, 500 posts of the Alzheimer Association forum were categorized in 10 categories: feelings, symptoms, doctors and services, physical safety, hygiene, general info, medicine, conflicts, solutions and ethics. Another 250 posts randomly selected included their solutions and were included in the below categories. The problems were mostly negative, and solutions provided by other carers or moderators were neutral. The solutions were also categorized into 6 categories: information, communication with experts, assisted care facilities, memory problems, safety, care at home (Scharett et al., 2017).

Information search and coping

A model developed to associate information seeking and information forwarding among carers of PwD and coping strategies online. Information seeking was associated more with problem-solving techniques and information forwarding with emotion-based techniques (Jeong, Kim, & Chon, 2018)

Needs and benefit among carers of PwD

Carers considered as important elements for using the technology: to have on-time access to related tailored information and be able to receive information online for direct behavioural management (Werner et al., 2017). According to the American National Alliance for Caregiving (Alwan, Orlov, Schulz, & Vuckovic, 2011), benefits for accessing online health-related information were:

- Time-saving
- Support with caregiving
- Safety of the person receiving care
- A sense that carer is effective

Table 4-1Results of the scoping review of carers' internet use

authors, year	country	qualitative assessment	participants	design	category	main outcomes	theory
(Chiu & Eysenbach, 2010)	CHINA	STROBE 17/22	46 family carers of PwD	multiphase, longitudinal design, interventional quantitative	understanding patterns of internet intervention use	Consideration stage (easy technology matters), initiation (acceptance of technology matters), utilisation (frequency of use matters)	Andersen's Behavioral Model of Health Service use & Venkatesh's Unified Theory of Acceptance and Use of Technology
(Chiu & Eysenbach, 2011)	CHINA	COREQ: 12/32	14 family carers of PwD	qualitative analysis (in depth interviews)	conceptualisation patterns of internet intervention use	dimension of the web-based intervention use:(a) caregiver needs, influenced by personal capacity, social support, and caregiving belief; (b) information communication technology (ICT) factors (accessibility barriers and perceived efforts) and (c) style of using the technology,	Anderson's model of health service utilization, Venkatesh's theory of technology acceptance, and Chatman's and Wilson's information behavior theories
(Kim, 2015)	USA	STROBE= 19/22	450 family carers of PwD	descriptive correlational design	Internet use	59% identified as internet users. Health -related internet users were younger, more educated, higher income, fewer hours of caregiving. Sociodemographic characteristics and subjective response to stress indicators of health-related internet use, followed by the hours of caregiving	stress process model
(Larner, 2003)	UK	STROBE= 5/22	104 carers of people with cognitive decline	descriptive study	use of internet and NHS help line of patients and carers	More than 50% of patients and families/carers had internet access; 27% had accessed relevant information.82% expressed interest in, or willingness to access, websites with relevant medical information if these were suggested by the clinic doctor. Although 61% had heard of the NHS Direct telephone helpline, only 10% of all patients had used this service	N/A
(Blackburn et al., 2005)	UK	STROBE= 16/22	3198 carers	cross-sectional survey	internet use	Half (50%) of all carers had previously used the Internet. Of this group, 61% had used it once a week or more frequently. Factors significantly associated with having previously used the Internet were carer's age, employment status, housing tenure and number of hours per week they spent caring.	N/A

						Frequency of Internet use was significantly associated with carer's age, sex, employment status and number of hours spent caring	
(Alwan et al., 2011)	USA	REPORT	1000 carers of adults with mental, physical illness	quantitative online study	usability and needs met by 12 technologies	Reported benefits of web-based use: saving time, facilitating caring, safety, self-efficacy and reduction of stress.	N/A
(Kernisan et al., 2010)	USA	COREQ: 14/20 OR CHERRIES 30/30	2161 carers (50% caring for parents of elders	5 questions pop up survey	Internet use	people visiting a caregiving-related website search for general information on caring, specific assistance (custoial, medical, emotional and financial), training, disease progression and symptoms, caring support, peer support	N/A
(Lam & Lam, 2009)	AUSTRALIA	STROBE: 16/20	784 carers of older adults over 60 with disability	national health survey	Internet use	significant association between use of internet and better mental health status	N/A
(Fox & Brenner, 2012)	USA	REPORT	860 carers of adults	national telephone survey	Internet use	Caring is associated with being online and with online e-health behaviors. Carers are active health care consumers.	N/A
(Kim, 2012)	USA	DISSERTATION	752 family carers of PwD	telephone surveys	Internet use	Carers' stress may predict carers' perception of poor health status. Health-related Internet use did not mediate this relationship effectively.	N/A
(Li, 2015)	USA	STROBE: 19/22	800 carers of older adults over 65		Internet use	Carers search for care receivers' conditions or treatments (77.2%), available services for care receivers (52.7%), and care facilities (35.3%). Only a small percentage search for support for themselves	Wilson's model of information-seeking behavior
(Anderson et al., 2017)	USA	COREQ 18/21	3245 carers' posts of PwD	descriptive study/ qualitative research/ analysing samples of blogs	Internet use	Themes derived from carers' posting social support through communication and engagement, information gathering and seeking, reminiscing and legacy building, altruism	N/A
(Werner et al., 2017)	USA	COREQ 18/32	26 carers of PwD	qualitative (4 focus groups)	information needs	Authors find three critical information needs: 1) timely access to information, 2) access to information that is tailored to caregiver's needs and	System Engineering initiative for Patient Safety

					assessment/ internet use?	3) usable information that can directly inform how caregivers' manage behaviors.	
(Yoo et al., 2010)	USA	COREQ 9/21	798 carers' messages of PwD	qualitative study/ content analysis	socio-affective regulation (SAR) and goods-and information acquisition (GIA).	The results indicated that Korean caregivers expressed more family burden than U.S. caregivers. Also, the Korean caregivers expressed more negative emotions than the U.S. caregivers,	N/A
(Jeong et al., 2018)	USA /south Korea	STROBE= 16/22	104 dementia carers	descriptive correlational design	information seeking and forwarding- cybercoping	information seeking is associated with the affective coping and physical coping than information forwarding. information seeking is associated with problem focused coping.	Chiu and Eysenbach, 2011 and Lazarus (emotion based and problem-based coping)
(Allen et al., 2018)	UK	CHERRIES 13/30	212 dementia carers	Online and postal survey (questions adapted from the US health & services 2014)	dementia information seeking, access and understand	Source of information accessed: 1st source: Internet (almost all except 2 people)- 82% search dementia specific information,57% accessed the web through mobile. 2nd source: health and social care professionals Factors related to frequency of use: Age In majority, they were searching info by dementia charities websites Relational information source: GP and friends and family Friends and family most popular information resource for emotional support Passive information resources: Newspapers, television and internet Health and social care professional as most inaccessible sources and internet as the most accessible source followed by the published material Most important characteristic of information source: trustworthiness, accessibility and answer questions	N/A
(Lucero et al., 2018)	USA	COREQ21/ 32	20 carers and 11 caregiving counselors	qualitative (6 focus groups of 4-6 people)/	effectiveness of Family-HIMS intervention	Three tasks and 6 skills were presented in the analysis: Tasks: medical management, role management and emotional management. emotional management and resource utilization mentioned more often, by carers and counsellors, medical	*chronic disease self-management program framework: improvements in health status and outcome are result of an*

				exploratory study		management more often by the caregivers. 6 self-management skills: 1) Problem solving 2) Decision making 3) Resource utilization 4) The formation of patient-provider partnership 5) Action planning 6) Self tailoring	*individual's knowledge ability and confidence in practicing self-management*
(Ruggiano et al., 2018)	USA	COREQ 14/32	36 dementia carers	beta test interviews for Care IT	use of technology and an app	Current technology use: all had access to internet, spouses less active on the internet in comparison with children. They do not use the technology for caregiving activities. Only 3 people use apps for caregiving. Importance to the usefulness of the technology to generate interest to use.: social networking, and personalized technology Half of the participants support that IT would be helpful for medication management information	Technology acceptance model
(Scharett et al., 2017)	USA	COREQ 11/19	250 posts and related responses (randomly selected) of dementia carers	post qualitative analysis	emotions of problems stated and given solutions	Categories from initial analysis of 500 posts: Problem categorisation: Carers feelings/ Symptoms/ Doctors and nursing homes/ Physical safety/ Basic hygiene/ General info/ Medicines/ Conflicts / Solutions / ethics. Solution categories: informational resources for carers, contact professional assistance, assisted care facilities, doctor consultations, caregivers well-being, patients well-being, memory problems, safety, medication, bathing and sanitation, anxiety or depression, hallucinations, home care.	linguistic inquiry and word count system: provide an emotional rating 0 to 100 (0 negative emotion and 100 positive emotion)

4.1.3. Conclusions of the internet use among carers systematic scoping review (1)

This systematic scoping review (1) searched all available published research of health-related or dementia-related internet use among carers of PwD, elderly and adults with mental or physical chronic conditions. In the papers included, the importance of internet use was identified, and predictors of the use are reported such as age, relationship with the patient, education, socioeconomic position and other characteristics. Carers searched online for dementia information and services, and they tried to communicate with other carers or health professionals.

eHealth literacy was not reported in any of the above published papers of the search period (2000-2018) neither as a theory or as survey concept, even if in many cases the related questions may have been part of the concept of eHealth literacy.

4.2. The association of Health Literacy and eHealth Literacy with self-efficacy, coping strategies and social support among carers: A literature review (2)

There is a lack of research regarding the association of Health Literacy and eHealth Literacy with caregiving variables among carers of PwD, like self-efficacy, coping strategies and social support. We searched the literature to identify relative studies on the association of Health Literacy or eHealth Literacy and self-efficacy, coping Strategies and social support.

The final results included: 23 studies on the topic of Self Efficacy, 1 in the case of coping and 8 in the case of social support.

There were not any published paper on the topic of eHealth Literacy and self-efficacy, coping and social support. Detailed methodology is available in the Appendix I.B

4.2.1. Association of Health Literacy and self-efficacy

In this section, the results of the association of Health Literacy with self-efficacy are presented. Detailed information of the self-efficacy including information on the countries, the aim, the study design and the sample, the measures are available in the Appendix I.B.3

The outcomes present the association of Health Literacy with other variables (14 papers), the predictors (4 papers) or the mediating or moderating role of self-efficacy (5 papers) (Table 4.2). Limited Health Literacy was associated with SES, comorbidities, poor access to health care, poorer physical and mental health status, education, income, social support, lower parental self-efficacy, lower level knowledge of Genomics, lower awareness, lower perceived importance of FHH, frequent communication with a doctor and lower reading of food labels (Cha et al., 2015; Fong et al., 2018; Kaphingst et al., 2016; Kim & Yu, 2010; Lee, Murry, Ko, & M.T., 2018; Sudore et al., 2006). In 4 studies, they discussed the mediating role of self-efficacy on the association of Health Literacy and compliance with physical activity guidelines (Geboers, de Winter, Luten, Jansen, & Reijneveld, 2014), on Health Literacy and poorer physical and mental health (Kim & Yu, 2010), on the association of maternal Health Literacy with early parenting practices (Lee et al., 2018), on numeracy and diabetes medication adherence (Huang, Shiyanbola, & Chan, 2018). In one study, we found the self-efficacy as a moderator for the Pap screening and Cervical Cancer knowledge (Tiraki & Medine, 2018).

In the case of predictors, lower Health literacy predicted Self-Efficacy (Donovan-Kicken et al., 2012), higher Health literacy predicted higher level of knowledge and Self Efficacy among women for pap test screening (Kim, Xue, Walton-Moss, Nolan, & Han, 2018), self-efficacy and Health literacy also predicted the reading of food label (Cha et al., 2015).

Table 4-2 Literature review of Health Literacy and Self-Efficacy

Authors	**Country**	**aim**	**study design**	**sample**	**Measures**	**Outcomes**
(Edwards et al., 2012)	Wales, SCOTLAND, UK	how patients with Long-term conditions practice HL	longitudinal qualitative study	18 participants	Interviews	Health Literacy Pathway Model: 5 stages: 1) gaining knowledge of the condition, 2) developing self-management skills, 3) communicating with HP, 4) producing treatment options and 5) making an informed decision. The role of friends and family and HP as health literacy facilitators. Barriers personal (not accepting condition, emotional barriers and HP barriers
(Sudore et al., 2006)	Memphis, Tennessee, and Pittsburgh, Pennsylvania. USA	association of HL and demographics and access to health care	Cross-sectional study	2512 participants	REALM[1], demographics, health status, BMI[2], CES-D[3], items from Health ABC[4] study,	Limited HL was associated with SES, comorbidities, poor access to health care
(Geboers et al., 2014)	Eastern Groningen, The Netherlands	assess the association of HL and physical activity, fruit and vegetable consumption, attitude, self-efficacy and risk perception	secondary analysis from previously conducted intervention study: pre-post quasi-experimental design	643 **older** adults (55+)	HL 3 questions by Chew, questions on Physical activity, self-efficacy, insufficient physical activity, levels of physical activity SQUASH [5], questionnaire on nutrition.	Self -Efficacy partially mediates the association of HL and compliance with physical activity guidelines
(Chen, Hsu, Tung, & Pan, 2013)	Indiana, USA	association of HL and SE and preventive care utilisation	longitudinal survey	3479	S-TOFHLA[6], Heart failure knowledge Questionnaire, Self-Care Heart Failure index, demographics, BMI[2]	HL increases SE among older people

(Donovan-Kicken et al., 2012)	Texas, USA	association of HL and SE	face to face interviews	254	NVS[7], Self-efficacy questionnaire self-reported ability to effectively evaluate the potential hazards of the medical procedure and make an informed decision	lower HL predicts lower SE
(Bohanny, et al., 2013)	Marshal islands	association of HL and SE and self-care behaviours	Cross-sectional study	150 patients with **diabetes**	S-TOFLHA[6], DMSES [8] (Self-efficacy), SDSCA [9] (Self-Care)	patients receiving education had higher HL and better self-efficacy. Patient married with higher SE had better self-care behaviours
(Kim & Yu, 2010)	Korea	mediating effect of SE among HL and health outcomes	Cross-sectional study	103 community-dwelling Korean older adults	K-TOFHLA [10], General Self-Efficacy Scale, Physical Component summary, Mental Component summary	low HL associated with poorer physical and mental health status. The effect was mediated through self-efficacy
(Lee et al., 2018)	Texas, USA	association of Maternal HL and Parenting SE	Cross-sectional study	186 low income **mothers**	Demographics, NVS [7], Karitane Parenting Confidence Scale, Postpartum Social support scale, Early Parenting Practices Index, safety practices, development promotion practices, health care utilization, 3 questions on consent document, overall confusion question, accurate translation, demographics	3 in 4 low MHL [13]. MHL correlated with education, income, social support, self-efficacy. Parenting SE mediating effect on MHL and early parenting practices
(Fong et al., 2018)	Boston, USA	HL with parental SE	Cross-sectional study	253 **parents**	SAHL-E[11] AND SAHL-S [12], Perceived Maternal Parenting Self-Efficacy, demographics parents, children and environmental characteristics	parents with low HL had lower parental SE
(Huang et al., 2018)	Midwestern state, USA	medication self -efficacy: moderates of mediates HL and medication adherence	Cross-sectional study	174 participants with type 2 **diabetes**	NVS [7], Self-Efficacy for Appropriate Medication Use Scale, 8 items Morisky Medication Adherence Scale, diabetes control HbA1-c	medication SE mediates and not moderates the association of numeracy and diabetes medication adherence

(Kim et al., 2018)	Northern-Eastern region of USA	investigate pathway that HL influences PAP TEST	Secondary analysis of Randomised Control Trial	560 Korean American women	Provider's advice question about Pap test, HL assessment in Cancer screening (52 items), Cervical cancer knowledge test, questions on perceived pros and cons of Pap tests, Korean-translated Cervical Cancer Self-Efficacy scale	higher HL predicts higher level knowledge and higher SE, high knowledge predicts pap test
(Kaphingst et al., 2016)	Montreal, Canada	association of HL and Genomic related knowledge, SE	Cross-sectional study	624 patients in primary care clinic	REALM-R[14], Genetic Knowledge index, FHH[15] Self-efficacy, item for importance of genetic information	Low HL associated with lower level knowledge of Genomics, lower awareness, greater perceived importance of genetic info, lower perceived importance of FHH and frequent communication with doctor about FHH
(Lee, Lee, & Moon, 2016)	South Korea	Health literacy in association with SE for health outcomes	Cross-sectional study	459 patients with type 2 **diabetes**	HLS [16], HRQOL [17], Summary of Diabetes Self-Care Activities, Diabetes Management Self-Efficacy Scale	HL plays a significant role on self-care activities and has indirect effect on HRQOL. HL and self-efficacy need to be considered in the research
(Guntzviller, King, Jensen, & Davis, 2017)	Indiana, USA	Self-efficacy and interaction with nutrition and exercise behaviors	Cross-sectional study	100 low income participants	5-item scales: nutrition self-efficacy, physical exercise self-efficacy, TOFHLA-S [6]	SE positively linked with to all four outcomes: eating 5 fruits and vegetables day, fatty food avoidance, exercise3 times a week for at least 20 min
(Ozkaraman, Uzgor, Dugum, & Peker, 2019)	Turkey	assess HL on SE and QoL of Cancer patients	Cross-sectional study	111 patients	HLS-EU-Q[18], Self-efficacy to manage Chronic Disease Scale, European Organisation for Research and Treatment of Cancer Quality of Life-C30 scale	positive association among HLS-EU and general health subscale and a negative association with the symptom subscale. Positive relationship among SE and functional and general health, and negative relationship among SE and symptom subscale
(Alinejad-Naeini, Razavi, Sohrabi, & Heidari-Beni, 2019)	Iran	association of HL, SS and SE of mothers of preterm neonates	Cross-sectional study	200 mothers	demographics, maternal HL, maternal SE and MSPSS[19]	positive correlation among maternal HL and SS. MHL correlated with SE, SE positively correlated with SS

(Tiraki & Medine, 2018)	Turkey	level of cervical cancer knowledge, self-efficacy perception and HL of married women, association of knowledge levels, SE and HL, association of Pap smear screening and HL	descriptive correlation study	400 married women	Interview form, Cervical Cancer Prevention Knowledge Form, SE scale and REALM [1]	As the pap smear and cervical cancer levels increased so did the behavior of having Pap. Older people, higher (tertiary) education and had a pap had higher cervical cancer knowledge. Self-efficacy levels moderate. Pap screening and CC knowledge increased as SE increased. HL increased as the education level increased
(Fry-Bowers, Maliski, Lewis, Macabasco-O'Connell, & DiMatteo, 2014)	USA	Antecedents and processes of care and the association of maternal HL, access to social support and self-efficacy of interpersonal interactions	descriptive cross-sectional design	124 Latina mothers and female caregivers	Demographics, NVS-E [7] and NVS-S [7], Family Support Scale, Perceived Efficacy in Patient -Physician Interactions, Interpersonal Processes of Care in Diverse Populations survey	Maternal HL increased maternal acculturation, Formal support scale trended to negative association with HL. Maternal HL not associated with SE. Maternal HL associated with Interpersonal Processes of Care subscale. Maternal SE positively correlated with Informal support score and total support score. Formal support predicted self-efficacy
(Cha et al., 2015)	USA	Association of HL, SE, food label use, dietary quality	correlational cross-sectional study design	103 young adults	Socio-demographics, NVS [7], Weight Efficacy Lifestyle Questionnaire, self-reported item on food label use behaviour, Dietary Quality index,	SE AND HL were predictors of food label use. Lower HL- lower use of food labels, no significant differences between medium and high level of HL groups
(Inoue, Takahashi, & Kai, 2013)	Japan	Association of communicative, functional and critical HL with SE of diabetes management and understanding of diabetes care	Cross-sectional observational study	269 patients with type 2 diabetes	HL scale developed in Japan, 6 items on the communication with HP [20], 8-item scale from Diabetes Quality Improvement Project	50% didn't access the internet. Functional HL had higher score and critical had the lowest. Communicative and critical HL highly correlated. Patient physician communication was associated with communicative HL. Internet use was associated with functional HL and communicative HL and not with SE. Social support was associated with communicative, critical HL and clarity of Physician's explanation. SS was associated with SE for diabetes management. SE associated with communicative and critical HL. Higher self-efficacy associated with SS, time since the diagnosis and absense of diabetic complications

(Colbert, Sereika, & Erlen, 2012)	USA	Association of functional HL and medication adherence, mediated by medication taking SE	Cross-sectional secondary analysis	302 adults living with HIV/AIDS	S-TOFHLA [6], EEM [21] (adherence), Self-efficacy Beliefs subscale of the HIV Self-Efficacy Scale for Medication Taking, Health Survey, Medical Record Review	high functional HL, Higher medication SE associated with higher medication adherence. Functional HL did not associate with SE and medication adherence. Hypothesis wasn't confirmed
(Osborn, Cavanaugh, Wallston, & Rothman, 2011)	Tennessee, USA	association HL, numeracy, diabetes self-efficacy in types 1 and 2 diabetes	Cross-sectional study	398 participants	REALM [1], WIDE RANGE ACHIEVEMENT TEST 3RD EDITION, 8-item perceived diabetes self-management scale, most recent hemoglobin (A1C)	HL and numeracy skills associated with SE. Higher Diabetes SE with lower A1C levels. HL, numeracy and SE predictors of A1C
(Torres & Marks, 2009)	NY, USA	association of HL and knowledge, SE, intent to take hormone therapy	exploratory study	106 women	17-items of Hormone therapy assessment, decision self-efficacy scale, 2 questions for the intent to take hormone therapy, TOFHLA[6]	Positive relationship HL and knowledge about hormone therapy, HL and SE regarding hormone therapy

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[1]Rapid Estimate of Adult Literacy in Medicine, [2]Body Mass Index, [3] Centre of Epidemiologic Study Depression Scale, [4]Health, Aging and Body Composition Study, [5]Validated Dutch Questionnaire to measure physical activity [6] Test of Functional Health Literacy Assessment in Adults-Short Form, [7]Newest Vital Sign (NVS-E for English version and NVS-S for Spanish version), [8]Diabetes Management Self-Efficacy Scale (DMSES), [9]the Summary of Diabetes Self-Care Activities (SDSCA), [10] Test of Functional Health Literacy Assessment in Adults-Korean version [11]Short Assessment of Health Literacy -English [12] Short Assessment of Health Literacy-Spanish, [13]Maternal Health Literacy, [14] Rapid Estimate of Adult Literacy in Medicine Revised [15] Family Health History, [16] Health Literacy Scale, [17] Health-related Quality of Life, [18]Health Literacy Survey-European Union-Questionnaire, [19]Multidimension Scale of Perceived Social Support, [20]Health Professionals, [21]Electronic Event Monitoring,

4.2.2. Association of Health Literacy and coping strategies

As a result of the search for coping strategies in association with Health Literacy, we included only (1) paper from the three found through the search(Fraser & Pakenham, 2009).

The study came from Australia and aimed to identify the association between adjustment and caregiving experiences of carers of people with mental health disorders. The measure used in the study for Health Literacy was the mental Health literacy tool and for Coping, the Stress Questionnaire-Family Stress Version.

Primary and secondary control engagement were the two dimensions of coping. Poorer adjustment was associated with disengagement. Life satisfaction was associated with secondary control engagement and caregiving confidence with primary control engagement (Table 4.3)

Table 4-3 Literature review of Health Literacy and coping strategies

Authors	**Country**	**aim**	**study design**	**sample**	**Measures**	**Outcomes**
(Fraser & Pakenham, 2009)	Australia	association between adjustment and caregiving experiences, resilience for factors of the COPMI [1] intervention	Quantitative	44	demographics, mental health literacy tool,20 item social connectedness scale, Stress Questionnaire-Family Stress Version, Children's Depression Inventory-SF, Life Scale, Strengths and Difficulties questionnaire, Young caregiver of Parents Inventory	knowledge and awareness of mental illness associated with perceived maturity. Social connectedness correlated with adjustment and to less adverse caregiving experiences. Secondary control engagement related with life satisfaction and primary control engagement with caregiving confidence and prosocial behaviour. Poorer adjustment related with disengagement and the involuntary coping strategies

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[1] Children of Parents will Mental Illness

4.2.3. *Association of Health Literacy and Social Support*

Health Literacy was associated with social support (Yang, Zhang, Meng, Liu, & Sun, 2019) and maternal Health Literacy with maternal social support (Alinejad-Naeini et al., 2019). Lower Health Literacy was associated with lower perceived support (Stewart, Thrasher, Goldberg, & Shea, 2012).

Social support, Health Literacy and marital status were predictors of the self-management behaviours, with social support to be a stronger predictor than Health Literacy (Chen et al., 2018). Low health literacy and social support predicted more depressive symptoms (A. Stewart et al., 2012). Social support and Health literacy mediated most health outcomes (Kamimura, Christensen, Tabler, Ashby, & Olson, 2013) (Table 4.4)

Table 4-4 Literature review of Health Literacy and social support

Authors	Country	aim	study design	sample	Measures	Outcomes
(Alinejad-Naeini et al., 2019)	Iran	association of HL, SS and SE of mothers of preterm neonates	descriptive Cross-sectional design	200 mothers	demographics, maternal HL, maternal SE and MSPSS [1]	positive correlation among maternal HL and SS. MHL correlated with SE, SE positively correlated with SS
(Yang et al., 2019)	China	Association among SS, HL, productive aging and self-rated health in older adults	Cross-sectional study	992 older people	socio-demographics, Chinese Citizen Health Literacy Questionnaire, questions regarding productive aging, 1 question for self-rated health	SS directly related to self-rated health. Productive aging and HL had a direct association with social support. Productive aging mediates the relationship among HL and SS
(Chen et al., 2018)	Taiwan	association of HL, SS, self-management of patients with chronic kidney disease	Cross-sectional study	410 patients with kidney disease	demographics, s-MHLS [2], Social support scale, original chronic kidney disease self-management instrument	Health literacy and SS with self-management behaviours positive association. SS, HL and marital status predictors of the SM behavior. SS stronger predictor than HL
(Stewart et al., 2014)	Texas USA	mediator effect of SS between HL and depressive symptoms	correlation descriptive study	200 low SES smokers enrolled in cessation treatment	Computer administered self-report interview system: demographics and smoking characteristics, S-TOFHLA [3], Interpersonal support evaluation list, CES-D [4]	lower HL associated with lower perceived SS, which predicted higher depressive symptoms in a simple mediation model. SS is critical factor for HL-Depressive symptoms

(Amoah, 2019)	Ghana	impact of SS to functional HL and self-rated health status	Cross-sectional study (secondary analysis)	521 participants	modified version of Swedish Functional HLS [5], adapted social capital assessment tool, demographic characteristics	young adults more possible to have higher HL than older adults. HL positive associated with health status
(Kamimura et al., 2013)	USA	assess physical and mental health, health literacy and SS of uninsured patients who were using a free clinic	Cross-sectional study	197 participants	SF-12[6], Patient Health questionnaire 9, Michigan Oral Health -related Quality of Life Scale, 16-items HL developed by Chew, MOS-SSS[7] 19 items for emotional support	US born English speakers had lower health status, SS and HL mediated most of health outcomes
Lee et al 2009	Chicago, USA	interaction of social support with HL and if affects health status of older adults	cross-sectional study	489 people	S-TOFHLA [3], Medical outcome study social support scale, general health (1 question), SF-12 [6] (Physical and mental health), demographics	more positive impact on physical health in older adults

[1]Multidimensional Scale of Perceived Social Support, [2], Short-form Mandarin Health Literacy Scale, [3] Test of Functional Health Literacy Assessment in Adults-Short Form, [4] Centre of Epidemiologic Study Depression Scale, [5]Health Literacy Survey, [6] 12 items Short Form Survey [7] Medical Outcomes Study Social Support Survey

4.2.4. Conclusions of the literature review of the association between Health Literacy and self-efficacy, coping and social support

The review provided us with information on the association of Health Literacy with self-efficacy, coping strategies and social support. The research come from parental, cancer and diabetes studies or healthy adults. The sample sizes ranged from small numbers such as 18 people to thousands (e.g. 3479). Health Literacy was associated with self-efficacy, even if researchers measured different types of self-efficacy, making comparisons difficult. Possible predictors reported, are SES, comorbidities, poor access to health, health status, education, income and social support. In coping strategies, we found only 1 paper related to Health Literacy and in social support, research found an association between these two concepts, and researchers reported them as predictors for the self-management behaviours.

Research on eHealth literacy and self-efficacy, coping strategies and social support could not be retrieved from the available databases.

4.3. Available eHeals validations: a scoping review (2)

In this section we expand our knowledge regarding the eHealth Literacy Scale and all available validations are presented through a literature review methodology. The search strategy, eligibility criteria and data collection are part of the Appendix I.C
All available validations of the eHeals tool were identified, following the methodology of scoping review as described in Arksey and O'Malley and Peters et al (Arksey & O'Malley, 2005; Peters et al., 2015) for relevant validations of eHeals in order to identify all possible alternatives regarding the different languages, population, statistics, ratings and to identify any available carers' adapted version. Main research questions were the type of statistical analysis was used to extract factors for eHeals, the Web 2.0 problem in relation to eHeals, the rating of the scale and the available validations. This review was important as we proceeded in our own validation of eHeals presented in Chapter 7, section 7.4.1. The search generated 382 results, after excluding for duplicates (64 papers), 318 were screened by title, 55 studies by abstract and finally 32 by full text. Finally, 26 studies were included in this review (Appendix I.C.3)

4.3.1. Results of the eHeals scoping review

The scale has been validated and adapted in many different languages, population groups, using either convenient sample recruitment strategies or randomized recruitment techniques (such as random telephone dialling). We found validations in English, Dutch, Chinese, Japanese, Israeli, German, Spanish, Korean, Persian, Italian, Arabic, Slovenian, Spanish and Serbian. During the last three years, the validation studies of the specific tool have increased, showing a tendency towards eHealth literacy research. The validations started in 2011 and there was a rapid increase in next years with 2017 and 2018 surpassing the previous years. In Appendix II, we summarise the validations of the eHeals including information on the study design and sample characteristics, statistics, results, mean score.

The tool has 8 items, and, in some cases, we found an additional two items. Only in one study from Slovenia, was the validation was an extended version of 20 items (6 factors) including the web 2.0 parameter as discussed earlier by Norman (Norman, 2011; Petrič, Atanasova, & Kamin, 2017), in another study 6 items (Neter & Brainin, 2012) and 7 items (Hyde, Boyes, Evans, Mackenzie, & Sanson-Fisher, 2018). In almost all cases, the scoring system distinguished between high and low scores without providing information for a medium level. The reliability in the majority of the studies was quite high, over Cronbach alpha= .80. The lowest reliability was presented in a student sample in Bangladesh (Cronbach alpha=.74) and in the 6 dimensions of the Slovenian version (Islam et al., 2017; Petrič et al., 2017).

In 12 papers the level was calculated by summarizing all items and in 4 validation studies by summing up all items and dividing the score with the number of the scale or of the factor. A higher score of all studies presented by the study of Chung and Nahm (Chung & Nahm, 2016) for a sample of 886 adults with mean age 62 years and eHeals literacy mean score 30.94 (SD 6) was found. A series of studies has identified or confirmed the single dimensionality of the eHeals scale (Caro et al., 2016; Chung, Park & Nahm, 2016; Koo, Norman & Chang, 2012; Neter & Brainin, 2012; Nguyen et al., 2016; Paramio Pérez, Almagro, Hernando Gómez, & Aguaded Gómez, 2015; Van Der Vaart et al., 2011). However, the latest studies proposed either a 2-factor model (Dashti, Peyman, Tajfard, & Esmaeeli, 2017; Diviani, Dima, & Schulz, 2017; Gazibara, Cakic, Cakic, Pekmezovic, & Grgurevic, 2018; Soellner, Huber, & Reder, 2014) or a 3-factor model (Hyde et al., 2018; Paige et al., 2017; Paige, Miller, Krieger, Stellefson, & Cheong, 2018; Stellefson et al., 2017; Sudbury-Riley, FitzPatrick, & Schulz, 2017). In 3 out of 6 studies, the sample was of older adults (Stellefson et al., 2017; Sudbury-Riley, FitzPatrick, & Schulz, 2017; Chung & Nahm, 2016;). The mean eHeals score ranged from 22.35 for older Hispanic people with type 2 Diabetes to 30.34 (sd=5.30) for older people with chronic diseases. In one study they found weak correlation but significant with internet use and significant correlations with age and education (Van Der Vaart et al., 2011). In a second study, they did not find any correlation with age, but with gender (Aponte & Nokes, 2017a). Computer knowledge had also a strong correlation with eHeals among older adults (Chung & Nahm, 2016). Cronbach alpha ranged from .89 to .99 in these 6 studies.

4.3.2. Conclusions of the eHeals validation scoping review

With this literature review, all available validation and metric properties (dimensionality, internal consistency) of the eHealth Literacy Scale were presented. Norman’s and Skinner’s scale has been a widely used scale for the last decade, without major advances regarding this domain of eHealth Literacy measurement. Even if many researchers identified the lack of the Web 2.0 dimension only a few expanded this initial version during their validation process. The majority of researchers decided to add additional question for Web 2.0 (internet access, digital literacy, health information sources, content search strategies, evaluation criteria and time spend online). Furthermore, age and education were associated with the eHeals in case of older adults and the scale had a weak correlation with internet use

4.4. Enhancement of eHealth Literacy Learning Skills among carers of older people and PwD- Erasmus+ eLILY project

As part of the study proposal, a project proposal was prepared and submitted in the Erasmus+ funded programme initially in Cyprus, but because of the small number of proposals accepted in the country, it was decided to submit it in Poland via the Collegium Balticum. Collegium Balticum is a private educational institution with the leading faculties of humanistic and social sciences. The selection of this Polish organisation was decided on previous fruitful collaborations with Poland and the specific organization, and finally, the application was successful in getting the funding.
This project aimed to provide a blended training programme (face to face and eLearning course) for carers of frail older people and PwD based on Lily theory model developed by Norman & Skinner, (2006b), integrating additionally dimensions presented by Chan & Kaufman, (2011), Gilstad, (2014) and adapted to fit the web 2.0 technology requirements.
The proposal included three core intellectual outputs:
1) development of the face to face training for carers of frail older people and PwD,
2) development of a students' toolkit including Handbook with exercises, Glossary and a training manual
3) development of an eLearning tool of all modules: presentations, video tutorials and videos.

The consortium of the eLILY project consists of Collegium Balticum (Poland)- coordinator, the Cyprus University of Technology (Cyprus), Athens Association of Alzheimer's Disease and Related Disorders (Greece), Anziani e non Solo (Italy) and Alzheimer's Association Bulgaria (Bulgaria). The Cyprus University of Technology is the leader of the first Output and the development and piloting of the curriculum in face to face training. Athens Alzheimer Association is the leader of the Students' toolkit and Anziani e non solo for the development of the eLearning. The duration of the project is 2 years, starting from September 2018 to August 2020.
The development of the curriculum had several steps from the beginning of the project:

1. Health literacy and eHealth literacy survey of existing policies and projects in all partners' countries
2. Development of the curriculum according to the submitted application: 6 modules: -- Module 1- Digital literacy, Module 2- Communication skills, Module 3 Introduction to Health and eHealth literacy, Module 4- Introduction to selected sources-national specific module, Module 5- Media Literacy- Videos (learn how to find and evaluate videos) and Module 6 Use of Interactive Services (learn how to use Social media).
3. Delphi survey in all partners' countries
4. Update of the curriculum based on the Delphi survey results
5. Content development of the face to face training and pilot testing in carers to all partners' countries
6. eLearning development materials and pilot testing to a group of carers

All partners searched for relevant information based on specific questions send by the CUT:

1. Is there a national strategy on Health Literacy issues in your country and/or related policy network: if yes please describe briefly a summary of the strategy?
2. Is there any research work published on Health Literacy in-country?
3. Is there any research work published on eHealth Literacy in your country?
4. What are the most recent statistics of internet use among older people in your country according to the Census report?
5. Is there any related Erasmus+ funded projects on the use of the internet by older people or carers (eg. Enhancing ICT skills etc)? Please include also related website links

The results of this report can be found online: https://elily.eu/wp-content/uploads/2019/03/SUMMARY_RESULTS_FINAL_elily_content.pdf

After this step, all partners undertook a module based on the 6 modules of the proposal:

Figure 4-1 First version of the eLILY curriculum

Module 1
Digital Literacy
Lead: Alzheimer Bulgaria

Module 2
Communication skills
Lead: Alzheimer Athens

Module 3
Introduction to Health literacy and eHealth literacy
Lead: CUT

Module 4
Introduction to selected sources – national specific module
Lead: CUT (national specific sources)

Module 5
Media Literacy-Videos
Learn how to find and evaluate videos
Lead: CB

Module 6
Use of Interactive Services-Learn how to use Social media
Lead: ANS

Following this decision, all partners developed the steps for every module and then decided to run a modified Delphi survey to finalise the contents. The research team defined the problem and invited a group of experts and carers to give feedback. Based on this first round, the research team updated all modules and during the meeting in Cyprus, the research team reached a consensus. Summary report of the results and the final modules can be found in Appendix III. The final adapted curriculum included 4 modules: Module 1: Health literacy and communication skills, Module 2: Digital literacy, Module 3: eHealth Literacy (Introduction to selected source), Module 4 use of Interactive services (Learn how to use Social media).

Figure 4-2 Final version of the eLILY curriculum based on the Delphi survey results

Module 2 = new Module 1
Health literacy and Communication skills
Lead: Alzheimer Athens and CUT

Module 1 = new Module 2
Digital Literacy
(adding step on the basic use of videos)
Lead: Alzheimer Bulgaria

Module 4 and 5= new Module 3
eHealth literacy
Introduction to selected sources – national specific module
- Learn how to find and evaluate videos
Lead: CUT and CB (national specific sources)

Module 6= New module 4

Use of Interactive Services-
Learn how to use Social media
Lead: ANS

Results of the piloting and eLearning version will be announced.

4.5.Summary

In conclusion, there is much information on web-based interventions among carers of older people with chronic disease and PwD. In an attempt to gather the descriptive data of the research that has been carried out up to the present on internet use, health-related and dementia-specific internet use made by carers, a systematic scoping review (1) was carried out. Following Prisma- ScR and Arksey and O'Maley five steps, four databases were searched, and 19 papers were included related to the health-related internet use. Furthermore, carers' characteristics such as socioeconomic factors, age and education, theories relevant with the internet use made by carers, ways of using the internet (communication, information seeking for the care-recipient, chat-sites, forums, emails) were identified.

In the second main section, a literature review (2) was presented between the association of Health Literacy and self-efficacy, coping and social support. There was a lack of evidence in the case of Health Literacy with coping strategies and between eHealth Literacy and self-efficacy, coping and social support. As part of the evidence report, a scoping review (2) with all the eHeals validations was carried out. eHeals validations review for the adaptation of this scale for Carers were considered essential.

Finally, this chapter closes, with the eLILY project, a project developed as part of this protocol in an attempt to introduce eHealth Literacy training to carers of older people with chronic diseases and carers of PwD. In the following chapter, Part I- the general introduction ends with the conceptualisation of our research study and with all concepts discussed until now together.

5. Chapter - Conceptualisation and significance of the problem

This chapter introduces the conceptualisation and the research questions of this research study, as now the target population (carers of PwD) and all the core concepts were defined: Health Literacy, eHealth Literacy, Perceived Social Support and all the caring concepts of interest (self-efficacy, coping strategies, perceptions of caring).

Before the presentation of the research questions, we discuss briefly the way that people use the internet in Greece and Cyprus, focusing when there is evidence, specifically on the age group over 60 years old.

5.1.Proposed framework

As it was discussed earlier (section 3.6, 3.7, 3.8), social support and coping strategies are part of Pearlin's stress process model of carers of PwD. Pearlin considered these concepts as mediators – for a carer to cope with life stressors and maintain physical and psychological health (Pearlin et al., 2016). In a recent tribute to Pearlin's work, stress process model was updated to include social network, neighbourhood and social position as crucial dimensions (Avison et al., 2010)

Self-efficacy is related to cognitive appraisal and acts as a motivator of action and selection of coping strategies (Bandura, 1978) and is also influenced by the social support a person receives. Perceived carer's role is related to coping strategies (Zucchella, Bartolo, Pasotti, Chiapella, & Sinforiani, 2012).With this term, a person with enhanced self-efficacy may search for health awareness opportunities and feel empowered (being in control of one's own health). Higher self-efficacy was associated with more positive aspects of caring, such as satisfaction derived from the carers' role, positive gain and affect and resilience (Crellin et al., 2014). In another study among a large sample of older people in Taiwan, Health Literacy was associated with self-efficacy and preventive care utilisation (Chen et al., 2013). In an earlier study by Kim and Yu, among a small sample of 103 Korean older adults, self-efficacy had a mediating role among Health Literacy and health status reported by the Korean adults (Kim & Yu, 2010)

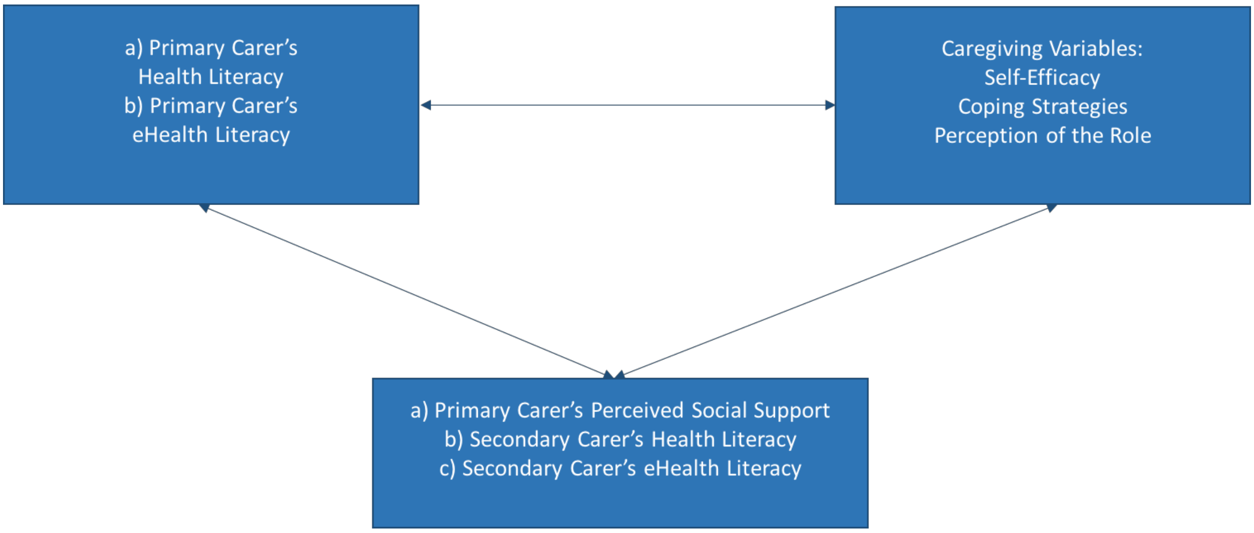
Social support is a concept commonly connected with Health Literacy as a moderator upon low health literacy and modifying its effect on poor health and is defined as "*the degree to which individuals have access to social resources, in the form of relationships, on which they can rely*" (Johnson & Sarasosn, 1979; Lee, Arozullah, & Cho, 2004). The support of social networks seems to play a crucial role in the management of a person's health problem and acts as a coping behaviour. Two types of social support are distinguished: structural and functional. The structural support refers to the different roles that a person has in the community (professional role, volunteering role, family role etc.). The sense of belonging may facilitate the communication of a health problem without directly improving the health literacy, but instead, decrease the feeling of shame and possible stigma due to inability to read and write health information or to seek medical advice of a health problem. Family and friends may also be facilitators in a decision about health or may make the decisions for the patient. This also may act in the opposite direction, where family and friends with low health literacy have a negative influence on the person's health decisions (Lee et al., 2004).

The second dimension of social support which possible interacts with the level of Health Literacy, as described by Lee et al (2004, 2006) includes the tangible, medical information, health reminder support and is referred as functional support. Lee (2006) measured levels of health literacy among older adults and their relationship with the types of social support. Older adults with low health literacy had higher support concerning medical information and health reminder support. Furthermore, the tangible support was rather low among older adults with low level of Health Literacy. Lee et al justified this finding due to lack of social network on behalf of people with low Health Literacy.

eHealth Literacy and Health literacy share common dimensions. In Norman's and Skinner's model, Health Literacy was presented as part of the framework. Still, Health Literacy is highly connected with eHealth Literacy and may act as an umbrella term for eHealth Literacy and not as an equal part with the other 5 literacies presented in the model. The reason for this assumption is that as this concept also requires other types of Literacy: Traditional Literacy, Information Literacy, Science Literacy, Contextual/Cultural Literacy, Bodily experience and Procedural literacy. eHealth Literacy may influence the Intrapsychic stressors, knowledge and motivation and as a consequence, self-efficacy (Soerensen et al 2012).

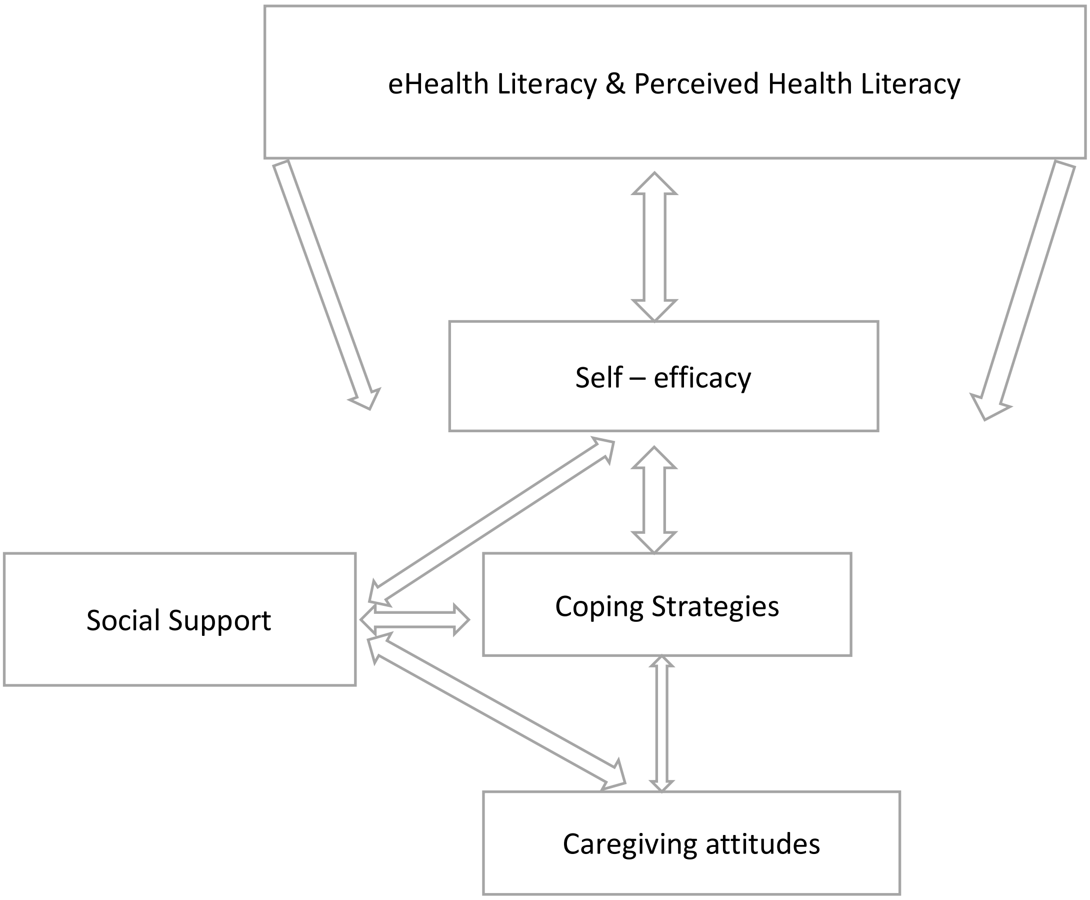
There is limited research into the associations between self-efficacy, coping strategies, social support in relation to Health and eHealth literacy. The figure 5.1 connects the concepts of the association of Health and eHealth Literacy of primary and secondary carer and the social support provided by the secondary carer (a relative, friend or neighbor supporting the primary carer) with self-efficacy, coping strategies and perception of carer's role.

Figure 5-1 Health and eHealth Literacy of primary and secondary carer in association with the selected caregiving variable



In order to elaborate more on the above figure, below we present the full proposed model for the primary carer and our concepts

Figure 5-2 Health and eHealth Literacy of primary carer in association with Self-efficacy, Coping strategies, caregiving attitudes and perceived social support



The present study did not aim to reveal moderating effects of social support, but mainly the correlations between Health Literacy and eHealth Literacy, social support and the caring variables. This is the first step to understand the studied phenomenon since Health Literacy and eHealth Literacy among carers of PwD are not well studied and are new concepts.

5.2. Significance of the problem

The dramatic increase of PwD and the lack of tailored services, has as a consequence families and friends undertaking care responsibilities in an effort to fill this gap.
Aiming to understand the variables that may influence the care of patients with dementia by their families, our hypothesis lied on the important role that Health and eHealth literacy plays on carers' lives, as carers may be benefited and empowered by the enhancement of eHealth literacy skills and obtain access to services that did not know existed. Through this study we investigated the associations among Health Literacy and eHealth Literacy and the other caregiving variables, self-efficacy, coping strategies, attitudes and social support and in the second phase we will focus research on the training of the carers to enhance the aforementioned skills with the development of eLILY training curriculum that we have presented in section 4.4, that has been already funded by Erasmus+.

We assume that the education of families with chronic patients can be proven cost-effective for national health systems. The need for citizens to make health-oriented decisions would become more essential in the years to come and would support health care professionals work. Many countries of the European Union have announced national eHealth and Health Literacy strategies as an effort to raise awareness to EU citizens. As Levin-Zamir & Peterburg, (2001) presented in a relevant paper on health literacy strategy in Israel, Health Literacy strategies have been proven helpful with many chronic diseases, as the case of diabetes and there are a prerequisite to develop relevant health-information tools for citizens that could be used in different care setting as well as through different media, to train health care professionals and to develop assessment tools.

The increased number of chronic diseases among older people sets the starting point for Health Literacy awareness strategies throughout the world. Awareness campaigns for dementia have increased all over the world in the last two decades with Alzheimer's Associations to promote informed decision making for the families of PwD. Furthermore, new eHealth tools have been developed as deliverables of small-scale training projects and this is expected to increase in the next decade. Especially in South-Eastern European countries, families are not used to new eHealth technologies related to care-recipient care. We identify a gap between the development of tools that carers could use and the lack of skills for using this technology. Here we find technologies such as platforms, applications, telehealth and smart houses, forum and in future years robotics will be added to this large list. However, basic skills in browsing the internet, does not safeguard the proper use and assessment of the information. The literature has suggested that it is not uncommon for people with a high level of digital literacy (to know how to find, understand, appraise and compose information through the use of digital platforms), to have low skills of health literacy, even among young ages (Van Deursen & Van Dijk, 2011). On the other hand, we have identified health care professionals that have low digital skills and do not inform their patients about the existing tools that could facilitate their everyday lives (McCleary-Jones, 2015). As Levin-Zamir & Bertschi, (2018) suggested, apart from developing new technologies for carers, there is a need to train health care professionals and families of PwD in the use of these technologies in order for them to be able to raise awareness and to promote the development of eHealth literacy strategy in the South Eastern European countries. Initially we need to develop or adapt tools measuring carers' eHealth literacy and as a following step to identify the specific training needs. Recently, we studied the use of the internet among informal carers of PwD in Greece (Efthymiou, Middleton, Markatou, Papastavrou, & Sakka, n.d.), and this remains to be carried out for carers in Cyprus in order to be able to adjust technological developments to carers' needs. In the last year, we participated in a small-scale Erasmus+ project promoting carers eHealth literacy training needs "eLILY" project. This study aims to fill the existing gap concerning the lack of tools measuring perceived Health Literacy and eHealth Literacy, to provide the first evidence regarding the levels of these concepts among this population and understand how these concepts influence caregiving. In this way, we will be in a better position to develop tailored eHealth Literacy and Health Literacy programmes to support carers in their role.

5.3.Internet Use and Health Literacy of people in Greece and Cyprus

According to Piirto et al (2015) between 2009 to 2014, household internet access increased by 28 percentage points in Greece and by almost 20 points in Cyprus. The percentage of daily users was 45% in Greece and 56% in Cyprus. According to the **press release** (HELLENIC STATISTICAL AUTHORITY. PRESS RELEASE HOUSEHOLDS AND INDIVIDUALS : 2015, 2016) on the usage of ICT released at the end of 2015 by the Hellenic Statistical authority, 7 out of 10 households had access to Internet and own a Personal Computer. During the period 2010 to 2015, there was an increase of 46% of internet use at home. The city of Athens had a higher percentage of use in comparison with central Greece. Interestingly, in Central Greece, the Aegean Islands and Crete, there was a decrease in the internet access between 2014 to 2015. No further interpretation of this decrease was found in the report. We may only assume that it is associated with the financial crisis in Greece during that time and the late expression of its consequences in rural Greece. The main reason for not accessing the internet at home was the lack of skills (60.7%). The largest increase in use compared with 2014 was recorded in age group: 45-54 years old. In age groups 65-74 years old and 55-64 years old, people used the internet daily (77% and 76% respectively. Seven out of ten people accessed the internet through a mobile device. Most common internet activities included reading the news, finding information, sending/receiving emails, participating in social networks, seeking health-related info, telephone with the use of the internet, looking for a job, downloading software. Participation in social networks was lower the older the person is.

According to the Greek report of the HLS-EU, 1000 people were interviewed, with an average age of 46 years, 55% of the sample reported excellent and sufficient health literacy, 74% can easily find information on illnesses, 81% were able to make health decisions, 87% understood what doctor said, 93% understood instructions, 85% understood health warnings. On the other hand, 45% have difficulty to assess information from the media (Kondilis et al (2012),.

In Cyprus, almost all Cypriots had internet access according to the World Internet Report: The Internet in Cyprus (2014), (Millioni & Stylianos, 2016). The percentage of people with internet access was 94,3% and 96.6% among Greek-Cypriots and Turkish-Cypriots respectively. Eurostat (Piirto et al., 2015) provided a slightly lower percentage (71%). The main reasons for not accessing the internet were the lack of interest and lack of skills. In the age group 55-64, an increase was observed from 2012 to 2014. This was not the case for Greek-Cypriots in comparison with Turkish Cypriot for the same period. In the age group 65-74, among Greek-Cypriots was a decrease from 17,6% in 2012 to 11,1% in 2014 and in the age group, 75-99, from 12,7% in 2012 to 6,4% in 2014. Only 9,6% of the participants searched the internet for health information weekly and 43% had never searched the internet for health topics (Millioni & Stylianos, 2016).

5.4. Aim of the present study

The present study aimed to explore the association of caregiving variables (perceived self-efficacy, perceived caregiving role, coping strategies) and eHealth literacy (as well as Health Literacy) of carers of PwD. Furthermore, in this study, the role of the perceived social support and the support provided by the secondary carers (the person who supports the primary carer) for the level of eHealth Literacy and Health Literacy were investigated.

The main research questions were:

RQ 1:Are there any available tools in Greek to assess the level of Health Literacy and eHealth Literacy?

RQ2a: What is the level of Health Literacy, eHealth Literacy, perceived social support and of the other caregiving variables of primary carers of PwD?

RQ2b: What is the level of Health Literacy and eHealth Literacy of secondary carers of PwD?

RQ3: Is there a difference between Health Literacy and eHealth Literacy level of primary and secondary carers?

RQ4: What is the association between Health Literacy and eHealth Literacy of primary carers of PwD with the sociodemographic characteristics?

RQ5: What is the association (if any) between Health Literacy and eHealth Literacy of primary carers and caregiving self-efficacy, their coping style, their perceptions towards the caregiving role and the perceived social support?

PART II

6. Chapter. Method

In the methodology, the reader can find all the different phases of the study. In the first phase, the study design is presented and then the Consensus on the terminology of Health Literacy and eHealth Literacy in the Greek language among a group of experts follows. This was the first step in the method followed by the piloting after the 6 months period of the primary and secondary carers recruitment. In this phase, 25 primary carers and 13 secondary carers replied to the questionnaires. During this phase, we employed all the possible alternatives to increase the sample recruitment. The final phase of the methodology introduces the full-scale study, presents the recruitment of the full-scale study, the selected questionnaires and the statistical analysis.

6.1. Study design

This was a five-phased study-using descriptive correlational research design to explore the level of Health Literacy, eHealth literacy and their associations with the caregiving variables (self-efficacy, coping strategies, perceived caregiving role and social support) among carers of PwD in Greece and Cyprus. Secondary carers' levels of Health Literacy and eHealth literacy were also compared to the primary carers' levels. This design was selected as most appropriate to describe the variables, including the association among them. The methodology of the study consisted of 5 main phases: a) two scoping review and two literature reviews presented in introductory part (Chapter 2 and 4), b) a consensus approach related to the terminology and the concept of health and eHealth literacy (section 6.2), c) cultural adaptation and evaluation of the psychometric properties of the selected research instruments (section 7.4), d) pilot study (section 6.6) and e) the field study (Chapter 7 & 8).

6.2. Consensus on Terminology of Health Literacy and eHealth literacy in Greek language

6.2.1. Methodology of the consensus process

One of the first steps in this process was the consensus on the terminology of Health Literacy and eHealth Literacy in the Greek language, as various researchers have used different Greek terms to present these concepts. The consensus meeting aimed to promote a common understanding and use of the term Health and eHealth Literacy in Greece and Cyprus. According to Sørensen & Brand, (2014) in their paper "*lost in translation*", the issue of Health Literacy translations in Europe has emerged. In the USA and English-speaking countries, the term is quite self-explanatory in comparison with non-English speaking countries. Consensus building processes commonly use three core methods: nominal group process, consensus development panel and Delphi survey. Even if they are widely used, no specific guidelines are available for these techniques. The methodology of Nair, Aggarwal & Khanna, (2011) was followed. A modified version of the nominal group process method was used and based on this, the expert team developed ideas and discussed them with the moderator and all group members to find an alternative and proceed to consensus.

6.2.2. Consensus' participants

In total, 12 people participated in the event that took place in the premises of the Department of Nursing, 9 invited experts and 3 members of the research team. All experts were selected based on their experience with the topic of Health literacy or their expertise in the Linguistics or in the Greek language as language science researchers. More specific, six people participated due to their work on health promotion and Health Literacy (C. N., C.K., P.S., A.M., B.K, C.M.). Four experts (C.N., A.M., S.P., M.K) were academic staff (2 Associate Professors of the Nursing Department, one from the Speech Therapy/Speech Pathology of the Rehabilitation Department and one from the Language Centre) and they were not members of the core research team. A doctoral student (C.K.) was also invited because of her interest in this work and two members of the HLS-EU team (B.K and C.M). We invited an Associate Professor due to her work in the area of health promotion from the Department of Nursing in Athens (S.P) and an Assistant Professor of the Medical School of a private University in Cyprus (A.P.). The language experts were C.M. and S.P.Three members of the research team attended (A.E., N.M and E.P.). N.M, Associate Professor of the Nursing Department, was the moderator, together with E.P, Associate Professor of the Nursing Department and Scientific Supervisor of this research (E.P.). From the nine (9) invited participants, three (3) participants were men and seven (7) women.

The invitation to the experts' team was made either by phone or email. All members decided on the agreed date. They all agreed to participate due to their shared interest in the topic of Health Literacy, public health and chronic diseases. The primary investigator (A.E.) distributed the agenda and related informational material to all members. The experts also shared their presentations and content for discussion. The meeting was audiotaped, and the researcher (A.E) kept field notes. The total duration of the meeting did not exceed five hours. In the first part of the meeting, all members expressed their ideas and discussed them with the moderators. In the second phase, all members decided on the term that adequately described Health Literacy in the Greek language. As part of this consensus meeting, an informative day was organised the day before with the participation of the HLS-EU members (Appendix IV).

6.2.3. Data collection and analysis

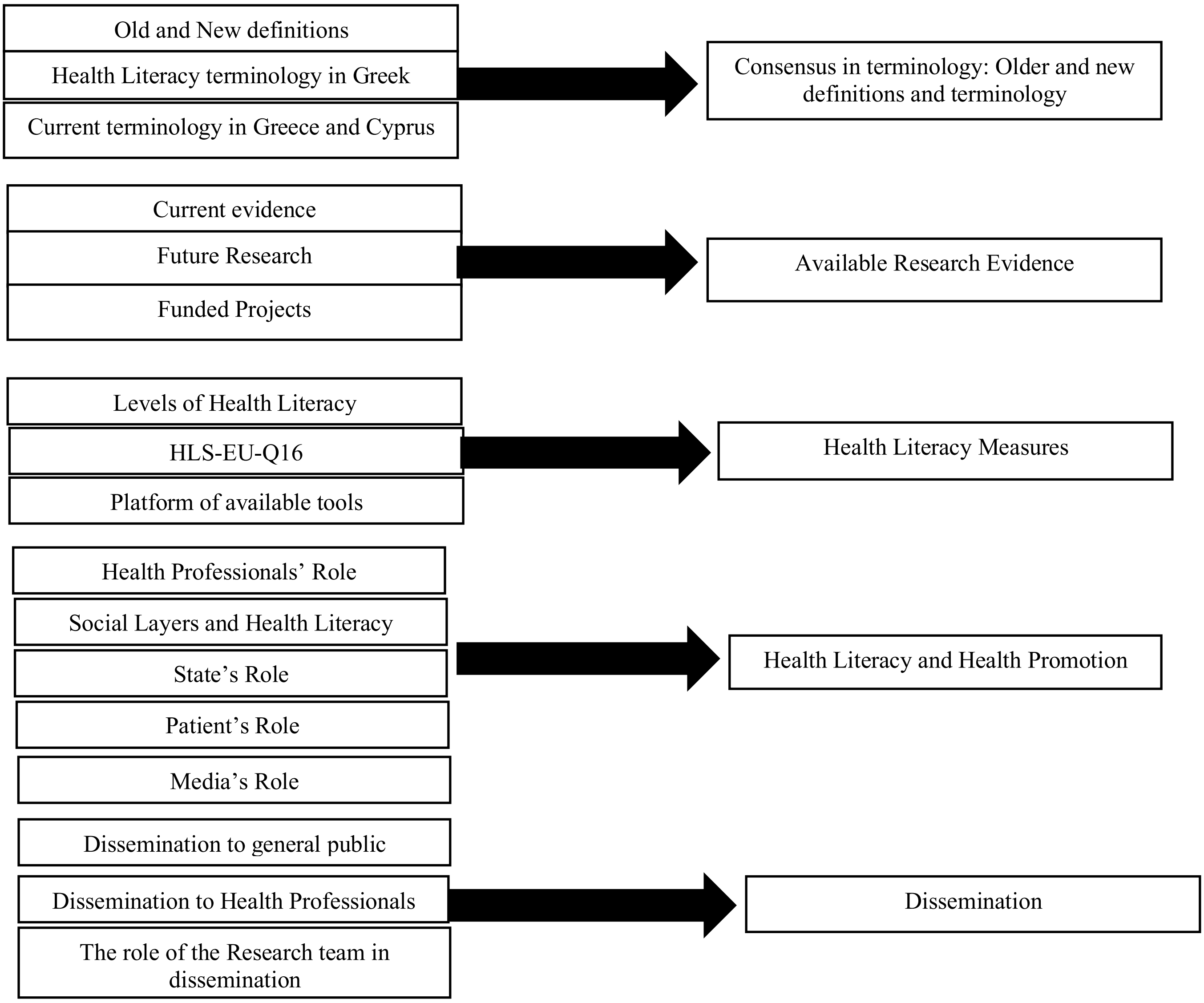
Three PhD students of the Nursing Department transcribed the audio material of the consensus meeting. After transcription, two coders (A.E and I.M), PhD students proceeded with the content analysis. Following this process, both worked in parallel and then met to agree on the coding system and to finalise the analysis. They have used excel forms to organize codes ,and they were based on the methodology as it is described by Bengtsson, (2016); Erlingsson & Brysiewicz, (2017) to keep records for Meaning Unit, Condensed meaning Unit, Code subcategory, Generic category and Theme. Themes had not been identified before the content analysis.

6.2.4. Consensus results

Based on the results, five categories were derived:

1) Older and new definitions and terminology. Older definitions were considered the ones before the WHO adoption and older terminology is considered before the HLS-EU survey
2) Current and future research on Health Literacy
3) Health Literacy measures
4) Health Promotion and Health Literacy
5) Dissemination of the term

Figure 6-1 Consensus Themes



Consensus on terminology: Older and new definitions and terminology

One of the first definitions of Health Literacy is the one proposed by Nutbeam, (2000), including the three types of Health Literacy: functional, communicative and critical.The new definition of Health Literacy was adopted by the World Health Organisation, in the report *EU Health Literacy in the solid facts* and is the one proposed by Sorensen (section 2.1- Soerensen et al., 2012, p. 3). According to this definition, experts agreed that they discussed acquired skills and not the process. In this definition, knowledge, skills and motivation do not only depend on education.

"…is a skill you need to communicate and navigate in the health system, to find the doctor, to cope with your health problem. To sustain your health, to improve your symptoms or even earlier before dealing with health issues, to promote your health." as N.M. explained.

The terminology of Health Literacy was discussed among other countries too. It was not only Greece and Cyprus that encountered this difficulty. Spanish speaking countries used the term Health Literacy without translating it, that was the case also in Germany. If we search the term on Wikipedia and in the most used book of Greek terms, we do not find the exact translation, only "Αλφαβητισμός" and "Γραμματισμός".

"these terms are outdated; the educators do not use them" as P.S. reported.

"the term «Αλφαβητισμός» does not cover the meaning as it refers to more basic processes." A.M agreed.

"an illiterate person may have health literacy and may be motivated to learn about health issues, to discuss with the doctor, from his own experiences and to understand health matters.", K.B added.

In Greece and Cyprus, before the term Health Literacy we discussed Health Promotion and before that in the '80s we found the term health education, which is now no longer used.

Health promotion is better correlated with the term " Εγγραμματισμός", as we better understand this as a process.

"Health promotion is the means to increase Health Literacy." as NM said.

On the other hand, Health communication is another term associated with Health Literacy and is more policy-related and does not include only the training process.

In the case of the Greek translation of Health Literacy, initially, the HLS-EU team organised Delphi surveys and focus groups with the psychologist and language scientists to determine the term and translate the definition provided by Sorensen (Kondilis et al., 2012).

The consensus team agreed that literacy in Greek could be translated in two different ways with different meanings: “Εγγραμματοσύνη” and “Εγγραμματισμός”. In the first case, the outcome of the learning process is presented. This learning process is covered by the term “Εγγραμματισμός”.

“*The term Εγγραμματισμός entails awareness, effort and should not be used interchangeably with Εγγραμματοσύνη” as NM explained.*

“Εγγραμματισμός is an ongoing process and may concern the person or a group of people.” A.M. added

“Εγγραμματισμός refers to lifespan, to all stages of human life.”, according to P.S.

“*The outcome in the process of Εγγραμματισμός ... is to develop culture and make health a cultural value. So, we may speak about culture*” as C.M. discussed

“*Εγγραμματοσύνη*” as a translation of the term Literacy is not a common term in Greek everyday language. On the other hand, it may be essential to select the most frequently used word, such as: αλφαβητισμός , γραμματισμός.

“*Even if a person understands the term* αλφαβητισμός*,it does not entail the dimensions of Εγγραμματοσύνη. We need to try to promote the correct term and not focus on the existing term just because people understand this better*” NM explained.

“In Cyprus, the use of the Greek language is different.”, A.M. added

The linguistic expert, S.P, explained: “*there are two ways of reporting language, the traditional one based on research by academics and the one based on the frequency of use by the public. In this case, to select the second way may be dangerous as we may omit dimensions of this concept*”.

“*When we have discussed with students the term Εγγραμματοσύνη or Εγγραμματισμός, they did not understand what we meant*” as A.M discussed.

“*We cannot translate accurately from English to Greek or use the English term as it is. We need to find the most appropriate word. Even in Greek among health professionals in Greece and Cyprus, we face difficulties in understanding*” as A.M and E.P suggested

“*Language is progressing, in future we may find another term that explains our term better”, P.S agreed.*

In our experts’ group, we discussed the translation of the term Health and how to combine it with the term literacy. The HLS-EU Greek team noted that the translation of the term Health was a problem for their team too. The group discussed the translation of Health in Greek: Health issues or topics –Θεμάτων Υγείας. Other proposals were health-related (in Greek: σχετιζόμενων με την Υγεία) or related to health (in Greek: σχετικά με την υγεία) or Health (in Greek: Υγείας). In the case of the translation of Health Literacy as Εγγραμματοσύνη Υγείας, the meaning did not fully enclose the way that Health is connected with Literacy.

"*When we translate Health in Greek, we need to paraphrase it and translate it as Health topics instead of Health… In this way, we do not refer only to health promotion. To avoid the bipolar nature of Health and Disease, we decided to translate it as Health issues - (Θεμάτων Υγείας). In this way, we also included the dimension of Quality of life. We also thought of translating Health as an adjective, but this doesn't explain the concept*" C.M. explained.

"*Health-related may explain better this concept, because in this way we include the range of different diseases, as in the case of Alzheimer's Disease*" added E.P.

"*Health- related does not cover the concept but only a part of the concept, we want to cover all dimensions of Health."* N.M.opposited

"In English, the term -Health issues- does not express the exact translation" C.M. added.

There was a brief discussion on the term eHealth Literacy and how we should translate eHealth. Should we include only the digital aspect: Digital Literacy or should consist of other dimensions?.The main discussion included the terms electronic and digital.

Current and future research on Health Literacy

In Greece, there is available literature on Health Literacy, even if it includes the term health promotion. In Cyprus, there is limited literature and for the first time we study this concept for the carers of PwD with this study protocol. For many years, researchers in Cyprus as NM reported, were "flirting" with the term Health Literacy: "*we find students' presentation for health promotion and education, aiming to empower, increase self-efficacy, manage symptoms and increase coping.*"

In PUBMED, studies of this topic start from the early '90s and increasing rapidly in the last 15 years. Almost half of the papers are categorised in medicine in Scopus, but they refer to subcategories as health promotion, health communication or public health. The most popular countries of origin are the United States, Australia and the United Kingdom. Other researchers focus on readability, and we find published research in the field of nursing science.

In research, it is essential to understand how to treat hard-to-reach population groups when we develop health promotion campaigns or specialised applications to increase inclusion. NM set the question "*Do we support people in this way, or we invite only people who already have these skills?"*

Future research should focus on the above question, as researchers usually focus on other concepts as empowerment, self-efficacy, coping, self-management and do not measure the participants' level of Health Literacy. Health Literacy may mediate or moderate these variables.

It is vital to develop a first tool able to measure levels of Health Literacy and use it for future research in public health issues.

In this framework, the invited members of the HLS-EU presented the findings of the survey in 8 countries (Austria, Bulgaria, Germany, Greece, Ireland, Spain, Netherlands, Poland) and the overall process that the consortium undertook to determine the definition and the tool.

According to their findings, we encountered problematic Health Literacy in Health Care in 43% in Greece, 49% in Bulgaria and 25% in the Netherlands, in prevention 42% in Greece, 59% in Bulgaria and 26% in Netherlands and in health promotion, 46% in Greece, 70% in Bulgaria and 36% in the Netherlands (Pelikan, Röthlin, & Ganahl, 2012). No differences were found by gender. Younger people trusted better their knowledge. Three out of four people perceived their health as "good" and believed that it is easy to have access to disease-specific information. Unemployed, pensioners, people with low socioeconomic position, in poor health and people over 55+ with low education trusted their knowledge and skills less. In Greece, people understood information from family and friends (88%) and they made decisions based on family's and friends' advice (81%), understood the doctor's directions (87%), medicine prescription (93%), the risk factors for their health (85%), the information they found from media (80%) and could judge reliability of this information (83%) and everyday behaviours related to health (92%) (Kondilis et al., 2012).

Health Literacy Measures

Health Literacy starts early in life and is a process, starting with simple instructions regarding health by the parents and continues throughout life. There is not a zero-point in this concept, or lack the concept, only unidirectional levels of this dimension. In a continuum, Health Literacy is assessed in levels, e.g. low, moderate and high. There are perceived and objective measures of Health Literacy, and that may influence our measurement, since people may not assess their Health Literacy adequately.

"*We may think Health Literacy as in the case of intelligence, where we may receive many different scores. Even in Health Literacy, a person may not acquire traditional literacy but may be health literate. It is important to measure this concept and to be able to intervene*" `K.B. suggested.

"*When we discuss the perceived Health Literacy, we may not able to compare between countries*" NM added.

The members of the Greek team of HLS-EU presented the methodology of the development of the HLS-EU-Q16. Initially, the instrument was developed in English and focus groups in 3 countries, including Greece, followed. As the third step, they piloted the tool, and then we adapted the questionnaire based on the findings of the piloting. As a fifth step, all consortium translated the Questionnaire. CM and K.B translated it for Greece, and the scientific team validated the translation. There was a discussion on the copyright issue following the validation of the tool and the importance of open-access, citing the HLS-EU team since the tool is a European project product. The Cyprus team proposed that in the case of validation of the instrument, we should refer the HLS-EU team regarding the permission to validate the tool.
The team discussed the translation of HLS-EU-Q16, pointing out several issues."

"*The HLS-EU-Q initially included 85 items, so we should decide what to include. We did not organise piloting for the translated version afterwards, that would be important*." C.M. added.
"*We identify the limit in research here. We find here in the first part of the questionnaire the Likert scale (very easy, easy, difficult, very difficult) ... to assess difficulty is also an issue and here are the limitations of this research. This type of research needs follow-up*" A.M. discussed.
A.M. continued "*In the majority of the HLS-EU-Q16 questions, we find the source of information. In the first question, there is no indication of the source: How easy is it to find information on disease symptoms? I may ask my friend and provide all the information, that does not mean that I am health literate.*"
"*We may consider the functional and structural type of support, for Health Literacy. In Functional, we ask about the available support and in structural the type of source. So, somebody could ask about the structure of the support*" NM added.

Other issues regarding the comprehension of the items referred to the use of the words, e.g. "understand" and the actual activity (action). The participants may have misinterpreted this difference. The group agreed to provide exemplars as an effort to decrease misinterpretation. For example, in item 6, 10, 11, 13 and 16, instructions are included in every item to facilitate understanding.

"If you provide this questionnaire to my mother and ask her to judge the reliability of the information, she might understand something completely different to you and me. So even the use of the word reliable is difficult" A.M. explained.

HLS-EU Greek team informed the team on the available online platform of Health Literacy tools, where all can find available Health Literacy tools and all available translations.

https://healthliteracy.bu.edu

Health Promotion and Health Literacy

Health professionals act as educators for the public. Patients and health professionals have a responsibility in the process of Health Literacy (Εγγραμματισμός σε θέματα για την υγεία). Health professionals do not always undertake this role.

"*If you ask parents of cancer patients where they find information and support, they will say from friends, parents with the same problem, other parents and as the last choice by the health professionals"* explained N.M and added "*we may improve our practices by increasing the Health Literacy of our students*"

Experts discussed the importance of inclusiveness. Health care professionals need to reassure that they do not broaden the gap among low and high health literate participants during the process of training (health promotion training campaigns)

The state needs to find ways to support Health Literacy training as it constitutes responsibility towards citizens. The citizens also need to be motivated and activated to improve their Health Literacy levels.

"*Health Literacy is the responsibility of the person, family, the environment (school) and is related to the literacy of health professionals. Is health Literacy a personal characteristic or an element of our community? Is it only a matter of the patient's adherence?" NM discussed.*

In this section, the group discussed the role of the media and journalists in the dissemination of the concept. The majority of people are not interested in the process of Health Literacy, but the outcome. It is the responsibility of the media and educators to promote the idea.

"*There are Health Journalists in Cyprus to promote the idea. In some cases, even they have difficulty in understanding health information.", E.P suggested*

"There is the term media literacy, which also needs to be translated., C.M added.

Dissemination

The concept of Health Literacy does not only refer to the patient; there is a larger audience that needs to be informed: carers, older people, policymakers, politicians, administrative staff other than the patient and health professionals.

The term needs to be disseminated to health professionals to inform their patients adequately.

"if I am a doctor or a nurse, I need to explain to my patient the dosage and what will happen if s/he takse an overdose.", A.M explained.

It is the responsibility of this experts' group to disseminate the concept in academia, not only through publications.

"*We should present the idea in Greece and Cyprus, to discuss the terminology, the history of this term, to organize sessions of Health Literacy and to add a course in our curricula.*", E.P suggested.

"*There is an online repository of translated Greek terms started by Giannis Trikalliotis as an effort to include all available translations. This was a common effort, gathering all translations for health terminology in Greece*" P.S. concluded.

6.2.5. Conclusions of the Consensus meeting

As conclusions of the consensus meetings, the group decided:

- to use the word "Εγγραμματοσύνη σε θέματα για την Υγεία" as the Greek translation of Health Literacy and rejected other terms.
- to use the term "Εγγραμματισμός σε θέματα για την Υγεία» as the Greek translation of the active, lifespan process of becoming Health Literate
- to use the term "Ψηφιακή Εγγραμματοσύνη σε θέματα για την Υγεία» as the Greek translation of the eHealth Literacy
- to promote measures and actions for improving Health Literacy: such as state campaigns, universities' courses
- to collaborate in future research and use the HLS-EU-Q as a tool of the perceived Health Literacy, and publish a position paper on the term in Greek

6.3. Sample of the full-scale Study

As a second step after consensus, the main parts of this study are discussed: sample, data collection, selected tools and piloting. A convenient sample of carers of PwD were recruited for participating in the study and signed informed consent (Appendix VI). The sample consisted of primary carers, spouses, children or other relatives and friends from dementia centres and Alzheimer's Associations in Athens, Glyfada, Hlioupoli, Voula, Vari and Thessaloniki, Greece and from Limassol, Pafos and Nicosia, Cyprus.

Furthermore, to explore the level of eHealth literacy and Health Literacy among primary and secondary carers, for each primary carer, a secondary carer who provides support to the primary carers was identified by asking the primary carer to nominate that person. This was decided in order to investigate how the support received and the levels of secondary carers' Health Literacy and eHealth Literacy were associated with those of primary carers. Not all carers were willing to involve their supporting source in the study. The most common reason for this was the lack of time of the secondary carer (as perceived by the primary carer).

Initial estimation of recruitment based on the study protocol was 12 months: years 2017-2018. Actual recruitment and collection of data (this was done concurrently) lasted 24 months: years 2017-2019. The reason for this one extra year was due to the acceptance rate by carers to participate in the study. The estimated sample size of primary carers to ensure correlations with statistical power of 95% and confidence level of 5% was 168 carers in total. We decided to include 200 carers as an effort to adjust for any missing values. We invited in total 273 primary carers, 207 Greek and 66 Greek-Cypriots. The final sample consisted of 174 primary carers (participation rate of 63%) and 67 secondary carers. Due to the difficulty approaching this target group, we could not follow other sample recruitment techniques. The challenge concerns the type of the study (duration and face to face survey) in combination with the inflexibility of carers to participate in research studies and to respond to the survey in parallel with their everyday caregiving tasks and their difficulty to obtain respite.

The participation of both Cypriot and Greek carers had been decided, as a solution to possible problematic recruitment that was foreseen in Cyprus. Since in Greece and Cyprus, there are many social-cultural similarities related to caregiving, given the common language and shared historical values, it was decided to use a sample from both countries. In both countries, non-for-profit associations play the most critical role in the care of PwD. At present, in Greece, associations, under the supervision of the Ministry of Health, support carers and PwD. In Cyprus, there is one dementia centre established by a non-for-profit association and Alzheimer's Association organizes awareness campaigns. Due to this lack of public services for carers, the family most of the times, undertakes this role for the older person with dementia.

Furthermore, the inclusion of the two metropolitan cities from Greece, Athens and Thessaloniki has been decided due to convenience and since the study investigates correlations and is not a prevalence study.

6.3.1. Inclusion criteria for the primary carer:

1) Being a primary carer of a person with dementia (supporting the relative in activities of daily living). This criterion was assessed by asking the person if s/he considers her/himself primary carer and is responsible for supporting the care-recipient in everyday tasks.
2) Being over 18 years old
3) Being able to read and write in the Greek language

6.3.2. Inclusion criteria for the secondary carer:

1) Being nominated by the primary carer.
2) Being able to read and write in the Greek language

   The researcher asked the primary carer:

   a) If s/he is supported by a significant other and who that person is

   b) Is there any significant other (family, friend) supports you apart from that person?

   This second question aims to identify bias on behalf of carers, who might feel ashamed not indicating their children even if another person provides support for them.

   c) In what way does that person help you?

   For this question, we provided a set of options concerning tangible and psychosocial support: housekeeping, caring activities, mobility, errands, financial management, caring management or provides psychological or social support.

   d) If s/he would need to find and understand disease-specific information on the internet, who would s/he consult from family and/or friend (e.g. spouse, children, sister, ant, friend etc.)"

The final participants in the survey were selected according to the above questions. In case a carer replied only to question a), we proceeded with including this person in the survey.

If more than two people were reported (questions a) and b) then, we asked the primary carer to nominate the person that was willing to participate in the survey.

If participants replied more than one person in a) and d), then we asked them to bring us in contact with the person who assisted the carer to find and understand disease-specific information.

6.4. Recruitment process and data collection

Cyprus

In Cyprus, the participants were recruited from the Pancyprian Alzheimer Association, the Alzheimer's day centre of Ithaki and a private nursing home for frail older people, all located in Limassol. Furthermore, in the framework of the awareness campaigns of the Association Ithaki in Limassol, Pafos and Nikosia, carers were informed about the study by the researcher and a number of participants attending these events, gave their informed consent to participate in the study. After that, a follow-up appointment was arranged either at the carers' home or at the facilities available (Shiakolio Educational Center of Clinical Medicine in Nicosia, in collaboration with the Cyprus University of Technology in Limassol). We tried to identify all possible services that we could approach the carers of PwD in Cyprus. Alzheimer's association and Ithaki were the only associations that provide services to carers of PwD. We were not granted permission for data collection in the memory clinic in Nicosia.

In the case of the dementia day centre Ithaki, we attended the daily programme of the centre and directly informed the carers. If they accept, we proceeded with the process and either filled in the questionnaires with the assistance of the researcher or a new appointment was arranged for a face to face survey.

In the case of the nursing home, the Manager introduced us to the carers used their services. The researcher established communication and delivered the face to face survey during the daily visit of the carers to the nursing home.

Finally, a small number of participants was introduced via the snowball technique through colleagues' relatives and acquaintances.

In all the above cases, carers were asked to point out the person who regularly supported them in everyday tasks, such as housekeeping, caring activities, mobility, errands financial management, caring management or provides psychological or social support. Carers also pointed out the person who assisted them to find dementia-specific information. The set of questions used for this purpose are presented in the inclusion criteria of the secondary carer. The researcher discussed with the secondary carer either on the same day as the primary carers, if they attended the appointment together, or on another day. To maximise the number of secondary carers, we allowed flexibility with a telephone survey for those who could not participate in person due to their work or other reasons. This alternative increased the number of secondary carers.

Attica region and Thessaloniki

In the Attica region and Thessaloniki, the Alzheimer's Associations were approached and, in several cases, the Municipality of Voula and Vari in the Southern part of Athens. At the moment, in Athens, there are 6 dementia daycare centres developed by the Alzheimer Associations and supervised by the Ministry of Health: in municipalities of Maroussi (1), in Chalandri (1), in Athens (3), in Ilioupoli (1), Glyfada (1) and in Thessaloniki there are 2 dementia daycare centres. The associations organise awareness campaigns in September during the World Alzheimer's Day (21 September) and as part of the Carers Day activities, usually organized by the associations during March.

The social workers and the scientific supervisors of the dementia centres informed the carers who used their services, and they arranged the appointment for the face to face survey.

The researcher attended the awareness campaigns, distributed information about the study and provided her contact details if carers were interested in participating in the study. After the event, the researcher arranged an appointment with the interested carers in one of the dementia centres in Attica according to carers availability. In the Municipality of Voula and Vari, the researcher received approval by the social work department to arrange the surveys in the leisure Club for older people.

6.5. Data Collection tools

The selection of the questionnaires for the primary carers included different aspects of evaluation:

a) identifying the most appropriate tool for measuring the specific variables
b) assessing the tool based on the time duration needed for completion
c) assessing the tool based on the appropriacy for carers' population
d) availability of the instrument in the study language: Greek
e) Need to validate in Greek

For the Health literacy, there are a lot of questionnaires available in English measuring the functional Health literacy and the majority of them require more than 10 minutes to administer as we report on the introduction section 2.2 (Table 2.1.).

For eHealth literacy, we searched all available tools, and we identified the most appropriate for this study. There is only a small number of questionnaires for this type of assessment and commonly these are self-perceived assessments. In the case of PRE-HIT (Koopman et al., 2014), an instrument measuring eHealth literacy among older people, the research team did not consider it as appropriate for our population based on the type of questions included in the tool. Even though, PRE-HIT was developed to assess eHealth literacy for older people; we considered that the items would not facilitate understanding in our population. eHeals was selected to measure eHealth literacy as it is a short tool, with short sentences and has been widely used and adapted in many different languages (Table 2)

6.5.1. Demographic characteristics (Appendix VI)

For all primary carers, we collected information on demographic characteristics, including:
a) age, b) gender, c) education, d) occupation, e) hours of care per week, f) years of care, g) caring for others, h) relationship with the person with dementia (PwD), i) living condition, j) professional care support at home or at a centre, k) PwD gender l) PwD age, M)PwD diagnosis, N)PwD stage of the disease, O) Instrumental Activities of Daily Living (IADL).

The socio-economical position was assessed with ladder, a visual-analogue scale for within country comparison. The researcher asked carers "*Think of this ladder as representing where the people stand Greece/Cyprus. At the TOP of the ladder are the people who are the best off-those who have the most money, the most education, and the most respected jobs. At the BOTTOM are the people who are the worst off-who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top. The lower you are, the closer you are to the people at the very bottom. Where would you place yourself on this ladder, compared to all the other people in Greece/Cyprus? Place a large X on the rung where you think you stand*"(Goodman et al., 2001)

Figure 6-2 The ladder- SES status

The secondary carer provided the following demographic characteristics:
Age, gender, education, employment status, relationship with primary carers, type of support provided to primary carers and living conditions.

6.5.2. Selected measures:

In Figure 6.2, selected measures are summarised in the order presented in the subsequent sections. All measures are provided in the Appendix VI, as translated in Greek.

Figure 6-3 Selected measures

Perceived eHealth Literacy

- eHealth Literacy Scale (eHeals) (Norman & Skinner, 2006)- adapted to eHeals-Carer

Selected questions for internet use profile

- The type of personal use, 3 most common types of use, knowledge on how to use internet services and dementia-specific internet use and mobile internet use

Perceived Health Literacy

- HLS-EU-Q16 (Kondilis et al, 2012, Pelikan et al, 2012)

Perceived Health Literacy screening question

- Single Item Literacy Screener (Chew, 2004)

Perceived Caregiving Self-Efficacy

- Revised Scale for Caregiving Self-Efficacy (Steffen et al, 2002)

Perceived caregiving perceptions

- Carers of Older People in Europe (COPE) (McKee et al, 2003)

Coping Strategies

- BRIEF COPE (Carver et al, 1989, Kapsou et al, 2010)

Perceived Social Support

- Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al, 1990, Theofilou et al, 2015)

6.5.2.1. **eHeals adapted for dementia carers in the Greek language** (C. D. Norman & Skinner, 2006a) **(Appendix VI)**

eHeals is a self-reported tool, developed by Norman and Skinner (2006), based on the Lily model, a theory of eHealth literacy, assesses the users' perceived skills at using health technology. The tool was tested by the authors to 664 adolescents. It consisted of 8 questions (plus two supplementary questions) with internal consistency a=0.88 and modest stability over time (r=.49). The score ranges from 8 to 40:

(1) I know how to find helpful health resources on the Internet,

(2) I know how to use the Internet to answer my health questions,

(3) I know what health resources are available on the Internet,

(4) I know where to find helpful health resources on the Internet,
(5) I know how to use the health information I find on the Internet to help me,
(6) I have the skills I need to evaluate the health resources I find on the Internet,
(7) I can tell high quality from low-quality health resources on the Internet,
(8) I feel confident in using information from the Internet to make health decisions.

There was also a suggestion of 2 supplementary items: 1) how useful do you feel the internet is in helping you in making decisions about your health? And 2) How important is it for you to be able to access health resources on the Internet?

The tool has been validated in Dutch, Chinese, Japanese, Israeli, German, Spanish, Korean, Persian, Italian, Arabic, Persian, Slovenian, Serbian. Populations tested include adolescents, people with rheumatic diseases, general population, six-graders, students, patients or caregivers of otolaryngology head and neck surgery, people with cardiovascular disease, arthritis, mental health disorder, chronic lung disease, cancer and older adults. Detailed table with references is included in Appendix II.

For this specific study, eHeals has been validated for carers of PwD in the Greek language (Chapter 7, section 7.4.1), and as part of the validation methodology we contacted literature review on the available eHeals validations (Chapter 4, section 4.3 & Appendix II). Internal consistency of the adapted version total score was Cronbach alpha=.83.

6.5.2.2. The Internet Use Carers Profile (Appendix 4)

The internet use carers profile has been measured with 10 questions that investigate the type of use that a carer makes, e.g. websites, emails, e-learning, social media, interactive services, forums, blogs and mobile internet. These questions have been added to support the eHeals scale since there has been much criticism concerning the web evolution during the last decade and the lack of relevant items in the eHeals scale (C. Norman, 2011; Van Der Vaart et al., 2011).

The questions were:

1) The type of personal use of the internet and the 3 most common types of use. Carers selected from a list of 8 online activities, including entertainment, online purchases, information browsing, socializing, emails, blogging, professional use and news feed.
2) The assessment of the perceived knowledge of how to use websites, social networks, emails, interactive services and e-learning courses
3) Dementia specific internet use.

a. Websites (information on the disease, financial and legal issues, behavioural symptoms, available services, communication with experts, search for experts, entertainment options for the care-recipient (cognitive exercises, music)
b. Social networks (e.g. facebook, twitter, LinkedIn for communication with health care professionals, carers networks, family members, disease-specific information and information on caregiving everyday tasks
c. Emails (communication with other carers, health care professionals, family members, Alzheimer's associations and medical services)
d. Interactive services (communication with experts, carers, family members and carers group)
e. e-Learning courses (carers training, disease-specific training)

4) Mobile Use of internet for the caregiving management (use of websites, social networks, emails, interactive services and e-Learning courses

These questions are the result of the scoping review of carers' internet use (3.2.2) and the discussion on eHeals scale and web 2.0 made by Van Der Vaart et al., (2011) and Norman, (2011).

6.5.2.3. **HLS-EU-Q 16 Short form** (Kondilis et al., 2012; Pelikan et al., 2012) **(Appendix VI)**

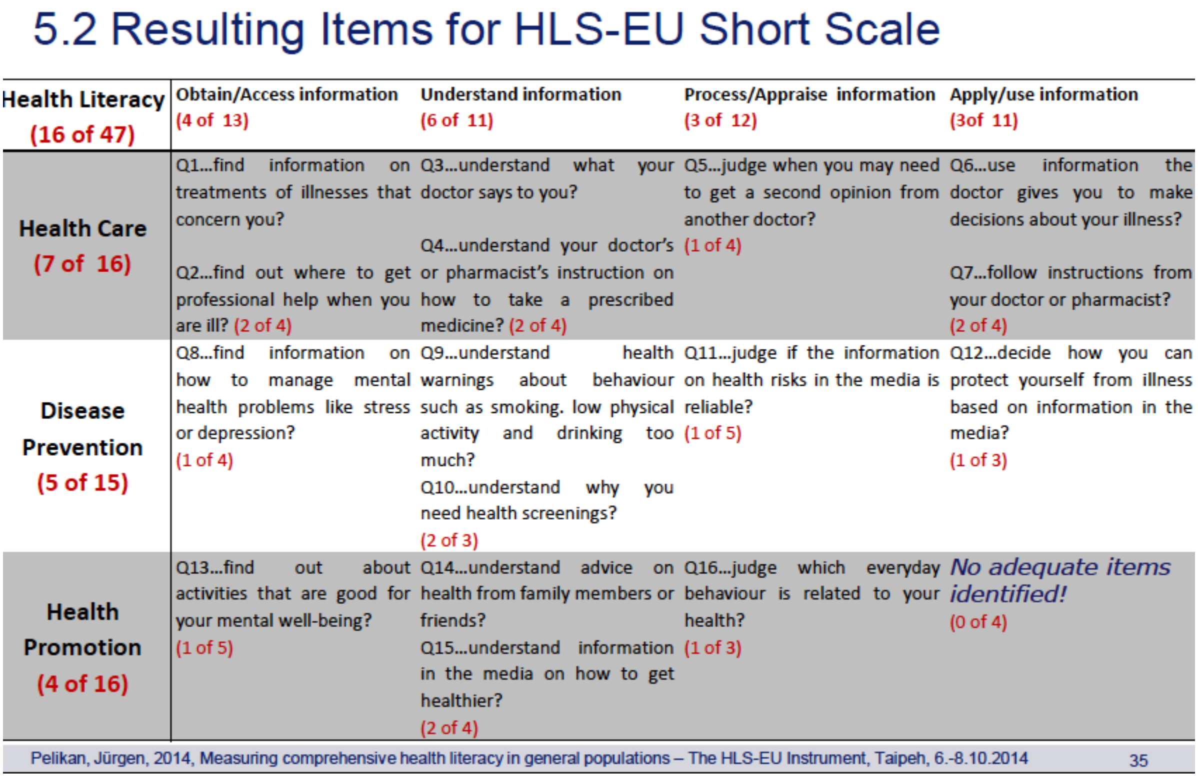
HLS-EU-Q is the outcome of a European Health Literacy Survey realized in 2011 in Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain collecting data from 1000 people per country over 15 years old. The long-form includes 47 questions, short form 16 and the short-short-form: 6 items. The 47-questions version covers 12 dimensions and scores in 4 categories: inadequate (0-25), problematic (>25-33), sufficient (>33-42) and excellent (>42-50).

Reliability was calculated for all countries, providing a mean total of Cronbach alpha =.97 and for Greece Cronbach alpha = .97. The country-specific reliabilities were high and over Cronbach alpha = .95 in all cases. We may find index specific reliabilities of the 12 dimensions, ranged from Cronbach alpha =.61 to Cronbach alpha =.98

The translation process of the 47-questions questionnaire were completed for Bulgarian, German, Greek, Polish and Spanish.

The HLS-EU-Q16 was developed as part of Rasch modelling covering the 12 sub-dimensions. The tool thought to be appropriate for use in long protocols, and when health literacy sub dimensions are not the main variables under research. Below we find the items per index as presented by Pelikan et al., (2012).

Figure 6-4 Items per HLS-EU index for the HLS-EU-Q16



5.2 Resulting Items for HLS-EU Short Scale

Health Literacy (16 of 47)	**Obtain/Access information** (4 of 13)	**Understand information** (6 of 11)	**Process/Appraise information** (3 of 12)	**Apply/use information** (3of 11)
Health Care (7 of 16)	Q1…find information on treatments of illnesses that concern you? Q2…find out where to get professional help when you are ill? (2 of 4)	Q3…understand what your doctor says to you? Q4…understand your doctor's or pharmacist's instruction on how to take a prescribed medicine? (2 of 4)	Q5…judge when you may need to get a second opinion from another doctor? (1 of 4)	Q6…use information the doctor gives you to make decisions about your illness? Q7…follow instructions from your doctor or pharmacist? (2 of 4)
Disease Prevention (5 of 15)	Q8…find information on how to manage mental health problems like stress or depression? (1 of 4)	Q9…understand health warnings about behaviour such as smoking. low physical activity and drinking too much? Q10…understand why you need health screenings? (2 of 3)	Q11…judge if the information on health risks in the media is reliable? (1 of 5)	Q12…decide how you can protect yourself from illness based on information in the media? (1 of 3)
Health Promotion (4 of 16)	Q13…find out about activities that are good for your mental well-being? (1 of 5)	Q14…understand advice on health from family members or friends? Q15…understand information in the media on how to get healthier? (2 of 4)	Q16…judge which everyday behaviour is related to your health? (1 of 3)	*No adequate items identified!* (0 of 4)

Pelikan, Jürgen, 2014, Measuring comprehensive health literacy in general populations – The HLS-EU Instrument, Taipeh, 6.-8.10.2014 35

On a Likert scale from 1 to 4, very easy to very difficult, in the short-form, participants may reply to questions regarding the access of health information, health services, doctor-patient communication, doctor's or pharmacist's instructions, judgement regarding a doctor's second opinion, access of information on how to manage mental health problems, understand health warnings, health screening, reliability of media health information, activities for mental well-being, family and friends advice and everyday behavior in relation to health. When the scale is administered by an interviewer, an additional category is added "I do not know", only for the interview. According to the instructions by the HLS-EU consortium, for the short version, the scoring is dichotomised to 2 categories: easy and difficult with a maximum score of 16. The short tool categorises 3 levels of literacy: sufficient HL (0-8), problematic HL (9-12) and inadequate HL (13-16).

The instrument has been validated in 2 phases in the Greek-Cypriot sample using a convenient sample of 100 older people from the outpatients' eye disease clinic in Limassol Cyprus and a second phase as part of this study with the sample of carers. The validation process is presented in section 7.4.2. The internal consistency for the sample of carers was Cronbach alpha =.69, ranging from Cronbach alpha =.40 to Cronbach alpha =.60 for the dimensions explored.

6.5.2.4. **Single Item Literacy Screener (SILS)** (Chew LD Boyko EJ, 2004; Morris et al., 2006)**(Appendix VI)**

Single Item Literacy Screener has been part of the 16 questions developed by Chew & Boyko, (2004) to assess inadequate Health Literacy. Initially, 3 questions were identified as better predictors of low Health Literacy and difficulty in reading printed material. Chew et al. (2004) proceeded in developing SILS which had better sensitivity (rating <2, 39%) and specificity (rating <2, 93%) than the other two questions in predicting inadequate health literacy. The item "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" is replied with a 5-point Likert scale from 1=Never to 5=Always. Adequate health literacy level is considered > 2 and low literacy <2.
SILS according to Brice et al., (2014) does not assess marginal literacy accurately but is easy to use in a clinical setting for quick screening of health literacy, can discriminate between inadequate and adequate reading ability and predicts well S-TOFHLA scores of low health literacy.

6.5.2.5. Revised Scale for Caregiving Self-Efficacy (A. Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002) **(Appendix VI)**

The scale includes 15 items and has 3 categories: 1) Self-Efficacy for Obtaining Respite (SE-OR, Cronbach alpha =.85), Self-Efficacy for Responding to Disruptive Patient Behaviors (SE-BM, Cronbach alpha =.82), Self-Efficacy for Controlling Upsetting Thoughts about Caregiving (SE-TC, Cronbach alpha =.85). The carers report their self-perceived confidence with percentages (%) in the above 3 domains. The scale originated from the self-care self-efficacy and problem-solving self-efficacy scales of Zeiss, including additional caregiving situations (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999). Revised Scale for Caregiving Self Efficacy has a high correlation with depression, anxiety, anger and social support scales. Test-retest reliability was *acceptable* according to the authors (SE-OR r_{12}=.76, SE-BM r_{12}=70, SE-TC r_{12}=.76), and the respite subscale has weaker correlation with the other 2 subscales. According to a recent review by Steffen et al. available published validations are in Arabic, Chinese, French, Italian, Spanish. In this review, Steffen discussed the limitations of the scales in relation to Alzheimer's Disease stage. The subscale for obtaining respite is challenging for carers of early-stage dementia and subscale for managing behavioural disorders is more suitable for people with the middle-stage disease (Steffen et al., 2018). The scale has been translated with the forward and backward translation, and the reliability of the scale has been calculated (section 7.4.3.). The Cronbach α in the case of the SE-OR is Cronbach alpha =.86, for SE-BM Cronbach alpha =.80 and SE-TC Cronbach alpha =.76.

6.5.2.6. **Carers of Older People in Europe (COPE)- index** (McKee et al., 2003) **(Appendix VI)**

COPE index, part of a study protocol realized in 5923 carers from 5 countries: Italy, Greece, Sweden and the UK, consists of 15 items. COPE index measures carers' attitudes towards positive and negative values of caring (Balducci et al., 2008). Prior to this analysis, McKee et al., (2003) published a first stage validation of the COPE index in a sample of 577 carers from the above 5 countries.

According to the full-scale validation, the positive value of caring included 5 items, negative values 6 items, the quality of support 3 items and 1 item of the financial hardships. Negative value items had high internal consistency (Cronbach alpha =.83 overall, Greece Cronbach alpha =.85) in comparison with Positive value items with modest internal consistency (Cronbach alpha =64 overall, Greece Cronbach alpha α=.58). Quality of support subscale internal consistency was modest (Cronbach alpha =.66 overall).

Criterion validation was assessed with the use of World Health Quality of Life-BREF, SF-36 (quality of life and health status items), Barthel Index, Behavioral and Instrumental Stressors in Dementia instrument (BISID) and Social restriction scale. Positive dimension had a stronger association compared to other dimensions. WHO-BREF, SF-36 quality of life and Barthel index correlated with negative items. The quality of life subscale was correlated with WHO-BREF, SD-36 quality of life and BISID (Balducci et al., 2008). Due to the available internal consistency in a Greek sample of carers we did not proceeded with further analysis of the psychometric characteristic of this scale. The internal consistency for the study sample was for negative dimension, Cronbach alpha =.75, positive dimension, Cronbach alpha =.54 and for Quality of Support, Cronbach alpha =.51.

6.5.2.7. **BRIEF COPE** (Kapsou, Panayiotou, Kokkinos, & Demetriou, 2010) **(Appendix VI)**

Brief COPE is the short version of COPE (60 items), an instrument assessing the different coping styles of stress. The instrument includes 3 types of coping styles: problem-solving (active coping, planning, suppression of competing activities, restraint coping, social support for instrumental reasons), emotion-focused (positive reinterpretation and growth, acceptance, denial, turning to religion) and problematic coping (focusing on and venting of emotions, behavioral disengagement and mental disengagement) (Carver et al., 1989). Brief COPE consists of 28 items (14 two-item scales): acceptance (Cronbach alpha =.57), active coping (Cronbach alpha =.68), positive reframing (Cronbach alpha =.64), planning (Cronbach alpha =.73), use of instrumental support (Cronbach alpha =.64), use of emotional support(Cronbach alpha =.71), behavioural disengagement (Cronbach alpha =.65), self-distraction (Cronbach alpha =.71), self-blame (Cronbach alpha =.69), humour (Cronbach alpha =.73), denial (Cronbach alpha =.54), religion (Cronbach alpha =.75), venting (Cronbach alpha =.50) and substance use (Cronbach alpha =.90). Restraint coping and suppression of Competing Activities were omitted, and the scale of self-blame was added in BRIEF-COPE. As an attempt to simplify the analysis, we decided to develop three categories according to Carver's categorisation. Only for this purpose, we have proceeded in EFA to check the reported dimensions in the sample of carers and then to develop the three categories according to existing theory. The factor analysis is available in the section 7.4.4. The internal consistency of the subscales is: 1) Activity Planning, Cronbach alpha =.77, 2) Support seeking, Cronbach alpha α=.75, 3)Substance use, Cronbach alpha =.80, 4) Religion, Cronbach alpha =.78, 5)Avoidance, Cronbach alpha =.54, 6)Express Negative feelings, Cronbach alpha =.53, 7) Behaviour disengagement, Cronbach alpha =.65, 8) Denial, Cronbach alpha =.61, 9)Humor, Cronbach alpha =.40

6.5.2.8. **Multidimensional Scale of Perceived Social Support** (Theofilou, 2015; Zimet, Dahlem, Zimet, & Farley, 1988; Zimet, Powell, Farley, Werkman, & Berkoff, 1990) **(Appendix VI)**

The Multidimensional Scale of Perceived Social Support is a brief screening instrument measuring perceived social support and includes 3 categories: support received by a significant person (items 1,2,5,10) family (3,4,8,11) and friends (6,7,9,12). The scale consists of 12 items, and the scoring ranges in a 7 Likert scale from very strongly disagree to very strongly agree. We received total scores for the 3 categories, when we divided the sum with the items per category and for the questionnaire when we divided the sum of all items with the number of items. As we saw in the previous chapter, we find two types of support tangible and emotional support. In this scale, we are able to identify both types of support. The scale has a high internal consistency (Cronbach alpha =.85 to .91). The tool has good test-retest reliability (.72-.85). The instrument was validated in samples of pregnant women, adolescents, pediatric residents and undergraduate students. According to the above validation, high levels of stress may influence the association of depression with social support. For the Multidimensional Scale of Perceived Social Support, we find a publication of translation and cultural adaptation of the scale made by Theofilou in a sample of 10 patients with Multiple Sclerosis. Recently, a Greek validation has been published among 150 oncology nurses, where the 3 factors were confirmed, and the internal consistency was high (>.90), with significant other" (Cronbach alpha =.95), family (Cronbach alpha =.96) and friends (Cronbach alpha =.96) and total (Cronbach alpha =.93) (Tsilika, Galanos, Polykandriotis, Parpa, & Mystakidou, 2019).In the case of this sample, the internal consistency was: 1) MSPSS SO, Cronbach alpha =.87, 2) MSPSS FA, Cronbach alpha =.90, 3)MSPSS FR, Cronbach alpha =.88, 4) MSPSS TOT, Cronbach alpha =.88.

6.6. Piloting phase

Prior to the full-scale research study, a pilot phase was planned, to assess the appropriacy and length of the selected questionnaires, the face to face completion time and researcher's skills, the acceptance of the research material by the primary and secondary carer and the challenges in sample recruitment. According to Connelly (2008), the adequate number of people for a pilot study design is 10% of the total sample. Other researchers (Hertzog, 2008; Hill, 1998) suggest a number of 10 to 30 people. Taking into consideration the above, 25 primary carers and 13 secondary carers were recruited for the piloting.

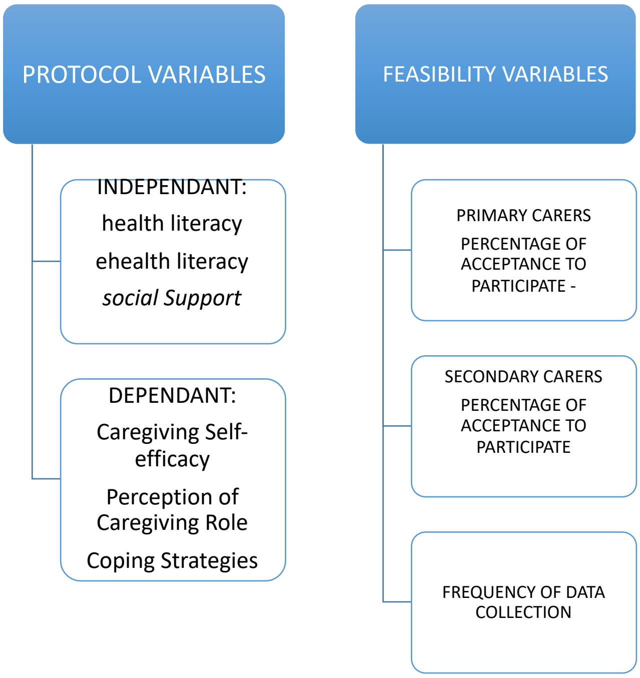
Eligibility criteria for the participation of the carers were identitical as in the case of the full-scale study: being over 18 years old, primary carer, speaking the Greek language and willing to participate in the study.
Secondary Carers participated after the primary carer informed them about the study, and if they consent it, the researcher would contact them either in person or by phone. The researcher asked two main questions that helped to identify the secondary carer according to the methodology of the study protocol in section 5.3: All participants were informed of the aims of the study and provided their informed consent. The pilot study was organised between June 2017 and November 2017 (6 months). The location of the recruitment included the dementia Daycare centre in Athens, in Limassol and the awareness campaign of Alzheimer's Association for the World's Alzheimer's Day (WAD) 2017.

6.6.1. *Aim of the Piloting Study*

The aims of the piloting study were twofold:

1) To implement and assess the recruitment process of the sample: initial communication (who would make the first contact with the primary carer), informed consent processes, researchers interview skills, frequency of participation, percentage of refusal to participate
2) To assess the questionnaire suitability and delivery process: time of administration, carers' reactions, the suitability of the questionnaires, analysis of first demographics of the sample.

Figure 6-5 Protocol variables and feasibility variables of the Pilot study



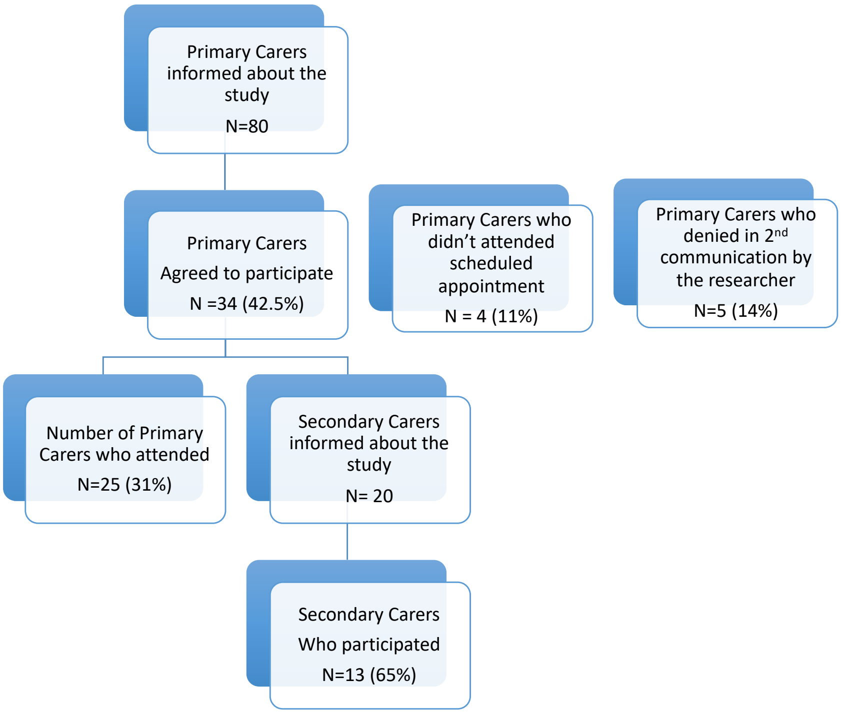
6.6.2. *Results of the Pilot Study*

The first communication with the Primary Carer was made by the social worker or psychologist of the Dementia Centres in Athens and Limassol. During the World Alzheimer's Day (WAD) event, communication was made by the psychologists in collaboration with the researcher.

Immediately after the acceptance, the supervisor of the Centres or the researcher arranged the first appointment in the Dementia Centre. The survey lasted from 50 min to 90 min maximum. All participants filled in the informed consent form prior to the survey taking place. The researcher initially introduced the study goals and then provided the form for the carers to sign.

In total, the supervisors of the centres informed 80 primary carers about the study. From them 34 replied positively and finally, 25 accepted. Those who did not agree refused to attend during the second communication or they did not appear in person for their arranged appointment. The figure below provides detailed information about the acceptance rate for primary and secondary Carers.

Figure 6-6 Flow chart of the recruitment and data collection during the Piloting study



6.6.2.1. Data collection timetable

The data collection differed every month from the period of June to November. The mean number of participants recruitment per month was 5 people (SD 2) in comparison with the estimated mean (11.6, SD 1).

August is not included in the data collection period, as it is considered as an annual leave month for both countries Greece and Cyprus, and it would be challenging to reach carers during that specific month.

6.6.2.2. Questionnaire suitability and delivery process

In the pilot study, 19 women and 6 men participated as primary carers. Almost 2/3 (64%) were below 60 years old, 32% (8 participants) between 60-80 and 4% (1 person) over 80 years old. Almost half of the sample had secondary education, 40% (10 carers) tertiary education and 4% (1 person) primary education. In the pilot study, mainly children participated caring for their parents (72%) and the most common diagnosis, according to the carer, was Alzheimer's Disease (16 participants). Primary carers also reported the perceived stage of their care-recipient disease and almost half (57%) reported being in the medium stage of the disease.

Concerning the question of the secondary carer, 88% (21) replied that they receive support from a family member or a friend. The most common type of support included assistance with everyday activities (73%- 16 carers) followed by psychological support (55% - 12 carers).

The majority of the primary carers reported sufficient level of health literacy (76%-19 carers), eHealth literacy (26.2 /40 SD=4,81) and SILS (1.32/5 SD =0,75). Secondary carers also reported high levels of health literacy (92%-12 secondary carers) and eHealth literacy (28.8/40 SD 6.26).

6.6.2.3. Conclusions

Based on the pilot study results, the recruitment and questionnaires administration were modified as follows:

1) The accurate identification of the secondary carer based on the original questions identified 2 different types of secondary carers: one person who supported with various tasks and one person who supported the primary carers to find health-related information online.

   Additionally, to the first question, a clarification question was added to facilitate researcher identify the secondary carer: "Is there any significant other (family, friend) who supports you apart from that person?

   In the case of the second question, the majority of the primary carers replied that they received their information by the dementia daycare centres, internet or their doctors and not from a relative or a friend. The second question was transferred after the internet use questions and was modified to include the internet: "If you need to find and understand disease-specific information on the internet, who would you consult from family and/or friend (e.g. spouse, children, sister, aunt, friend etc)".

2) During the pilot study, the researcher administered the demographics, the HLS-EU-Q16, eHeals-Carer and self-efficacy scale at the same time. After the piloting ended, it was decided that the participants would complete HLS-EU-Q16 and eHeals-Carer by themselves, and only

if the participants required assistance, would the researcher provide assistance, ensuring that the same explanations and same examples would be available to all participants. All other scales: COPE index, COPE- BRIEF, Multidimensional scale of Social Support were completed by the participant without the presence of the researcher in the room.

3) The majority of the sample in the pilot study were children who were digital literate. In this respect, future steps were planned to include a more extensive sample and people who might be less digitally literate and not necessarily members of Dementia Centres or Alzheimer's Association.

4) The participants found the questionnaires acceptable. Revised Scale of Self -Efficacy had some minor issues as it was developed mainly for people with middle-stage dementia in the case of the SE-BM and not for people with mild dementia or mild cognitive impairment. In the case of mild dementia, carers did not recognised the need for a break, and in many cases, PwD lived alone, or in the case of severe dementia, carers could not reply to the section of self-efficacy for behavioural disorders management. In this case and according to the author's instructions, a number of questions or a whole category for the people with severe or early-stage dementia were ommitted.

6.7. Statistical analysis of the main study

The analysis was performed by the Statistical Package for Social Sciences software (v.25).

As part of the analysis, descriptive statistics were computed for the three samples (primary carers, secondary carers and PwD) and the internet use by primary carers.

In the second phase of the analysis, the validation of eHeals-Carer, HLS-EU-Q16, Revised Scale of Caregiving Self-Efficacy and BRIEF-COPE followed. For all scales, the literature was examined to identify any available validated translations of these questionnaires. In the case of eHeals-Carer, the scoping review (2) (Chapter 4, section 4.3) was performed, in order to understand what statistical tests other researchers used. Permissions for adaptations from all the authors, both for English versions and available Greek translations and validations were received. Content validity was computed for eHeals-Carer and HLS-EU-Q16. Content validity index was assessed by experts in dementia and Health Literacy with a 4-point scale on the relevance of the items. Item-Content Validity index, Scale -Content Validity index/Average and Universal agreement were calculated.

Internal consistency (Cronbach's alpha) was calculated for all the questionnaires. Construct validity (Exploratory Factor Analysis) was computed only for eHeals-Carer, HLS-EU-Q16 and BRIEF-COPE. In the case of BRIEF COPE, factors were extracted from the first-order Exploratory Factor Analysis. Correlations among the factors and second-order EFA did not provide meaningful higher order categorisation. For this reason, the factors of the BRIEF COPE were further categorised according to the categories provided by Carver et al., (1989) and Monteiro, Santos, Kimura, Baptista, & Dourado, (2018).

Then the data for normality was assessed , the findings were described regarding the core concepts using descriptive statistics and any possible sociodemographic predictors with multiple linear regression identified. In the case of linear regression, the stepwise method was selected and variables included based on their statistical significance with the dependent variable ($p<.05$). Descriptive statistics for internet use and the levels of all the core concepts were calculated: Health Literacy, eHealth Literacy, Self-efficacy, coping strategies (BRIEF-COPE), COPE index, perceived social support. All variables were treated as continuous. Only in the case of Health Literacy, was the variable used both as categorical and as continuous. Internet use was a binary categorical variable (Yes/No). Descriptive statistics were computed for the secondary carers for the Health Literacy and eHealth literacy variables.

The comparison of the primary and secondary carers' levels of Health Literacy and eHealth literacy was assessed with paired sample non-parametric test Wilcoxon. This was decided since the sample was small (67 secondary carers).

The differences of primary carers' Health Literacy, eHealth Literacy and other caring variables levels based on the sociodemographic characteristics, were assessed with analysis of variance. Predictors were identified with the use of multiple linear regression and stepwise analysis.

This was repeated for the secondary carers' Health Literacy and eHealth literacy levels with their sociodemographic characteristics, where a non-parametric test for independent samples Mann-Whitney was used.

The association of these variables with clustering analysis was explored, and primary carers' profiles were reported: Health Literacy, eHealth Literacy, self-efficacy, coping strategies, perceptions and social support. The clustering technique is highly essential for competing markets and market science as profiling assist companies in determining their audience; they are interested in based on specific characteristics. The methodology of clustering could be considered quite flexible; it seems that there are no rules of thumb for this. According to a systematic review focusing on clustering methods of 243 studies, researchers used from 10 to 20.000 participants, and in half of the studies, they had used fewer than 300 people. The included variables in the cluster analysis ranged from 10 to 66 and in the case of Hierarchical clustering, Ward analysis was the most used technique and the partitioning method, k-means (Dolnicar, 2002).

All correlations among the variables and multiple linear regression (Enter method) were computed, In the case of the confounding factors, they were entered in the linear regression with two criteria: being associated with our target group (p <.25) and reported in existing literature.

6.8. Ethics of the study

Permissions to conduct the research was granted by the National Committee of Bioethics in Cyprus on January 10, 2017, according to the National Law (ΕΕΒΚ ΕΠ 2016.01.151). The Cyprus Commissioner Bureau of Privacy Protection has been informed and confirmed on December 19, 2016 (study number 3.28.460).

In Greece, the scientific committee of the Athens Alzheimer's Association approved participation of their members in the survey on March 17, 2017. Greek Alzheimer's Association in Thessaloniki also approved the involvement of their members in the study as well as the IASIS non-for-profit association agreed on their members' participation.

Permission was granted to use all scales by their authors. All participants were informed fully on the purpose and methods of the specific study before their participation. Participants signed the informed consent forms and were informed of their right to withdraw at any time (Appendix VI.A.1). The forms were kept separately from the questionnaire, and only the researcher and the supervisor had access to them.

Confidentiality of the participants was respected throughout the study duration. The face to face survey took place in an available office of the dementia centres without the presence of any other person. In this way, confidentiality of the information provided by the carers was reassured.

Researcher safeguarded the well-being of the participants during the data collection. When carers felt overwhelmed, the researcher provided time for participants to discuss, to omit the question or the option to stop the session if this was needed.

Participants interested in receiving feedback were contacted by email or telephone and were informed on their replies to the specific questionnaires.

The researcher, during the whole process, reassured carers' privacy and resolved any conflict. Many times carers cancelled their appointment due to unexpected situations. The researcher always rescheduled next session to a date and time that was convenient for them.

Data collected included physical and mental health information. To safeguard sensitive personal information, a password-protected database was developed, managed only by the research team and only members of the research team had access to the database. Hard copies of all data were stored and locked in the office of the scientific supervisor.

6.9. Summary

In the chapter of methodology, all phases of the study preparation were described. This presentation begun with the Consensus meeting, as it was the first step. During the meeting, experts agreed on the Greek term of Health Literacy and eHealth literacy and discussed the new and old terms and definitions, the association of Health Literacy with Health promotion, the current and future research, the available Health Literacy measure and the dissemination activities. The Greek term "Εγγραμματοσύνη σε θέματα Υγείας" was decided as the common term for Greece and Cyprus. Furthermore, the use of HLS-EU questionnaires for measuring these concepts in research in Greece and Cyprus were agreed. Dissemination activities included press releases, conferences' workshops and training programmes.

Then, a detailed description of this study design (correlation descriptive) followed, this study sample and the eligibility criteria for the primary carer. The selection process for the secondary carer was presented. Information was shown on the location of the survey and the disease-specific associations involved in the study from Athens, Thessaloniki, Limassol, Nicosia and Pafos.

Selected questionnaires were presented: HLS-EU-Q16, eHeals, SILS, the Revised Scale of Caregiving Self-Efficacy, BRIEF-COPE, COPE index (carers' perceptions), Multidimensional Scale of Perceived Social Support.

The pilot phase was part of this chapter, where the recruitment process (participation rat 31%), the carers' acceptability of the selected questionnaires and the whole process of the face to face administration were assessed. This phase provided the first valuable data for the feasibility of this study. Modifications were made and then proceeded with the full-scale study.

In the final part of the methodology, the statistical analysis was introduced, providing information on the selected statistical measures following the research questions. Finally, the Ethical Committee permission and the ethics of this study were presented for Cyprus and Greece.

7. Chapter – Results

In this chapter, the results of the analysis are presented, always taking into consideration our initial research questions:

RQ 1: Are there any available tools in Greek to assess the level of Health Literacy and eHealth Literacy?

RQ2a: What is the level of Health Literacy, eHealth Literacy, perceived social support and of the other caregiving variables of primary carers of PwD?

RQ2b: What is the level of Health Literacy and eHealth Literacy of secondary carers of PwD?

RQ3: Is there a difference between Health Literacy and eHealth Literacy level of primary and secondary carers?

RQ4: What is the association between Health Literacy and eHealth Literacy of primary carers of PwD with the sociodemographic characteristics?

RQ5: What is the association (if any) between Health Literacy and eHealth Literacy of primary carers and caregiving self-efficacy, their coping style, their perceptions towards the caregiving role and the perceived social support?

The results section starts with the description of our participants:1) primary carers (section 7.1), 2) patients (section 7.2) and 3) secondary carers (section 7.3) and with the validation studies of the measurement tools, specifically:

1) eHeals-Carers (section 7.4.1.)
2) HLS-EU-Q16 (section 7.4.2.)
3) Revised scale of caregiving self-efficacy (section 7.4.3)
4) BRIEF-COPE (section 7.4.4.)

The chapter continues with the style of internet use among primary carers (section 7.5), the description of the core concepts (section 7.6), the exploring of carers' profiles (section 7.7), the associations with the socioeconomic variables as well as with the other caregiving variables (section 7.8). In the end of this chapter, the possible predictors and the description of the secondary carer's Health Literacy and eHealth literacy in comparison to primary carers described.

7.1. Primary Carers’ Characteristics

In this study, 174 primary carers participated, mostly women (n=132, 76%), who spent in average 87 hours of care per week, most of them children of the person with dementia, with more than 12 years of education (n=101-58%), married (n=125, 72%). One in three participants reported that they are carers 24/7 (n=62, 36%). The vast majority of carers were over 45 years old (n=160, 92%). Primary carers mostly cared for their relatives at home (n=120, 69%) for an average of 4 years (SD= 2.83). In the final sample, there were, people who provided care for less than one year to a maximum of 14 years. The majority of the sample reported that one more person was assisting in everyday care (n=134, 77%).

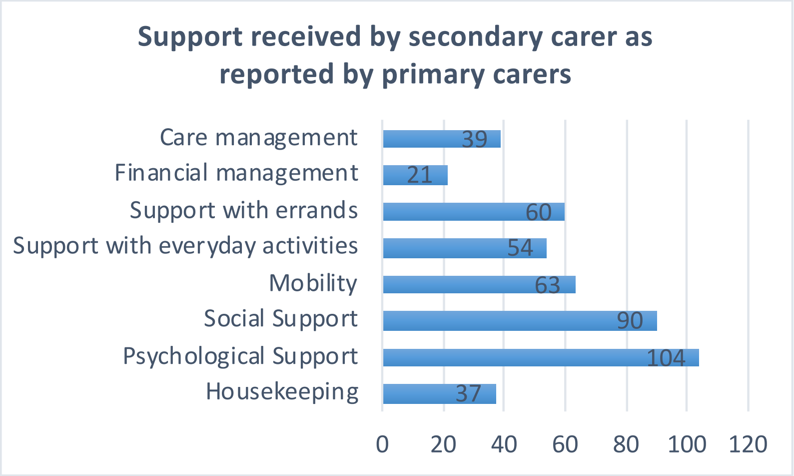
In terms of their employment status, the sample consisted of pensioners’ (n=77, 44%), people in employment (n=51,31%) and unemployment (n=44, 25%). Unemployed included people who reported not working, housekeeping or full- time students. According to their socioeconomic position as measured by the ladder visual analogue scale (section 6.5.1), the average was 5,86 (SD=1,53). Only one (1) carer in three (3) reported over 6 on this scale (n=55, 32%). The majority of the sample was recruited in Greece (n=140, 80%) and 34 primary carers in Cyprus (20%). More details on the specific characteristics of the study sample are provided in Table 7.1.

Table 7-1 Descriptive statistics of the total sample N=174

Primary Carers	N (%)
Gender	
Men	42 (24%)
Women	132 (76%)
Hours of Care/ week	90 (63)
1-28	57 (33%)
29-70	36 (21%)
71-168	80 (46%)
Relationship with the care-recipient	
Children of the care-recipient	81 (47%)
Spouses of the care-recipient	74 (43%)
Other (siblings, nephews, cousins)	19 (11%)
Age	
<44	14 (8%)
45-54	47 (27%)
55-64	43 (25%)
65-74	43 (25%)
75+	27 (16%)
Education	
No school education	4 (2%)
Primary education	19 (11%)
Lower Secondary education	13 (7.5%)
Upper Secondary education	37 (21%)
After secondary and tertiary education	101 (58%)
Marital Status	
Single/Divorced/Widowed	49 (28%)
Married/ Cohabitation	125 (72%)
Occupational Status	
Employed	53 (31%)
Unemployed	44 (25%)
Pensioner	77 (44%)
Caring for others	105 (60%)
Secondary carer reported	134 (77%)
Country	
Greece	140 (80%)
Cyprus	34 (20%)
Ladder	5.86 (1.53)

Primary carers in this sample reported that they received mostly psychological support (n=104, 60%), secondly social support (n=90, 52%), support with mobility (n=60, 34%) and support with errands (60, 34%) from the secondary carer (Figure 6.1.).

Figure 7-1Support received by the secondary carer as reported by the primary carer



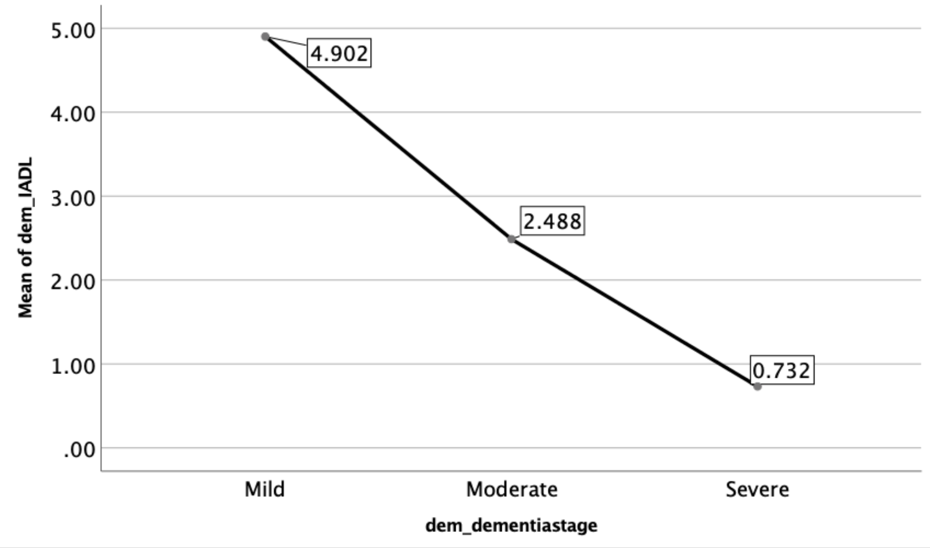
7.2. Patients' Characteristics

Regarding the patients' characteristics, mostly women (n=109, 63%) with diagnosis of Alzheimer's disease (n=157, 90%) were reported. Carers reported their estimation of the stage of the disease, with 52 reporting mild stage (52%), 81 moderate (47%) and 41 (24%) severe stage. This information was confirmed with the Instrument of Activities of Daily Living (IADL) score. After comparing the means of the IADL scores with the three (3) stages as reported, there was a statistically significant negative assosiation among the reported stages and the level of the patients' functionality (F=64.574, p <.001, Figure 7.2). IADL scores range from 0 to 8 with higher score declaring better functional ability and this sample's mean score was 2.78 (SD 2.35) (Figure 7.2.)

Table 7-2 Patients demographics

Patients' characteristics	**N (%)**
Gender	
Men	65 (38%)
Women	109 (63%)
Age	
<69	22 (13%)
70-79	69 (40%)
80+	83 (48%)
Diagnosis	
Alzheimer's disease	157 (90 %)
Parkinson with dementia	7 (4%)
Other dementias	10 (6%)
Carers reported stage of the disease	
Mild	52 (30%)
Moderate	81 (47%)
Severe	41 (24%)
IADL	
Mean (SD)	2.78 (2.35)

Figure 7-2 IADL mean scores in three different dementia stages



7.3. Secondary Carers' characteristics

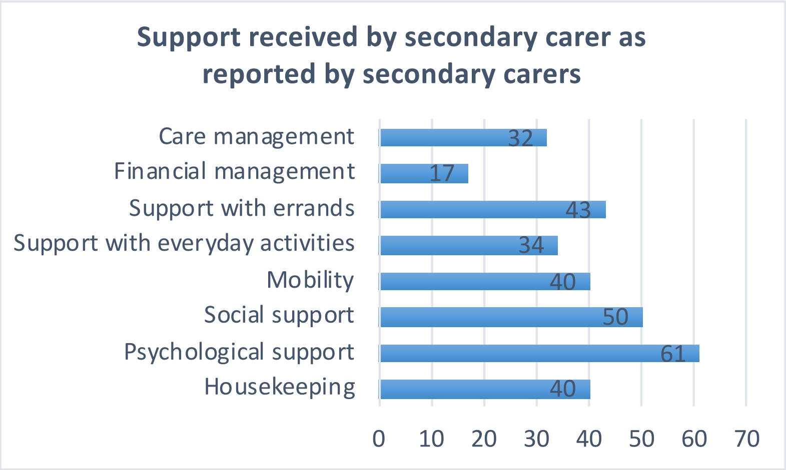
A smaller number of secondary carers in relation to the primary carers (67/174) was recruited. Not all carers reported a secondary carer or the secondary carer was not interested in participating in the study. As in all previous cases, women were the majority of the respondents (n=48, 72%), mostly employed (n=48,71%), children of the primary carer (n=41, 61%). The secondary carer's age was mostly below 60 years old (n=61, 91%) (Table 7.3.).

Table 7-3 Secondary carers characteristics

Secondary Carer characteristics	N (%)
Gender	
Men	19 (28%)
Women	48 (72%)
Age	
<39	23 (34%)
40-49	16 (24%)
50-59	22 (33%)
60+	6 (9%)
Relationship with the primary carer	
Child	41 (61%)
Spouse	11(16%)
Other (Friends, neighbors, extended family)	15 (22%)
Education	
<12	25 (55%)
>12	21 (45%)
Living with the primary carer	22 (33%)
Occupational Status	
Employed	48 (71%)
Unemployed	11 (16%)

According to the responses received by the secondary carers, the first two reasons for the support provided to the primary carer, were a) the psychological/emotional support and b) the social support (e.g. spending time with the carer or the PwD), followed by support with errands, housekeeping, mobility, everyday activities, care and financial management (Figure 6.3). These replies were in accordance with the primary carers replies on the support they had received by the secondary carers.

Figure 7-3 Support received by the secondary carer as reported by the secondary carers



7.4. Validation of the Questionnaires

In this section, the validation of four tools is discussed: eHeals-Carer, HLS-EU-Q16, Revised Scale of Caregiving Self-Efficacy and BRIEF-COPE. All questionnaires apart of the BRIEF-COPE have been validated in a smaller sample of primary carers of PwD (eHeals-Carer n=101 and HLS-EU-Q16 n=107, RSCSE n=100).

The majority (86%) of the sample included for the eHeals-Carers validation, was part of the full-scale study sample, apart from 15 carers, who filled in only demographics and the eHeals-Carer. For this reason, there is a difference in the descriptive statistics of the validations of eHeals-Carer presented here from those of the Revised Scale of Caregiving Self-Efficacy.

Initially, in the case of HLS-EU-Q16, a sample of older people and not carers of older people participated. The dimensions derived by the factor analysis could not be easily interpreted. For this reason, factor analysis was repeated with the full-scale sample of 174 carers.

The BRIEF-COPE was already validated in 1127 Greek-speaking participants (students, parents, young adults, community sample, education teachers) from Greece and Cyprus by Kapsou et al., (2010). During data collection and statistical analysis, the subscales were categorised to fit in three (3) categories as provided by Carver using factor analysis and theoretical approach.

7.4.1. Reliability and Validation of eHeals for Carers of People with Chronic Diseases (Appendix VIII- Published paper)

The validation of eHeals adapted for carers proceeded with a convenience sample of 101 carers from Greece and Cyprus, based on the subject to item ratio 10:1 (Anthoine, Moret, Regnault, Sbille, & Hardouin, 2014; Morgado, Meireles, Neves, Amaral, & Ferreira, 2017).

The validation study aimed to adapt the eHeals among a population of Greek-speaking carers of PwD in Greece and Cyprus in order to provide an easy to use and related to carers tool for eHealth literacy in the Greek language.

The validation process of the eHeals included the following phases and analysis:

1) Literature review on available eHeals validation (section 1.5 Introductory part)
2) Translation of the scale
3) Face validity
4) Content validity
5) Pilot testing during the phase of the study protocol
6) Construct validity of the scale in 101 carers of PwD

Following the scoping review (2) (Chapter 4, section 4.3), the validation and adaptation of the eHeals among Greek and Cypriot carers of PwD were designed. Permission to use and adapt was granted by the authors. The study followed the validation process as described by the World Health Organisation following a double forward and backward translation strategy (Tsang, Royse, & Terkawi, 2017).

Initially, two independent translators, both native speakers of Greek and fluent in English translated the scale into Greek. After comparing and merging the two translations into a single Greek translation by consensus, two independent back translations into English were derived by an additional set of two bilingual translators, one care professional and one researcher - nurse trainer. In case of disagreement, a consensus meeting among the research team members based on expert opinion and existing literature was employed.

In the second step, face validity by the research team followed. During this phase, researchers assessed the available Greek translation of eHeals and if the translated items corresponded to the English version of eHeals. The research team selected the final version in the Greek language and adapted it accordingly by adding a reference to the caregiving concept in every item of the scale. All items were modified accordingly in order to refer to the health and caregiving issues of a friend/relative, for example in item 1: “I know what health resources are available” adapted to item 1: “I know what resources/information are available on the Internet concerning the health and caregiving issues of my friend/relative”. The caregiving issues on the scale were explained as the practical, financial, legal issues, information about the disease and available services. In the case of items 2,3 and 4, short clarification to facilitate understanding was added. Modifications of the scale are available in Table 7.6.

The content validity of the adapted items in the Greek language was assessed by a panel of experts in the field of eHealth and dementia or older people. After this process, the questionnaire was piloted in 25 carers. Finally, the internal consistency of the final version of the adapted Greek scale was tested among a sample of primary carers and construct validity followed with exploratory factor analysis.

Content Validity of eHeals-Carers in Greek

In Content Validity, three indexes are reported: mean Content Validity index (mean I-CVI) measuring the proportion of relative and very relative responses of the items, scale level Content Validity Index average (S-CVI/Ave) measuring average score of the responses of quite relevant and very relevant of every expert and the Scale Content Validity index Universal Agreement (S-

CVI/UA), measuring all items that all raters assessed as quite or highly relative. As scale CVI we usually consider the S-CVI/Ave, since the S-CVI/UA decreases as the number of raters increases (Polit & Beck, 2006)

The panel of experts for the Content Validity Index- eHeals Carer

In order to proceed with the content validity index, 10 experts were invited to reply to the content validity of the questionnaire. The experts were invited because of their work on eHealth and dementia domain. Eight experts were Health professionals: 3 health care professionals, nurses and psychologists, working in the field of technology (robotics, digital literacy of older people), 1 member of the Greek team of the Health Literacy Survey-EU and 4 care professionals working in dementia care. Two IT experts were working in the field of eHealth. Content validity index in mean item-CVI (Mean I-CVI) and scale level CVI average (S-CVI/Ave) was .93 in both cases. Universal agreement Scale- CVI (S-CVI/universal agreement) was .60 (Table 7.4). Experts made no further comment on the phrasing of the scale, apart from 3 comments for minor modifications on 3 different items (item 1, 2, 9), that did not change the final meaning of these items.

Table 7-4 Content validity indexes for eHeals – Carers

Sample	Mean I-CVI	S-CVI/Ave	S-CVI/UA
Group of experts (N=10)	.93	.93	.60

Demographic information of the sample of 101 primary carers

As part of the reliability and construct validity, the sample consisted by primary carers, mostly women (n=76, 75%), caring for their parents (n=62, 61%), living in the same household (n=62, 61%) below 60 years old (n=68, 67%), having completed 12 years of education or more (n=93, 92%), mostly unemployed or pensioners (n=63, 62%), receiving assistance from a secondary carer (n=79, 78%). Detailed demographics are presented in Table 7.5. Socioeconomic position was assessed with the use of perceived social position ladder scale with 10 steps, providing a mean score of 5.76 (SD =1,52)

Table 7-5 Demographic information of the carers sample (N=101)

	Subcategory	N	n (%)
Gender	Women	76	75%
	Men	25	25%
	Total	101	100%
Age	<59	68	67%
	60-79	33	33%
	>80	0	0%
Education	No primary education (ISCED, Level 0)	0	0%
	Primary education (ISCED, Level 1)	8	8%
	Secondary education (ISCED, Level, 2, 3,4)	54	53%
	Tertiary education (ISCED, Level 5.1, 5.2, 6)	39	39%
Employment Status	Employed	38	38%
	Unemployed (inc. Pensioners)	63	62%
Carers Relationship	Caring for Parent	62	61%
	Caring for Spouse	28	28%
	Caring for other (relative/friend/neighbor)	11	11%
Secondary Carer support	Yes	79	78%
	No	22	22%
Living Status	Together with PwD	62	61%
	Living to other house	39	39%
Most Frequent Internet use for carers	Search of information	40	43%
	Reading news	15	16%
	Entertainment (movies, music, etc)	12	13%
	social networks	8	9%
	emails	9	10%
	professional reasons	8	9%

Construct Validity and Reliability of eHeals-Carer

The internal consistency of the scale was assessed with Cronbach's alpha coefficient, and the dimensionality of the scale was explored with Exploratory Factor Analysis (EFA). It was the first time that the scale was validated in Greek among carers, and dimensions were not assumed prior to the validation.

Taking into consideration the literature review (section 4.3), in 5 studies, the researchers used a Principal Component Analysis (PCA), in 11 cases Exploratory Factor Analysis (EFA), in 8 studies Confirmatory Factor Analysis (CFA) and 3 studies either PCA or EFA and then CFA (Appendix II). In 4 studies, they followed Item response theory and Rasch modelling.

Based on these results, eHeals classical validation and the use of EFA followed. As many available validations provide different dimensions, it was decided to explore the dimensions in this target group and confirm these factors in a larger study sample of carers.

Construct Validity

The dimensionality of the scale was explored in Exploratory Factor Analysis (EFA), principal axis factoring with Varimax rotation. Kaiser-Meyer-Olkin Measure sampling Adequacy was .80 and Bartlett test of sphericity statistical significant (x^2_{28}=261.52 p<.001). Two factors with eigenvalue over 1 were extracted, with the first factor explaining 24% of the variance and the second factor 23% (rotation sums of squared loadings). After varimax rotation, a clear structure was revealed with no cross-loadings. Items 1 to 5 loaded on the first factor and tapped on the "information seeking" aspect of eHealth literacy. Items 6 to 8 loaded on the second factor and tapped on the "evaluation" aspect of eHealth literacy.

Reliability

Internal consistency of the scale was measured with Cronbach's alpha =.83. All items appeared necessary with item-total correlations ranging between .48- .59. In all cases, Cronbach's alpha was lower if any of the items were removed.

Reliability analysis for factor 1 of eHeals-Carer provided Cronbach's alpha= .77 (mean=18.48, median=19, SD=3) and for factor 2, Cronbach's alpha=.78 (mean=10.77, median=11, SD= 2.62)

The items with the highest frequency of replies of agreement (agree and strongly agree) were:

- the item 3 "I know how to find helpful information on the Internet concerning health and caregiving of my friend/relative (e.g. concerning the process: google search)",
- item 4 "I know how to use the Internet to answer my questions about the health and caregiving of my friend/relative (e.g. how to ask in order to receive a proper reply to my question)" and

- item 5 “I know how to use the information about the health and caregiving of my friend/relative I find on the Internet to help me (practical, financial, legal issues, information about the disease and available services)”.

Item 8 “I feel confident about using information from the Internet to make decisions concerning the health and caregiving of my friend/relative” had the lowest scores of agreement (figure 7.4). Mean scores of every item of the scale are presented in Table 7.6. The total mean score of the scale eHeals-Carer was 29.27 (SD= 5.30).

Figure 7-4 Frequencies of responses of eHeals-Carer items

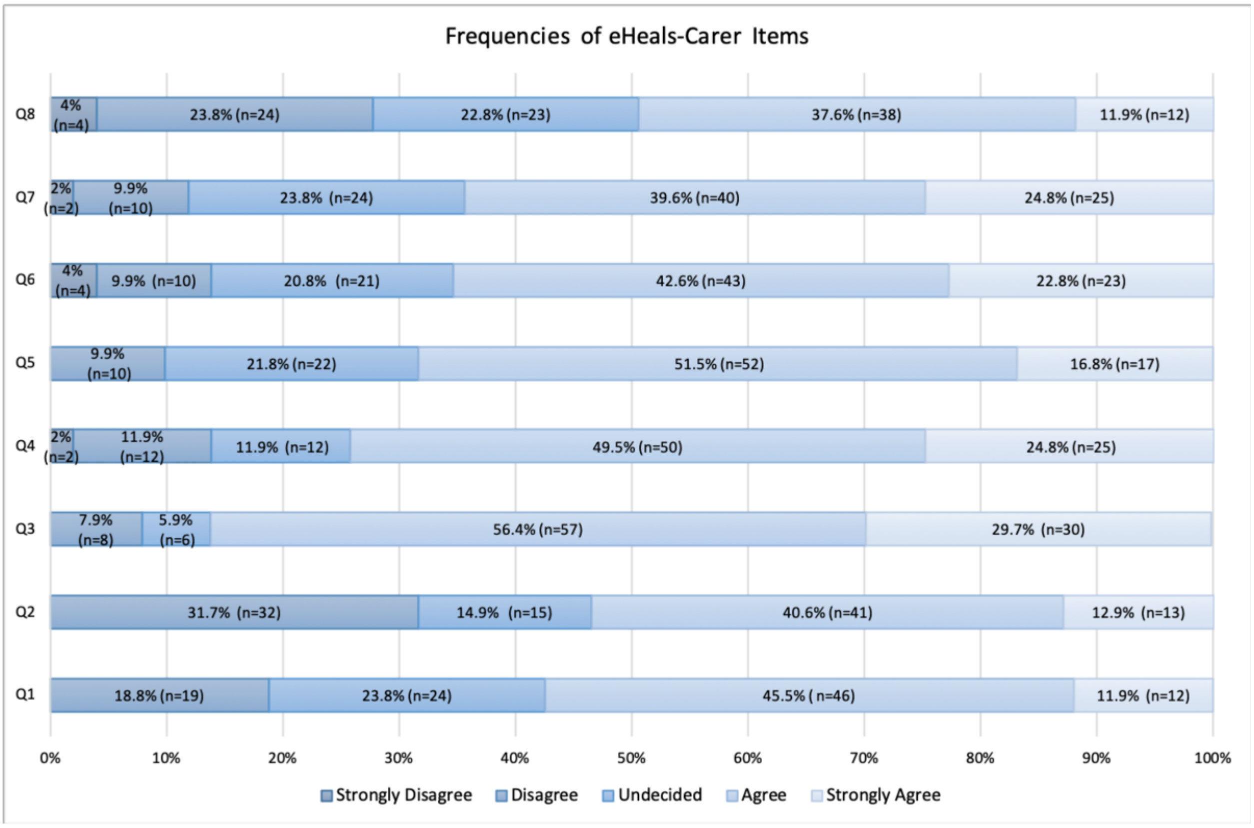


Table 7-6 eHeals –Carer items: Item difficulty, corrected item-total correlation and factor loadings

		M (SD)	Median	Corrected Item-Total Correlation	Factor loadings
		Factor 1			
Q1	"I know what resources/information are available on the Internet concerning the health and caregiving issues of my friend/relative (practical, financial, legal issues, information about the disease and available services)"	3.5 (.93)	4	.48	.49
Q2	"I know where to find helpful information on the Internet concerning the health and caregiving of my friend/relative (e.g. which websites I will search)"	3.34 (1.06)	4	.59	.54
Q3	"I know how to find helpful information on the Internet concerning the health and caregiving of my friend/relative (e.g. concerning the process: google search)"	4.08 (.82)	4	.55	.74
Q4	"I know how to use the Internet to answer my questions about the health and caregiving of my friend/relative (e.g. how to ask in order to receive a proper reply to my question)"	3.83 (1)	4	.53	.66
Q5	"I know how to use the information about the health and caregiving of my friend/relative I find on the Internet to help me (practical, financial, legal issues, information about the disease and available services)"	3.75 (.85)	4	.55	.50
	Total score	18.48 (19)	19	-	-
	Cronbach's a	.77			

	Factor 2				
Q6	“I have the skills I need to evaluate the resources/information I find on the Internet concerning the health and caregiving of my friend/relative”	3.70 (1.05)	4	.59	.76
Q7	“I can tell high quality resources/information from low quality resources/information on the Internet concerning the health and caregiving of my friend/relative”	3.75 (1)	4	.59	.73
Q8	“I feel confident in using information from the Internet to make decisions concerning the health and caregiving of my friend/relative”	3.29 (1.08)	3	.57	.60
	Total score	10.77 (2.62)	11	-	-
	Total scores from both factors	29.27 (5.30)	29	-	-
	Cronbach’s a	.78			

7.4.2. Reliability and Validation of HLS-EU-Q16

As part of the study protocol, a sample of 107 people in Greece and Cyprus from an outpatients’ eye clinic in Cyprus and Open Clubs for Leisure Activities for Older People in Athens, Greece was recruited. The majority of the sample of older adults were over 60 years old. In 9 cases, people of the age group 55-60 years were included. The majority of the sample had low education, below 12 years and no more than 6 years (primary education), mostly married and pensioners. Almost half of the sample assessed their health literacy as problematic or sufficient and only a small percentage (8%) as inadequate. The participants assessed their perceived health and quality of life as good. Almost half of the sample had one chronic condition.

In this case, the internal consistency, the Cronbach’s alpha was adequate (α=.77).

The exploratory factor analysis did not provide a meaningful structure of the five dimensions extracted, as the reliability within subscales was not high. In many cases, there were questions not related to the majority of the included questions in the subdimension. The total variance percentage, in this case, was 45.52%

Taking this into consideration, the research team decided to repeat the exploratory Factor analysis within the sample of 174 primary carers (section 5.3 of the Method Chapter).

The validation of HLS-EU-Q16 was repeated in the full sample of primary carers in order to identify possible dimensions that were not interpretable. As the translation was available in Greek, and as part of the unpublished data, only the internal consistency was provided for the HLS-EU-Q48. No other analysis was available for this questionnaire at the time of this study.

Content Validity of HLS-EU-Q16

As in the case of eHeals-Carer, the same three indexes were used (section 7.4.1.1).

In content validity, a panel of experts (N=6) and a panel of Health professionals (N=10) assessed the scale. Experts were members of the Greek team of HLS-EU survey, professors of school of public health and a professor of the Department of Nursing with research interest on Health Literacy. The Group of Health Professionals comprised of professionals working in the field of dementia.

Item level Content Validity index (I-CVI) and Scale Level-Content Validity Index Average (S-CVI/Ave) in both groups were high. Scale level Content Validity Index/Universal Agreement (S-CVI/UA) was lower among health professionals compared to the group of experts (Table 7.7).

Table 7-7Content Validity Index Analysis of the HLS-EU-Q16

	Mean I-CVI	S-CVI/ Ave	S-CVI/UA
Group of experts (N=6)	.96	.96	.81
Group of Health professionals (N=10)	.99	.99	.94

Construct Validity and Reliability among the Sample of Primary Carers

As part of the reliability and construct validity, the full sample of primary carers was included. The demographics of this sample are available in section 7.1 and Table 7.1. Exploratory Factor Analysis (EFA), principal axis factoring with Varimax rotation was computed. Kaiser-Meyer-Olkin Measure sampling Adequacy was .69 and Bartlett test of sphericity statistically significant (x^2_{120}=437.357 p<.001). Five factors with eigenvalue over 1 were extracted (Table 7.8). The total variance explained from the 5 factors was 55%. Extracting three and four factors to assess if there was a better interpretability of the observed dimensions was tested. In all cases, Media literacy and Health Care-Access dimensions were always extracted. The remaining questions were not easy to be attributed to the remaining factors of either the three-factor and the four-factor models. In Appendix IX, the items per factor extracted for three (3) and four (4) factors are provided.

Table 7-8 Items per Factor extracted from factor analysis HLS-EU-Q16

	Factor 1 Health Promotion	Factor 2 Media Literacy	Factor 3 Compliance with doctors' instructions	Factor 4 Health Care and access of information	Factor 5 Health -related decision making
HLS-EU-Q16	9,10,13,14,16	11,12,15	3,4,7	1,2	5,6,8

Item 5 was loading in Factor 3 and 5. It was decided to include it in factor 5 as the items of this factor are better related to this item.

Item 4 was loading in Factor 1, Factor 3 and 4. After considering the three factors, it was decided that the most relevant factor considered Factor 3 which was named "Compliance with doctor's instructions" and item 4 precisely discussed this topic (Table 7.9).

The extracted factors were different from the HLS-EU-Q16 dimensions derived from the HLS-EU survey. The HLS-EU-Q16 was derived from the HLS-EUQ47 with Rasch analysis. The authors distributed the items to the 12 dimensions of Q47 (obtain, understand, appraise and apply information and Health Care, Disease Prevention and Health Promotion) based on the theoretical framework they had developed. At the moment, there is only one validation that discusses the same 3 factors for HLS-EU Q16 confirmed with CFA (Health Care, Disease Prevention and Health Promotion) (Emiral et al., 2018).The internal consistency of the scale assessed by Cronbach's alpha coefficient was α=.69, slightly lower than the internal consistency among the sample of older adults (α=.77).

Table 7-9 HLS-EU-Q16 items: Item difficulty, corrected item-total correlation and factor loading

		Percentage of dichotomous responses (easy) N (%)	Corrected Item-Total Correlation	Factor loadings
	Factor 1 (Health Promotion)			
Q9	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to understand health warnings about behaviour such as smoking, low physical activity and drinking too much?	166 (95%)	.26	.62
Q10	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to understand why you need health screenings? **(Instructions: breast exam, blood sugar test, blood pressure)**	169 (97%)	.35	.48
Q13	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to find out about activities that are good for your mental well-being?	139 (80%)	.31	.44
Q14	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to understand advice on health from family members or friends?	144 (83%)	.35	.39
Q16	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to judge which everyday behaviour is related to your health? **(Instructions: Drinking and eating habits, exercise, etc.)**	165 (95%)	.36	.49
	Cronbach's a	.60		
	Factor 2 (Media Health literacy)			
Q11	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to judge if the information on health risks in the media is reliable? **(Instructions: TV, Internet or other media)**	131 (75%)	.37	.41
Q12	On a scale from «very easy» to «very difficult», how easy or difficult would	115 (66%)	.25	.48

	you say it is to decide how you can protect yourself from illness based on information in the media?			
Q15	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to understand information in the media on how to get healthier? **(Instructions: Internet, newspapers, magazines)**	165 (95%)	.40	.82
	Cronbach's a	.60		
	Factor 3 Compliance with doctors' instructions			
Q3	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to understand what your doctor says to you	172 (99%)	.29	.33
Q4	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?	171 (98%)	.38	.32
Q7	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to follow instructions from your doctor or pharmacist?	169 (97%)	.28	.69
	Cronbach's a	.53		
	Factor 4 (Health Care and access)			
Q1	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to find information on treatments of illnesses that concern you?	153 (88%)	.32	.65
Q2	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to find out where to get professional help when you are ill?	139 (80%)	.27	.54
	Cronbach's a	.55		
	Factor 5 (Health-related Decision-making)			
Q5	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to judge when you may need to get a second opinion from another doctor?	132 (76%)	.29	.34
Q6	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to use information the doctor gives you to make decisions about your illness?	124 (71%)	.13	.61

Q8	On a scale from «very easy» to «very difficult», how easy or difficult would you say it is to find information on how to manage mental health problems like stress or depression?	127 (73%)	.29	.46
	Cronbach's a	.44		

7.4.3. *Reliability of the Revised Scale of Caregiving Self Efficacy*

Revised scale of Caregiving self-efficacy was not available in Greek. For this scale, we followed the same process as in the case of eHeals of the forward and backward translation provided by the WHO guidelines. The scale was translated into the Greek language by two independent translators, a standard version was derived and two bilingual translators back-translated into English. As in the case of HLS-EU-Q16 and eHeals-Carer, a consensus meeting was planned to finalise the Greek version based on the existing literature. The scale initially was tested during the piloting phase in the small group of carers (N=25) and then used in the full-scale study.

Since the scale is widely used in the population of interest with the three dimensions: obtain respite (SE-OR), behaviour management (SE-BM) and thought control (SE-TC), it was decided to use it without any further analysis of its dimensionality and proceed the analysis with these three initial dimensions.

Internal consistency was calculated in a smaller sample of the study (N= 100) for the 3 subscales (Table 7.11).

Table 7-10 Demographic information of the carers sample (part of the full sample) (N=100)

	Subcategory	N (%)
Gender	Women	71 (71%)
	Men	29 (29%)
	Total	100 (100%)
Age	<59	56 (56%)
	60-79	41 (41%)
	>80	3 (3%)
Education	No primary education	1 (1%)
	Primary education	7 (7%)
	Lower Secondary education	7 (7%)
	Upper Secondary education	18 (18%)
	Tertiary education	67 (67%)
Employment Status	Employed	42 (42%)
	Unemployed (inc. Pensioners)	58 (58%)
Carers Relationship	Caring for Parent	53 (53%)
	Caring for Spouse	37 (37%)
	Caring for other (relative/friend/neighbor)	10 (10%)

Secondary Carer support	Yes	81 (81%)
	No	19 (19%)

In these three categories, the internal consistency was over Cronbach's α=.75, starting from SE-TC from Cronbach's α=76, SE-BM Cronbach's α=.80 and SE-OR Cronbach's α=.86 (Table 7.11)

Table 7-11 Mean scores, SDs and Cronbach alpha for a sample of 100 primary carers

Items	**MEAN (SD) N=100**
Obtain respite	
SELFEFFICACY_RES1	74.58 (34.29)
SELFEFFICACY_RES2	70.31 (35.90)
SELFEFFICACY_RES3	67.71 (34.12)
SELFEFFICACY_RES4	52.45 (40.20)
SELFEFFICACY_RES5	30.36 (38.24)
	Cronbach a= .86
Managing Behaviours	
SELFEFFICACY_BEH1	69.19 (28.64)
SELFEFFICACY_BEH2	70.32 (23.01)
SELFEFFICACY_BEH3	78.06 (22.42)
SELFEFFICACY_BEH4	75.16 (24.75)
SELFEFFICACY_BEH5	68.39 (27.21)
	Cronbach a= .80
Thoughts Control	
SELFEFFICACY_THO1	63.39 (27.85)
SELFEFFICACY_THO2	71.44 (28.39)
SELFEFFICACY_THO3	64.92 (29.92)
SELFEFFICACY_THO4	69.24 (23.69)
SELFEFFICACY_THO5	51.86 (30.20)
	Cronbach a= .76

7.4.4. Construct Validity and Reliability of BRIEF COPE

In order to assess the association of the BRIEF-COPE with carers' characteristics and the other caregiving variables, the BRIEF-COPE dimensions were categorised based on the 3 proposed coping strategies by Carver et al., (1989).

According to Carver, avoidance could be considered under specific circumstances as an adaptive emotion-focused strategy before problem-focused action planning. In this sample of carers, who also replied to the questionnaire through their caregiving experience. During the survey the researcher reminded them that they needed to consider themselves in everyday life. Respondents, as discussed after the end of the survey, may have replied to BRIEF COPE through their caregiving filter.

Support seeking, as in the Greek validation, included both social support and instrumental support, active planning and emotion-focused coping elements. Furthermore, the expression of feelings was not always perceived by the participants as a maladaptive coping strategy, as they reported during the survey. Taking the above into consideration and before the categorisation into 3 categories, a factor analysis was conducted with principal axis factoring as the extraction method and varimax rotation. Kaiser-Meyer-Olkin Measure sampling Adequacy was .64 and Bartlett test of sphericity statistically significant (x^2_{378}=1346.74 p<.001).

Nine factors with eigenvalue over 1 were extracted, explaining 63% of the variance.

These 9 factors included (Table 7.12):

1) Activity planning (8 questions)
2) Support seeking (4 questions)
3) Substance use (2 questions)
4) Religion (2 questions)
5) Avoidance Q1 and Q19 as adaptive coping for carers (2 questions)
6) Expressing of negative feelings (4 questions)
7) Behaviour disengagement (2 questions)
8) Denial (Q3 and Q8) (2 questions)
9) Humour (2 questions)

Table 7-12 BRIEF-COPE items: Item descriptives, corrected item-total correlation and factor loading

		Mean (SD)	Median	Corrected Item-Total Correlation	Factor loadings
		Factor 1 (Activity Planning)			
Q14	I've been trying to come up with a strategy about what to do.	3.29 (.82)	3	.54	.66
Q7	I've been taking action to try to make the situation better.	3.16(.91)	3	.51	.57
Q25	I've been thinking hard about what steps to take.	3.45(.72)	4	.53	.58
Q17	I've been looking for something good in what is happening.	2.91(1.02)	3	.40	.56
Q12	I've been trying to see it in a different light, to make it seem more positive.	3.05(.99)	3	.48	.54

Q2	I've been concentrating my efforts on doing something about the situation I'm in.	2.97(.88)	3	.45	.41
Q20	I've been concentrating my efforts on doing something about the situation I'm in.	3.30(.90)	4	.41	.40
Q24	I've been learning to live with it.	3.36(.79)	4	.38	.39
	Cronbach's a	.77			
		Factor 2 (Support Seeking)			
Q10	I've been getting help and advice from other people.	2.71(.95)	3	.58	.81
Q5	I've been getting emotional support from others.	2.65(1.02)	3	.55	.59
Q23	I've been trying to get advice or help from other people about what to do.	2.59(.96)	3	.48	.57
Q15	I've been getting comfort and understanding from someone.	2.68(1.04)	3	.58	.55
	Cronbach's a	.75			
		Factor 3 (Substance Use)			
Q11	I've been using alcohol or other drugs to help me get through it.	1.06(.31)	1	.73	.89
Q4	I've been using alcohol or other drugs to make myself feel better.	1.12(.46)	1	.73	.80
	Cronbach's a	.80			
		Factor 4 (Religion)			
Q22	I've been trying to find comfort in my religion or spiritual beliefs.	2.38(1.19)	2	.64	.80
Q27	I've been praying or meditating.	2.72(1.15)	3	.64	.78
	Cronbach's a	.78			
		Factor 5 (Avoidance)			
Q19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	2.91(.96)	3	.37	.54
Q1	I've been turning to work or other activities to take my mind off things.	2.82(.98)	3	.37	.44

	Cronbach's a	.54			
	Factor 6 (Express Negative Feelings)				
Q9	I've been saying things to let my unpleasant feelings escape.	2.45(1.08)	2	.39	.59
Q21	I've been expressing my negative feelings.	2.66(.99)	3	.40	.54
Q13	I've been criticizing myself.	2.91(.99)	3	.32	.40
Q26	I've been blaming myself for things that happened.	1.72(.95)	1	.17	.26
	Cronbach's a	.53			
	Factor 7 (Behaviour Disengagement)				
Q16	I've been giving up the attempt to cope.	1.46(.83)	1	.48	.79
Q6	I've been giving up trying to deal with it.	1.46(.83)	1	.48	.56
	Cronbach's a	.65			
	Factor 8 (Denial)				
Q8	I've been refusing to believe that it has happened.	1.76(1.03)	1	.44	.72
Q3	I've been saying to myself "this isn't real."	2.06(1.06)	2	.44	.59
	Cronbach's a	.61			
	Factor 9 (Humor)				
Q28	I've been making fun of the situation.	1.51(.90)	3	.26	.70
Q18	I've been making jokes about it.	2.58(1.14)	1	.26	.34
	Cronbach's a	.40			

These 9 categories were further grouped into 3 categories based on the theory provided by Carver and the feedback received by carers during the administration of the questionnaire concerning their experience of expression of feelings and how they perceived these questions through the caregiving filter.

1. Active Coping strategies (active planning) – 8 questions (score 8 to 32)
2. Emotion-focused coping (support seeking, expression of negative feelings, avoidance (Q1 and Q19, religion, humour) – 14 questions (score 14-56)
3. Problematic (dysfunctional) coping (substance use, behavioural disengagement, denial) – 6 questions (score 6 to 24)

7.4.5. Summary

An eHealth Literacy Scale for carers was adapted and validated. The HLS-EU-Q16 was validated for the aims of this study and the internal consistency of the Revised Scale of Caregiving Self-Efficacy was calculated. Furthermore, the factors of the BRIEF-COPE to provide 3 categories based on the theory of Carver were explored.

In the adapted version of the eHealth Literacy Scale for carers, two dimensions were extracted a) Information seeking and b) evaluation. This validation was realised in a sample of 101 carers.

In the HLS-EU-Q16, 5 dimensions were derived: a) Health Promotion, b) Media Health Literacy, c) Compliance with doctors' instructions, d) Health Care and Access and e) Health-related Decision-making. The validation was realised in the full sample.

In the case of Revised Scale of Caregiving Self-Efficacy, the construct validity was not conducted, as the tool was widely used with the three dimensions: obtain respite (SE-OR), behaviour management (SE-BM) and thought control (SE-TC).

Finally, for the BRIEF-COPE, 9 dimensions were extracted: a) active planning, b) support seeking, c) substance use, d) religion, e) avoidance, f) expressing of negative feelings, g) behaviour disengagement, h) denial, i) humour. These 9 categories were further regrouped in a) problem-focused strategies, b) problematic (dysfunctional) coping, c) emotion-focused strategies

7.5. Style of Internet use among primary carers

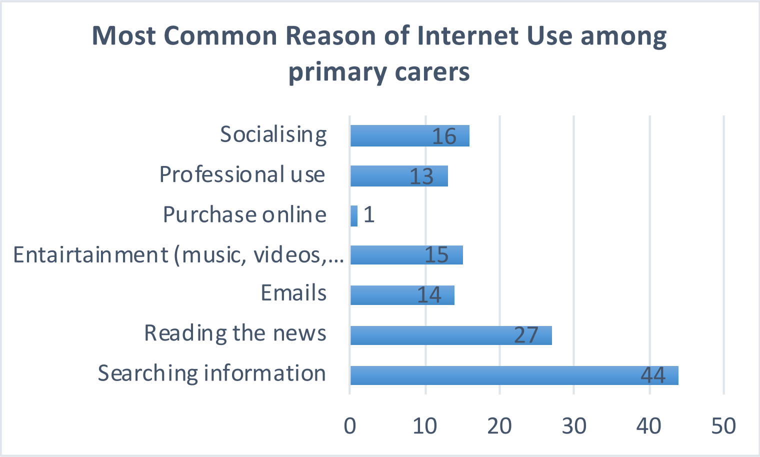
Data on the descriptive statistics of internet use and mobile use and predictors for internet use are presented. Primary carers, who used or did not the internet, did not differ within their gender, with almost no difference between men and women among the internet user and non- users. As in our original sample, women were the majority representing ¾ of this sample (n=102, 77%). Internet users and non-users did not differ regarding the number of carers reporting a secondary carer. There were statistical significant differences of the type of the relationship with the care-receiving person, with children reporting the highest percentage of internet use, followed by other relatives and spouses (90% vs others: 84%, spouses 62%, x^2=17.92, df=2, p<.001), in age and education, with younger carers and with higher education to report being internet users (**Age**: <44:100%, 45-54: 99%, 55-64: 79%, 65-74: 67%, >75+: 44%, x^2=34.82,df=4, p<.001,**education** :no school:0%, primary:26%, lower secondary: 46%, upper secondary:73%, after secondary:96%, x^2=70.183,df=4, p<.001). Differences according to marital status and occupational status were identified, with singles and employed reporting highest percentage use of the internet (**marital status**: single/divorced/widowed: 94%, married:71%, x^2=10.41, df=1, p=.001, **occupational status**: employed: 94%, unemployed: 73%, Pensioners: 69%, x^2=12.55, df=2, p=.002). Primary carers who reported internet use, reported fewer hours of care (1-28h:86%, 29-70h:83%, 71-168h:69%, x^2=6.55, df=2, p=.038) and higher socioeconomic position. People with higher ladder score reported being internet users (<4:56%, 5-7:81%, >7:86%) x^2=9.15, df=2, p=.10) (Table 7.13)

Table 7-13 Primary carers who are internet users- demographic characteristics

		Internet Users	**No Internet Users**	**P-Value**
Gender	Men	33 (79%)	9 (21%)	.860
	Women	102 (77%)	30 (23%)	
Hours of Care/ week	1-28	49 (86%)	8 (14%)	**.038**
	29-70	30(83%)	6 (17%)	
	71-168	55(69%)	25 (31%)	
Relationship with the care-recipient	Children of the care-recipient	74(90%)	8 (10%)	**<.001**
	Spouses of the care-recipient	46(62%)	28 (38%)	
	Other (siblings, nephews, cousins)	16 (84%)	3(15.8%)	
Age	<44	14 (100%)	0 (0%)	**<.001**
	45-54	46(99%)	1(2%)	
	55-64	34 (79%)	9 (21%)	
	65-74	29 (67%)	14 (33%)	
	75+	12(44%)	15 (56%)	
Education	No school education	0 (0%)	4 (100%)	**<.001**
	Primary education	5(26%)	14(74%)	
	Lower Secondary education	6 (46%)	7(54%)	
	Upper Secondary education	27 (73%)	10(27%)	
	After secondary and tertiary education	97(96%)	4(4%)	
Marital Status	Single/Divorced/Widowed	46 (94%)	3(6%)	**.001**
	Married/ Cohabitation	89(71%)	36(29%)	
Occupational Status	Employed	50 (94%)	3(6%)	**.002**
	Unemployed	32(73%)	12(27%)	
	Pensioner	53(69%)	24 (31%)	
Secondary carer reported	Yes	103 (77%)	31(23%)	.677
	No			
Ladder	<4	15 (56%)	12(44%)	**.010**
	5-7	102 (81%)	24(62%)	
	>8	18 (86%)	3(14%)	

Concerning the style of the internet use, almost 80% (n=135) used the internet and the most preferred reason for using the internet for personal reasons was firstly searching for information (n=44/135, 33%), secondly reading the news (n=27/135, 20%), and thirdly socializing (n=16/135, 12%) (figure 7.5).

Figure 7-5 Most Common Reasons for Internet Use among the Primary Carers



After running a binary regression analysis, for predicting factors of internet use (backward conditional method), all factors that provided statistical significance were entered: education, occupational status, relationship (child or not), hours of care and SES. A model providing only education as a predictor of the internet use was found.

Age and marital status even if initially were included in the model, were excluded stepwise due to collinearity with education and of age with marital status. Education remained in the model as provided the highest odds ration from the three variables. Additionally, the education variable was gradually increased in five categories of internet use, and for that reason, it was treated as a linear variable. The use of internet differed according to educational attainment (x^2=70.18, df=4, p<.001). The odds ratio of internet use as estimated in logistic regression was 4.12 (2.69, 6.31). Higher educational attainment was related to 4-times more likely use of internet among carers (Table 7.14).

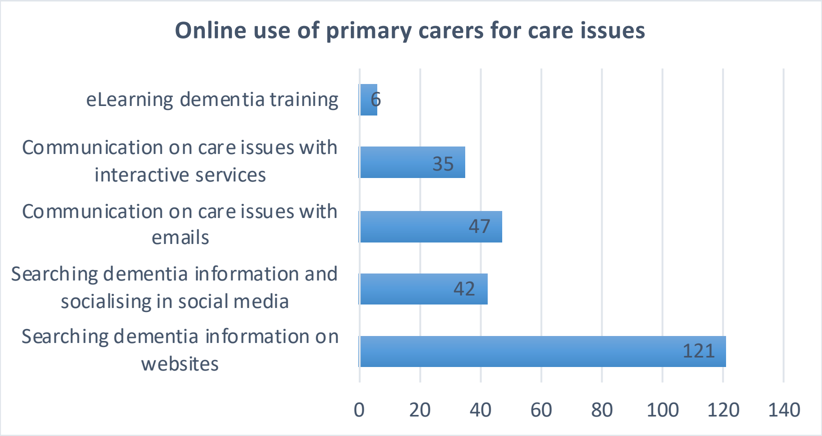
Table 7-14 binary regression analysis with the backward conditional method and dependent variables Internet use and independent variables: age, education, marital status, relationship, occupation, SES and hours of caregiving per week

	Internet Use among Primary Carers	
Independent variable	OR (95% CI)	p-value
Education (treated as linear)	4.12 (2.69-6.31)	<.001

Backward conditional method. Variables included in the model: age, education, marital status, relationship, occupation, SES, hours of caregiving, gender. Excluded for collinearity: age and marital status

Regarding the use of the internet for caregiving issues, the primary carers of this sample reported mostly searching for dementia-specific information on the websites (n=121/135, 90%). They also preferred to use emails (n=47/135, 35%) and social media (n=42/135, 31%). The use of interactive services among carers come in the fourth place of preference and eLearning had the least responses of all the choices, as most of the participants in the study, did not know how to use eLearning tools and had never tried it as revealed during the face to face survey (Figure 7.6).

Figure 7-6 Online use of the primary carers for care issues

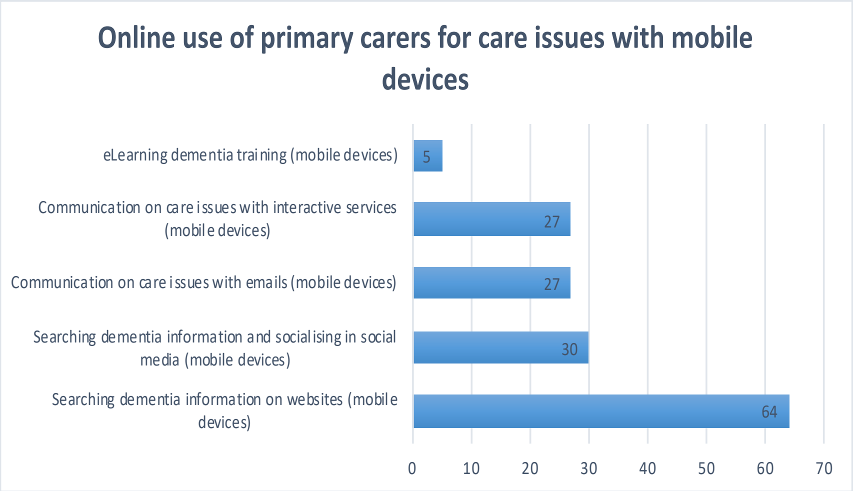


Almost half of the sample using the internet used mobile devices for the same reasons (figure 7.7) (n=70/135, 52%). Due to the small sample of mobile users seeking dementia information, differences in gender were found with a higher percentage of men reporting no use of mobile seeking dementia-specific information (n=21, 64%) in comparison with women (n=44, 43%) (x^2=4.20, df=1, p=.041). A difference regarding the occupational status was observed, with pensioners reporting a higher percentage of mobile non-use in comparison with the other two groups of employed and non-employed (incl. unemployed and students) (employed: 40%, unemployed: 41%, pensioners: 60%, x^2=5.23, df=2, p=.073), even if not statistical significant at the 5% level. In this case, the carers also added the use of the apps as a type of mobile use (n=7/70) (Table 7.15).

Table 7-15 Demographic characteristics of primary carers who are mobile users

Primary Carers-Mobile dementia - seeking		**Mobile Users**	**No User of mobile**	**P-Value**
Gender	Men	12 (36%)	21(64%)	**.041**
	Women	58 (57%)	44 (43%)	
Hours of Care/ week	1-28	25(51%)	24(49%)	.976
	29-70	16 (53%)	14(47%)	
	71-168	29 (53%)	26 (47%)	
Relationship with the care-recipient	Children of the care-recipient	41(56%)	32 (44%)	.382
	Spouses of the care-recipient	23 (50%)	23 (50%)	
	Other (siblings, nephews, cousins)	6 (37%)	10 (63%)	
Age	<44	10 (71%)	4 (29%)	.144
	45-54	24 (52%)	22(48%)	
	55-64	20 (59%)	14(41%)	
	65-74	13(45%)	16(55%)	
	75+	3 (25%)	9(75%)	
Education	Primary education	2(40%)	3 (60%)	.932
	Lower Secondary education	3 (50%)	3 (50%)	
	Upper Secondary education	15(56%)	12(44%)	
	After secondary and tertiary education	50 (51%)	47(49%)	
Marital Status	Single/Divorced/Widowed	21(68%)	25(54%)	.300
	Married/ Cohabitation	49(55%)	40(45%)	
Occupational Status	Employed	30 (60%)	20(40%)	**.073**
	Unemployed	19 (60%)	13(41%)	
	Pensioner	21(40%)	31 (60%)	
Secondary carer reported	**Yes**	54 (52%)	48(46%)	.810
Ladder	**<6**	49 (55%)	40 (45%)	.300
	>6	21 (46%)	25(54%)	

Figure 7-7 Online use of primary carers for care issues with mobile devices



7.5.1. Summary

In this sample, 80% (n=135) used the internet, and statistical significant differences were identified based on the relationship with the care-recipient, age, education, marital status, hours of care. The strongest predictor variable after running the binary logistic regression was the educational level, with internet users reporting higher educational attainment than non-users.

The three most common reasons for Internet use were: searching for information, reading the news and socialising. Carers also searched the internet for dementia-specific information, and they preferred websites, emails and social media.

Almost half of the carers used mobile devices to find dementia-specific information on the internet (n=70/135, 52%), and they also preferred websites, social media and emails or other interactive services

7.6. Descriptive statistics of our core concepts (Health Literacy and eHealth Literacy)

Health Literacy and HLS-EU-Q16 descriptive statistics presented, eHealth literacy and eHeals-Carer follows, and then we the caregiving variables are described: Perceived Caregiving Self-Efficacy (Revised scale of perceived caregiving self-efficacy), Coping strategies (COPE-BRIEF) and finally we present Perceived Social Support (MSPSS).

7.6.1. Perceived Health Literacy (HLS-EU-Q16, Chapter Method 6.5.2.3)

Perceived Health literacy was measured with the HLS-EU-Q16. In the following subsections, two types of analysis are presented: a) treating the variable as categorical and b) treating the variable as continuous.

Categorical Analysis of HLS-EU-Q16

Among this sample of primary carers, a high level of HLS-EU-Q16 scores was identified, and not able to support the categorisation as was provided by Pelikan et al., (2012) with 3 levels (below 8, 9-12, 13-16) as the majority of these scores gathered above 9 (Table 7.16).

Table 7-16 Frequencies of the HLS-EU-Q16 categories according to the HLS-EU team

HLS-EU-Q16 Primary carer	N (%)
Adequate HL (9-12)	41(24%)
Sufficient HL (13-16)	133(76%)

For this reason, a statistical criterion was used to classify the participants based on the quartiles of observed scores, and the results are provided below (Table 7.17).

Table 7-17 Frequencies of the HLS-EU-Q16 categories according to the statistic criterion - quartiles of this sample

HLS-EU-Q16 Primary carer	N (%)
<12	41 (24%)
13-14	70 (40%)
>15	63 (36%)

As the next step, the 3 new categories that were developed follow. Statistical differences were identified by age (<54: HL12:15%, HL13-14:36%, HL=15-16: 50%, x^2=7.87, df=2, p=.020), education (upper secondary: HL12: 20%, HL13-14: 43%, HL15-16:41%, x^2=8.07, df=2, p=.018), relationship with care recipient (being spouse: HL12:33%, HL13-14: 41%, HL15-16: 26%, x^2=8.25, df=2, p=.016), hours of care (<70: HL12: 24%, HL13-14:30%, HL15-

16:46%, x^2=12.99, df=6, p=.043), Internet use (yes: HL12:20%, HL13-14:39%, HL15-16:33%, x^2=6.81, df=2, p=033) and reporting a secondary carer (yes: HL12: 19%, HL13-14: 44%, HL15-16: 41%, x^2=8.25, df=2, p=.016). In the case of occupation, socioeconomic position and marital status, a difference is identified in the expected direction but not a statistically significant. Gender and years of care did not influence the HLS-EU-Q16 scores.

Table 7-18 Crosstabs analysis of HLS-EU-Q16 and sociodemographic variables

Variables	Categories	HL <12	HL 13-14	HL >15	p
Gender	Male	12 (29%)	13 (31%)	17(15%)	.358
	Female	29 (22%)	57 (43%)	46(35%)	
Age	Primary carers age <54	12 (15%)	22 (36%)	30 (50%)	**.020**
	Primary carers age >55	32 (28%)	48 (43%)	33 (29%)	
Education	Lower Secondary and below	14(39%)	15(42%)	7(19%)	**.018**
	Upper Secondary and Tertiary	27(20%)	55 (40%)	56 (41%)	
Marital Status	Single_divorced_ widowed	10(20%)	16(33%)	23(47%)	.180
	Married or cohabitation	31(25%)	54(43%)	40(32%)	
Occupation	Employed	7(13%)	21(40%)	25 (47%)	.068
	Unemployed	9 (21%)	18(41%)	17 (39%)	
	Pensioner	25 (33%)	31 (40%)	21(27%)	
Relationship	Spouse	24 (33%)	30 (41%)	19 (26%)	**.016**
	Other relative (children, siblings, nephews, grandchildren)	17 (17%)	40 (40%)	44 (43%)	
Hours of care	Fewer than 70 hours per week	22 (24%)	28 (30%)	42(46%)	**.006**
	More than 71 hours per week	19 (24%)	42 (52%)	20 (25%)	
Years of care	Fewer than 3 years	19 (20%)	42(45%)	32(35%)	.324
	More than 3 years	21(27%)	27(34%)	31(39%)	
reporting secondary carer	Yes	25 (19%)	59 (44%)	50 (37%)	**.016**
	No	16 (40%)	11 (28%)	13 (32%)	
Internet use	Yes	27 (20%)	53 (39%)	55 (41%)	**.033**
	No	14 (36%)	17 (44%)	8 (20%)	
Ladder	Less than 6	26 (22%)	54 (45%)	39(33%)	.124
	More than 6	15(27%)	16 (29%)	24 (44%)	

HLS-EU-Q16 was treated as binary and set the cut-off in 13, the point where a rapid increase of the scores is found (μ=13.64 and median= 14), below model was presented when age, education, occupation dummy variables, relationship dummy variables, hours of care, reporting secondary carer, internet use and SES were entered. Being a carer with upper secondary education, employed, and reporting a secondary carer was more likely to report a higher level of HLS-EU-Q16 (Table 7.19).

Table 7-19 Binary regression analysis with the backward conditional method and dependent variable HLs-EU-Q16 and independent variables: education, employment status and reporting secondary carer.

Independent variable	**Perceived Health Literacy (HLS-EU-Q16)**	
	OR (95% CI)	p-value
Education (Upper secondary and above=1)	2.41(1.03-5.63)	**.043**
Dummy1_Employed (employed=1)	2.18 (.86-5.56)	**.102**
Secondary carer (reporting secondary yes=1)	3.19 (1.43-7.13)	**.005**

*Backward Stepwise (conditional): variables included initially in the model: age, education marital, being Pensioner, being Employed, being child, being spouse, hours of care, reporting secondary carer, internet use and SES.

Analysis of HLS-EU-Q16 as a continuous variable

The normality of these data following 5 basic rules were estimated:

1) median to be close to mean
2) skewness and kurtosis between – 3 and 3
3) one standard deviation to be equal or lower of half of the mean
4) statistical test for normality
5) normality plots

In case of all variables, Kolmogorov-Smirnov was calculated and provided statistically significant results. Taking this into consideration the test for normality and the Histograms, both non-parametric and parametric analysis were carried out. In both analyses, similar results were received, so parametric analysis was decided (Appendix X).

Additionally, below scores for the five dimensions of HLS-EU-Q16 were computed: health promotion, media health literacy, compliance with the doctor, health care and access, health-related decision making (chapter 7, section: 7.4.2.2).

From the Table below (Table 7.20), health promotion and compliance with the doctor dimensions received the highest scoring as a mean score in comparison with the other three dimensions.

Table 7-20 Descriptive statistics of the HLS-EU-Q16 total and five factors

	Theoretical Range	Min	Max	Mean	SD	(%) Of the total score	Median
HLS-EU-Q16	0-16	8	16	13.64	1.92	85%	14
Health Promotion	0-5	2	5	4.5	.77	90%	5
Media Literacy	0-3	0	3	2.28	.87	76%	2.5
Compliance with doctor	0-3	2	3	2.94	.23	98%	3
Health care and access	0-2	0	2	1.67	.57	84%	2
Health-related Decision making	0-3	0	3	2.20	.87	73%	2

Statistical significant mean differences of carers' age (t=-2.79, df=172, p=.006), education (t=-2.37, df=172, p=.019), carers' occupation (F=3.81, df=2, p=.024), type of relationship (F=4.36, df=2, p.014), hours of care (t=2.00 df=171, p=.047) and internet use (t=2.79, df=172, p=.006) were identified (Table 7.21). No differences for gender, years of care and socioeconomic position were found. In the case of marital status, there was a tendency among people who are single and higher scores of HLS-EU-Q16.

Bonferroni Post-Hoc analysis for occupation (Appendix XI Table XI.1) and the type of relationship was carried out (Appendix XI, Table XI.2) and the differences between the group of employed and pensioners and between children and spouses were identified (Table 7.21)

Table 7-21 Mean differences between the total score of HLS-EU-Q16 and sociodemographic variables

		HLS-EU-Q16	
Variables	**Categories**	Mean (SD)	P-value
Gender	Male	13.43 (2.21)	.418
	Female	13.70 (1.82)	
Age	<54	14.18(1.82)	**.006**
	>55	13.34(1.11)	
Education	Lower Secondary and below	12.97(1.90)	**.019**
	Upper Secondary and Tertiary	13.81(1.88)	
Marital	Not married or cohabitating	13.98(1.99)	.142
	Married or cohabitating	13.50(1.88)	
Occupation	Employed	14.13(1.81)	**.024**
	Unemployed	13.77(1.93)	
	Pensioner	13.22(1.90)	
Relationship	Child	14.01(1.87)	**.014**
	Spouse	13.15(1.97)	
	Other	13.95(1.51)	
Hours of care	1-70	13.90(1.88)	**.047**
	71-168	13.32(1.93)	
Reporting Secondary carer	No	13.38(2.17)	.370
	Yes	13.72(1.84)	
Internet Use	No	12.88 (1.93)	**.006**
	Yes	13.85(1.87)	
Years of Care	< 3 years	13.73(1.81)	.609
	>3 years	13.58(2.00)	
Ladder	<6	13.54(1.93)	.312
	>6	13.85(1.87)	

After the five factors had been extracted for the HLS-EU-Q16, they were checked for any influences regarding the differences among carers' characteristics and HLS-EU-Q16 total score.

From Table 7.22, **media health literacy factor** influenced the differences of the sociodemographic variables age (t=2.38, df=155.052, p=.019), occupation (F=3.14, df=2, p=.046), carers' type of relationship (F=6.61, df=2, p=.002), hours of care (t=2.76, df=171, p=.006) and internet use (t=-2.99, df=172, p=.003). Education (t =-2.06, df=172, p=.041) and marital status (t=1.99, df=172, p=.048) were added as significant characteristics for media literacy. In the case of the occupational status, the statistical mean differences were present in the group of employed with the Pensioners and in case of the relationship status, among children with spouses and children with others (Appendix XI, Table XI.3 & Table XI.4).

Table 7-22 Mean differences between the five factors of HLS-EU-Q16 and sociodemographic variables

		HEALTH PROMOTION		MEDIA LITERACY		COMPLIANCE		HEALTHCARE & ACCESS		HEALTH RELATED DECISION MAKING	
Variables	**Categories**	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value
Gender	Male	4.52 (.74)	.820	2.23 (1.03)	.711	2.95 (.22)	.754	1.69 (.56)	.873	1.90 (1)	**.026**
	Female	4.49 (.79)		2.30 (.81)		2.94 (.24)		1.67 (.57)		2.3 (.81)	
Age	<54	4.57 (.69)	.357	2.48 (.70)	**.019**	2.98 (.13)	**.039**	1.82 (.39)	**.006**	2.28 (.86)	.391
	>55	4.46 (.81)		2.18 (.93)		2.92 (.27)		1.60 (.63)		2.16 (.88)	
Education	Lower Secondary and below	4.44 (.84)	.630	1.92 (1.02)	**.004**	2.92 (.28)	.457	1.56 (.69)	.220	2.02 (.91)	.182
	Upper Secondary and Tertiary	4.51 (.76)		2.38 (.80)		2.95 (.22)		1.71 (.53)		2.25 (.86)	
Marital	Single_divorced_ widowed	4.55 (.74)	.587	2.49 (.71)	**.048**	2.94 (.24)	.895	1.78 (.42)	.099	2.2 (.89)	.978
	Married or cohabitation	4.48 (.79)		2.2 (.92)		2.94 (.23)		1.64 (.42)		2.2 (.87)	
Occupation	Employed	4.57 (.69)	.442	2.52 (.72)	**.046**	2.98 (.14)	.346	1.75 (.48)	.435	2.25 (.9)	**.087**
	Unemployed	4.57 (.82)		2.18 (.95)		2.93 (.25)		1.68 (.47)		2.41 (.73)	
	Pensioner	4.41 (.80)		2.17 (.89)		2.92 (.27)		1.62 (.66)		2.05 (.87)	
Relationship	Child	4.52 (.78)	.432	2.53 (.69)	**.002**	2.96 (.19)	.503	1.68 (.54)	.632	2.27 (.85)	.106
	Spouse	4.43 (.83)		2.07 (.93)		2.92 (.27)		1.65 (.63)		2.05 (.90)	
	Other	4.68 (.48)		2.28 (.87)		2.84 (.23)		1.79 (.42)		2.47 (.77)	
Hours of care	1-70	4.54 (.75)	.403	2.45 (.78)	**.006**	2.09 (.94)	.658	1.75 (.48)	**.075**	2.2 (.90)	.915
	71-168	4.44 (.81)		2.09 (.94)		2.93 (.10)		1.59 (.65)		2.21 (.85)	
Reporting Secondary carer	No	4.35 (.97)	.245	2.2 (.99)	.501	2.95 (.22)	.818	1.65 (.62)	.722	2.13 (.97)	.531
	Yes	4.54 (.70)		2.31 (.83)		2.94 (.24)		1.69 (.55)		2.23 (.85)	
Internet Use	No	4.31 (.92)	.078	1.92 (.92)	**.003**	2.9 (.31)	.272	1.64 (.58)	.645	2.03 (1.06	.155
	Yes	4.56 (.72)		2.39 (.83)		3 (.21)		1.69 (.57)		2.25 (.81)	
Years of Care	< 3 years	4.51 (.77)	.994	2.27 (.89)	.717	2.98 (.15	**.035**	1.68 (.53)	.712	2.24 (.84)	.637
	>3 years	4.51 (.77)		2.32 (.83)		2.9 (.30)		1.71 (.58)		2.15 (.92)	
Ladder	<6	88.04	.805	84.65	.230	87.38	.910	84.96	.206	86.82	.529
	>6	86.33		93.66		87.75		93		88.96	

When the predictor variables for HLS-EU-Q16 as a continuous variable were computed, with multiple linear regression, no factors were significant in the model, and the adjusted R^2 did not exceed 6%.

7.6.2. Perceived eHealth Literacy (eHealth Literacy Scale)

In order to measure the levels of eHealth literacy among primary and secondary carers, the eHeals-Carer with the 2 subdimensions of awareness and evaluation was adapted, validated and used (Chapter 7, section 7.4.1). The mean scores for the eHeals-Carer total score, eHeals-Carer 1- "information seeking" and eHeals-Carer 2 "evaluation" are below (Table 7.23).

Table 7-23 Descriptives statistics of eHeals-Carer among 135 primary carers

	Theoretical Range	Min	Max	Mean	SD	% of total score	Median	Skewness	Kyrtosis
eHeals Carer total*	8-40	13	40	29.21	4.8	73%	29	.17	.40
eHeals 1*	5-25	11	25	18.35	3.23	73%	18	-.01	-.17
eHeals 2*	3-15	4	15	10.70	2.39	71%	11	-.35	-.11

*N=135

In order to understand if the means of the different groups within this sample of primary carers differed for the eHealth literacy scores, t-tests for variables with two categories and analysis of variance for more than two were calculated. eHeals-Carer fulfilled the assumption for normal distribution (section 6.6.1.2). From this analysis, statistical differences in means of eHeals-Carer1 "information seeking" (F=4.46, df=2, p.013) and eHeals-Carer 2 "evaluation" (F=2.80, df=4, p=.064) in the different age groups with younger to report higher scores than older people were found. After running Post-Hoc comparisons, this difference was identified among the age group below 54 and the age group over 75 years old for eHeals-Carer 1 "information seeking" (Appendix XI, Table XI.9).

After Post-Hoc comparisons, mean differences were identified in the case of eHeals total (F=3.4962.490, df=2, p=.033) and the relationship status of being a child or not (Appendix XI, Table XI.8)

Occupation status provided statistically significant difference in the means of eHeals-Carer total score (F=3.48, df=2, p=.034) and eHeals-Carer 1 "information seeking" (F=4.05, df=2, p=.020). After the Post-Hoc comparisons, employed carers in comparison with the Pensioners differed statistically in the eHeals-Carer total and eHeals-Carer 1 “information seeking” (Appendix XI, Table XI 5 and XI.6).

Interesting findings derived from the t-tests that were carried out for the eHeals-Carer mean scores (total, dimension1 and dimension2) in the **dementia-specific internet variables:** search on the websites, social media, emails, interactive services and eLearning. Carers who used social media and carers who used email reporting a higher score in eHeals-Carer (total, dimension1 and dimension2) in comparison with carers who did not use these web-based services. Carers who searched the websites for dementia-specific information reported higher score in eHeals-Carer total and eHeals Carer 2 “evaluation”. Carers who used the eLearning and interactive services also reported higher score in eHeals-Carer total (Table 7.24).

Tendencies for the age, education (lower secondary and upper secondary education), reporting secondary carer and socioeconomic position (ladder below and over 6) for the eHeals-Carer total were also identified. No statistical differences were found in case of gender and caring for others in eHeals-Carer total scores and its subdimensions. Occupational, relationship status and age were included in Post-Hoc analysis, for eHeals-Carer total and eHeals-Carer 1. In the case of occupational status, the difference in eHeals-Carer Total and eHeals-Carer1 was derived by employed compared with Pensioners (Appendix XI, Table XI.5 & Table XI.6). In the case of the relationship status, we identified differences among children with spouses and others for both eHeals-Carer and eHeals-Carer Total (Appendix XI, Table XI.7 & XI.8). The Post-Hoc analysis of the age groups for eHeals-Carer 1 “information seeking” was calculated. Carers below <54 years differed statistically with the carers over 75+ (Appendix XI, Table XI.9).

Table 7-24 eHeals-Carers means scores among carers’ characteristics

Variable	**Categories**	**Mean eHeals total (SD)**	**p**	**Mean eHeals 1 (SD)**	**p**	**Mean eHeals 2 (SD)**	**p**
Gender	Male	29.35 (4.9)	.847	18.26 (3.16)	.863	11.23 (2.51	.158
	Female	29.17 (4.8)		18.37 (3.27)		10.55 (2.38)	
Age	<54	31.12(4.53)	.110	18.95(3.03)	**.013**	11.03(2.33)	**.064**
	55-74	28.67(4.99)		18.20(3.25)		10.21(2.41)	
	75+	27.45(4.61)		15.91(3.17)		11.64(2.16)	
Education	Lower Secondary and below	27.09 (4.46)	.127	16.81(3.37)	.101	10.45(1.97)	.701
	Upper Secondary and Tertiary	29.40 (4.80)		18.48(3.20)		10.75(2.47)	

Marital	Single_Divorced_Widowed_Other	29.96 (4.6)	.198	18.7(3.23)	.371	11.15 (2.10)	.143
	Married_Cohabitating	28.83(4.89)		18.17(3.23)		10.51(2.56)	
Relationship	Child	30.19(4.54)	**.033**	18.99(3.03)	.052	11.04(2.42)	.175
	Spouse	28.07(4.99)		17.6(3.49)		10.33(2.36)	
	Other	27.94(4.75)		17.63(2.94)		10.12(2.52)	
Occupational Status	Employed	29.98 (4.46)	**.034**	19.08(2.64))	**.020**	10.84(2.51)	.139
	Unemployed	30.22 (4.74)		18.78 (3.45)		11.250 (2.5)	
	Pensioner	27.89 (4.93		17.4(3.41		10.23(2.42)	
Caring for others	No	29.10(4.54)	.733	18.27(3.16)	.733	10.80(2.37)	.656
	Yes	29.39(5.21)		18.46(3.35)		10.611(2.53)	
Ladder	<6	28.69 (4.69)	.072	18.03(3.06)	.110	10.44(2.49)	**.057**
	>6	30.27(4.91)		18.98(3.49)		11.289 (2.22)	
Reporting secondary carer	No	27.74(4.97)	.052	17.90(3.30)	.384	9.87(2.29)	**.025**
	Yes	29.65(4.68)		18.48(3.21)		10.981(2.42)	
Website search for dementia information	No	25.50(4.84)	**.037**	16.67(3.07)	.158	8.83(2.13)	**.039**
	Yes	29.62 (4.66)		18.55 (3.18)		10.90(2.37)	
Social media use for dementia information	No	28.39(4.5)	**<.001**	17.92(3.02)	**.005**	10.31(2.28)	**.001**
	Yes	31.59(4.49)		19.61(3.27)		11.83(2.33)	
Emails use for dementia specific information	No	27.85(4.17)	**<.001**	17.46(2.97)	**<.001**	10.24(2.36)	**<.001**
	Yes	32.11(4.45)		20.17(2.82)		11.77(2.16)	
Interactive service use for dementia specific information	No	28.74(4.67)	**.007**	18.03(3.31)	**.011**	10.57(2.39)	.070
	Yes	31.29(4.45)		19.65(2.51)		11.44(2.31)	
eLearning use for dementia	No	29.23(4.66)	**.038**	18.39(3.19)	.228	10.74(2.42)	.212
	Yes	33.33(4.97)		20 (2.89)		12(1.41)	
Mobile devices use for dementia information	No	27.79(4.40)	**<.001**	17.41(3.19)	**<.001**	10.31(2.31)	**.028**
	Yes	30.88(4.56)		19.43(2.92)		11.23(2.38)	

A multiple linear regression was calculated to predict eHeals-Carer total scores based on Independent variables included in the model: age dummy variables, education binary, marital status binary, relationship dummy variables, occupation dummy variables, reporting secondary carer, and SES. The stepwise method provided one predictor, the independent variable (Occupation: Pensioner or not). A significant regression equation was found (F (1,133) =6.96, p=.009) with and R^2 =5%. Unemployed (due to studies, unemployment, housekeeping) carers reported 2.186 higher in the eHeals-Carer score than Pensioners.

Table 7-25 Multiple linear regression of N=135, dependent variable eHeals total and independent variable, occupation

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
Occupation (Pensioner=1)	-2.19	.83	-.223	-2.64	.009	-3.83 -.55	4%

*Stepwise: variables included initially in the model: age dummy variables, education binary, marital status binary, relationship dummy variables, occupation dummy variables, reporting secondary carer, and SES.

7.6.3. Revised Scale of Perceived Caregiving Self-Efficacy

Below, the self-efficacy scale scores with the lowest scores to be observed for the perceived Self-Efficacy Obtain Respite (59%) and the higher in case of the behaviour management are found below (Table 7.26):

Table 7-26 Descriptives statistics of the Revised Scale of Caregiving Self-Efficacy

	Theoretical Range	Min	Max	Mean	SD	Median	Skewness	Kyrtosis
Self-efficacy obtain respite (SE-OR)	0-100	0	100	59.2	28.44	60	-.33	-.82
Self-efficacy managing behaviours (SE-BM)	0-100	10	100	72.80	21.72	76	-.52	-.65
Self-efficacy thought control (SE-TC)	0-100	0	100	61.13	23.10	61	-.37	-.23

T-tests and one-way analysis of variance follow. The carers who reported that caring for other people apart from their relative or friend with dementia (t=-2.13, df=168, p=.035) and have a secondary carer as a supporter (t=-4.130, df=168, p=>.001), have a higher score in SE-OR.

Concerning this same perceived self-efficacy dimension, SE-OR, a tendency in occupation, with employed carers to report higher scores was identified.

No statistically significant differences in the SE-OR for gender, age education and marital status, relationship with patient, hours and years of care, internet use and socioeconomic position were found.

In the second dimension, SE-BM, statistically significant differences in the occupation groups (F=7.72, df=2, p=.001, and relationship groups (F=4.28, df=2, p=.015) were identified (Table 7.27).

After Post-Hoc comparisons, employed carers reported higher scores for SE-BM in comparison with pensioners carers and unemployed, unemployed differed with Pensioners (Appendix XI, Table XI.10) and spouses with others (Appendix XI, Table XI.12)

In the third dimension, SE-TC, there were statistically significant differences among occupation groups (F=4.89, df=2, p=.009) and their reported socioeconomic position. People with high socioeconomic position (over 6) reported higher scores of perceived thought control in caregiving self-efficacy scale (t=-2.49, df=172, p=.014). After Post-Hoc comparisons Benferroni, employed carers reported higher scores in SE-TC in comparison with unemployed carers (Appendix XI, Table XI.11).

A tendency in gender was found, with male carers reporting higher caregiving perceived self-efficacy than female carers in managing behaviours of their relatives (t=1.96, df=163, p=.052) and controlling their thoughts (t=1.82, df=58.54, p=.075).

Table 7-27 Perceived Self Efficacy dimensions mean scores among carers' characteristics

		SE-OR		SE-BM		SE-TC	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Gender	Male	63.23 (26.98)	.307	78.6 (20.49)	.052	67.4 (26.9)	.075
	Female	57.96 (28.86)		70.93 (21.86)		59.13 (21.46)	
Age	<54	63.09 (28.33)	.401	74.45 (19.79)	.736	63.97 (23.43)	.410
	55-64	57.56 (28.21)		72.24 (22.53)		58.85 (23.29)	
	74+	55.50 (29.52)		70.72 (23.91)		61.96 (21.67)	
Education	Lower Secondary and below	58.51 (27.97)	.874	70.47 (25.99)	.504	57.52 (24.36)	.294
	Upper Secondary and Tertiary	59.37 (28.66)		73.35 (20.64)		62.07 (22.74)	
Marital	Single_divorced_ widowed	55.66 (29.63)	.318	74.97 (21.52)	.431	63.75 (25.21)	.349
	Married or cohabitation	60.55 (27.98)		71.97 (21.84)		60.1 (22.22)	
Occupation	Employed	64.49 (26.58)	.148	82.43 (17.28)	**.001**	68.18 (21.02)	**.009**
	Unemployed	60.63 (23.84)		69.57 (22.55)		53.88 (26.54)	
	Pensioner	54.62		68.01		60.41	

		(31.65)		(22.11)		(21.11)	
Relationship	Child	60.46 (28.16)	.434	73.62 (20.87)	**.015**	60.74 (25.87)	.969
	Spouse	56.36 (28.13)		69.04 (22.7)		61.28 (20.46)	
	Other	65.18 (31.15)		86.50 (15.66)		62.17 (21.18)	
Hours of care	0-70	60.42 (28.16)	.530	74.76 (20.84)	.235	63.4 (21.75)	.145
	71-168	57.65 (28.99)		70.70 (22.72)		58.26 (24.37)	
Caring for others	No	55.5 (27.7)	**.035**	72.82 (21.81)	.985	60.32 (23.5)	.571
	Yes	64.89 (28.82)		72.75 (2.77)		62.35 (22.57)	
Reporting Secondary carer	No	43.42 (28.2)	**>001**	68.79 (22.69)	.189	59.31 (25.07)	.572
	Yes	63.89 (26.87)		74.02 (21.36)		61.67 (22.53)	
Internet Use	No	58.29 (28.15)	.824	71.17 (23.75)	.608	59.63 (27.57)	.648
	Yes	59.46 (28.62)		73.26 (21.18)		61.56 (21.72)	
Years of Care	< 3 years	58.19 (27.46)	.695 .	72.44 (22.15)	.828	61.07 (22.75)	.981
	>3 years	59.92 (29.66)		73.18 (21.63)		61.15 (23.9)	
Ladder	<6	60.86 (27.66)	.266	71.95 (22.76)	.463	58.21 (23.07)	**.014**
	>6	55.63 (30)		74.63 (19.37)		67.43 (22.04)	

After running multiple linear regression, reporting a secondary carer and caring for others were the predictors for reporting a higher score in the dimension obtain respite (Table 7.28).

A significant regression equation was found (F (2,167) =10.82, p <.001) with R^2 =12%. Carers who reported that they received support by a secondary carer had almost 20 points higher than carers who did not report a secondary carer. If they cared for another person, they reported almost 8 points higher in the SE-OR than people that cared for only the PwD.

In the dimension, SE-BM, occupation was a significant predictor after including variables: occupation, relationship, gender, and reporting secondary carer.

A statistically significant regression equation was found (F (1,163) =15.36, p <.001) with R^2 =8%. Carers who were employed had almost 14 points higher on average in SE-BM score than carers who were unemployed (reference category) (Table 7.29).

In the dimension, SE-TC, occupation and SES were significant predictors after including the variables in stepwise linear regression analysis: Occupation, SES, age, gender and hours of care. A significant regression equation was found (F (1,170) =6.72, p <.002) with R^2 =7%.

Carers who were employed had almost 9.6 points higher on average in the SE-TC score than carers who were unemployed. Carers who reported more than 6 points in the 10 points ladder (high SES) had 8.6 points higher than carers with lower SES (Table 7.30).

Table 7-28 Multiple linear regression of N=170, dependent variable Perceived Caregiving Self-Efficacy "OBTAIN RESPITE" and independent variables caring for others and reporting of secondary carer.

Independent Variables	**B**	**Std. Error**	**Std Beta**	**t**	**Sig**	**95%CI**	**Adjusted R^2**
Reporting secondary carer (Yes=1)	20.08	4.91	.29	4.07	<.001	10.38-29.78	12%
Caring for others apart from PwD (Yes=1)	8.71	4.23	.15	2.06	.041	.36-17.06	

* Stepwise: variables included initially in the model: caring for others, reporting secondary carer, occupation (dummy variables) and age (dummy variables)

Table 7-29Multiple linear regression of N=165, dependent variable Perceived Caregiving Self-Efficacy "MANAGING BEHAVIOURS" and independent variables occupation

Independent Variables	**B**	**Std. Error**	**Std Beta**	**t**	**Sig**	**95%CI**	**Adjusted R^2**
Dummy 1_Employed	13.83	13.53	.29	-3.92	<.001	6.86-20.80	8%

* Stepwise: variables included initially in the model: Occupation (dummies), relationship with PwD (dummies), gender and reporting carer

Table 7-30 Multiple linear regression of N=173, dependent variable Perceived Caregiving Self-Efficacy "THOUGH CONTROL" and independent variables

Independent Variables	**B**	**Std. Error**	**Std Beta**	**t**	**Sig**	**95%CI**	**Adjusted R^2**
Dummy_Employed	9.62	3.70	.19	2.60	.010	2.32-16.93	7%
Ladder	8.63	3.66	.18	2.36	.020	1.40-15.86	

* Stepwise: variables included initially in the model: Occupation dummy variables, SES, age dummy variables, gender and hours of care

7.6.4. Coping Strategies (COPE BRIEF)

Based on the 3 coping categories, mean, median, standard deviations, skewness and kurtosis were calculated. Considering the scoring range of the three categories, a high average score on problem-focused coping strategies was encountered (Table 7.31)

Table 7-31 Descriptive statistics of the BRIEF COPE categories

	Theoretical Range	Min	Max	Mean	SD	Median	(%) Total score	Skewness	Kurtosis
BC_problem-focused	8-32	12	32	25.44	4.36	26	80%	-.55	-.08
BC_problematic (dysfunctional)	6-24	6	16	8.92	2.6	8	37%	.75	-.25
BC_emotional-focused	14-56	19	51	35.35	6.16	35	63%	-.02	-.15

When the categories were analysed into subcategories, it was understood that carers had a rather low score in denial, substance use and behavioural disengagement (problematic/dysfunctional coping). The highest score was provided in avoidance (adaptive) and active coping (problem-focused coping). All other subcategories of the emotional-focused strategies ranged from 61 to 66% and only humour received lowest score in the emotional -focused strategies (Table 7.32).

Table 7-32Descriptive statistics of the BRIEF-COPE subcategories

	Theoretical Range	Min	Max	Mean	SD	(%) Total score
Avoidance adaptive	2-8	2	8	5.72	1.61	71.5%
Denial	2-8	2	8	3.82	1.77	47.75%
Active Coping	8-32	12	32	25.44	4.36	80%
Substance use	2-8	2	6	2.18	.71	27.25%
Support Seeking	4-16	4	16	10.63	3.04	66.44%
Behaviour disengagement	2-8	2	8	2.92	1.43	36.5%
Expressing negative feelings	4-16	4	16	9.78	2.62	61.13%
Humour	2-8	2	8	4.09	1.63	51.12%
Religion	2-8	2	8	5.10	2.12	63.75

After conducting a series of t-tests and analysis of variance, means differences in problematic coping (dysfunctional) by hours of care were identified (more and fewer than 70 hours, t=-2.02, df=171, p=.045).

Tendencies in the case of gender were found, with women scoring higher than men in problematic (dysfunctional) coping and in occupation, internet use, years of care and socioeconomic position, with unemployed carers, carers who did not use the internet, caring for fewer than 3 years and carers reporting below 6 in SES ladder reporting higher scores in problematic (dysfunctional)coping strategies.

In the third category, emotion-focused coping strategies, statistical significant mean differences were found: between women and men (t=-4.24, df=172, p<.001), between carers with more than upper secondary education and those with lower secondary education or below (t=2.10, df=172, p=.37) and between internet non-users and users (t=2.03, df=172, p=.043).

There were tendencies regarding the mean score of unemployed, other relatives, if they were caring for other people and if carers reported a secondary carer (Table 7.33).

Table 7-33 mean scores of three dimensions of BRIEF COPE among carers' characteristics

		BC-PF		**BC-PROB**		**BC-EF**	
Variables	**Categories**	Mean (SD)	p-value	Mean (SD)	p-value	Mean (SD)	p-value
Gender	Male	25.52 (4.57)	.882	8.26 (2.33)	**.070**	32 (5.68)	**>.001**
	Female	25.41 (4.31)		9.12 (2.66)		36 (5.94)	
Age	<44	24.86 (5.96)	.871	8.36 (7)	.816	34.36 (7)	.675
	45-54	25.89 (4.11)		8.89 (2.76)		35.04 (5.87)	
	55-64	25.37 (4.28)		8.93 (2.76)		35.51 (6.08)	
	65-74	25.02 (3.78)		9.35 (2.68)		36.21 (5.71)	
	75+	25.70 (5.03)		8.56 (1.95)		34.78 (7.24)	
Education	Lower Secondary and below	24.89 (4.5)	.399	9.28 (2.54)	**.**355	37.25 (5.89)	**.024**
	Upper Secondary and Tertiary	25.58 (4.32)		8.83 (2.62)		34.85 (6.16)	
Marital	Single_divorced_ widowed	25.8 (4.66)	.498	8.71 (3)	.516	34.41 (6.26)	.207
	Married or cohabitation	25.3 (4.25)		9 (2.43)		35.72 (6.11)	
Occupation	Employed	25.72 (4.94)	.482	8.47 (2.62)	.166	34.32 (6.23)	.060
	Unemployed	24.75 (4.04)		9.48 (2.85)		37.18 (6.04)	
	Pensioner	25.64		8.91		35.35	

		(4.12)		(2.6)		(6.16)	
Relationship	Child	25.36	.614	8.9	.989	34.62	.189
		(4.33)		(2.84)		(5.81)	
	Spouse	25.28		8.9		35.64	
		(4.45)		(2.36)		(6.45)	
	Other	26.37		9		37.36	
		(4.23)		(2.56)		(6.26)	
Hours of care	1-70	25.42	.917	8.57	**.045**	34.93	.271
		(4.47)		(2.62)		(5.96)	
	71-168	25.49		9.36		35.96	
		4.26)		(5.96)		(6.23)	
Caring for others	No	25.59	.568	8.9	.927	34.71	.093
		(4.54)		(2.48)		(6)	
	Yes	25.2		8.94		36.32	
		(4.1)		(2.79)		(6.32)	
Reporting Secondary carer	No	26	.353	8.8	.742	33.75	.061
		(4.36)		(2.74)		(7.1)	
	Yes	25.27		8.96		35.83	
		(4.36)		(2.57)		(5.8)	
Internet Use	No	25.67	.710	9.51	.106	37.1	**.043**
		(4.58)		(2.57)		(6.09)	
	Yes	25.37		8.74		34.84	
		(4.31)		(2.59)		(6.11)	
Years of Care	< 3 years	25.35	.851	9.15	.144	35.02	.605
		(4.33)		(2.75)		(5.95)	
	>3 years	25.48		8.6		35.5	
		4.44)		(2.37)		(6.31)	
Ladder	<6	25.33	.629	9.12	.140	35.73	.232
		(4.14)		(2.62)		(5.97)	
	>6	25.67		8.49		34.53	
		(4.83)		(2.52)		(6.54)	

A multiple linear regression was calculated to predict problematic (dysfunctional) coping based on hours of care after including variables in stepwise method: gender, occupation, hours of care, internet use and SES. A significant regression equation was found (F (1,171) =4.08, p <.045) with R^2 =2%. Carers who cared for more than 71 hours report almost 1 point (.869) higher in the problematic coping score than carers who cared for fewer.

Table 7-34Multiple linear regression of N=171, dependent variable Problematic (dysfunctional) Coping and independent variable Hours of Care

Independent Variables	**B**	**Std. Error**	**Std Beta**	**t**	**Sig**	**95%CI**	**Adjusted R**
Hours of Care	.869	.39	.15	2.21	.028	.09-1.64	2%

* Stepwise: variables included initially in the model: Gender, occupation (dummies), Hours of Care, Years of Care, Internet use and SES

A multiple linear regression was calculated to predict emotion-focused coping based on gender and internet use after including variables in stepwise method: gender, education, marital, occupation, hours of care, caring for others, secondary carer, internet use and SES.

A significant regression equation was found (F (1,171) =10.31, p <.001) with R^2 =11%. Female carers reported almost 4 points higher in the emotion-focused coping score than male carers and carers who did not use the internet reported 2.14 higher in the emotion-focused coping scale than internet users.

Table 7-35 Multiple linear regression of N=173, dependent variable emotion-focused Coping and independent variable gender and internet use

Independent Variables	B	Std. Error	t	Sig	95%CI	Adjusted R
Gender (female=1)	4.21	1.04	4.05	<.001	2.15-6.26	11%
Internet Use (yes=1)	-2.14	1.06	-2.03	.044	-4.23- -.06	

* Stepwise: variables included initially in the model: Gender, education, marital, occupation, Hours of Care, caring for others, secondary carer, Internet use and SES

The multiple linear regression with dependent variable problem-focused was not performed, as no variables from the socio-economic characteristics (gender, age dummies, marital binary, education binary, occupation dummies, kinship, years and hours of care, secondary carer, internet use, ladder binary) were statistical significant and the model did not proceed with stepwise analysis.

7.6.5. Perceptions towards caring (COPE index)

As part of the overall assessment the perceptions about caregiving including 3 dimensions were measured: COPE positive (4-16), negative (7-28) and quality of support (4-16) (Chapter 7, section 7.5.3.2.). In the case of higher scoring for positive dimension, carers perceived positive in their role and higher negative score provided more negative perceptions by carers for their caregiving role.

From the Table below (Table 7.36), primary carers reported a mean score of 13.83 (SD 1.88) on the positive dimension for COPE index, 16.87 (SD= 4.86) on the negative dimension and 10.43 (SD =2.80) on the quality of support. From the percentages of the score range, the quality of support was low (65%), since the mean score was 10.43 with maximum score of 16. In the case of negative dimension, a lower score meant that the carers perceived their tasks more positively.

Table 7-36 mean, median, standard deviation, skewness and kurtosis for the 3 dimensions of COPE index

	Theoretical range	Min	Max	Mean	SD	(%) Total score	Median	Skewness	Kurtosis
COPE positive dimension	4-16	8	16	13.83	1.88	86%	14	-.79	.14
COPE negative dimension	7-28	7	28	16.87	4.86	60%	16	.17	-.65
COPE quality of support	4-16	4	16	10.43	2.80	65%	10	-.12	.-37

In the case of the dimension of COPE positive, statistically significant mean differences for internet users and nonusers were found, with non-users reporting a higher score in positive dimension (t=2.32, df=172, p=.021). For this dimension, a tendency in educational levels was found, with carers with lower educational level reporting a higher positive score (t=1.72, df=172, p=.087)

In the case of negative dimension, carers with more hours of care reported a higher score of COPE negative (t=-2.38, df=171, =.019). A tendency in this dimension among carers with more than 3 years, women and carers who cared for their parents was found.

Statistical significant mean differences were identified in COPE index- the quality of support and reporting a secondary carer or not (t=-3.64, df=172, p<.001) and there was also a tendency in the group of internet non-use, with a higher mean score of quality of support in comparison with internet users(Table 7.37).

Table 7-37 mean scores of the three dimensions of COPE index in carers' characteristics

		COPE POSITIVE		COPE NEGATIVE		QUALITY OF SUPPORT	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Gender	Male	13.57 (1.71)	.312	15.74 (4.47)	.082	10.31 (2.40)	.735
	Female	13.91 (1.93)		17.23 (4.94)		10.48 (2.91)	
Age	<44	14.07 (1.77)	.682	16.07 (3.93)	.438	10 (2.29)	.944
	45-54	13.57 (1.77)		17.55 (5.17)		10.31 (2.39)	
	55-64	13.67 (1.84)		17.53 (4.33)		10.63 (2.77)	
	65-74	14.07 (1.84)		16.4 (5.01)		10.4 (3.13)	
	74+	14 (2.08)		15.81 (5.26)		10.63 (3.26)	
Education	Lower Secondary and below	14.30 (2.05)	.087	16.83 (5.73)	.961	10.72 (3.29)	.942
	Upper Secondary and Tertiary	13.70 (1.81)		16.88 (4.62)		10.36 (2.65)	
Marital	Single_divorced_ widowed	13.69 (1.92)	.558	17.41 (4.8)	.365	9.59 (2.57)	.365
	Married or cohabitation	13.88 (1.87)		16.66 (4.89)		10.77 (2.81)	
Occupation	Employed	13.75 (1.83)	.798	16.98 (5.15)	.319	10.49 (2.47)	.756
	Unemployed	13.72 (1.87)		17.70 (4.95)		10.66 (3.06)	
	Pensioner	13.94 (1.94)		16.32 (4.59)		10.44 (2.79)	
Relationship	Child	13.74 (1.74)	.743	17.73 (5.03)	.091	10.26 (2.87)	.706
	Spouse	13.85 (2.10)		16.20 (4.71)		10.64 (2.85)	
	Other	14.11 (1.52)		15.84 (4.25)		10.42 (2.24)	
Hours of care	1-70	13.82 (1.75)	.899	16.08 (4.87)	**.019**	10.29 (2.55)	.467
	71-168	13.85 (1.03)		17.81 (4.73)		10.60 (3.06)	
Caring for others	No	13.88 (1.77)	.675	16.73 (4.87)	.640	10.24 (2.75)	.248
	Yes	13.75 (2.05)		17.09 (4.88)		10.74 (2.85)	
Reporting Secondary carer	No	13.73 (1.81)	.695	17.05 (5.36)	.794	9.08 (3.12)	**.001**
	Yes	13.85 (1.90)		16.82 (4.72)		10.84 (2.56)	
Internet Use	No	14.44 (1.85)	**.021**	16.9 (5.85)	.972	11.15 (3.56)	.135

	Yes	13.65 (1.86)		16.87 (4.56)		10.23 (2.51)	
Years of Care	< 3 years	13.75 (1.80)	.468	16.18 (4.59)	.054	10.28 (2.78)	.411
	>3 years	13.96 (1.96)		17.62 (5.12)		10.63 (2.82)	
Ladder	<6	13.74 (1.86)	.365	17.14 (4.95)	.284	10.43 (2.64)	.955
	>6	14.02 (1.92)		16.29 (4.65)		10.45 (3.11)	

In Tables below (7.37, 7.38 and 7.39), the predictors for the three dimensions are presented. In Positive dimension of COPE index internet use acted as a predictor after inserting with stepwise method: education and internet use. A significant regression equation was found (F (1,172) =5.40, p <.021) with R^2 =3%. Carers who used the internet report almost 1 point lower to the positive perceptions towards caring in comparison with non-users (Table 7.38).

In the Negative dimension of COPE index, caring for a longer time, more hours and being a child could predict a higher score in the Negative dimension. A significant regression equation was found (F (1,167) =6.25, p <.001) with R^2 =10%. People with more than 70 hours of care reported 2.26 higher in average in the negative dimension of COPE and children reported 2.00 higher in average than other carers, as well as carers with more than 3 years, reported 1.65 higher in negative dimension (Table 7.39).

Reporting a secondary carer is a predictor for the perceived quality of support. A significant regression equation was found (F (1,172) =13.249, p <.001) with R^2 =7%. Carers who reported a secondary carer report 1.77 higher in the COPE index-quality of support scale (Table 7.40).

Table 7-38 Multiple linear regression of N=174, dependent variable Cope Positive and independent variable internet use

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R
Internet Use	-.784	.34	-.18	-2.32	.021	-1.45- -.12	2%

* Stepwise: variables included initially in the model: education and internet use

Table 7-39 Multiple linear regression of N=171, dependent variable Cope Negative and independent variable Hours of Care, Relationship (dummy_Child or not), Years of Care

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R
Hours of care	2.26	.73	.23	3.10	.002	.82-3.70	10%
Relationship (Child=1)	2.00	.73	.21	2.75	.007	.57- 3.44	
Years of care	1.65	.72	.17	2.30	.023	.23-3.07	

* Stepwise: variables included initially in the model: gender, relationship (dummies), Hours of care and Years of care

Table 7-40 Multiple linear regression of N=174, dependent variable Quality of Support and independent variables Secondary Carer

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R
Secondary Carer (Yes=1)	1.77	.49	.28	3.65	<.002	.81-2.73	7%

Stepwise: variables included initially in the model: secondary carer and internet use

7.6.6. Perceived Social Support (Multidimensional scale of perceived social support)

The Multidimensional Scale of Perceived Social Support was divided into significant-other subscale, support received by family and friends. This scale receives a total score. The mean score for the significant other dimension was 5.81 (SD 1.19), for family 5.48 (SD 1.43) and friends 4.95 (SD=1.39). The total mean score of the scale reached 64.79 (SD=12.67). The carers of this sample reported high levels of support for all three distinct dimensions (Table 7.41).

Table 7-41mean, median, standard deviation, skewness and kyrtosis of the Multidimensional scale of social support

	Theoretical range	Min	Max	Mean	SD	%	Median	skewness	Kyrtosis
MSPSS SO	1-7	1.25	7	5.81	1.19	83%	6	-1.08	.98
MSPSS FA	1-7	1	7	5.48	1.43	78%	5.75	-.92	.44
MSPSS FR	1-7	1	7	4.95	1.39	70%	5	-.66	.35
MSPSS TOTAL	12-84	20	84	64.79	12.67	77%	66	-.74	.40
MSPSS AV	1-7	1.67	7	5.39	1.06	77%	5.5	-.72	.37

In the case of perceived social support by the significant other (SO), married carers reported a higher mean in comparison with single carers (t=-3.42, df=172, p=001).

In this same dimension, tendencies were found if the carer reported a secondary carer, cared for others apart from the care-recipient, reported fewer than 70 hours of care, cared for other relative than a spouse or a parent, and was female.

Education levels (t=2.51, df=172, p=.013), marital status (t=-5.62, df=172, p<.001), relationship (child, spouse, other – F=5.68 df=2, p=.004) and reporting or not secondary carer (t=-457, df=172, p<.001) had statistical significant mean differences among the family dimension of social support in MSPSS (FA). Carers who reported lower secondary education and below, were married, cared for a spouse and reported a secondary carer had a higher score in the perceived family support (MSPSS FA). After Post-Hoc comparisons Bonferroni, the groups that differed in the relationship variable were the spouses with the children carers (Appendix XI, Table XI.13). Tendencies for gender, internet use and age were found. Female carers, internet non-users and carers over 55 years old, were more likely to report higher scores in perceived family support. Occupation, Hours of Care, Years of Care and ladder had no statistical mean differences.

In the third dimension, perceived social support by friends MSPSS FR, there were statistical differences in the means of carers relationship groups (F=3.31, df=2, p=.039). After Post-Hoc Bonferroni, the groups that differed in MSPSS FR were children and spouses (Appendix XI, Table XI.14). Carers who used the internet report higher score of MSPSS FR from nonusers (t=-3.19, df=48.049, p=.002). Carers with upper secondary (t=-2.46, df=172, p=.018) and younger carers (t=3.07, df=172, p=.003) scored higher in this dimension in relation with lower secondary and below. Being a female carer, employed, reporting a secondary carer and socioeconomic position below 6 in the 10-point ladder provided us with higher mean scores with a tendency to become statistical significant. Marital status, Hours of Care, Years of care and caring for others were not statistically significant (Table 7.42).

Table 7-42 Mean scores of MSPSS dimension and total among carers' characteristics

		MSPSS SO		MSPSS FA		MSPSSFR		MSPSS TOT	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Gender	Male	5.54 (1.33)	.088	5.21 (1.58	.163	4.63 (1.36)	.078	60.95 (13.22)	**.024**
	Female	5.9 (1.14)		5.57 (1.37		5.06 (1.39)		66.02 (12.3)	
Age	<54	5.74 (1.13)	.848	5.25 (1.37)	.273	5.34 (1.02)	**<.001**	65.75 (11.48)	.151
	55-74	5.85 (1.15)		5.62 (1.37)		4.99 (1.32)		65.48 (12.61)	
	75+	5.82 (1.45)		5.57 (1.71)		3.97 (1.83)		60.44 (14/86	
Education	Lower Secondary and below	5.99 (1.27)	.321	6.01 (1.23)	**.013**	4.34 (1.75)	**.018**	64.89 (14.20)	.960
	Upper Secondary and Tertiary	5.76 (1.17)		5.34 (1.43)		5.11 (1.23)		64.76 (12.30)	
Marital	Single_divorced_ widowed	5.33 (1.27)	**.001**	4.59 (1.48)	**>001**	5.04 (1.13)	.629	60.16 (11.96)	**.002**
	Married or cohabitation	5.99 (1.11)		5.83 (1.25)		4.92 (1.48)		66.61 (12.52)	
Occupation	Employed	5.76 (1.15)	.714	5.31 (1.32)	.554	5.2 (1.14)	.077	65.23 (11.67)	.452
	Unemployed	5.94 (1.17)		5.59 (1.55)		5.13 (1.3)		66.48 (11.99)	
	Pensioner	5.77 (1.25)		5.54 (1.44)		4.69 (1.56)		63.53 (1.56	
Relationship	Child	5.63 (1.23)	.196	5.19 (1.45)	**.004**	5.14 (1.13)	**.039**	64.1 (12.49)	.706
	Spouse	5.96 (1.17)		5.9 (1.27)		4.65 (1.59)		65.73 (13.41)	
	Other	5.96 (1.06)		5.12 (1.56)		5.36 (1.40)		64.11 (10.73	
Hours of care	1-70	5.93 (1.15)	.194	5.43 (1.44)	.611	5.08 (1.30)	.215	65.46 (12)	.500
	71-168	5.69 (1.230		5.55 (1.42)		4.81 (1.49)		64.15 (13.47)	
Caring for others	No	5.7 (1.24)	.140	5.35 (1.55)	.138	4.85 (1.43)	.204	63.33 (12.86)	.061
	Yes	5.97 (1.11)		5.68 (1.21)		5.12 (1.32)		67.01 (12.15)	
Reporting Secondary carer	No	5.45 (1.47)	.068	4.63 (1.81)	**.001**	4.53 (1.62)	**.051**	58.28 (14.99)	**.002**
	Yes	5.92 (1.08)		5.74 (1.86)		5.08 (1.29)		66.74 (11.24)	
Internet Use	No	5.97 (1.4)	.330	5.75 (1.56)	.185	4.21 (1.78)	**.002**	63.84 (13.94	.598
	Yes	5.76 (1.13)		5.41 (1.38)		5.17 (1.18)		65.07 (12.32)	

Years of Care	< 3 years	5.74 (1.27)	.472	5.42 (1.51)	.610	4.88 (1.37)	.495	63.74 (13.10)	.306
	>3 years	5.87 (1.11)		5.53 (1.34)		5.02 (1.42)		65.72 (12.14)	
Ladder	<6	5.84 (1.2)	.631	5.53 (1.44)	.509	5.38 (1.4)	.070	65.89 (12.54)	.093
	>6	5.75 (1.20)		5.38 (1.40)		5.08 (1.28)		62.42 (12.74)	

A multiple linear regression was calculated to predict MSPSS SO based on marital status, reporting secondary carer and hours of care. This model was derived after including in stepwise regression: gender, marital status, relationship, hours of care, caring for other and reporting secondary carer.

A significant regression equation was found (F (3,169) =6.98, p<.001) with an R^2=11%

Carers married or cohabitating had by .709 higher score in MSPSS SO than single carers and carers with a secondary carer reported .490 higher in the MSPSS SO than carers without a secondary carer. Carers who reported that they cared for fewer than 70 hours reported .374 higher MSPSS SO than carers who reported more than 70 hours (Table 7.43).

Table 7-43Multiple linear regression of N=173, dependent variable MSPSS-significant others and independent variable Marital status, reporting secondary carer, Hours of care

Independent Variables	**B**	**Std. Error**	**Std Beta**	**t**	**Sig**	**95%CI**	**Adjusted R**
Marital status (Married=1)	.709	.19	.27	3.62	.000	.32-1.10	11%
Secondary carer (Yes=1)	.490	.21	.17	2.39	.018	.08-.90	
Hours of Care (>71=1)	-.374	.18	-.16	-2.13	.035	-.72--.027	

* Stepwise: variables included initially in the model: gender, marital status, relationship (dummies), hours of Care, caring for other and reporting secondary carer

A multiple linear regression was calculated to predict MSPSS FA based on marital status. This model was derived after including in stepwise regression: gender, age, marital status, relationship and internet use.

A significant regression equation was found (F (1,172) =31.60, p<.001) with an R^2=16%.

Carers married or cohabitating have 1.247 higher MSPSS FA score than single carers (Table 7.44).

Table 7-44Multiple linear regression of N=174, dependent variable MSPSS-Family and independent variable Marital status,

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R
Marital status (Married=1)	1.25	.22	.39	5.62	<.001	.81-1.69	16%

Stepwise: variables included initially in the model: gender, age (dummies), marital status, relationship (dummies) and internet use

A multiple linear regression was calculated to predict MSPSS FR based on age, internet use, secondary carer and SES. This model was derived after including in stepwise regression: gender, age, occupation, relationship, hours of care, caring for others, reporting secondary carer, internet use and SES (ladder).

A significant regression equation was found (F (4,168) =9.39, p<.001) with an R^2=18%. Carers who were younger than 75 years reported .829 higher in the MSPSS FR scale than carers who were older than 75 years. Carers who used the internet also reported .792 higher in MSPSS FR than non-user and carers who reported a secondary carer reported .532 higher in MSPSS FR than those who did not report a secondary carer. People with lower SES (according to the ladder score) reported .444 higher in the MSPSS FR than people with higher SES (Table 7.45).

Table 7-45 Multiple linear regression of N=173, dependent variable MSPSS-Friends and independent variable age (75+=1), internet use, secondary carer, ladder

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R
Dummy Age (75+=1)	-.829	.29	-.22	-2.91	.004	-1.39 – -27	18%
Internet use (Yes=1)	.792	.25	.24	3.18	.002	.30-1.28	
Secondary Carer (Yes=1)	.532	.23	.16	2.31	.022	.08-.98	
Ladder (>6=1)	-.444	.21	-.15	-2.11	.036	-.86- -.029	

Stepwise: variables included initially in the model: gender, age (dummies), occupation (dummies), relationship (dummies), hours of Care, caring for others, reporting secondary carer, Internet use, SES (ladder)

Finally, a multiple linear regression was conducted to predict the MSPSS total score based on the secondary carer, marital status and age after including in stepwise regression secondary carer, marital status, hours of care, age, internet use and SES.

A significant regression equation was found (F(3,169)=11.01, p<.001) with an R^2=16%.

Carers with a secondary carer reported 8.169 higher in the perceived social support scale than carers who did not report a secondary carer. Carers who were married or cohabitating also reported 7.20 higher in MSPSS total than carers who were single. Carers who were younger than 75-year-old reported 6.68 higher in MSPSS total than older carers (Table 7.46).

Table 7-46 Multiple linear regression of N=173, dependent variable MSPSS-TOTAL and secondary carer, marital status, independent variable age (75+=1)

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
Secondary Carer (Yes=1)	8.17	2.11	.27	3.86	<.001	3.99-12.34	16%
Marital Status (Yes=1)	6.14	2.02	.26	3.55	<.001	3.20-11.21	
Age (75+)	-6.68	2.50	-.19	-2.67	.008	-11.62- -1.74	

Stepwise: variables included initially in the model: secondary carer, dem_marital2, Hours CAT2, Age 3(dummies), internet use, ladder (SES)

7.6.7. Summary

In this section, the core concepts are introduced.

For all concepts, the mean differences are presented, and the possible predictors discussed.

The HLS-EU-Q16 was treated as a categorical and continuous variable, and statistically significant differences were observed in Health Literacy according to age groups, educational attainment, relationship with the care-recipient, hours of care, reporting a secondary carer and internet use. After binary logistic regression, predictors of Health Literacy were education, occupation and reporting a secondary carer. From the five dimensions of the HLS-EU-Q16, media literacy factor was identified to influence the statistically significant mean differences of the carers' characteristics.

In the case of eHeals-Carer, the analysis provided information for the total score and the two dimensions "information seeking" and "evaluation". There were statistically significant differences among the carers according to their relationship and occupational status. After multiple linear regression, occupation status (being or not Pensioner) could predict the level of the eHeals total.

The associations that were observed among dementia-specific internet use and eHeals-Carer total provided useful information. There were statistically significant differences among all the dimensions of eHeals-Carer and the mobile use, social media and email use for dementia-specific information. In eHeals-Carer total and eHeals-Carer 2 “evaluation”, there were differences among carers who visited the websites to find information about dementia. Carers who used the interactive services reported statistically significant differences among eHeals-Carer total and eHeals-Carer 1 “information seeking”.

For the Revised Scale of Caregiving Self-Efficacy, there were statistically significant mean differences of SE-OR in carers who cared for others and reported a secondary career. The SE-BM differed significantly according to the occupation and relationship status, and the SE-TC differed significantly according to the occupation. After a multiple linear regression was conducted, caring for others and reporting a secondary carer predicted SE-OR. In SE-BM, the occupation remained a predictor and in SE-TC, occupation and SES (ladder).

Hours of care may predict the selection of problematic coping strategies among carers and gender and education were the predictors for the carers of this sample who selected emotion-focused strategies.

The final concept that was analysed in this section is Perceived Social Support measured with MSPSS, including 4 aspects (significant others, family, friends and total score).

In the dimension of significant others, three predictors were computed from the linear regression: marital status, secondary carer and hours of care. Regarding the second dimension (Family), only marital status acted as a predictor and in the third dimension (Friends), age, internet use, secondary carer and ladder (SES).

7.7. Cluster analysis for profiling primary carers

In order to further explore this sample on the basis of our initial hypothesis on the way that eHealth literacy and Health Literacy might influence perceived caregiving self-efficacy, coping style, perceptions towards caregiving and the role of social support on this relationship, the cluster analysis was employed and presented in this section.

In this case, the following variables were included:

1) Health Literacy, HLS-EU-Q16 scores
2) eHealth Literacy, eHeals-Carer
3) Coping strategies, 3 coping dimensions of BRIEF COPE
4) Caregiving Self-efficacy, Revised Scale of Caregiving Self-efficacy 3 dimensions
5) Carers’ perceptions of caring, Cope index 3 dimensions
6) Perceived Social Support, MSPSS total

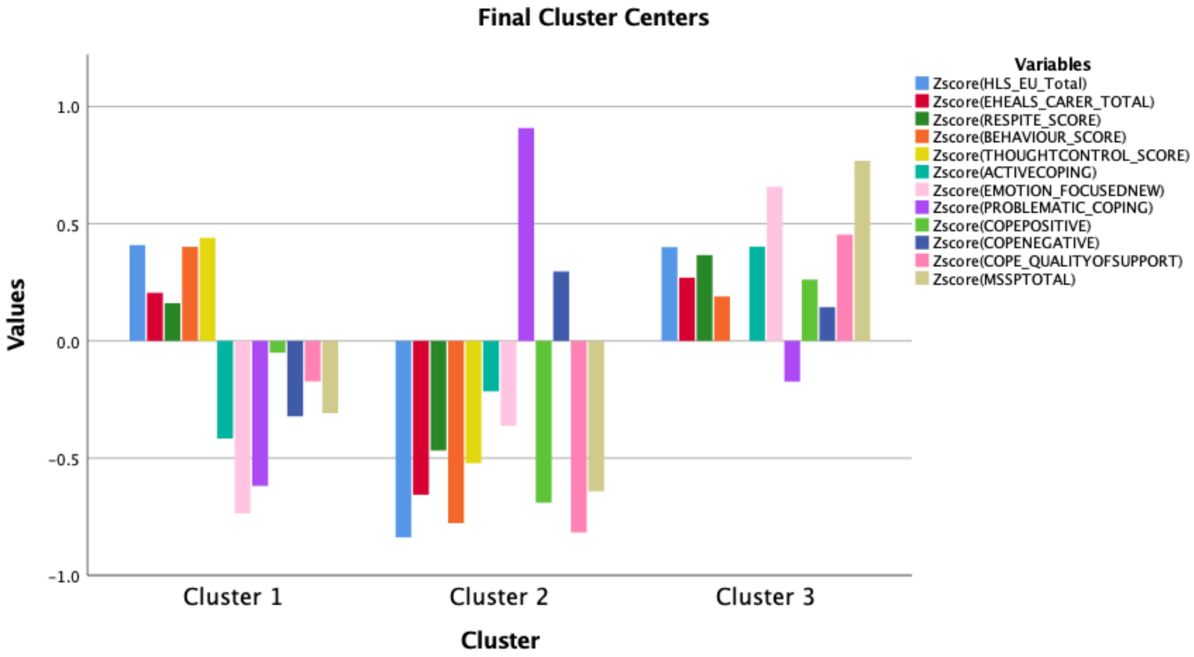
The total number of participants for the cluster analysis did not exceed 124 primary carers, making the sample smaller. This number was primarily influenced by the number of participants that filled in the eHeals-Carer questionnaire who did not exceed 135 carers. In a relevant study, focusing on the clustering of coping style with BRIEF COPE, perceived stress and health outcomes, 4 categories were revealed: High Copers, Adaptive Copers, Avoidant Copers and Low Copers. According to the authors, the categorisation provided classical analysis did not consider the complexity of these characteristics and individual differences (Doron, Trouillet, Maneveau, Neveu, & Ninot, 2015). In their study, the number of the clusters was made with hierarchical cluster analysis (dendrogram, the agglomeration schedule coefficients, interpretability of the clusters) and they also performed a k- means cluster analysis.

In order to determine the number of clusters, the dendrogram was generated and provided 2-3 clusters, and then the variables' dataset in Z-scores was used, and k-means for 3 clusters followed.

From Figure (7.8), 3 primary carers' profiles are derived:

1) Carers with high HLS-EU-Q16, eHeals-Carer and high self-efficacy
2) Carers with high problematic (dysfunctional) coping and COPE-negative perceptions and all the other dimensions decreased
3) Carers with high HLS-EU-Q16, eHeals-Carer, high emotion-focused coping, high positive caregiving perceptions, perceived social support, quality of support

Figure 7-8 Cluster analysis for primary carers



An ANOVA with cluster statistical differences was computed in: Zscores HLS-EU-Total (F=27.05, df=121, p.<.001), Zscore eHeals (F=10.72, df=121, p.<.001), Zscores Self efficacy (respite; F=8.315, df=121, p=.004, Behaviour management F=20.10, df=121, p<.001 and thought control: F=11.34, df=121,p<.001), Zscore active coping (F=9.58, df=121, p=.001), Zscore emotion-focused dimension(F=41.42, df=121, p<.001), Zscore problematic coping (F=32.62, df=121, p<.001), Zscore Cope positive (F=10.35, df=121, p<.001), Zscore cope negative (F=5.22, df=121, p=.007), Zscore Quality of support (F=28.50, df=121, p<.001), and MSPSS total (F=40.98, df=121, p<.001).

7.7.1. Demographic characteristics of the 3 groups of carers according to the clustering

From the bivariate analysis, only gender had a tendency to differ among the three profiles, with the carers in the High HL, eHL and SE to be in a higher percentage male and in the case of Social Network, High HL and eHL were more likely to be female carers (χ^2=5.48, df=2, p=.065).

Table 7-47 Crosstabs analysis of 3 types of carers and sociodemographic variables

Variables	Categories	**High HL, eHL and SE**	**Problematic Copers**	**High HL, eHL, Social Network**	**p**
Gender	Male	16 (54%)	7(23%)	7 (23%)	.065
	Female	29 (31%)	25(27%)	40(43%)	
Age	<54	20(36%)	13 (23%)	23 (41%)	.891
	55-74	22 (37%)	16 (27%)	22 (37%)	
	75+	3(38%)	3(38%)	2(25%)	
Education	Lower Secondary and below	2(25%)	2(25%)	4(50%)	.729
	Upper Secondary and Tertiary	43(37%)	30(26%)	43 (37%)	
Marital Status	Single_divorced_ widowed	15(37%)	13(32%)	13(32%)	.559
	Married or cohabitation	30(36%)	19(23%)	34 (41%)	
Occupation	Employed	19(41%)	8(18%)	19(41%)	.571
	Unemployed	10(32%)	9(29%)	12(39%)	
	Pensioner	16 (34%)	15 (32%)	16 (34%)	
Relationship	Child	26 (37%)	18 (26%)	26(37%)	.958
	Spouse	14(33%)	11(26%)	17(41%)	
	Other relative (siblings, nephews, grandchildren)	5(42%)	3 (25%)	4 (33%)	
Hours of Care	<70 hours	27 (37%)	16(22%)	30(41%)	.444
	>71 hours	17(34%)	16(32%)	17(34%)	
Years of Care	<3 years	22(33%)	20(30%)	25(37%)	.402
	>3 years	23(42%)	11(20%)	21(38%)	

7.7.2. Core Concepts among the 3 profiles of carers according to the clustering

In this section, the core concepts among the 3 groups that were derived from the clustering analysis are presented.

Health Literacy (HLS-EU-Q16)

In order to present the levels of Health Literacy in the 3 profiles of carers, a crosstabs analysis for the categorical version of the HLS-EU-Q16 was calculated, and statistically significant differences were encountered (x^2=36.64, df=4, p<.001) (Table 7.48).

Table 7-48 Crosstabs analysis of 3 types of carers and HLS-EU-Q16

Variables	Categories	HLS-EU-Q16 <12	HLS-EU-Q16 13-14	HLS-EU-Q16 >15	p
Groups of Carers	**High HL, eHL and SE**	4 (9%)	20(44%)	21 (47%)	**<.001**
	Problematic Copers	18(56%)	10(31%)	4(13%)	
	High HL, eHL, Social Network	3(6%)	21(45%)	23(49%)	

eHealth Literacy (eHeals-Carer)

In the ANOVA for the eHeals-Carer, there were statistical significant differences for all three profiles (eHeals total: F=10.72, df=2, p<.001, eHeals-Carer1: F=7.32, df=2, p=001, eHeals-Carer2: F=9.00, df=2, p<.001) (Table 7.49)

After Bonferroni comparisons (Appendix XI, Table XI.16), the differences in means were identified among "High HL, eHL and SE" profile and Problematic Copers, Problematic Copers and carers with "High HL, eHL and Social Network".

The profile of high HL, eHL and SE did not differ from the profile of high HL, eHL and social support, as they also reported high levels of HLS-EU-Q16 and eHeals-Carer. The core differences were found to the Quality of Support, the perceived social support scale, the negative perceptions towards caring and the adoption of the emotion-focused strategies.

Table 7-49Analysis of Variance of the eHeals-Carer and the 3 profiles of carers

Variable	Categories	Mean (SD) eHeals total	p	Mean (SD) eHeals 1	p	Mean (SD) eHeals 2	p
Profiles of Carers	**High HL, eHL and SE**	30 (4.57)	**<.001**	18.91(3.22)	**.001**	11.16(2.35)	**<.001**
	Problematic Copers	26.1(4.14)		16.65(2.88)		9.16(2.31)	
	High HL, eHL, Social Network	30.51(4.75)		19.19(3.05)		11.19(2.28)	

Perceived Self-Efficacy

The mean scores of SE-OR (F=8.32 ,df= 2, p<.001), SE-BM (F=20.10 ,df= 2 , p<.001) and SE-TC (F= 11.34, df=2 , p<.001) differed in the three profiles of carers (Table 7.50)

After Post-Hoc comparisons, the differences in SE-OR and SE-BM were found among the profiles "High HL, eHL and SE" and Problematic Copers, Problematic Copers and "High

HL, eHL and Social Network”. In the case of SE-TC the difference was found between the groups of “High HL, eHL and SE” and Problematic Copers (Appendix XI, Table XI.17)

Table 7-50 Analysis of Variance of the Revised Scale of Perceived Caregiving Self-Efficacy and the 3 profiles of carers

		SE-OR		SE-BM		SE-TC	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Profiles of Carers	**High HL and SE**	63.78 (24.52)	**<.001**	81.51 (15.92)	**<.001**	71.27 (17.75)	**<.001**
	Problematic Copers	45.91 (28.20)		55.91 (16.77)		49.09 (21.31)	
	High HL, eHL,Social Network	69.60 (25.38)		76.91 (20.98)		61.11 (21.51)	

Coping Strategies

The mean scores of BRIEF-COPE Active Planning (F=9.58,df= 2, p=.001), Emotion-Focused (F=41.42 ,df= 2 , p<.001) and Problematic Coping (F= 32.62, df=2 , p<.001) differed in the three profiles of carers (Table 7.51).

Based on Post-Hoc analysis, there were differences in the mean scores of active coping among the “High HL, eHL and SE” and the “High HL, eHL and Social Network”, the Problematic Copers and the two other profiles. The differences of the emotion-focused strategies concerned the “High HL, eHL and SE” and the “High HL, eHL and Social Network”, the Problematic Copers and the “High HL, eHL and Social Network”. The differences in the problematic coping strategies concerned the profiles of the “High HL, eHL and SE” with the Problematic Copers and “High HL, eHL and Social Network”, the Problematic Copers with the “High HL, eHL and Social Network” (Appendix XI, Table XI.18).

Table 7-51 Analysis of Variance of the Revised Scale of Perceived Self-Efficacy and the 3 groups of carers

		Active Coping		Emotion-focused		Problematic	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Profiles of Carers	**High HL and SE**	23.62 (4.42)	**<.001**	30.82 (4.79)	**<.001**	7.31 (1.64)	**<.001**
	Problematic Copers	24.50 (4.05)		33.82 (4.79)		11.28 (2.62)	
	High HL, eHL, Social Network	27.19 (3.66)		39.40 4.31		8.47 (2.65)	

Caregiving perceptions

The mean scores of COPE index -Cope Positive (F=10.35 ,df= 2, p<.001), Cope Negative (F=5.22 ,df= 2 , p=.007) and Quality of Support (F= 28.50, df=2 , p<.001) differed in the three profiles of carers (Table 7.52).

Based on Post-Hoc analysis, there were differences in the mean scores of Cope Positive among "High HL, eHL and SE" and Problematic Copers , Problematic Copers "High HL, eHL and Social Network", in the mean scores of Cope Negative among "High HL, eHL and SE" and both other profiles. In the case of Quality of Support, all profiles differed statistically significant with each other (Appendix XI, Table XI.19).

Table 7-52Analysis of Variance of the Cope Index and the 3 groups of carers

		Cope Positive		Cope Negative		Quality of Support	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Profiles of Carers	**High HL and SE**	13.73 (1.78)	**<.001**	15.31 (3.72)	**.007**	9.96 (2.19)	**<.001**
	Problematic Copers	12.53 (1.77)		18.31 (4.13)		8.15 (2)	
	High HL, eHL, Social Network	14.31 (1.61)		17.57 (5.02)		11.70 (1.97)	

Perceived Social Support

The mean scores of Perceived Social Support- Significant Other (F=32.88 ,df= 2, p<.001), Family (F=12.02 ,df= 2 , p<.001) , Friends (F= 32.55, df=2 , p<.001) and Total score (F= 40.99, df=2 , p<.001) differed in the three profiles of carers (Table 7.53).

Based on Post-Hoc analysis, there were differences in the mean scores of Significant-Other between the profiles “High HL, eHL and SE” and “High HL, eHL and Social Network” and the Problematic Copers and the “High HL, eHL and Social Network”. In the case of Family and Friends dimension and total score, there were differences among the “High HL, eHL and SE” and the Problematic Copers, and the Problematic Copers and the “High HL, eHL and Social Network” (Appendix XI, Table XI.20).

Table 7-53 Analysis of Variance of the Multidimension Scale of Perceived Social Support and the 3 groups of carers

		MSPSS-SO		MSPSS-FA		MSPSS-FR		MSPSS-TOTAL	
Variables	**Categories**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**	**Mean (SD)**	**p-value**
Profiles of Carers	**High HL and SE**	5.38 (1.09)	**<.001**	5.28 (1.28)	**<.001**	4.71 (1.07)	**<.001**	60.89 (11.54)	**<.001**
	Problematic Copers	4.93 (1.11)		4.65 (1.30)		4.55 (.84)		56.66 (19.77)	
	High HL, eHL, Social Network	6.57 (.62)		6.02 (1.13)		6.03 (.83)		74.53 (6.41)	

7.8. Associations of Health Literacy and eHealth Literacy with the other caregiving variables and Perceived Social Support

HLS-EU-Q16 was used as a continuous variable in order to proceed with the analysis and the associations with eHeals-Carers, social support and other caregiving variables. Pearson R was conducted to identify associations of Health Literacy and eHealth Literacy scale with other caregiving variables. Overall, the correlations of Health Literacy scale had the expected direction with eHeals, caregiving self-efficacy, coping dimensions of brief cope and COPE index for caregiving perceptions.

7.8.1. HLS-EU-Q16 & eHeals-Carer

Health literacy scale was positively associated with eHeals-Carer (total score and two dimensions) presenting statistically significant small to medium associations (Table 7.54)

Table 7-54 Correlation coefficients of HLS-EU-Q16 and eHeals

PRIMARY	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2
HLS-EU-Q16	**1**			
eHeals-Carer	.37**	1		
eHeals 1	.26**	.88**	1	
eHeals 2	.38**	.76**	.42**	1

HLS-EU-Q16 in 3 levels

One way ANOVA for the association of **the 3 levels of HLS-EU-Q16 and the eHeals-Carer total score** (F=9.10, df=2, p<.001), eHeals-Carer 1 (F=3.47, df=2, p=.034) and eHeals-Carer 2 (F=11.47, df=2, p<.001) was computed and a Post-Hoc Bonferroni analysis was calculated to identify the mean group differences. In the Table 7.55, eHeals total mean score statistically differed among the first group (<12) of HLS-EU-Q16 and the third and higher group (>15) and among the second group (13-14) and the third group (>15). These mean differences among the first group (<12) and the second group (13-14) were not confirmed.

In the *first* dimension of eHeals, differences among the first group (<12) and the third (>15) were identified.

In the *second* dimension of evaluation for eHeals 2, the differences are confirmed as precisely in the case of eHeals total, among the first and third group and among second and third.

Table 7-55 eHeals means per HLS-EU-Q16 category

	HLS-EU <12			HLS-EU 13-14			HLS-EU 15			p-value
	N	Mean	SD	N	Mean	SD	N	Mean	SD	
eHeals-Carer total	26	26.69	4.90	54	28.56	4.5	55	31.05	4.39	<.001
eHeals-Carer 1	26	17.27	3.2	54	18.06	3.29	55	19.16	3.00	.034
eHeals-Carer2	26	9.34	2.55	54	10.33	2.19	55	11.76	2.19	<.001

Multiple Linear Regression of the eHeals-Carer total as dependent variable and dependent HLS-EU-Q16

For the multiple linear regression, the confounders based on the predictors for eHeals Carer, HLS-EU-Q16 and the theoretical framework (age, education, SES, Internet use) were selected. The collinearity was also assessed (Table 7.57). The unadjusted model is also reported as part of this analysis (Table 7.56).

A Multiple linear regression analysis (enter method) was conducted to predict eHeals-Carer based on HLS-EU-Q16 and adjusted for internet use, education (lower and upper secondary education), occupation dummy variable (Pensioner=1), reporting secondary carer (binary), age and SES. A significant regression equation was found (F (7,127) =5.22, p<.001) with an adjusted R^2 from 13% (unadjusted model) to 18% (adjusted model). eHeals Carer was increased by .862 for each point of HLS-EU-Q16 score. (Table 7.56 and Table 7.57)

Table 7-56 Simple linear Regression of N=135, dependent variable eHeals total and independent variable, HLS-EU-Q16 (unadjusted)

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	.959	.21	.37	4.61	<.001	.55-1.37	13%

Table 7-57 Multiple linear Regression of N=135, dependent variable eHeals total and independent variable, HLS-EU-Q16 and confounding factors: internet use, education, occupation (Pensioner or not and Employed or not), secondary carers, age and SES

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	.862	.21	.33	4.19	<.001	.46-1.27	18%
Internet use (Yes=1)	1.12	3.23	.028	.35	.729	-5.27-7.52	
Education (Upper secondary=1)	1.12	1.42	.06	.79	.431	-1.68-3.92	
Occupation dummy 2 (Pensioner=1)	-1.39	.84	-.14	-1.65	.102	-3.06 -- .28	
Secondary Carer (Yes=1)	2.02	.89	.17	2.25	.026	-.24-3.80	
Age (over 75+ =1)	-.979	1.49	-.06	-.65	.514	-3.94 -1.98	
Ladder (>6=1)	1.41	.82	.14	1.73	.086	-20- 3.02	

7.8.2. HLS-EU-Q16, eHeals-Carer & Revised scale of Perceived Caregiving Self-efficacy (RSPCSE)

A positive direction and small statistically significant associations with HLS-EU-Q16 with all 3 dimensions: SE-OR, SE-BM, SE-TC was identified. For eHeals-Carer, low positive non statistically significant associations with SE-OR, SE-BM, SE-TC were found. Additionally, SE-TC had a low positive correlation with SE-OR, which was in accordance with the validation results provided by Steffen et al. (A. Steffen et al., 2002) (Table 7.58).

Table 7-58 HLS-EU-Q16, eHeals correlation coefficients with Revised scale of Perceived Caregiving Self-efficacy

PRIMARY	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	SE-OR	SE-BM	SE-TC
SE-OR	.18*	.15	.15	.10	1		
SE-BM	.28**	.10	.11	.11	.20*	1	
SE-TC	.16*	.14	.10	.12	.06	.26**	1

HLS-EU-Q16 in 3 levels

The univariate analysis of variance was used to compare the means of the self-efficacy subscales in the three levels of HLS-EU-Q16. According to this test, there were statistically significant differences among the 3 HLS-EU-Q16 levels regarding the mean scores of the **SE-OR and SE-BM** (F=3.15, df=2, p=.046, F=12.26, df=2, p>.001)

Table 7-59 Means of the 3 self-efficacy dimensions in the 3 levels of HLS-EU-Q16

	HLS-EU-Q16 <12		**HLS-EU-Q16 13-14**		**HLS-EU-Q16 15**		
	N	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean SD)**	**P value**
SE-Obtain Respite	41	49.61(34)	69	62.32(25.2)	60	62.15 (26.78)	**.046**
SE-Managing Behavior	39	58.34(24.05)	68	78.29(19.72)	58	5.73(18.35)	**>.001**
Thought Control	41	56.34(25.43)	70	60.98(22.53)	63	64.40(21.9)	.220

Multiple Linear Regressions with Self-Efficacy dimensions as dependent variables

In the description of the basic concepts (section 7.6.3.), two predictors of the SE-OR were identified: 1) being a secondary carer and 2) caring for others. The first of these two was also a predictor for HLS-EU-Q16. Furthermore, according to the theory of Self-Efficacy, possible predictors may be social support, income, SES, education. In this case, taking into consideration the SE-OR, possible confounders were added in the model: occupation, ladder (SES) and education. Social support was excluded due to collinearity with reporting of secondary carer and education due to collinearity with the occupation. A significant regression equation was found (F (5,164) = 5.99, p<.001), with an adjusted R^2 = 3% (unadjusted model) to R^2 = 15% adjusted. SE-OR is increased by 2.74 for each point of HLS-EU-Q16 (Table 7.60 and 7.61).

Table 7-60 Simple Linear Regression of N=170 , dependent variable Self-Efficacy "OBTAIN RESPITE" and independent variable HLS-EU-Q16 (unadjusted)

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	2.74	1.13	.18	2.43	.016	.52-4.96	3%

Table 7-61Multiple linear Regression of N= 170, dependent variable Self-Efficacy Obtain Respite and independent variable HLS-EU_Q16, and confounding factors: secondary carer, caring for others, Occupation, Ladder (SES)

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	2.34	1.10	.16	2.12	**.035**	.17-4.51	13%
Secondary carer (Yes=1)	18.39	4.89	.27	3.76	<.001	8.72-28.05	
Caring for Others (Yes=1)	9.05	4.19	.16	2.16	.032	.78-17.33	
Occupation (Pensioner=1)	-3.76	4.24	-.07	-.89	.37	-12.12- 4.61	
Ladder (>6=1)	-5.69	4.41	-.10	-1.29	.213	-14.41-3.02	

In the case of the second dimension, SE- BM, occupation was included in the confounding variables as it was a predictor for both variables independent and dependent (section 7.6.3) and based on the theory, COPE positive and SES were also added (Table 7.62 and 7.63). Education was excluded due to collinearity with the occupation. A significant regression equation was found (F (4,160) = 9.25, p<.001) and with an adjusted R^2=8% (unadjusted model) to adjusted R^2=17%. The SE-BM increased 2.215 for each point of HLS-EU-Q16 (Table 7.62 & 7.63).

Table 7-62Simple linear Regression of N=174, dependent variable Self-Efficacy Behaviour management and independent variable HLS-EU-Q16 (unadjusted)

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	3.14	.85	.28	3.71	<.001	1.47-4.81	8%

Table 7-63 Multiple linear Regression of N= 170, dependent variable Self-Efficacy Behaviour management and independent variable HLS-EU_Q16, and confounding factors: occupation , COPE positive and ladder (SES)

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	2.22	.83	.20	2.68	**.008**	-.58-3.85	17%
Occupation (Employed=1)	12.39	3.45	.26	3.59	<.001	5.59-19.20	
Cope positive	2.60	.83	.23	3.17	.003	.97-4.23	
Ladder (>6=1)	.419	3.35	.01	.13	.870	-6.19-7.03	

Multiple linear regression was also conducted for the third dimension, SE- TC and HLS-EU-Q16. Based on the theory and predictors previously identified, occupation, SES and Cope Positive were included in the analysis as possible confounders and analysed with the enter regression method. A significant regression equation was found (F (4,169) = 5.65, p<.001) and with an adjusted R^2=3% (unadjusted model) to adjusted R^2=13%, even if the association of SE-TC was not statistically significant after the adjustment for confounders (Table 7.64 & 7.65).

Table 7-64Simple linear Regression of N=174, dependent variable Self-Efficacy Thought Control and independent variable HLS-EU-Q16 (unadjusted)

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	1.97	.91	.16	2.17	.031	.18-3.75	3%

Table 7-65 Multiple linear Regression of N= 174, dependent variable Self-Efficacy Thought control and independent variable HLS-EU_Q16, and confounding factors: occupation (employed=1), SES (ladder), Cope Positive

Independent Variables	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	.966	.89	.08	1.10	.273	-.77-2.70	13%
Occupation (Employed=1)	7.15	3.66	.14	1.95	.053	-.10-14.40-1.469	
Ladder (SES)	3.66	3.74	.24	3.30	.001	5.84-15.77	
Cope Positive	2.20	.88	.18	.2.49	.014	.46-3.93	

7.8.3. HLS-EU-Q16, eHeals-Carer & BRIEF COPE

In the case of the association of HLS-EU-Q16 and the 3 dimensions of the BRIEF-COPE scale, the correct direction in all 3 variables with Health Literacy were found. In the case of the association of Problematic (dysfunctional) coping with Health Literacy scores, a statistically significant, small association was computed (Table 7.66)
A positive, low, statistical significant association, for eHeals-Carer 1 (information seeking) with emotion-focused coping was found.

Table 7-66 HLS-EU-Q16 and eHeals correlation coefficients with BRIEF COPE

primary	HLS-EU-Q16	Eheals -carer	eheals 1	eheals 2	active coping	emotion-focused	problematic coping
active coping	.01	.06	.09	-.02	1		
emotion-focused	.03	.14	.18*	.06	.35**	1	
Problematic (dysfunctional) coping	-.26**	-.14	-.10	-.16	-.20**	.13	1

Taking into consideration the eHeals-Carer 1 “information seeking” association with the emotion-focused coping strategies, this relationship was further searched, based on the hypothesis, that this difference may be due to the supportive element of internet use (e.g. searching for support and not necessarily for information). This was confirmed when the analysis of variance for the different types of use (socialising, receiving emails, information and professional reasons) was calculated, where we have found a statistical significant mean differences for the emotion-focused coping strategies in the different types of internet use (F=2.67, df=4, p=.035) and more specifically, this difference could be attributed to the differences among the group of carers who used the internet to socialise in comparison with those using the internet for entertainment (Appendix XI, Table XI.22)

HLS-EU-Q16 in 3 levels

Analysis of variance was used to assess differences in the means of HLS-EU-Q16 and the 3 different coping styles categories.

Problem-focused (action planning) and emotion-focused coping mean scores did not differ in the three levels of HLS-EU-Q16. On the other hand, **problematic (dysfunctional) coping**

mean scores were different in the 3 levels of HLS-EU-Q16 (F=4.95, df=2, p=.008) (Table 7.67).

Table 7-67 mean score of the 3 coping categories in the 3 levels of HLS-EU-Q16

	HLS-EU <12		HLS-EU 13-14		HLS-EU 15-16		P value
	N	Mean SD	N	Mean SD	N	Mean SD	
Active Coping style	41	25.54(3.83)	70	25.09(4.26)	63	25.76(4.81)	.664
Emotion-focused coping style	41	34.49(6.78)	70	36.03 (6.01)	63	35.16(5.92)	.427
Problematic (dysfunctional) coping style	41	9.76 (2.71)	70	9.09(2.44)	63	8.19(2.55)	.008

Multiple Linear Regressions with coping dimensions as dependent variables

As it is discussed in section 7.6.4 of this same chapter, the predictor of the problematic (dysfunctional) coping dimension was the variable "Hours of care". According to relevant literature (section 3.9, p.91) predictors of coping behaviour are identified: age, education, occupation, self-efficacy, emotional support and Activities of Daily Living (ADL). Taking into consideration the associations revealed in section 7.8.6 of problematic coping and HLS-EU-Q16 with SE-BM and SE-TC, possible confounders included were: hours of care, MSPSS SO, SE-TC, SE-BM and ladder (SES). Age, education, occupation, IADL were not included as the associations were too small. Only SES was selected as possible confounder based on the theoretical criteria. A significant regression equation was found (F (6,157) = 6.15, p<.001) and with an adjusted R^2=6% (unadjusted model) to adjusted R^2=16%. The problematic (dysfunctional) coping score decreased .231 for each point of HLS-EU-Q16 among carers (Table 7.68 & 7.69)

Table 7-68 Simple linear Regression of N-174, dependent variable problematic (dysfunctional) coping and independent variable HLS-EU-Q16 (unadjusted)

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	-351	.10	-.26	-3.51	.001	-.55--.15	6%

Table 7-69 Multiple linear Regression of N= 164, dependent variable problematic (dysfunctional) coping and independent variable HLS-EU_Q16, and confounding factors: hours of care per week, MSPSS SO ,SE-BM , SE-TC and SES (ladder)

Independent variable	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
HLS-EU-Q16	-.231	.10	-.17	-2.26	.025	-.43--.029	16%
Hours of Caring (>70=1)	.372	.38	.07	.97	.335	-.39-1.13	
MSPSS SO	-.435	.16	-.20	-2.70	.008	-.12--.98	
SE-BM	-.013	.009	-.14	-1.78	.078	-.035-.002	
SE-TC	-.020	.008	-.19	-2.47	.015	-.038--.004	
Ladder (>6=1)	-.209	.41	-.05	-.61	.545	-1.07 - .57	

A simple linear regression analysis was conducted to predict emotion-focused coping strategies based on eHeals-Carer 1 "information seeking" (Table 7.70). A Multiple linear Regression of the same variables was computed, adjusting for the gender, education, internet use, MSPSS SO, years of care, IADL, SES and age and an adjusted R^2 =19% from 1% and a significant regression equation of F(9,121)=4.32, p<.001 were obtained.

Emotion-focused coping strategies score were increased .383 for each 1-point of eHeals-Carer 1 "information seeking (Table 7.71)

Table 7-70 Simple Linear Regression of N=135, dependent variable Emotion-Focused coping strategies and independent variable eHeals-Carer1

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
eHeals-Carer 1	.233	.14	.14	1.66	.100	-.05-.51	1%

Table 7-71 Multiple linear Regression of N=131, dependent variable emotion-focused coping strategies and independent variable eHeals Carer1 and confounders: gender, education, internet use, MSPSS SO, years of care, IADL, ladder, Age

Independent variable	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
eHeals 1	.383	.15	.21	2.51	.014	.08-.97	19%
Gender (Female=1)	3.17	1.11	.23	2.85	.005	.97-5.37	
Education (Upper secondary=1)	-.2.81	1.88	-.13	-.1.49	.137	-6.53-.91	
Internet Use (Yes=1)	2.65	5.93	.04	.45	.656	-9.10--14.39	
MSPSS SO	1.44	.43	.28	3.36	.001	.59-2.30	
Years of Care	.447	1.02	-.04	.44	.661	-1.56-2.46	
IADL	-.076	.22	-.03	-.35	.726	-.51-.35	

Ladder (>6=1)	-1.53	1.03	-.12	-1.49	.140	-3.51-.51
Age (>55=1)	-.074	.98	-.01	-.08	.940	-2.02-1.87

7.8.4. HLS-EU-Q16, eHeals-Carer & COPE index (caregiving attitudes)

COPE index presented the expected direction concerning the association of the 3 subdimensions with the Health Literacy scores, even though non-statistically significant low correlations were found.

Positive, statistically significant low correlations were identified with the eHeals-Carer total score and the eHeals-Carer 1 “information seeking” with COPE positive. Positive, statistically significant low correlations were found among the Quality of Support with eHeals-Carer 1 “information seeking”.

Table 7-72 HLS-EU-Q16, eHeals-Carer correlation coefficients with COPE index

PRIMARY	**HLS-EU-Q16**	**eHeals-Carer**	**eHeals 1**	**eHeals 2**	**COPE POSITIVE**	**COPE NEGATIVE**	**QUALITY OF SUPPORT**
COPE POSITIVE	.12	.19*	.24**	.16	1		
COPE NEGATIVE	-.14	.08	.10	.06	-.16*	1	
QUALITY OF SUPPORT	.09	.12	.18*	.02	.32**	-.17*	1

The association of eHeals-Carer total score and eHeals Carer 1 “information seeking” with Cope Positive, was further explained when the mean differences of the internet use with COPE Positive were assessed (section 7.6.5, t=2.32, df=172, p=.021).

HLS-EU-Q16 in 3 levels

When the analysis of variance followed, no differences in means of the 3 HLS-EU-Q16 levels for the three subdimensions were found (Table 7.73)

Table 7-73 mean scores of the three dimensions of COPE index in the 3 levels of HLS-EU-Q16

	HLS-EU <12		**HLS-EU 13-14**		**HLS-EU 15-16**		
	N	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**P value**
Cope Positive	41	13.51(2.13)	70	13.87(1.94)	63	13.98 (1.62)	.445
Cope Negative	41	17.71(4.91)	70	16.5 (4.98)	63	16.75(4.70)	.438
Quality of support	41	9.76(2.96)	70	10.66(2.62)	63	10.63(2.83)	.203

Multiple Linear Regressions with Coping dimensions as dependent variables

Internet use was the predictor that was identified in the description of the section 7.6.5 for Coping Positive. Cope Positive also was correlated with problematic coping strategies, active coping, perceived social support. Other sociodemographic information according to literature was gender, age, education and relationship with the care-recipient. Due to low correlations with gender, age and relationship (<.09), education was included in this model as possible confounder due to existing literature.

A multiple linear regression was conducted to predict COPE index positive based on eHeals-Carer total after adjusting for confounders Internet use, education, problematic coping and perceived social support (method enter). A significant regression equation was found (F(5,129)=4.41, p=.001 with an adjusted R^2 =1% (unadjusted model) to adjusted R^2 =11%. COPE index-Positive increases .063 for each 1-point of eHeals -Carer total (Table 7.74 and 7.75).

Table 7-74 Simple Linear Regression of N=135, dependend variable, COPE Positive and independent variable eHeals-Carers total (unadjusted)

Independent Variables	**B**	**Std. Error**	**Std B**	**t**	**Sig**	**95%CI**	**Adjusted R^2**
eHeals-Carer total	.072	.032	.19	2.25	.026	.009-.14	1%

Table 7-75 Multiple linear Regression of N= 135, dependent variable Cope Positive and independent variable eHeals total, and confounding factors: Internet Use, Education, problematic coping and perceived social support

Independent variable	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
eHeals total	.063	.03	.17	2.03	.045	.001-.13	11%
Internet Use (Yes=1)	-.937	1.30	-.06	-.72	.471	-3.50-1.63	
Education (Upper secondary=1)	-.943	.55	-.14	-1.72	.090	-2.04-1.63	
Problematic coping	-.094	.06	-.14	-1.64	.104	-.21-.020	
MSPSS total	.036	.012	.25	2.92	.004	.012-.06	

eHeals Carer 1 "information seeking" had a statistically significant association with the dimension COPE Positive and this was confirmed with simple linear regression with an adjusted R^2 of 5% (unadjusted model), to adjusted R^2 of 14% after controlling for confounders. COPE index-positive was increased .127 for each 1-point of eHeals-Carer 1 "information seeking" score (Table 7.76 and 7.77)

Table 7-76 Simple linear regression of N=135 and dependent variable, COPE positive and independent variable eHeals-Carer1(unadjusted)

Independent Variables	B	Std. Error	Std B	t	Sig	95%CI	Adjusted R^2
eHeals-Carer 1	.135	.05	.24	2.87	.005	.04-.23	5 %

Table 7-77 Simple linear regression of N=135 and dependent variable, COPE positive and independent variable eHeals-Carer1(unadjusted)

Independent variable	B	Std. Error	Std Beta	t	Sig	95%CI	Adjusted R^2
eHeals 1	.127	.05	.23	2.76	.007	.036-.22	14%
Internet Use (Yes=1)	-1.02	1.28	-.07	-.79	.428	-3.55-1.52	
Education (Upper Secondary=1)	-1.00	.55	-.15	-1.84	.069	-2.08-.08	
Problematic coping	-.096	.06	-.14	-1.69	.093	-.21-.016	
MSPSS total	.035	.012	.24	2.88	.005	.011-.06	

eHeals Carer 1 "information seeking" had a statistical significant association with the dimension Quality of Support and this was confirmed with a simple linear regression, when there was an adjusted R^2 of 3%, and when adjusted for the same confounding variables as in the case of eHeals-Carer total, the adjusted R^2 of 20% was calculated (Table 7.78 and 7.79). The confounding variables were selected from the predictors of section 7.6.6. and existing literature. MSPSS Total was excluded as it provided an adjusted R^2 of 49% as it measured similar concept as in the case of perceived Quality of support. A significant regression equation was found (F (5, 129) =7.49, p<.001 with an adjusted R^2=3% (unadjusted model) to R^2=20%.

Table 7-78 Simple Linear Regression of N=135 with dependent variable Quality of Support and independent variable eHeals-Carer1

Independent Variables	**B**	**Std. Error**	**Std B**	**t**	**Sig**	**95%CI**	**Adjusted R^2**
eHeals-Carer 1	.141	.07	.18	2.11	.037	.009-.27	3 %

Table 7-79 Multiple linear Regression of N= 135, dependent variable Quality of Support and independent variable eHeals 1, and confounding factors: Secondary carer, problematic coping, MSPSS total and emotion focused coping

Independent variable	**B**	**Std. Error**	**Std Beta**	**t**	**Sig**	**95%CI**	**Adjusted R^2**
eHeals 1	.088	.06	.11	1.40	**.165**	-.037-.21	20%
Secondary carer (Yes=1)	1.74	.47	.29	3.69	<.001	.81-2.67	
Problematic coping	-.238	.08	-.25	-3.13	.002	-.39- -.09	
Emotion focused	.098	.034	.23	2.91	.004	.031-.16	
Relationship (Spouse=1)	.677	.43	.13	1.59	.114	-.16-1.52	

7.8.5. HLS-EU-Q16, eHeals-Carer & Multidimensional Scale of Perceived Social Support

MSPSS (total and the three subdimensions) had a positive direction with the HLS-EU-Q16 even if non-statistically significant low correlations. High correlations between the subscales of MSPSS significant other, friends and family were found (Table 7.80)

Table 7-80 HLS-EU-Q16 correlation coefficients with MSPSS

	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	MSPSS SO	MSPSS FA	MSPSS FR	MSPSS TOT
MSPSS SO	.04	.10	.10	.04	1			
MSPSS FA	.02	.02	.00	-.01	.63**	1		
MSPSS FR	.10	.09	.14	.01	.45**	.25**	1	
MSPSS TOT	.07	.11	.12	.04	.83*	.78**	.69*	1

7.8.6. Correlations of the caregiving variables

Checking for the associations among the caregiving variables of Self-Efficacy, COPE index dimensions, BRIEF COPE and MSPSS total and subdimensions the relations below were found (Appendix XII):

- **Self -Efficacy-Obtain Respite** was associated positively, with medium statistical significant correlation to all dimensions of MSPSS (SO r=.29, FA r=.35, FR r=25, TOT r=.38) and with Quality of Support (r=.34) and negatively with the COPE index-Negative (r=-27)
- **Self-Efficacy-Behaviour Management and Thought Control** were associated with medium statistical significant correlations with the COPE index-Positive (SE-BM r=.24 and SE-TC r=.20), COPE index-Negative (SE-BM r=-.22 and SE-TC r=.-33) and BRIEF COPE- Problematic (dysfunctional) coping (SE-BM r=-.25 and SE-TC r=-.26). The direction of the associations was in accordance with the concepts they measure (positive for COPE Positive, Negative for COPE Negative and Negative for Problematic /Dysfunctional coping).
- **COPE index Positive** was associated, with low to medium statistical significant associations, with the MSPSS (SO r=.32, FA r=.21, FR r=16), with the two dimensions of Self-Efficacy as was discussed above and to Problem-focused coping strategies (r=.20) and Problematic(dysfunctional) coping strategies (r=-.23). In all these cases, the direction of the associations followed our assumptions for these concepts.
- **COPE index Negative** was associated negatively with all dimension of Self-Efficacy (associations reported earlier in this section) and positively with Emotion-focused

coping strategies and Problematic (dysfunctional)coping with medium size associations (BRIEF COPE Emotion-focused r=.17 and Problematic(dysfunctional) r=.20)

- **Quality of support** (COPE index) was associated with positive direction and medium to high correlations to MSPSS (r=.61) (SO r=.53, FA r=.56, FR r=.41, TOT r=.62) and with medium positive correlations to Self-Efficacy Obtain Respite, Emotion-focused coping (r=27) and Problematic(dysfunctional) coping (r=22)
- **Problem-focused coping strategies** were associated with positive direction and low statistically significant association to MSPSS SO (r=.14) and to COPE Positive as discussed above.
- **Emotion-focused coping strategies** were associated with positive direction and medium statistically significant correlations to MSPSS (SO r=.33, FA r=.18, FR r=.21, TOT r=.32), COPE Negative and Quality of support (discussed above).
- **Problematic (dysfunctional) coping strategies** were associated with the two dimensions of MSPSS and had negative direction. (SO r=-.20, FA r=-.18). In the case of the MSPSS-SO, a statistically significant association was found. Problematic coping was correlated with positive statistically significant correlations with COPE Negative and Quality of Support and with negative direction with COPE positive (as discussed above).

7.8.7 Mediating effects of caregiving concepts

Following the methodology for mediating factors by Baron & Kenny, (1986), and after finding the associations among Perceived Social Support and Self-Efficacy Obtain respite, Quality of Support and Self-Efficacy, Quality of Support and Perceived Social Support, three regression analyses were carried out:

a) Independent variable, perceived social support with dependent variable: Quality of support (b=.136, t=10.27, p<.001),
b) Independent variable perceived social support with dependent variable: SE-OR (b=.860, t=5.34, p<.001)
c) Independent variables MSPSS-TOT and SE-OR and QoS as dependent (b=.126, t=8.69, p<.001, b.=.012, t=1.896, p=.060)

From the above associations, self-efficacy which might have acted as partially mediator of the association of perceived social support and quality of support were deduced.

Other associations that could be explained in these ways were among problematic (dysfunctional) coping, negative attitudes and self-efficacy for behaviour management.
In this case, the following were obtained:

a) Independent variable SE-BM with dependent variable: negative attitudes (b=-.048, t=-282, p=.005)
b) Independent variable SE-BM with dependent variable problematic (dysfunctional) coping (b=-.030, t=-3.33, p=.001
c) Independent variables SE-BM, problematic coping with negative attitudes (b= -.038, t=-2.18, p.031, b=.339, t=-234, p.020)

7.8.9. *Correlations of caregiving variables among children caring for their parents with dementia*

Considering the correlations of the independent variables with the dependent among children, the correlations discussed for the full sample were confirmed, in the case of the correlations for :

- HLS-EU-Q16 and eHeals-Carer (incl. subdimensions),
- HLS-EU-Q16 and problematic (dysfunctional) coping, SE-OR, COPE index positive,
- Quality of Support and MSPSS,
- Problematic (dysfunctional) coping and MSPSS SO,
- Self-Efficacy and COPE negative,
- COPE positive and problem-focused coping strategies,
- COPE positive and problematic(dysfunctional) coping strategies,
- COPE negative and emotion-focused coping strategies,
- Quality of Support and problematic(dysfunctional) coping strategies (Appendix XII).

The major changes (statistically significant medium correlations or losing the correlation) were observed in the following variables:

- Self-efficacy lost the statistically significant correlation with HLS-EU-Q16
- eHeals-Carer “information seeking” lost the statistical significance for the correlation of emotion-focused coping strategies, COPE positive and Quality support
- eHeals-Carer total score lost the significance with COPE positive
- Cope negative and Quality of support were now associated statistically significant with HLS-EU-Q16 (COPE negative r=-.24 and r=.27)

- HLS-EU-Q16 was now associated with the MSPSS (SO r=.26, FA r=19, FR=17, TOT=.23)
- Among the caregiving variables, a similar pattern with associations to lose significance or the opposite was observed. Interestingly, the correlations of SE-BM and MSPSS SO, FA and TOTAL become statistically important and were increased, that was also the case for the problematic (dysfunctional) coping for the dimensions of MSPSS FA, FR, TOTAL.

7.8.10. Correlations of caregiving variables among spouses

Considering the correlations of the independent variables with the dependent among spouses, the correlations discussed for the full sample were confirmed, in the case of the correlations for :

- HLS-EU-Q16 and eHeals-Carer (incl. subdimensions), SE-BM, problematic (dysfunctional) coping,
- eHeals -Carer 1 "information seeking" and COPE positive,
- Self-efficacy obtain respite and MSPSS,
- COPE positive and MSPSS SO, FA, SE-BM,
- Quality of support and MSPSS, emotion-focused strategies and MSPSS and Quality of support,
- Problematic (dysfunctional) coping and SE-TC, COPE negative (Appendix XIII).

The major changes were observed in the following variables:

- SE-OR and SE-TC lost the correlations with HLS-EU-Q16, and gained correlations with eHeals -Carer 2 "evaluation" (r=.34)
- Active coping strategies were now associated with eHeals-Carer1 "information seeking"
- eHeals -Carer 1 lost the correlation with the emotion-focused strategies and Quality of Support
- eHeals -Carer total lost the correlation with COPE positive
- Among the caregiving variables, we also observed a similar pattern with several correlations to lose significance and others to obtain (Appendix XIII).

7.8.11. Summary

In this subsection, the correlations among the independent and dependent variables were presented. Analysis of variance, simple linear regressions and multiple linear and logistic regressions were employed to identify these relationships.

The correlation of eHeals Carer with HLS-EU-Q16 was confirmed after adjusting for confounders, and this correlation remained in the sample of children and spouses.

The correlation of HLS-EU-Q16 with SE-OR, SE-BM and problematic coping strategies after adjusting for confounder were confirmed.

Additionally, the correlation of eHeals -Carer and eHeals-Carer 1 “information seeking” with COPE-index Positive perceptions towards caring and among eHeals-Carer 1 and emotional-focused coping strategies were confirmed.

7.9. What is the association between Health literacy and eHealth literacy of dementia patient’s primary and secondary carers?

One of the questions (RQ3) in this survey included the comparison between primary and secondary carers. As data were collected on HLS-EU-Q16 and eHeals-Carer by the secondary carer, a reply to this question for this specific sample was provided. The sample of secondary carers did not exceed 67 people. Detailed demographics of the secondary carers are presented in chapter 7 section: 7.3.

7.9.9. Descriptive data of the Secondary carer and HLS-EU-Q16

The levels of the HLS-EU-Q16 for secondary carers were presented, based on the new categorisation that followed for the primary carers and the sample of the secondary carers was compared with the subsample of the primary carers related to and the full sample of carers (Table 7.81).

According to these frequencies, the majority of scores were gathered between the second and third category. There was no statistically significant difference between the two samples (x^2=1.55, df=2, p=.460)

Table 7-81 Frequencies of the HLS-EU-Q16 scores of primary and secondary carers

HLS-EU-Q16	N (%) secondary carers N=67	N (%) primary carers N=67	N (%) primary carers full sample (174)
<12	12 (18%)	14 (21%)	41 (24%)
13-14	26 (39%)	31 (46%)	70 (40%)
15-16	29 (43%)	22 (33%)	63 (36%)

In the Table below, the descriptive statistics of the HLS-EU-Q16 as a continuous variable are presented. Similar to the results of the primary carers, the mean score replies of the HLS-EU-Q16 were gathered in the upper part of the scale (86.8%) (Table 7.82)

Table 7-82 Descriptive statistics of the HLS-EU=Q16 as a continuous variable

	Theoretical Range	Min	Max	Mean	SD	(%) Of the total score	Median
HLS-EU-Q16	0-16	7	16	13.9	2.05	86.8%	14

Table 7-83 Crosstabs analysis of secondary carers HLS-EU-Q16 and sociodemographic variables

Variables	Categories	**HL <12**	**HL 13-14**	**HL >15**	**p**
Gender	Male	4 (21%)	8(42%)	7(37%)	.789
	Female	8 (17%)	18 (38%)	22(46%)	
Age	<39	4 (17%)	8 (35%)	11 (48%)	.686
	40-54	7 (23%)	11 (36%)	13 (42%)	
	55+	1(8%)	7(54%	5(39%)	
Education	Lower Secondary and below	0(0%)	2(67%)	1(33%)	**.**532
	Upper Secondary and Tertiary	12(19%)	24 (25%)	28 (44%)	
Marital Status	Single_divorced_ widowed	5(26%)	6(32%)	8(42%)	.494
	Married or cohabitation	7(15%)	20(42%)	21(44%)	
Occupation	Employed	9(19%)	15(31%)	24 (50%)	.285
	Unemployed	2(18%)	7(64%)	2 (18%)	
	Pensioner	1 (13%)	4 (50%)	3 (38%)	
Relationship	Child	10 (24%)	14(34%)	17(42%)	.413
	Spouse	1(9%)	4(36%)	6 (55%)	

	Other relative (siblings, nephews, grandchildren)	1 (7%)	8 (53%)	6 (40%)

The secondary carers mean scores HLS-EU-Q16 in comparison with the HLS-EU-Q16 of the primary carers follow.

Non-parametric tests were selected since the sample was small. An independent samples Mann-Whitney was selected to compare the means as two independent samples, primary and secondary carers' HLS-EU-Q16 (Mann-Whitney U=2014, p=.269).Then the paired sample non-parametric test Wilcoxon signed ranked test for the HLS-EU-Q16 (Z=-1.32, p=.186) among a sample of 67 primary carers and their secondary carers followed. No statistical significance was identified between the paired groups of primary and secondary carers for the HLS-EU-Q16

7.9.10. Analysis of the eHeals-Carer of the secondary carer

The analysis was continued with the eHeals-Carer, the second questionnaire distributed to the secondary carer apart from the HLS-EU-Q16.

The average eHeals-carer total score for the secondary carer was 30.54 (SD=4.34). Not all secondary carers used the internet to search for information online; for this reason, 64 from 67 people replied to this scale.

Table 7-84 eHeals descriptive statistics of secondary carers N=64

	Theoretical range	Min	Max	Mean	SD	%	Median
SEC_eHeals-Carer total*	8-40	20	40	30.54	4.34	76.35	30
SEC_eHeals-Carer 1*	5-25	13	25	19.22	3.16	76.88	19
SEC_eHeals-Carer 2*	3-15	3	15	11.12	2.49	74.13	11

Table 7-85 Crosstabs analysis of secondary carers eHeals-Carer and sociodemographic variables

Variable	Categories	Mean Rank eHeals total	p	Mean Rank eHeals 1	p	Mean Rank eHeals 2	p
Gender	Male	37.40	.421	31.90	.841	44.30	**.038**
	Female	32.20		33.20		30.95	
Age	<39	34.43	.846	33.43	.987	34.67	.769
	40-54	31.60		32.61		31.24	
	55+	33.95		33.18		34.45	
Education	Lower Secondary and below	40.17	.499	35.67	.802	47.33	.174
	Upper Secondary and Tertiary	32.65		32.87		32.31	
Marital	Single_Divorced_Widowed_Other	36.87	.286	33.61	.868	35.66	.462
	Married_Cohabitating	31.40		32.75		31.90	
Relationship	Child	32.02	.298	32.33	.577	31.54	.119
	Spouse	41.89		39		44.83	
	Other	30.33		31.23		29.90	
Occupational Status	Employed	32.13	.813	33.10	.992	31.05	.378
	Unemployed	34.50		32.36		36.91	
	Pensioner	36.50		33.36		39.93	

Non-parametric tests for independent sample Mann-Whitney to compare the means were computed for the two independent samples eHeals-Carer (Mann-Whitney U=1314, p=.189), eHeals-Carer1 (Mann-Whitney U=1366, p=.257) and eHeals Carer 2 (Mann-Whitney U=1308, p=.140) among primary and secondary carers.

Paired sample non-parametric test Wilcoxon signed ranked test followed for: eHeals-Carer total (Z= -1.04, p=.301), eHeals-Carer 1 (Z= -1.15, p=.909) and eHeals-Carer 2 (Z= -1.29, p=.194) among a sample of 64 primary carers and their secondary carers. No statistical significance was identified between the paired groups of primary and secondary carers for the eHeals-Carer.

7.9.11. Summary

The final part of the statistical analysis presented the information that was acquired for the secondary carer. The Health Literacy and eHealth Literacy of the secondary carers who participated in the study did not differ in comparison with their primary carers. Secondary carers involved had a high Health Literacy and eHealth Literacy level.

8. Chapter-Discussion

Carers of older people with chronic diseases and PwD undertake a somewhat burdensome role by supporting their relatives or friends in the activities of daily living. World Health Organisation, (2015) defines the carer of a person with dementia as a person who is related to the person with dementia, living together or separately and providing regular or occasional care. The service provision for carers and PwD depends on the health care system. In a recent estimation, informal carers in Europe range from 10-25% of the total population (Zigante, 2018). Informal carer concept is different from country to country and depends a lot from the care model typologies that we encounter per country. In an early work by Bettio & Plantenga, (2004) regarding the informal care in Europe, five care models of older people caring were discussed: 1) the Mediterranean countries with family to undertake the caring tasks, 2) the collective societies with both informal and residential care equally important (e.g. the UK, the Netherlands), 3) the countries with informal care being a private matter, but primarily supported by collective arrangements such as pension schemes and residential care (e.g. Austria, Germany), 4) the countries with the provision of formal services to be provided at a higher degree than private care (e.g. Belgium and France). Finally, the last care model describes the Scandinavian model, where formal services replace family, and this does not concern only vulnerable populations (e.g. children, older people) but is expanded to the majority of people. The above typologies ,even if they were described in 2004 and included 14 European countries, have analogies with the care models that we find today (Zigante, 2018). In the three of the five models described by Bettio and Platenga, the carer is considered to be a "*co-worker*" and in some extent a "*co-client*" as was described by the work carried out by Twigg, (1989)

In South-Eastern Europe, the families undertake the role of caring when there is a lack of public long-term care service, and this is considered cost-effective by the governments. As in the case in Greece and Cyprus, the highest percentage of PwD stays at home and are cared for by their families and friends and carers usually do not identify their role (Eurofamcare, 2006; Papastavrou et al., 2007). The non-for-profit associations provide services to assist carers and patients with everyday living. These types of services include cognitive training and physical exercise for the patients and psychosocial interventions for the carers. Psychosocial interventions can be grouped in psycho-educational skill-building ,psychotherapy-counselling, multicomponent and technology-based interventions (Dickinson et al., 2017; Elvish, Lever, Johnstone, Cawley, & Keady, 2013).

For at least two decades now, researchers have focused on the development of new web-based services that aim to facilitate carers during their caring, starting from simple access services to the more complicated. These types of services are for example informative websites and platforms, online counselling and social support services with the use of interactive services, psychoeducational and therapeutical (Cognitive Behavioural Therapy) programmes and applications and more advanced technologies as in the case of telemedicine and telehealth services (Barbabella et al., 2016; Chi & Demiris, 2015; Cristancho-Lacroix et al., 2015; Papa et al., 2016).

According to the European Quality of Life Survey (Eurofound, 2017), around 43% of the participants access the internet daily in Greece and 54% in Cyprus. Moreover, people report a low score on the question regarding how informed and consulted about health they are, with 7.8 in Greece and 7.6 in Cyprus on a scale from 1 to 10. The access and offer of web-based health services depend on several factors as well as cultural aspects. In Greece and Cyprus, we know that the main reason for internet non-use for the general population is the lack of skills (*Hellenic Statistical Authority: Population Census 2011*, 2011; Millioni & Stylianos, 2016).
The promotion of eHealth literacy training and the enhancement of carers' use of web-based services is a dual process. An important step is to understand the level of skills that carers have and on a secondary basis, to develop web-based services tailored for their needs. As we have already mentioned in the first chapter of this dissertation, the study aimed to identify the levels of perceived Health Literacy and eHealth Literacy of primary and secondary carers and to answer the main research questions by adapting and validating the Health Literacy and eHealth literacy tools in Greek:

- What are the levels of Health Literacy and eHealth Literacy and of the other caring variables of the primary carers
-Is there a difference between Health literacy and eHealth literacy level of primary and secondary carers of PwD?
- What is the association between Health literacy and eHealth literacy of primary and secondary carers of PwD?

- What is the association between Health Literacy and eHealth Literacy of primary carers of PwD with the sociodemographic characteristics?
- What is the association (if any) between Health literacy and eHealth literacy of carers and caregiving self-efficacy, coping strategies, their perceptions towards the caregiving role and perceived social support?

In the previous chapter, the results of the analysis among 174 primary carers and 67 secondary carers are presented. In this chapter, the core results concerning our research questions are discussed and the key relationships are revealed through the analysis. The study strengths and weaknesses, practical implications and future research follow.

8.1. Discussion of Principal Results

8.1.1. Demographics in relation to other research

Women carers were the majority in this sample (132/174, 76%). Children and spouses were almost equally represented in this research, with a slight increase in children caring for their parents with dementia (81, 47%). The age group 50-54 had the most significant representation in comparison with the other age groups (29 cases, 16.7%) and the majority of the carers were gathered in the age group 45-74 years (n= 133, 77%). On the other side, the patients with dementia were women (n=109, 63%) and half of this sample was over 80 years old (83, 48%). The demographics of this sample is in accordance with other studies in the field of carers in Greece and Cyprus (Dimakopoulou et al., 2015; Eurofamcare, 2006; Mougias et al., 2015; Papastavrou et al., 2015, 2007). Furthermore, considering caregiving stress process model by Pearlin, age, education, occupation, socio-economic position, gender and family history influence the way that a person reacts towards a stressor and define responsibilities, opportunities and rewards (Pearlin et al., 1990). Women carers, spouses and daughters, experience higher levels of burden, consider their role as obligation, care for more hours, face role strains (mother, daughter, wife, employed) and role captivity which may lead to physical and mental health problems (Sharma, Chakrabarti, & Grover, 2016)

The majority of this sample cared for over 71 hours per week. The mean reported hours of care per week were 87 hours. A large number of participants could not assess the number of hours and would reply 24/7. That was the case for 62 primary carers (35.6%), which is following relevant literature in Greece (Dimakopoulou et al., 2015). If we include, in the analysis, only the people who provided a response based on practical criteria (the perceived duration of the actual care offered to try to estimate the everyday tasks such as dressing, bathing, hygiene) and exclude responses of the type "I care all the time 24/7", then the mean reported time of the care is decreased to a mean of 42 hours per week. This finding is in accordance with the results as derived by EUROFAMCARE survey, one of the most extensive caregiving surveys in Europe, where primary carers of older people cared for a mean 45.6 hours (Eurofamcare, 2006). In another more recent report by the Alzheimer Disease International in collaboration with the Karolinska Institute (Wimo et al., 2018), the hours of care provided by carers of PwD are estimated in 82 billion in 2015, which is translated to 2089 per year and almost 42 hours per week or 6 hours per day. This report also relates women with the highest provision of hours of care (71%). In the report by Zigante, (2018), picturing the economic aspects of Informal Care in Europe including EQLS recent data, 15% of the total population and 13% of the people over 65 years old in Cyprus are informal carers of vulnerable populations (older people, adults with disabilities and children). For Greece, this is increased in 34% of the total population and 34% of people over 65 years old. The mean years of care for carers of PwD were 4 years which confirms relevant research (Papastavrou et al., 2007).

Other important characteristics for this sample are the years of education, employment and socioeconomic position since we measure the level of Health literacy and previous research has shown associations of these characteristics and Health literacy. Groups that are susceptible to limited health literacy are people with lower education, older age, lower SES and those reporting poorer health and make frequent use of health services (Sørensen et al., 2015). In this sample, over 79% (n=138) had an education of 12 years or more, with 58% (n=101) reporting tertiary education. A high percentage are pensioners (n=77, 44%), followed by employed (n=44, 25%) carers with a mean socioeconomic position of 5.86 (μ=1.53). Our carers' demographics could foresee a higher level of Health Literacy based on the findings of HLS-EU-Q16 as we will discuss in following sections.

8.1.2. Perceived Health Literacy

HLS-EU-Q16 Validation results

This study aims to fill in the gap of knowledge in the care of PwD and the association with Health literacy, eHealth literacy, perceived social support and caregiving variables such as self-efficacy, coping strategies and caregiving attitudes.

As part of this study, the first step was the validation of the HLS-EU-Q16 that revealed a slightly different model depicting possibly the cultural aspects of Greek and Cypriot carers: health promotion, media health literacy, compliance with doctor's instructions, health care and access and health-related decisions. The HLS-EU-Q16 follows the model provided by the HLS-EU team with 12 dimensions (Chapter 2, section 2.1) including 3 fields: health-care, disease prevention and health promotion and 4 cognitive dimensions: access, understand, appraise and apply. This model has been extracted as part of the HLS-EU-47 and Pelikan discussed the need for further investigation of the HLS-EU-Q16 dimensionality in his related presentations of this topic.

Health promotion

Health promotion includes 5 items regarding risk factors, health screenings, activities for mental well-being, family advice and everyday behaviour related to health. It includes the 3 dimensions of finding, understanding and judging.

In the initial version of HLS-EU-Q16, there are questions as for example activities for mental well-being, everyday behaviour related with health, family's and friends' advice, media health information, health risks and screening to disease prevention dimension. Health promotion could be considered as the means to promote Health Literacy. In a recent scoping review of the health promotion among carers of PwD, only seven studies, most of them were pilot and feasibility studies discussed this topic. According to the findings of this review, causes for carers' poor health are the age of the carers (usually older age), caregiving demands, avoidance of self-care, lack of knowledge and national services for carers' needs(Oliveira et al., 2019). In this sample, carers score high on this HLS-EU-Q16 subscale, with a mean score of 4.5 (range 0-5). This score is in accordance with the overall Health Literacy level that we will discuss in the following section, proving a first clue to the level of knowledge and motivation regarding self-care.

Media Health Literacy

In these results, we identify a new dimension, that gathers all three questions related to media into one dimension. Media Health literacy is not provided by the HLS-EU framework, even if we find it as a fundamental concept in the eHealth Literacy model. eHealth Literacy could be considered as a subcategory of Media Health Literacy since Media Health Literacy includes both digital and non-digital media (Levin & Bertschi, 2018). In the sample of this study, carers responded in this way, as they consider the media a source of health-related information, but without relying on this type of source. We can understand the above by the mean score for these three questions as they cover the second-lowest percentage (76%) of the total score range of the five dimensions. Furthermore, mistrust of the media was an overall comment of the participants during the face to face survey. This dimension of perceived Health Literacy was related with the majority of the sociodemographic characteristics, and it may also justify the association of HLS-EU-Q16 with the perceived eHealth literacy questionnaire, eHeals-Carer, that we will discuss in the following section.

Compliance with doctor's instructions

Compliance with doctor's instructions dimension includes 3 items about understanding the communication with the doctor, her/his instructions, and to follow them.

In this sample of carers, it is worth saying that the compliance with doctors' instructions depicts the culture towards the health care system since almost all carers find it easy to comply with doctors or pharmacist instruction and to understand instructions (mean score 2.98, range 0-3). The doctor is perceived as a healer following a mysticism method where the sick person has no saying on this (Harbishettar, Krishna, Srinivasa, & Gowda, 2019). According to Foucault, (2003), the doctor-patient relationship used to be influenced by societal factors. The doctor was perceived as an authority, and the patient is dependent on the doctor's orders.

The term compliance is an older term used to describe a more paternalistic and passive acceptance of the health professionals' directions and sometimes interchangeably used with the term adherence. Stimson presented the current terminology of that period for non-compliers as "defaulters, disobedient, unreliable, they deviate, uncooperative" (Stimson, 1974). There are several factors (over 200) related to non-compliance with medical advice, including trust, satisfaction and older age (Krot & Sousa, 2017).

Adherence on the other hand is defined by WHO "*the extent to which a person's behaviour-taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider*" and describes a decision-making process, respecting the autonomy of the patient (World Health Organization, 2003). The difference between the two terms is observed in the motivation to follow the suggested instructions and patients' active role (Sandman, Granger, Ekman, & Munthe, 2012).

The question regarding the compliance or adherence depends a lot on the organisation of the health care systems and as Foucault introduced by the patients' knowledge of the disease.

At the moment, even if there are studies measuring the level of Health Literacy among carers of adult care-recipients and older adults, there are limited studies focusing on carers of PwD (Jiang et al., 2018; Yuen et al., 2018). We may only make assumptions considering that they need to take care of their relatives and thus to gain disease-specific knowledge.

Health care and access

The two first questions of the questionnaire, concerning the skills to find information on treatments and to find the professional help somebody may require, were grouped and include the access component to information regarding Health care according to the categorisation made by Pelikan et al., (2012) In the HLS-EU framework, healthcare includes five more questions regarding communication with doctor and compliance with doctor's instructions that in this study form two separate dimensions. The carers in this sample replied high in this subcategory (mean 1.67, range 0-2), which follows the overall score of the perceived Health Literacy as we have seen for Health promotion dimension.

Health-related decision making

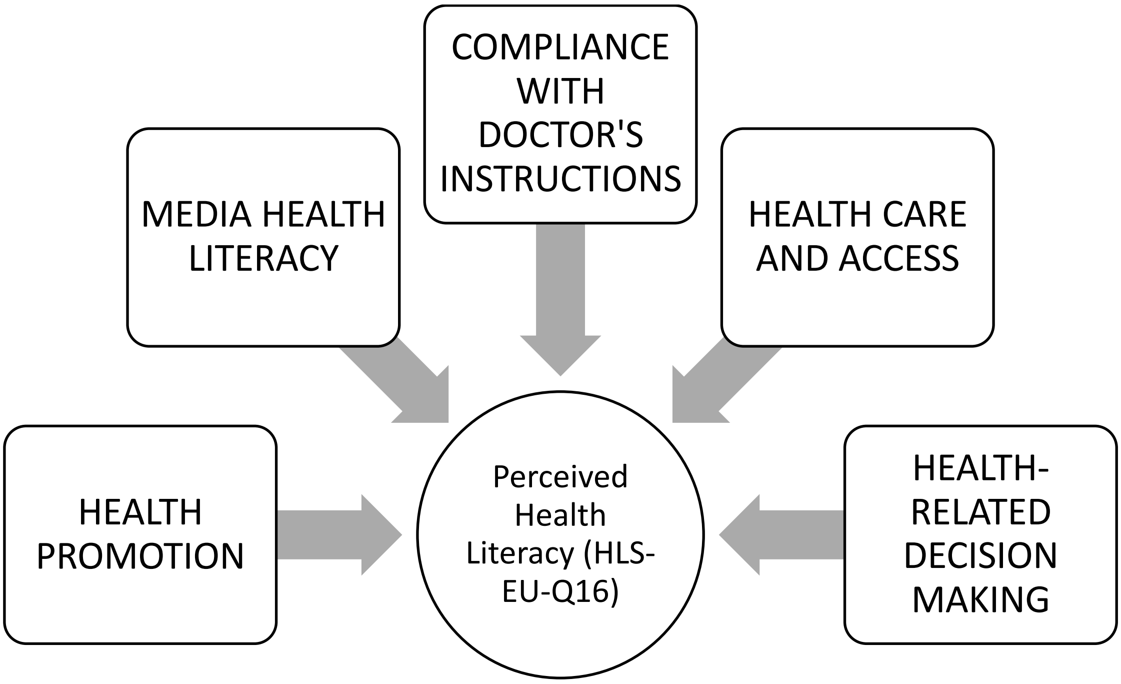
This domain includes 3 final questions of taking a doctor's second opinion, making decision on illness based on the information provided by the doctor and finding information to manage mental health problems. This dimension provides a lower percentage of replies (73%) of the score range (0-3). Health-related decision making may be negatively connected with compliance with the doctor's instructions. A higher score in compliance would provide lower scores in health-related decision making. This finding is confirmed in the study analysis, as compliance with the doctor's instructions has a higher mean score in comparison with the health-related decision making.

We have discussed the difference between compliance and adherence and how adherence may be better associated with patients' autonomy. In the case of carers' adherence and decision making process, we find a qualitative study by Kelly, McCarthy, & Sahm, (2014) focusing on medication adherence and introducing topics related to carers such as polypharmacy, side effects, family support, relationship and communication with the health care professional, disease severity, self-regulation and cost of the medication.

In the case of carers of PwD, the issue of shared decision-making is more complicated as during the last decade there is an international movement for patients' involvement in the decision-making process. According to the Mental Capacity Act 2005, the UK provided flexibility in the decision-making process recognising the capacity as "decision-specific" and regarding the successful process through the involvement of the person with dementia, the carers and the professionals (Dening, Sampson, & de Vries, 2019).

In this sample of carers, health-related decision making has appeared as a dimension of Health Literacy, even if represented with three questions in the HLS-EU-Q16. Carers provided the higher percentages of adverse responses on this scale in comparison with the other subscales. Researcher's observations also confirmed this finding during the face to face survey as carers had difficulty in understanding the specific question "how easy would you say it is to use the information the doctor gives you to make decisions about your illness?". To facilitate understanding, the researcher provided a specific example that included the treatment choice or medication adherence. Most of the time, carers commented on this example that they always follow the doctor's instruction.

Figure 8-1 The five dimensions of the HLS-EU-Q16



Health Literacy among Primary carers

Based on the results of this study and comparing to the HLS-EU Survey in Greece, carers of PwD provided results in only 2 out of 3 categories: problematic (9-12, n=41, 24%) and sufficient (13-16, n =133, 76%). There was no response categorised as an inadequate level of Health literacy. Three new categories were developed based on a statistical criterion of quartiles to proceed with the analysis. This categorisation was necessary as carers in this sample were considered as an educated population, supporting the hypothesis that they need the knowledge of the disease to support the patient, especially in later stages of the disease (Yuen et al., 2018). The high perceived Health Literacy scores of this sample can be explained if we consider the carers' characteristics, since the majority of this sample were women, caring for their parents, with more than 12 years of education, belonging in the age group 45-74 years. It was confirmed through bivariate analysis the differences of Health Literacy level according to age, education, occupation, relationship status, hours of care, reporting a secondary carer and internet use. A tendency was also found regarding marital status (Section 7.6.1.1., Table 7.18).

Furthermore, the dimension of media Health Literacy of the five dimensions of HLS-EU-Q16 played the most critical role in influencing the mean differences of Health Literacy levels with the carers characteristics (section 7.6.1.2). Carers of this sample consider the information that they receive from the media (including internet, television, press) as difficult to evaluate for reliability. They also consider that they take some actions regarding primary care (screening options) from the information they find online, in health tv shows or press, but nothing else apart from that, and always ask their doctor for advice. Finally, language and terminology used in the media, are easy for carers to understand.

When we have proceeded to identify the predictor variables in this sample, we have confirmed the role of education, occupation and reporting a secondary carer with the perceived Health Literacy but we do not confirm age and socioeconomic position.

Carers with upper secondary education or tertiary education, being employed or receiving assistance from another person is more likely to report higher levels of perceived Health Literacy in comparison with people with less than 9 years of education, not employed and without reporting a second person for assistance.

Age, education, social status and occupation are considered to be essential factors for the HLS-EU-Q according to the literature (Pelikan et al., 2012; Sørensen et al., 2015). The above is also partially in accordance with previous literature of Health Literacy, where older people, with higher use of health services, poor health status, lower socioeconomic status is possible to report limited Health Literacy (Sørensen et al., 2015; World Health Organization, 2013). In a recent scoping review paper on Health Literacy among carers of adults, demographic characteristics associated with carers' Health Literacy are age, race and education (Yuen et al., 2018). Education was also a predictor in another study of carers in Brazil (de Almeida et al., 2019). Adequate Health Literacy has been a predictor for internet use in a study with carers of children with asthma, but in this case, functional Health Literacy was measured (Fagnano et al., 2012).

Additionally, in the findings of this study reporting a secondary carer is a predictor for Health Literacy. This term is not so frequently used, and we did not find available research regarding this topic within this specific context. In this study, for the first time, the secondary carer is a predictor for the higher level of perceived Health Literacy. If a carer reports a secondary carer, this might be equivalent to report the available received tangible social support. In this study, as a small number of secondary carers was recruited, it was confirmed that, the received tangible support reported by the carers was in accordance with the tangible social support reported by the secondary carers. When a person suffers from dementia more than one carer is involved. Until now the way that the secondary carers influence the primary carers' work is unknown, even if there is vast literature for the role of social network and social support. We have already discussed the buffering role of social support as presented in the perceived stress model and the health problems derived from the restricted social network and social exclusion experienced by carers. In this sample secondary carers were either children (61%), friends, neighbours and extended family (22%) or spouses (16%).

8.1.3. Internet use and the perceived eHealth Literacy

How the Primary Carers use the Internet

From this sample the majority of primary carers were internet users (n=135/174) and mostly women of the age group 45-74, married or cohabitating, with more than 12 years of education, being employed or pensioners and reporting a secondary carer (n=103, 77%). In the questions regarding the reasons for internet use, information seeking is the most frequent reason, followed by reading the news and socializing. Regarding the care-related use, 121 out of 174 used the internet to find this type of information. The carers mostly search for dementia - specific information on the websites, communication by emails and social media. eLearning function seems to be rather a rare choice, and this is probably due to the lack of relevant tailored eLearning services for carers in Greece and Cyprus. Web-based care-related information-seeking may be translated in the emotional/informational dimension of social support as it will be discussed in a later section.

The smartphones are used to seek dementia-specific information almost by half of the sample of the carers (n =70/135) who are internet users. Carers characteristics in this subgroup were similar to our total sample with a slightly higher SES and the majority of the sample being employed.

Taking into consideration the findings by Kim, (2015), there is a higher percentage of dementia-related internet use 69 in comparison with 59%. Kim expressed this as health-related internet use (health-related information and caregiving issues), which may include general information regarding the health of the carer and the care-recipient.

Furthermore, in this sample, differences by the bivariate analysis were identified:

- in the use of the internet based on the hours of care, with people with fewer hours of care to be more likely to use the internet,

- in kinship status, with children also to report using the internet than the spouses,
- in education and marital status, with carers with higher education, younger, single and employed to report using the internet in comparison with lower education, married, unemployed and pensioners carers.

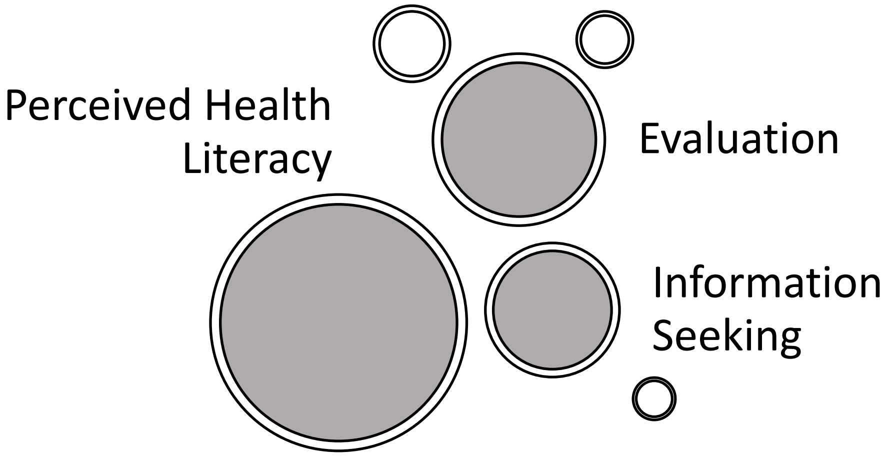
When the predictors were identified, education was the only predictor variable for internet use among this sample of carers. As it is discussed in the relevant research of internet use among carers (Chapter 4), the socioeconomic characteristics that influence internet use and access are the age of the carer and care-recipient, gender, occupation, living arrangements, hours of care, education, relationship, emotional stress, level of dependency, type of carer (primary or secondary carer), health status, caregiving strain, service needs (Blackburn et al., 2005; Kim, 2015; Li, 2015). In this study, even if there is an association with hours of care, relationship and education, only education remains as a predictor for internet use.

eHeals-Carer Validation

The eHeals - Carer was developed as a way to measure eHealth literacy levels of carers with a brief scale, easy to relate. The adapted version of eHeals included two dimensions: "information seeking" and "evaluation" (section 7.4.1.3.). In the case of the Information seeking, the first five questions of the questionnaire were included and in the evaluation section, the three last questions. According to the relevant research, there are different categories derived from the analysis of eHeals scale such as awareness (1,2) skills (3-5), information seeking (1-5 & 8 or 3-4), information appraisal (6,7), information engagement (5-8), evaluation (6-8). This difference from other researchers might derive from the cultural adaptation of the tool. Taking for example item 5 "I know how to use the information about the health and caregiving of my friend/relative I find on the Internet to help me (practical, financial, legal issues, information about the disease and available services)" was perceived as a competence/skill item on how to do instead as an item for evaluating the information.

It was essential to include the element of caregiving with this scale because there are no available tools to measure eHealth literacy for this population and carers usually search information for their care-recipients (Alwan et al., 2011; Fox & Brenner, 2012). By adapting the tool to the needs of carers, we made the tool easy to use and understand. Furthermore, the use of the specific tool will facilitate the research and the inclusion of this population in this research field. As it was discussed earlier, there is research only on issues related to the health-related internet use, and we cannot find references on the level of carers' eHealth literacy across the literature until 2019 (Soleimaninejad et al., 2019). Carers of PwD play a different role in every stage of the disease. They manage the communication with the healthcare professionals on behalf of the care-recipient. They manage care-recipients' care in many different levels, making health-related decisions, and they are usually seeking information for the care-for person either through the channel of healthcare services or online. They may look for information about the disease, prognosis and treatment, available services, practical issues and communication (Fox & Brenner, 2012; Kim, 2015; Li, 2015).

Figure 8-2 Dimensions of the eHeals-Carer Scale



After the analysis of the results, a high mean score of eHeals-Carer questionnaire for the total sample of primary carers who used the internet was obtained (29.21, SD=4.8 / n=135). This score is an overall high score in comparison with other studies and populations (Appendix II, Table II.1). More specifically, in the studies of older adults with a chronic condition or not, we find mean eHealth Literacy Scale scores from 28 to maximum 30.94 (Chung & Nahm, 2016; Paige, Krieger, Stellefson, & Alber, 2017; Stellefson et al., 2017; Van Der Vaart et al., 2011). Only in one case with older adults of mean age 74, we find a mean score of 22.35 (SD 12.96), and in the case of carers of patients from otolaryngology and neck department, the score is in percentage transformation of 0-100, 66.3%. From the above, the score of this study is considered high in comparison with other samples of people over 50 years old, according to the findings of the scoping review (2) (APPENDIX II)

In this group of carers, there are differences in the means for education, relationship (child or not), occupation (pensioner or not), reporting a secondary carer. Perceived eHealth literacy was filled in by the carers who used the internet, so was not possible to assess the association of eHealth literacy with internet use, as other researchers have done (C. Norman, 2011; Van Der Vaart et al., 2011).

To overcome this difficulty, a set of supplementary questions was added regarding dementia-specific internet search to support the lack of web 2.0 questions in the eHeals-Carer version. Mean scores of the eHeals are different in these set of questions, being higher when using these online services for searching dementia information and lower if not. The online services covered website search, social media, email and interactive service (Viber, messenger, skype) use for dementia-specific information, eLearning use and dementia information seeking from mobile internet.

After multiple linear regression, only the occupation was a predictor variable for eHeals-Carer, with pensioners to report lower levels of eHealth literacy.

In Greece, the only recent work on perceived eHealth literacy with the use of eHeals is that of Xesfingi & Vozikis, (2016). Xesfingi and Vozikis differentiate eHealth Literacy to four levels, low, fair, enough and high, and they report fair as the most frequent level of the study sample. According to this work, age and education were strong predictors of eHealth literacy.

The above finding is confirmed by other researchers also adding income, race minorities, number of electronic devices, internet use, confidence completing medical forms, time spend on the internet, physical exercise, computer stress, occupation (Arcury et al., 2018; Bonner et al., 2018; Choi & Dinitto, 2013; Halwas et al., 2017; Noblin & Rutherford, 2017; Richtering et al., 2017; Tennant et al., 2015).

In this sample, being a Pensioner played a predictive role in the eHealth Literacy level. Occupation as sociodemographic characteristic encloses age and SES and is considered as a more complex variable than age alone. Being a pensioner is associated with older age and with social and economic status. In the findings of this study, carers who are pensioners report a lower level of perceived eHealth literacy in comparison with carers who are still studying or unemployed.

8.1.4. The association of perceived Health Literacy with perceived eHealth Literacy

A medium positive correlation with the eHeals – Carer was found, with higher scores of perceived health literacy to be associated with higher scores of perceived eHealth literacy among primary carers of PwD. After the regression analysis and the adjustment of internet use, education, occupation, secondary carer, older age and SES, this association remains, making

HLS-EU-Q16 a good predictor for eHeals-Carer, or otherwise, the levels of perceived Health Literacy are possible to predict perceived eHealth literacy. This study fills the gap in the carers' literature for these two concepts. Taking into consideration the model of Norman and Skinner, Lily, Health Literacy is one dimension that explains this concept. On the other hand, and based on these findings, Health Literacy is actually an umbrella term that includes the concept of eHealth Literacy (Norman & Skinner, 2006b). It is not possible to be eHealth literate without being first Health literate, and this is also confirmed by our findings with the sample of carers of PwD.

Perceived eHealth Literacy apart from the associations with perceived Health Literacy, as earlier discussed, was not associated with the three dimensions of self-efficacy in this sample. Associations with coping strategies and caregiving attitudes were found.

8.1.5. The other caregiving variables: Perceived Social Support, caregiving self-efficacy, coping strategies and perceptions towards caring

Perceived Social Support

In this sample, the mean score of perceived social support total score and subscales were high (Total score 64.79/84).

Social isolation among carers of PwD is a frequently researched topic with ambiguous findings according to a recent metanalysis by del-Pino-Casado et al. on the social support among carers of adults and older people (del-Pino-Casado, Frías-Osuna, Palomino-Moral, Ruzafa-Martínez, & Ramos-Morcillo, 2018).

As the disease progresses, carers have difficulty in following the social interactions and roles that they used to have and in most of the times, they stay at home with few close relatives to provide support. A term that we usually find in carers' studies instead of social support is "social inclusion" and "social exclusion". Social exclusion is strongly related to stigma and discrimination and sometimes even considered as mediators, and there is a lack of available studies among carers of PwD (Greenwood, Mezey, & Smith, 2018)

Carers' perceived social support alleviates the burden. There is research on the perceived and received support by carers, according to del-Pino-Casado et al. (del-Pino-Casado et al., 2018). Furthermore, we know that social capital, "*networks together with shared norms, values and understandings that facilitate co-operation within or among groups*", is negatively associated with the burden (Papastavrou et al., 2015)

In this sample, perceived social support by the significant other differed among carers who were married or cohabitating and carers who lived alone, with the latter to report lower scores. Carers reporting a secondary carer had a higher perceived social support score by a significant other than those who did not. Additionally, carers with fewer hours of care (below 70 hours) reported a higher score for the support by the significant other. The family dimension of perceived social support was well explained by marital status, with married people reporting higher perceived social support by the family in comparison with carers who lived alone. Age, internet use, reporting a secondary carer and SES were the predictors for social support by friends. Carers over 75 years reported less perceived social support by friends than younger carers. Using the internet, reporting a secondary carer and SES lower than 6 predicted a higher score in the friends' dimension. The overall perceived social support (including all three dimensions) were predicted by the secondary carer, the marital status and age.

Interestingly, an association for Health Literacy with the perceived social support among children who care for their parents with dementia was found, when the associations were checked according to the relationship status. The relationship between social support and network for Health Literacy was not very clear, and we received confusing results (del-Pino-Casado et al., 2018). There was the assumption that the reporting of the secondary carers would act as an information resource and facilitate carers. As a result, the secondary carer was a predictor for the perceived Health literacy and a confounder variable for the association of perceived Health Literacy and eHealth literacy with the other caregiving variables such as (caregiving attitudes, emotion-focused coping strategies and Self-efficacy to obtain respite).

On the other hand, there was no association of MSPSS with Health Literacy and eHealth Literacy. It is thought that probably in one occasion the received tangible social support that has an actual association with the Health Literacy was measured and in the case of MSPSS, the perceived social support, and that is probably the reason for these findings. In a related study of the association of Health Literacy and social support, older people with lower Health Literacy (measured with S-TOFHLA), were more likely to receive reminders for doctors' appointments and support for medical information and less likely to receive tangible support(Lee et al., 2006). Furthermore, satisfaction with social support was associated with the positive caregiving attitudes, something that we also found in the perceived social support and the positive caregiving attitudes of this sample (Lee & Choi, 2013).

Perceived caregiving self-efficacy

In this sample, some carers were not able to reply to all three dimensions of the revised scale of perceived self-efficacy. Carers of patients with early-stage dementia did not consider it necessary to find a friend or a relative to stay with the care-recipient (4 primary carers). In the second subsection of Self-Efficacy to manage behavioural symptoms, carers whose care-recipient was in a severe stage of dementia (9 primary carers) could not reply to this section as no behavioural disorders were apparent. The third and final section of Self-Efficacy of controlling upsetting thoughts was the only section that all carers replied to and in many cases, felt emotionally overwhelmed by the questions. This difficulty in the three categories has also been discussed by the authors who created this questionnaire in a recent cross-national review, where they included all available validations until 2018 (Steffen et al., 2018). According to this review, the authors do not advise distributing SE-OR to early-diagnosis, as well as the SE-BM to the early, severe or non-existent stage of dementia. They also add that they observe cultural-specific aspects based on different validations. They discuss the SE-OR dimension and especially the question "*asking a friend/relative to stay with the care-recipient for a day when the caregiver needs a break*", since it may be a complicated item to reply to when carers come from countries with "*collectivist cultural background*" as this is the case of South-Eastern European countries (Steffen et al., 2018). In Greece and Cyprus, respite care is an unknown term and not easily accepted especially for women, who undertake the caring role. This was revealed during the face to face survey and especially in the question "*How confident are you that you can ask a friend/family member, that s/he can stay with your relative with dementia for a week when you need the time for yourself?"* Carers replied with a negative response immediately, without usually a second thought. Almost half of the sample replied 0% (54%) and 75% of the participants replied below average (50%).

The above observation was also confirmed in this study. The higher mean score was in the section of self-efficacy managing behaviours and the lowest in the case of obtaining respite. In this sample, since the level of Health Literacy was high, an association with the SE-BM was found, so we can easily justify the high score of SE-BM. On the other hand, the low score of SE-OR was easily explained by Steffen et al. observation. The fourth and fifth question in the SE-OR received the lowest score. These two questions ask the carers if they can find a friend or relative to stay with the care-recipient for a day or a week if carers wish to relax.

Carers who reported another relative or friend assisting with the care in everyday tasks (secondary carer) reported a higher score in the SE-OR. Interestingly, the same result is found if carers reported that they also cared for others and not only for the person with dementia. In this question, carers mostly reported caring for other relatives such as their children or grandchildren, providing information for a family network that might explain their ability to obtain respite.

In the case of SE-BM scores, gender, occupation and type of relationship played a role, with men reporting higher scores than women carers, and employed rather than unemployed.

Carers, in this study with a higher SES, provided a higher score in self-efficacy of thought control.

The subdimension of controlling upsetting thought may be more challenging to understand as it is based on the Cognitive Behavioural Therapy (CBT) and the participants may lack the skills to identify the degree of certainty to control the thoughts. "Controlling" a thought is a frequently used expression in CBT but can be quite difficult outside CBT framework (Romero-Moreno et al., 2011; Steffen et al., 2018).

Relationship, gender, the onset of dementia and ethnicity were some of the predictors of the revised Scale of Caregiving Self-Efficacy. Also, self-efficacy has been identified as a predictor of health-related quality of life, and other variables of physical and mental health (Crellin et al., 2014; Steffen et al., 2018).

Perceived caregiving self-efficacy in association with perceived Health Literacy, eHealth literacy and other caring concepts

In this case, the previously established association of Health literacy and self-efficacy was confirmed. There was a lack of research regarding Health literacy and self-efficacy concepts among carers of older adults and PwD, but this association was identified in other samples such as older people, low-income mothers and parents of pediatric patients, patients with diabetes (Chen et al., 2013; Fong et al., 2018; Fry-Bowers et al., 2014; Huang et al., 2018; Inoue et al., 2013; Lee et al., 2018). In the research among older adults, Chen et al., (2013) presented their findings on the association of Health Literacy, self-efficacy and health care utilisation. They found a positive effect of Health Literacy on self-efficacy and health care utilisation. In another study, among older Korean people, self-efficacy acted as a mediator among Health Literacy and physical and mental health (Kim & Yu, 2010). The mediating role of self-efficacy among Health Literacy and health outcomes or behaviours is supported by other studies too (Huang et al., 2018);

Self-efficacy in obtaining respite was considered by carers as a rather difficult dimension of caregiving, as most of the time the carers may report that they cared 24/7 and it was challenging for them to find a person even a paid person to stay with their care-recipient for a few hours.

After adjusting for the secondary carer, caring for others, occupation and SES, the statistically significant association of perceived Health Literacy with caregiving self-efficacy remained. Carers who were well informed, understood better their role and as a consequence felt sure to request support by the other family, friends, neighbours to stay with their relative. A familiar feeling among carers was guilt for self-care connected with doing other tasks than caring (e.g. going out with friends, going shopping, doing exercise), this is a comment that consulters hear from carers regularly and is strongly related to burden (Losada, Márquez-González, Peñacoba, & Romero-Moreno, 2010). Self-efficacy for obtaining respite could be facilitated by the Health Literacy level of the carer, as through information and better management, the carer may understand easier the caregiving role.

Adding to the above, a carer who can search for, find and apply dementia-related information is more likely to be able to better manage the behavioural disorders of a person with dementia. On the other hand, the caregiving self-efficacy controlling upsetting thoughts is not so easy to be explained by the level of Health Literacy, even if initially, an association was idenified, after the adjustment for occupation, SES and COPE positive, this association has not been confirmed.

Self-Efficacy was not associated with eHealth literacy, but relations were found with the perceived social support, quality of support, negative caregiving attitudes, positive caregiving attitudes, problematic (dysfunctional) coping. In the case of social support and self-efficacy, there is research to confirm this finding with carers' self-efficacy to have a mediating role for family carers among social support and depression (Au et al., 2010). Optimism is also considered to be a mediator of self-efficacy, perceived social support and well-being (Karademas, 2006). The positive caregiving attitudes could be partially considered as optimism as even in difficult situation derived from the care-recipient disease, the carer has positive attitudes and find positive aspects in caring. According to the systematic review by Crellin et al., (2014), self-efficacy is related with the positive aspects of caring in 9 studies, with higher levels of self-efficacy to have an increase in caregiving aspects, as satisfaction, gain, resilience. Carers with a higher caregiving self-efficacy and sense of mastering are more satisfied by their role and better cope with challenging situations (Crellin et al., 2014).

Additionally, self-efficacy to obtain respite may have acted as a partial mediator for the association of perceived social support and quality of support. Quality of support measures the attitudes regarding support by family, friends and social services during caring and was associated with the overall perceived social support by significant other, family and friends. This association seemed to be mediated by the self-efficacy to obtain respite. This mediation needs to be treated with caution as the study design did not search for these causal effects and appeared through the analysis. There is strong theoretical background on the role of self-efficacy as a mediator in the association of social support with other variables.

Coping Strategies

Coping strategies were measured with COPE BRIEF that was validated in Greek by Kapsou et al., (2010). In the validation of Kapsou et al., 8 dimensions from the initial 14 were included in the instrument. In order to facilitate analysis, the number of factors for this sample of carers were investigated and regrouped according to related research (Monteiro et al., 2018). To group the dimensions, we also took into consideration the qualitative comments made by the carers during the survey process. As it was revealed and discussed also in the results section, the expression of negative feelings was not always considered by carers as maladaptive. Additionally, avoidance had also a positive and negative dimension.

According to Carver et al., (1989), there are three coping strategies: problem-focused, emotion-focused and less useful coping strategies, based on this categorisation we proceeded with ours, as problem-focused, emotion-focused and problematic (dysfunctional) coping. In this way, it was easier to interpret our results in coping.

The coping theory has progressed a lot during the last 30 years as we presented in the introductory part (Chapter 3, section 3.9). Lazarus and Folkman have developed one of the most popular theories of coping, describing the emotion-focused and problem-focused strategies and the appraisal process, when the person initially assesses the stimulus as threatening or not and then assesses his/her resources to cope with them (Lazarus, Richard S.; Folkman, 1984). The role of stress and coping in caregiving is well explained by Pearlin's model. In the Pearlin's model, coping strategies are considered to mediate, and he admits that the stress sources cannot merely explain caregiving concepts, but coping and social support have an important role (Pearlin et al., 1981). Coping for Pearlin has three functions "*management of the situation giving rise to stress; management of the meaning of the situation such that its threat is reduced and management of the stress symptoms that result from the situation*"(Pearlin, Leonard, Mullan, Joseph, Sepmle, Shirley, Skaff, 1990). As Carver et al. discuss, coping responses are quite different within the categories interpreting successful coping hard. For example, in the emotion-focused strategies, we have both positive and negative coping styles. Seeking instrumental support could be considered as problem-focused strategy and mental disengagement, depending on the situation, could be considered quite adaptive (Carver et al., 1989).

In a recent systematic review of coping strategies adopted by the carers of people with Alzheimer's disease, emotion-focused strategies are frequently used by carers and especially regarding religion and spirituality, assisting in alleviating mental health problems such as depression and anxiety. Problem-focused coping alleviate burden and dysfunctional coping increase burden. Furthermore, in this review, the frequently used strategies were acceptance, emotional support, humour, positive reframing and religion. In the problem-focused strategies are included active coping, instrumental support and planning and in the dysfunctional coping strategies, behavioural disengagement, denial, distractive strategies, self-blame and venting (Monteiro et al., 2018).

In this study, problem-focused strategies were the more frequently used coping strategies, followed by adaptive coping. Adaptive coping questions included the two questions concerning the distraction strategies from caregiving difficulties (doing something else to think about it less, e.g. going to movies and turning to work or other activities to take my mind off things). The other emotional-focused subcategories did not receive a high score and humour had the lowest percentage. The reason for this largely depends on the two ambiguous questions for humour in Greek translation. The first included the humour element and the other had a negative meaning of irony. These items were discussed with the authors who developed the Greek translation and confirmed that the participants did not face any difficulties in comprehending the meaning of these items.

Problematic (dysfunctional) coping received the lowest score for all the 3 subdomains, and substance use had the lowest score. We could explain the above finding by the available Greek translation. In the two questions, there was drugs and alcohol as a means to cope. Carers, as soon as they read about drugs, did not assess the other elements, e.g. smoking, alcohol. Their reaction could be considered an attempt to normalise their behaviour according to social norms. Only in a few cases, they needed clarification if they could reply only for their smoking habit or alcohol intake. As in previous case, the authors of the Greek translation explained to us that they proceeded with this translation and they did not encounter any problems in the analysis.

Emotion-focused coping (including support seeking, expression of feelings, adaptive avoidance, religion and humour) had differences in the mean scores among male and female carers, upper secondary and lower secondary education and internet use. After the regression analysis, only gender and internet use remained as predictors of this emotion-focused coping. The gender differences among carers who use emotion-focused strategies are confirmed by other studies, as they are mainly adopted by women and are associated with a higher burden. Internet use in this study could be explained based on the information we received by carers on the way they use the internet. When carers who used the internet for socialising (social media and interactive services), adopted emotion-focused coping in comparison with carers who used the internet for entertainment. This finding also influenced our results in relation to eHealth literacy scores, as we discuss in the relevant section.

In other studies, emotion-focused coping is also associated with higher psychological and environmental aspects of the quality of life, reduced depression and anxiety, behavioural disorders, lower perceived stress, burnout, better care outcomes (Monteiro et al., 2018; Rodríguez-Pérez, Abreu-Sánchez, Rojas-Ocaña, & del-Pino-Casado, 2017). Successful caregiving is relying on problem-focused strategies, and the role of avoidance coping is still unclear, associated in some studies with depression. (Cooper et al., 2008; Lavarone et al., 2014; Papastavrou et al., 2007; Roche et al., 2016). Higher education has been identified as a predictor for problem-focused coping strategies and lower education for emotion-focused coping in a recent systematic review by Roche et al. The differences in the emotion-focused strategies' score according to the education attainment were confirmed in this study. However, education was not confirmed as a predictor

In the case of problematic (dysfunctional) coping, hours of care have been considered as a predictor in this study. Carers with more hours of caregiving were more likely to report higher scores in problematic coping. In the review by Roche et al., predictors for emotion-focused coping and problematic (dysfunctional) coping were ethnicity, quality of the premorbid relationship, duration of care. In the case of the behavioural disorders in dementia, the majority of studies find an association with negative direction between the emotion-focused strategies and BPSD and a positive direction with the problematic (dysfunctional) coping (Roche, MacCann, & Croot, 2016).

Coping strategies in association with perceived Health Literacy, eHealth literacy and other caring concepts

Problematic (dysfunctional) coping and burden may predict anxiety and depression in carers, decreased quality of life, higher BPSD and institutionalisation (García-Alberca et al., 2012; Li, Cooper, Bradley, Shulman, & Livingston, 2012; Roche et al., 2016). In this study, problematic (dysfunctional) coping was associated to Health Literacy. It can be predicted among carers with a lower perceived Health Literacy when adjusted for hours of care, perceived social support by a significant other, self-efficacy behaviour management and thought control and SES.

Problematic (dysfunctional) coping could also be regarded as a mediating factor in the association of self-efficacy in behaviour management and negative aspects of caregiving. As we have presented earlier, the self-efficacy of the management of behavioural disorders was associated with the attitudes of caregiving. Negative perceptions of caregiving as part of the COPE index discusses the views of carers (is caregiving demanding, does it influence relationships with friends, family, does it influence mental and physical health and financial life). The Problematic (dysfunctional) coping, in this case, may have acted as a third variable that mediated the association as mentioned above.

In the findings of this study, emotion-focused strategies were associated with the eHeals-Carer "information seeking". Emotion-focused strategies included support seeking, expression of feelings, "adaptive" avoidance (2 questions on activities in order to think less), religion and humour (section 7.4.4.). After adjusting for gender, education, internet use, perceived social support – significant other, years of care, activities of daily living, SES and younger age, carers with a higher score in the perceived skills in searching and finding web-based care information expressed higher score in emotion-focused coping strategies.

The above could be justified if we consider that in this sample of carers, the specific scale may have expressed the social aspect of the web-based internet use through the use of social media and other interactive services. To confirm this assumption, the coping styles in relation to the internet use preferences reported by the carers were checked. There were differences in the emotion-focused strategies among carers who used mostly social media in comparison with carers who used the internet for entertainment (e.g. watching videos, listening to music, gaming). The above adds to the justification and provides evidence on the way that carers may report dementia-specific internet skills according to the eHeals-Carer 1 "information seeking". The questions of the first part of eHeals-Carer may described the social aspect of the internet use made by the carers.

Perceptions towards caring

The perceptions towards caring were measured with COPE index, and we obtained 3 dimensions: positive, negative and quality of support. The questionnaire has been developed considering the positive and negative outcomes discussed by Kramer, (1997) and was used in the large study among carers in 6 European countries, EUROFAMCARE (Balducci et al., 2008). In Kramer's work, we find the definition of positive aspects of caring as the gain, "*the more positive appraisals of the caregiving experience*". The importance to investigate the positive aspects, according to Kramer includes 4 axes: 1) carers' report positive experience, 2) clinicians need this information to better understand, 3) positive aspects are part of our understanding for the quality of care and 4) the positive appraisals of caregiving adds in the theoretical framework of carers' adaptation. Negative aspects are well researched and usually discuss the dimensions of burden (physical, mental, emotional, social and financial). The items of COPE index include all these aspects with an additional item of role captivity. In section 3.8, the association of self-efficacy and positive aspects of caring are discussed. Positive aspects of caring include different outcomes such as gain, satisfaction, rewards, mastery.

In this study, the mean score for positive aspects of caring was quite high in comparison with the other two dimensions of negative thoughts and quality of support. Taking into consideration, the findings from the secondary analysis of EUROFAMCARE study, the mean overall score for positive value was 13.45 and for Greece, 13.77 and the mean overall score for the negative value was 11.89 and for Greece 14.30. In this sample, carers expressed a high negative attitude score (>16). The positive perceptions score was in accordance with the findings of Balducci et al (2008).

The mean score of Quality of support was statistically different for the group of carers that they reported receiving assistance by a secondary carer.

Mean score differences of positive perceptions were found in education and internet use. After the regression, only internet use remained as a predictor. This finding related to internet use and the positive aspects of caring could be justified as in the cases of emotion-focused strategies, perceived eHealth literacy "information seeking".

In the mean scores of negative aspects, we found differences in the hours of care, years of care, gender and kinship. After regression, years of care, gender and kinship remained predictors. The negative experience of caregiving is a well-searched concept and is associated with ethnicity, education, occupation, poor health, behavioural disorders, dependency, hours of caregiving, social support and family conflict. In relevant research, gender and kinship have been associated with the positive experience, with female carers and adult-children to report higher in the negative experience scales (Lin, Fee, & Wu, 2012)

Perceptions towards caring in association with perceived Health Literacy, eHealth literacy and other caring concepts

In caregiving perceptions, associations of COPE positive with eHeals-carer total and eHeals-Carer 1"information seeking" were found.

Perceived eHealth literacy predicted positive perceptions towards caring after adjusting for internet use, education, problematic coping and perceived social support and this is confirmed for the "information seeking" dimension.

Considering the above justification of the emotion-coping strategies, we could continue our rationale based on this hypothesis, of eHeals-Carer capturing the social (interactive) aspect of internet use among carers. In this respect, it makes sense that the positive perceptions were associated with the eHeals -Carer 1.

8.2. Carers' Profiles exploring the perceived Health Literacy and eHealth Literacy with the other caregiving variables and perceived social support

Additionally, in the above discussion on the association of the Health literacy and eHealth literacy, we have extracted 3 carers' profiles through the cluster analysis:

1) Carers with high HLS-EU-Q16 and eHeals-Carer and a high self-efficacy
2) Carers with high problematic (dysfunctional) coping, COPE -negative attitudes and all the other dimensions decreased
3) Carers with high HLS-EU-Q16, eHeals-Carer, high emotion-focused coping, positive perceptions and high social support, quality of support.

The above profiling provides us with a quick categorisation of all available variables, based on the core concepts perceived Health Literacy and eHealth literacy. According to these three profiles, there was a group of carers that had a high level of Health Literacy, eHealth Literacy and self-efficacy. This group seemed not to depend on social support and to handle their caring role adequately, revealing the association of Health Literacy with self-efficacy that is already available in previous literature (Chen et al., 2013; Donovan-Kicken et al., 2012).

The second group is also self-explanatory, with carers engaging in problematic (dysfunctional) coping strategies and reporting higher negative perceptions in comparison with the other two groups. All other variables did not affect this group, and also the levels of Health Literacy and eHealth Literacy were low.

The third group could be considered as more complex to explain as in this case, carers report high levels of Health Literacy and eHealth literacy, self-efficacy-obtain respite, active coping and emotion-focused coping, high positive attitudes for caregiving, high quality of support and perceived social support. There was a low level of thought-control and problematic (dysfunctional) coping strategies. Here it is essential to say that the quality of support, emotion-focused coping and perceived social support could be considered the dimensions that characterised this carers' profile.

In a similar clustering, where BRIEF-COPE created profiles, perceived stress and health-related behaviours, four coping profiles were derived: high copers, adaptive copers, avoidant and low copers (Doron et al., 2015).

8.3. The secondary carers

One of the few references we found about the secondary carer is in the study by Li, (2015), searching the caregiving-specific internet use, with primary carers to be more likely to use the internet in comparison with the secondary users frequently. In this paper, Li, did not define the secondary carer, only defined not being the primary. In this study, the definition of the secondary carer was a topic discussed during the piloting and was adapted. The main concern involved the question of secondary carer identification. This research interest initially would focus on the person who supported the primary carer with information and assisted with the use of the internet. However, this question provided confusing replies such as "my doctor", "the dementia centre", "carers' training" "nobody, I find by myself", "internet". In other cases, the replies were identical with the person who provided tangible social support to primary carers, who might be the children, siblings, friends, spouses. Only on rare occasions, did the person assisting with everyday caring activities or providing psychological support was not mentioned as the person who provided information to the carer when needed. The secondary carer was also the person who the carer mentioned as the significant other in the case of Perceived Social Support scale.

The role of the secondary carers' Health Literacy and eHealth literacy in the perceived Health Literacy, eHealth Literacy and caring concepts of the primary carer was part of our research questions. Secondary carers were considered the children, spouses or friends and other relatives. The majority of this sample were women (72%, n=48), below 60 years (61=91%), mostly children (n-41, 61%), employed (71%, n=48).

In the findings of this study, the secondary carers reported, psychological, social support and support with everyday activities as the first 3 reasons of support, which was in accordance with the reported support by the primary carers.

Following paired analysis, differences were not identified between the group of primary and secondary carers in the perceived Health Literacy and eHealth literacy levels. Differences were found in means of eHeals-Carer among the three group of HLS-EU-Q16.

There was the assumption that the secondary carers' Health Literacy and eHealth literacy would impact the primary carers' Health Literacy and eHealth literacy. From our findings, this was not confirmed, even if there was a tendency with slightly higher perceived eHealth literacy. Primary carers' perceived Health Literacy and eHealth literacy were considered high for the specific population in comparison with other studies with older people.

8.4. Practical implications

This study is considered as the first phase to enhance eHealth literacy skills among carers of PwD. Now that the first data on the level of perceived Health literacy and eHealth Literacy are obtained, it would be much easier to create interventions that will target the specific needs of carers.

Education and Training

With this study, the concept of eHealth Literacy and Health Literacy for the population of carers of PwD is promoted and this is the first step for all stakeholders (carers, researchers, health care professionals) to consider this concept in their work. Until now, we discussed health promotion, education or awareness and training campaigns, and always there is the dimension of health literacy in this research. If we are aware of the critical dimensions that we need to enhance, it would be easier to target specific skills. Stakeholders, such as non-for profit organisations, health care professionals, ICT trainers involved in the adult learning could integrate eHealth literacy and Health literacy in the carers' training. In parallel with this research on the level and the association of these concepts, the Erasmus+ eLILY (Chapter 4) has started. An intervention is developed to enhance Health literacy, necessary digital skills, eHealth literacy and interactive service use.

The face to face training and the eLearning course will be ready no later than the end of September 2020.

Moreover, apart from the target group of carers, considering general population, Health Literacy as an outcome of Health Promotion could be integrated in formal education curricula. Taking into consideration that Health Literacy starts from the early years within the family and then continues with formal education, integration of relevant courses in the curriculum of primary, secondary and tertiary education could be the most significant action of raising awareness and promoting healthy lifestyle among the general population.

Practical implications

eHealth literacy is quite an innovative field for carers. Notably, in Greece and Cyprus, few technological advances could be helpful to carers. Only during the last three years, have two to three apps been developed targeting this population, a platform for carers, online counselling through skype. Researchers and health care professionals become interested in developing MOOCs for carers through small funded projects and usually run pilots to test the user-friendliness and usability without any follow up to understand how this technology could facilitate the carer of the person with dementia. Furthermore, electronic Health records (EHR) are adopted recently in Greece (Law 4238/2014, active in March 2019) and in Cyprus, EHR are in an early stage, even if the legal framework has been developed (N 59(I)/2019). It seems that researchers and health professionals develop web-based tools as they consider the carers' needs. From this study a positive message was received for the use of technology and that carers acquire skills, that are not recognised by the health care professionals. The involvement of carers throughout all phases of the tool development is mandatory and in parallel healthcare professionals training on their own beliefs regarding technology in the health domain. If we consider the theories of technology use apart from the user skills and access opportunities, the social network and beliefs of the person towards technology are two other factors that we need to consider in developmental, implementation and dissemination phase.

Research

It was found that carers might be a health literate population with a high perceived eHealth Literacy level. So, in this case, as a second step, research will follow with functional measures of eHealth Literacy and Health Literacy and compare with the results of this study.

As a third step, the development of eHealth innovations tools could be included in the process to assess Health Literacy and eHealth Literacy and adapt the products to the actual carers' needs, developing sustainable technologies that could be in long-term use by carers. Additionally, the eHealth literacy, Health Literacy and perceptions towards technology among health care professionals could be assessed. The validated tools in Greek, eHeals-Carer, HLS-EU-Q16 and Revised Scale of Caregiving Self-Efficacy could also be used in future research. Finally, in future research, the results of the associations between Health Literacy with SE-OR and SE-BM, received social support and eHealth Literacy with emotion-focused coping strategies and positive caregiving perceptions could be integrated in a theoretical model expanding the existing knowledge as regards to the way that coping strategies and social support mediates the primary and secondary stressors and advancing the nursing science. It could be a tool in the hands of nurses to understand and assist the carers of PwD to navigate in the Health care system.

8.5. Strengths and weaknesses

This study is considered innovative for carers of older PwD in Greece and Cyprus, nevertheless we encounter some limitations that we need to take into account when interpreting the results. Issues strongly related with the limitations of the study are the study design, as it is a cross-sectional study. The selection of this study design was the best option for our population, since carers are a difficult sample to recruit and follow up option would result in large percentage of drop-outs. Nevertheless, this study design provides data for a specific period in time, and we cannot predict all the possible parameters that may influence our outcomes. In this way, we cannot discuss causality at all. Longitudinal studies provide this element even if the process is more complicated than cross-sectional, descriptive correlation studies. We have selected this design as we considered it more convenient for the group of carers.

Carers’ everyday lives are too demanding and approaching them to participate in a study with face to face survey over 60 minutes was inconvenient for most of them. On the other hand, the researcher met all the carers’ requirements to achieve participation and make the carer feel comfortable. Requirements included specific meeting place (dementia day centre) and in parallel with patients’ activities. If the person with dementia did not attend the day centre, then researcher had to adapt to the request of preferred day centre (based on the distance from home), time of the day that the patient could stay at home with another relative. In this latter case, some carers become stressed due to the feeling of guilt for leaving the patient alone or with a relative. In another case, even if the appointment was scheduled, carers may not appear, or cancel at the last minute and reschedule. The researcher sent several reminders to reassure participation. When the carers felt guilt and anxiety, the researcher provided the time needed to feel better.

In relevant research, as identified by the scoping review (1), the sample size of carers may range from 36 to over 3.000 carers. During the pilot phase, the difficulty to gather the carers sample was identified and modified the recruitment strategy, by including study presentation during Alzheimer's campaign, carers training events and older people's leisure activity clubs. These modifications improved recruitment, but still, after 18 months the sample remained at 174 carers. This number was in accordance with the power analysis for correlations (statistical power 95% and confidence level 5%). The research team decided to stop recruitment after this period. Carers in Greece and Cyprus are not so positive in research participation, but these attitudes will change in years to come.

For this reason, this sample is considered convenient, which is the third limitation. Convenience impacts the outcomes and is not easy to control. Representativeness of this sample was confirmed by other carers' studies in Greece and Cyprus. This sample had a high Health Literacy level, and during the discussion chapter, the element of convenience was included to justify this outcome. On the one hand, it is more likely for people who have a higher education to be willing to attend a study instead of people with a lower education. On the other hand, carers caring for another person are willing to learn and gain knowledge of the disease, which is in accordance with our findings.

In the pilot study, a large number of this sample were members of day centres and had received dementia-specific training, making them dementia-specific literate. The researcher employed strategies to include a sample of carers with different characteristics. For this reason, the researcher visited different cities, attended awareness campaigns, organised information days and used the snowball method. After the pilot study, people who were carers but did not attend a day centre were recruited. To recruit a person who is not registered in a day centre was only possible if the carer attended an event. People who did not attend event and day services was challenging to be recognised as carers, only if they got informed for the research by other carers or friends. In this sample, a small number of carers participated through snowball technique.

Following the representation of the study, it is important to mention the generalisability too. In Greece and Cyprus, carers share common cultural aspects, such as the important role that family plays in the care of its members. The findings of this study could be generalised to carers of countries with similar cultural background as in the case of South-Eastern Europe

The self-reported questionnaires of the study could be considered as a limitation. Tools were used to measure perceived Health Literacy and eHealth literacy. Alternatively, functional Health Literacy measure could be included to compare as in the case of HLS-EU study. Functional measures of Health Literacy will be the next phase of this research. The selected questionnaires were sufficient for the aims of our research, always considering the innovative aspect of our theme.

8.6. Summary of Findings and Recommendations

From this study, much valuable information was derived concerning Health Literacy and eHealth literacy among carers. Data were found for the other caregiving variables.

If we consider the validation of the tools, five factors were derived regarding HLS-EU-Q16: health promotion, media health literacy, compliance with the doctor's instructions, health care and access and health-related decision making. From these five factors, health promotion and health care and access received a high score confirming the high Health Literacy score.

In this stage, we may admit that carers act for the benefit of the care recipients and usually against their self-care.

Apart from Health Literacy, internet use was investigated. In this sample, 77% carers used the internet, and from them, 69% for dementia-specific reasons and 55% were mobile devices users. Higher education could predict internet use. The most frequent types of use were information seeking, finding news and socialising.

With this study, eHeals to eHeals Carer was adapted, which provided us with two core dimensions: Information seeking and evaluation of the caregiving information. The overall score of the eHealth Literacy scale was high (mean 29.21) and was related to the dementia-specific search. Only one predictor was identified, occupation. Pensioners reported lower levels of eHeals-Carers in comparison with student and people in unemployment.

Interestingly, the association of HLS-EU-Q16 with the eHeals-Carer was confirmed and the perceived Health Literacy was identified as a predictor for perceived eHealth Literacy.

The associations with all other variables were searched such as social support, perceived caregiving self-efficacy, coping strategies and caregiving attitudes.

In case of Social support, two types of support were measured with the selected questions, the received social support (reporting of secondary carers) and the perceived social support (perceived multidimensional scale of social support). The above finding was considered responsible for reporting the secondary carer as the predictor for Health Literacy and also acted as a confounding factor, but perceived social support is not significant in this case.

In the case of perceived self-efficacy for obtaining respite, a low score was found in comparison with the other subscales of self-efficacy, justified by the familial care model in Greece and Cyprus. Predictors of the obtaining respite subscale were the report of a secondary carer and caring for others. The association of perceived Health Literacy with Self-Efficacy was confirmed.

In this sample, the most used coping strategies were problem-focused, even if not related to Health Literacy. eHealth Literacy "information seeking" was associated with the emotion-focused strategy. The assumption for this association was related to the social aspect of internet use. Only one dimension of strategies was associated with Health Literacy, dysfunctional coping.

Finally, eHealth literacy "information seeking" was associated with positive attitudes, and in this case, internet use was a predictor of positive attitudes.

Apart from the above findings, three carers' profiles appeared after clustering analysis:

1) High Health Literacy, eHealth Literacy and Self-Efficacy
2) High problematic coping and negative attitudes
3) High Health Literacy, eHealth Literacy, perceive emotional-focused coping, perceived social support and quality of support.

Based on the above results, it is considered essential, that future research should continue with the association of perceived Health Literacy and Functional Health Literacy among carers, develop appropriate tools for both types (functional and perceived) and also involve the health care professionals in the process of increasing the motivation of web-based tools. Additionally, it is important to confirm the mediating effects among behavioural management and negative coping attitudes as well as perceived social support and quality of support.

8.7. Conclusions

In conclusion, even if some critical topics for carers, such as burden and depression are well documented, the appearance of new concepts and interventions related to health provide space for more research.

Technological advances gain attention rapidly not only from the research community but also from people who search for ways to facilitate their lives. Technology is becoming especially helpful for people with disabilities and their families. For the carers of older people with chronic diseases and PwD we find solutions providing tips and advice for managing behaviours, databases, care coordination tools among families, online assessment tools, web-based support groups, activities for the older people, reminders, trackers, emergency alarms, personal health record tracking (Grossman, Zak, & Zelinski, 2018).

Through this study, it is concluded that there is a need to develop more ways to measure these concepts for this population on the one hand and to develop training related to health information evaluation on the other hand. A start was made with the eLILY project as we have seen in chapter 4 and this could be continued with related training for the nurses and other Health care professionals. Since nurses are the professionals who are spending most of their time at the patients' side, either at the hospital settings or in the community it is important to understand the significance of health and e-health literacy. Their contribution can be made at several levels, for example in evaluating patients' and carers' health and e-health literacy levels and in designing and implementing training programs focusing on increasing patients' and carers' skills and empowering self-care. Therefore, exploring and improving nurses knowledge and skills in health literacy and how this can be used for the benefit of their patients could be the next step in research.

Dementia-specific organisations need to motivate the use of technology among their members. This could be a possibility through consultation and providing information with available web-based tools and support groups. In Greece and Cyprus, there is still a few web-based services and usually, are not tailored for the specific needs of carers. Only recently, do we find a few tailored apps for the carers of PwD such as Dianoia and Apps4carers. A few years earlier, a platform was developed, providing much useful information to carers available in Greece and Cyprus (Barbabella et al., 2016). At the moment, no follow up is available for the use of the specific web-based tools. There is an issue of sustainability derived from the funding of these resources and probably health-care professionals' attitudes to promote these tools to carers.

Furthermore, the availability of the carers to participate in research is a matter for thought, as in this sample the high educational level and eHealth Literacy level is directly connected with the carers who attend the dementia centres. We could not avoid including this sample since dementia centres and Alzheimer's associations in Greece and Cyprus are the only places where carers are registered. We need to consider alternative ways in research to involve carers that do not receive dementia services and investigate the reasons for this behaviour and assist this specific group to receive the information they need.

Through this study, the first milestone was provided for the research of Health Literacy and eHealth Literacy in Greece and Cyprus for carers of PwD. In parallel we have communicated this idea through the eLILY project and the participation of the Alzheimer's Association not only in Greece but also in Bulgaria, realizing that this is a matter that concerns countries with high involvement of the families in caregiving and low service provision.

In years to come, more and more research will be available in this domain as the technology will rapidly progress. Will this problem disappear in future decades, when we will be the people who use these services? The above question could be considered rhetorical and for the time being, remain unanswered. People who are using the internet still needs more skills to be considered as Health literate and eHealth Literate. Even if we are digitally literate, it does not mean that we are eHealth Literate, we always need to keep that in mind.

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I. APPENDIX -METHODOLOGY OF THE REVIEWS

A. Method of the systematic scoping review (1)

1. Search strategy

We have followed Preferred Reporting Items for Systematic Reviews and Meta-analysis for scoping reviews (Tricco et al., 2018) as well as the five stages of (Arksey & O'Malley, 2005) on scoping reviews. There is no available review protocol (systematic registration number), only the research protocol of our main study (Appendix VII: Efthymiou, Middleton, Charalambous, & Papastavrou, 2017).

We initially defined the research questions:

- What are the characteristics of the carers that may predict the internet use and dementia-specific internet use?
- How do the carers of PwD use the internet?
- What are the theoretical frameworks of dementia-specific internet use?
- What are the needs of carers of PwD when using an online source?

The keywords that we have used searching in PUBMED, MEDLINE, CINAHL, PSYCHINFO, included the terms:

eHealth/ e-Heath /website/web-based/ website-based/ online/ internet/ online use/ internet use AND Carers/caregivers/family member AND dementia/ Alzheimer's/ Alzheimer's disease.

2. Eligibility criteria

In the second stage, we have identified all relevant studies by searching all available resources: electronic databases, conference proceedings and grey literature.

The studies selected based on below criteria:

- Carers of older people and PwD were the target population
- The study should be related to the topic of internet use or online services or interventions

- Published in English
- Published the period 2000 to 2018
- The paper was original research

We have included carers of older people and PwD as in this way we broaden our research search and is possible to find related information on our topic that is important for us to understand the phenomenon. Based on this we have also included interventional studies, even if not related directly with internet use, as this type of research is an indicator of online service usage and we were also interested to map the existing research on online use and services. Additionally, usually in the interventional studies, there is always the usability issue and how ready and friendly the carers consider this type of technology, which was a question of interest for our research.

Studies were excluded if the language wasn't English, there was no full paper available and if they referred to carers of people below 50 years old. Systematic reviews of the relevant topic were also identified but not included. No type of study design was excluded as the area is new and we are interested in identifying all possible aspects.

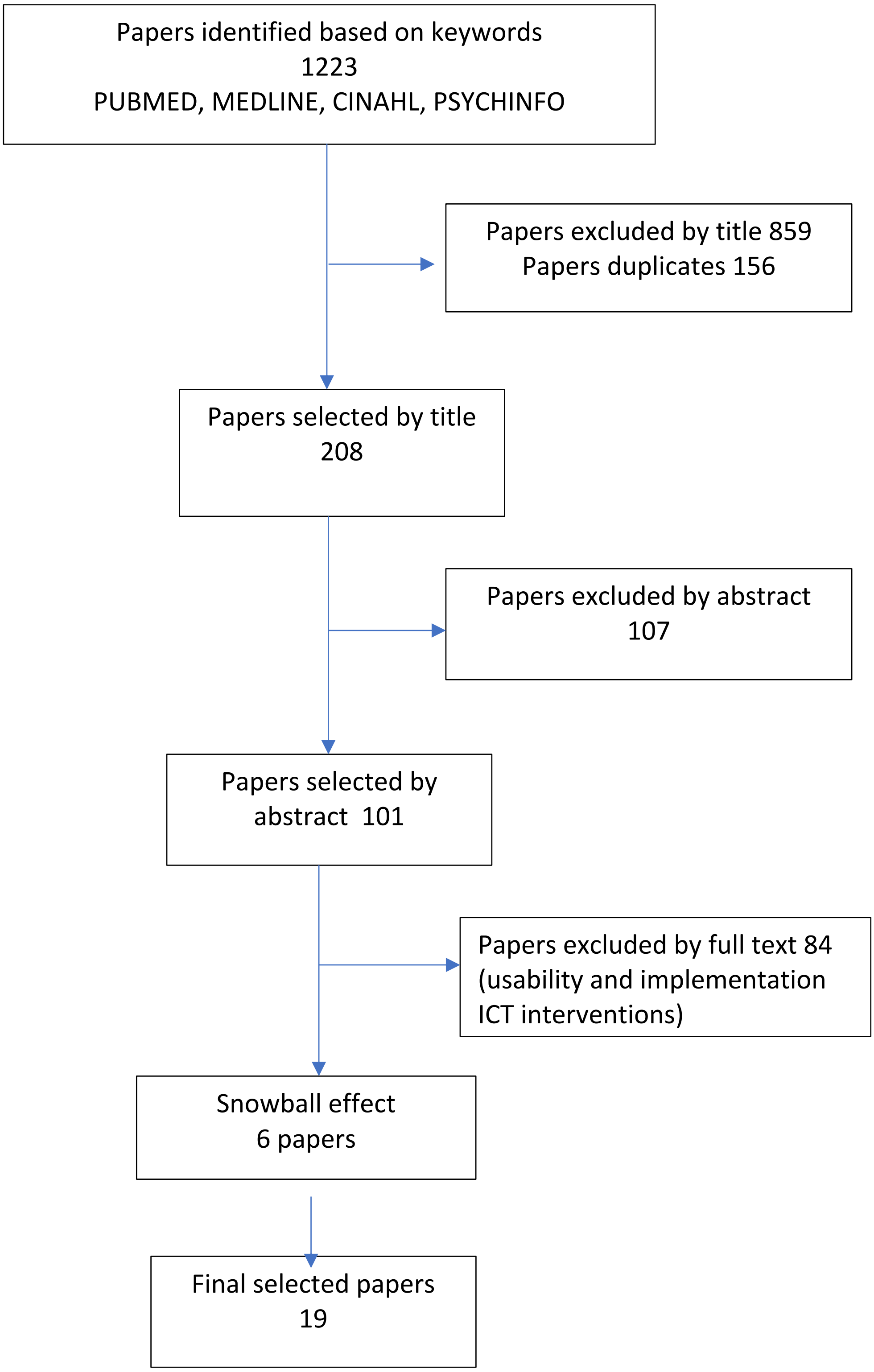
3. Study selection

Two reviewers assessed the studies. The first reviewer monitored all titles, abstracts according to the eligibility criteria and included the information of the selected studies based on the abstract in related excel lists including information of the authors, titles, year and abstract. During this process, the first reviewer received advice from the research team. In this first step, the first reviewer excluded papers in duplicate. The same reviewer selected the full texts based on the abstract selection and included data in the tables with information of authors, title, year, study design, publication status, size, characteristics (type of the disease) and type of the sample, aim and outcomes of the study, categorisation of the study type.

The categorisation included four types of studies: efficacy and effectiveness studies, usability studies, use of the internet, reviews, theoretical papers. The reviewers screened the four categories for internet use information for carers and research team validated as an effort to manage the risk of bias across studies.

The search resulted in 1223 Papers and after reading titles we included 208 papers. Through abstracts reading, we included 101 papers and after full-text reading, we concluded in 13 papers. Another 6 articles were included by the snowball effect. The final number of included papers raised in 19 full texts.

Figure I-11Flow Chart of the studies selection of the carers internet use



4. Quality assessment

The reviewer also included a quality appraisal section in the same section for the selected papers. In case of qualitative studies (interviews and focus groups), we have used Consolidated Criteria for Reporting Qualitative research (COREQ), 32 items and for the observational study we have selected Strengthening the Reporting of Observational Studies in Epidemiology Statement (STROBE). For online surveys, we have used the Checklist for Reporting Results of Internet E-Surveys (Cherries). A small number of studies even if qualitative could not be assessed with Cherries or with COREQ. This was due to the new type of study and the content analysis of online material provided by carers or older people as posts in a forum. In this case, even if we proceed with COREQ we have excluded several items as were not relevant. Furthermore, we have included 2 reports on Internet use and 1 dissertation on the carers' internet use. The second reviewer validated the selection of the full texts based on the available list of abstracts.

B. Method of the literature review (2) for the association of Health Literacy and eHealth Literacy with self-efficacy, coping and social support

1. Search strategy

There is a lack of research regarding the association of Health Literacy and eHealth Literacy with caregiving variables among carers of PwD, like self-efficacy, coping strategies and social support.

We have searched the literature to identify relative studies on the association of Health Literacy or eHealth Literacy and self-efficacy, coping Strategies and social support.

Three databases were visited, PUBMED, MEDLINE complete and PSYCHINFO, using the keywords:

Health Literacy (TITLE) OR eHealth Literacy (TITLE) AND self-efficacy (TITLE)
Health Literacy (TITLE) OR eHealth Literacy (TITLE) AND Coping (TITLE)
Health Literacy (TITLE) OR eHealth Literacy (TITLE) AND Social Support (TITLE)

The final results included:

- 109 papers and 1 dissertation of Health Literacy and self-efficacy
- 9 papers of Health Literacy and coping strategies
- 32 papers and 1 dissertation on Health Literacy and social support

After excluding for doubles and not relevant papers by reading the title, we included 22 papers of Health Literacy and self-efficacy, 2 papers for Health literacy and coping, and 11 of Health literacy and social support. In the following step, 21 studies were included by abstract for the topic of Self Efficacy, 1 in case of coping and 10 in case of social support.

After full-text reading, 20 full texts were included in the topic of Health Literacy and self-efficacy and 3 papers from the snowball process, 1 paper of Health Literacy and coping strategies and 8 papers of Health Literacy and social support.

We did not find any published paper on the topic of eHealth Literacy and self-efficacy, coping and social support.

The selection of the papers was made by the main researcher and the research team randomly checked the selection process for inconsistencies.

All the data were kept in an excel form, including information about the authors, the country, the aims, the measures and the outcomes.

2. *Eligibility criteria*

The eligibility criteria included:

- The papers should be accessible as full texts
- The period of publication to be from 2009 to 2019
- The papers should be available in English language

3. *Descriptive results of the self-efficacy results*

a) Origin of Research

The majority of the research took place in the USA (13 papers), Korea (2), Japan (1), Turkey (2), Iran (1), the Netherlands (1), the UK (1)

b) Aim of the studies

The aim of the studies investigated the association of Health literacy with self-efficacy and in association with demographics. access to health care utilization (Chen, Hsu, Tung, & Pan, 2013; Sudore et al., 2006), self-care behaviours and screening (Bohanny, Lecturer, Wu, & Associate, 2013; Inoue, Takahashi, & Kai, 2013; K. Kim, Xue, Walton-Moss, Nolan, & Han, 2018; Tiraki & Medine, 2018) , other health outcomes (Edwards, Wood, Davies, & Edwards, 2012; K. Kim et al., 2018; S. H. Kim & Yu, 2010; Y.-J. Lee et al., 2016), Quality of life (Ozkaraman, Uzgor, Dugum, & Peker, 2019), Genomic-related knowledge, medication adherence (Colbert, Sereika, & Erlen, 2012; Huang, Shiyanbola, & Chan, 2018), physical activity (Geboers, de Winter, Luten, Jansen, & Reijneveld, 2014; Guntzviller, King, Jensen, & Davis, 2017), nutrition (Cha et al., 2015; Geboers et al., 2014), hormone therapy (Torres & Marks, 2009), early parenting practices(J.-Y. Lee, Murry, Ko, & M.T., 2018). These topics are discussed in parental research, cancer patients, diabetes and general audience.

c) Study designs

The majority of the studies are cross-sectional studies (19), 2 secondary analyses and 2 longitudinal studies.

d) Sample

The sample sizes ranged from 18 to 3479 participants. We find samples of older people, patients with diabetes, parents and low-income mothers and other patients of care clinics.

e) Measures

The tools of Health Literacy were: Rapid Estimate of Adult Literacy Test in Medicine (REALM), REALM-R (revised version), 3 questions of Chew, Newest Vital Sign (NVS), NVS-S(Spanish version), Short-form Test of Functional Health Literacy in Adults (S-TOFHLA), K-TOFHLA (Korean version), Short Assessment of Health Literacy in English (SAHL-E) and Short Assessment of Health Literacy in Spanish (SAHL-S), Health Literacy assessment in Cancer screening, Health Literacy Scale (HLS), TOFHLA-S (Spanish version), HLS-EU-Q 47, Maternal Health Literacy tool, Cervical Cancer Prevention Knowledge Form.
Self-efficacy measures include: 1 item assessing self-efficacy developed by authors for the aim of the specific study, Self-Care Heart Failure index, self-efficacy questionnaire self-reported ability to effectively evaluate the potential hazards of the medical procedure and make an informed decision, Diabetes Management Self-Efficacy Scale (DMSES), General Self-Efficacy Scale, Karitane Parenting Confidence Scale, Perceived Maternal Parenting Self-Efficacy, Self-Efficacy for appropriate medication use, Korean-translated cervical-cancer Self-Efficacy scale, FHH Self-Efficacy, nutrition Self-Efficacy, Self-Efficacy to manage Chronic Disease Scale, perceived Self-Efficacy in Patient-Physician interactions (PEPPI), Weight Efficacy Lifestyle Questionnaire. Self-Efficacy Beliefs subscale of the HIV Self-Efficacy Scale for Medication Taking, perceived diabetes self-management scale, decision self-efficacy scale. Based on the above information, it would be very difficult to synthesise and compare results as in almost all studies, they have used different scales to measure self-efficacy.

4. Descriptive results of the social support results

a) Origin of Research

As in the case of the association of Health Literacy and self-efficacy, we find papers from USA (3), Iran (1), China (1), Taiwan (1), Ghana (1)

b) Study designs

All 7 papers were cross-sectional correlational studies. In only one case there is a secondary analysis from a cross-sectional study.

c) Sample

The sample size ranges from 197 to 992 participants including, mothers, older people, patients with kidney disease, smokers and the general public.

d) Measures

Health literacy is measured with maternal Health Literacy, Chinese Citizen Health Literacy Questionnaire, s-MHLS, S-TOFHLA, a modified version of the Swedish Functional Health literacy scale and the Health Literacy items by Chew.

Social support is measured with the Multidimensional Scale of Perceived Social Support, questions developed by authors, social support scale, Interpersonal support evaluation list, adapted social capital assessment tool and Medical Outcome Study Social Support Survey.

C. Method of the scoping review of eHeals validations (2)

1. Search Strategy

We have identified all available validations of the eHeals tool, following the methodology of scoping review as described in Arksey & O'Malley, (2005) and Peters et al., (2015) for relevant validations of eHeals in order to identify all possible alternatives regarding the different languages, population, statistics, ratings and to identify any available carers adapted version.

Main research questions of this review included:

1. What type of statistical analysis is used to extract factors for eHeals?
2. How the Web 2.0 problem is handled in existing validations of eHeals?
3. Is there any difference in rating the scale?
4. Is any eHeals validation for carers available?

We searched for all validations of eHeals in relevant databases (PUBMED, CINAHL, MEDLINE, PSYCHINFO, SCOPUS) and grey literature (eScholarship) until December 2018. Keywords used: eHeals and eHealth Literacy Scale.

2. Eligibility Criteria

The studies included, based on the following eligibility criteria.

- The study should be related to the topic of eHealth literacy
- The study should be related to the scale reliability and validation
- The study should be published in English

We did not include studies that used eHeals as a measure of eHealth literacy but no other information on validation was provided for the specific tool.

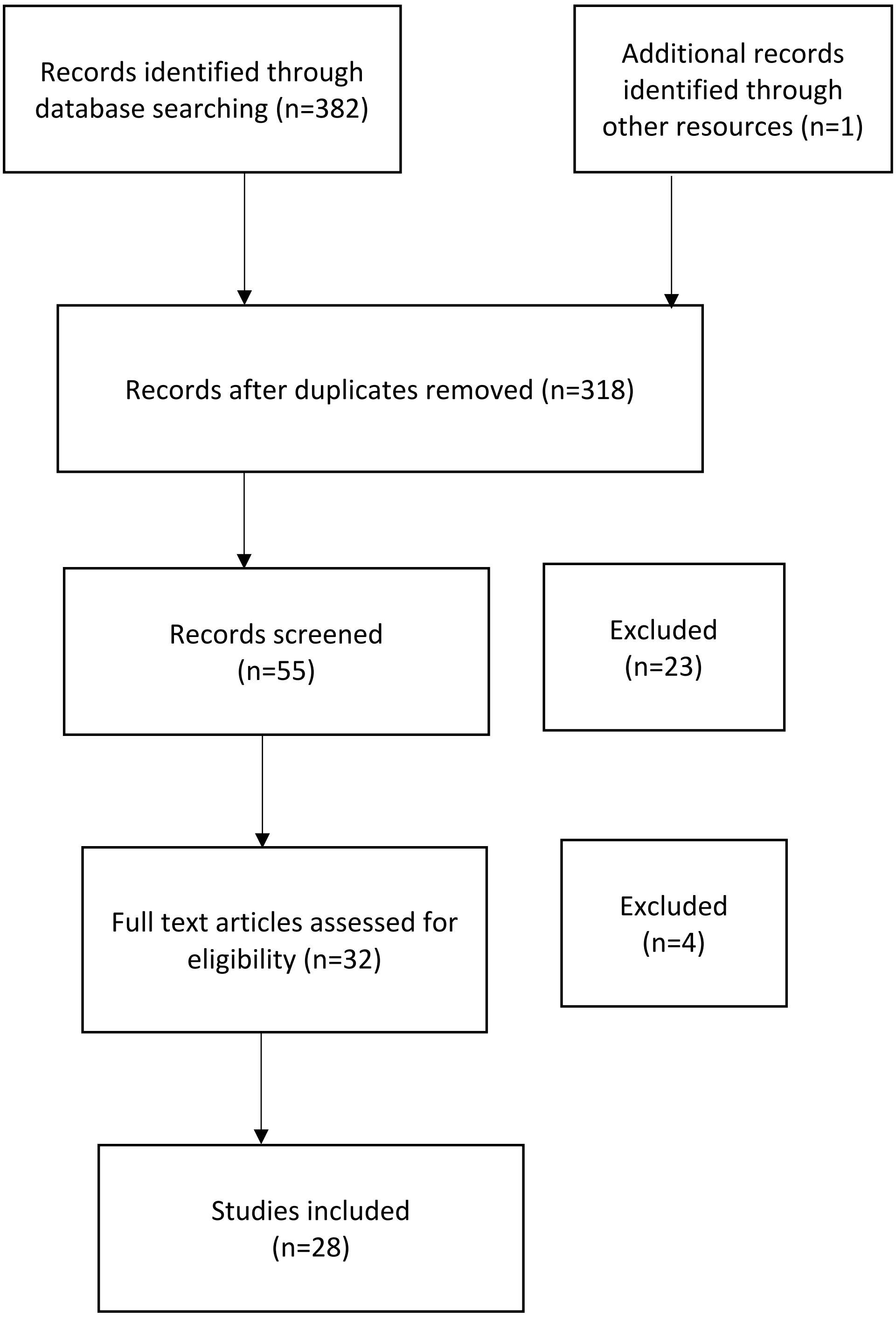
3. Data Collection

All studies were reviewed by title, abstract and full text by the main researcher and data were included in an excel form. The researcher team advised the main researcher through this process and discussed any issues derived.

Data collected including information of the authors, date, number of eHeals items, aim of the study, language, reliability information, dimensions, type of sample and recruitment process, scoring of the tool, mean score of the sample. The research team assessed the form for consistency and proposed alterations for the data to be better explored by combining and adding data categories.

The search generated 382 results, after excluding for duplicates (64 papers), 318 were screened by title, 55 studies by abstract and finally 32 by full text. Finally, 28 studies were included in this review (Appendix I)

Figure I-2 Scoping Review of eHeals Flow Chart



4. *Descriptives results of the eHeals validation literature review*

The scale has been validated and adapted in many different languages, population groups, using either convenient sample recruitment strategies or randomized recruitment technics (as random telephone dialling). We find validations in English, Dutch, Chinese, Japanese, Israeli, German, Spanish, Korean, Persian, Italian, Arabic, Slovenian, Spanish and Serbian.

During the last three years, the validation studies of the specific tool were increased, showing a tendency towards eHealth literacy research. The validations start in 2011 and there is a rapid increase in next years with 2017 and 2018 to surpass the previous years.

Figure I-3 Number of Publications per Year

2011	2012	2013	2014	2015	2016	2017	2018
2	2	0	1	3	5	9	5

In Appendix II, we summarise the validations of the eHeals including information on the study design and sample characteristics, statistics, results, mean score.

a) Number of items

The tool has 8 items, and, in some cases, we find an additional two items. Only in one study from Slovenia, the validation is an extended version of 20 items (6 factors) including the web 2.0 parameter (Petrič, Atanasova, & Kamin, 2017) as discussed earlier by Norman (2011) , in another study 6 items (Neter & Brainin, 2012) and 7 items (Hyde, Boyes, Evans, Mackenzie, & Sanson-Fisher, 2018).

In most cases, the majority of authors, in order to deal with the web 2.0 problem, added additional questions regarding the Internet for example:

- Internet access
- Digital literacy
- Health information sources
- Content search strategies

- Evaluation criteria
- Time spend online

And in other cases, based on the topic of research, we find information on:

- Perceived health outcomes
- Health competences
- Self-Efficacy scale
- Well-being scales

b) Scoring system and mean score of eHeals

In almost all cases, the scoring system distinguishes between high and low scores without providing information for a medium level.

In 12 papers the level is calculated by summarizing all items and in 4 validation studies by summing up all items and dividing the score with the number of the scale or of the factor. Higher score of all studies presented by the study of Chung & Nahm, (2016) for a sample of 886 adults with mean age 62 years and eHeals literacy mean score 30.94 (SD)

c) Construct validity and reliability of eHeals studies

In 5 studies, the researchers used Principal Component Analysis (PCA), in 11 cases Exploratory Factor Analysis (EFA), in 8 studies Confirmatory Factor Analysis (CFA) and 3 studies either PCA or EFA and then CFA. In 4 studies they followed Item response theory and Rasch modelling.

Series of studies have identified or confirmed the single dimensionality of the eHeals scale (Caro et al., 2016; Chung, S., Park, B.K, Nahm, 2016; Koo, M., Norman, C. , Chang, 2012; Neter & Brainin, 2012; Nguyen et al., 2016; Paramio Pérez, Almagro, Hernando Gómez, & Aguaded Gómez, 2015; Van Der Vaart et al., 2011). However, the latest studies seem to propose either a 2-factor model (Dashti, Peyman, Tajfard, & Esmaeeli, 2017; Diviani, Dima, & Schulz, 2017; Gazibara, Cakic, Cakic, Pekmezovic, & Grgurevic, 2018; Soellner, Huber, & Reder, 2014) or a 3-factor model (Hyde et al., 2018; Paige, Krieger, Stellefson, & Alber, 2017; Paige, Miller, Krieger, Stellefson, & Cheong, 2018; Stellefson et al., 2017; Sudbury-Riley, FitzPatrick, & Schulz, 2017). The study by Soellner et al (2014) was one of the first to propose a two-factor model with information seeking (questions 1,2,3,4,5,8) and an information appraisal (questions 6, 7) component. This model was later confirmed by Diviani et al (2017). Subsequent studies also supported a 2-factor model, yet with a different set of questions, for example, the first four questions tapping on factor 1 and the last four questions on factor 2 (Gazibara et la, 2018, Dashti et al, 2017). With regard to the 3-factor model, the most commonly accepted dimensions were: awareness (questions 1, 2), skills (questions 3,4,5) and evaluation (6,7,8). Paige et al (2018) proposed a 3-factor model with a different categorisation which, instead of skills and evaluation, includes information seeking (questions 3,4) and information engagement (questions 5,6,7,8).

The reliability in the majority of the studies was quite high, over Cronbach's a= .80. The lowest reliability was presented in a student sample in Bangladesh (Cronbach's a=.74) and in the 6 dimensions of the Slovenian version (Islam et al., 2017; Petrič et al., 2017).

d) Sample of the eHeals validation studies

In 6 studies out of 28, the sample recruitment has focused to chronic patients and/or older adults, as Rheumatic disease, type 2 diabetes, cardiovascular diseases, mental health problems, chronic lung disease and cancer (Aponte & Nokes, 2017; Chung & Nahm, 2016; Paige et al., 2017; Stellefson et al., 2017; Sudbury-Riley et al., 2017; Van Der Vaart et al., 2011). In 3 out of 6 studies, the sample was older adults (Stellefson et al., 2017; Sudbury-Riley, FitzPatrick, & Schulz, 2017; Chung & Nahm, 2016;). The mean eHeals score ranged from 22.35 for older Hispanic people with type 2 Diabetes to 30.34 (sd=5.30) for older people with chronic diseases. In one study they find weak correlation but significant with internet use and significant correlations with age and education (Van Der Vaart et al., 2011). In a second study, they did not find any correlation with age, but with gender (Aponte & Nokes, 2017). Computer knowledge had also a strong correlation with eHeals among older adults (Chung & Nahm, 2016). Cronbach's alpha ranged from .89 to .99 in these 6 studies.

Other samples were adolescents, six graders school children, students, nursing undergraduate students, patients of otolaryngology head and neck surgery, youth people, medical students and MRI and CT outpatients.

II. APPENDIX – Table of eHeals Validations

Table II-1 eHeals Scoping Review

	Authors	number of items	aim	Language	Reliability	Dimensions	sample	recruitment process	scoring
1	Norman & Skinner, 2006a	8 items (+ internet use questions), self-administered	to assess eHealth literacy in wide population	English	Cronbach alpha =.88,intra-class correlation in test retest reliability .49 (modest stability over time	1 factor (PCA)	664 adolescents (age 13-21)	single session randomised intervention trial	5 point Likert scale, perceived skills (high - low reference not specific categories)
2	Van Der Vaart et al, 2011	8 items (+ in study 1 general and health related internet use and in study 2: general internet use and performance test), administration way not defined	reliability and construct validity of a Dutch version	Dutch	Study 1: Cronbach alpha=.93 Study 2: .92	Study 1 &2: 1 factor (PCA)	Study 1: 227 people with rheumatic diseases with mean age 52 Study 2: 88 general population with mean age 43	Study 1: randomised sample by patient database Study 2: random recruitment by random dialing numbers	5 point Likert scale Study 1: mean sum score: 28.2 , mean 5.9S tudy 2: mean sum: 27.6, mean 5.9
3	Koo et al (2012)	8 items, self-administered	validation of eHeals to Chinese school children	Chinese	Cronbach alpha=.92, assessment of concurrent validity	1 factor (PCA)	219 six graders School children	single group cross sectional study, part of a larger study	5 point Likert scale , total score: 8 to 40 , mean score 28.4, SD 7.6)

4	Mitsutake et al, 2011 Original Paper in Japanese	8 items, self-administered		Japanese	Cronbach alpha=.93	1 factor (CFA)	3000 participants	randomly selected	5 point Likert scale, total score: 8 to 40,
5	Neter & Brainin, 2012	6 items (+ internet access, digital literacy, health information sources, content, search strategies, evaluation criteria, perceived outcomes of health information search, perceived health), telephone interview	Assess levels of eHealth literacy among Israeli random population	Israeli	Cronbach alpha=.86	1 factor (EFA/PCA)	4286 adults	Random digital-dial telephone survey	5 point Likert scale, mean 3.34 (SD .88), 2 groups (high level >3.4 and low level <3.4)
6	Soellner et al, 2014	8 items (+ subscales of the Health competences questionnaire, self efficacy scale, internet use as information source and time spent online), self-administered, paper and pencil survey	Validation of eHeals in German among adolescents	German	Cronbach alpha for dimension information seeking: .877 and for information appraisal .828	2 dimensions: information seeking (1-5 & 8) and information appraisal (6 & 7) (CFA)	327 students with mean age 18.10	administered as part of a larger study, cross sectional paper-pencil survey, Grade 12 class sessions in 4 Gymnasia in Cologne	5 point Likert scale , Factor 1: 3.57 sd .78, Factor 2: 3.70 sd: .96

7	Paramio Perez et al, 2015 in Spanish	8 items scale (+ well being scales), self-administered	validation in Spanish	Spanish	Cronbach alpha=.87	1 factor (EFA)	447 university students	Convenience sample	5 point Likert scale, total score: 8 to 40, high and low scores
8	Park & Lee, 2015	8 items (+internet use and 2 supplementary items), self-administered online	Assess levels of undergraduate nursing students in South Korea	Korean	Cronbach alpha= .86	n/A	176 nursing undergraduate student between age 20-30	Convenience sample	5 point Likert scale, total score: 8 to 40, mean 27.06 SD 4.2 (high over 27 and low below 27)
9	Saffarzadeh, Areo, 2015	8 items (+ health related internet use, internet use) self-administered paper and pencil	to explore health related internet use (use of high quality of websites and quality of the physician), the internal consistency of eHeals and subscales,	English	Cronbach alpha= .94, Cronbach alpha of items 3-5= .93, Cronbach alpha of items 6,7)= .88, Cronbach alpha of (items 8,9,10)= .82	1 Factor (PCA) 2 & 3 factors (Varimax rotation factor analysis)	79 patients or their caregivers of Otoryncology head and Neck Surgery	Convenience sample	5 point Likert scale , 0-100 scale transformation, mean 66.3 (sd: 20.5)

			profile of health related internet use						
10	Bazm et al, 2016	8 items (+ 10 questions to assess computer and internet skills), self-administered	Validation of the Iranian version of eHeals	Persian	Cronbach alpha=.88	1 factor (PCA)	525 youth people	Randomly selected	5 point Likert scale , total score: 8 to 40, mean score not available
11	Chung & Nahm, 2016	8 items, self-administered	Validate eHeals for older adults	English	Cronbach alpha=.94	1 factor (EFA)	866 adults (mean age 62.8)	Original sample from Bone Power study. Online recruitement from Senior health and healthyVet	5 point Likert scale , total score: 8 to 40, mean 30,94 SD 6
12	Nguyen et al, 2016	8 items, self-administered	to investigate the eHeals properties with RASCH modelling	Engllish	Study 1: Person reliability (equivalency of Cronbach alpha= .80. Study 2: Person reliability .81	study 1 & 2: 1 factor (EFA) Rasch modeling (rating scale analysis)	Study 1: 164 undergraduate students (18-34- 83.6%: 20-21) Study 2. 366 individuals 59% aged 18-32 years	1. convenience sample 2. acquired by Amazon's Mechanical Turk (Mturk)	5 point Likert scale, total scroe: 8 to 40, no mean score available
13	Caro et al, 2016 , only	8 items (+ 2 scales of self esteem and life	validate in Italian	Italian	Cronbach alpha=.87, Test	1 factor (EFA)	650 university student (age 18-45)		5 point Likert scale, total scote: 8 to 40, high and low scores

	abstract available	satisfaction), self-administered			retest correlation=.78				
14	Tubaishat & Habiballah, 2016	8 items (+ perceived level of internet skills, frequency of internet use, perceived usefulness of internet on health decisions, importance of health related internet access), self-administered	Assess the levels of eHealth literacy among nursing students in Jordan	Arabic	Cronbach alpha=.81	N/A	541 nursing students	Discriptive cross sectional sample, Convenient sample	5 point Likert scale , high and low scores, mean= 3.62 SD=.58
15	Paige et al, 2017 [	8 items scale, self-administered web based	Explore unidimensionality (1 factor) and reliability of the eHeals scale	English	Classical test: Cronbach alpha=.90, item response theory technique	3 factor model (CFA) , 70% explained by factor 1, 9% and 5% by 2 and 3 and Partial Credit Model (PCM)	811 participants of online survey with cardiovascular disease, arthritis, mental health disorder, chronic lung disease and cancer	web based survey	5 point Likert scale , total score: 8 to 40, high and low scores, (mean =30.34 SD=5.30)
16	Stellefson et al, 2017	8 items (+perceived health status and experience with social media platforms to access and share health	aiming to validate telephone version of eHeals for	English	exploratory structural equation modeling, and IRT analysis	Exploratory structural equation modeling (PCM) : 3	283 older adults	telephone survey: random digital dialing as part of Florida Consumer Confidence index	5 point Likert scale, total score: 8 to 40, high and low scores, mean= 29.05 SD= 5.75

		information), self-administered	older adults, investigae 2 and 3 factor models			factor model (2 of the 3 factors are correlated and provide evidence for unidimensional structure for older adults			
17	Diviani et al, 2017	8 items (+ general and health related internet use), self-administered web based	validate in Italian	Italian	Cronbach alpha= .89 (Classic theory and Rasch modeling)	2 factor solution (PCA & CFA)	296 Italian speaking region of Switzerland	2 surveys (summer 2013 and Spring 2015	5 point Likert scale , total score: 8 to 40, high and low scores, (mean =26.65 SD= 6.28), study 1: 27.21 SD= 6.083 and study 2: 26.27 SD= 6.388)
18	Sudbury-Riley et al, 2017	8 items (+information and resources to cover the web 2.0 with use of social media, self-administered online	measurement invariance: measuring the same traits in different groups and investigate a 3 factor model	English (UK, new Zealand, USA)	USA Cronbach alpha=.92, uk.93, new Zealand=.91	3 factor structure: awareness (1,2), skills (3, 4,5) and evaluation (6, 7, 8), CFA	996 baby boomers	random sample of 3 countries	5 point Likert scale, table with mean item scores

19	Dashti et al, 2017	8 items (+ websites for health related information, frequency of internet use), self-administered	Assess the level of eHealth literacy among Medical science students, validation of the tool	Persian	CVI (10 experts)Cronbach alpha = .89	2 categories:Q1, 2,3,4 AND Q 5,6,7,8 (EFA)	192 Medical students	Convenient sample	5 point Likert scale , total score: 8 to 40, high and low scores, (mean =28.21 SD= 6.95)
20	Richtering et al, 2017	8 items (+ Health Literacy Questionnaire), self-administered online	Assess levels of eHealth literacy and health literacy among population with high cardiovascular risk	English (Australia)	Rasch Modeling, PSI (internal constancy: 0.90)	Unidimensionality is not well supported- probable 2 concepts	392 participant of CONNECT study , a randomized control trial	Randomized sample	5 point Likert scale , total score: 8 to 40, high and low scores, mean=27.1 SD=6.67
21	Islam et al, 2017	8 items (+ computer knowledge and internet use, use of Web 2.0 for health information and	eHealth literacy levels in Southeast Asia	English (even If not clearly stated0	Cronbach alpha=.074	1 factor (EFA)	199 students in Bangladesh	Convenient Sample	5 point Likert scale , total score: 8 to 40, high and low scores, 5 point Likert scale (2 reverse questions)

		perceived health), self-administered							
22	Petric et al, 2017	20 items extended version (+ users' activities), online self administration	eHealth literacy level among online health communities and Development of extended eHeals	Slovenian	Validating information (Cronbach alpha=.75), understanding information (Cronbach alpha=.81), awareness of sources (Cronbach alpha=.80), perceived efficiency (Cronbach alpha=.75), recognizing quality (Cronbach alpha=.52) and being smart on the net	6 dimensions (EFA and CFA)	644 users (mean age 40 years0	Random sample, MedOver Net users	5 point Likert scale (2 reverse questions), dimension 1: mean=3.80 SD= .61 dimension 2: mean=3.11 SD= .75, dimension 3: mean=3.98 SD= .67, dimension 4: mean=3.94 SD= .65, dimension5: mean=3.84 SD= .80, dimension 6: mean=3.74, SD=0.78)

					(Cronbach alpha=.70)				
23	Aponte & Nokes, 2017	10 items (+ focus groups), paper pencil administration	To assess the internet use and eHealth literacy of older Hispanic with Diabetes 2	Spanish (USA)	Cronbach alpha=. 98	1 factor (EFA)	20 Hispanic adults with Type 2 diabetes(mean age 74 years)	Senior Center in East Harlem, Convenience Sample, Mixed method design	5 Likert scale, range 8 to 40, Mean score=22.35 (SD= 12.96)
24	Hyde et al, 2018	7 items scale (item 3 removed) (+ internet characteristics), elf-administered web based	verify 3 factor model structure	English	Factor 1: Composite reliability: .89, factor 2: . 92 and factor3 .89	3 factor structure: awareness (1,2), skills (3, 4,5) and evaluation (6, 7, 8) (CFA)	256 MRI and CT outpatients	convenient sample, MRI and CT outpatients	5 point Likert scale, no mean score available
25	Paige et al, 2018	8 items scale (+ health related internet use), web-based self-administered	invariance measurement, better model fit	English (US)	Factor1. Cronbach alpha =.84, Factor 2, Cronbach alpha=.88, Factor 3	1-4 factors structure (CFA). Better fit=3 factor model: information awareness (1,	829 adults: millennials, generation X, baby boomers, silent generation	stratified by race (Caucasian, black/African)	5 point Likert scale , Factor 1(mean =7.48 SD= 1.71), Factor 2(mean 7.85 SD=1.51), Factor 3 (mean= 14.89 SD=2.88)

					Cronbach alpha=.84	2), information seeking (3,4), information engagement (5,6,7,8)			
26	Gazibara et al, 2018	8 items scale (+ age of 1st internet use), self-administered	validate in Serbian and evaluate eHealth literacy	Serbian	Cronbach alpha=.85	1st factor: Q1,2,3,4 and 2nd factor: Q 5,6,7,8 EFA	702 students	4 high schools in Belgrade (randomly selected)	5 point Likert scale, total score: 8 to 40, high and low scores, mean 26 (20-30)

III. APPENDIX

A. Erasmus+ eLILY PROJECT- SUMMARY REPORT OF DELPHI SURVEY AND TEMPLATE OF MODULE

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LIMASSOL, JULY 2019

Abstract

This report summarises the results of the delphi survey for the eLILY project, an Erasmus+ funded projects for enhancing eHealth Literacy skills among carers of older people and PwD. The report aims to receive feedback of the experts in health care and carers concerning carers' eHealth literacy training needs. We followed a modified version of the Delphi method, including two rounds: one with experts and carers and a second one with the research team reaching the consensus.

In total, 58 Health Care professionals (HCP) and 39 carers participated in the first round of the survey and 11 Health Care professionals in the second round.

The results of the 1st round demonstrated high percentages of agreement among both groups of HCP and carers. Modules with percentages of agreement lower than 85% considered as candidates for modification.

Qualitative results provided valuable input including suggestions for the duration of the modules and steps, the importance of basic digital skills, of in-depth information, management of emotionality, accessing online networking skills, internet security issues, identifying unreliable information.

As part of the second round, 11 HCP assessed the modified version of Modules and agreed to the proposed training curriculum.

In conclusion, as a result of the two rounds modified delphi survey, a revised version of the eHealth literacy training was produced including 4 modules: module 1 on Health literacy and communication skills, module 2 on Digital literacy, module 3 on eHealth literacy-introduction to selected sources and how to find and evaluate videos and module 4 use of interactive services.

As final step of the process will be the pilot testing of the curriculum among 50 carers in all 5 partners' countries.

1. Introduction

Carers considered to be a vulnerable population with high risk of anxiety, depression, use of antidepressants and high morbidity (Pinquart & Sörensen, 2003, 2004; Vitaliano et al., 2003).

With the increase use of technologies, new services emerge to support carers in their role, but little is known on the way carers use the internet or related services (forums, telemedicine, platforms). Only recently research has focused on this topic among this population. In many instances, even if carers are positive to use technology, may not be aware of the existing service, they may lack the skills to use, or the services may no longer be available or updated after the end of the funding period(Wasilewski, Stinson, & Cameron, 2017).

In an effort to improve the health-related online skills of carers aiming to support their caring role, we have developed eLILY project. eLILY Erasmus+ project is a 2-years funded project, aiming to provide a blended training programme (class sessions and elearning course) for carers of frail older people and PwD based on Lily theory model developed by Norman and Skinner (2006), integrating additionally dimensions presented by Chan & Kaufman (2011), Gilstad (2014) and adapted to fit the web 2.0 technology requirements. The e-learning programme will facilitate the class goals and will include selected modules that will assist carers training.

eHealth Literacy was initially defined by (Norman & Skinner, 2006) as a concept including 6 core dimensions: 3 analytic and 3 context specific: traditional, media and information literacy as analytic and computer, scientific and health literacy as context specific. The specific framework is known as Lily framework and has accepted critic in recent years, as doesn't include parameters of Web 2.0 (C. Norman, 2011).

The most recent definition of eHealth literacy is: *The ability to locate, understand, exchange, and evaluate health information from online environments in the presence of dynamic contextual factors and to apply the knowledge gained across ecological levels for the purposes of maintaining or improving health* (Paige, Stellefson, et al., 2018).

This report summarises the findings of a modified Delphi survey which was planned and delivered in the framework of IO2 of eLILY project and as an effort to integrate stakeholder knowledge and expertise in the proposed curriculum. Delphi method is a process that attempts to receive feedback by experts by using specific set of questions and is considered a consensus methodology, usually used when the research team requires consensus on specific topics from a larger sample (Nair, R, Aggarwal, R, Khanna, 2011). We consider this approach as the most appropriate for the project aims, as in this way we would receive feedback by a high number of experts in the field and carers.

2. Method

The aim of the survey was to assess the appropriateness and adequacy of the proposed curriculum, as well to receive qualitative feedback of the proposed curriculum for enhancing the eHealth literacy skills among carers of frail older people and PwD including 6 modules

According to the Erasmus+ application, the development of IO2 includes below steps:

1. Brief survey on the Health literacy (HL) and eHealth literacy (eHL) policies and projects in all partners countries
2. Development of curriculum
3. Development of contents in English and partners' languages
4. Development of trainers manual
5. Piloting testing of the curriculum
6. Analysis and reporting

7. Fine tuning

In the start of the project, all partners agreed to include one more step in the aforementioned methodology and add the Delphi survey as part of tasks.
The amended steps are:

1. Brief survey on the HL and eHL policies and projects in all partners countries
2. Development of the curriculum
3. Development and implementation of Delphi survey among 10 health care professionals and 5 carer in every country.
4. Finalisation of curriculum
5. Development of contents in English and partners' languages
6. Development of trainers' manual
7. Piloting testing of the curriculum
8. Analysis and reporting
9. Fine tuning

2.1 Delphi survey methodology

Based on the methodology of the Delphi survey includes several steps to come to consensus. Initially is important that the research team defines the problem. Then the research team invites the experts to provide their feedback at least in 3 rounds. The number of experts should not be less than 10. The participants should be experts in their field (dementia or adult education).

In the first round, opinions are provided using open-ended questions, gathering items and groups. The opinions are drafted in statements, developing a short questionnaire and send to the experts to provide more items or feedback.

In the second round, unresolved topics are sent back to participants in an effort to reach consensus. In this phase, experts either reply yes/no on focused questions or rank their agreement or disagreement.

In the third-round experts reconsider their percentages of agreement and disagreement and if they have reached consensus then the process may end, otherwise the process continues. A cut-off of agreement should be decided before starting the whole process (Nair, R, Aggarwal, R, Khanna, 2011).

In our case, we present a modified version of the Delphi method, where the research team provided the questionnaire and then invited the experts and a small group of carers to provide their feedback on the questions. After adapting the modules based on the first-round results, then the research team assessed the results and provided their percentage of agreement, reaching consensus as second round of the Delphi.

2.2 Participants

The suggested number per country included 10 Health Care professionals (HCP), experts in dementia or adult education and 5 carers. The involvement of carers would assist in our final decision as they are "experts" in caregiving and their needs would assist us in determining the final modules.
Initially inclusion criteria were:

- being a health care professional (HCP) working in the field of dementia or with frail older people
- being an adult educator
- being a carer of an older person or a person with dementia

2.2 Questions used in the Survey round 1 (annex 1)

Based on previous Delphi surveys and having in mind the scope of the survey, partnership developed the set of questions:

- closed questions to evaluate the appropriateness and adequacy of modules 1-6, using a 5 likert scale:

☐1	☐2	☐3	☐4	☐5
Not appropriate at all	Not appropriate	Unsure	Appropriate	Very appropriate

☐1	☐2	☐3	☐4	☐5
Not adequate at all	Not adequate	Unsure	Adequate	Very adequate

  Modules and sections included in the survey could be considered as appropriate, if they meet the needs for eHealth literacy training among carers and adequate, considering duration and number of steps of every module.
- open questions on the number, duration and steps of the modules in every section. Replying to these questions was optional.

The data collection lasted one month (April 2019)

2.3 Process

During the 1st kick-off meeting, all partner discussed and agreed in the development of below 6 modules, as stated in the application.

The structure of the proposed curriculum:

Module 1 – Digital Literacy (duration 3hours)

The main goal is to introduce to trainees more effective ways of using tablets/smartphones in their day-to-day needs as care-givers so that they feel confident enough using technology as a source of information as well as a mean of communication

Module 2- Communication skills (duration 2 hours)

The general aim of the module is to understand a health problem and to be able to learn how to express health worries and problems to health professionals

Module 3- Introduction to health literacy and ehealth literacy (duration 2hours)

The general goals to understand the significance of health literacy in current health care systems, to learn about health literacy dimensions, to understand the role of empowerment in health decision making.

Module 4- Media literacy – evaluation health websites (duration 1 ½ - 2hours)

In this module, carers of PwD will learn how to search specific health information based on health scenarios of specific problems (e.g aggressiveness, and other behavioral and psychological problems they could potentially face, learn how to evaluate and take effective decisions based on the information/sources currently available.

Module 5 – Learn how to find and evaluate health videos (duration 2 hours)

The general goal of this module is acquisition of the ability to search and play videos about health matters as well as learning how to filter and distinguish between useful information and non-useful. Moreover, ways to facilitate use of new technologies among carers and PwD will be discussed.

Module 6- Use of Interactive services – learn how to use social media (duration 2 ½ hour)

The general aim of this module is to learn how to have access and use social networks and interactive services, how to find useful resources and services on social media in order to support informal caregivers of PwD and how to use social networks and interactive services while applying critical thinking skills and choosing valid health information.

As a method to assess, all countries agreed to distribute a set of questions to the target group in paper / or online format.

Partners invited the experts and carers to participate either by email or face-face communication. Agreed percentage of agreement was set to over 85%

The survey was anonymous and participants provided their informed consent to participate in the study.

In the second round, research team assessed the feedback received by round 1 and reached consensus.

3. Results

3.1 Demographic characteristics of the sample round 1

In the tables below demographics results are presented from all 5 countries, 58 health care professionals, mostly women, mean age 40 years old, with tertiary education and 39 carers, of mean age 54.8 years old (table 1).

In the case of HCP, in the majority of the partners, participants were middle-aged in comparison with HCP from Bulgaria where we find older age and lowest education in this category, depicting the social situation for this profession working with older people.

Table 1. Health Care Professionals demographic characteristics

	CYPRUS	BULGARIA	GREECE	ITALY	POLAND	
HCP	11	15	10	11 +3	8	58
Age	38 (9.5)	55 (6.5)	34 (6)	38 (11)	38.5 (14)	
Female	7	14	7	12	8	
Education	tertiary	6 Lower 5 Higher 4Tertiary	tertiary	11 tertiary 3 higher	7 tertiary 1 higher	

Additionally, we identify the youngest carers in Cyprus and Poland in relation to other 3 countries: Bulgaria, Greece and Italy. This could be justified as the majority of the carers in this survey were the children of the frail older people, possible the secondary carers assisting the primary carer with the use of technology. In Poland, we encounter the higher education among the sample of carers as well as the largest sample of all partners (table 2).

In both cases of HCP and carers, the majority are women.

Table 2. Carers demographic characteristics

	CYPRUS	**BULGARIA**	**GREECE**	**ITALY**	**POLAND**	
CARERS	5	5	5	8	15	39
Age	41 (13)	66 (17)	66 (13)	54 (12)	47 (8)	
Female	5	3	2	5	8	
Education	4 higher 1 tertiary	2 tertiary 2 higher 1 lower		5 higher 3 lower	12 tertiary 2 higher 1 no edu	

The close questions of the survey regarding the appropriateness and the adequacy of the modules were analysed using the percentage of agreement. We considered replies 4 and 5 of the 5-likert scale as agreement in favor of the statement.

All modules had a high percentage of agreement, so the modules with the lowest percentage were reviewed. In the case of HCP, lowest percentage of agreement we encounter for Module 6 (interactive services), followed by Module 2 and 3. In the case of Bulgaria, we identify the lowest percentages among the partners for the specific module and this may depict the low use and access of internet among older adults as has been presented in eLILY survey for the HL and eHL partner's status.

Table 3. Health Care Professionals Positive responses

	CYPRUS (11)	**BULGARIA (15)**	**GREECE (10)**	**ITALY (14)**	**POLAND (8)**	
			APPROPRIATENESS			
Mod 1	11 (100%)	11 (73%)	10 (100%)	12 (85%)	8 (100%)	91.6%
Mod 2	11 (100%)	10 (67%)	9 (90%)	11 (78%)	8 (100%)	87%
Mod 3	11(100%)	10 (67%)	9 (90%)	10 (71%)	8 (100%)	87%
Mod 4	11(100%)	9 (60%)	8 (80%)	13 (93%)	8 (100%)	87%%
Mod 5	11(100%)	8 (53%)	10 (100%)	13 (93%)	8 (100%)	89.2%
Mod 6	11(100%)	10 (67%)	8 (80%)	10 (71%)	7 (87.5%)	81.1%
			ADEQUACY			
Mod 1	10 (91%)	10 (67%)	9 (90%)	11 (78%)	8 (100%)	85.2%
Mod 2	10 (91%)	11 (73%)	9 (90%)	10 (71%)	8 (100%)	86.4%
Mod 3	11 (91%)	11 (73%)	8 (80%)	12 (85%)	8 (100%)	85%
Mod 4	10 (91%)	10 (67%)	8 (80%)	13 (93%)	8 (100%)	86%
Mod 5	11 (91%)	10 (67%)	9 (90%)	13 (93%)	7 (87.5%)	88%
Mod 6	11 (91%)	8 (53%)	8 (80%)	10 (71%)	7 (87.5%)	76.5%

Concerning the adequacy questions, we encounter high percentages of agreement in all countries with the exception of Bulgaria. Module 6 is the module with the lowest percentage.

Carers provided low scores for appropriateness in case of Module 6 and 1 and for adequacy in Modules 5 and 1.

Table 4. Carers Positive responses

	CYPRUS (5)	**BULGARIA (5)**	**GREECE (5)**	**ITALY (8)**	**POLAND (15)**	
			APPROPRIATENESS			
Mod 1	4 (80%)	5 (100%)	4 (80%)	6 (75%)	13 (87%)	84.4%
Mod 2	4 (80%)	5 (100%)	5 (100%)	7 (88%)	14 (93%)	92.2%
Mod 3	4 (80%)	5 (100%)	5 (100%)	7 (88%)	12 (80%)	89.6%
Mod 4	4 (80%)	5 100%)	5 (100%)	8 (100%)	14 (93%)	94.6%
Mod 5	4 (80%)	4 (80%)	5 (100%)	6(75%)	15 (100%)	87%
Mod 6	4 (80%)	5 (100%)	3 (60%)	6(75%)	14 (93%)	81.6%
ADEQUACY						
Mod 1	4 (80%)	4 (80%)	4 (80%)	6(75%)	13 (87%)	80.4%

Mod 2	5 (100%)	5 (100%)	5 (100%)	5 (63%)	13 (87%)	90%
Mod 3	5 (100%)	5 (100%)	4 (80%)	8 (100%)	14 (93%)	94.6%
Mod 4	4 (80%)	5 (100%)	5 (100%)	6(75%)	14 (93%)	89.6%
Mod 5	4 (80%)	4 (80%)	5 (100%)	5 (63%)	13 (87%)	82%
Mod 6	5 (100%)	5 (100%)	3 (60%)	6(75%)	14 (93%)	85.6%

3.2 Qualitative results

The most important information was derived from the comments received during the survey. Three topics were discussed: a) Combination of modules, b) addition of modules c) addition or modification of steps in every module.

Combing modules

In the open question, regarding the combination of modules, we received many different replies from almost all countries:

Proposals per country (HCP):

Cyprus: Module 1 and 6, Module 1 and 2 and 3, 4 and 5, 4 and 5 and 6. Module 1 and 2, Module 3 and 4

Greece: Module 5 and 6

Italy: Module 4 and 5, 5 and 6, 4 and 6. In Italy we encounter comments on the duration in this section: “fewer modules should be provided” “. I would create basic modules with in depth information”, “6 meetings are too many”

Poland: Module 1 and 6 and 1 and 4

Proposals from Carers per country: Cyprus: Module 4 and 5, Greece: Module 1 and 6 and Italy 4 and 6

Adding modules or not

In the open question regarding the addition of modules, in Cyprus HCP consider that “all modules are important” and “if we add more it would be chaotic”

On the contrary, HCP in Greece propose the addition of more modules as they consider the topic multidimension and it is not easily covered.

In Italy, HCP and carers, discuss the need to include sections or module for the **management of emotionality, management of self-help groups and if possible to unify modules**

Module 1 – digital literacy_ ADD OR CHANGE STEPS

In Module 1 and digital literacy, HCP considers important to add more duration in every step (section) (CY), to add more time in final step or run focus groups (CY), “enhancing training in the use of apps” (IT). One HCP considers that is too long in duration.

Carers set questions on this “ How we are sure that all people have appropriate phones for this ?” (CY) and on the importance to add information about **the dangers of websites** (GR) and use of apps (IT)

Module 2- COMMUNICATION skills_ADD OR CHANGE STEPS

In Module 2, most qualitative comments were received by Italian HCP.

Proposals included: add exercise on active listening skills, basic communication skills, **management of emotions**, interaction with doctor and nurse, what carers expect from doctors, **more time** to introductory steps 1-4 (introduction to the topic, exercise to distinguish between personal and patient's needs and emergency steps), more time for role-playing, evaluation of simulation activities.

Work with emotions was also comment of the carers in Italy.

In this module, professionals and carers discussed negatively the short duration of the steps:
"too many activities for 2 hours" (IT), "extent time" (PL).

Module 3- Introduction to health literacy and ehealth literacy ADD OR CHANGE STEPS

In the introduction of the concept of HL and eHL, we didn't receive many comments. Carers provided comment requesting to introduce dementia specific topics (IT) and to keep this module short as may be most appropriate for Health carer professionals and not for carers.

Module 4- Media literacy – evaluation health websites ADD OR CHANGE STEPS

Comments received by the health care professionals included: **more time in step 2** (searching dementia info online (CY), **clarify the process of website assessment** (CY), add info about **false literature (GR, IT)**

One HCP added that "the topic is very complex and risky if the caregivers are not adequately trained on the disease".

On the other hand, carers, requested specific **focus on dementia issues** (IT)

Module 5- Learn how to find and evaluate health videos ADD OR CHANGE STEPS

In module 5, HCP and carers from Italy comment on this and propose to add step on **reliable and unreliable websites**, add more time in step 6 (working on film material) and **basic training on the use of videos.**

No other partner commented on this module

Module 6- Use of Interactive services – learn how to use social media ADD OR CHANGE STEPS

In module 6, we find comments from HCP on the steps from Italy including not focusing only in facebook when discussing for social media, add real examples of creating an interaction network and to extend this module as might be difficult for people not using technology already.

A carer stated "I would exclude skype, I don't think is useful, focus on whatapp, facebook and **messenger**, finding and installing health-related apps.

Overall comments

In the overall comments of the final section we identify 2 categories: positive responses and comments on the duration.

In 26 cases, participants commented positive the curriculum, or they didn't comment at all.

In 15 cases we find comments regrading the duration and the need to shorten the modules and the curriculum.

Other interesting comments include: add glossary, summaries in an easy way, more space to interactive exercises, info on mobile devices, more empathy and directional training

reaching consensus and conclusions- round 2

Taking into consideration the percentages of agreement and the qualitative information of the first round. A second round was organised to assess the results of the first round. An updated version of the training was presented to a smaller group of experts. This time we did not include the group of carers.

A smaller group of 11 experts participated and after discussing the results of round 1, reassessed their percentage of agreement reaching consensus on the proposed curriculum.

They provided their feedback and opinions regarding issues raised from the 1st round:

- Short duration
- Basic digital skills
- In depth information per module
- Management of emotionality
- Accessing online networking (carers groups)
- Internet security issues
- Identifying unreliable information

As a final step, the research team worked during the 2nd transnational meeting in Limassol, Cyprus, on 16-17th May, 2019 into small working groups to combine the sections in 4 modules based on the consensus instead of the proposed 6 making.

Deciding on the inclusion of sections working on emotionality, decreasing number of modules and including online networking training and internet security issues.

The experts team decided to introduce the curriculum with the concept of HL and communication skills, as the new module 1. Comments regarding the duration have been considered.

Basic Internet skills included as the new module 2, integrating basic use of videos, unreliable resources and other safety issues.

Module 3,4 and 5 from old version are now adapted in new module 3 renamed to eHealth literacy Introduction to selected sources – national specific module - Learn how to find and evaluate videos.

Module 6 renamed as module 4 and was adapted according the comments and working group discussion. More time has added in every step according to the comments.

In conclusion, the final curriculum aims to integrate experts and carers knowledge on the training needs of eHL and HL. We understand the difficulty of the task, these concepts even if are part of our every day life, we don’t understand them and as consequence neither the training needs that they might require.

Considering the modified Delphi survey among HCP and carers, we will reassess the modules during Piloting, in a group training of 15 carers. In this phase, we will receive feedback and readapt the sections and contents of every module, making an effort to increase sustainability of this deliverable as it will meet the needs of our target group.

Carer eHealth literacy training version 1.0

Figure III-1 First version of eHealth literacy training among carers of frail older people and PwD before the Delphi survey

Module 1
Digital Literacy
Lead: Alzheimer Bulgaria

Module 2
Communication skills
Lead: Alzheimer Athens

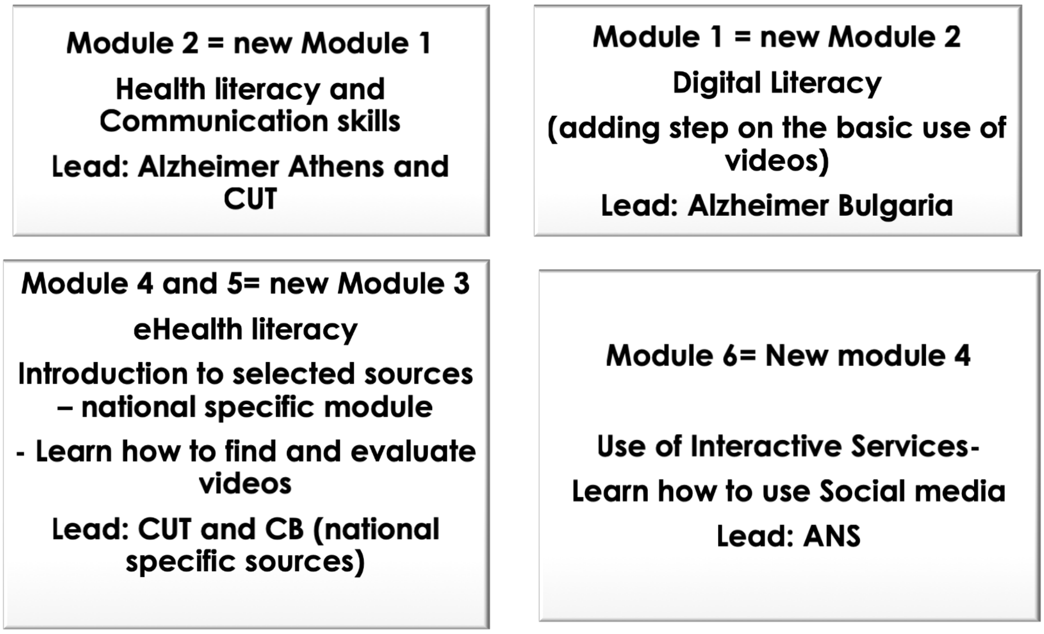
Module 3
Introduction to Health literacy and eHealth literacy
Lead: CUT

Module 4
Introduction to selected sources – national specific module
Lead: CUT (national specific sources)

Module 5
Media Literacy- Videos
Learn how to find and evaluate videos
Lead: CB

Module 6
Use of Interactive Services-Learn how to use Social media
Lead: ANS

Figure III-2 Carer eHealth literacy training version 2.0- consensus reached



Module 2 = new Module 1
Health literacy and Communication skills
Lead: Alzheimer Athens and CUT

Module 1 = new Module 2
Digital Literacy
(adding step on the basic use of videos)
Lead: Alzheimer Bulgaria

Module 4 and 5= new Module 3
eHealth literacy
Introduction to selected sources – national specific module
- Learn how to find and evaluate videos
Lead: CUT and CB (national specific sources)

Module 6= New module 4
Use of Interactive Services-
Learn how to use Social media
Lead: ANS

Fig 2. Updated version of eHealth literacy training among carers of frail older people and PwD

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IV. APPENDIX

A. Agendas of the Consensus meeting and the 1st Health Literacy event in Cyprus (in Greek)

Πρόγραμμα
Ανοικτής Εκδήλωσης για θέματα Εγγραμματισμού για την Υγεία
28 Σεπτεμβρίου 2017
Κτήριο Ανδρέας Θεμιστοκλέους
Αίθουσα Λάρνακα
Λεμεσός, Κύπρος

18.00- 18.20 Εισαγωγή – Καλωσόρισμα

Δρ Ε. Παπασταύρου, Αν. Καθηγήτρια, Τμήμα Νοσηλευτικής, ΤΕΠΑΚ
Δρ Κ. Μακρής, Αν. Καθηγητής, Κοσμήτορας Σχολής Επιστημών Υγείας

18.20 –18.40 Τι είναι το Health Literacy και ποια ιστορία και η εξέλιξή του;
Δρ Παναγιώτα Σουρτζή, Καθηγήτρια Τμήμα Νοσηλευτικής, ΕΚΠΑ

18.40-19.00 Παρουσίαση του ερευνητικού προγράμματος HLS-EU για τηνΕλλάδα

Βαρβάρα Κονδύλη, Καθηγήτρια στο Hellenic American University
Δρ Χαράλαμπος Μαγουλάς, Γλωσσικές Επιστήμες, Ερευνητής, πρώην εκπαιδευτής ΕΣΔΥ (και εάν θέλουν συνολικά)

19.20-19.40 Παρουσίαση και συζήτηση πρωτόκολλου «**The association of health and ehealth literacy with self-efficacy, coping and caregiving perceptions among carers of PwD: a research protocol for a descriptive correlational study**
Α. Ευθυμίου, Διδακτορική Φοιτήτρια ΤΕΠΑΚ

19.40-20.00 Κλείσιμο και συζήτηση

Συντονιστές συζήτησης: Δρ Ε. Παπασταύρου και Δρ Νίκος Μίτλεττον, Αν. Καθηγητές, Τμήμα Νοσηλευτικής, ΤΕΠΑΚ

Cyprus
University of
Technology

Πρόγραμμα
Συνάντησης Ειδικών για θέματα Εγγραμματισμού για την Υγεία
29 Σεπτεμβρίου 2017
Τμήμα Νοσηλευτικής
Βραγαδίνου 15, Λεμεσός

9.30-10.00	Εισαγωγή και συντονισμός: Δρ Νίκος Μίτλεττον, Αναπληρωτής Καθηγητής
10.00- 12.00	Συζήτηση σε σχέση με την ορολογία και την έννοια του health literacy και του ehealth literacy.
11.20-12.00	**Διάλειμμα για καφέ**
12.00- 13.00	Συζήτηση και συνοπτική παρουσίαση προβλημάτων που καταγράφονται από έρευνες στο χώρο του health literacy και ehealth literacy: συνοπτική παρουσίαση του ερευνητικού προγράμματος HLS-EU και των αποτελεσμάτων για την Ελλάδα. Βαρβάρα Κονδύλη, Καθηγήτρια στο Hellenic American University Δρ Χαράλαμπος Μαγουλάς, Γλωσσικές Επιστήμες, Ερευνητής, πρώην εκπαιδευτής ΕΣΔΥ Αρετή Ευθυμίου, Διδακτορική Φοιτήτρια ΤΕΠΑΚ
13.00- 15.00	**Διάλειμμα – Ελαφρύ Γεύμα**
15.00-15.30	Παρουσίαση των αποτελεσμάτων της εγκυροποίησης του HLS-EU-:16 για την Κύπρο Α. Ευθυμίου, Διδακτορική Φοιτήτρια ΤΕΠΑΚ
15.30-18.00	**Συζήτηση σχετικά μελλοντικές συνεργασίες στο τομέα του Health Literacy και eHealth literacy** **κλείσιμο συνάντησης**

V. APPENDIX

A. Approval emails for the use of questionnaires

1. HLS-EU-Q16

Dear Mrs. Efthymiou,

Thank you so much for your interest in using the HLS-EU-Q16 instrument in your PHD research.

Regarding the scoring of the HLS-Eu-Q16 scale, please be aware that the scoring for the short-form is very
different from that of the long-form!

The HLS-EU-Q16 score ranges from 0 to 16 and not from 0 to 50!!!

Please find attached a short overview of the calculation methods for the HLS-EU-Q16!

Good luck with your PhD project!

Kind regards,

Jürgen Pelikan

Jürgen M. Pelikan, Professor em. sociology (University of Vienna), PhD
Director, WHO-CC Health Promotion in Hospitals and Health Care,
at Gesundheit Österreich GmbH (Austrian Public Health Institute)
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Latest publications:
Mittelmark et al. (eds.) Handbook of Salutogenesis,
get it FREE at http://link.springer.com/book/10.1007/978-3-319-04600-6
Schaeffer & Pelikan (Hg.) Health Literacy. Forschungsstand und Perspektiven. Hogrefe

PERMISSION TO USE THE GREEK VERSION AVAILABLE:
Αγαπητή κα. Ευθυμίου,

Χαίρομαι που συνεχίζεται η έρευνα και σας στέλνω 3 διαφορετικά – το ερωτηματολόγιο το μεγάλο (και στις 2 γλώσσες), το πιο μικρό με 16 ερωτήσεις που θεωρούμε πως είναι εξίσου αποτελεσματικό (το έχω οργανώσει εγώ και στις δύο γλώσσες), υπάρχει και αυτό με τις 6 ερωτήσεις που επίσης δείχνει αποτελεσματικό με βάση αυτά που βρήκαν οι συνάδελφοι Dr. Pelikan (presented in Taipei oral presentation in 2014). Και τελευταία το NVS και στις δύο γλώσσες μεταφρασμένο. Για το HLS-EU εάν είναι εύκολο παρακαλώ να βάλετε τα ονόματα τις ομάδας που είναι στην βιβλιογραφία για το HLS=EU project.

Θα βρίσκομαι πάλι στην διάθεσή σας από τις 22-8 και μετά εάν θέλετε να σας γνωρίσω και από κοντά.

Επίσης όταν και εσείς είσαστε διαθέσιμοι να γίνετε μέλος και του “working group”
(see attached).

Βαρβάρα Κονδύλη

Barbara Kondilis, MSW, MPH
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2. *eHeals*

Dear Areti,

Thank you for your kind note and interest in using the eHEALS instrument. You have my full permission to use it, adapt it and translate it for ythis study.

I hope that it works well for you and I wish you the very best with your research.

Regards,

Cameron

3. *Revised Scale of Caregiving Self-Efficacy*

Areti:

You certainly have our permission to do the translation into Greek as needed.

Best wishes for a successful project,

Ann Steffen

Ann M. Steffen, Ph.D., ABPP
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http://www.umsl.edu/~steffena/images/HealthcareStudies_GeneralAudience.pdf

4. COPE index

Hello Areti

Thanks for getting in touch. Prof Philp doesn’t have much involvement with the COPE Index these days, as far as I know, so you have done the right thing in emailing me.

I am a little busy just now (I have some teaching at the moment), but I will answer your questions by the end of the week.

Best Wishes
Kevin

Kevin McKee
Professor of Gerontology, Head of Subject for Social Work
School of Education, Health and Social Studies, Dalarna University,
791 88 Falun, Sweden. Email: kmc@du.se; Tel: 0046 (0)23 77 8238
Director,
Research Centre for Ageing and Later Life

5. BRIEF COPE

Αγαπητή κυρία Ευθυμίου,

Το Brief COPE στα Ελληνικά είναι διαθέσιμο από τη σελίδα του συγγραφέα του C. Carver από όπου μπορείτε να το πάρετε.

Από εμένα έχετε την άδεια χρήσης του.

hLp://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html

Ευχαριστώ για το ενδιαφέρον σας,

Georgia Panayiotou, Ph.D.
Chair, Department of Psychology
Associate Professor of Clinical Psychology
Board Member, Center of Applied Neuroscience
University of Cyprus
PO Box, 20537, 1678 Nicosia
TEL:22892081; FAX: 22892081
Cyprus

6. Multidimensional Scale of Perceived Social Support

Dear Areti Efthymiou,

You have my permission to use the Mul'dimensional Scale of Perceived Social Support

(MSPSS) in your research (the Greek transla'on). I have attached the original English language version of the scale (with scoring informa'on on the 2nd page), a document lis'ng several of the ar'cles that have reported on the reliability and validity of the MSPSS, and a chapter that I wrote about the scale.

I hope your research goes well.

Best regards,

Greg Zimet

Gregory D. Zimet, PhD, FSAHM | Professor of Pediatrics & Clinical Psychology
Co-Director, IUPUI Center for HPV Research
Division of Adolescent Medicine, Department of Pediatrics
Indiana University School of Medicine
410 W. 10th Street, HS 1001, Indianapolis, IN 46202, USA
T +1 317-274-8812 | Fax +1 317-274-0133
Email gzimet@iu.edu
hDp://pediatrics.iu.edu/center-hpv-research/about-us/
hDp://pediatrics.iu.edu/sec'ons-and-faculty/adolescent-medicine/our-team/faculty/bio-zimet/

PERMISSION FOR THE GREEK VALIDATION:
Καλησπέρα. Παρακαλώ όπως συμπληρωθεί η σχετική φόρμα και μου αποσταλεί προκειμένου να χρησιμοποιηθεί το ερωτηματολόγιο.
Π. Θεοφίλου

7. SILS

From: Lisa Chew lchew@uw.edu

Subject: Re: Permission request-SILS in Greek

Date: July 29, 2019 at 19:07

To: Areti Efthymiou arefthymiou@yahoo.com

Yes, please feel free to use the SILS.

VI. APPENDIX

A. Consent Forms and Questionnaires in Greek of the Main Study

1. Consent Forms

ΕΝΤΥΠΑ ΣΥΓΚΑΤΑΘΕΣΗΣ για συμμετοχή σε πρόγραμμα έρευνας (Τα έντυπα αποτελούνται συνολικά από 5 σελίδες)

Καλείστε να συμμετάσχετε σε ένα ερευνητικό πρόγραμμα. Πιο κάτω (βλ. **«Πληροφορίες για Ασθενείς ή/και Εθελοντές»**) θα σας δοθούν εξηγήσεις σε απλή γλώσσα σχετικά με το τι θα ζητηθεί από εσάς και εάν συμφωνήσετε να συμμετάσχετε στο πρόγραμμα. Θα σας περιγραφούν οποιοιδήποτε κίνδυνοι μπορεί να υπάρξουν ή ταλαιπωρία που τυχόν θα υποστείτε από την συμμετοχή σας στο πρόγραμμα. Θα σας επεξηγηθεί με κάθε λεπτομέρεια τι θα ζητηθεί από εσάς και ποιος ή ποιοι θα έχουν πρόσβαση στις πληροφορίες που εθελοντικά θα δώσετε για το πρόγραμμα. Θα σας δοθεί η χρονική περίοδος για την οποία οι υπεύθυνοι του προγράμματος θα έχουν πρόσβαση στις πληροφορίες ή/και υλικό που θα δώσετε. Θα σας επεξηγηθεί τι ελπίζουμε να μάθουμε από το πρόγραμμα σαν αποτέλεσμα και της δικής σας συμμετοχής. Επίσης, θα σας δοθεί μία εκτίμηση για το όφελος που μπορεί να υπάρξει για τους ερευνητές ή/και χρηματοδότες αυτού του προγράμματος. **Δεν πρέπει να συμμετάσχετε, εάν δεν επιθυμείτε ή εάν έχετε οποιουσδήποτε ενδοιασμούς που αφορούν την συμμετοχή σας στο πρόγραμμα.** Εάν αποφασίσετε να συμμετάσχετε, πρέπει να αναφέρετε εάν είχατε συμμετάσχει σε οποιοδήποτε άλλο πρόγραμμα έρευνας μέσα στους τελευταίους 12 μήνες. **Είστε ελεύθεροι να αποσύρετε οποιαδήποτε στιγμή εσείς επιθυμείτε την συγκατάθεση για την συμμετοχή σας στο πρόγραμμα.** Έχετε το δικαίωμα να υποβάλετε τυχόν παράπονα ή καταγγελίες, που αφορούν το πρόγραμμα στο οποίο συμμετέχετε, προς την Επιτροπή Βιοηθικής που ενέκρινε το πρόγραμμα ή ακόμη και στην Εθνική Επιτροπή Βιοηθικής Κύπρου. Πρέπει όλες οι σελίδες των εντύπων συγκατάθεσης να φέρουν το ονοματεπώνυμο και την υπογραφή σας.

Σύντομος Τίτλος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε
Η σχέση της Εγγραμματοσύνης και της Ψηφιακής Εγγραμματοσύνης σε θέματα για την υγεία με την αυτό-αποτελεσματικότητα, τις στρατηγικές αντιμετώπισης και τις απόψιες στη διαχείριση της φροντίδας σε φροντιστές ατόμων με άνοια
Υπεύθυνος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε
Αρετή Ευθυμίου, Δρ.Ευριδίκη Παπασταύρου

Επίθετο:	....	Όνομα:	....
Υπογραφή :		Ημερομηνία :	

....

ΕΝΤΥΠΑ ΣΥΓΚΑΤΑΘΕΣΗΣ
για συμμετοχή σε πρόγραμμα έρευνας
(Τα έντυπα αποτελούνται συνολικά από 5 σελίδες)

Σύντομος Τίτλος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε
Η σχέση της Εγγραμματοσύνης και της Ψηφιακής Εγγραμματοσύνης σε θέματα για την υγεία με την αυτό-αποτελεσματικότητα, τις στρατηγικές αντιμετώπισης και τις απόψιες στη διαχείριση της φροντίδας σε φροντιστές ατόμων με άνοια

Δίδετε συγκατάθεση για τον εαυτό σας ή για κάποιο άλλο άτομο;	
Εάν πιο πάνω απαντήσατε για κάποιον άλλο, τότε δώσετε λεπτομέρειες και το όνομα του.	

Ερώτηση	ΝΑΙ ή ΟΧΙ
Συμπληρώσατε τα έντυπα συγκατάθεσης εσείς προσωπικά;	
Τους τελευταίους 12 μήνες έχετε συμμετάσχει σε οποιοδήποτε άλλο ερευνητικό πρόγραμμα;	
Διαβάσατε και καταλάβατε τις πληροφορίες για ασθενείς ή/και εθελοντές;	
Είχατε την ευκαιρία να ρωτήσετε ερωτήσεις και να συζητήσετε το Πρόγραμμα;	
Δόθηκαν ικανοποιητικές απαντήσεις και εξηγήσεις στα τυχόν ερωτήματά σας;	
Καταλαβαίνετε ότι μπορείτε να αποσυρθείτε από το πρόγραμμα, όποτε θέλετε;	
Καταλαβαίνετε ότι, εάν αποσυρθείτε, δεν είναι αναγκαίο να δώσετε οποιεσδήποτε εξηγήσεις για την απόφαση που πήρατε;	
(Για ασθενείς) καταλαβαίνετε ότι, εάν αποσυρθείτε, δεν θα υπάρξουν επιπτώσεις στην τυχόν θεραπεία που παίρνετε ή που μπορεί να πάρετε μελλοντικά;	
Συμφωνείτε να συμμετάσχετε στο πρόγραμμα;	
Με ποιόν υπεύθυνο μιλήσατε;	

Επίθετο:	…………………………………………………	Όνομα:	………………………………………
Υπογραφή:		Ημερομηνία:	

……………………………………………………………………

ΕΝΤΥΠΑ ΣΥΓΚΑΤΑΘΕΣΗΣ για συμμετοχή σε πρόγραμμα έρευνας (Τα έντυπα αποτελούνται συνολικά από 5 σελίδες)
Σύντομος Τίτλος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε
Η σχέση της Εγγραμματοσύνης και της Ψηφιακής Εγγραμματοσύνης σε θέματα για την υγεία με την αυτό-αποτελεσματικότητα, τις στρατηγικές αντιμετώπισης και τις απόψιες στη διαχείριση της φροντίδας σε φροντιστές ατόμων με άνοια

ΠΛΗΡΟΦΟΡΙΕΣ ΓΙΑ ΦΡΟΝΤΙΣΤΈΣ ΑΝΘΡΏΠΩΝ ΜΕ ΑΝΟΙΑ:

Η Εγγραμματοσύνη σε θέματα για την Ηλεκτρονικής υγείας ανάφερεται σε ένα συνδυασμό **ικανοτήτων** που περιλαμβάνουν: την εύρεση, κατανόση και αξιολόγηση γενικών, επιστημονικών πληροφοριών και ειδικοτερα πληροφοριών σχετικών με θέματα που αφορούν την Υγεία, αλλά και σε δεξιότητες χρήσης του Ηλεκτρονικού Υπολογιστή, άλλων μέσων διάδοσης της πληροφορίας, και στην βασική δεξιότητα χρήσης της γλώσσας και των μαθηματικών.

Στις μέρες μας υπάρχει γρήγορη εξέλιξη της τεχνολογίας, σε σημείο που πολλές φορές είναι δύσκολο να ακολουθήσουμε. Ειδικότερα πολλές ομάδες, άνεργοι, άτομα άνω των 65 ετών, χαμηλου κοινωνικοοικονομικού επιπέδου, φαίνεται ότι δεν μπορούν να ακολουθήσουν το ρυθμό εξέλιξης με το τρόπο που ίσως να συμβαίνει σε άτομα μικρότερης ηλικίας ή υψηλότερου κοινωνικοοικονομικού επιπέδου. Το αποτελέσμα είναι τεχνολογίες που αναπτύσσονται για τη βελτίωση της ποιότητας ζωής ευάλωτων ομάδων να παραμένουν ανεκμετάλλευτες, μιας και δημιουργείται ένα χάσμα ανάμεσα στο χρήστη και στην τεχνολογία.

Τα τελευταία χρόνια, πολλά Ευρωπαικά προγράμματα μικρής κλίμακας χρηματοδοτούν την ανάπτυξη τεχνολογικών μέσων για τη βελτίωση της ποιότητας ζωής ανθρώπων που φροντίζουν ηλικιωμένους με χρόνιες παθήσεις και ειδικότερα με άνοια. Τέτοιου τύπου τεχνολογία αποτελούν τα προγράμματα υποστήριξης, εκπαίδευσης, αισθητήρες και πλατφόρμες ενημέρωσης. Με τη λήξη της χρηματοδότησης συνήθως τα προγράμματα σταματούν. Η χρήση των παραπάνω τεχνολογιών θα μπορούσε να συνεισφέρει στη βελτίωση της ποιότητας ζωής αλλά και της φροντίδας που παρέχουν οι φροντιστές.

Επίθετο:	....	Όνομα:	....
Υπογραφή		Ημερομηνία:	

……………………………………………………………………

ΕΝΤΥΠΑ ΣΥΓΚΑΤΑΘΕΣΗΣ
για συμμετοχή σε πρόγραμμα έρευνας
(Τα έντυπα αποτελούνται συνολικά από 5 σελίδες)

Σύντομος Τίτλος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε

Η σχέση της Εγγραμματοσύνης και της Ψηφιακής Εγγραμματοσύνης σε θέματα για την υγεία με την αυτό-αποτελεσματικότητα, τις στρατηγικές αντιμετώπισης και τις απόψιες στη διαχείριση της φροντίδας σε φροντιστές ατόμων με άνοια

ΠΛΗΡΟΦΟΡΙΕΣ ΓΙΑ ΦΡΟΝΤΙΣΤΈΣ ΑΝΘΡΏΠΩΝ ΜΕ ΑΝΟΙΑ:

Η παρούσα έρευνα πραγματοποιείται στο πλαίσιο διδακτορικής διατριβής της Αρετής Ευθυμίου και έχει στόχο να διερευνήσει πως συνδέεται η Εγγραμματοσύνη σε θέματα Ηλεκτρονικής Υγείας των φροντιστών ανθρώπων με άνοια και του άμεσα υποστηρικτικού τους περιβάλλοντος με την ικανότητα που έχει το άτομο να αντιμετωπίζει προβλήματα που προκύπτουν κατά τη παροχή φροντίδας και με τις στάσεις και πεποιθήσεις για τη φροντίδα.

Η έρευνα είναι **ανώνυμη**, δε συμπληρωνεται το Ονοματεπώνυμο του συμμετέχοντα πέρα από το έντυπο συγκατάθεσης, όπου και θα διασφαλιστεί να μην υπάρξει σύνδεση της φόρμας με τις κλίμακες που θα συμπληρωθούν ανώνυμα. Οι συμμετέχοντες στην έρευνα θα κληθούν να συμπληρώσουν με τη βοήθεια του ερευνητή:

1) Φόρμα δημογραφικών στοιχείων
2) Μία κλίμακα για την Εγγραμματοσύνη σε θέματα για την Ηλεκτρονική Υγεία (10 ερωτήσεις)
3) Συμπληρωματικές ερωτήσεις για τη χρηση του διαδικτύου από τους φροντιστές (4 ερωτήσεις)
4) Μία κλίμακα για την Εγγραμματοσύνη για την Υγεία (16 ερωτήσεων)
5) Μία ερώτηση screening για την Εγγραμματοσύνη για την Υγεία (1 ερώτηση)
6) Μία κλίμακα για την αυτοαποτελεσματικότητα του Φροντιστή (12 ερωτήσεις)
7) Μία κλίμακα για στάσεις των Φροντιστών απέναντι στη Φροντίδα (15 ερωτήσεις)
8) Μία κλίμακα στρατηγικών αντιμετώπισης (28 ερωτήσεις)

Η διαδικάσία θα πραγματοποιηθεί σε ώρα, μέρα και σε χώρο που βολεύει το συμμετέχοντα. Η συνολική της διάρκεια δεν είναι πάνω από **1 ½ ώρα**.

Κατόπιν άδειας του συμμετέχοντα, ο ερευνητής θα επικοινωνήσει τηλεφωνικά στο πρόσωπο που θα υποδείξει ο φροντιστής, ως το αμέσως πιο εμπλεκόμενο στη φροντίδα του ατόμου με άνοια προκειμένου να χορηγηθούν οι κλίμακες :1, 2, 3, 4, 5

Επίθετο:	…………………………………………………	Όνομα:	………………………………………
Υπογραφή:		Ημερομηνία:	

ΕΝΤΥΠΑ ΣΥΓΚΑΤΑΘΕΣΗΣ
για συμμετοχή σε πρόγραμμα έρευνας

(Τα έντυπα αποτελούνται συνολικά από …………… σελίδες)
Σύντομος Τίτλος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε
Η σχέση της Εγγραμματοσύνης και της Ψηφιακής Εγγραμματοσύνης σε θέματα για την υγεία με την αυτό-αποτελεσματικότητα, τις στρατηγικές αντιμετώπισης και τις απόψιες στη διαχείριση της φροντίδας σε φροντιστές ατόμων με άνοια

<u>ΠΛΗΡΟΦΟΡΙΕΣ ΓΙΑ ΦΡΟΝΤΙΣΤΈΣ ΑΝΘΡΏΠΩΝ ΜΕ ΑΝΟΙΑ:</u>

Αφού συμπληρωθεί ο αριθμός των ατόμων που είναι απαραίτητος για την έρευνα, θα γίνει ανάλυση των δεδομένων και θα ακολουθήσει η συγγραφή των αποτελεσμάτων.

Όλα τα δεδομένα θα φυλλάσσονται στο γραφείο της Επιβλέπουσας Καθηγήτριας: Δρ Ευριδίκη Παπασταύρου, γρ. 311, Τμήμα Νοσηλευτικής, Βραγαδίνου 15, Λεμεσός, Κύπρος, για διάστημα τουλάχιστον 5 ετών. Επιπλέον τα δεδομένα θα τηρούνται σε ηλεκτρονική βάση, η οποία θα φυλάσσεται στον υπολογιστή του ερευνητή και θα υπάρχει κωδικός πρόσβασης.

Σε περίπτωση που οι συμμετέχοντες επιθυμούν να ενημερωθούν για την έκβαση της έρευνας θα μπορούν να επικοινωνούν απευθείας με την ερευνήτριας Αρετής .Ευθυμίου (+357 97807492, +30 6948409254).

Η παρούσα έρευνα θα αποτελέσει τη βάση για το σχεδιασμό ειδικού προγράμματος παρέμβασης και ενδυνάμωσης της Εγγραμματοσύνης σε Θέματα Ηλεκτρονικής Υγείας για φροντιστές ανθρώπων με άνοια και θα προωθήσει τη δυνατότητα χρηματοδότησης του εξειδικευμένου αυτού προγράμματος από ενδιφερομένους φορείς.

Επίθετο:	…………………………………………………	Όνομα:	………………………………………
Υπογραφή:		Ημερομηνία:	

ΕΝΤΥΠΟ ΕΝΗΜΕΡΩΣΗΣ ΚΑΙ ΛΗΨΗΣ ΣΥΓΚΑΤΑΘΕΣΗΣ ΓΙΑ ΤΗΝ ΕΠΕΞΕΡΓΑΣΙΑ ΠΡΟΣΩΠΙΚΩΝ ΔΕΔΟΜΕΝΩΝ

Ονομάζομαι Αρετή Ευθυμίου, είμαι Ψυχολόγος, Μεταπτυχιακός Συνεργάτης, Βοηθός Ερευνητή Α' και Υποψήφια Διδάκτωρ του τμήματος Νοσηλευτικής του Τεχνολογικού Πανεπιστημίου Κύπρου και για το σκοπό απόκτησης διδακτορικού τίτλου διεξάγω μία έρευνα με τίτλο: "Η σχέση της Εγγραμματοσύνης και της Ψηφιακής Εγγραμματοσύνης σε θέματα για την υγεία με την αυτό-αποτελεσματικότητα, τις στρατηγικές αντιμετώπισης και τις απόψιες στη διαχείριση της φροντίδας σε φροντιστές ατόμων με άνοια".

Η συμμετοχή σας στην έρευνα αυτή είναι εθελοντική. Είστε ελεύθεροι να αποσύρετε οποιαδήποτε στιγμή εσείς επιθυμείτε την συγκατάθεση για την συμμετοχή σας στο πρόγραμμα.

Οι απαντήσεις δε θα δοθούν σε οποιονδήποτε αποδέκτη και έχετε το δικαίωμα πρόσβασης και διόρθωσης των δεδομένων σας.

Για σκοπό άσκησης αυτών των δικαιωμάτων μπορείτε να επικοινωνήσετε μαζί μου στα τηλέφωνα:

Έχω ενημερωθεί και δίνω τη συγκατάθεσή μου για την επεξεργασία των προσωπικών δεδομένων για τις ανάγκες της πιο πάνω επιστημονικής έρευνας.

Ημερομηνία:

Ο Συμμετέχων Φροντιστής

……………………

(υπογραφή)

Ο συμμετέχων συγγενής με άνοια

Ή το άτομο που νόμιμα σας εκπροσωπεί

…………………..

(υπογραφή)

2. *Demographics Forms*

Φορμα δημογραφικων στοιχειων κυριου φροντιστη

1. **Φύλο**

Αρρεν	1
Θήλυ	2

2. **Ηλικία**

<24	1
25-29	2
30-34	3
35-39	4
40-44	5
45-49	6
50-54	7

55-59	8
60-64	9
65-69	10
70-74	11
75-79	12
80-84	13
>85	14

3. **Επίπεδο εκπαίδευσης βάσει ISCED**

Προσχολική εκπαίδευση (3-5 και 5-7, περιλαμβάνει το προνηπιο και το νηπιαγωγείο)	1
Βασική εκπαίδευση- (Δημοτικό σχολείο)	2
Κατώτερη δευτεροβάθμια εκπαίδευση (Γυμνάσιο 3 τάξεων)	3
Ανώτερη δευτεροβάθμια εκπαίδευση (Λύκειο ή και Επαγγελματική εκπαίδευση- 15 έως 18/20)	4
Επίπεδο μετά την ολοκλήρωση της δευτεροβάθμιας εκπαίδευσης(όχι Πανεπιστημιακή)	5
Πανεπιστημιακές σπουδές	6
Μεταπτυχιακό	7
Διδακτορική και Μεταδιδακτορική εκπαίδευση)	8
ΆΛΛΟ	9

4. **Οικογενειακή Κατάσταση**

Έγγαμος	1
Άγαμος	2
Διαζευγμένος	3
Χήρος	4
Άλλο:…………….	5

5. **Επαγγελματική Κατάσταση**

Πλήρης απασχόληση	1
Ημιαπασχόληση	2
Διευκρινίστε εάν η ημιαπασχόληση είναι λόγω της φροντίδας	ναι όχι
Ανεργία	3
Διευκρινίστε εάν δεν εργάζεστε λόγω της φροντίδας	ναι όχι
Συνταξιούχος	4
Οικιακά	5
Αλλο	6

6. **Ποια είναι η σχέση σας με τον άνθρωπο με άνοια, για παράδειγμα: Είμαι (σύζυγος, παιδί, αδελφός) του ανθρώπου που φροντίζω..**

Παιδί	1
Σύζυγος	2
Φίλος	3
Γείτονας	4
Άλλο:…………….	5

7. **Σημειώστε τις ώρες Φροντίδας την εβδομάδα που παρέχετε στο συγγενή σας (αφορά μόνο τη φροντίδα για την άνοια)**

8. **Σημειώστε τα χρόνια που φροντίζετε το συγγενή σας (αφορά μόνο τη φροντίδα για την άνοια)**

9. **Φροντίζετε και άλλα άτομα;**

Ναι	Εάν ναι, διευκρινίστε:	1
Οχι		2

10. **Λαμβάνετε στήριξη/βοήθεια από Επαγγελματία Υγείας (π.χ ψυχολόγο, νοσηλευτή, φυσικοθεραπευτή ή και έμμισθο Φροντιστή (άνθρωπο που σας βοηθάει καθημερινά με πληρωμή);**

Ναι	**Εάν ναι, διευκρινίστε:**	**1**
Οχι		**2**

11. **Λαμβάνετε στήριξη/βοήθεια οποιασδήποτε μορφής από άλλο μέλος της οικογένειας ή και φίλο;**

Ναι	Εάν ναι, διευκρινίστε:	1
Οχι		2

12. **Επιλέξτε, τον τύπο στήριξης/βοήθειας που σας παρέχει το άτομο που συμπληρώσατε στην ερώτηση 11. Μπορείτε να επιλέξετε όσους τύπους υποστήριξης θέλετε. Είναι το ίδιο άτομο που παρέχει την υποστήριξη ή διαφορετικά άτομα;**

Οικιακή βοήθεια	1	
Συναισθηματική/Ψυχολογική υποστήριξη	2	
Κοινωνική υποστήριξη (π.χ. να περνάει χρόνο μαζί σας ή με τον ασθενή	3	
Βοήθεια στη μετακίνηση	4	
Βοήθεια σε πρακτικά θέματα φροντίδας του ανθρώπου (π.χ προσωπική υγιεινή)	5	
Βοήθεια σε εξωτερικές εργασιες	6	
Οικονομική διαχείριση	7	
Διαχείριση φροντίδας (πχ ιατρικά ραντεβού, επικοινωνία με τον έμμισθο φροντιστή)	8	
Άλλο:	9	
Όλα τα παραπάνω	10	

13. **Μένετε μαζί με το άτομο που φροντίζετε;**

Ναι	1
Οχι	2
Εάν όχι:	
Μένετε στην ίδια πολυκατοικία	3
Στην ίδια γειτονία	4
Στην ίδια πόλη	5
Σε άλλη πολη	6
Άλλο	7

14. **Κάνετε Χρήση του Διαδικτύου**

Ναι	**1**

Οχι		**2**
	Εάν ναι: για ποιους από τους παρακάτω λόγους χρησιμοποιείτε το διαδίκτυο συχνότερα. Επιλέξτε τους 3 συχνότερους, με σειρά προτίμησης (π.χ 1ος, 2ος, 3ος λόγος)	
	Διασκέδαση/Ψυχαγωγία (ταινίες, μουσική, videos)	
	Αγοροπωλησίες (αγορά και πώληση προϊόντων, κρατήσεις εισιτηρίων κα)	
	Αναζήτηση πληροφοριών για θέματα που σας ενδιαφέρουν	
	Κοινωνικοποίηση (μηνύματα /IM, chat sites, forums, κοινωνικά δίκτυα)	
	Emails	
	Blog (γράφετε σε blog, ή ενημερώνετε την προσωπική σας σελίδα)	
	Για επαγγελματικούς λόγους (αναζήτηση εργασίας, ανάρτηση δουλειάς κα)	
	Κλασσική ενημέρωση (ειδησιογραφικά μέσα)	

15. **Εάν θα χρειαζόσταν να βρείτε και να κατανοήσετε κάποια πληροφορία για τη διαχείριση της νόσου στο διαδίκτυο, ποιο είναι το πιο κοντινό σας άτομο από το οικογενειακό ή/ και φιλικό περιβάλλον που θα σας βοηθούσε (πχ ο/η σύζυγός, αδελφός, θεία/ος κα);**

16. **Εάν δεν έχετε απαντήσει την ερώτηση 15. Από ποια πηγή βρίσκετε κάποια πληροφορία για τη διαχείριση της νόσου, όταν τη χρειάζεστε;**

17. Από τις παρακάτω υπηρεσίες, ποιες γνωρίζετε πως να χρησιμοποιήσετε, κυκλώστε την απάντησή σας. Μπορείτε να κυκλώσετε όσες υπηρεσίες γνωρίζετε:	
Ιστοσελίδες	1
Κοινωνικά δίκτυα (facebook, twitter, LinkedIn, κα)	2
Emails	3
Διαδραστικές υπηρεσίες (forums, chats/μηνύματα, skype, viber, messager)	4
e-learning courses	5

Στοιχεία ασθενούς			
Φύλο. Κυκλώστε το φύλο του ασθενούς:			**1ΑΡΡΕΝ 2 ΘΗΛΥ**
Ηλικία. Κυκλώστε την κατηγορία που εντάσσεται η ηλικία του ασθενούς:			
40-44	**1**	**65-69**	**6**
45-49	**2**	**70-74**	**7**
50-54	**3**	**75-79**	**8**
55-59	**4**	**80-84**	**9**
60-64	**5**	**>85**	**10**
ΔΙΑΓΝΩΣΗ (εφόσον γνωρίζετε από το θεράποντα γιατρό)			
Στάδιο της Νόσου			**ΗΠΙΟ ΜΕΣΟ ΣΟΒΑΡΟ**
CDR (στοιχείο που συλλέγεται από συνέντευξη)			
Instrumental Activities of daily Living (στοιχεία που συλλέγονται με συνέντευξη) 1.Ικανότητα χρήσης τηλεφώνου 2. Ψώνια 3. Προετοιμασία γευμάτων 4. Οικιακές εργασίες 5.Πλύσιμο ρούχων			**/8**

6. Μέσο μεταφοράς **7. Υπευθυνότητα ως προς τη θεραπευτική αγωγή** **8. Ικανότητα στη διαχείριση χρήματος**	

Φορμα δημογραφικων στοιχειων δευτερευοντα φροντιστη

1. Φύλο

Αρρεν	1
θηλυ	2

2. **Ηλικία**

<24	1	55-59	8
25-29	2	60-64	9
30-34	3	65-69	10
35-39	4	70-74	11
40-44	5	75-79	12
45-49	6	80-84	13
50-54	7	>85	14

3. Επίπεδο εκπαίδευσης βάσει International Standard Classification of Education (ISCED)

Level 0 (προσχολική εκπαίδευση, 3-5 και 5-7, περιλαμβάνει το προνηπιο και το νηπιαγωγείο)	1
Level 1 (βασική εκπαίδευση- Δημοτικό σχολείο)	2
Level 2 (Κατώτερη δευτεροβάθμια εκπαίδευση- Γυμνάσιο)	3
Level 3 (Ανώτερη δευτεροβάθμια εκπαίδευση – Λύκειο ή και Επαγγελματική εκπαίδευση- 15 έως 18/20)	4
Level 4 (Επίπεδο μετά την ολοκλήρωση της δευτεροβάθμιας εκπαίδευσης, όχι Πανεπιστημιακή)	5
Level 5.1 Πανεπιστημιακές σπουδές	6
Level 5.2 Μεταπτυχιακό	7
Level 6 (Διδακτορική και Μεταδιδακτορική εκπαίδευση)	8
ΆΛΛΟ	9

4. Οικογενειακή Κατάσταση

Έγγαμος	1
Άγαμος	2
Συμβίωση	3
Διαζευγμένος	4
Χήρος	5
Άλλο:…………….	6

5. **Επαγγελματική Κατάσταση**

Πλήρης απασχόληση	1
Ημιαπασχόληση	2
Ανεργία	3
Συνταξιούχος	4
Σε πρόωρη σύνταξη ή αποχώρησε από την εργασία του λόγω φροντίδας	5
Οικιακά, γονέας ή φροντιστής	8
Αλλο	9

6. Η σχέση με τον Φροντιστή

Παιδί	1
Σύζυγος	2
Φίλος	3
Γείτονας	4
Άλλο:…………….	5

7. Τύπος στήριξης/βοήθειας που παρέχετε στον κύριο Φροντιστή

Οικιακή βοήθεια	1
Συναισθηματική/Ψυχολογική υποστήριξη	2
Κοινωνική υποστήριξη	3
Βοήθεια στη μετακίνηση	4
Βοήθεια σε πρακτικά θέματα φροντίδας του ανθρώπου (π.χ προσωπική υγιεινή, απασχόληση)	5
Βοήθεια σε εξωτερικές εργασιες	6
Οικονομική διαχείριση	7
Διαχείριση φροντίδας (πχ ιατρικά ραντεβού, επικοινωνία με τον έμμισθο φροντιστή)	8
Άλλο:	9
Όλα τα παραπάνω	10

8. Μένετε μαζί με τον κύριο φροντιστή ;

Ναι	1
Οχι	2

Εάν όχι:	
Μένετε στην ίδια πολυκατοικία	3
Στην ίδια γειτονία	4
Στην ίδια πόλη	5
Σε άλλη πολη	6
Άλλο	7

3. Questionnaires

Εργαλείο Ανίχνευσης της Εγγραμματοσύνης με μία μοναδική ερώτηση

Πόσο συχνά χρειάζεστε κάποιον να σας βοηθήσει όταν διαβάζετε οδηγίες, φυλλάδια ή άλλο έντυπο υλικό από τον γιατρό σας ή το φαρμακείο?

☐1	☐2	☐3	☐4	☐5
Ποτέ	Σπάνια	Καμιά φορά	Συχνά	Πάντα

Η Σκάλα

Σκεφτείτε μία σκάλα να αντιπροσωπεύει όλους τους ανθρώπους στην Ελλάδα. Στην κορυφή της σκάλας βρίσκονται οι άνθρωποι που ζουν στις καλύτερες συνθήκες- έχουν περισσότερα χρήματα, καλύτερη εκπαίδευση και εργασία.

Στο τελευταίο σκαλοπάτι είναι οι άνθρωποι που ζουν στις χειρότερες συνθήκες- έχουν τα λιγότερα χρήματα, χειρότερη εκπαίδευση και εργασία ή ανεργία

Που θα τοποθετούσατε τον εαυτό σας σε αυτή τη σκάλα, σε σύγκριση με τους άλλους ανθρώπους στην Ελλάδα; Παρακαλώ βάλτε ένα μεγάλο Χ πάνω ακριβώς στο σκαλοπάτι που είστε εσείς. **Προσέξτε**, μην τοποθετήσετε το Χ στο κενό ανάμεσα στα σκαλοπάτια.

HLS-EU-Q16

Στην κλίμακα από «πολύ εύκολο» σε «πολύ δύσκολο», πόσο εύκολο ή δύσκολο θα λέγατε είναι να:

[ΔΙΑΒΑΣΤΕ ΤΗΝ ΚΛΙΜΑΚΑ - ΜΙΑ ΑΠΑΝΤΗΣΗ ΑΝΑ ΓΡΑΜΜΗ]		Πολύ εύκολο	Αρκετά εύκολο	Αρκετά δύσκολο	Πολύ δύσκολο	ΔΓ – Δεν Γνωρίζω (Αυθόρμητα)*
Q1	…να βρείτε πληροφορίες σχετικά με τα συμπτώματα ασθενειών που σας απασχολούν?	1	2	3	4	5
Q2	…να βρείτε που μπορείτε να λάβετε βοήθεια από επαγγελματίες υγείας όταν είσαστε άρρωστος/η;	1	2	3	4	5
Q3	…να κατανοήσετε αυτό που σας λέει ο γιατρός σας;	1	2	3	4	5
Q4	…να κατανοήσετε τις οδηγίες του γιατρού ή του φαρμακοποιού σας σχετικά με το πως πρέπει να πάρετε ένα φάρμακο που σας έχει γράψει στη συνταγή;	1	2	3	4	5
Q5	… να κρίνετε πότε χρειάζεται να πάρετε μία δεύτερη γνώμη από κάποιον άλλον γιατρό;	1	2	3	4	5
Q6	…να χρησιμοποιήσετε τις πληροφορίες **(Οδηγίες: θεραπευτική αγωγή, επιλογές θεραπείας)** που σας δίνει ο γιατρός σας ώστε να πάρετε αποφάσεις για να αντιμετωπίσετε την ασθένειά σας;	1	2	3	4	5
Q7	…να ακολουθήσετε τις οδηγίες του γιατρού ή του φαρμακοποιού σας;	1	2	3	4	5
Q8	…να βρείτε πληροφορίες για το πως να διαχειριστείτε προβλήματα όπως το στρες ή η κατάθλιψη;	1	2	3	4	5
Q9	…να κατανοήσετε τους κινδύνους για την υγεία από συμπεριφορές όπως το κάπνισμα, η απουσία σωματικής άσκησης, η υπερβολική κατανάλωση αλκοόλ;	1	2	3	4	5
Q10	…να κατανοήσετε γιατί είναι αναγκαίο να κάνετε προληπτικές ιατρικές εξετάσεις; ***(Οδηγίες: μαστογραφία, εξέταση διαβήτη, έλεγχος αρτηριακής πίεσης)***	1	2	3	4	5
Q11	… να κρίνετε εάν οι πληροφορίες για τους κινδύνους για την υγεία (λ.χ κακή διατροφή, έλλειψη σωματικής και νοητικής άσκησης, παχυσαρκία, κάπνισμα, μόλυνση περιβάλλοντος κλπ) όπως προβάλλονται στα μέσα ενημέρωσης είναι αξιόπιστες; ***(Οδηγίες: τηλεόραση, διαδίκτυο ή άλλα μέσα ενημέρωσης)***	1	2	3	4	5
Q12	…να αποφασίσετε πως μπορείτε να προστατέψετε τον εαυτό σας από κάποια ασθένεια βάσει των πληροφοριών από τα μέσα ενημέρωσης;	1	2	3	4	5
Q13	…να βρείτε δραστηριότητες οι οποίες είναι καλές για την ψυχική σας διάθεση; ***(Οδηγίες: άσκηση, περπάτημα, έξοδος με φίλους, κλπ)***	1	2	3	4	5
Q14	…να κατανοήσετε συμβουλές για την υγεία από την οικογένεια και φίλους;	1	2	3	4	5
Q15	…να κατανοήσετε πληροφορίες από τα μέσα ενημέρωσης για το πως θα βελτιώσετε την υγεία σας;	1	2	3	4	5
Q16	…να κρίνετε ποιες καθημερινές σας συνήθειες σχετίζονται με την υγεία σας; ***(Οδηγίες: διατροφικές συνήθειες, άσκηση κτλ.)***	1	2	3	4	5

Ερωτήσεις για τη διερεύνηση της χρήσης του διαδικτύου από τους Φροντιστές ατόμων με άνοια

1. **Από τις παρακάτω υπηρεσίες ποιες χρησιμοποιείτε και με ποιο τρόπο για να λάβετε βοήθεια στη διαχείριση της φροντίδα που παρέχετε;**
   Επιλέξτε βάζοντας ένα ✓ όσες υπηρεσίες χρησιμοποιείτε και στη συνέχεια διαλέξτε τους λόγους που χρησιμοποιήσατε αυτή την υπηρεσία.

1. **Ιστοσελίδες**	
Εάν επιλέξατε τις ιστοσελίδες, ποιες πληροφορίες σχετικές με την άνοια αναζητήσατε; Επιλέξτε παρακάτω:	
Ενημέρωση για τη νόσο	
Πληροφόρηση για οικονομικά και νομικά θέματα	
Πληροφόρηση για τη διαχείριση συμπεριφορικών συμπτωμάτων	
Ενημέρωση για υπηρεσίες και τρόπους υποστήριξης του φροντιστή	
Αναζήτηση επικοινωνίας με ειδικούς	
Εξεύρεση ειδικών επαγγελματιών για τη νόσο	
Ψυχαγωγία και απασχόληση για το άτομο που φροντίζετε	
Άλλο, διευκρινίστε	

2. **Κοινωνικά δίκτυα** (facebook, twitter, LinkedIn, κα)	
Εάν επιλέξατε τα κοινωνικά δίκτυα, με ποιο τρόπο τα χρησιμοποιήσατε; Επιλέξτε παρακάτω:	
Επικοινωνία με ειδικούς επαγγελματίες υγείας	
Επικοινωνία με φροντιστές	
Επικοινωνία με άλλα μέλη της οικογένειας σχετικά με τη φροντίδα	
Ενημέρωση για τη νόσο και για πρακτικά ζητήματα	
Άλλο, διευκρινίστε	

3. **Emails**	
Εάν επιλέξατε τα emails, με ποιο τρόπο τα χρησιμοποιήσατε; Επιλέξτε παρακάτω:	
Επικοινωνία με άλλους φροντιστές	
Επικοινωνία με ειδικούς επαγγελματίες υγείας	
Επικοινωνία με άλλα μέλη της οικογένειας σχετικά με τη φροντίδα	
Επικοινωνία με εταιρείες Alzheimer	
Επικοινωνία με ιατρικές υπηρεσίες γενικότερα	
Άλλο, διευκρινίστε	

4. **Διαδραστικές υπηρεσίες** (forums, chats/μηνύματα, skype, viber, messager)	
Εάν επιλέξατε τις διαδραστικές υπηρεσίες, με ποιο τρόπο τις χρησιμοποιήσατε; Επιλέξτε παρακάτω:	
Ατομική επικοινωνία με ειδικούς	
Ατομική επικοινωνία με φροντιστές	
Ατομική επικοινωνία με άλλα μέλης της οικογένειας σχετικά με τη φροντίδα	
Ομάδα υποσήριξης/εκπαιδευσης	
Άλλο, διευκρινίστε	

5. **Μαθήματα μέσω διαδικτύου/ εξ'αποστάσεως εκπαίδευση (elearning courses)**	
Εάν επιλέξατε τα μαθήματα μέσω διαδικτύου, με ποιο τρόπο τις χρησιμοποιήσατε; Επιλέξτε παρακάτω:	
Εκπαίδευση στη φροντίδα και σε πρακτικά ζητήματα	

Εκπαίδευση για τη νόσο	
Άλλο, διευκρινίστε	

2. **Χρησιμοποιείτε το διαδίκτυο από το κινητό σας τηλέφωνό όταν θέλετε να βρείτε πληροφορίες και υπηρεσίες για την άνοια; Κυκλώστε την απαντήσή σας**

1. ΝΑΙ 2.ΟΧΙ

a. **Εάν ΝΑΙ, ποιες από τις παρακάτω υπηρεσίες χρησιμοποιείτε από το κινητό σας τηλέφωνο;** Κυκλώστε την όσες υπηρεσίες έχετε χρησιμοποιήσει από το κινητό σας.

1. Ιστοσελίδες
2. Κοινωνικά δίκτυα (facebook, twitter, LinkedIn, κα)
3. Emails
4. Διαδραστικές υπηρεσίες (forums, chats/μηνύματα, skype, viber, messager)
5. e-learning courses

Κλίμακα της Ψηφιακής Εγγραμματοσύνης σε θέματα για την Υγεία Οικογενειακών Φροντιστών ατόμων με Χρόνιες Παθήσεις

Θα ήθελα να μου πείτε την άποψή σας και τις εμπειρίες σας από τη χρήση του διαδικτύου για πληροφορίες που αφορούν την υγεία και ειδικότερα τη φροντίδα και στήριξη που παρέχετε. Για κάθε δήλωση, διαλέξτε την απάντηση που ανταποκρίνεται καλύτερα στην άποψη και τις εμπειρίες σας αυτήν τη στιγμή.

1. Πόσο **χρήσιμο** νιώθετε ότι είναι το Διαδίκτυο στη βοήθεια που σας προσφέρει για να πάρετε αποφάσεις σχετικές με την υγεία του ανθρώπου που φροντίζετε;

☐1	☐2	☐3	☐4	☐5
Καθόλου χρήσιμο	Δεν είναι χρήσιμο	Αναποφάσιστος/η	Χρήσιμο	Πολύ χρήσιμο

2. Πόσο **σημαντικό** είναι για σας να έχετε πρόσβαση σε πηγές (π.χ πληροφορίες) σχετικές με τη φροντίδα που παρέχετε;

☐1	☐2	☐3	☐4	☐5
Καθόλου σημαντικό	Δεν είναι σημαντικό	Αναποφάσιστος/η	Σημαντικό	Πολύ σημαντικό

3. Γνωρίζω **ποιες** πληροφορίες για θέματα υγείας και φροντίδας του συγγενή μου είναι διαθέσιμες στο Διαδίκτυο. (Παράδειγμα: πρακτικά ζητήματα, οικονομικές και νομικές πληροφορίες, πληροφόρηση για τη νόσο και για διαθέσιμες υπηρεσίες)

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

4. Γνωρίζω που να βρω στο διαδίκτυο χρήσιμες πληροφορίες για θέματα υγείας και φροντίδας του συγγενή μου. (Παράδειγμα: ποιες ιστοσελίδες θα αναζητήσω)

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

5. Γνωρίζω **πώς** να βρω στο διαδίκτυο χρήσιμες πληροφορίες για θέματα υγείας και φροντίδας του συγγενή μου. (παράδειγμα: αναφορικά με τη διαδικασία: θα μπω στο google)

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

6. Γνωρίζω **πώς να χρησιμοποιήσω** το Διαδίκτυο για να απαντήσω στις ερωτήσεις μου που αφορούν την υγεία και τη φροντίδα του συγγενή μου (Παράδειγμα : με ποιο τρόπο θα θέσω τις ερωτήσεις για να λάβω απαντήσεις).

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

7. Γνωρίζω πώς να χρησιμοποιήσω **τις πληροφορίες για την υγεία και τη φροντίδα** (πρακτικά ζητήματα, οικονομικές και νομικές πληροφορίες, πληροφόρηση για την άνοια) που βρίσκω στο Διαδίκτυο για να με βοηθήσουν

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

8. Έχω τις δεξιότητες που χρειάζομαι για να **αξιολογήσω** τις πηγές (π.χ πληροφορίες) που βρίσκω στο Διαδίκτυο για θέματα υγείας και φροντίδας του συγγενή μου.

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

9. Μπορώ να διακρίνω στο Διαδίκτυο πληροφορίες **υψηλής ποιότητας** για την υγεία και τη φροντίδα του συγγενή μου από πληροφορίες **χαμηλής ποιότητας**.

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

10. **Νιώθω σίγουρος/η** να χρησιμοποιήσω πληροφορίες στο Διαδίκτυο για να πάρω αποφάσεις σχετικές με την υγεία και τη φροντίδα του συγγενή μου.

☐1	☐2	☐3	☐4	☐5
Διαφωνώ έντονα	Διαφωνώ	Δεν είμαι σίγουρος/η	Συμφωνώ	Συμφωνώ απόλυτα

Ευχαριστώ πολύ!

Οδηγίες συμπλήρωσης της αναθεωρημένης κλίμακας για την αυτό-αποτελεσματικότητα των φροντιστών (2002)

Οδηγίες
Μας ενδιαφέρει πόσο βέβαιοι είστε ότι μπορείτε να ασχοληθείτε με τις δικές σας δραστηριότητες ενώ παράλληλα ασχολείστε με τη φροντίδα. Παρακαλώ σκεφτείτε προσεκτικά τις ερωτήσεις και απαντήστε όσο πιο ειλικρινά μπορείτε κατά πόσο πιστεύετε ότι αυτό που δηλώνει η κάθε ερώτηση μπορείτε να το κάνετε. Θα διαβάσω τις δραστηριότητες και σκέψεις που θα μπορούσατε να έχετε ως φροντιστής. Παρακαλώ, σε κάθε περίπτωση σκεφτείτε και πείτε μου κατά πόσο είστε βέβαιοι ότι θα μπορούσατε να κάνετε αυτό που περιγράφει η ερώτηση. Βαθμολογήστε με βαθμό 0-100, χρησιμοποιώντας την κλίμακα που δίνετε πιο κάτω, για να απαντήσετε ως προς το βαθμό που είστε βέβαιοι ότι θα μπορούσατε να κάνετε αυτό που περιγράφει η ερώτηση.

0 10 20 30 40 50 60 70 80 90 100

Καθόλου δεν μπορώ να το κάνω	Σχεδόν βέβαιος ότι μπορώ να το κάνω	Απόλυτα βέβαιος ότι μπορώ να το κάνω

Για παράδειγμα, βαθμολογία 20% βεβαιότητας σημαίνει ότι είναι απίθανο, αλλά όχι εντελώς αδύνατο για εσάς να κάνετε τη δραστηριότητα που περιγράφει η ερώτηση. Βαθμολογία 100% σημαίνει ότι είστε απολύτως βέβαιοι ότι θα μπορούσατε να κάνετε τη δραστηριότητά όποτε εσείς θέλετε. Βαθμολογία 50% βεβαιότητας σημαίνει ότι όταν προσπαθήσετε όσο καλύτερα μπορείτε τότε οι πιθανότητες να κάνετε τη δραστηριότητά είναι 50-50. Δηλαδή, μπορείτε να χρησιμοποιήσετε οποιαδήποτε βαθμολογία μεταξύ του 0 και του 100 (10, 20, 30, κ.λ.π.) για να εκφράσετε το βαθμό της βεβαιότητας σας κατά πόσο θα μπορούσατε να κάνετε τη δραστηριότητά που περιγράφει η ερώτηση.

Παρακαλώ όπως όλες οι βαθμολογίες να αφορούν τι θα μπορούσατε να κάνετε ΣΗΜΕΡΑ ως το άτομο που είστε ΤΩΡΑ, παρά ως τι θα μπορούσατε να κάνετε ως το άτομο που ήσασταν παλαιότερα ή ως προς το τι θα επιθυμούσατε να κάνετε. Απλά βαθμολογήστε τι θα μπορούσατε να κάνετε ΣΗΜΕΡΑ. Έχετε ερωτήσεις;

Α. ΠΡΑΚΤΙΚΗ ΕΞΑΣΚΗΣΗ ΣΤΗ ΒΑΘΜΟΛΟΓΗΣΗ

Για να εξοικειωθείτε με τη βαθμολόγηση, παρακαλώ αρχικά συμπληρώστε την πιο κάτω άσκηση

0 10 20 30 40 50 60 70 80 90 100

Καθόλου δεν μπορώ να το κάνω	Σχεδόν βέβαιος ότι μπορώ να το κάνω	Απόλυτα βέβαιος ότι μπορώ να το κάνω

Αν σας ζητηθεί να σηκώσετε αντικείμενα με διαφορετικό βάρος τώρα, πόσο βέβαιος είστε ότι μπορείτε να ανασηκώσετε το κάθε ένα από τα βάρη που περιγράφονται;
Ερευνητή: Πριν από κάθε δραστηριότητα διάβαζε τις λέξεις «Πόσο βέβαιος είστε ότι μπορείτε να…»

ΒΕΒΑΙΟΤΗΤΑ ΦΥΣΙΚΗΣ ΔΥΝΑΜΗΣ (0-100)
1. Σηκώσετε ένα αντικείμενο βάρους 10 κιλών
2. Σηκώσετε ένα αντικείμενο βάρους 20 κιλών
3. Σηκώσετε ένα αντικείμενο βάρους 50 κιλών
4. Σηκώσετε ένα αντικείμενο βάρους 100 κιλών

«Πόσο βέβαιος είστε ότι μπορείτε να κάνετε τις ακόλουθες δραστηριότητες;» (Όταν αυτό που περιγράφει η ερώτηση δεν ισχύει στη δική σας περίπτωση παρακαλώ ενημερώστε με απαντώντας με «Δεν ισχύει»). Στην αρχή της κάθε ερώτησης, πριν τη λέξη «μπορείτε», διαβάστε «Πόσο βέβαιος είστε ότι…». Δείξτε την κάρτα #1

Αυτό-αποτελεσματικότητα για ανάπαυλα
____ 1. ... Μπορείτε να ζητήσετε από ένα φίλο ή μέλος της οικογένειας να μείνει με ____ για μια μέρα, που πρέπει να δείτε το γιατρό μόνος/μόνη σας; (M _ 71.4, SD _ 34.4)
____ 2. ... Μπορείτε να ζητήσετε από ένα φίλο ή μέλος της οικογένειας να μείνει με ____ για μια μέρα, όταν έχετε κάποια δουλειά που πρέπει να γίνει; (M _ 63.1, SD _ 37.1)
____ 3. ... Μπορείτε να ζητήσετε από ένα φίλο ή μέλος της οικογένειας να κάνει κάποια δουλειά που πρέπει να γίνει από εσάς; (M _ 62.4, SD _ 36.2)
____ 4. ... Μπορείτε να ζητήσετε από ένα φίλο ή μέλος της οικογένειας να μείνει με ____ για μια μέρα, όταν αισθάνεστε την ανάγκη για ένα διάλειμμα; (M _ 57.1, SD _ 37.8)
____ 5. ... Μπορείτε να ζητήσετε από ένα φίλο ή μέλος της οικογένειας να μείνει με ____ για μια εβδομάδα, όταν έχετε την ανάγκη να δώσετε χρόνο στον εαυτό σας; (M _ 27.4, SD _ 36.2)

Αυτο-αποτελεσματικότητα στην αντιμετώπιση αποδιοργανωμένων συμπεριφορών του ασθενούς
____ 6. Όταν ____ ξεχνά την καθημερινή σας ρουτίνα και σας ρωτά αν έχετε φάει αμέσως μετά που έχετε ήδη πάρει το γεύμα σας, …του/της απαντάτε χωρίς να υψώσετε τον τόνο της φωνή σας; (Διευκρινίστε ότι αυτή η «απάντηση» μπορεί να είναι άμεση ή μια απόσπαση της προσοχής.) (M _ 74.4, SD _ 25.9)
____ 7. Όταν θυμώνετε επειδή ____ επαναλαμβάνει την ίδια ερώτηση ξανά και ξανά,. . .μπορείτε να πείτε κάποια πράγματα στον εαυτό σας που θα σας ηρεμήσουν; (M _ 65.8, SD _ 25.4)
____ 8. Όταν ____ παραπονιέται σε σας για τον πως τον/την μεταχειρίζεστε,. . .μπορείτε να του απαντήσετε χωρίς να καυγαδίσετε; (Π.χ., να τον/την καθησυχάσετε ή να αποσπάσετε την προσοχή του/της;) (M _ 62.9, SD _ 25.2)
____ 9. Όταν ____ σας ρωτά 4 φορές μέσα στην πρώτη μία ώρα μετά το γεύμα, πότε είναι το γεύμα. . .μπορείτε να του/της απαντήσετε χωρίς να υψώσετε τον τόνο της φωνή σας; (M _ 59.4, SD _ 29.8)
____10. Όταν ____ σας διακόπτει, για τέταρτη φορά, ενώ εσείς ετοιμάζετε το δείπνο,. . .μπορείτε να ανταποκριθείτε χωρίς να υψώσετε τον τόνο της φωνή σας; (M _ 58.7, SD _ 29.7)

"Μερικές φορές όλοι οι φροντιστές έχουν αρνητικές σκέψεις για την κατάστασή τους. Μερικές από αυτές τις σκέψεις μπορεί να είναι πρόσκαιρες και εύκολα απαλλάσσονται από αυτές. Άλλοτε όμως, μπορεί να είναι πολύ δύσκολο να βγάλετε από το μυαλό κάποιες σκέψεις, όπως συμβαίνει όταν σας μένει στο μυαλό μια μελωδία. Θα θέλαμε να γνωρίζουμε πόσο εύκολα μπορείτε να απαλλαχθείτε από οποιαδήποτε από τις ακόλουθες σκέψεις. Χρησιμοποιήστε την ίδια βαθμολόγηση βεβαιότητας. Μην εστιαστείτε πόσο συχνά σας έρχονται αυτές οι σκέψεις. Απλά θέλουμε να βαθμολογήσετε το βαθμό της βεβαιότητας σας στο ότι μπορείτε να απαλλαχθείτε από την κάθε σκέψη, όταν αυτή σας έρχεται στο μυαλό. "
(Ερευνητή: Όταν οι φροντιστές δηλώνουν με βεβαιότητα ότι δεν είχαν ποτέ τις σκέψεις που αναφέρονται σε μια ερώτηση, απαντήστε με το «Δεν ισχύει», στο πεδίο της βαθμολόγησης της βεβαιότητας. Αρχίστε την κάθε ερώτηση με τη φράση, «Πόσο βέβαιος είστε ότι μπορείτε να ελέγξετε τη(ν)…» Δείξτε την κάρτα #1.)

Αυτο-αποτελεσματικότητα στον έλεγχο των σκέψεων για την παρεχόμενη φροντίδα
____11. ... Σκέψη για τις δυσάρεστες πτυχές της φροντίδας του/της ____; (M _ 68.5, SD _ 25.4)
____12. ... Σκέψη για το πόσο άδικο είναι ότι θα πρέπει να ανεχτείτε αυτή την κατάσταση (παρέχοντας φροντίδα στον/στην ____); (M _ 67.9, SD _ 30.6)
____13. ... Σκέψη για το πόσο καλή ζωή είχατε πριν από την ασθένεια του/της ____ και πόσα έχετε χάσει; (M _ 67.5, SD _ 28.2)
____14. ... Σκέψη για τα πράγματα που σας λείπουν ή τα έχετε εγκαταλείψει εξαιτίας του/της ____; (M _ 66.0, SD _ 25.2)
____15. ...Ανησυχία για τα μελλοντικά προβλήματα που μπορεί προκύψουν με τον/την ____; (M _ 55.8, SD _ 29,6)

Κλίμακα των αντιλήψεων των φροντιστών ηλικιωμένων ατόμων για τη φροντίδα που παρέχουν στην Ευρώπη

	Εδώ εξετάζουμε την υποστήριξη που έχετε εσείς ως φροντιστής	**Πάντα**	**Συχνά**	**Μερικές φορές**	**ποτέ**	**Δ/Α**
82 C82COP1	Αισθάνεστε ότι τα βγάζετε καλά πέρα ως φροντιστής;	☐	☐	☐	☐	✕
83 C83COP2	Πιστεύετε πως η παροχή φροντίδας είναι πολύ απαιτητική;	☐	☐	☐	☐	✕
84 C84COP3	Η παροχή φροντίδας δημιουργεί προβλήματα στις σχέσεις σας με τους φίλους σας;	☐	☐	☐	☐	☐
85 C85COP4	Η φροντίδα που προσφέρετε επιδρά αρνητικά στη σωματική σας υγεία;	☐	☐	☐	☐	✕
86 C86COP5	Δημιουργεί προβλήματα η παροχή φροντίδας στις σχέσεις σας με την οικογένειά σας;	☐	☐	☐	☐	☐
87 C87COP6	Σας επιβαρύνει οικονομικά η παροχή της φροντίδας	☐	☐	☐	☐	✕
88 C88COP7	Αισθάνεστε παγιδευμένος στον ρόλο σας ως φροντιστής;	☐	☐	☐	☐	✕
89 C89COP8	Αισθάνεστε ότι έχετε αρκετή υποστήριξη από τους φίλους και/ ή τους γείτονες;	☐	☐	☐	☐	☐
90 C90COP9	Βρίσκετε ότι η παροχή φροντίδας αξίζει τον κόπο;	☐	☐	☐	☐	✕
91 C91COP10	Αισθάνεστε αρκετή υποστήριξη από την οικογένειά σας;	☐	☐	☐	☐	☐
92 C92COP11	Έχετε καλή σχέση με τον άνθρωπο που φροντίζετε;	☐	☐	☐	☐	✕
93 C93COP12	Αισθάνεστε ότι έχετε αρκετή υποστήριξη από υπηρεσίες υγείας και κοινωνικές υπηρεσίες; (π.χ. δημόσιες, ιδιωτικές ή εθελοντικές)	☐	☐	☐	☐	☐
94 C94COP13	Πιστεύετε ότι υπάρχει κάποιος που να σας εκτιμά ως φροντιστή;	☐	☐	☐	☐	✕
95 C95COP14	Επιδρά αρνητικά η παροχή φροντίδας στην συναισθηματική σας ευεξία;	☐	☐	☐	☐	✕
96 C96COP15	Γενικά, αισθάνεστε αρκετά υποστηριγμένος στον ρόλο σας ως φροντιστής;	☐	☐	☐	☐	✕

Σύντομο ερωτηματολόγιο Προσανατολισμών στην Αντιμετώπιση Προβλημάτων

Οι επόμενες ερωτήσεις έχουν να κάνουν με τον τρόπο που αντιμετωπίζετε το άγχος (στρες) στη ζωή σας. Απαντηστε με βάση το κατά πόσο κάνετε αυτό που αναφέρεται στη δήλωση, ΌΧΙ κατά πόσο ο τρόπς αυτός δουλεύει για σας ή όχι. Για κάθε ερώτηση βάλτε σε κύκλο τον αριθμό που αντιστοιχεί.

1= δεν το κάνω καθόλου
2= το κάνω λίγο
3= το κάνω σε μέτριο βαθμό
4=το κάνω πολύ

		Δεν το κάνω καθόλου	Το κάνω λίγο	Το κάνω σε μέτριο βαθμό	Το κάνω πολύ
1	Στρέφομαι προς τη δουλειά ή άλλες ασχολίες για να παίρνω το μυαλό μου από τα προβλήματα	1	2	3	4
2	Επικεντρώνομαι στο να κάνω κάτι για να αλλάξω την κατάσταση στην οποία βρίσκομαι	1	2	3	4
3	Λέω στον εαυτό μου «αυτό δεν μπορεί να συμβαίνει»	1	2	3	4
4	Χρησιμοποιώ αλκοολούχα ποτά ή ναρκωτικά για να αισθάνομαι καλύτερα	1	2	3	4
5	Παίρνω συναισθηματική υποστήριξη από άλλους	1	2	3	4
6	Παραιτούμε από την προσπάθεια να το αντιμετωπίσω	1	2	3	4
7	Λαμβάνω μέτρα για να βελτιώσω την κατάσταση στην οποια βρίσκομαι	1	2	3	4
8	Αρνούμαι να πιστέψω ότι συμβαίνει	1	2	3	4
9	Λέω πράγματα για να εκτονωθούν τα αρνητικά μου συναισθήματα	1	2	3	4
10	Παίρνω βοήθεια και συμβουλές από άλλους	1	2	3	4
11	Χρησιμοποιώ αλκοολούχα ποτά ή ναρκωτικά για να μπορέσω να το ξεπεράσω	1	2	3	4
12	Προσπαθώ να δω την κατάσταση με διαφορετικό τρόπο, πιο θετικά	1	2	3	4
13	Εξασκώ κριτική προς τον εαυτό μου	1	2	3	4
14	Προσπαθώ να σκεφτώ κάποια στρατηγική για το τι θα κάνω	1	2	3	4
15	Παίρνω παρηγοριά και κατανόηση από κάποιον	1	2	3	4
16	Παραιτούμαι από την προσπάθεια να αντεπεξέλθω	1	2	3	4
17	Ψάχνω για κάτι θετικό σε αυτό που συμβαίνει	1	2	3	4
18	Κάνω αστεία για αυτό που συμβαίνει	1	2	3	4
		Δεν το κάνω καθόλου	Το κάνω λίγο	Το κάνω σε μέτριο βαθμό	Το κάνω πολύ
19	Κάνω κάτι για να μην το σκέφτομαι, όπως πηγαίνω στο σινεμά, βλέπω τηλεόραση, διαβάζω, ονειροπολώ, κοιμούμαι, πάω για ψώνια	1	2	3	4
20	Αποδέχομαι την πραγματικότητα για αυτό που έγινες	1	2	3	4
21	Εκφράζω τα αρνητικά μου συναισθήματα	1	2	3	4
22	Προσπαθώ να βρω παρηγοριά στη θρησκεία ή άλλες πνευματικές ενασχολήσεις	1	2	3	4

23	Προσπαθώ να πάρω συμβουλές και βοήθεια από άλλος για το τι να κάνω	1	2	3	4
24	Μαθαίνω να ζω με το πρόβλημα	1	2	3	4
25	Σκέφτομαι σοβαρά για το τι βήματα πρέπει να ακολουθήσω	1	2	3	4
26	Ρίχνω το φταίξιμο στον εαυτό μου για αυτό που έγινε	1	2	3	4
27	Προσεύχομαι ή αυτοσυγκεντρώνομαι	1	2	3	4
28	Ειρωνεύομαι την κατάσταση	1	2	3	4

Πολυδιάστατη κλίμακα αντιλαμβανόμενης κοινωνικής υποστήριξης

Απαγορεύεται η χρήση του ερωτηματολογίου χωρίς τη χορήγηση άδειας.
Μετάφραση - Πολιτισμική Προσαρμογή: Δρ. Παρασκευή Θεοφίλου

ΟΔΗΓΙΕΣ:
Ενδιαφερόμαστε για τις απόψεις σας σχετικά με τις παρακάτω προτάσεις. Διαβάστε την καθεμία πρόταση προσεκτικά. Σημειώστε πώς αισθάνεστε σχετικά με το περιεχόμενο της κάθε πρότασης.

Κυκλώστε τον αριθμό «1», αν **διαφωνείτε απόλυτα**
Κυκλώστε τον αριθμό «2», αν **διαφωνείτε πολύ**
Κυκλώστε τον αριθμό «3», αν **διαφωνείτε**
Κυκλώστε τον αριθμό «4», αν **είστε ουδέτερος/η**
Κυκλώστε τον αριθμό «5», αν **συμφωνείτε**
Κυκλώστε τον αριθμό «6», αν **συμφωνείτε πολύ**
Κυκλώστε τον αριθμό «7», αν **συμφωνείτε απόλυτα**

	Διαφωνώ Απόλυτα	**Διαφωνώ Πολύ**	**Διαφωνώ**	**Ουδέτερος/η**	**Συμφωνώ**	**Συμφωνώ Πολύ**	**Συμφωνώ Απόλυτα**
1.Υπάρχει ένας άνθρωπος κοντά μου όταν τον χρειάζομαι	1	2	3	4	5	6	7
2.Υπάρχει ένας άνθρωπος με τον οποίο μπορώ να μοιράζομαι χαρές και λύπες	1	2	3	4	5	6	7
3.Η οικογένειά μου προσπαθεί πραγματικά να με βοηθήσει.	1	2	3	4	5	6	7
4. Παίρνω τη συναισθηματική βοήθεια και υποστήριξη που χρειάζομαι από την οικογένειά μου.	1	2	3	4	5	6	7
5. Έχω έναν άνθρωπο ο οποίος είναι πραγματική	1	2	3	4	5	6	7

πηγή ανακούφισης για μένα.							
6. Οι φίλοι μου προσπαθούν πραγματικά να με βοηθήσουν.	1	2	3	4	5	6	7
7. Μπορώ να στηρίζομαι στους φίλους μου όταν τα πράγματα δενπάνε καλά	1	2	3	4	5	6	7
8. Μπορώ να συζητώ τα προβλήματά μου με την οικογένειά μου.	1	2	3	4	5	6	7
	Διαφωνώ Απόλυτα	**Διαφωνώ Πολύ**	**Διαφωνώ**	**Ουδέτερος/η**	**Συμφωνώ**	**Συμφωνώ Πολύ**	**Συμφωνώ Απόλυτα**
9. Έχω φίλους με τους οποίους μπορώ να μοιράζομαι χαρές και λύπες	1	2	3	4	5	6	7
10. Υπάρχει ένας άνθρωπος στη ζωή μου ο οποίος νοιάζεται για τα αισθήματά μου.	1	2	3	4	5	6	7
11. Η οικογένειά μου είναι πρόθυμη να με βοηθήσει να παίρνω αποφάσεις.	1	2	3	4	5	6	7
12. Μπορώ να συζητώ τα προβλήματά μου με τους φίλους μου.	1	2	3	4	5	6	7

VII. APPENDIX

A. Published Paper of Protocol

https://www.researchprotocols.org/2017/11/e221/pdf

Protocol

The Association of Health Literacy and Electronic Health Literacy With Self-Efficacy, Coping, and Caregiving Perceptions Among Carers of People With Dementia: Research Protocol for a Descriptive Correlational Study

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Abstract

Background: In the last decade, electronic health (eHealth) literacy has attracted the attention of the scientific community, as it is associated with the self-management of patients with chronic diseases and the quality and cost of care. It is estimated that 80% of people with chronic diseases are cared for at home by a family member, friend, or relative. Informal carers are susceptible to physical and mental health problems, as well as social and financial hardships. Nevertheless, there seems to be a research gap in terms of carers' needs, skills, and available resources in the age of new technologies, with the vital role of eHealth literacy of the carers remaining unexplored.

Objective: The aim of this study was to investigate the level of eHealth literacy and health literacy of primary and secondary carers of people with dementia, to explore the association between health and eHealth literacy, as well as their association with the caregiving variables: self-efficacy, coping, and caring perceptions.

Methods: A sample of 200 primary carers (the carer who supports the people with dementia in everyday living) and 200 secondary carers (family member, friend, or other person in the social network assisting the primary carer in their role) will be recruited from dementia day care centers and Alzheimer's associations in Greece and Cyprus. The study will be a cross-sectional correlational descriptive study. Tools to be used include the eHealth Literacy Scale adapted for carers to measure eHealth literacy, European Health Literacy Survey Questionnaire 16 (HLS-EU-Q16), Single Item Literacy Screener, Revised Scale for Caregiving Self-Efficacy, Carers of Older People in Europe (COPE) index for caregiving perceptions, and COPE brief to measure selected coping strategies. Descriptive statistics will be reported, and correlations between different variables will be explored with parametric and nonparametric measures.

Results: As a preliminary study, the HLS-EU-Q16 has been validated in 107 older people. The internal consistency of the scale as estimated using Cronbach alpha coefficient was .77, somewhat lower than other validation studies. Recruitment of pilot study participants started in May 2017.

Conclusions: Carers' eHealth literacy is a new field. Whereas previous studies have focused on the role and impact of low eHealth literacy and health literacy among older adults, the eHealth literacy of carers, and in fact carers of people with dementia, has not been explored. We hypothesize an association between eHealth literacy and health literacy level with carers' perceptions about caregiving role, self-efficacy, and coping strategies. A possible moderator in these associations is the secondary carers' eHealth and health literacy level, which will also be explored. By confirming the above hypotheses, tailored eHealth literacy interventions for carers of people with dementia and their families will be developed as a direct outcome of this research.

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KEYWORDS

health literacy; carers; dementia; ehealth

Introduction

Carers and Internet Use

In the new digital era, new technologies are developed to support carers in their everyday role. However, most of the time, this is done without taking into consideration carers' health literacy, digital skills, and electronic health (eHealth) literacy level. According to Eurocarers Association, "a carer is the person who provides unpaid care to someone with chronic illness, disability, or other long lasting health and care needs, outside a professional or formal framework." People who provide care at least once or twice per week are those in the age range of 50 to 64 years, followed by the 35 to 49 age group according to the third European Quality of Life Survey [1]. In the case of carers of people with dementia, the age range is almost certainly older, as spouses and children older than 64 years are likely to become carers [2].

Older adults are considered to be the population group with the most difficulty in using new technology. In recent years, many studies have investigated the eHealth literacy of older adults, providing evidence that increased age and lower educational level are good predictors of lower eHealth literacy level and low Internet use [3-7]. Although there is vast literature about eHealth literacy in older adults **,** the level and the role of eHealth and health literacy among carers and, in particular, carers of people with dementia is very limited. There is, nevertheless, abundant information, mainly of descriptive nature, with regard to the type of Internet use among carers of people with different chronic diseases, without any further exploration or recommendation.

In a recent study in the United States, Kanthawala et al [8] investigated the type of questions and replies that people with diabetes and their carers post on the Web in the WebMD online diabetes website. People usually search information on their suggested treatment, questions that doctors have not replied to, and information on health habits. Most people consider the information on the Internet of good quality. Kanthawala et al classified questions searched into three categories: questions of fact, those related to policy or action, and those of value. Furthermore, they tried to address which type of resource is more adequate and clinically relevant for carers, concluding that community resources provided better quality results than search results of a common search engine such as Google.

In another study in the United Kingdom, Blackburn et al [9] explored the Internet use among 3014 carers. The study provided an overview of the digital gap among carers, which relates to both age as well as socioeconomic position. Half of the sample had never used the Internet. Of those using the Internet, 61% were frequent users (accessing the Internet once or more per week). Internet access by carers seems to be influenced by demographic and socioeconomic factors. Specifically, the age of the carer and the age of the patient, gender, employment status, living conditions, and hours of care are factors associated with Internet use. Similar findings have been reported by Kim [10] for a sample of carers of people with dementia. Specifically, younger carers (children and grandchildren), more educated, with a higher income, and fewer hours of caregiving are most likely to be health-related Internet users. Li [11] provided similar results for a sample of 812 carers of older adults.

According to Lam and Lam [12], the most common use of Internet among carers in Australia included chat sites and emails, indicating carers' need to communicate. However, carers also used the Internet to retrieve information, as well as to access governmental services, for example, to pay bills. Interestingly, the study reported that carers who had been using the Internet 12 months before the study had better mental health in comparison with carers who had not used the Internet during that period. This is also supported by Kinnane and Milne [13] who have reviewed the literature for carers of cancer patients and have found that carers mostly use the Internet for information search for themselves or at a request by the cared for person for support group activity and email usage.

In a qualitative study, carers visiting a caregiving website mostly looked for health information and practical, legal, and financial issues. These preferences were directed by the type of caregiving. Kernisan et al [14] categorized replies in four categories: caring for parent, caring for self only, other caregiving situation, and unknown caregiving situation. In the case of carers of older people, practical issues were most frequently searched.

There is also a large number of studies looking at the effectiveness and the usability of Web-based support programs such as online communities, fora, and psychoeducational programs that aim to improve education and communication of carers [15]. A recent scoping review by Wasilewski et al [15] found that most studies mainly discuss carers' experiences from participating in the programs or interventions, generally suggesting a positive attitude toward Web-based services. However, commonly no follow-up studies report either the usage and/or effectiveness of the specific interventions.

Key Concepts and Their Associations Within the Proposed eHealth Literacy and Carers' Research Framework

eHealth Literacy

As a term, eHealth literacy has gained considerable attention in recent years with the increased use of new technologies in health. Nevertheless, there is accumulating evidence that available technologies provided to people with chronic diseases or their carers are not properly used, or people are not using them because of lack of digital skills. In 2006, Norman and Skinner [16] presented the Lily model in an attempt to describe the different dimensions of eHealth literacy, defining the term as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem." The Lily model refers to six basic types of eHealth literacy and categorizes them in two central types of skills: analytic- and context-specific skills. The analytic type includes:

1. Traditional literacy, which includes basic skills to read, understand, write, and speak language.
2. Information literacy, which describes the skills needed by a person to find, select, and use information available of any type.
3. Media literacy, which is defined as a process of metacognitive reflective strategies to place the information from several media sources in a social and political context.
4. Health literacy, for which several definitions have been used in the literature. One of the most frequently cited definitions is the one proposed by Ratzan and Parker [17], which refers to "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." More recently, the construct of health literacy was explored in a cross-national European Health Literacy Survey among 8000 people from eight countries: Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain. As a result, a new definition and conceptual framework was derived that incorporated elements from previous definitions, namely, "Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" [18].

In the context-specific type of skills, Norman and Skinner include (5) computer literacy, which is the ability to use computers, and (6) scientific literacy, which is the skill to understand the aims, methods, implementation, limitations, and politics of creating knowledge. As part of this theory, Norman and Skinner [19] developed the eHealth Literacy Scale (eHeals), one of the few and most frequently used tools to measure eHealth literacy.

Chan and Kaufman [20] have proposed a methodological and theoretical framework to analyze and measure eHealth literacy based on the Lily model and Bloom's taxonomy. Bloom's taxonomy describes the cognitive dimensions that are a prerequisite for any type of literacy and includes remembering, understanding, applying knowledge, analyzing, evaluating, and creating a coherent meaning. Furthermore, in their model, Chan and Kaufmann separated traditional literacy into three types: reading, writing, and numeracy.

Norman [21] discussed the need for eHealth literacy to be revised, taking into consideration the latest progress in Internet tools and environment with Web 2.0 and the use of social media and mobile Internet. Norman discusses the eHeals scale that had a good correlation with Web 1.0 and was tested with youth and youth workers, who were the frequent users during that period from 1990 to 2000. In 2011, the study of Van der Vaart et al [15] made the first critique to the model and the weak correlation between eHeals and Web 2.0, suggesting the revision of the tool.

After the revision of the Lily model, which actually included the cognitive factors of users, additional attempts to expand the model have taken place [22,23]. Gilstad [22] redefined eHealth literacy as "...the ability to identify and define a health problem, to communicate, seek, understand, appraise and apply eHealth information and welfare technologies in the cultural, social and situational frame and to use the knowledge critically in order to solve the health problem." Four new dimensions were included to the Lily model: bodily experience (the ability to identify a health problem), procedural literacy (the "how" dimension of knowledge), contextual and cultural literacy (knowledge of a social situation: norms, values, rules, and regulations), and communicative expertise (the ability to convey personal health issues). Additionally, identifying the age bias toward young adults inherent to the Lily model and the eHeals questionnaire of Norman and Skinner, Koopman et al [23] considered dimensions that are relevant for older adults. The result was the Patient Readiness to Engage in Health Internet Technology instrument to measure the eHealth literacy of older adults.

More recent suggestions are the ones proposed by Norgaard et al [24] and Bautista [25]. Norgaard et al [24] have used concept mapping workshops with relevant stakeholders: information technology (IT) users, nonusers, patients, health care providers, and IT experts to update the dimensions contained in the eHealth literacy framework. Core dimensions that have been identified are the ability of info processing, a person's motivation and interest in health and in using the digital services, feeling of safety and control, accessibility, sustainability, and appropriateness of Web-based services. Bautista [25] tried to redefine eHealth literacy as a term that "...involves the interplay of individual and social factors in the use of digital technologies to search, acquire, comprehend, appraise, communicate and apply health information in all contexts of healthcare with the goal of maintaining or improving the quality of life throughout the lifespan."

Carers' Self-Efficacy, Coping Strategies, and Social Support

Considering the important role that carers play for the national health systems, both the scientific community and policy makers alike have become more interested in maintaining carers' health in recent years. Carers experience more stress than the general population, and they report higher use of antidepressants, are more susceptible to infections and cognitive decline, and have high mortality rates [26-28]. Furthermore, there are 3 close relatives for every person with Alzheimer disease [29]. For the purpose of this protocol, we will define the supporter relative or friend to the primary carers as the secondary carer. The term secondary carer is not a term regularly used; however, it has been previousy used in studies with carers of traumatic brain injury and cancer [30-32].

The stress process model [33] includes the core dimensions that influence carers' well-being, mental and physical health, including concepts such as carers' personality, primary stressors related to the severity of disease and perceived burden, secondary role strains, and secondary intrapsychic strains, including self-esteem, mastery, competence, and loss of self. According to Pearlin et al [34], self-esteem is influenced by four dimensions: role captivity, loss of self, competence, and gain. In caregiving, competence refers to the person's ability to cope with the caregiving demands, and gain refers to the satisfaction that the carer might receive from caregiving tasks. Self efficacy and competence are often used interchangeably. Self-efficacy determines the various characteristics of a coping behavior; for example, when and if the coping strategy will be initiated, how long will it last, and the coping resources that will be used. Self-efficacy is influenced by "performance accomplishments, vicarious experiences, verbal persuasion, and psychological states" [35].

The coping strategies and the social support of the carer in combination with the different types of the stressors, according to Pearlin's model, act as mediators of the mental and physical health of the carer [34].

Social support is included in Pearlin's stress process model as part of the personal resources that are important to cope with life stressors [34]. The model has been subsequently adapted by Pearlin to conceptualize stress as a dynamic process with its origins in the social world. Economic and social position, as well as the neighborhood context plays a crucial role [36]. According to the convoy model of social relations, four types of networks are available: the diverse, family-focused, friend-focused, and restricted. The social convoy is actually the protective base of each person and is differentiated according to the specific structure (size, frequency, proximity of members, marital status, and participation in social organizations) and the quality of the relationships [37].

In the initial model by Pearlin [29], as part of the personal resources, aside from social support, there are also the coping strategies, including problem-focused, emotion-focused, and meaning-focused. According to Pearlin and Schooler [38], when a person has control over a role (ie, a family role), it is more effective to follow a problem-focused strategy. Where personal control over a role is lower (work and finances), the person may adopt emotion-focused or meaning-focused strategies when reappraising the situation. In some cases, there is the so-called compensatory coping, when after reappraisal, the person may proceed to a problem-focused strategy to reinvest [36].

Additionally, Lazarus and Folkman [39] distinguish within the transactional framework between coping processes and coping styles: the relationship between person and environment and the traits of the person, respectively. Part of the transactional framework is the appraisal theory **,** discussing the primary and secondary appraisal. In primary appraisal, the person focuses on the importance of the event, if it is irrelevant to their own well-being, benign, positive, or stressful. In the secondary appraisal, we encounter the contextual factor and the ability of the person to cope with the stressor.

There is limited research on the associations between the abovementioned concepts, with research especially limited in terms of the role of eHealth literacy. Figure 1 connects the concepts in an effort to conceptualize the associations of health and eHealth literacy of primary and secondary carer and social support provided to the primary carer with self-efficacy, coping strategies, and perception of carer role.

In Figure 1, eHealth literacy is associated with health literacy, as described by Norman [16]. Taking into consideration the new definition provided by Soerensen et al [18], health literacy "entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information."

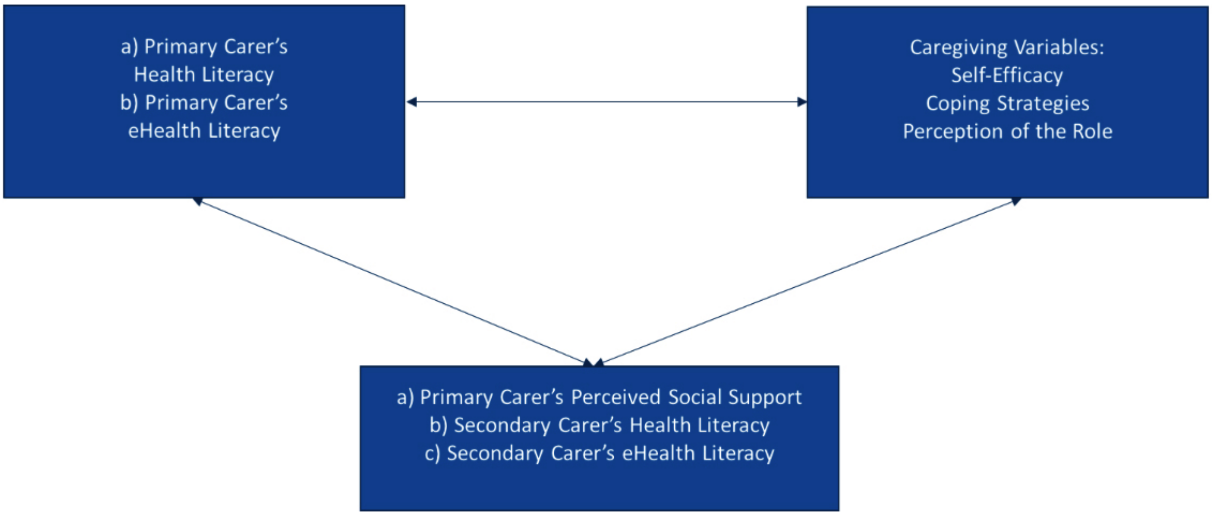
Concerning the selected caregiving variables, self-efficacy is related to cognitive appraisal and acts as a motivator of action and selection of coping strategies [35]. Perceptions of carers' role are related to coping strategies [40]. A person with enhanced self-efficacy is more likely to search for health awareness opportunities and feel empowered (being in control of one's own health).

We presume the effect of health and eHealth literacy of the secondary carer and primary carer's perceived social support on the health and eHealth literacy of the primary carer and the selected caregiving variables.

Social support is also a concept connected with health literacy, acting as a possible moderator in the relationship between low health literacy and poor health and is defined as "the degree to which individuals have access to social resources, in the form of relationships, on which they can rely" [41,42]. The support of social networks seems to play a role in the management of a person's health problem and acts as a coping behavior. We can distinguish two types of social support: structural and functional. The structural support refers to the actual support network and as such the sources and extent of support as a result of the different roles that a person may have in the community (professional role, volunteering role, family role, and other roles). The social network a person belongs to may facilitate the communication of a health problem without directly improving health literacy but instead decrease the feeling of shame and possible stigma because of the inability to read and write about health information or seek medical advice for a health problem. Family and friends may also be facilitators in a decision about health or may take the decisions for the patient. This also may work in the opposite direction, where family and friends with low health literacy have a negative influence on the person's health decisions [41].

The second dimension of social support, which may possibly interact with the level of health literacy, includes the emotional, informational, health reminder support, and tangible aspect of support and is referred to as functional support [41,43]. According to Lee [43], older adults with low health literacy had higher support concerning medical information and health reminder support. However, tangible support was rather low in this population with low health literacy, probably because of a lack of social networks [41,43].

Figure 1. Health literacy and electronic health (ehealth) literacy of primary and secondary carer in association with primary carer's perceived social support and the selected caregiving variables.jpg.



Aim of This Study

According to a recent review [15], we find a large number of Web-based support services for carers of people with dementia. Carers and new technologies is a topic of interest, so we consider it important to identify any issues related with carers' health and eHealth literacy. Although there is some literature for older people or for carers of people with other chronic diseases, health and eHealth literacy have not been explored in carers of people with dementia. Furthermore, other than the primary carer, the role of health and eHealth literacy of the secondary carer will be assessed in this study. In addition, this study aims to explore the associations between health literacy, eHealth literacy and self-efficacy, coping strategies, social support, and caregiving perceptions of dementia carers, taking into consideration the role and support provided by the secondary carer.

As part of the study, health and eHealth literacy tools, as well as the Revised Scale for Caregiving Self-Efficacy will be validated in the Greek language for use among this population group.

The main research questions are

- RQ1a: What is the level of health literacy and eHealth literacy of dementia patients' primary carers?
- RQ1b: What is the level of health literacy and eHealth literacy of dementia patients' secondary carers?
- RQ2: Is there a difference between health literacy and eHealth literacy level of dementia patients' primary and secondary carers, given the generation gap?
- RQ3: What is the association between health literacy and eHealth literacy of dementia patients' primary and secondary carers?
- RQ4: What is the association (if any) between health literacy and eHealth literacy of dementia patients' carers and caregiving self-efficacy?
- RQ5: What is the association (if any) between health literacy and eHealth literacy of dementia patients' carers and their ability to cope with the stressors of caring?
- RQ6a: What is the association (if any) between health and eHealth literacy of dementia carers and their perceptions toward the caregiving role?
- RQ6b: What is the association (if any) of the health literacy and eHealth literacy of the dementia patients' secondary carer and the primary carers' self-efficacy, coping, and caregiving perceptions, and to what extent does the observed association between health literacy or eHealth literacy and caregiving variables in the primary carer differ according to the health and eHealth literacy of the secondary carer?
- RQ7: What is the association (if any) between social support and caregiving variables and to what extent the observed association between health literacy or eHealth literacy and caregiving variables in the primary carer differ according to the levels of social support?

Methods

Study Design

The study will be a cross-sectional correlational descriptive study design to explore the level of health literacy, eHealth literacy, and their association with caregiving self-efficacy, coping strategies, social support, quality of support, positive value, and negative impact of caregiving in Greece and Cyprus.

Pilot Phase

Before the full scale research study, a pilot phase will be conducted to assess the appropriateness of selected questionnaires, the mode of data collection and length of interview, the acceptance of the research material by the primary and secondary carer, and expected challenges in sample recruitment. According to Connelly [44], the adequate number of people for a pilot study design is 10% of the total sample. Other researchers [45,46] suggest a number of 10 to 30. The minimum number of pilot participants in this case was set to a minimum of 17 to 30 primary carers.

Sample

Carers of people with dementia will be recruited from dementia centers and Alzheimer's associations in Greece, (Athens, Thessaloniki) and Cyprus. They will be invited to participate in the study following informed, signed consent. The sample will include primary carers (the carers who support the people with dementia in activities of daily living) and secondary carers (named family member, friend, or other person in the social network assisting the primary carer in their role). For each primary carer, a secondary carer who provides support to the primary carer will be identified. The secondary carer will be named by the primary carer as the closest person who supports the primary carer in his or her caring role. Selected questions will assist the primary carer to identify the supporter carers.

As there are many social cultural similarities related to caregiving between Greece and Cyprus, given the common language and historical and sociocultural background of both countries, it was decided to recruit one sample from both countries. Carers in both countries have the most important role in the care of people with dementia substituting for gaps in the national health care systems. The non-for-profit associations have undertaken the role of supporting and providing services to carers in Greece and Cyprus. In Greece, a number of services provided to carers by the not-for-profit associations are funded by the Ministry of Health through the mental health reform program [47].

Furthermore, the inclusion of two metropolitan cities from Greece, Athens and Thessaloniki, offers the opportunity to involve very active Alzheimer's associations in Greece with both a high as well as more heterogeneous number of users, in an effort to achieve the inclusion of as wide as possible set of members from the target population in terms of their sociodemographic characteristics, as well as the variables of interest. As this is a correlational study, the multicenter convenience sampling aims to increase the observed variability in the variables of interest.

The sample size was calculated considering carers in Greece and Cyprus as one sample according to the above requirement The minimum required sample size with 95% power to detect a statistically significant correlation of the aforementioned variables of the magnitude of r=.25 (type I error 5%) is 168 primary carers and 168 secondary carers. To account for issues with possible inconsistencies in data, incomplete questionnaires, and missing values, it was decided to increase the recruitment to a sample of 200. Moreover, in this way, we ensure that the number of the secondary carers (and thus primary-secondary carers dyads) will not fall under the minimum required sample size, as it is likely that not all secondary carers may agree to participate. Estimated duration of the recruitment period will be 12 months.

Recruitment Process

In Cyprus, prospective participants will be recruited from the Pancyprian Association of Alzheimer's Disease and from the Alzheimer's day centers, Ithaki, which are located in the city of Limassol and Pafos. We have selected these two day centers as they are currently the only services for carers. In Athens and Thessaloniki, recruitment will be done through the Alzheimer's association. In Athens, there are currently six dementia day care centers: in the municipalities of Marousi (1), in Halandri (1), in the city of Athens (3), and in Ilioupoli (1). In Thessaloniki, there are two dementia centers. Furthermore, a sample will also be selected during the events on Carers' day, which is usually organized by the associations annually.

Inclusion criteria for the primary carer include being a self-appointed carer of a person with dementia; supporting the person in activities of daily living, irrespective of the relationship with the person (spouse, children, sibling, friend, or neighbor); being over 18 years of age; and able to read and write in Greek.

The carers will be first approached by the manager of the centers and/or associations who will explain to them the aims of the study. If a carer fulfills the inclusion criteria and is willing to participate, she or he will be referred to the researcher for data collection.

Secondary carers will be nominated by the primary carer and will also be invited to participate in the study. The primary carer will initially contact the secondary carer asking if they are interested in participating, and the researchers will follow this communication to arrange the face-to-face or telephone survey interview.

The face-to-face surveys will be conducted at a place and time convenient for the primary carer. In the case of the secondary carer, an effort will be made to collect the data in face-to-face survey interviews, but the option for a telephone survey interview will be provided to reduce the likelihood of nonparticipation by the secondary carers. The primary carers will respond to the full questionnaire pack, whereas the secondary carers will be asked to respond to the health literacy and eHealth literacy scales (using the same tools as in the case of the primary carers), as well as providing information with regard to sociodemographic characteristics.

Study Questionnaires

Information on sociodemographic characteristics will be collected from both the primary and secondary carers, as well as for the people with dementia they are caring for. Primary and secondary carers information will include age, gender, education, employment status, living situation, hours of care per week (primary carer), years of care (primary carer), number of care recipients (primary carer), relationship with the person with dementia (primary carer), care professional help (primary carer), relationship with primary carers (secondary carer), and type of support provided to primary carers (secondary carer). Information of the person with dementia will include age, gender, diagnosis, stage of the disease, and functional level.

Health Literacy Measures

eHealth Literacy: eHeals Adapted for Dementia Carers in the Greek Language

eHeals, a self-report tool measuring eHealth literacy based on the Lily model, will be used [19]. The scale consists of 8 questions, and it assesses the users' perceived skills at using health technology. In the original study, the scale showed good internal consistency with Cronbach alpha=.88. The eHealth scale taps into the usefulness, importance, perceived knowledge, and evaluation of Web-based health information, with a theoretical range for the overall score from 8 to 40. To date, the tool has been validated in Dutch [48], Italian [49], Chinese [50], and German [51] among varied population groups as school children, university students, and chronic disease patients. In the Dutch, Italian, and Chinese version, the questionnaire was treated as a unidimensional tool. In the German version, there were two dimensions (information-seeking and information appraisal). In all versions, the tools showed high internal consistency with Cronbach alpha ranging from .82 to .92 across the aforementioned studies. Only in the Dutch study were the participants people with rheumatic diseases, whereas the scale has not been previously used among carers of people with dementia.

For this study, the eHeals will be translated into the Greek language using backward-forward translation of the original English version. The questionnaire items will be adapted accordingly where necessary to address carers based on a review by an expert panel. The metric properties of the Greek version will be assessed using the Content Validity Index (CVI) based on the responses of an expert panel in the field of eHealth and health care to assess its content validity. Furthermore, the construct validity of the scale will be assessed in exploratory and confirmatory factor analyses as necessary. The internal consistency of the scale will be assessed using Cronbach alpha coefficient. The validation will be part of the analysis of data derived from the final sample.

The Internet Use Carers Profile

The Internet use carers profile will be measured using a series of 10 questions that assess the frequency and type of use, for example, use of websites, emails, e-learning, social media, interactive services, forums, blogs, mobile, and the Internet. It was deemed important to supplement the eHeals scale with these profile questions, as there has been much criticism with regard to the lack of relevant questions in the eHeals scale, given the Web evolution during the last decade [21,48].

European Health Literacy Survey Questionnaire 16 (HLS-EU-Q16) Short Form

In addition to eHealth literacy, the health literacy of the primary and secondary carers will be assessed using the European Health Literacy Survey Questionnaire 16 (HLS-EU-Q16) [52,53]. The long form of the questionnaire consists of 47 questions, whereas there are also two shorter forms, one with 16 and one with 6 questions. Due to the large number of questionnaires included in this study, it was decided to use the 16-item short form of the scale. The short form was developed based on Rasch modeling and is considered one-dimensional and discriminates three levels of literacy: sufficient health literacy, problematic health literacy, and inadequate health literacy. The tool has been validated in German [54,55], Bulgarian [53], Dutch [53], Israeli [56], and Swedish [57]. As far as we are aware, there is no published validation in Greek, even though Greece participated in the original cross-national survey.

Single Item Literacy Screener (SILS)

Single Item Literacy Screener (SILS) assesses inadequate health literacy and together with the HLS-EU-Q16 provides the information on the health literacy level of the study participants. SILS has been part of 16 questions developed by Chew et al [58]. Initially, 3 questions were identified as better predictors of low health literacy and difficulty in reading printed material. Chew et al [59] proceeded in selecting the single item (SILS) that had better sensitivity (ie, 39% at a score <2) and specificity (93%) than the other 2 questions in predicting inadequate health literacy. The question “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” is replied with a 5-point Likert scale from 1=never to 5=always. A score of 2 and above is considered adequate health literacy level. SILS according to Brice et al [60] does not assess marginal literacy accurately, as it is defined based on the Short Test of Functional Health Literacy in Adults (S-TOFHLA): the person “has difficulty in reading and interpreting health texts.” SILS is easy to use in a clinical setting for a quick screening of health literacy, can discriminate between inadequate and adequate reading ability, and predicts well S-TOFHLA scores of low health literacy. For this specific study, SILS will be validated in Greek to assess the sensitivity and the specificity of the question and adjust the selected cut-off score for this specific population.

Other Constructs (Dependent Variables)

Revised Scale for Caregiving Self-Efficacy

The scale assesses the self-efficacy of carers [61]. It consists of 15 items organized in three subscales, namely, (1) self-efficacy for obtaining respite, (2) self-efficacy for responding to disruptive patient behaviors, and (3) self-efficacy for controlling upsetting thoughts about caregiving. Internal consistency of the three scales was high with Cronbach alpha over .80. The Revised Scale for Caregiving Self-Efficacy has high correlation with depression, anxiety, anger, and social support scales [57]. This scale will be validated in Greek.

Perceptions Toward Caring: COPE Index

COPE index measures carers’ perceptions toward positive and negative values of caring [62]. It consists of 15 items and is part of a study protocol realized in five countries: Italy, Greece, Poland, Sweden, and the United Kingdom. Positive value of caring includes five items, and negative values includes six items. Furthermore, three additional items measure the quality of support, and one item taps into the financial hardships. Negative values items had high internal consistency (Cronbach alpha=.88) in comparison with positive values items with a more modest internal consistency (Cronbach alpha=.67). The criterion validity of the scale was assessed with the use of General Health Questionnaire, Hospital and Depression Scale, and World Health Organization Quality of Life-BREF [62]. Negative values items had significant association with all measures in all countries. Positive values of caring items demonstrated significant association with all measures but was restricted to certain countries (Sweden and Greece).

Brief COPE

Brief COPE assesses the coping strategies adopted by carers [63]. It consists of 28 items organized in pairs in 14 groups of strategies, namely, acceptance, active coping, positive reframing, planning, use of instrumental support, use of emotional support, behavioral disengagement, self-distraction, self-blame, humor, denial, religion, venting, and substance use.

Multidimensional Scale of Perceived Social Support—MSPSS

Multidimensional scale of perceived social support consists of 12 items measuring social network support, including three factors: significant other, family, and friends. The items are scored on a Likert scale from 1 (very strongly disagree) to 6 (very strongly agree) [64,65]. The higher score is 84 and, commonly, a cut-off score of 65 is used. The scale has been tested among different population groups from students to older adults, including patients with chronic diseases. High internal consistency was reported for overall scale (Cronbach alpha=.88), as well as for the subscales (significant other Cronbach alpha=.72, family Cronbach alpha=.85, and friends Cronbach alpha =.75) [63].

Statistical Analysis

Descriptive statistics will be reported, and bivariate correlations between all variables of interest will be explored with parametric and nonparametric measures. Sociodemographic correlates associated with health literacy will also be assessed. Additional data analysis (eg, *t* test, analysis of variance) will be used as needed, for example, to investigate differences in eHealth and health literacy according to sociodemographic characteristics of the participants. The association between dependent variables (coping, self-efficacy, and caregiving perceptions) and independent variables (health literacy, eHealth literacy of primary and secondary carers) will be assessed in multiple regression models before and after adjusting for sociodemographic variables. The extent to which the observed association between health literacy and coping and caregiving perceptions among primary carers differs according to self-efficacy, social support, and the secondary carer's eHealth and health literacy (moderators) will also be explored.

Concerning the adaptation and validation of the health literacy questionnaire, SILS, and Revised Scale of Caregiving Self Efficacy, face and content validity will be assessed by an expert panel. The metric properties (construct validity and internal consistency) will be assessed using exploratory and confirmatory factor analyses and internal consistency reliability analysis. Analysis will be performed by Statistical package for the Social Sciences (SPSS) version 22 (IBM Corp) and exploratory factor analyses with SPSS AMOS.

Ethics Approval

Permission to conduct the study was granted by the National Committee of Bioethics in Cyprus on January 10, 2017, according to the National Law (EEBK ΕΠ 2016.01.151). The commissioner of personal data protection in Cyprus has been notified accordingly and confirmed notification on December 19, 2016 (study number 3.28.460). In Greece, the scientific committee of the Athens Association of Alzheimer's Disease and Related Disorders have also been notified and approved the study on March 17, 2017, with a decision by the Executive Board. This process will be repeated for the Alzheimer's association in Thessaloniki.

All participants will be fully informed about the purpose and the requirements of participation in the study. Consent forms will be signed, and participants will have the right to withdraw at any time. Confidentiality of the participants will be respected. Researchers will safeguard the well-being of the participants during the data collection.

Participants who are interested in receiving feedback will be contacted by email or telephone as soon as the results are analyzed and drafted. Researchers will try to make the participants feel comfortable and resolve any kind of conflict concerning the time, the place of the meetings, and the way that the secondary carers will be contacted.

To safeguard personal sensitive data, a database protected by a password will be developed and will be stored by the research team university computers. Only members of the research team will have access to the database. Hard copies of all measurements will be stored and locked in the Office of the Scientific Supervisor.

Results

The pilot phase of the study is in progress. In the following section, we report some preliminary results of the validation of HLS-EU-Q16 in Greek for the purposes of this protocol.

A convenience sample of 107 older people from an outpatients' eye clinic in Cyprus and open clubs for leisure activities for older people in Athens, Greece, participated in the validation of the scale (Table 1).

The internal consistency of the scale as estimated using Cronbach alpha coefficient was .77 and was adequate, even though it was somewhat lower that the respective figure observed in validation studies elsewhere. CVI for each item, as well as the overall scale was also calculated with a panel of experts (N=6) and a panel of health professionals (N=20), providing high scores for item-level CVI and scale-level CVI/average (S-CVI/Ave) in both groups. S-CVI/universal agreement (S-CVI/UA) was lower among health professionals compared with the group of experts (Table 2).

In-depth analysis of the results derived by the validation of HLS-EU-Q16 will be presented in a subsequent paper. The data collection of the pilot study started in May 2017, and the data collection for the main study is projected to start in October or November 2017.

Table 1. Sociodemographic characteristics of the participants to Health Literacy Scale-Europe-Questionnaire 16 (HLS-EU-Q16) validation.

Characteristics	n (%)
Gender	
Women	62 (57.9)
Men	45 (42.1)
Total	107 (100)
Age in years	
<60	9 (8.4)
61-80	80 (74.8)
>81	18 (16.8)
Education	
No primary education	9 (8.4)
Primary education	47 (43.9)
Secondary education	40 (37.4)
Tertiary education	11 (10.3)
Profession	
Pensioner	84 (78.5)
Employed	12 (11.2)
Unemployed	2 (1.9)
Other (eg, housekeeping)	9 (8.4)
Family status	
Married	82 (76.6)
Single	3 (2.8)
Divorced	2 (1.9)
Widowed	18 (16.8)
Other	1 (0.9)
Comprehensive health literacy level	
Sufficient	49 (45.8)
Problematic	49 (45.8)
Inadequate	9 (8.4)
Health perception	
Good	77 (72)
Neither good or bad	26 (24.3)
Bad	4 (3.7)
Quality of life perception	
Good	84 (78.5)
Neither good or bad	20 (18.7)
Bad	3 (2.8)
Chronic illness	
Yes	58 (54.2)
No	49 (45.8)
Country	
Cyprus	69 (64.5)
Greece	38 (35.5)

Table 2. Content validity index analysis of the European Health Literacy Survey Questionnaire 16 (HLS-EU-Q16).

Panel	Mean I-CVI[a]	S-CVI/Ave[b]	S-CVI/UA[c]
Group of experts (N=6)	.96	.96	.81
Group of health professionals (N=20)	.97	.97	.69
Total	.93	.97	.63

[a] I-CVI: item-level content validity index.

[b] S-CVI/Ave: single-level content validity index/average.

[c] S-CVI/UA: single-level content validity index/universal agreement.

Discussion

Principal Findings

In this study protocol, we have presented the preliminary results of the HLS-EU-Q16 validation. The validation was carried out among 107 older people in Greece and Cyprus, providing information for the comprehensive health literacy level of older people in these two countries. The main study will investigate the relationship of eHealth literacy and health literacy with caregiving self efficacy, coping strategies, and care management perceptions of carers of people with dementia. Previous studies have explored the associations between health literacy and coping strategies, health literacy and self-efficacy, coping strategies and care management, caregiving and self-efficacy, social support and self-efficacy, and social support and health literacy in different target groups. However, no previous study has adopted a unified approach or explored these issues in carers of people with dementia [36,66-69]. Furthermore, studies commonly focus on the primary carer. In this study, information will be also collected from the supporter carer (or secondary carer). The support provided by the secondary carer to the primary carer may influence the primary carer's self efficacy, coping strategies, and/or caregiving perception. Furthermore, the health and eHealth literacy of the secondary carer may influence both the health and eHealth literacy of the primary carer, as well as acting as a moderator in the association between health literacy and caregiving variables in the primary carer.

eHealth literacy is a rather underresearched concept among this population, taking into consideration the age of the majority of carers (above 50 years). The idea of connecting eHealth literacy with caregiving becomes more challenging. New technologies are a core part of everyday life for a large percentage of the population worldwide, but still there are specific groups with low access to technological advances. Low income, low socioeconomic status, and racial or ethnic minorities are considered a predictor of Internet nonuse [5].

Carers and especially spouses could be considered to be a minority in the use of technology. On the other hand, several projects are funded to develop technological innovations to support carers in their role, including Web-based psychoeducational programs and support groups [70-73], interactive services (forums, online communities) [74-76], interventions for depression and stress management [77], e-learning courses and carer platforms or websites [76,78-81], telemedicine, and telehealth (global positioning system, sensor technologies) [82,83]. The need to investigate the level of eHealth literacy and related skills and resources in this population becomes more important considering the possible discrepancy between the development of new technologies for carers on the one hand and the actual frequency of use, and thus benefit, of such technology.

This is also confirmed by the systematic review by Chi et al [84]. Six types of technology-based interventions for carers were identified:

1. Education using mainly telephone-based, Web-based, and video interventions
2. Consultation using videoconferencing
3. Psychosocial or cognitive behavioral therapy intervention using telephone and videoconferencing tools
4. Social support using videoconferencing tools
5. Data collection or monitoring, including response center, sensors, and fall detectors
6. Clinical care delivery using videoconferences

Taking into consideration the large amount of research available on the usability and feasibility of this type of research, it is interesting that there is little focus on the skills required by this target population to use the aforementioned services.

Limitations and Strengths

The challenges of this study concern the recruitment of carers, both in terms of access (hence a convenient sample of people in contact with services), as well as the time requirements and other elements of the recruitment procedure, mainly the survey completion time (estimated at 60 min) and potential difficulties in contacting and recruiting secondary carers. We expect that the majority of secondary carers will be the children or friends of the primary carer, making the arrangement of the survey interview challenging both in terms of time and location but also in terms of motivation to participate.

This study presents numerous strengths. Even though a convenience sample will be recruited, the recruitment will be from a variety of settings to increase the heterogeneity of the sample in terms of their sociodemographic characteristics, as well as the variables of interest. Furthermore, the eHeals questionnaire will be adapted to the needs of carers, and the HLS-EU-Q16 will be used and validated for the first time in this specific population. More importantly, the study will assess the level of health and eHealth literacy of Greek and Cypriot carers of people with dementia for the first time, as well as explore the role of these constructs in the caregiving process. This has important implications about the services provided.

Moreover, screening tools will be available to measure health and eHealth literacy levels for this specific population, and future research on eHealth literacy training of carers in Greece and Cyprus will follow.

Conclusions

Taking into consideration the fast technological progress, the demand for Web-based training and eHealth literacy training is only a matter of time. More and more resources are being developed to support carers on the Web, and the use and assessment of this type of technologies by carers are becoming essential skills that in future years will become obligatory. Focusing on training and developing, training classes and e-learning courses could facilitate the development of these specific skills among this population. Furthermore, the usage of new technologies and the Internet could act as a facilitator in the caregiving demands of carers.

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Authors' Contributions

AE has written the manuscript. AC and NM have contributed in writing, consultation, and reviewing. EP supervised the writing process, consulted the first author, and reviewed the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

COPE: Carers of Older People in Europe
CVI: content validity index
eHeals: eHealth Literacy Scale

eHealth: electronic health
HLS-EU-Q16: European Health Literacy Survey Questionnaire 16
I-CVI: item level content validity index
IT: information technology
S-CVI/Ave: scale level content validity index/average
S-CVI/UA: scale level content validity index/ universal agreement
SILS: Single Item Literacy Screener
S-TOFHLA: Short Test of Functional Health Literacy in Adults

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VIII. Appendix

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A. eHeals-Carer Published Paper

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Original Paper

Adapting the eHealth Literacy Scale for Carers of People With Chronic Diseases (eHeals-Carer) in a Sample of Greek and Cypriot Carers of People With Dementia: Reliability and Validation Study

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Abstract

Background: As the population ages, many more people will be in need of long-term care. According to a recent report by Alzheimer's Disease International and the Karolinska Institute, 84% of people with dementia are cared for at home and 16% in nursing homes. Several Web-based interventions have been developed to assist the work of carers at home. Measuring the levels of electronic health (eHealth) literacy is of top priority to facilitate inclusion of this population and develop training programs to enhance eHealth literacy skills.

Objective: This study aimed to adapt the eHealth Literacy Scale (eHeals) for carers of people with dementia, who speak Greek as their native language and live in Greece and Cyprus, and to test the reliability and validity of the scale for carers.

Methods: The content validity of the eHealth Literacy Scale for Carers of People With Chronic Diseases (eHeals-Carer) was assessed with an expert panel (N=10). A descriptive study with face-to-face interviews among 101 primary carers of people with dementia was conducted. In addition to the eHeals-Carer to assess their perceived eHealth literacy, participants responded to a brief questionnaire regarding characteristics of internet use and provided sociodemographic data. The internal consistency of the tool and the construct validity via an exploratory factor analysis (EFA) were explored.

Results: The Mean Item-Level Content Validity Index (CVI) and Scale-Level CVI Average was 0.93. The participants were mostly women (75.2%, 76/101), aged less than 60 years (67.3%, 68/101) with secondary education. The internal consistency was estimated at a Cronbach alpha of .83. Two factors were extracted from the EFA: information seeking questions 1 to 5 (factor 1) and evaluation questions 6 to 8 (factor 2).

Conclusions: eHeals-Carer is the first perceived eHealth literacy tool adapted for carers of people with dementia. The use of Web-based services available for carers could help them and improve the health care system in the long term. In Greece and Cyprus, there is a lack of services, and improving the digital skills of carers could provide them with the means to support themselves at home and improve care provision.

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KEYWORDS

eHealth; literacy; scales; carers; technology; chronic disease

Introduction

Background

As the population ages, old age diseases are on the rise, that is, many more people will be in need of long-term care in the years to come. In many countries, family and friends usually undertake the role of the carer filling the gap from the lack of organized health and social services, a phenomenon that is more common in Mediterranean and Eastern European regions [1].

According to a recent report by Alzheimer's Disease International and the Karolinska Institute, 84% of people with dementia are cared for at home and 16% in nursing homes [2]. Most carers of people with chronic diseases are aged older than 55 years, and women provide 71% of the annual informal care hours [3,4]. The global number of informal care hours is estimated to be around 6 hours per day or, on an annual basis, 82 billion hours of care. Carers experience stress, making them more vulnerable to infections and memory disorders, and they report a higher use of antidepressants and have high mortality rates [5-7]. The care of people with dementia can be rather demanding, as most patients may develop behavioral disorders in the course of the disease [8]. Carers search for information of the disease prognosis and treatment, services, and support as a way to manage the negative aspects of caregiving and use their social network, friends, families, health providers, and media (newspapers, television, and internet) to do so [9,10].

Carers' Pattern of Use of Web-Based Interventions and the Role of Electronic Health Literacy

Several Web-based interventions have been developed to assist the work of carers at home. They are easy to use and provide quick access to disease-specific information, as in the case of health care websites, psychoeducational platforms, applications, and telehealth and telemonitoring devices [11-13]. In most cases, these services have been provided only during the period of the research intervention, and no further information is provided on their use by carers [14]. According to Chiu and Eysenbach [15], a pattern of use of Web-based interventions made by carers is influenced by several factors such as accessibility, perceived effort, carers' needs (personal skills, social support, carers' beliefs, and years of care), and the style of use. In a modern framework developed to explain factors influencing the design of new technologies based on electronic health (eHealth) literacy level of the users, there is a discussion based on the individual characteristics (being a patient or a carer), the task dimension, and the experience using the technology [16]. Skills in searching, finding, appraising, and applying health information online have also been defined by Norman and Skinner [17], discussing eHealth literacy, which includes the following 6 literacies: traditional, information, media, health, scientific, and computer literacy. The latter 3 (ie, health, scientific, and computer literacy) are categorized according to the authors as context specific. This model has been modified and extended by other researchers [18-20], and a recent definition of eHealth literacy is provided by Bautista [21] and Paige et al [22]. eHealth literacy is redefined and "...involves the interplay of individual and social factors in the use of digital technologies to search, acquire, comprehend, appraise, communicate and apply health information in all contexts of healthcare with the goal of maintaining or improving the quality of life throughout the lifespan." Taking the above into consideration, the individual characteristic, being a carer or a patient, may influence the person's perceived eHealth literacy level. Low health literacy among carers of adults is associated with poorer health provision, care recipient health outcomes, and increased burden [23].

Adapting the eHealth Literacy Scale for Carers of People With Chronic Diseases

There is a lack of published data on eHealth literacy level among carers of people with dementia and adapted or newly developed tools for this purpose.

Norman and Skinner [24] developed the eHealth Literacy Scale (eHeals) to measure the perceived skills that influence the eHealth literacy and consists of 8 items. It was originally tested among 664 adolescents, aged 13 to 21 years, in Canada and showed good metric properties. The scale is easy to administer. The items are short and incorporate a combination of the literacies presented in the Lily model, take no more than 10 min, and assess the way a person searches, assesses, and applies health information online. Even if there is a discussion concerning the lack of Web 2.0 questions [25], at present, it has been translated and used in many different languages and population groups. In the past 5 years, research studies seem to focus on the dimensionality and construct validity of the scale (eg, the number of factors the tool taps on) as well as other related variables such as internet access and use, computer skills, and determinants of eHealth literacy such as age, monthly income, health status, education, and chronic diseases [26-32].

The need for the eHeals to be adapted for the carers population as the eHealth Literacy Scale for carer of chronic diseases (eHeals-Carer), is associated with their caring needs. They usually search information for another person instead of for themselves and their personal health issues, and they are more receptive to technologies that assist them in their caregiving [33,34]. Adapting eHeals items to fit carers' online style of use would facilitate their understanding of the topic and make the questions more comprehensible for their specific needs. This also facilitates their inclusion in the new technological era, as new online tailored services are increasingly provided to carers.

Electronic Health Literacy Among Carers and Available Research in Greece and Cyprus

At the moment, we may only find information on the style of health-related internet use and possible predictors of this type of use made by carers [35,36].

In Greece, recently, a study identified older age and lower education among the main predictors of lower functional eHealth literacy in a Greek-speaking population [32]. We know that in Greece and Cyprus, the main reason for internet nonuse among older adults is the lack of skills [37,38]. In Greeks and Cypriots, among people aged 65 to 74 years, there is a decrease in internet use from 17.6% in 2012 to 11.1% in 2014 and from 12.7% in 2012 to 6.4% in 2014 for the age group of 75 to 99 years. On the basis of data from the *Internet in Cyprus* report, only 9.6% of the Greek Cypriots search the internet for health information on a weekly basis, and 43% of the sample has never searched the internet for health topics [38].

Objectives

The aim of the study was 2-fold: (1) to identify available validated eHeals as part of a scoping review and (2) to evaluate the validity and reliability of the proposed eHeals for carers among a sample of Greek-speaking carers of people with dementia in Greece and Cyprus.

Methods

Literature Review on Available eHealth Literacy Scale Validations

As part of the validation process, we have searched following the methodology of a scoping review as described in the studies by Arksey and O'Malley and Peters et al [39,40] for relevant validations of eHeals to identify all possible alternatives regarding the different languages, population, statistics, and ratings and any available carers adapted version.

The main research questions of the review are as follows: (1) What type of statistical analysis is used to extract factors for eHeals? (2) How the Web 2.0 problem is handled in existing validations of eHeals? (3) Is there any difference in rating the scale? and (4) Is any eHeals validation for carers available?

We searched for all validations of eHeals in relevant databases (PubMed, CINAHL, MEDLINE, PsycINFO, and Scopus) and gray literature (eScholarship) until December 2018. Keywords used were eHeals and eHealth Literacy Scale.

The studies assessed are based on the following inclusion criteria: (1) the study should be related to the topic of eHealth literacy; (2) the study should be related to the scale reliability and validation; and (3) the study should be published in English

We did not include studies that used eHeals as a measure of eHealth literacy, but no information on validation was provided. The flowchart and related table of results are included in this paper as Multimedia Appendices 1 and 2.

Validation Process of eHeals Carers in Greece and Cyprus

Following the literature review, we designed the validation and adaptation of the eHeals among Greek and Cypriot carers of people with dementia. Permission to use and adaptation of the scale were obtained by the authors [24]. The study followed the validation process as described by the World Health Organization following a double forward and backward translation strategy [41].

As part of the first step, we proceeded with the double forward and backward translation between the original English and Greek. Initially, 2 independent translators, both native speakers of Greek and fluent in English translated the scale into Greek. After comparing and merging the 2 translations into a single Greek translation by consensus, 2 independent back translations into English were derived by an additional set of 2 bilingual translators, 1 care professional and 1 researcher (ie, nurse trainer). In case of disagreement, we employed consensus meeting among the research team members based on expert opinion and existing literature.

In the second step, face validity by the research team followed. During this phase, researchers assessed the available Greek translation of eHeals and if the translated items corresponded to the English version of eHeals. The research team selected the final version in the Greek language and adapted it accordingly by adding a reference to the caregiving concept in every item of the scale. All items were modified accordingly to refer to the health and caregiving issues of a friend/relative, as, for example, in item 1: "I know what health resources are available" adapted to item 1: "I know what resources/information are available on the Internet concerning the health and caregiving issues of my friend/relative." The caregiving issues on the scale are explained as the practical, financial, legal issues and information about the disease and available services. In the case of items 2, 3, and 4, we also added short clarification to facilitate understanding. Modifications of the scale are available in Table 1.

The content validity of the adapted items in the Greek language was assessed by a panel of experts in the field of eHealth and dementia or older people. Following this process, the questionnaire was piloted in 25 carers. Finally, the internal consistency of the final version of the Greek-adapted scale was tested among a sample of primary carers, and construct validity was followed with exploratory factor analysis (EFA).

Table 1. eHeals-Carer (Electronic Health Literacy Scale for Carers of People With Chronic Diseases) items: item difficulty, corrected item-total correlation, and factor loading.

Questions per factor	Mean (SD)	Median	Corrected item-total correlation	Factor loadings
Factor 1				
Item 1: "I know what resources/information are available on the Internet concerning the health and caregiving issues of my friend/relative (practical, financial, legal issues, information about the disease and available services)."	3.51 (0.93)	4	0.48	0.485
Item 2: "I know where to find helpful information on the Internet concerning the health and caregiving of my friend/relative (e.g. which websites I will search)."	3.35 (1.06)	4	0.59	0.540
Item 3: "I know how to find helpful information on the Internet concerning the health and caregiving of my friend/relative (e.g concerning the process: google search)."	4.08 (0.82)	4	0.55	0.735
Item 4: "I know how to use the Internet to answer my questions about the health and caregiving of my friend/relative (e.g how to ask in order to receive a proper reply to my question)."	3.83 (1)	4	0.53	0.656
Item 5: "I know how to use the information about the health and caregiving of my friend/relative I find on the Internet to help me (practical, financial, legal issues, information about the disease and available services)."	3.75 (0.85)	4	0.55	0.500
Total	18.49 (19)	19	—[a]	—
Factor 2				
Item 6: "I have the skills I need to evaluate the resources/information I find on the Internet concerning the health and caregiving of my friend/relative."	3.70 (1.05)	4	0.59	0.756
Item 7: "I can tell high quality resources/information from low quality resources/information on the Internet concerning the health and caregiving of my friend/relative."	3.75 (1)	4	0.59	0.731
Item 8: "I feel confident in using information from the Internet to make decisions concerning the health and caregiving of my friend/relative."	3.30 (1.08)	3	0.57	0.595
Total	10.77 (2.62)	11	—	—
Total scores from both factors	29.27 (5.30)	29	—	—

[a] Not applicable.

Recruitment

Recruitment Panel of Experts for the Content Validity Index

To proceed with the content validity index, we invited 10 experts to reply to the content validity of the questionnaire. The experts were invited because of their work on eHealth and/or dementia domain. Of 10 experts, 8 were health professionals: 3 health care professionals, nurses, and psychologists working in the field of technology (robotics and digital literacy of older people), 1 member of the Greek team of the European Health Literacy Survey, and 4 health care professionals working in dementia care. The remaining 2 were information technology experts working in the field of eHealth.

Recruitment of Primary Carers

The data collection of primary carers was made in the framework of the research protocol for "the Association of Health Literacy and Electronic Heath Literacy with Self-Efficacy, Coping and Caregiving Perceptions Among Carers of People with Dementia: Research Protocol for a Descriptive Correlational Study" [42].

The final sample of the protocol was estimated with 95% power and a type 1 error of 5% to 168 primary carers. All questionnaires were pilot tested in 25 primary carers of people with dementia [43].

The validation of eHeals adapted for carers proceeded with a convenience sample of 101 carers from Greece and Cyprus, based on the subject-to-item ratio 10:1 [43-45]. Participation in the study was voluntary, and the recruitment of the sample lasted for 1 year. Eligibility criteria were broad and included being a carer of a person with dementia, speaking Greek, and being aged older than 18 years. Researchers approached carers at Dementia Day Care Centers in Athens, Greece, and Limassol, Cyprus, or during training courses and public awareness campaign events directed to carers of people with dementia. In the case of Dementia Centers, the scientific supervisors assisted the researcher to arrange the appointment at the time of the day that carers were available. In the case of public events, the researcher distributed leaflets, and carers expressed their interest in participating. The researcher arranged a face-to-face survey appointment to administer the questionnaire.

Measures

The measures were as follows:

- Content Validity Index [46]: all expert panel participants received the questionnaire adapted for carers in the Greek language and assessed item phrasing, simplicity by commenting on every item and relevance on a 4-point scale: not relative, somehow relative, quite relative, and relative.
- Carers replied to the Greek version of eHeals-Carer, which includes 8 items, each with a 5-point response scale from 1 (strongly disagree) to 5 (strongly agree). As shown in Table 1, all 8 items were adapted accordingly to specifically refer to the caregiving role.
- Carers also provided the following basic sociodemographic information: gender, age, education level (based on the international standard classification of education), employment status, carers' relationship, living status, and being supported by a secondary carer or not), and replied to a series of questions with regard to internet use, either personal or dementia-specific online use. As part of the sociodemographic information, we have used a visual analog scale for measuring the socioeconomic position, Ladder questionnaire [47,48]. The participants were asked to assess where they stood on a ladder in comparison with other people in Greece or Cyprus, given that in the bottom of the scale are the people with the worst profession or unemployment, least money, and lowest education.

Data Analysis

In content validity, we reported the following 3 indexes: (1) Mean Item-Level Content Validity Index (Mean I-CVI), measuring the proportion of relative and very relative responses of the items; (2) Scale-Level Content Validity Index Average (S-CVI/Ave), measuring the average score of the responses of quite relevant and very relevant of every expert; and (3) the Scale Content Validity Index Universal Agreement (S-CVI/UA), measuring all items that all raters assessed as quite or highly relative. As scale CVI, we usually consider the S-CVI/Ave because the S-CVI/UA decreases as the number of raters increases [46].

The internal consistency of the scale was assessed with a Cronbach alpha, and the dimensionality of the scale was explored with EFA. This was the first time that the scale was validated in Greek among carers, and dimensions were not hypothesized before the validation. Confirmatory factor analysis (CFA) will be calculated with the total sample of the study protocol based on the EFA findings.

Ethical Consideration

The Cyprus National Ethical Committee (EEBK ΕΠ 2016.01.151) and the Cyprus Commissioner for Personal Data Protection (3.28.460) approved the study. As the study was conducted in 2 countries, the study protocol also received approval by the Scientific Committee of Alzheimer Athens Association (March 17, 2017).

Results

Results of Literature Review on Available eHealth Literacy Scale Validations

According to the first step of the validation process, we conducted a review to identify all possible eHeals validations to decide on the methodology and avoid any replication of existing measures for this specific population.

The scale has been validated and adapted in many different languages and population groups, using either convenient sample recruitment strategies or randomized recruitment techniques (as random telephone dialing). In the last 3 years, the validation studies of the specific tool were increased, showing a tendency toward eHealth literacy research. Only in 1 study from Slovenia did we find the validation of an extended version of 20 items (6 factors) including the Web 2.0 parameter as discussed earlier by Norman [49,50]. In 21 cases, the authors preferred a combination of the original scale adding questions to assess health-related internet use and internet use in general [17,25,27-29,31,51-64]. The reliability in the majority of the studies was quite high, that is, over 0.80. The lowest reliability was presented in a student sample in Bangladesh and in the 6 dimensions of the Slovenian version [50,61]. In 6 of 26 studies, the sample recruitment focused on older adults [25,52,59,65-67].

A series of studies have identified or confirmed the unidimensionality of the eHeals [25,30,31,57,68-70]. However, the latest studies seem to propose either a 2-factor model or a 3-factor model [27-29,52,54,59,62,67]. The study by Soellner et al [64] was one of the first to propose a 2-factor model with an information seeking (questions 1-5 and 8) and an information appraisal (questions 6 and 7) component. This model was later confirmed by Diviani et al [28]. Subsequent studies also supported a 2-factor model, yet with a different set of questions, for example, the first 4 questions tapping on factor 1 and the last 4 questions on factor 2 [27,29]. With regard to the 3-factor model, the most commonly accepted dimensions are as follows: awareness (questions 1 and 2), skills (questions 3-5), and evaluation (questions 6-8). Paige et al [63] proposed a 3-factor model with a different categorization, which, instead of skills and evaluation, includes information seeking (questions 3 and 4) and information engagement (questions 5-8).

In almost all cases, the scoring system distinguished between high and low scores without providing information for a medium level. In 12 papers, the level was calculated by summarizing all items, and in 4 validation studies, the level was calculated by summing up all items and dividing the score with the number of the scale or of the factor. The highest score of eHeals among the studies included in this review is presented in the study by Chung and Nahm [65] for a sample of 886 adults, with a mean age of 62 years and eHeals literacy mean score of 30.94 (SD 6).

In 5 studies, the researchers used a principal component analysis (PCA), in 11 cases EFA, in 8 studies CFA, and in 3 studies either PCA or EFA and then CFA (Multimedia Appendix 2).

In 4 studies, they followed item response theory and Rasch modeling.

This review provided the basis for our validation study. On the basis of the above results, the discussion for the use of classical test theory and item response theory in behavioral and social science [71], and the aim of our study (to adapt an already developed short scale), we decided to follow the classical test theory validation and the use of EFA. As there were many available validations providing different dimensions, we decided to explore the dimensions in this target group and confirm these factors in a larger study sample of carers.

Our decision to adapt for a specific population was in accordance with the measurement modifications for diverse populations [72]. The reasons for modifying this scale were as follows: (1) carers were a different population from the one that participated in the development of the original scale; (2) the scale lacks the caregiving concept that carers would be related to; and (3) if the eHeals was used as it is, there might be a misinterpretation of the items through the caregiving filter. To proceed with the adaptation of the eHeals, we followed an extensive literature review on the eHealth literacy research among carers and older people. Carers' research on eHealth literacy was limited, but we encountered valuable information on the internet use among carers of frail older people and people with dementia. On the basis of this research, we were able to understand how carers may use the internet in relation to caregiving. They mostly searched for disease-specific information, services for the patients, practical issues, and legal and financial issues and to communicate through emails and chat sites [73-75]. In this regard, we decided to proceed with the context-specific modifications of the eHeals as has been discussed in the following subsections.

Content Validity of eHealth Literacy Scale Carers in Greek

Mean I-CVI and S-CVI/Ave was 0.93 in both cases. S-CVI/UA was 0.60.

Experts made no further comment on the phrasing of the scale, apart from 3 comments on 3 different items (items 1, 2, and 9), that did not change the final meaning of these items.

Demographic Information of Primary Carers

As part of the reliability and construct validity, our sample comprised primary carers, mostly women (75.2%, 76/101), caring for their parents (61.3%, 62/101) living in the same household (61.3%, 62/101), aged younger than 60 years (67.3%, 68/101), having completed 12 years of education or more (92.0%, 93/101), mostly unemployed or pensioners (62.3%, 63/101), and receiving assistance from a secondary carer (78.2%, 79/101). Detailed demographics are presented in Table 2. Socioeconomic position was assessed with the use of the ladder figure questionnaire with 10 steps, providing a mean score of 5.8.

Table 2. Demographic information of the carers sample (N=101).

Characteristics	Value, n (%)
Gender	
Women	76 (75)
Men	25 (25)
Age (years)	
<59	68 (67)
60-79	33 (33)
>80	0 (0)
Education	
No primary education (ISCED[a], level 0)	0 (0)
Primary education (ISCED, level 1)	8 (8)
Secondary education (ISCED, levels 2-4)	54 (53)
Tertiary education (ISCED; levels 5.1, 5.2, and 6)	39 (39)
Employment status	
Employed	38 (38)
Unemployed (including pensioners)	63 (62)
Carers' relationship	
Caring for parent	62 (61)
Caring for spouse	28 (28)
Caring for other (relative/friend/neighbor)	11 (11)
Secondary carer support	
Yes	79 (78)
No	22 (22)
Living status	
Together with person with dementia	62 (61)
Living in other's house	39 (39)
Most frequent internet use for carers	
Search of information	40 (43)
Reading news	15 (16)
Entertainment (movies and music)	12 (13)
Social networks	8 (9)
Emails	9 (10)
Professional reasons	8 (9)

[a] ISCED: International Standard Classification of Education.

Internet Use Characteristics

Of 101 participants, 92 used the internet with the more frequent reason of private internet use: *searching for information on different topics*. Of all participants, 97.0% (98/101) visited websites; 76.2% (77/101) used social networks, such as Facebook, Twitter, and LinkedIn; 81.1% (82/101) used email to communicate; 83.1% (84/101) used interactive services (eg, Viber, Skype, forums, and chatrooms); and only 42.5% (43/101) accessed electronic learning (eLearning) courses.

In the questions regarding online search of dementia-specific information such as disease information, practical issues, legal information, and available services, almost all participants 90.0% (91/101) stated that they had accessed online dementia resources and mostly websites. Almost half of the participants (40.5%, 41/101) had used social networks, and 42% (42/101) had used email to communicate and searched for information with other carers, family, and health professionals. The use of interactive services and eLearning courses were the least preferred resources to communicate and receive information or training with 32.6% (33/101) and 12% (11.8/101) users equivocally.

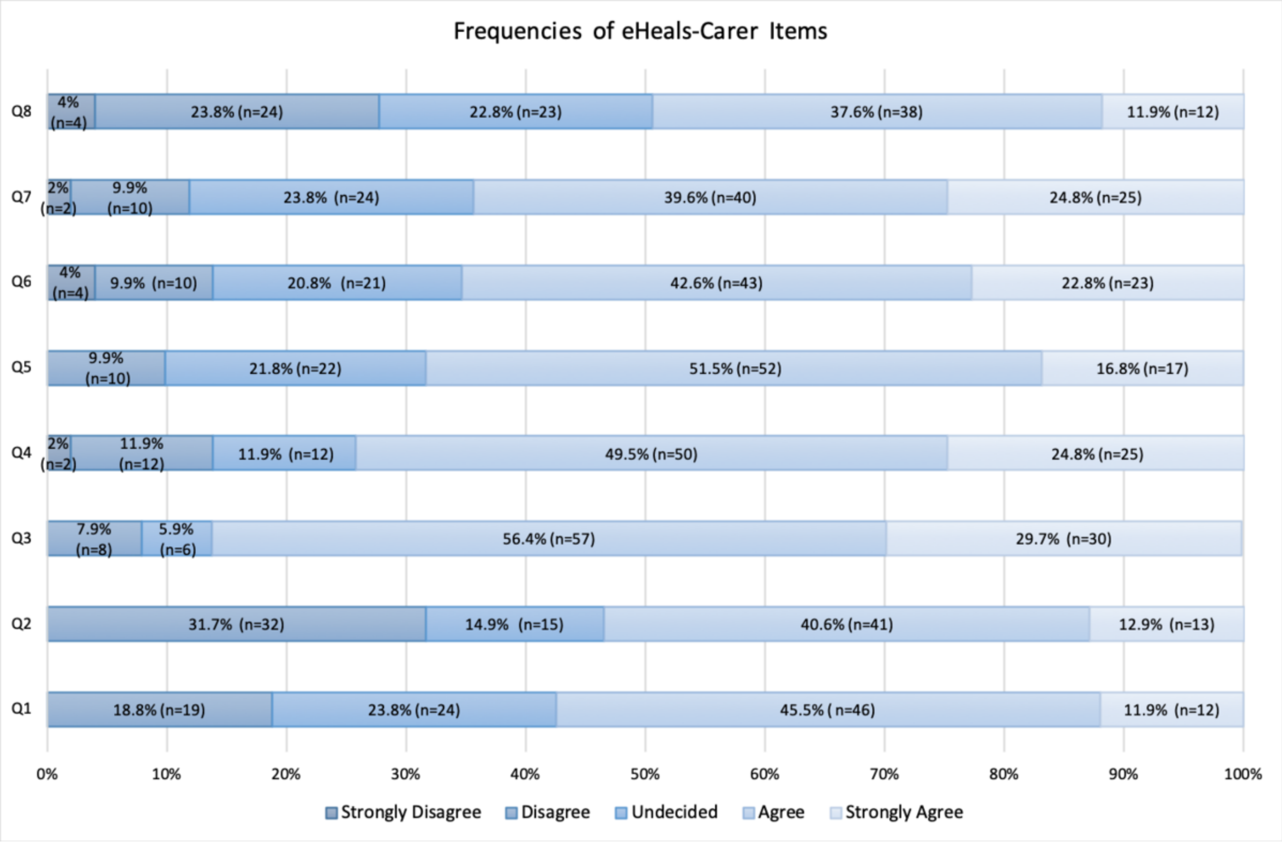
Among all participants, 51.4% (52/101) used a mobile phone to access information for dementia care or to communicate with other carers or health care professionals. Adding to the above result, of 52 participants who have used the internet on their mobile phone, 86% (45/52) have accessed websites, 54% (28/52) accessed social networks, 39% (20/52) used emails, 42% (22/52) used other interactive services, and 5% (3/52) used eLearning services through their mobile phone.

Reliability

Internal consistency of the scale was measured with Cronbach alpha of .83. All items appeared important with item-total correlations ranging between .48 and .59. In all cases, the Cronbach alpha was lower if any of the items was removed.

The items with the highest frequency of replies of agreement (agree and strongly agree) were item 3 “I know how to find helpful information on the Internet concerning health and caregiving of my friend/relative (e.g. concerning the process: google search),” item 4 “I know how to use the Internet to answer my questions about the health and caregiving of my friend/relative (e.g. how to ask in order to receive a proper reply to my question),” and item 5 “I know how to use the information about the health and caregiving of my friend/relative I find on the Internet to help me (practical, financial, legal issues, information about the disease and available services).” Item 8 “I feel confident about using information from the Internet to make decisions concerning the health and caregiving of my friend/relative” had the lowest scores of agreement (Figure 1). This was also confirmed by mean scores of every item of the scale as presented in Table 1. The total mean score of the scale eHeals-Carer was 29.27 (SD 5.30).

Figure 1. Frequencies of responses of eHeals-Carer (Electronic Health Literacy Scale for Carers of People With Chronic Diseases) items.



Construct Validity

The dimensionality of the scale was explored in EFA, principal axis factoring with Varimax rotation. Kaiser-Meyer-Olkin measure sampling adequacy was 0.80, and the Bartlett test of sphericity was statistically significant (χ^2_{28}=261.5 *P*<.001). Overall, 2 factors with eigenvalue greater than 1 were extracted, with the first factor explaining 24% of the variance and the second factor 23% (rotation sums of square loadings). After Varimax rotation, a clear structure was revealed with no cross-loadings. Items 1 to 5 loaded on the first factor and seem to tap on the *information seeking* aspect of eHealth literacy. Items 6 to 8 loaded on the second factor and tapped on the *evaluation* aspect of eHealth literacy. Reliability analysis for factor 1 provided a Cronbach alpha of .77 (mean 18.48 [SD 3], median 19), and for factor 2, a Cronbach alpha of .78 (mean 10.77 [SD 2.62], median 11).

Discussion

Principal Findings

We searched the literature to identify all possible validations of the eHeals and to check if there was any adapted version for this population. We adapted and validated the scale for carers, resulting in a scale with high Mean I-CVI (0.93) and high reliability (0.83). The data analysis supported 2 factors:

information seeking and evaluation. The first factor includes the 5 items of eHeals 1 to 5, and the second factor includes 3 items 6 to 8. In the literature, we identify different categories derived from the analysis of eHeals including awareness (1 and 2), skills (3-5), information seeking (1-5 and 8 or 3-4), information appraisal (6 and 7), information engagement (5-8), and evaluation (6-8). We have also identified 2 factors related to seeking and appraisal skills as in the case of Soellner et al [54], but with a different combination of the eHeals items for the 2 dimensions. This difference, from other researchers, might derive from the cultural adaptation of the tool. In item 5 “I know how to use the information about the health and caregiving of my friend/relative I find on the Internet to help me (practical, financial, legal issues, information about the disease and available services)” was perceived as a competence/skill item on how to do rather than as an item for evaluating the information.

In eHeals, as initially developed by Norman and Skinner, more than 1 literacy is included per item of eHeals [17,53]. For example, traditional, information, computer, and health literacy are included in all items of the scale. Media and scientific literacy can be identified in the evaluation subscale [53]. We adapted the short-scale 8-item eHeals for carers to investigate carers’ eHealth literacy levels. In this adaptation, we consider the different needs of carers regarding health and eHealth literacy skills. According to a recent scoping review, carers’ levels of health literacy are considered adequate, even if they largely depend on the scale used [23]. Carers are the people who manage the communication with the health care providers and the care recipient, manage support services for the dependent person, and make health-related decisions. We also know from previous studies that carers’ health literacy levels and eHealth literacy skills may vary according to the person’s characteristics: being a carer or not, as this has been identified for the health-related internet use in this population [36]. Carers report higher levels of health literacy in comparison with the care recipients [23]. They usually search for health-related information for the cared-for person and use the internet to find information about the disease prognosis and treatment, legal and financial issues, practical issues, and communication [34,36,73]. Online information and services are important for the health self- management [9]. This is also confirmed in a study by Anderson et al and the analysis of 2345 carers’ posts in 9 websites. Researchers have categorized posts in 4 topics: social support—communication and inclusion, search of information, sharing of memories with the person with dementia, and sharing information with other carers [76].

In Greece and Cyprus, carers are the core element in the care provision of people with dementia, covering the lack of tailored services by the National Health System [77,78]. The development of eHealth tools has been promising in this area, assisting carers in everyday tasks, but still much needs to be done to increase the use of these tools by carers. As a first step, we need to investigate the eHealth literacy levels of carers by using a short, easy-to-comprehend tool. In this study, we adapted the eHeals questionnaire to mirror the carers’ role as an effort to provide this adapted tool to carers in Greece and Cyprus. In Greece, Xesfingi and Vozikis [32] assessed the eHealth literacy level in a sample of 1064 citizens, ages ranging from 15 years to older than 80 years, with older people and the less educated to be less eHealth literate. In Cyprus, there is no available literature measuring eHealth literacy levels among older people or carers.

We consider that this scale assists in the assessment of eHealth literacy level of carers in 2 ways. Firstly, in practice, as the health care system, not-for-profit organizations, and academic institutions could develop tailored programs for the online needs of the carers. In this way, carers may improve the way they access and evaluate dementia-specific information or information regarding their health. Secondly, in research, as we provide a validated tool for use in future studies investigating the determinants of eHealth literacy, its association with the burden and other aspects of the caregiving role, as well as a process outcome measure in intervention studies targeting eHealth literacy. In this way, eHealth inequalities may be decreased, as carers improve the management of the disease and their burden because of a better use of the available Web-based services.

Finally, through the validation process in this diverse population, we identified culturally specific issues related to the understanding of the items of the first-dimension *seeking information*, and we consider important in future research on the development and validation of eHealth literacy tools that researchers include short exemplars to facilitate understanding of the *how to* items when related with internet users’ skills.

Limitations

Carers of people with dementia in this study are considered a convenient sample. Participation rate did not exceed 31% as revealed in the piloting phase of the study protocol. Carers in Greece and Cyprus were not easy to identify if they had not attended a dementia center. As a consequence, the final sample included in this validation was small. The study should be repeated in a larger sample, among carers of patients of other chronic diseases and could be used for cross-country comparisons between Greek and Greek-Cypriot carers.

Even if the eHeals has been adapted for carers, no item about Web 2.0 has been added in the 8-item scale. We only added it in the supplementary section of the internet use characteristics [49]. Carers use the internet to interact with health care professionals and other carers [79-81]. This type of internet use (interaction with social networks: forums and chatrooms) is not depicted in this scale, making this adapted version limited but convenient for use in large study protocols when there is a need of a short tool with high reliability and validity for measuring eHealth literacy among carers.

Conclusions

The validation of eHeals-Carer provides the first questionnaire measuring perceived eHealth literacy skills adapted to carers. At the moment, there is no other scale measuring eHealth literacy levels for carers available. The development of new tools on eHealth literacy measuring functional aspects adapted to specific needs seems to be the next step in this research area. Carers of people with dementia, in the majority, are people aged older than 50 years, children, or spouses, with low use of care-specific Web-based services. The use of the online services available for carers could facilitate the carers and the long-term health care system. In Greece and Cyprus, there is a lack of services for carers, and by improving their digital skills, we could provide them with the means to support themselves and improve the care they provide. With the increased offer of Web-based services tailored for carers, the improvement of their digital skills will become more demanding in the years to come. Furthermore, public and private services in Greece and Cyprus are updating their service systems to be following technological progress. In this era, carers can be included if we provide them with adequate and appropriate eHealth literacy training programs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Scoping review flowchart.
[PDF File (Adobe PDF File), 38 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Scoping review validation results of eHeals (Electronic Health Literacy Scale).
[PDF File (Adobe PDF File), 65 KB-Multimedia Appendix 2]

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Abbreviations

CFA: confirmatory factor analysis
CVI: content validity index
EFA: exploratory factor analysis
eHealth: electronic health
eHeals: eHealth Literacy Scale
eHeals-Carer: eHealth Literacy Scale for Carers of People With Chronic Diseases
I-CVI: Item-Level Content Validity Index
PCA: principal component analysis
S-CVI/Ave: Scale-Level Content Validity Index/Average
S-CVI/UA: Scale-Level Content Validity Index/Universal Agreement

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IX. APPENDIX

A. items per factor in case of 3 and 4 exploratory factor analysis for the validation of HLS-EU-Q16

Table IX-1 Items per Factor extracted from 4-factor analysis HLS-EU-Q16

	Factor 1	Factor 2 Media Literacy	Factor 3 Compliance with doctors instructions	Factor 4 Health Care and access of information
HLS-EU-Q16	4,8,9,10,13,14,16	11,12,15	3,5,7	1,2
Cronbach a	.60	.60	.54	.55

Table IX-2 Items per Factor extracted from 3-factor analysis HLS-EU-Q16

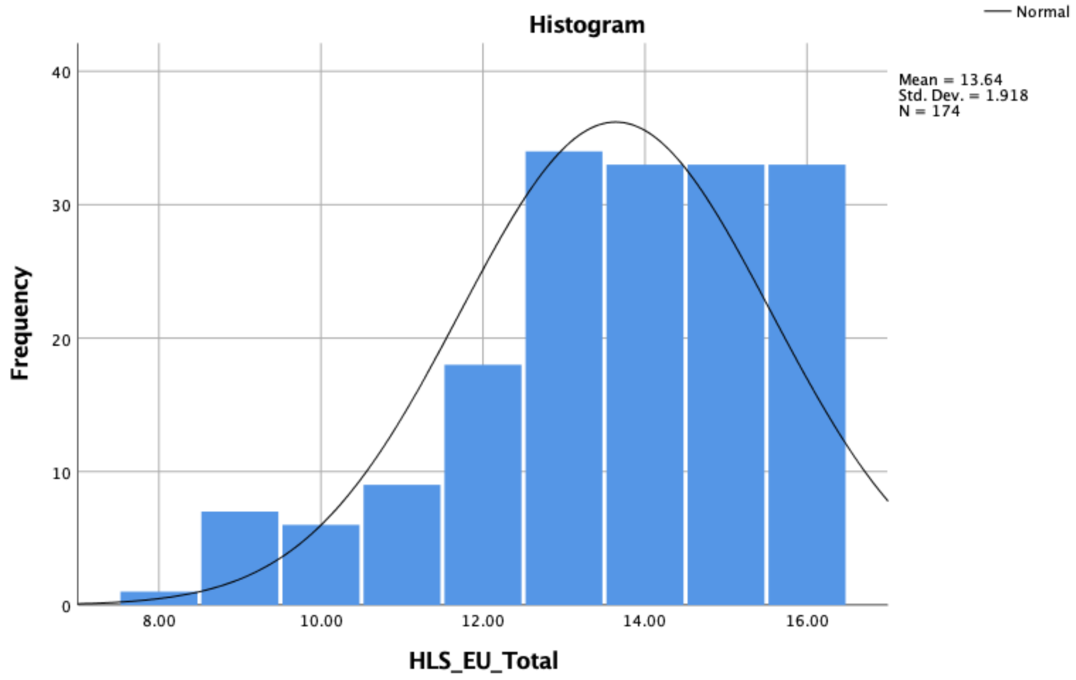
	Factor 1	Factor 2 Media Literacy	Factor 3 Health Care and access of information
HLS-EU-Q16	3,4,5,7, 8,9,10,13,14,16	11,12,15	1,2
Cronbach a	.60	.60	.55

X. APPENDIX

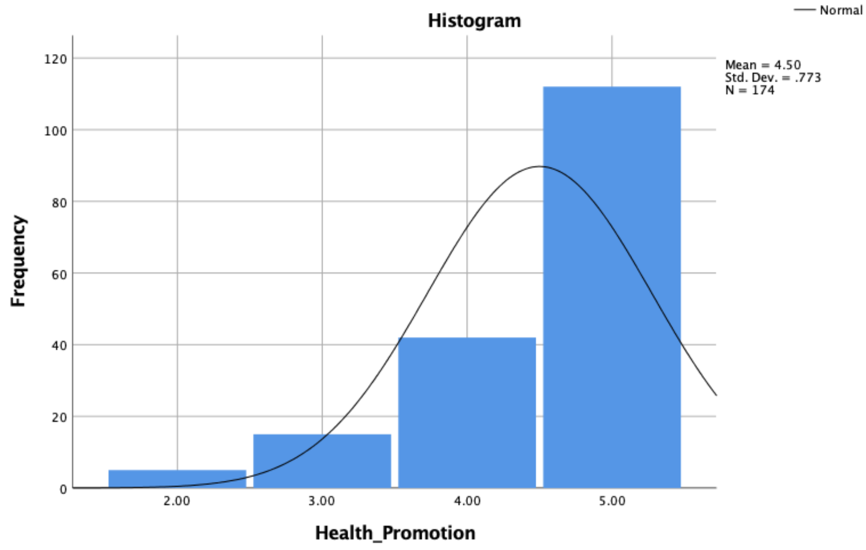
A. core concepts normality testing

1. HLS-EU-Q16 HISTOGRAMS

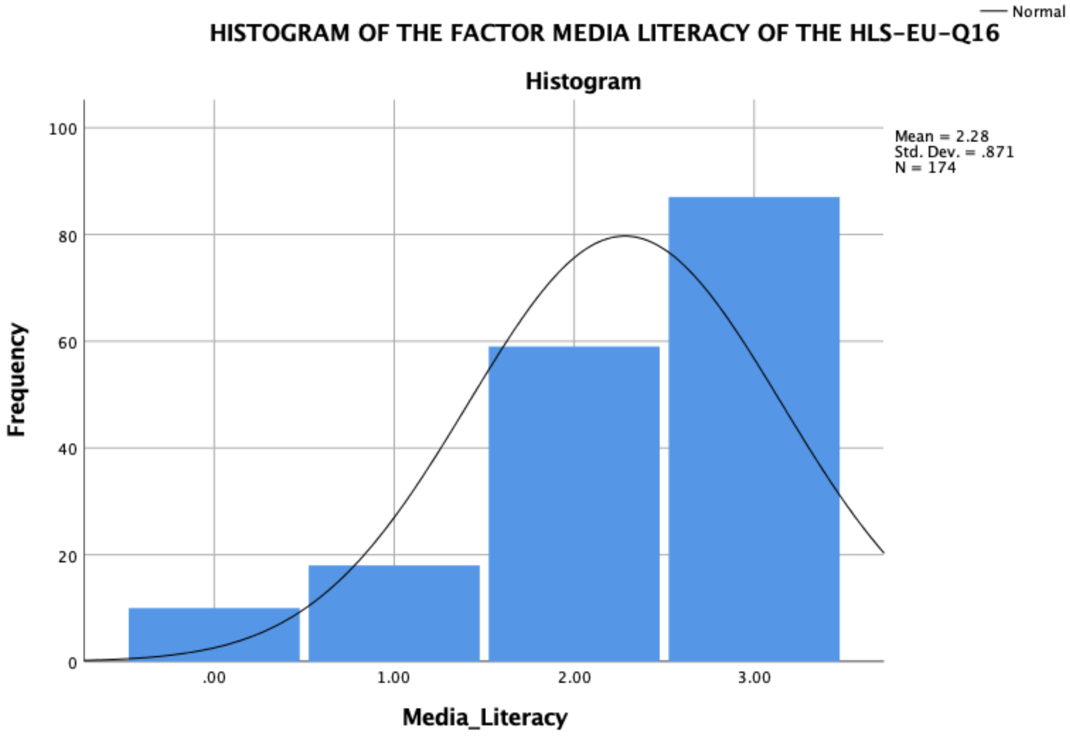
HISTOGRAM OF HLS-EU-Q16 TOTAL SCORE



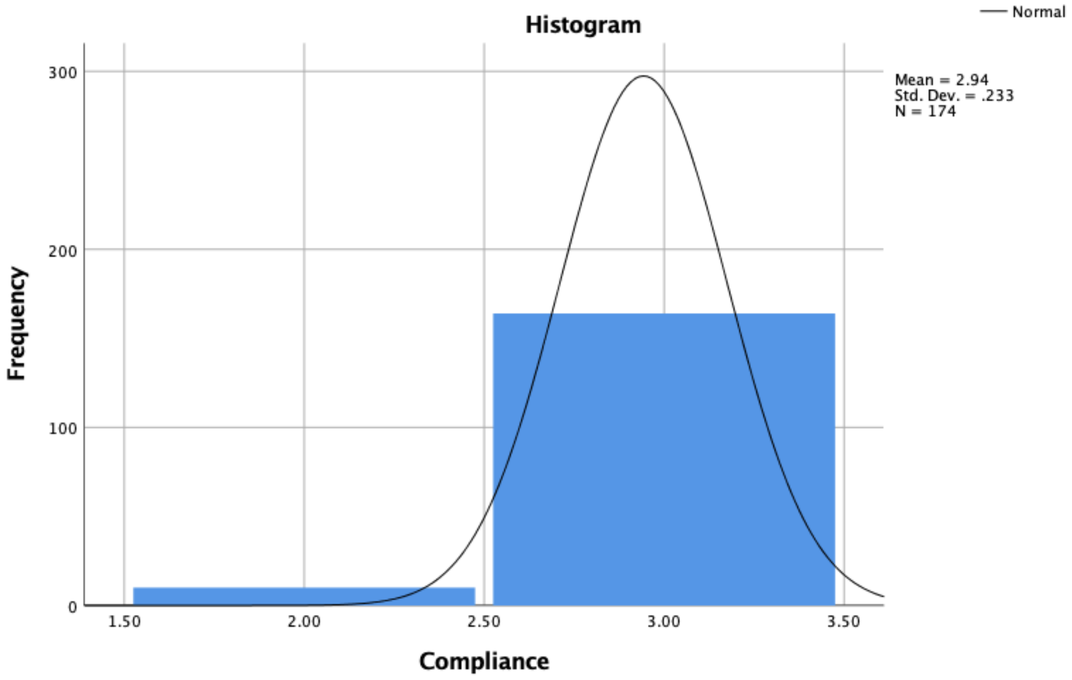
HISTOGRAM OF THE FACTOR HEALTH PROMOTION OF THE HLS-EU-Q16



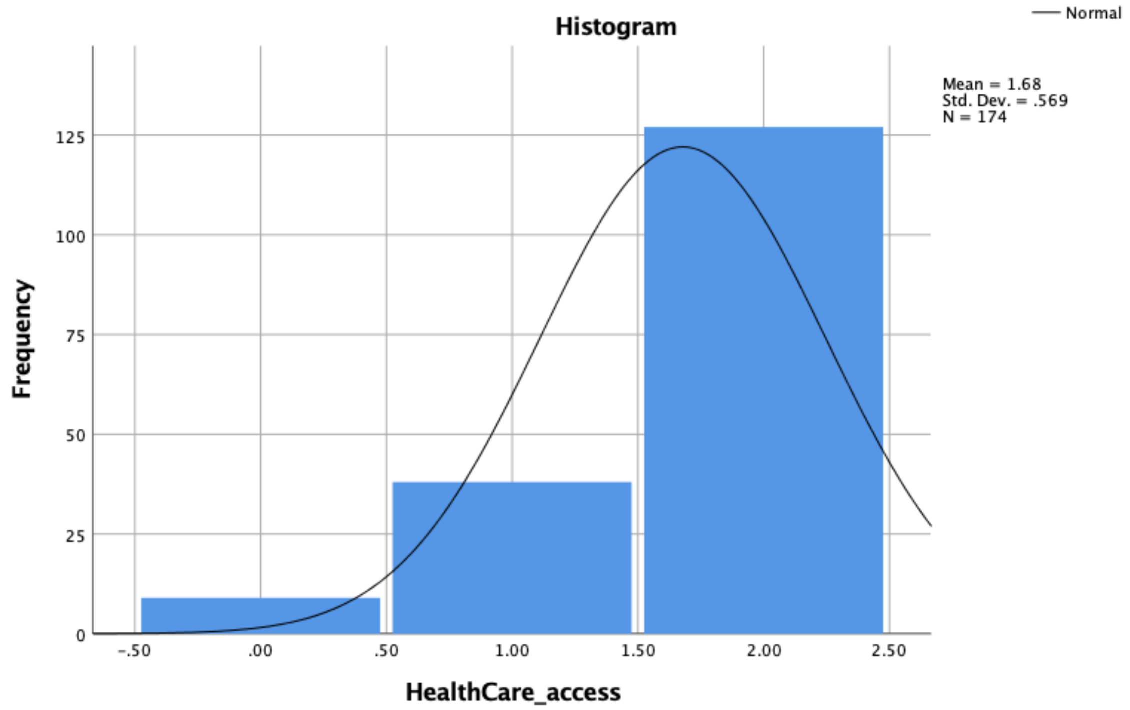
HISTOGRAM OF THE FACTOR MEDIA LITERACY OF THE HLS-EU-Q16



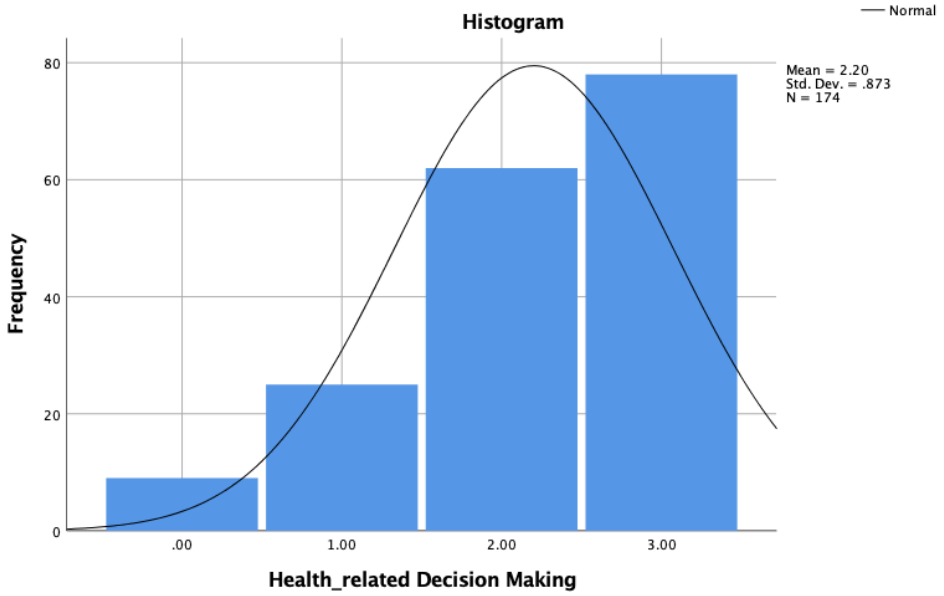
HISTOGRAM OF THE FACTOR COMPLIANCE WITH THE DOCTOR OF THE HLS-EU-Q16



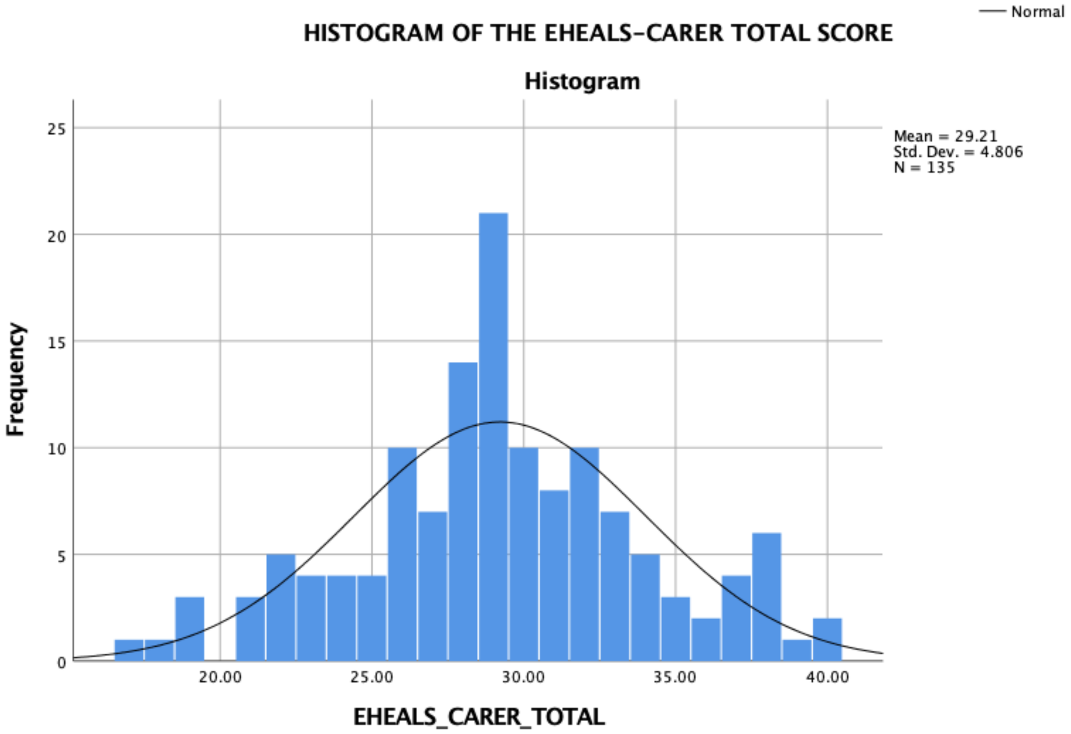
HISTOGRAM OF THE FACTOR HEALTHCARE-ACCESS OF THE HLS-EU-Q16



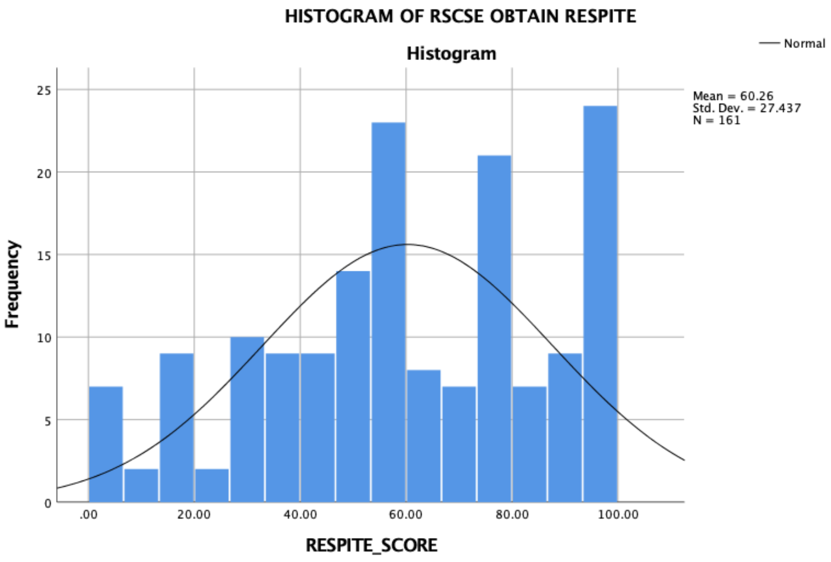
HISTOGRAM OF THE FACTOR HEALTH-RELATED DECISION MAKING OF THE HLS-EU-Q16



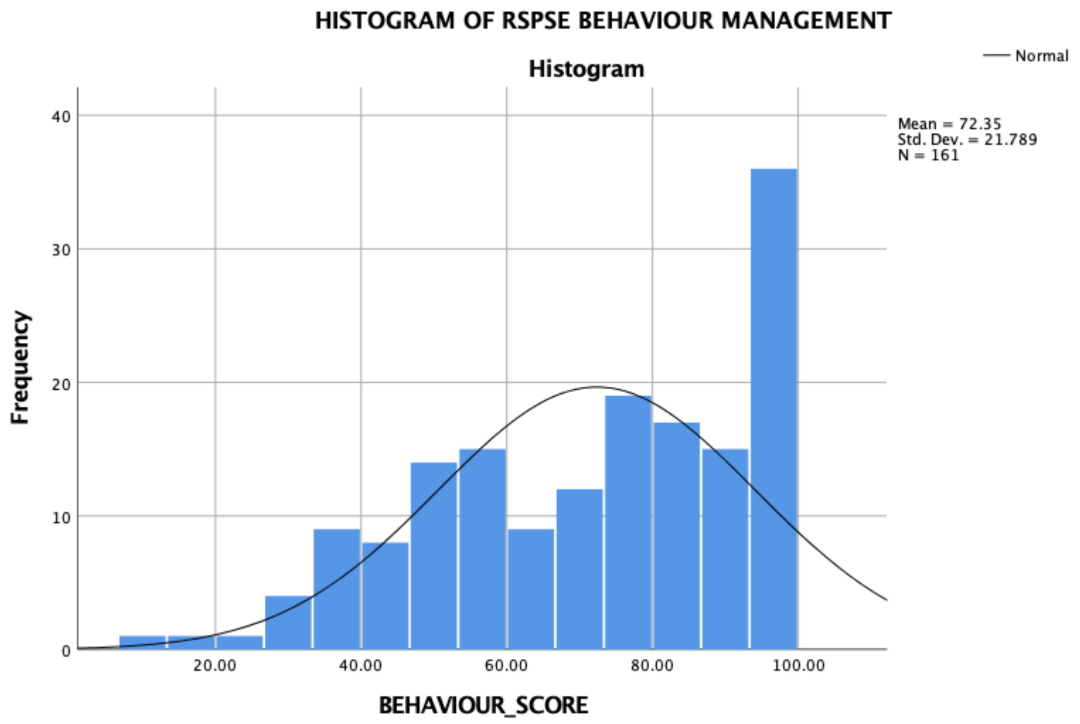
2. *eHeals-Carer*



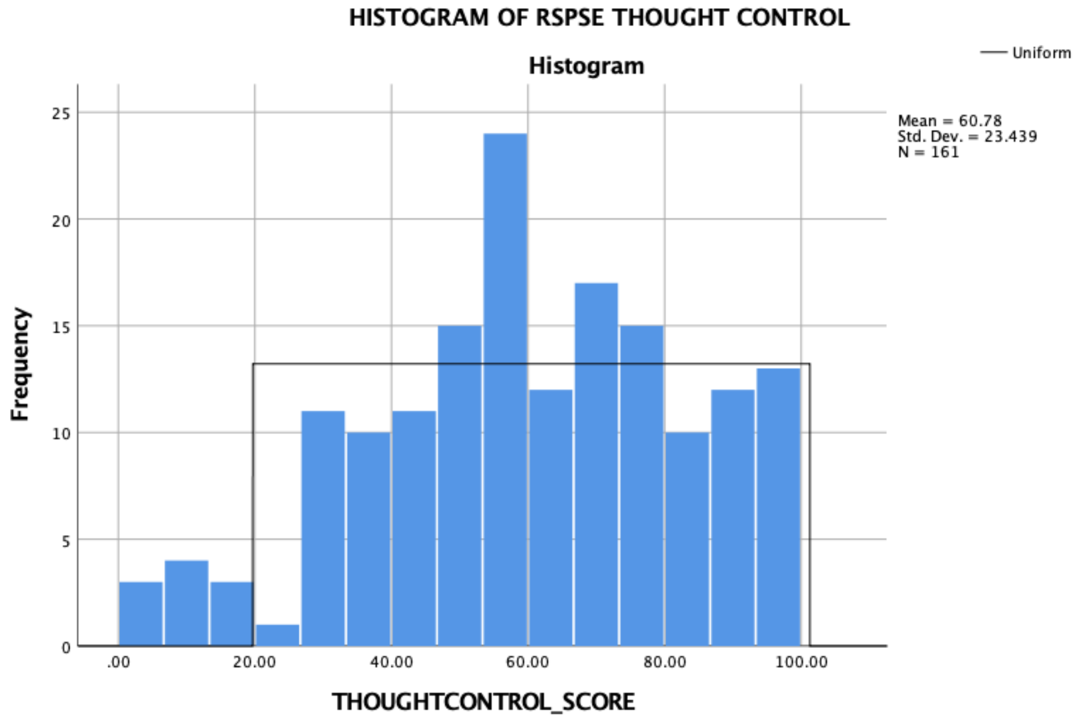
3. *Self-Efficacy Obtain Respite*



4. *Self-Efficacy Behaviour Management*



5. *Self-Efficacy Thought Control*



XI. APPENDIX

A. Post- Hoc Comparisons

Table XI-1 Multiple comparisons Bonferroni with dependent variable HLS-EU-Q16

(I)Primary carers occupation (I)	Primary carer's occupation (J)	Mean difference (I-J)	Std. Error	p-value
Employed	Unemployed	.36	.38	1.000
	Pensioner	.91	.34	.023
Unemployed	Employed	-.36	.39	1.000
	Pensioner	.55	36	.371
Pensioner	Employed	-.91	.34	.023
	Unemployed	-.55	.36	.371

Table XI-2 Multiple comparisons Bonferroni with dependent variable HLS-EU-Q16

(I)Primary carers relationship (I)	Primery carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	.86	.30	.015
	Other	.07	.48	1.000
Spouse	Child	-86	.30	.015
	Other	-.80	.48	.302
Other	Child	-.07	.30	1.000
	Spouse	.80	.48	.302

Table XI-3 Multiple comparisons Bonferroni with dependent variable Media Literacy

(I)Primary carers occupation (I)	Primary carer's occupation (J)	Mean difference (I-J)	Std.Error	p-value
Employed	Unemployed	.35	.18	.150
	Pensioner	.36	.15	.061
Unemployed	Employed	-.35	.18	.150
	Pensioner	.01	.16	1.000
Pensioner	Employed	-.36	.15	.061
	Unemployed	-.013	.16	1.000

Table XI-4 . Multiple comparisons Bonferroni with dependent variable Media Literacy

(I)Primary carers relationship (I)	Primary carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	.46	.13571	.002
	Other	.48	.21512	.083
Spouse	Child	-.46	. 13571	.002
	Other	.02	.21704	1.000
Other	Child	-.48	.21512	.083
	Spouse	- . 02	. 21704	1.000

Table XI-5 Multiple comparisons Bonferroni with dependent variable eHeals-Carer Total

(I)Primary carers occupation (I)	Primary carer's occupation (J)	Mean difference (I-J)	Std.Error	p-value
Employed	Unemployed	-.23	1.07	1.000
	Pensioner	2.10	.93	.078
Unemployed	Employed	.23	1.07	1.000
	Pensioner	2.33	1.06	.087
Pensioner	Employed	-2.10	.93	.078
	Unemployed	-2.33	1.06	.087

Table XI-6 Multiple comparisons Bonferroni with dependent variable eHeals-Carer1

(I)Primary carers occupation (I)	Primary carer's occupation (J)	Mean difference (I-J)	Std.Error	p-value
Employed	Unemployed	.30	.72	1.000
	Pensioner	1.68	.62	.023
Unemployed	Employed	-.30	.72	1.000
	Pensioner	1.39	.71	.157
Pensioner	Employed	-2.68	.62	.023
	Unemployed	-1.39	.71	.157

Table XI-7 Multiple comparisons Bonferroni with dependent variable eHeals-Carer total

(I)Primary carers relationship (I)	Primary carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	2.12	.89	.056
	Other	2.25	1.3	.257
Spouse	Child	-2.12	.89	.056
	Other	.13	1.37	1.000
Other	Child	-2.25	1.3	.257
	Spouse	-.13	1.37	1.000

Table XI-8 Multiple comparisons Bonferroni with dependent variable eHeals-Carer1

(I)Primary carers relationship (I)	Primary carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	1.36	.60	.077
	Other	1.33	.88	.392
Spouse	Child	-1.36	. 60	.077
	Other	-.03	.93	1.000
Other	Child	1.33	.88	.392
	Spouse	- . 03	. 93	1.000

Table XI-9 Multiple comparisons Bonferroni with dependent variable eHeals-Care1

(I)Age groups (I)	Age groups (J)	Mean difference (I-J)	Std.Error	p-value
<54	55-74	.75	.57	.568
	75+	3.04	1.03	.012
55-74	<54	-.75	.57	.568
	75+	2.29	1.03	.082
75+	<54	-3.04	1.03	.012
	55-74	-2.29	1.03	.082

Table XI-10 Multiple comparisons Bonferroni with dependent variable Perceived caregiving self-efficacy-Behaviour management

(I)Primary carers occupation (I)	Primery carer's occupation (J)	Mean difference (I-J)	Std.Error	p-value
Employed	Unemployed	12.87	4.34	.011
	Pensioner	14.41	3.85	.001
Unemployed	Employed	-.12.87	4.34	.011
	Pensioner	1.56	4.03	1.000
Pensioner	Employed	-.14.41	3.85	.001
	Unemployed	-1.56	4.03	1.000

Table XI-11 Multiple comparisons Bonferroni with dependent variable Perceived caregiving self-efficacy-Thought Control management

(I)Primary carers occupation (I)	Primery carer's occupation (J)	Mean difference (I-J)	Std.Error	p-value
Employed	Unemployed	14.30	4.6	.007
	Pensioner	7.77	4.03	.167
Unemployed	Employed	-.14.30	4.34	.007
	Pensioner	-6.54	4.26	.382
Pensioner	Employed	-.7.77	4.03	.167
	Unemployed	-6.54	4.26	.382

Table XI-12 Multiple comparisons Bonferroni with dependent variable Perceived caregiving self-efficacy-Behaviour management

(I)Primary carers relationship (I)	Primary carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	4.58	3.48	.572
	Other	-12.88	6	.100
Spouse	Child	-4.58	3.48	.572
	Other	-17.46*	6.05	.013
Other	Child	12.88	6	.100
	Spouse	17.46*	6.05	.013

Table XI-13 Multiple comparisons Bonferroni with dependent variable MSPSS Family

(I)Primary carers relationship (I)	Primary carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	-.70391*	.22	.006
	Other	.07294	.36	1.000
Spouse	Child	.70391*	.22	.006
	Other	.77685	.36	.094
Other	Child	-.07294	.35	1.000
	Spouse	-.77685	.36	.094

Table XI-14 Multiple comparisons Bonferroni with dependent variable MSPSS friends

(I)Primary carers relationship (I)	Primery carer's relationship(J)	Mean difference (I-J)	Std.Error	p-value
Child	Spouse	.48	.22	.089
	Other	-.22	.35	1.000
Spouse	Child	-.48	.22	.089
	Other	-.70	.35	.144
Other	Child	.22	.35	1.000
	Spouse	.70	.35	.144

Table XI-15 Multiple comparisons Bonferroni with dependent variable MSPSS friends

(I)Age groups (I)	Age groups (J)	Mean difference (I-J)	Std.Error	p-value
<54	55-74	.35	.22	.343
	75+	1.37	.30	<.001
55-74	<54	-.35	.22	.343
	75+	1.02	.29	.002
75+	<54	-1.37	.30	<.001
	55-74	-1.02	.29	.002

Table XI-16 Multiple comparisons Bonferroni with dependent variable eHeals-Carer

	(I)Cluster types (I)	Cluster types (J)	Mean difference (I-J)	Std. Error	p-value
eHeals Total	High HL and SE	Problematic Copers	4.14	1.05	<.001
		Strong Social network	-.31	.94	1.000
	Problematic Copers	High HL and SE	-4.14	1.05	<.001
		Strong Social network	-4.45	1.04	<.001

	Strong Social network	High HL and SE	.31	.95	1.000
		Problematic Copers	4.45	1.04	<.001

Table XI-17 Multiple comparisons Bonferroni with dependent variable perceived Self Efficacy

	(I)Cluster types (I)	Cluster types (J)	Mean difference (I-J)	Std. Error	p-value
SE-Obtain Respte	High HL and SE	Problematic Copers	17.87	5.97	.010
		Strong Social network	-5.82	5.39	.846
	Problematic Copers	High HL and SE	-17.87	5.97	.010
		Strong Social network	-23.70	5.92	<.001
	Strong Social network	High HL and SE	5.82	5.38	.846
		Problematic Copers	23.70	5.92	<.001
SE-Behaviour Management	High HL and SE	Problematic Copers	25.60	4.21	<.001
		Strong Social network	4.60	3.79	.684
	Problematic Copers	High HL and SE	-25.60	4.21	<.001
		Strong Social network	-21	4.17	<.001
	Strong Social network	High HL and SE	-4.60	3.79	.684
		Problematic Copers	21	4.17	<.001
SE-Thought Control	High HL and SE	Problematic Copers	22.19	4.67	<.001
		Strong Social network	10.16	4.20	.052
	Problematic Copers	High HL and SE	-22.19	4.67	<.001
		Strong Social network	-12.03	4.62	.031
	Strong Social network	High HL and SE	-10.16	4.20	.052
		Problematic Copers	12.03	4.62	.031

Table XI-18 Multiple comparisons Bonferroni with dependent variable Coping strategies

	(I)Cluster types (I)	Cluster types (J)	Mean difference (I-J)	Std. Error	p-value
Active Coping	High HL and SE	Problematic Copers	-.88	.93	1.000
		Strong Social network	-3.57	.84	<.001
	Problematic Copers	High HL and SE	.88	.93	1.000
		Strong Social network	-2.69	.93	.013
	Strong Social network	High HL and SE	3.57	.84	<.001
		Problematic Copers	2.69	.93	.013
Emotion-focused	High HL and SE	Problematic Copers	-2.30	1.08	.103
		Strong Social network	-8.58	.97	<.001
	Problematic Copers	High HL and SE	2.30	1.08	.103
		Strong Social network	-6.28	1.07	<.001
	Strong Social network	High HL and SE	8.58	.97	<.001
		Problematic Copers	6.28	1.07	<.001
Problematic Coping	High HL and SE	Problematic Copers	-3.97	.50	<.001
		Strong Social network	-1.16	.49	.033
	Problematic Copers	High HL and SE	3.97	.50	<.001
		Strong Social network	2.81	.50	<.001
	Strong Social network	High HL and SE	1.15	.45	.033
		Problematic Copers	-2.81	.50	<.001

Table XI-19 Multiple comparisons Benforroni with dependent variable COPE index

	(I)Cluster types (I)	Cluster types (J)	Mean difference (I-J)	Std. Error	p-value
COPE positive	High HL and SE	Problematic Copers	1.20	.40	.009
		Strong Social network	-.59	.36	.317
	Problematic Copers	High HL and SE	-1.20	.40	.009
		Strong Social network	-1.79	.39	<.001
	Strong Social network	High HL and SE	.59	.36	.317
		Problematic Copers	1.79	.39	<.001
COPE negative	High HL and SE	Problematic Copers	-3.00	1.00	.011
		Strong Social network	-2.26	.91	.042
	Problematic Copers	High HL and SE	3.00	1.00	.011
		Strong Social network	.74	.99	1.000
	Strong Social network	High HL and SE	2.26	.91	.042
		Problematic Copers	-.74	.99	1.000
Quality of Support	High HL and SE	Problematic Copers	1.80	.48	.001
		Strong Social network	-1.75	.43	<.001
	Problematic Copers	High HL and SE	-1.80	.48	.001
		Strong Social network	-3.55	.48	<.001
	Strong Social network	High HL and SE	1.75	.43	<.001
		Problematic Copers	3.55	.48	<.001

Table XI-20 Multiple comparisons Bonferroni with dependent variable MSPSS

	(I)Cluster types (I)	Cluster types (J)	Mean difference (I-J)	Std. Error	p-value
MSPSS SO	High HL and SE	Problematic Copers	.45	.22	.122
		Strong Social network	-1,19	.20	<.001
	Problematic Copers	High HL and SE	-.45	.22	.122
		Strong Social network	-1.64	.22	<.001
	Strong Social network	High HL and SE	1.19	.20	<.001
		Problematic Copers	1.64	.22	<.001
MSPSS FA	High HL and SE	Problematic Copers	.63	.28	.083
		Strong Social network	-.73	.26	.015
	Problematic Copers	High HL and SE	-.63	.28	.083
		Strong Social network	-1.37	.28	<.001
	Strong Social network	High HL and SE	.73	.26	.015
		Problematic Copers	1.37	.28	<.001
MSPSS FR	High HL and SE	Problematic Copers	.15	.21	1.000
		Strong Social network	-1.32	.19	<.001
	Problematic Copers	High HL and SE	-.15	.21	1.000
		Strong Social network	-1.47	.21	<.001
	Strong Social network	High HL and SE	1.32	.19	<.001
		Problematic Copers	1.47	.19	<.001
MSPSS TOTAL	High HL and SE	Problematic Copers	4.23	2.18	.162
		Strong Social network	-13.64	1.96	<.001
	Problematic Copers	High HL and SE	-4.23	2.18	.162
		Strong Social network	-17.87	2.16	<.001

	Strong Social network	High HL and SE	13.64	1.96	<.001
		Problematic Copers	17.86	2.16	<.001

Table XI-21Multiple comparisons Bonferroni with dependent variable eHeals

	(I)HLS-EU-Q16 (I)	HLS-EU-Q16 (J)	Mean difference (I-J)	Std.Error	p-value
eHeals Total	<12	13-14	-1.86	1.08	.264
		>15	-4.36*	1.08	>.001
	13-14	<12	1.86	1.08	.264
		>15	-2.5*	.87	.014
	>15	<12	4.36*	1.08	>.001
		13-14	2.5	.87	.014
eHeals 1	<12	13-14	-.79	.76	.903
		>15	-1.88*	.76	.043
	13-14	<12	.79	.76	.903
		>15	-.1.08	.60	.226
	>15	<12	1.88*	.76	.043
		13-14	1.08	.60	.226
eHeals 2	<12	13-14	-.99	.54	.208
		>15	-2.42*	.54	>.001
	13-14	<12	.99	.54	.208
		>15	-1.43*	.43	.004
	>15	<12	2.42*	.54	>.001
		13-14	1.43*	.43	.004

Table XI-22 Multiple comparisons Bonferroni with dependent variable emotion-focused coping strategies

	(I)Type of internet use (I)	Type of internet use (J)	Mean difference (I-J)	Std.Error	p-value
Emotion-focused coping strategies	Socialising	Emails	4.70	1.93	.166
		Entertainment	5.43	1.90	.050
		Information Search	2.24	1.46	1.000
		Professional reasons	2.55	1.93	1.000

XII. APPENDIX

A. Associations of the caregiving variables

Table XII-1 Correlations among Caregiving variables

	SO	FA	FR	MSPSS TOT	SE-OR	SE-BM	SE-TC	COPE POS	COPE NEG	QOS	PF	EF	PROB
SE-OR	.29**	.35**	.25**	.38**	1								
SE-BM	.08	.04	.00	.04		1							
SE-TC	-.04	-.11	-.14	-.11			1						
COPE POS	.32**	.21**	.16*	.27**	.00	.24**	.20**	1					
COPE NEG	-.13	-.15	.08	-.08	-.27**	-.22**	-.33**		1				
QOS	.53**	.56**	.41**	.62**	.34**	.09	-.08			1			
PF	.14*	-.04	.07	.09	-.08	.11	.17	.20*	-.134	.114	1		
EF	.33**	.18*	.21*	.32**	.09	-.09	-.17	.10	.166*	.272**		1	
PROBL	-.20**	-.18	-.09	-.19	-.09	-.25**	-.26**	-.23**	.200**	.223**			1

XIII. APPENDIX

A. Associations of the caregiving variables among children

1. *Demographic characteristics*

Table XIII-1 Mean differences of the total score of HLS-EU-Q16 among carers characteristics

		HLS-EU-Q16	
Variables	**Categories**	**Mean (SD)**	**P-value**
Gender	Male	14.2 (2.19)	.632
	Female	13.97 (1.77)	
Age	<60	14.15 (1.93)	.319
	>60	13.68(1.67)	
Education	<12	14.48(1.44)	.172
	>12	13.85(1.99)	
Marital	Single_divorced_ widowed	13.90(2.07)	.561
	Married or cohabitation	14.14(1.66)	
Occupation	Employed	14.19(1.82)	.083
	Unemployed	13.27(1.94)	
Hours of care	1-70	14.25(1.84)	.134
	71-168	13.61(1.89)	
Reporting Secondary carer	No	14.07(1.94)	.923
	Yes	14.01(1.86)	
Internet Use	No	14.25(1.38)	.721
	Yes	14(1.91)	
Years of Care	< 3 years	13.97(1.81)	.805
	>3 years	14.08(1.96)	
Ladder	<6	13.89(1.96)	.360
	>6	14.3(1.66)	

Table XIII-2 eHeals-Carers means scores among carers' characteristics

Variable	**Categories**	**Mean eHeals total (SD)**	**p**
Gender	Male	31 (4.47)	.322
	Female	29.81(.60)	
Age	<60 years	30.22 (4.37)	.682
	>60 years	29.71 (5.01)	
Education	Less that 12 years	28.59 (3.67)	.116
	More that 12 years	30.54 (4.66)	
Marital	Single_Divorced_Widowed_Other	30.38(4.62)	.583
	Married_Cohabitating	29.81(4.44)	

Occupational Status	Unemployed_employed_housekeeping-student	30.7(4.52)	**.016**
	Pensioner	27.5(3.5)	
Caring for others	No	30.2(4.82)	.833
	Yes	30.25(4.02)	
Reporting secondary carer	No	29.87(4.22)	.821
	Yes	230.16(4.61)	

Table XIII-3HLS-EU-Q16, eHeals association with Revised scale of Perceived Caregiving Self-efficacy among carers caring for their parents

PRIMARY	**HLS-EU-Q16**	**eHeals-Carer**	**eHeals 1**	**eHeals 2**	**SE-OR**	**SE-BM**	**SE-TC**
HLS-EU-Q16	**1**						
eHeals-Carer	.37**	1					
eHeals 1	.27*	.86**	1				
eHeals 2	.39**	.78**	.40**	1			
SE-OR	.13	.12	.21	-.02	1		
SE-BM	.22	.11	.08	.14	.27*	1	
SE-TC	.18	.20	.14	.20	-.03	.24*	1

Table XIII-4 HLS-EU-Q16, eHeals association with BRIEF COPE among carers caring for their parents

PRIMARY	**HLS-EU-Q16**	**eHeals-Carer**	**eHeals 1**	**eHeals 2**	**ACTIVE COPING**	**EMOTION-FOCUSED**	**PROBLEMATIC COPING**
ACTIVE COPING	.08	-.11	-.07	-.13	1		
EMOTION-FOCUSED	.20	.15	.23	.01	.46**	1	
PROBLEMATIC COPING	-.26*	-.22	-.18	-.22	-.	.05	1

Table XIII-5 HLS-EU-Q16, eHeals association with COPE index among carers caring for their parents

PRIMARY	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	COPE POSITIVE	COPE NEGATIVE	QUALITY OF SUPPORT
COPE POSITIVE	.21	.11	.15	.11	1		
COPE NEGATIVE	-.24*	-.00	.04	-.03	-.06	1	
QUALITY OF SUPPORT	.27*	.10	.06	-.03	.31**	-.16	1

Table XIII-6 HLS-EU-Q16, eHeals association with MSPSS among carers caring for their parents

	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	MSPSS SO	MSPSS FA	MSPSS FR	MSPSS TOT
MSPSS SO	.26*	.17	.19	.08	1			
MSPSS FA	.19*	.01	. .02	.01	.65**	1		
MSPSS FR	.17	.13	.26	-.02	.60**	.26	1	
MSPSS TOT	.23*	.10	.13	.03	.89**	.80**	.71**	1

Table XIII-7 Association of MSPSS, Revised scale of Perceived Caregiving Self-efficacy, COPE index and COPE BRIEF among carers caring for their parents

	SO	FA	FR	MSPSS TOT	SE-OR	SE-BM	SE-TC	COPE POS	COPE NEG	QOS	PF	EF	PROB
SE-OR	.39**	.47**	.28*	46**	1								
SE-BM	.31**	.35**	-.11	-.35**		1							
SE-TC	-.03	-.04	-.18	-.09			1						
COPE POS	.35**	.17	.32**	.36**	-.18	.26*	.28*	1					
COPE NEG	-.03	-.25*	-.07	-.12	-.28*	-.23*	-.31**		1				
QOS	.64**	.56**	.61**	.73**	.39**	.25*	-.10			1			
PF	.10	-.06	.17	.09	-.14	.05	.18	.29**	-.06	-.01	1		
EF	.34**	-.07	.33**	.31**	.06	-.10	-.12	.21	.22*	.18		1	
PROBL	-.38**	-.34**	-.27*	-.39**	-.15	-.36*	-.21	-.31**	.17	-.30**			1

XIV. APPENDIX

A. Associations of the caregiving variables among spouses

1. *Demographic characteristics*

Table XIV-1 Mean differences of the total score of HLS-EU-Q16 and sociodemographic variables

		HLS-EU-Q16	
Variables	Categories	Mean (SD)	P-value
Gender	Male	12.85 (2.08)	.430
	Female	13.26 (1.95)	
Age	<60	12.3(2.95)	.146
	>60	13.29(1.78)	
Education	<12	13.02(1.97)	.472
	>12	13.37(2.02)	
Occupation	Employed	13.1(2.02)	.894
	Unemployed	13.17(1.99)	
Hours of care	1-70	13.21(1.92)	.134
	71-168	13.11(2.05)	
Reporting Secondary carer	No	12.86(2.31)	.426
	Yes	13.27(1.84)	
Internet Use	No	12.61(1.99)	.064
	Yes	13.49(1.93)	
Years of Care	< 3 years	13.48(1.87)	.167
	>3 years	12.84(2)	
Ladder	<6	13.13(1.96)	.897
	>6	13.2(2.09)	

Table XIV-2 eHeals-Carers means scores in variables groups

Variable	**Categories**	**Mean eHeals total (SD)**	**p**
Gender	Male	26.93 (4.62)	.292
	Female	28.67(5.2)	
Age	<60 years	28.25 (4.3)	.934
	>60 years	28.08 (5.24)	
Education	Less that 12 years	27.78 (4.19)	.717
	More that 12 years	28.35 (5.61)	
Occupational Status	Unemployed_employed_housekeeping-student	27.55(4.11)	.671
	Pensioner	28.3(5.35)	
Caring for others	No	28.11(3.96)	.997

	Yes	28.12(6.53)	
Reporting secondary carer	No	25.38(5.39)	.018
	Yes	29.26(4.49)	

Table XIV-3 HLS-EU-Q16, eHeals association with Revised scale of Perceived Caregiving Self-efficacy among carers caring for their spouses

PRIMARY	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	SE-OR	SE-BM	SE-TC
HLS-EU-Q16	**1**						
eHeals-Carer	.40**	1					
eHeals 1	.27	.87**	1				
eHeals 2	.36**	.70**	.37**	1			
SE-OR	.22	.27	.07	.34*	1		
SE-BM	.33*	.14	.18	.15	.16	1	
SE-TC	.23	.05	.07	-.07	-.24*	.29*	1

Table XIV-4 HLS-EU-Q16, eHeals association with BRIEF COPE among carers caring for their spouses

primary	HLS-EU-Q16	eheals-carer	eheals 1	eheals 2	active coping	emotion-focused	problematic coping
active coping	-.05	.28	.32*	.11	1		
emotion-focused	-.09	.23	.15	.26	.26*	1	
problematic coping	-.31*	-.05	-.03	-.10	-.27*	.16	1

Table XIV-5 HLS-EU-Q16, eHeals association with COPE index among carers caring for their spouses

PRIMARY	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	COPE POSITIVE	COPE NEGATIVE	QUALITY OF SUPPORT
COPE POSITIVE	.11	.29	.37*	.27	1		
COPE NEGATIVE	-.19	.7	.7	.12	-.18	1	
QUALITY OF SUPPORT	-.03	.25	.21	.21	.29*	-.15	1

Table XIV-6 HLS-EU-Q16, eHeals association with MSPSS among carers caring for their spouses

	HLS-EU-Q16	eHeals-Carer	eHeals 1	eHeals 2	MSPSS SO	MSPSS FA	MSPSS FR	MSPSS TOT
MSPSS SO	-.04	.03	.03	.02	1			
MSPSS FA	-.03	.13	.10	.12	.68**	1		
MSPSS FR	.02	.01	-.05	.02	.45**	.48*	1	
MSPSS TOT	-.06	.13	.08	.10	.82**	.82**	.76**	1

Table XIV-7 Association of MSPSS, Revised scale of Perceived Caregiving Self-efficacy, COPE index and COPE BRIEF among carers caring for their spouses

	SO	FA	FR	MSPSS TOT	SE-OR	SE-BM	SE-TC	COPE POS	COPE NEG	QOS	PF	EF	PROB
SE-OR	.234	.32**	.23*	.36**	1								
SE-BM	-.17	-.13	-.15	-.20		1							
SE-TC	-.13	-.20	-.14	-.16			1						
COPE POS	.24*	.26*	.10	.19	-.13	.24*	.04	1					
COPE NEG	-.16	-.01	-.11	-.00	-.30*	-.18	-.33*		1				
QOS	.43**	.55**	.42**	.53**	.33**	.01	-.15			1			
PF	.14	.05	.03	.10	.04	.16	.06	.12	-.24*	.23*	1		
EF	.32**	.23*	.26*	.36**	.13	-.17	-.24*	.03	.20	.36**		1	
PROBL	-.02	-.07	-.03	-.02	-.08	-.13	-.26*	-.14	.24*	-.16			1

XV. APPENDIX

A. References of the appendices

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