## We are IntechOpen, the world's leading publisher of Open Access books Built by scientists, for scientists

6,900

185,000

200M

Downloads

154
Countries delivered to

Our authors are among the

 $\mathsf{TOP}\:1\%$ 

most cited scientists

12.2%

Contributors from top 500 universities



WEB OF SCIENCE™

Selection of our books indexed in the Book Citation Index in Web of Science™ Core Collection (BKCI)

Interested in publishing with us? Contact book.department@intechopen.com

Numbers displayed above are based on latest data collected.

For more information visit www.intechopen.com



#### Overburden in Alzheimer's Patient Caregivers

María del Carmen Pérez-Fuentes, María del Mar Molero Jurado and José Jesús Gázquez Linares

Additional information is available at the end of the chapter

http://dx.doi.org/10.5772/intechopen.69148

#### **Abstract**

The figure of the caregiver of dependent elderly people is presently the subject of a large volume of scientific publications. In various disciplines of health and social sciences, an analysis of the terminology referring to these caregivers, specifically those who are untrained and unpaid for such care, in recent scientific publications, is considered necessary. This chapter makes a comprehensive analysis of the characteristics and needs of caregivers of elderly dependents with Alzheimer's disease. From a realistic and practical point of view, it is the impact of research on improving the quality of life of caregivers which is important. In addition, this analysis attempts to complete a process addressing theoretical and methodological aspects, in which various problems are detected, for their effective application in the field of care of dependency.

Keywords: overburden, Alzheimer's patients, caregivers, intervention, quality of life

#### 1. Introduction

Sometimes, living longer involves dependence on care in which the needs become more and more obvious. One of the most frequent causes of such dependency in the elderly population is Alzheimer's disease. Over 35 million people were suffering from some type of dementia in 2010 and world forecasts for 2030 and 2050 double and triple this figure, respectively [1]. In this urgent scope of action, the World Health Organization [2] takes a stand by identifying dementia as one of today's priority public health problems.

Even though there are a multitude of care models and resources placed at the service of these patients [3, 4], a large part of this population receives care within their own family setting [5]. This is why the volume of research analyzing the profile of the family caregiver, skills



for their patient's care, and improving their relationship with the patient has intensified [6]. In this field, the concept of caregiver overburden [7] and its repercussion on their physical and mental health, social relations, mood, etc., as well as their quality of life [8], is of special interest.

This chapter provides a complete analysis of the characteristics and needs of the caregivers of the elderly who have become dependent because of Alzheimer's disease. All of this is from a realistic and practical viewpoint that what is important is the repercussion of research on the improvement of the quality of life of the caregiver. Furthermore, this analysis attempts to make a complete review covering all the theoretical and methodological where problems are found in their effective application in the area of care of dependency.

First, the terminology used to refer to the different caregiver profiles is reviewed, and the problem which could arise in research on the subject as a consequence is analyzed. Once the specific profile to be studied has been identified, the needs that should be considered in an intervention for this specific caregiver typology are discussed. At this point, having set the basis for intervention, we propose an inventory for evaluating caregiver overburden in Alzheimer's patient family caregivers who have no specialized training.

#### 2. Conceptual approach to the concept of caregiver

The term "care" is widely used and has been studied from different approaches, especially in the areas of study which refer to overburden of the caregiver [9–11], associated factors [12–15], or instruments for its measure [16–18].

On a conceptual level, the contributions of Heidegger [19] in developing the phenomenological concepts of care and cure are significant. From this perspective, care becomes the way in which human beings exert control over themselves, or, in other words, feel that they are in possession of their own existence or not. In this phenomenological discourse, the relationship established between lifestyle and state of health-illness is important to the extent that they are closely related to care. It is precisely through care behavior that daily structure is formed, where man is positioned between satisfaction of his needs and health.

As inferred from Heidegger's theoretical proposal, although the action of caring for someone is inherent in human nature, the concept as such is relatively new. This novel character of the terminology related to care reveals difficulties in its operationalization and its limits for use in the concept of caregiver, especially in research [20].

The traditional definitions of caregiver have been characterized by elements related directly to the tasks typical of caregiving [21]. Nevertheless, sometimes emotional aspects are included, which, according to authors such as Pearlin et al. [22], are inevitably present in the caregiving relationship. These authors define caregiving as "the behavior expression of commitment to the wellbeing or protection of another person" (p. 583).

#### 2.1. Types of "family" caregivers

In spite of the surge in the concept of the caregiver since the 1970s, to date, there is a wide diversity in the terms used synonymously in the literature, making this a concept vulnerable to lack of specificity [23].

In the study of the concept of the caregiver, attention has been given to the skills necessary to perform the work [24], the consequences or impact it has on their well-being [25], and even the profile itself [26]. But in any case, it deals with a word that maintains a close bond with the family.

Family care models, in which one member undertakes care of another who has become dependent, make family dynamics a variable of interest [27]. Such is the bond created between the caregiver and his relative that in fact studies have revealed that even after the patient has been admitted to an institution, the relatives still keep acting as caregivers [28].

Starting out from the family context as the source of care, different questions may be asked which lead to different senses of the term. The most basic would be the answer to the question, who is providing the care? In this case, there are two specific possibilities, a relative or someone in the immediate social circle, such as neighbors, family friends, etc. In any case, it is someone significant to the person receiving the care.

Some of the terms identified in the literature include the concept "informal caregiver," and characterize them as those who perform the work of caring for dependent persons in their home, without being associated to any health care and/or service entity [29].

When full responsibility for care falls on a single person, normally someone in the immediate social circle, without training in the tasks of caregiving and for which no payment is received, some authors [30] use the term "primary informal caregiver."

Although they sound similar, and their meanings are as well, the use of the terms "primary" and "main" caregiver is differentiated.

"Primary caregiver" is discussed in the literature with regard to attention to the most immediate and basic needs (physical and emotional), with affective involvement, and therefore an important figure for the person receiving care [31–33]. Other studies have chosen the term "main caregiver," but with the same characteristics as the first. That is, again, a person who is close to the recipient and gives priority attention to their physical and emotional needs in a commitment to continuous assistance [34, 35].

Another question that could be derived from the use of different terms is with regard to the type of work done by the caregiver [36]. For example, while some caregiving work may need to be meticulous, other tasks deal with protection or help. The view of the patient is also different depending on the term applied. Assistance is directed at a necessarily vulnerable individual and/ or who is unprotected, whereas the term attention is oriented toward a goal of intervention, more toward action than covering primary needs. Thus, the particular use of concepts, such as help, care, assistance, or attention, becomes the basis of the ambiguity in which the caregiver works.

#### 2.2. The main caregiver of elderly dependents

Caregivers form a social class in itself [37]. From this perspective, different models are proposed for analyzing the figure of the main caregiver, with direct involvement in intervention and help strategies.

The caregiver-resource model defines the main caregiver as an instrument for optimizing attention given to the dependent, so their well-being falls onto a second plane. In this case, the purpose of intervention is to maintain or increase informal help as much as possible. Thus, caregivers are trained in patient needs and how to care for them, that is, provide them with the skills necessary to perform caregiving work adequately. Professional caregivers may often include family members who give care as a resource collaborating in the dependent person's care [38].

In the caregiver-client model, the recipient is understood as a secondary receiver of formal services. Therefore, the need argued is for the main caregiver to have recourse to services during intervention that improve their quality of life and decrease the negative impact of caregiving on their own well-being. From this perspective, interventions would include the main caregiver as a vulnerable agent, and therefore with important needs that have to be covered by help and/or relief services, alternative service resources, and training in strategies to lessen overburden [39].

To start with, the care of a family member in one's own home is something conceived of as natural, to the extent that it is a responsibility expected from the family. However, if the caregivers do not have social help or do not have access to the resources necessary for it, they are going to be compelled to develop "home" remedies for their care and to transform/adapt their homes [40], which are then no longer natural contexts for the family to live together in, and become a substitute for a service center.

Since the beginning of the century, there has been exponential growth in the population over 65 years of age and a noticeable increase in those over 80 [41]. Demographic reports show the prevalence and incidence of illnesses that are plainly higher in the more advanced age groups, as well as chronicity, disability, and dependency rates. Neurological pathologies are one of the most costly groups of diseases for the health-care system and for the society as a whole, since in addition to the process of the illness itself, there is a psychological impact, diminishing quality of life, disability for work, loss of social skills, and the burden of caregivers and dependency (p. 175) [42].

#### 2.3. Review of the terminology used to refer to the caregiver in scientific publications

At the present time, the figure of the caregiver of elderly dependents is the subject of a large volume of scientific publications [43]. In various health-care and social science disciplines, the terminology used to refer to caregivers is often confusing [44]. Some of the difficulties identified on a conceptual level of care are related to the lack of operative definitions and terminology incoherent with its multidimensional character [45] and the concept of overburden [46]. From a more operative approach to the design of effective intervention with caregivers, it

may be said that the existence of problems for its conceptual delimitation leads to trouble differentiating case-specific care typologies [47]. This specificity in data processing is precisely a characteristic which should be present from the moment a study is proposed, directed toward a specific type of care, instead of a generic typology which is only theoretically common to all caregivers [48].

From this viewpoint, the terminology referring to the caregiver, especially for those who have no technical training and are unpaid for their caregiving labor, must be analyzed in recent scientific publications. Therefore, a review of the terminology used in scientific publications on the subject was done to provide data on the current state of the problem described [49].

The study methodology consisted of systematically reviewing scientific literature on the subject. Publications in several different international databases were reviewed for this, comparing two production periods, 1996–2005 and 2006–2016.

Given the characteristics and scope of database coverage, the descriptors in Spanish and/ or English ("family caregivers," "informal caregivers," and "non-professional caregivers") are presented. For all cases, it is limited to the search in the title of the document. In addition, the results were filtered by the document type "journal article," and were limited to the search at the time interval. As for the language of the publication, the options "Spanish" and "English" were selected in the databases that have this filter, and they were manually revised in the cases for which they did not have this function. On the other hand, for the selection of publications, the inclusion criteria are established, which were applied in the manual review of the titles, in each of the databases. The established inclusion criteria were as follows: (1) journal articles, (2) papers published in Spanish or English, and (3) containing the title of the descriptors used. On the other hand, for the exclusion criteria, the following were applied: (1) work that deals with the care of a relative, but does not include the terminology analyzed in the title, and (2) works published in a language other than Spanish or English.

The preliminary results suggest a more frequent use of the term "family caregiver" in publications, both in English and in Spanish. At the same time, differences were detected in the use of terminology, with attention to variables such as production period, subject matter, and type of journal. The Z-statistic was applied for comparative analysis to check for significant differences in percentages.

First, examining the scientific production periods (**Table 1**), it is observed that in general, the volume of publications including the descriptors (both in Spanish and in English) in the title was higher in 2006–2016. However, when the percentages of the two periods are compared, the term "family caregivers" (in Spanish) is significantly more representative (Z = 3.91; p < 0.001) in 1996–2005 than in 2006–2016. The same thing occurred for the English descriptor ("family caregivers"), which was significantly higher (Z = 4.48; p < 0.001) than in 2006–2016.

The percentage use of the descriptor "non-professional caregivers" (in Spanish) was also significantly higher (Z = -2.02; p < 0.05) in 2006–2016. It was also in this second period when a significantly higher percentage (Z = 6.84; p < 0.001) of the descriptor "informal caregivers" appeared in the titles.

Descriptors	1996–2005		2006–2016	
	$\overline{N}$	%	N	%
"family caregivers" (in Spanish)	65	3.66	104	2
"non-professional caregivers" (in Spanish)	0	0	12	0.23
"informal caregivers" (in Spanish)	39	2.19	124	2.39
"family caregivers"	1430	80.60	3907	75.39
"non-professional caregivers"		0.05	17	0.32
"informal caregivers"	239	13.47	1018	19.64
Total	1774	100	5182	100

Table 1. Number of publications containing descriptors in the title by production period.

No significant differences in the total percentages of the number of publications that included each of the descriptors in the title by subject (Health Sciences and Social Sciences) were found for any of them in 2006–2016. However, the descriptor which appeared the most in the title was "family caregivers" (in Spanish) in both Health Sciences and Social Sciences (**Table 2**).

In Health Sciences, the descriptor most used in nursing publications was "family caregivers" (in Spanish) (n = 34), followed by "informal caregivers" (in Spanish) (n = 21). In Geriatrics, "informal caregivers" (in Spanish) was in first place (n = 6) followed by "informal caregivers" (n = 3) in second.

The secondary subject matter Generalities stressed more frequent use by publications that included the descriptor "family caregivers" (in Spanish) (n = 10) in the title, followed by "informal caregivers" (in Spanish) (n = 3).

On the other hand, in the Social Sciences, in Psychology, the term most frequently used was "family caregivers" (in Spanish) (n = 16) and second "informal caregivers" (in Spanish) (n = 8).

Descriptors	Health Sciences		Social Sciences	
	N	%	N	%
"cuidadores familiares" (in Spanish)	48	44.85	17	44.73
"cuidadores no profesionales" (in Spanish)	2	1.86	3	7.89
"cuidadores informales" (in Spanish)	35	32.71	15	39.47
"family caregivers"	19	17.75	3	7.89
"non-professional caregivers"	0	0	0	0
"informal caregivers"	3	2.80	0	0
Total	107		38	

**Table 2.** Number of publications containing the descriptors in the title by subject.

This one "informal caregivers" (in Spanish) was also in first place (n = 7) in Sociology/Social Work, followed by the term "non-professional caregivers" (in Spanish) (n = 2).

Finally, the number of articles that contain each of the descriptors in the title, classified by journal (**Table 3**), shows a trend toward the preferential use of the term "family caregivers" (in Spanish) in nursing journals (Aquichan, International Nursing Review, and Index de Enfermería), Geriatrics (Gerokomos and Revista Española de Geriatría y Gerontología), and psychology/education/multidisciplinary (Anales de Psicología and European Journal of Investigation in Health, Psychology and Education).

Descriptors	Journals	No. of titles
"cuidadores familiares" (in Spanish)	Aquichan	6
	Gerokomos: Revista de la Sociedad Española de Enfermería Geriátrica y Gerontológica	3
	International Nursing Review	3
	Index de Enfermería	2
	Revista Española de Geriatría y Gerontología	2
	Revista Ciencia y Cuidado	2
	Anales de Psicología	2
	European Journal of Investigation in Health, Psychology and Education	2
	Investigación y Educación en Enfermería	1
	Evidentia: Revista de Enfermería basada en la Evidencia	1
	Respuestas	1
	Enfermería Global	1
	Metas de Enfermería	1
	Cultura de los Cuidados	1
	Clínica y Salud  Duazary  Facultad Nacional de Salud Pública	1 1 1
	Revista de Psicología	1
	Revista de Calidad Asistencial	1
"cuidadores no profesionales" (in Spanish)	Revista Española de Geriatría y Gerontología	1
	Metas de Enfermería	1
	Clínica y Salud	1
	Estudios Financieros: Revista de trabajo y seguridad social	1
	Humanismo y Trabajo Social	1
	Revista de Derecho Social	1
	Revista del Ministerio de Trabajo e Inmigración	1

Descriptors	Journals	No. of titles
"cuidadores	Enfermería Clínica	2
informales" (in Spanish)	Revista ROL de Enfermería	2
	Enfermería Global	2
	Trabajo Social y Salud	2
	Gerokomos: Revista de la Sociedad Española de Enfermería Geriátrica y Gerontológica	1
	Revista Española de Geriatría y Gerontología	1
	Revista Multidisciplinar de Gerontología	$\sqrt{1}$ $\square$
	International Journal of Developmental and Educational Psychology	1
	Aquichan	1
	Hygia de Enfermería	1
	Actas Españolas de Psiquiatría	1
	International Nursing Review	1
	Metas de Enfermería	1
	Neurología	1
"family caregivers"	Research in Nursing and Health	4
	Cancer Nursing an International Journal for Cancer Care	4
	Revista de Pesquisa: Cuidado é Fundamental online	4
	Investigación y Educación en Enfermería	3
	Journal of the American Geriatrics Society	2
	Nursing Research, an AJN Company Publication	2
	Aquichan	1
	American Journal of Occupational Therapy	1
	Sociology of Health & Illness	1
informal caregivers"	Journal of the American Geriatrics Society	3
	Documentos de Trabajo (FEDEA)	1
	Cancer Nursing an International Journal for Cancer Care	

**Table 3.** Number of publications with the descriptors in the title by journal.

In addition to representative journals in the disciplines mentioned above, the descriptor "family caregivers" (in Spanish) was found in titles in journals in other disciplines, such as law (Revista de Derecho Social) and social work (Estudios Financieros, Humanismo y Trabajo Social, and Revista del Ministerio de Trabajo e Inmigración).

The term "informal caregivers" (in Spanish) was used the most as part of the titles published in nursing journals (Enfermería Clínica, Rol de Enfermería, and Enfermería Global) and social work (Trabajo Social y Salud).

Of the two English descriptors, more titles were found with "family caregivers," most of them in nursing journals (Research in Nursing and Health, Cancer Nursing and International Journal for Cancer Care, and Revista de Pesquisa Cuidado è Fundamental Online).

When the descriptor "informal caregivers" was entered, the most frequent presence was found in publications in geriatrics journals (Journal of the American Geriatrics Society). Finally, no journals with publications that included the term "non-professional caregivers" in the title were found in the database searched dated in the last decade.

These data suggest that, in spite of a generalized trend toward the use of the expression "family caregivers" (in Spanish) (and "family caregivers" in English), it would be necessary to review the characteristics of each of the caregiver profiles in each concrete case.

One of the reasons for these differences in the use of terminology could be related to the desire to differentiate this type of caregiver from the assistance provided by health-care professionals [50]. Another of the questions inherent in this diversity of terms is the volume of publications generated in a certain discipline. Since, as seen in the data found by subject matter (and secondary subjects), even though not significant, differences were observed in the use of terms such as "non-professional caregivers" (in Spanish), more frequent in the social sciences (especially sociology and social work). This diverse use of the terminology also occurs in journals published in different scientific disciplines and/or professional fields.

In brief, the trend in the use of terminology associated with caregivers without technical training who are unpaid for their work has been identified and described. The need for updating terms and a proposal for alternatives sufficiently operative to overcome the difficulties in comparing the results of different studies where concepts related to caregiving are dealt with are justified.

### 3. Needs for intervention in the family caregiver without specialized training: variables related to overburden levels

Alzheimer's disease continues at present to be the most frequent type of dementia and one of the main causes of dependency in the population over 65 years of age [51]. It affects all the dimensions of life (emotional, cognitive, and social) of the patients, and in turn leads to a series of consequences which make it extensive to their closest family setting [52]. Therefore, it is of interest to analyze the patient-caregiver relationship to find out the feelings present in the caregiver, as a result of interaction with the patient [53]. Caron and Caron [54] found that the family response to the impact of the diagnosis may vary from negation to overprotection and even aggressiveness in care. According to the authors, all this would be to reduce the anxiety which incoherencies in interaction with the patient can cause.

Information on the diagnosis of Alzheimer's disease is currently under debate, with no unanimity yet arrived at. The details that surround the communication of the diagnosis are complicated, and affect both the patient and caregivers [55]. Scientific literature on the subject has found advantages in making and communicating the diagnosis to the person affected [56, 57]. Some of these advantages are ending the feeling of uncertainty by knowing the changes they are undergoing better, having information on the course and evolution of the disease, its treatment and

the options for care available, as well as taking part in planning short-term goals, and participating in decision-making on care to be received in the more advanced stages.

Some authors believe that communicating Alzheimer's diagnosis to the patient involves more negative effects than positive. Some of the arguments from this perspective refer to the moderate effect of available treatments, lack of understanding as cognitive deterioration progresses, in addition to a diagnosis based on probability, so knowledge of the diagnosis could have negative effects on the health of the person affected [58].

It is usually thought that a timely, precise explanation of the diagnosis and its implications is basic to better planning and management of the disease [59]. In the study Who cares? [60], in which caregivers were asked what type of information they received in the diagnosis, half of them provided information on the disease and the medication available. However, few of them received any information on the resources and help available to the caregiver.

After the critical moment of the diagnosis, the caregiver is left in a situation of uncertainty and uneasiness. This is due in part to ignorance of the disease and the care it requires. In this situation, prior beliefs the caregiver has about the disease may positively or negatively influence the feeling of burden. Along this line, some authors [61] affirm that the more negative beliefs of the caregiver are, the more likely intense feelings of overburden, thereby making the caregiver more vulnerable to stress and anxiety.

In the case of family caregivers, the responsibility for providing quality care and the anxiety of not having technical preparation for it can lead to risk to their mental health [62, 63]. These and other concerns about ignorance of the disease and the care it requires arise at the critical moment of diagnosis of the disease [64], moment at which the caregiver is the most vulnerable to the feeling of burden. Situations such as these become more evident in the case of Alzheimer's patient caregivers, since they have the added difficulty of not having an early diagnosis and the consequent negative impact on emotional responses of the caregiver which usually affect the quality of care. Situations such as these, which become more evident in caregivers of Alzheimer's patients, must have already dealt with the added difficulty of not having an early diagnosis, with the consequent negative impact on the emotional responses of the caregiver, and which usually affect the quality of care. Therefore, training of family caregivers in symptomatology and evolution of the disease, or in the management of daily situations, could reduce the level of overburden and even largely avoid its appearance [65]. It is therefore a matter of providing the caregiver with tools that assist in approaching stressful situations that take place during care and interaction with the patient.

The care of a dependent person is often associated with significant risk to the health and well-being of the caregiver [66]. The burden perceived by the caregiver is related to the functional state of the patient, the time devoted to care, social support, and perception of their own health condition [67]. In a sample of non-professional caregivers, it was observed that almost 50% evaluated their health as poor or very poor [68].

In other cases, more somatic complaints [69], more frequent demand for and use of health-care services and drugs have been found in caregivers [70]. Depression is often a problem in

non-professional caregivers; however, the proposals for intervention continue to be mostly palliative [71]. Thus, there are proposals for intervention programs based on solving the problems to prevent clinical depression in family caregivers [72].

Another problem that arises up for caregivers of Alzheimer's patients is variability and evolution of their psychiatric symptoms and behavior, making them more dependent. In this respect, some authors [73] positively correlate this symptomatology with the feeling of burnout in caregivers of this type of patient. The European survey [60] showed that carers found that difficulties in performing daily activities, such as washing, and behavioral symptoms are the most problematic to cope with, and they were the reason for seeking help in just as many cases as cognitive problems. Behavioral symptoms such as aggression and personality changes, which often cause a familiar to behave completely out of normative, are especially distressing for carers.

Given the impact of neurodegenerative diseases such as Alzheimer's, it becomes necessary to give attention to the variables that can deteriorate the main caregiver's well-being, but also to the extent that it is going to have a direct or an indirect repercussion on the quality of care being given, from a psychosocial adjustment approach [74]. Most of the initiatives along this line concentrate on recovering physical health and reestablishing support networks and the personal and social well-being of the caregiver, who after several years of dedication to such care has developed a considerable burden [75].

In short, knowing the specific needs of the caregivers and the real situation of their care is the first step in defining adequate support, not to reduce overburden as much as to avoid its appearance by finding out what the critical needs are from the beginning.

## 4. Evaluation of overburden in caregivers without specialized training in Alzheimer's patients

The above review of both terminology and needs of a specific caregiver profile suggests the necessity for taking another step further and materializing these contributions in the proposal of a burden evaluation instrument that enables approach to the difficulties with which caregivers are faced before they develop into a certain degree of overburden [76].

Although a wide variety of resources for the evaluation of the caregiver's burden is available [17], a stable preference since the decade of the 1990s for the reiterative use of generic scales such as the Zarit has been observed [7].

The Zarit Caregiver Burden Interview (ZBI) was originally an interview for evaluating primary caregivers of patients with dementia. This interview, with items found based on the most frequent areas mentioned by caregivers (according to the experience of the authors themselves), caretaker health, psychological well-being, finances, social life, and social relations, was administered to a sample of caregivers. It consists of 29 items which the caregiver answers with the best choice from "not at all" to "extremely" [77].

The Revised Memory and Behavior Problems Checklist is an instrument designed to evaluate the behavior problems of patients with dementia, although in the original study, the sample was composed of patients and their caregivers. As described by the authors, the instrument may be used for medical, cognitive, or psychological evaluation in any older person. It contains two subscales, one of them concentrating on observable behavior of the patient and the other on the reactions of the caregiver. The test is a 24-item self-report which the caregiver answers on a five-point Likert-type scale. It is reliable and validated, with an alpha of 0.84 for the patient behavior subscale and 0.90 for caregiver burden [78].

The Caregiver Appraisal Inventory (CAI) was derived from two different projects, one in which a relief program for caregivers of persons with dementia was carried out, and another called "institutionalization study," in which they followed the process of caregiving in the time elapsed between the application of the family for admission in an institution and the first month after admission. It is made up of 21 items (two for evaluation of the caregiving domain, 10 for the subjective burden, five for satisfaction or positive aspects of care, and four on impact). Concerning psychometric properties, internal consistency is acceptable on all the subscales [79].

Finally, for construction of the Caregiver Burden Inventory, a sample of caregivers of persons with senile dementia, Alzheimer's, or organic syndrome was used. The CBI establishes a multidimensional five-factor model of burden (related to the restrictions on caregiver time, feelings of being "left out" with respect to their peers, psychological well-being, social, and emotional burden). It is made up of 24 items which the caregiver answers on a four-point Likert-type scale. The psychometric properties found by the authors were a Cronbach's alpha of 0.85 for the time and developmental burden factors, 0.86 on the factor psychological burden, 0.73 on social burden, and 0.77 on emotional burden [80].

In line with the contributions described above, a model is proposed that argues for the development of an instrument to evaluate the specific needs of the family caregiver of Alzheimer's patients [45]. Therefore, the following factors should be considered for early detection of burnout in this concrete profile of caregivers (**Figure 1**). On one hand, the authors propose factors related to the caregiver, such as reaction (feelings) to the diagnosis, physical health, and knowledge of the illness. On the other, attention is given to the factors related to the patient, such as level of dependence. Finally, special attention should be given to the symptomatology,

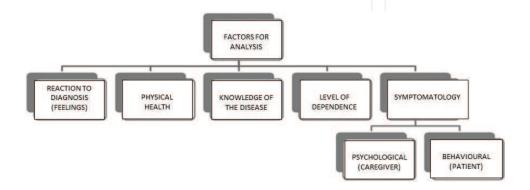


Figure 1. Factors of necessary for analysis of the family caregiver.

which in this case is presented as a two-dimensional factor, caretaker psychological symptomatology, and patient-behavioral symptomatology.

From this perspective and for the purpose of validating an instrument for early detection of the needs of family caregivers of Alzheimer-type dementia patients enabling the design of early intervention to avoid overburden syndrome in the caregiver, the Inventario de predictores de sobrecarga en cuidadores familiares sin formación especializada de enfermos de Alzheimer (Overburden Predictor Inventory for Alzheimer's patient family caregivers without specialized training) (IPSO-CA24) was developed. It is an evaluation instrument with a multidimensional approach to overburden in line with the current trend of considering the characteristics of patient and caregiver needs together. The psychometric properties are analyzed based on a descriptive study with a sample of caregivers. Starting from the results of the first implementation of the instrument, it is possible to identify six dimensions which function as overburden predictors [81]. Both the questionnaire and scales are available at the following link: www.grupocuidadores.com/ipso.

#### **Author details**

María del Carmen Pérez-Fuentes, María del Mar Molero Jurado\* and José Jesús Gázquez Linares

\*Address all correspondence to: mmj130@ual.es

University of Almeria, Almeria, Spain

#### References

- [1] Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: A systematic review and meta-analysis. Alzheimer's & Dementia. 2013;9(1): 63-75
- [2] World Health Organization and Alzheimer's Disease International. Dementia: A Public Health Priority. Geneva: World Health Organization; 2012
- [3] Herrera E, Muñoz I, Martín V, Cid M. Experiencias españolas en la promoción de la autonomía personal en las personas mayores. Gaceta Sanitaria. 2011;25(8):147-157
- [4] Rodríguez G. Políticas sociales de atención a la dependencia en los regímenes de bienestar de la Unión Europea. Cuadernos de Relaciones Laborales. 2011;**29**(1):13-42
- [5] Abellán A, Esparza C. Solidaridad familiar y dependencia entre las personas mayores. Madrid, Informes Portal Mayores, IMSERSO; 2010. p.99
- [6] Gázquez JJ, Pérez-Fuentes MC, Molero MM, Mercader I. Inteligencia emocional y calidad de vida del cuidador familiar de pacientes con demencia. Revista de Comunicación y Salud. 2015;5:1-15

- [7] Martos A, Cardila F, Barragán A, Pérez-Fuentes MC, Molero MM, Gázquez JJ. Instrumentos para la evaluación de la sobrecarga del cuidador familiar de personas con demencia. European Journal of Investigation in Health, Psychology and Education. 2015;5(2): 281-292
- [8] Molero MM, Pérez-Fuentes MC, Gázquez JJ, Mercader I, Abad T. Evaluación de la calidad de vida relacionada con la salud en población mayor: Revisión de instrumentos específicos. In: Gázquez JJ, Pérez-Fuentes MC, Molero MM, Mercader I, editors. Calidad de vida, Cuidadores e intervención para la mejora de la salud en el envejecimiento. Granada: Editorial GEU; 2013. pp. 93-100
- [9] Seidmann S, Stefani D, Pano CO, Acrich L, Pupko VB. Sentimiento de sobrecarga y apoyo social en cuidadores familiares de enfermos crónicos. Revista de Psicología. 2013;**22**(1): 45-62
- [10] Caqueo-Urízar A, Miranda-Castillo C, Lemos S, Lee S, Ramírez M, Mascayano F. An updated review on burden on caregivers of schizophrenia patients. Psicothema. 2014;26(2):235-243. DOI: 10.7334/psicothema2013.86
- [11] Fernández de Larrinoa P, Martínez S, Ortiz N, Carrasco M, Solabarrieta J, Gómez I. Autopercepción del estado de salud en familiares cuidadores y su relación con el nivel de sobrecarga. Psicothema. 2011;**23**(3):388-393
- [12] Delgado E, Suárez O, de Dios R, Valdespino I, Sousa Y, Braña G. Características y factores relacionados con sobrecarga en una muestra de cuidadores principales de pacientes ancianos con demencia. Medicina de Familia. 2014;40(2):57-64. DOI: 10.1016/j. semerg.2013.04.006
- [13] Flores N, Jenaro C, Moro L, Tomsa R. Salud y calidad de vida de cuidadores familiares y profesionales de personas mayores dependientes: Estudio comparativo. European Journal of Investigation in Health, Psychology and Education. 2014;4(2):79-88. DOI: 10.1989/ejihpe.v4i2.55
- [14] Kang HS, Myung W, Na DL, Kim SY, Lee JH, Han SH, Choi SH, Kim SY, Kim S, Kim DK. Factors associated with caregiver burden in patients with Alzheimer's disease. Psychiatry Investigation. 2014;11(2):152-159. DOI: 10.4306/pi.2014.11.2.152
- [15] Lanzón T, Díaz A. Papel predictor de las variables tipo de cuidador, nivel de dependencia y tiempo dedicado al cuidado en el impacto del estresor: Cuidar a un familiar dependiente. European Journal of Investigation in Health, Psychology and Education. 2015;4(3):193-202. DOI: 10.1989/ejihpe.v4i3.66
- [16] Graessel E, Berth H, Lichte T, Grau H. Subjective caregiver burden: Validity of the 10item short version of the Burden Scale for Family Caregivers BSFC-s. BMC Geriatrics. 2014;14:23. DOI: 10.1186/1471-2318-14-23
- [17] Crespo M, Rivas MT. La evaluación de la carga del cuidador: Una revisión más allá de la escala de Zarit. Clínica y Salud. 2015;**26**(1):9-16. DOI: 10.1016/j.clysa.2014.07.002

- [18] Martín-Carrasco M, Domínguez-Panchón AI, Muñoz-Hermoso P, González-Fraile E, Ballesteros-Rodríguez J. Instrumentos para medir la sobrecarga en el cuidador informal del paciente con demencia. Revista Española de Geriatría y Gerontología. 2013;48(6):276-284. DOI: 10.1016/j.regg.2013.06.002
- [19] Heidegger M. El Ser y el Tiempo. Madrid: Fondo de Cultura Económica; 2000
- [20] Hermanns M, Mastel-Smith B. Caregiving: A qualitative concept analysis. The Qualitative Report. 2012;17(75):1-18
- [21] Swanson EA, Jensen DP, Specht J, Johnson ML, Maas M, Saylor D. Caregiving: Concept analysis and outcomes. Scholarly Inquiry for Nursing Practice. 1997;11(1):65-76
- [22] Pearlin LK, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist. 1990;30(5):583-594
- [23] Rivas JC, Ostiguín, RM. Cuidador: ¿concepto operativo o preludio teórico?. Enfermería Universitaria. 2011;8(1):49-54
- [24] Eterovic CA, Mendoza SE, Sáez KL. Habilidad de cuidado y nivel de sobrecarga en cuidadoras/es informales de personas dependientes. Enfermería Global. 2015;**14**(2):235-248. DOI: http://dx.doi.org/10.6018/eglobal.14.2.198121
- [25] Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. Oncology Family Caregivers. 2012;**28**(4):236-245. DOI: http://dx.doi.org/10.1016/j.soncn.2012.09.006
- [26] Mendoza RM, Hernández EL, Medina M, Company MC, Gómez ML, Estrada L, Navarro FJ, Fiuza MD. Perfil del cuidador principal en el área de salud de Gran Canaria. Ene Revista de Enfermería. 2014;8(2): 0-0. DOI: http://dx.doi.org/10.4321/S1988-348X2014000200002
- [27] Moreno A, Ortega M, Gamero C. Los modelos familiares en España: Reflexionando sobre la ambivalencia familiar desde una aproximación teórica. Revista Española de Sociología. 2017;**26**(1):1-19
- [28] Kong EH. Family caregivers of older people in nursing homes. Asian Nursing Research. 2008;**2**(4):195-207
- [29] Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JH, Francke AL. Informal caregivers of people with dementia: Problems, needs and help in the initial stage and in subsequent stages of dementia: A questionnaire survey. The Open Nursing Journal. 2013;7:6-13. DOI: 10.2174/1874434601307010006
- [30] Islas NL, Ramos B, Aguilar MG, García ML. Perfil psicosocial del cuidador primario informal del paciente con EPOC. Revista del Instituto Nacional de Enfermedades Respiratorias. 2006;19(4):266-271
- [31] Seguí JD, Ortiz-Tallo M. Factores asociados al estrés del cuidador primario de niños con autismo: Sobrecarga, psicopatología y estado de salud. Anales de Psicología. 2008; 24(1):100-105

- [32] Caqueo-Urízar A, Segovia-Lagos P, Urrutia-Urrutia U, Castillo CM, Lechuga EN. Impacto de la relación de ayuda de cuidadores primarios en la calidad de vida de pacientes con cáncer avanzado. Psicooncología. 2013;10(1):95-108
- [33] Vázquez OG, Castillo ER, Huertas LA, García AM, Ponce JLA, Manzanilla EO. Aguilar SA. Guía de práctica clínica para la atención psico-oncológica del cuidador primario informal de pacientes con cáncer. Psicooncología. 2015;12(1):87-104
- [34] Calero-García MJ, Ortega AR, Jiménez C. El impacto del cuidador principal en el deterioro funcional y cognitivo del anciano hospitalizado. European Journal of Investigation in Health, Psychology and Education. 2012;2(2):41-52. DOI: 10.1989/ejihpe.v2i2.13
- [35] Martínez T, Serrano P, Del Rincón C, Martino R. Repercusiones en el cuidador principal del niño hospitalizado a domicilio en cuidados paliativos pediátricos. Medicina Paliativa. 2016;**23**(2):79-92. DOI: 10.1016/j.medipa.2013.12.004
- [36] Biurrun A. La asistencia de los familiares cuidadores en la enfermedad de Alzheimer. Revista Española de Geriatría y Gerontología. 2001;36(6):325-330. DOI: 10.1016/S0211-139X(01)74751-8
- [37] Twigg J. Cuidadores de los ancianos: Modelos para un análisis. In: Jamieson A, Illsley R, editors. Comparación de las políticas europeas de atención a las personas ancianas. Barcelona: SG Editores y Fundación Caja Madrid; 1993. pp. 35-51
- [38] Delicado MV, Candel E, Alfaro A, López M, García C. Interacción de enfermería y cuidadoras informales de personas dependientes. Atención Primaria. 2004;33(4):193-199
- [39] Tirado G, López-Saez A, Capilla C, Correa A, Geidel B. La Valoración en el Síndrome del Cuidador. Desarrollo Cientif Enferm. 2011;**19**(3):102-106
- [40] De la Cuesta C, Sandelowski M. The material world and craft of caregiving for relatives with dementia. Journal of Transcultural Nursing. 2005;16(3):218-225
- [41] Imserso. Informe 2014: Las Personas Mayores en España Datos Estadísticos Estatales y por Comunidades Autónomas. Madrid: Imserso; 2015
- [42] Domingo EP, Sierra MG, Valero MM, Castiñeira MPO. El Libro Blanco del Parkinson en España—Aproximación, análisis y propuesta de futuro. Madrid: Real Patronato sobre Discapacidad (Ministerio de Sanidad, Servicios Sociales e Igualdad) y Federación Española de Parkinson; 2015
- [43] García-Pereira S, Quevedo-Blasco R. Análisis de las revistas iberoamericanas de Psicología y de Educación indexadas en el Journal Citation Reports del 2013. European Journal of Education and Psychology. 2015;8(2):85-96. DOI: 10.1016/j.ejeps.2015.09.003
- [44] Ruiz-Robledillo N, Moya-Albiol L. El cuidado informal: Una visión actual. Revista de Motivación y Emoción. 2012;1:22-30
- [45] Pérez-Fuentes MC, Molero MM, Gázquez JJ, Mercader I, Soler F, Núñez A. Factores a tener en cuenta en la detección precoz del burnout en cuidadores familiares de enfermos

- de Alzheimer. In: Gázquez JJ, Pérez-Fuentes MC, Molero MM, Mercader I, Soler F, editors. Calidad de vida, cuidadores e intervención para la mejora de la salud en el envejecimiento Volumen II. Almería: ASUNIVEP; 2014. pp. 155-160
- [46] Van der Lee J, Bakker TJEM, Duivenvoorden HJ, Dröes RM. Multivariate models of subjective caregiver burden in dementia: A systematic review. Ageing Research Reviews. 2014;**15**:76-93. DOI: 10.1016/j.arr.2014.03.003
- [47] Papastavrou E, Tsangari H, Karayiannis G, Papacostas S, Efstathiou G, Sourtzi P. Caring and coping: the dementia caregivers. Aging and Mental Health. 2011;15(6):702-711. DOI: 10.1080/13607863.2011.562178
- [48] Zarit SH, Femia EE, Kim K, Whitlatch CJ. The structure of risk factors and outcomes for family caregivers: Implications for assessment and treatment. Aging & Mental Health. 2010;14(2):220-231. DOI: 10.1080/13607860903167861
- [49] Molero MM, Pérez-Fuentes MC, Gázquez JJ. Cuidadores familiars, no profesionales o informales: Revisión de la terminología en publicaciones científicas. Revista Facultad de Ciencias de la Salud UDES. 2016;3(1):59-67. DOI: 10.20320/rfcsudes.v3i1.107
- [50] Vives M, Orte C, Sánchez L. Identificación de competencias y habilidades del buen profesional que trabaja con personas mayores a través de la técnica Delphi. European Journal of Investigation in Health, Psychology and Education. 2016;6(1):37-46
- [51] Organización Mundial de la Salud. Demencia: Una prioridad de Salud Pública. Washington, DC: OMS; 2013
- [52] Armayor AC, Vivar C, Durán CN. Dependencia y familia cuidadora: reflexiones para un abordaje familiar. Anales del Sistema Sanitario de Navarra. 2012;34(3):463-469
- [53] Hooker SA, Grigsby ME, Riegel B, Bekelman DB. The impact of relationship quality on health-related outcomes in heart failure patients and informal family caregivers: An integrative review. The Journal of Cardiovascular Nursing. 2015;30(4):S52-S63. DOI: 10.1097/JCN.00000000000000270
- [54] Caron R, Caron L. The mental stress of the accompaniment in Alzheimer's disease. Encephale. 2011;37(6):439-447
- [55] Robles MJ, Cucurella E, Formiga F, Fort I, Rodríguez D, Barranco E, Catena J, Cubí D. La información del diagnóstico en la demencia. Revista Española de Geriatría y Gerontología. 2011;46(3):163-169
- [56] Drickamer MA, Lachs MS. Should patients with Alzheimer's disease be told their diagnosis? The New England Journal of Medicine. 1992;326:947-951. DOI: 10.1056/ NEJM199204023261410
- [57] Smith A, King E, Hindley N, Barnetson L, Barton J, Jobst KA. The experience of research participation and the value of diagnosis in dementia: Implications for practice. Journal of Mental Health. 1998;7:309-321. DOI: http://dx.doi.org/10.1080/09638239818120

- [58] Carpenter B, Dave J. Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. The Gerontologist. 2004;44(2):149-158
- [59] Pinner G, Bouman WP. Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. International Psychogeriatrics. 2003;15(3):279-288
- [60] Alzheimer Europe. Who Cares? The State of Dementia Care in Europe. 2006. Available from: http://www.alzheimer-europe.org/./Alzheimer-Europe./Whocares-The-state-of-dementia-care-in-Europe
- [61] Feldberg C, Tartaglini MF, Clemente MA, Petracca G, Cáceres F, Stefani D. Vulnerabilidad psicosocial del cuidador familiar. Creencias acerca del estado de salud del paciente neurológico y el sentimiento de sobrecarga. Neurología. 2011;3(1):11-16
- [62] De Valle-Alonso MJ, Hernández-López IE, Zúñiga-Vargas ML, Martínez-Aguilera P. Sobrecarga y Burnout en cuidadores informales del adulto mayor. Enfermería Universitaria. 2015;12(1):19-27. DOI: 10.1016/j.reu.2015.05.004
- [63] Vázquez FL, Blanco V, Hermida E, Otero P, Torres A, Díaz-Fernández O. Eficacia de las intervenciones psicológicas breves para reducir los síntomas depresivos en cuidadores: Revisión sistemática y meta-análisis. Revista de Psicopatología y Psicología Clínica. 2015;20(3):173-188. DOI: 10.5944/rppc.vol.20.num.3.2015.15891
- [64] Rosa E, Lussignoli G, Sabbatini F, Chiappa A, Di Cesare S, Lamanna L, Zanetti O. Needs of caregivers of the patients with dementia. Archives of Gerontology and Geriatrics. 2010;51(1):54-58. DOI: 10.1016/j.archger.2009.07.008
- [65] Saavedra FJ, Bascón MJ, Sánchez SA, Calderón MG, Moreno DM. Cuidadoras de familiares dependientes y salud: Influencia de la participación en un taller de control de estrés. Clínica y Salud. 2013;24(2):85-93
- [66] Brown RM, Brown SL. Informal caregiving: A reappraisal of effects on caregivers. Social Issues and Policy Review. 2014;8(1):74-102. DOI: 10.1111/sipr.12002
- [67] Richardson TJ, Lee SJ, Berg-Weger M, Grossberg GT. Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. Current Psychiatry Reports. 2013;15(7):1-7. DOI: 10.1007/s11920-013-0367-2
- [68] Gila MJ, Sánchez RO, Gómez-Caro S, Oropesa AS, Morena JC, Moreno FJ. El rol de cuidador de personas dependientes y sus repercusiones sobre su calidad de vida y su salud. Revista Clínica de Medicina Familiar. 2009;**2**(7):332-334
- [69] Manso ME, Sánchez MDP, Flores IC. Salud y sobrecarga percibida en personas cuidadoras familiares de una zona rural. Clínica y Salud. 2013;24(1):37-45. DOI: http://dx.doi.org/10.5093/cl2013a5
- [70] Urdaneta E, Etxeberria I, Galdona N, Yanguas JJ, García A, Buiza C. Perceived social help, psychosomatic complaints and burden: The relationship with negative affect in Alzheimer caregivers. Alzheimer's & Dementia. 2008;44:660

- [71] Cardila F, Martos A, Barragán AB, Pérez-Fuentes MC, Molero MM, Gázquez JJ. Prevalencia de la depresión en España: Análisis de los últimos 15 años. European Journal of Investigation in Health, Psychology and Education. 2015;5(2):267-279
- [72] Vázquez FL, Otero P, Torres A, Hermida E, Blanco V, Díaz O. Una intervención breve de solución de problemas para la prevención indicada de la depresión en cuidadoras. Psicothema. 2013;25(1):87-92
- [73] Corazza DI, Pedroso RV, Andreatto CA, Scarpari L, Garuffi M, Costa JL, Santos-Galduróz RF. Los predictores psiconeuroinmunológicos de la sobrecarga de cuidado en ancianos cuidadores de pacientes con enfermedad de Alzheimer. Revista Española de Geriatría y Gerontología. 2014;49(4):173-178. DOI: 10.1016/j.regg.2014.03.007
- [74] Rodríguez-Fernández A, Ramos-Díaz E, Madariaga JM, Arrivillaga A, Galende N. Steps in the construction and verification of an explanatory model of psychosocial adjustment. European Journal of Education and Psychology. 2016;9(1):20-28. DOI: 10.1016/j. ejeps.2015.11.002
- [75] Sánchez R, Molina E, Gómez-Ortega O. Intervenciones de enfermería para disminuir la sobrecarga en cuidadores: Un estudio piloto. Revista Cuidarte. 2016;7(1):1171-1184. DOI: http://dx.doi.org/10.15649/cuidarte.v7i1.251
- [76] Garand L, Rinaldo DE, Alberth MM, Delany J, Beasock SL, Lopez OL, Dew MA. Effects of problem a solving therapy on mental health outcomes in family caregivers of persons with a new diagnosis of mild cognitive impairment or early dementia: A randomized controlled trial. The American Journal of Geriatric Psychiatry. 2013;22(8):771-781
- [77] Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly. Correlates of feelings of burden. The Gerontologist. 1980;20:649-654
- [78] Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, Vitaliano PP. Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist (RMBPC). Psychology and Aging. 1992;7(4):622-631
- [79] Lawton MP, Kleban M, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. Journal of Gerontology. 1989;44:61-71
- [80] Novak M, Guest CI. Application of a multidimensional caregiver burden inventory. The Gerontologist. 1989;29:798-803
- [81] Pérez-Fuentes MC, Gázquez JJ, Ruiz MD, Molero MM. Inventory of overburden in Alzheimer's patient family caregivers with no specialized training. International Journal of Clinical and Health Psychology. 2017;17:56-64. DOI: http://dx.doi.org/10.1016/j.ijchp. 2016.09.004

## IntechOpen

# IntechOpen