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Development of the ELDICARE Psychometric Tool for Atypical Caregivers of the Elderly

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Abstract

In order to ensure mental skills for the provision of demanding care services to ageing population we established a psychometric tool for elderly care providers weighted and tested in Greece, Germany, Spain and the UK. The Psychometric Tool is part of the accreditation process of the European project "Eldicare: Matching Skills in a growing European Silver Economy", Project Ref: 601115–EPP–1–2018–EL–EPPKA2–SSA. For the purposes of the research, we interviewed 73 participants in the aforementioned countries and we gathered a sample of 160 responses for the statistical analysis of the tool. The research resulted in the development of a psychometric tool for atypical caregivers of the elderly, consisting of 27 items and examining the following categories: Burden, Empathy, Anxiety, Professionalism and Coping.

Introduction

Caregivers have a major role in the care of elderly, children and disabled patients either in institutional or residential setting. They provide their services not only for assisting them in the medical part of their lives, but also for enhancing the quality of their life.

According to data provided by the European Commission regarding Health Systems (2016) up to 2050 there will be a rise in the elder population in Europe by 37%, with an increase of the total European population by 1.6%. Consequently, there will be a simultaneous rise in the employment of care workers/caregivers due to the decrease of the family members to provide their services to relatives without payment.

Therefore, the need for the development of a psychometric tool focusing on certain areas emerges, as it can ensure the provision of high quality services to the elderly and the protection of the mental health of caregivers.

Research suggests that self-assessment questionnaires are a valid option, even if they have their own limitations such as exaggeration of the participants in some answers (Northrup, 1996) or answering what they believe will enable them to receive some services they desire (Heppner, 2016). However, since atypical and informal caregivers are hard to be reached, having an open self-assessment psychometric tool is the most viable option for those that might need support in caring for others.

Considering the above, it is important to note that for the design of a new psychometric tool it was considered necessary to make a consolidation of all existing validated and non-validated tools. However, focus was given on validated tools in order to examine specific areas of interest (personal information, medical record evaluation, psychological evaluation, work environment evaluation), as they have already a proven record and validity.

The methodology that was selected consisted of semi- structured interviews with the target group and experts, in order to explore their opinion on general themes surrounding the focus areas of the psychometric tool, the administration of the draft version of the psychometric tool to selected participants, the pilot implementation of the psychometric tool in 4 healthcare facilities and lastly the online sample collection for the statistical analysis of the psychometric tool.

Literature Review

As important and dutiful the role of the caregiver may seem, it comes with a price. Studies have shown that tending to the elderly puts an individual in heightened risk for several problems including mental health problems, health problems, functional impairment, secondary strains, care decisions, family difficulties and challenges, advocacy for care, and eligibility for services. Furthermore, a study of the American Medical Association in 1999 proved that caregiving could be an independent risk factor for mortality (Schulz & Beach, 1999).

Sufficient support for the caregivers, however, can improve their quality of life and alleviate those effects (Christakis & Iwashyna, 2003; Rossi, Ferrario et al., 2004). It is evident therefore, that assessing the caregivers' needs beforehand will help them substantially, not only in providing care but in taking care for themselves as well, before they end up being

On the other hand, as most kinds of interactions, caregiving is a give-and-take kind of relationship, meaning that the caregivers also take something back in return. That is usually satisfaction for the care they provide (Andren & Elmstahl, 2005) and a feeling of motivation that is found to give further meaning in their lives (Quinn et al., 2010), both of which should be taken into account when assessing their needs (Rapp & Chao, 2000).

Based on the preceding analysis, it is evident that the vast majority of home caregivers, and especially the atypical and informal ones, are in great risk of developing a number of health-related problems. The most prominent ones have to do with their emotional well-being, their physical capabilities, and the possibility of suffering from atypical work burnout and finally their mental health status.

However, there are no specialized psychometric tools that could be used in order to trace the psychological traits, the professional attitude and the possible burden atypical and informal caregivers are facing.

During the literature review we examined validated and non-validated psychometric tools related to healthcare professionals and caregivers.

Issue faced by caregiver	Name of psychometric test
Stress	BAI, PSS
Depression	BDI-II, CASQ
Work burnout	CBI, CWIA
Competence/Self-worth	COPE, CSNAT, ACS, BI, CB, CRA, CCI, FCCI
	1 · · · · · · · · · · · · · · · · · · ·

The following tools were examined:

Table 1: Psychometric tools evaluated during the literature review

The research identified 17 focus areas of interest that the psychometric tool could focus and 143 items (questions) that could become part of the psychometric tool.

Moreover, research suggested that self-assessment questionnaires are a valid option, even if they have their own limitations such as exaggeration of the participants in some answers (Northrup, 1996) or answering what they believe will enable them to receive some services they desire (Heppner, 2016). However, since atypical and informal caregivers are hard to be reached, having an open self-assessment psychometric tool was deemed as the most viable option for those that might need support in caring for others.

Methodology

For the development of the Psychometric Tool the following steps, as described below were implemented.

Field Research

Field research consisted of 41 semi constructed interviews with caregivers and managers in elderly care facilities in Greece, the UK, Germany and Spain.

The 41 participants represented a range of perspectives and professional experience related to elderly caregivers. The structure of the participants is the following:

Professional Experience	Number of interviewees
Management of healthcare facilities	15
Nursing	21
Social Workers working with caregivers & patients	3
Other healthcare workers (doctors & psychologists)	2
Total	41

Table 2: Professional structure of the field research participants

The aim of the field research was to confirm the findings of the desk research and identify the main areas of focus for the psychometric tool.

Participants identified the following focus areas for the development of the psychometric tool:

- > personality traits
- coping with stressors and life difficulties
- empathy and other personality characteristics
- ➢ education

- ➢ self-esteem, self-evaluation
- current physical & cognitive abilities
- social involvement
- burden (in personal and social life)

Moreover, the majority indicated that the psychometric tool should be on average approximately 30 questions (items) long and should be able to be a complementary part of the recruitment and evaluation process.

Based on the information provided during the interview, the research team created a psychometric tool of 52 items, which was then tested to a smaller sample of interviewees.

Face Validity Interviews

The first draft of the psychometric tool was administered to 20 participants, experienced caregivers, healthcare and social professionals working with the elderly from Greece, the UK, Spain and Germany. The structure of the psychometric tool was 52 questions in a 5-point Likert scale and about 30 minutes were given to each participant to fill it in.

The structure of the participants is the following:

Professional Experience	Number of interviewees
Caregiving	15
Social Workers working with caregivers patients	& 3
Other healthcare workers (doctors psychologists)	& 2
Total	20

Table 3: Professional structure of the face validity interviewees

Upon the completion of the draft psychometric tool, participants were interviewed in a semistructured interview. The aim of the interviews was to establish whether the target group of the psychometric tool understands the questions, their meaning and their importance. Moreover, we aimed at identifying mistakes regarding the grammar, the syntax in each language and the content.

Participants found that the structure of the tool was clear, simple and understandable. The 5point Likert scale used in the tool was commented as easy to navigate and the number of items in the tool as adequate. Participants, also, stated that they understood what the psychometric tool measures and its importance. Most of the original categories in the tool were identified by the participants.

The suggestions that were made in order to provide more clarity in the tool were adopted, in order to make the questions more understandable.

Changes were incorporated to the tool to provide us with the second version of 48 items, which was then tested with experts and the reference group of the tool.

Content Validity with Sector Experts/ Managers

The pilot testing involved 7 caregivers and 4 managers from Greece, the UK, Spain and Germany. The pilot test took place in 4 caregiving facilities, one in each participating country.

In each caregiving facility caregivers were requested to fill in a sample of the psychometric tool. Their results were introduced to the managers of the facilities. The managers at the beginning of the survey had to respond to questions regarding the precision of the results. On the second part of the survey, they were asked to rate each item on the psychometric tool as "Essential", "Important, but not essential" and "Not necessary".

Questions that were rated as "Not necessary" were withdrawn from the psychometric tool.

This evaluation step led to the reduction of the tool to 34 questions.

As far as the importance of the tool is concerned, managers replied that the tool is close to reality in terms of the results it provided and that it is a useful tool to be used in staff evaluation and as a complementary tool for the recruitment process.

Managers noted that the tool could be used to provide a discussion foundation for one-toone meetings with the staff in their organizations.

Data Collection & Statistical Analysis

For the data collection we used the LimeSurvey platform. This platform was chosen as it supports multilingual surveys and ensures anonymity, as it does not keep record of IP addresses.

In total we received 193 responses, out of which 33 were incomplete and 160 were fully completed. The collection of the sample was implemented on January and February 2020.

For the statistical analysis we used IBM SPSS Statistics for Windows version 26.0.

The collection of the sample for the statistical analysis took place in Greece, the UK, Spain and Germany. The psychometric tool was available online and was disseminated in healthcare and caregiving facilities for the elderly. In total we received 160 responses.

The structure of the participants is the following:

	Country	Number of participants
Greece		39
UK		44
Spain		43
Germany		34
Total		160

Table 4: Division of participants in the sample per country

60% of participants had more than 6 years of experience working as a caregiver. Out of them 30% has more than 10 years of relevant experience. In the chart below the age groups of the participants are presented.



Chart 1: Participants' Age Distribution

Results

Construct Validity/ Exploratory Factor Analysis

The sample adequacy was assessed prior to conducting a factor analysis. The KMO measure of sampling adequacy was 0.845 with a statistically significant BS (χ^2 = 2,170.241 P < 0.001) indicating sample adequacy.

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		,845
Bartlett's Test of Sphericity	Approx. Chi-Square	2170,241
	df	561
	Sig.	,000

Image 1: KMO and Barlett's Test

The construct validity was examined by conducting an Exploratory Factor Analysis (EFA). The responses of the participants were recorded using a 5-point Likert Scale (Completely Disagree, Disagree, Neutral, Agree, Completely Agree). There were no missing values, as all questions were mandatory to be completed in order to be submitted.

The EFA used the principal axis factoring method. Because the correlations between the factors were expected, the solution was Promax rotated (k = 5). Factors exceeding initial eigenvalues >1 (cf. Kaiser's criterion) were extracted, and factor loadings <0.4 were suppressed. In addition, a scree-plot of the eigenvalues was examined.

The EFA revealed eight factors with eigenvalues >1 that explained approximately 60% of the variance. The numbers of extracted factors were supported by examining the point of inflection in the scree-plot.



Image 2: Scree plot of the eigenvalues of the psychometric tool

The factors accounted for the following:

Factor Number	Label	Eigenvalue	Explained variance
1	Burden	9.243	27.2%
2	Empathy	3.019	8.9%
3	Anxiety	1.841	5.4%
4	Professionalism	1.445	4.2%
5	Coping	1.350	4.0%
6	Cooperation	1.240	3.6%
7	Personal Development	1.158	3.4%
8	Confidence	1.097	3.2%

 Table 5: Eigenvalues and explained variance of each factor. Labels were given after examining the items that

 loaded in each factor.

As some of the factors loaded in more than one factors, the following taxonomy was preferred, based on the theoretical relevance of each item. The final categorization is the following:

Factor Number	Label	Number of Items
1	Burden	6
2	Empathy	6
3	Anxiety	6
4	Professionalism	5
5	Coping	4
6	Cooperation	3

7	Personal Development	N/A
8	Confidence	N/A

Table 6: Number of items per factor

Two items did not load on any of the factors and therefore they were deleted. Two more items did not load satisfactory on the factors and were also excluded. Out of the eight factors, two were excluded, as they had insufficient items.

The new version of the psychometric tool has 30 questions which are describing 6 dimensions: Burden, Empathy, Anxiety, Professionalism, Coping and Cooperation.

Reliability Analysis

Cronbach's alpha was used to assess the internal consistency of each of the six factors. The internal consistency, which was evaluated using Cronbach's alpha (α), was:

Factor Number	Label	Cronbach's alpha (α)
1	Burden	0.830
2	Empathy	0.767
3	Anxiety	0.752
4	Professionalism	0.734
5	Coping	0.731
6	Cooperation	0.620
	Table 7. Creabash/s alaba (a) internal as	a state a su

Table 7: Cronbach's alpha (α) internal consistency

The internal consistency of all factors, but one, is acceptable. The reliability coefficient must be of 0.70 or more in order to be acceptable.

Factor 6, labelled as "Cooperation" scored 0.620, which was expected due to its low number of items, as Cronbach's alpha (α) is affected by the number of items. However, the factor was excluded from the psychometric tool.

Conclusions

The final version of the psychometric tool has the following structure:

Label	Number of items	Cronbach's alpha (α)	Items	EFA
Burden	6	0.830	I feel that caregiving affects my mental health	0.750
			Caregiving affects negatively my quality of life	0.748
			I feel that caregiving affects my personal life	0.692
			I frequently feel depressed	0.651
			I feel alone even in social situations	0.600
			I feel that caregiving affects my physical health	0.574
Empathy	6	0.767	Other people come to me for advice	0.633
			I am a good listener	0.623
			I find it easy to remain calm in challenging situations	0.622
			l feel confident	0.592
			I like helping other people	0.584
			I understand that older people may feel isolated and helpless	0.513
Anxiety	6	0.752	I have to check again and again when I do things	0.429
			I have difficulty in making decisions	0.730
			I am a kind person	0.656

		I frequently experience feelings of being trapped	0.619
		I get stressed easily	0.609
		I can easily relax even in stressful situations	0.561
5	0.734	I am well organized	0.734
		I complete all my professional tasks on time	0.652
		I enjoy taking initiatives at work	0.615
		I am resilient to the challenges of everyday life	0.586
		I find it difficult to comply with rules and procedures	0.510
4	0.731	I can cope with the physical and mental pain of others	0.506
		I am optimistic for the future	0.496
		I feel satisfied with my caregiving role	0.644
		l never give up	0.638
	5	5 0.734 4 0.731	I frequently experience feelings of being trappedI get stressed easilyI can easily relax even in stressful situationsI am well organizedI complete all my professional tasks on timeI enjoy taking initiatives at workI am resilient to the challenges of everyday lifeI find it difficult to comply with rules and proceduresI can cope with the physical and mental pain of othersI am optimistic for the futureI feel satisfied with my caregiving roleI never give up

Table 8: Final Psychometric Tool and EFA and Cronbach's alpha (α) measurements.

At the conclusion of the psychometric measurements, the developed tool was found to be valid and reliable for use. This scale needs to be further evaluated using Confirmatory Factor Analysis and in diverse settings and populations.

Appendix

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Informed consent

Written consent was obtained by all participants who were interviewed. Their participation was voluntary. Confidentiality and anonymity were guaranteed.

During the online collection of the sample, no written consent was obtained. Participants received written information on the project, the research and the psychometric tool. No data was kept that could identify the participants (Name, IP address). Confidentiality and anonymity were guaranteed. In the information page of the tool, participants were informed that their consent was given by completing and submitting the psychometric tool to the research team.

References

- American Medical Association, (2011). Caregiver Self-Assessment [on-line]. Available at <u>http://www.amaassn.org/ama/pub/physician-resources/publichealth/promotinghealthy- lifestyles/geriatrichealth/caregiver-health/caregiver-selfassessment.shtml
 </u>
- Andrén, S. & Elmståhl, S. (2005). Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. Scand J Caring Sci, 19, 157–168.
- Balducci, C., Mnich, E., McKee, K. J., et al. (2008). Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. Gerontologist, 48, 276–286.
- Bandeira, M., Calvazara M. G. P., Castro, I. (2008). [Burden of care in relatives of psychiatric patients: Validity study of the Family Burden Interview Scale]. Journal Brasileiro de Psiquiatria, 57, 2 [Internet]. 2008 [cited 2014 Dec 17];57(2), :98-104.
- Beck, A. T., Epstein, N., Brown, G. & Steer, R.A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. Journal of Consulting and Clinical Psychology. 56, 6, 893–897.
- Beck, A. T., Steer, R.A, Ball, R. & Ranieri, W. (1996). Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. Journal of Personality Assessment. 67, 3, 588–97. doi:10.1207/s15327752jpa6703_13
- Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. Dialogues Clin Neurosci, 11, 217–228.
- Carers of Dependent Older People in Europe: Characteristics, Coverage and Usage, retrieved from "<u>http://www.uke.unihamburg.de/extern/eurofamcare/documents/deliverables/nas</u>

<u>ure_el.pdf</u> (accessed on 12.11.2019).

- Carey, P. J., Oberst, M. T., McCubbin, M. A. & Hughes, S. H. (1991). Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. Oncology Nursing Forum, 18, 8, 1341-1348.
- Cartwright, J. C., Archbold, P. G., Stewart, B. J. & Limandri, B. (1994). Enrichment processes in family caregiving to frail elders. Advances in Nursing Science, 17, 31–43.
- Christakis, N. A. and & Iwashyna, T. J. (2003). The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. SocSci Med., 57, 465–-475.
- Cohen, S., Kamarck, T.& Mermelstein, R. (1983). A global measure of perceived stress. Journal of health and social behavior, 24, 385-396.
- Degoratis, L. R (1977). The SCL-90 Manual I. Scoring, Administration and Procedures for the SCL-90. Baltimore, MD: John Hopkins University School of Medicinem Clinical Psychometrics Unit, Baltimore, MD.)
- Elmstahl, S., Malmberg, B. & Annerstedt, L. (1996). Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. Archives of physical medicine and rehabilitation, 77, 177-282.

- Ewing G., Brundle C., Payne S. & Grande G. (2013). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study. Journal of Pain and Symptom Management, 46(3), 395-405.
- Ewing, G. and Grande, G. (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. Palliat Med., 27, 244–256.
- Fonareva, I. and & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. IntPsychogeriatr, 26, 725–747.
- Given, C. W., Given, B., Stommel, M., et al. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Research in Nursing & Health, 15, 271-283.
- Grande, G., Stajduhar, K., Aoun, S. et al. (2009). Supporting lay carers in end of life care: current gaps and future priorities. Palliat Med., 23, 339–-344.
- Heppner, P. P., Wampold, B., Owen, J., Thompson, M. & Wang, K. (2016). Research Design in Counseling. Boston, MA: Cengage Learning. p. 334. ISBN 9781305087316.
- Hérbert, R., Bravo, G., & Préville, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. Canadian Journal on Aging, 19, 494-507.
- Hudson, P.L., Trauer, T., Graham, S. et al. (2010). A systematic review of instruments related to family caregivers of palliative care patients. Palliat Med., 24, 656–668
- Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J. & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. Psychosomatic Medicine, 53, 345-362.
- Kiecolt-Glaser, J. K., Marucha, P. T., Malarkey, W. B., Mercado, A. M. & Glaser, R. (1995). Slowing of wound healing by psychological stress. Lancet, 346, 1194-1196.
- King, A. C., Oka, R. K. & Youg, D. R. (1994). Ambulatory blood pressure and heart rate responses to the stress of work and caregiving in older women. Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 49, 239-245.
- Kosberg, J. I.& Cairl, R. E. (1986). The cost of care index: A case management tool for screening informal care providers. The Gerontologist, 26, 3, 273-278.
- Kourasi, A., Koutivas, M., Petala, K. A. & Stefanaki, E. (2013). Mapping and exploration of the burden of caregiver to senior citizens. An intervention in rural community of Tylisos. Thesis retrieved from: https://apothesis.lib.teicrete.gr/bitstream/handle/11713/1264/Kourasi_Koutivas_P etala Steafanaki.2013.pdf?sequence=1&isAllowed=y (accessed on 12.11.2019)
- Kristensen, T. S., Borritz, M., Villadsen, E. & Christensn, K. B. (2005). The Copenhagen Burnout Inventory: A new tool for the assessment of burnout. Work & Stress, 19, 3, 192-207.
- Lai, D. W. L. (2007). Validation of the Zarit Burden Interview for Chinese Canadian caregivers. Social Work Research, 31, 45-53.
- Lamura, G., Mnich, E., Bien, B., Krevers, B., McKee, K., Mestheneos, E., Dohner, H. (2007). Dimensions of future social service provision in the ageing societies of Europe. Advances in Gerontology 3, 13, [pages].
- Leyfer, O. T., Ruberg, J. L. & Woodruff-Borden, J. (2006). Examination of the utility of

the Beck Anxiety Inventory and its factors as a screener for anxiety disorders. Journal of Anxiety Disorders. 20, 4, 444–-458.

- Mausbach, B. T., Chattillion, E. A., Roepke, S. K., et al. (2013). A comparison of psychosocial outcomes in elderly Alzheimer caregivers and non-caregivers. Am J Geriatr Psychiatry, 21, 5-–13.
- McKee K. J., Philp, I., Lamura, G., et al. (2203). The COPE index —a first stage assessment of negative impact, positive value and qual-ity of support of caregiving in informal carers of older people. Aging Ment Health, 7, 39–52.
- Middleton, L. (1994). Little boxes are not enough. Care Weekly. January 20.
- Moholt, J-M., Friborg, O., Wolff Skaalvik, M. & Henriksen, N. (2018). Psychometric validation of the Carers of Older People in Europe Index among family caregivers of older persons with dementia. SAGE Open Medicine, 6, 1-10.
- Northrup, D. A. (1996). The Problem of the Self-Report iIn Survey Research. 11 (3). Institute for Social Research, 11 (3), [pages].
- O'Malley, K. & Qualls, S. H. (2017). Preliminary evidence for the validity and eliability of the Caregiver Reaction Scale. Clinical Gerontologist, 40, 281-294., doi: 10.1080/07317115.2016.1198858
- Oberst, M. T., Gass, K. A. & Ward, S. E. (1989). Caregiving demands and appraisal of stress among family caregivers. Cancer Nursing, 12, 4, 209-215.
- Orbell, S., Hopkins, N.&Gillies B. (1993). Measuring the Impact of Informal Caring. Journal of Community & Applied Social Psychology, 3, 149-163.
- Ory, M. G., Hoffman, R. R.,, Yee, J. L., Tennstedt, S. & Schultz, R. (1999). Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. The Gerontologist, Vol. 39,, No. 2, 177-185.
- Payne, S., Smith, P. & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. Palliat Med., 1999; 13,: 37–-44.
- Pearlin, L. I., &Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior, 24, 2–-15.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: an overview of concepts and their measures. Gerontologist, 1990, 30, (5,):583--594.),
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-594.
- Picot SJF, Youngblut J, & Zeller R. (1997). Development and Testing of a Measure of Perceived Caregiver Rewards in Adults. Journal of Nursing Measurement. 1997;, 5, 1,: 33-52.
- Pinquart, M. and & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. Psychol Aging, 18, 250–267.
- Pinquart, M., & Sorensen, S. (2010). Correlates of physical health of informal caregivers: A meta-analysis. Journal of Gerontology: Psychological Sciences, 62, 126-137.

- Quinn, C., Clare, L. & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. IntPsychogeriatr, 22, 43–-55.
- Rapp, S.R. & Chao, D. (2000). Appraisals of strain and of gain: effects on psychological well-being of caregivers of dementia patients. Aging & Mental Health, 4, 142–147.
- Richter, P., Werner, J., Heerlein, A, Kraus, A. & Sauer, H. (1998). On the validity of the Beck Depression Inventory. A review. Psychopathology. , 31, 3, 160–8.
- Rossi Ferrario, S., Cardillo, V., Vicario, F., Balzarini, E. &, and Zotti, A.M. (2004). Advanced cancer at home: caregiving and bereavement. Palliat Med., 18, 129–136.
- Schulz, R. & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. JAMA, 282, 2215-2219.
- Schulz, R. & Quittner, A. L. (1998). Caregiving for children and adults with chronic conditions: Introduction to the special issue. Health Psychology, Vol. 17, 107-111.
- Schulz, R., O'Brien, A. T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. Gerontologist, 35, 771-791.
- Shaw, W. S., Patterson, T. L., Semple, S. J. et al. (1997). Longitudinal analysis of multiple indicators of health decline among spousal caregivers. Annual Behavior Medicine, 19, 101-109.
- Shyu, Y. I. L., Lee, H. C. & Chen, M.L. (1999). Development and testing of the family caregiving consequences inventory for home nursing assessment in Taiwan. Journal of Advanced Nursing, 30, 3, 646-654.
- Statharou, A., Papathanasiou, I., Gouva, M., Masdrakis, V., Berk, A., Daragiannis, D., & Kotrotsiou, E. (2011). Investigating the burden of carers of mentally ill patients. Interscientific Health Care, 3, 59-69.
- Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D. and Bandura, A. (2002). The revised scale for caregiving self-efficacy: reliability and validity studies. Journals of Gerontology: Psychological Sciences, 57, 74–-86.
- Takai, M., Takahashi, M., Iwamitsu, Y., Ando, N., Okazaki, S., Nakajima, K., Oishi, S. & Miyaoka, H. (2009). The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. Archives of Gerontology and Geriatrics, 49, e1-e5.
- Triantafillou, J., Mestheneos, E., Prouskas, C., Goltsi, V., Kontouka, S., Loukissis, A. (2006). "The National Survey Report for Greece. EUROFAMCARE – Services for Supporting Family
- Vitaliano, P. (1997). Physiological and physical concomitants of caregiving; introduction to special issue. Annual Behavioral Medicine, 19, 75-77.
- Zarit, S. H., Reever, K. E. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 6:=, 649-655.
- Zarit, S. H., Reever, K. E., Back-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist, 20, 649-655.
- Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: effects of adult day care use. Journal of Gerontology: Social Sciences, 53B, S267-S277.

• Zarot, J. M. (1982). Predictors of burden and distress for caregivers of senile dementia patients. Unpublished doctoral dissertation. University of Southern California, Los Angeles.



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