ARTIGO DE REVISÃO

A sobrecarga de cuidadores de idosos demenciados no Brasil: uma revisão integrativa da literatura

The burden of caregivers for elderly relatives with dementia in brazil: an integrative literature review

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RESUMO
Este estudo descreve a sobrecarga de cuidadores de idosos demenciados no Brasil por meio de uma revisão integrativa da literatura, no período de 1999 a 2009, publicado em português e em inglês. Os dados foram coletados pelas bases de dados eletrônicas Pubmed, Cinahl e Lilacs. As palavras-chave usadas na CINAHL e na Pubmed foram: dementia or cognitive impairment, aged or older people, Brazil, caregiver burden or caregiver stress or caregiver strain. Foram encontradas 14 pesquisas. As palavras-chave usadas nos LILACS na categoria DeCS foram: “idosos”, “cuidadores” e “demência” foram combinados com “e”, que conduziram a 25 estudos. Aproximadamente 39 estudos foram selecionados, os quais foram reduzidos então a vinte, após temas não relacionados, a língua espanhola, pesquisas repetidas, teses/dissertações e livros. As pesquisas foram organizadas em três temas: doze (60%) focalizaram na correlação entre a sobrecarga e as características dos cuidadores e dos idosos; seis (30%) reportaram as experiências e sentimentos dos cuidadores; e dois (10%) discutiram a definição de sobrecarga. Há necessidade de que os serviços sanitários governamentais brasileiros, as universidades, as organizações não governamentais e outras agências e redes planejem propostas formais e informais de intervenção dirigidas aos cuidadores informais.

Palavras-chave: idoso, demência, cuidadores, família

ABSTRACT
This study describes Brazilian caregiver burden in the case of demented aged people, through an integrative review, from 1999 to 2009, published in Portuguese and English. Data were collected through the electronic databases Pubmed, CINAHL and LILACS. The keywords used in CINAHL and Pubmed databases were: “dementia” OR “cognitive impairment”, “aged” OR “older people”, “Brazil”, “caregiver burden” OR “caregiver stress” OR “caregiver strain”. A total of 14 papers were found. The keywords used in LILACS in the field DeCS category were “aged”, “caregivers” and “dementia” combined with AND, which resulted in 25 studies. About 39 papers were selected, which were then reduced to 19, after unrelated themes, the Spanish language, duplicate papers, reviews, theses/dissertations and books. The studies were organized into three categories: 11 (57.9%) focused the correlation between caregiver burden and the characteristics of the caregivers and the demented elderly individuals; six (31.6%) reported the experiences and feelings reported by the caregivers; only one (5.3%) exclusively focused on the definition of burden and one (5.3%) even reported the reliability of a specific instrument directed to the Brazilian population addressing caregiver burden. The Brazilian government and city health services, universities, non-governmental organizations and other agencies and networks urgently need to organize in order to devise formal and informal intervention proposals directed to informal caregivers.

Keywords: elderly, dementia, caregivers, family
INTRODUCTION

Population aging is one of the greatest accomplishments of humanity, but it also represents one of the greatest challenges for health managers. According to demographic data, the world elderly population will grow 160%, from 375 to 975 million, between 1980 and 2020. Around 80% of this increase will occur in Third World countries. The forecast for Brazil is an increase of 280%, from 7.5 to almost 30 million, in the period mentioned above. Therefore Brazil, which used to rank the 16th position in the world in terms of its elderly population, will occupy the 6th position in 2020.

In addition to decreased physical capacity associated with the aging process, other factors contributing to elderly individuals becoming more vulnerable to pathological processes such as chronic diseases, includes cognitive decline, which consists of generalized and mild slowness, and loss of precision. Mental decline can be measured by objective tests relating situations in a person’s daily routine.

Cognitive impairment can occur in association with various factors, the most prevalent is dementia, which is seen as a medical condition or syndrome, clinically characterized by a gradual decline in cognitive functions, changes in personality and behavior, and deteriorated performance of tasks in the patient’s daily routine.

In terms of cognitive impairment, deficiency in the elderly individuals’ functional capacity, associated with either dementia or other problems, can also occur and lead to a progressive loss of autonomy and independence. Hence, the family is usually the body that, unexpectedly, assumes responsibility for care. This situation has frequently led caregivers to present depression and anxiety, which also contribute to the deterioration of their physical condition.

In this respect, this paper is part of a project that attempted to synthesize the knowledge of Brazilian caregiver burden as published in literature in order to answer the following question: What have Brazilian researchers published concerning caregiver burden involving elderly people with dementia?

Lack of knowledge regarding elderly individuals with cognitive impairment and the burden imposed by the activity of providing care at home, in Brazil, justifies conducting this study.

OBJECTIVES

This study describes Brazilian caregiver burden in the case of demented aged people, through papers published in national and international literature, from 1999 to 2009, published in Portuguese and English.

METHODS

An integrative literature review was carried out to identify publications addressing caregiver burden involving demented elderly individuals. Integrative reviews are the broadest category of research reviews and can encompass empirical or theoretical literature, or both, depending on the purpose of the research and a summary of the literature on a specific concept or content field whereby the research is summarized, analyzed, and overall conclusions are drawn.

The focus of this review was just of articles focusing on only Brazilian samples and the inclusion criteria used in were:

- Scientific studies carried out in Brazil with demented elderly individuals and family
caregivers, involving the specific content of caregiver burden;

- Published between 1999 and 2009;
- Written either in Portuguese or English;
- Only scientific papers; book’s chapters, thesis and dissertations were excluded;
- Available on line, or in the University of Alabama library.

Data were collected through the electronic databases Pubmed, CINAHL and LILACS. The keywords used in CINAHL and Pubmed databases were: “dementia” OR “cognitive impairment”, “aged” OR “older people”, “Brazil”, “caregiver burden” OR “caregiver stress” OR “caregiver strain”. These four searches were combined with the AND operator to identify the Brazilian studies addressing caregiver burden involving aged people with dementia. A total of 14 papers were found. After duplicate papers, papers addressing unrelated themes, and books and theses/dissertations were excluded, eight papers remained. The search was restricted to the period between January 1999 and November 2009.

The keywords used in LILACS in the DeCS category were “aged”, “caregivers” and “dementia” combined with AND, which resulted in 25 studies. When the same three keywords were combined in the field Words 58 studies were identified. Hence, 83 studies were identified, which were then reduced to 12, after unrelated themes, the Spanish language, duplicate papers, reviews, theses/dissertations and books were excluded.

With different methodological approaches, 97 full texts were identified, 19 of which addressed the focus of the study. All of them were read and data were collected through a validated form, which included the characterization of papers and that of authors, purpose and type of study, sample, inclusion criteria and interpretation of results.

**RESULTS**

Of the 19 reviewed papers, nine (47.3%) were published between 2007 and 2009, eight (42.1%) from 2004 to 2006, one (5.3%) from 2001 to 2003, and one (5.3%) were published between 1999 and 2000, showing that this theme has received more attention in recent years.

All of the papers concern studies carried out in Brazil and published in 18 different journals; only five (26.3%) were published in international journals. Fourteen (73.7%) were Brazilian papers and 11 (57.9%) were from the field of nursing. Eighteen (94.7%) studies had nurses as co-authors, including physicians, social workers, and psychologists, while one (5.3%) had only physicians as authors.

In analyzing the method used in the studies, seven (36.8%) were quantitative studies, four of which (57.1%) used a cross-sectional method, one (14.3%) a retrospective, another used the transversal method and another used the case study method. Of the 19 reviewed studies, six (31.6%) used the qualitative method and six (31.6%) did not mention the type of method used in the study.

In relation to the interpretation of results, 12 (63.1%) reported recommendations for policy or practice, followed by nine (47.4%) that presented suggestions for further research, one (5.3%) presented suggestions for future reviews, presented conditions that impact policy or practice and suggestions for in depth theory development. Some of these studies reported more than one interpretation of results. Some studies reported more than one interpretation (Tables 1, 2 and 3).
### Table 1. Articles reporting researches from Pubmed database focused on caregivers burden of demented elderly in Brazil, 1999 - 2009

<table>
<thead>
<tr>
<th>Study</th>
<th>Area</th>
<th>Purpose</th>
<th>Sample</th>
<th>Inclusion criteria</th>
<th>Research Methodology</th>
<th>Interpretation of Results*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Creese et.al 2008. Int Psychogeriatr. English</td>
<td>Medicine</td>
<td>To investigate the sleep characteristics of a sample of spousal caregivers currently residing with the dementia care recipient.</td>
<td>60 spousal caregivers of individuals with Alzheimer's disease</td>
<td>No</td>
<td>Not mentioned</td>
<td>A</td>
</tr>
<tr>
<td>2) Cassis et.al.2007. Rev Assoc Med Bras. Portuguese.</td>
<td>Medicine</td>
<td>To verify the correlation between caregiver burden in dementia and characteristics of patients and caregivers.</td>
<td>67 demented elderly and their respective caregivers</td>
<td>Yes</td>
<td>Retrospective study</td>
<td>A</td>
</tr>
<tr>
<td>3) Bandeira et.al, 2007 Ment Health. English.</td>
<td>Psychology</td>
<td>To evaluate stress, anxiety, depression, and feelings of hopelessness in caregivers of relatives with dementia.</td>
<td>129 caregivers and 145 non-caregivers of relatives with dementia</td>
<td>No</td>
<td>Not mentioned</td>
<td>A, B</td>
</tr>
<tr>
<td>5) Taub et.al, 2004. Cad Saude Publica. English.</td>
<td></td>
<td>To examine the reliability of the Brazilian version of the Zarit Caregiver Burden Interview (ZBI).</td>
<td>50 primary informal caregivers of demented patients.</td>
<td>No</td>
<td>Not mentioned</td>
<td>A</td>
</tr>
<tr>
<td>6) Scazufca et.al, 2002 Psychiatr Epidemiol. English.</td>
<td>Psychiatry</td>
<td>To examine the burden and distress reported by carers of elderly patients with depression.</td>
<td>82 patients and their relative caregivers</td>
<td>Yes</td>
<td>Cross-sectional study</td>
<td>B,D</td>
</tr>
<tr>
<td>Study</td>
<td>Area</td>
<td>Purpose</td>
<td>Sample</td>
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<tr>
<td>1) Inouye et al, 2009. Rev Latino-am Enfermagem. Port/English.</td>
<td>Nursing</td>
<td>To evaluate the perceived quality of life of elderly patients with dementia and their respective family caregivers and identify correlations between variables.</td>
<td>106 elderly with Alzheimer disease and their respective caregivers</td>
<td>Yes</td>
<td>Not mentioned</td>
<td>A</td>
</tr>
<tr>
<td>2) Fialho et al, 2009. Dement. Neuropsychol. English</td>
<td>Nursing</td>
<td>To investigate the relationship between the presence of neuropsychiatric symptoms and the level of caregiver burden in a group of Brazilian elderly with dementia.</td>
<td>83 family-caregivers of patients with dementia</td>
<td>Yes</td>
<td>Not mentioned</td>
<td>B</td>
</tr>
<tr>
<td>3) Fonseca &amp; Soares, 2008. Revista da Rede de Enfermagem do Nordeste. Portuguese</td>
<td>Nursing</td>
<td>To learn about the intervening factors that contribute with the difficulties felt by the care taker in the activities developed by the elderly with Alzheimer's disease.</td>
<td>Eight care takers</td>
<td>Yes</td>
<td>Qualitative study</td>
<td>B, C</td>
</tr>
<tr>
<td>4) Celich &amp; Batistella, 2007. Cogitare enferm; Portuguese.</td>
<td>Nursing</td>
<td>To describe the life experience and feelings of the family caregiver of Alzheimer's Disease patient.</td>
<td>Five female family members that are the principal caregivers of five elderly with this dementia</td>
<td>No</td>
<td>Qualitative study (Phenomenology)</td>
<td>B</td>
</tr>
<tr>
<td>5) Silveira et. al, 2006. Cad. Saúde Pública. Portuguese.</td>
<td>Nursing</td>
<td>To contribute to a better understanding of the main family caregivers of highly dependent elderly.</td>
<td>24 primary informal caregivers of demented patients</td>
<td>No</td>
<td>Qualitative study (Transversal)</td>
<td>E</td>
</tr>
<tr>
<td>6) Lemos et al, 2006. Saúde e Sociedade. Portuguese.</td>
<td>Social work</td>
<td>To evaluate the subjective impact of Alzheimer's Disease (AD) on the lives of the primary family caregivers of patients suffering from said disease.</td>
<td>29 primary informal caregivers of patients with DA</td>
<td>Yes</td>
<td>Transversal study</td>
<td>B</td>
</tr>
<tr>
<td>7) Luzardo et al, 2006. Texto Contexto Enferm; Portuguese.</td>
<td>Nursing</td>
<td>To describe the features of the elderly with Alzheimer's disease and of their caregivers.</td>
<td>36 elderly individuals with Alzheimer's disease and their respective caregivers</td>
<td>Yes</td>
<td>Exploratory descriptive and Cross Sectional study</td>
<td>A, B</td>
</tr>
<tr>
<td>8) Santana et al, 2005 Rev Bras Enferm. Portuguese</td>
<td>Nursing</td>
<td>To describe the characteristics of elderly and their caregivers in attendance at the neurogeriatric ambulatory and to identify nursing and care diagnosis used by caregivers, through EDG, MEEM, AIVDs and AIVs applied in nursing assessments.</td>
<td>16 elderly with dementia and their respective caregivers</td>
<td>No</td>
<td>Case study (Quantitative)</td>
<td>B</td>
</tr>
<tr>
<td>9) Caldeira &amp; Ribeiro, 2004. Arq Ciênc Saúde. Portuguese.</td>
<td>Nursing</td>
<td>To analyze the caregivers' knowledge in relation to the main care of older people with Alzheimer.</td>
<td>Eight primary informal caregivers of patients with DA</td>
<td>No</td>
<td>Qualitative study (Descriptive)</td>
<td>B</td>
</tr>
<tr>
<td>10) Coelho &amp; Alvim, 2004. Rev Bras Enferm. Portuguese.</td>
<td>Nursing</td>
<td>To describe the experiences of the family members in living with the elderly with AD and analyze aspects that interfere with the transformations of family dynamics since the onset of the disease.</td>
<td>Eight primary informal caregivers of patients with DA</td>
<td>No</td>
<td>Qualitative study</td>
<td>No</td>
</tr>
<tr>
<td>11) Silveira, 2000. Textos Envelhecimento. Portuguese.</td>
<td>Nursing</td>
<td>To analyze the changes in the familiar system after occurs the process of dementia in relative one, and the beliefs above the caring.</td>
<td>Eight primary informal caregivers of patients with DA</td>
<td>No</td>
<td>Not mentioned</td>
<td>No</td>
</tr>
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</table>

Table 2. Articles reporting researches from Lilacs database focused on caregivers burden of dementedelderly in Brazil, 1999 - 2009
Concerning the categories of discussion, the studies were organized into three categories: 11 (57.9%) focused the correlation between caregiver burden and the characteristics of the caregivers and the demented elderly individuals; six (31.6%) reported the experiences and feelings reported by the caregivers; only one (5.3%) exclusively focussed on the definition of burden; one (5.3%) even reported the reliability of a specific instrument directed to the Brazilian population addressing caregiver burden. Hence, these two last themes were combined into one category of discussion.

**DISCUSSION**

**Caregiver burden correlated with characteristics of demented elderly individuals and caregivers**

Twelve papers demonstrated the relationship between the characteristics of caregivers and care recipients with dementia and the impact on caregiver burden. Burden has been associated with behavioral disorders, dependency, cognitive impairment of the demented elderly individual, as well as the onset of symptoms, care giving and co-residency, caregiver age and gender, caregiver knowledge and care costs.

Taking care of elderly demented individuals, especially when they present behavioral changes, can be exhausting for both the family and caregivers. Generally, this leads to changes in family lifestyle, and the caregiver must deal with a range of problems. A study conducted with 67 patients (76.8 years, 53.7% women) and 82% female caregivers demonstrated that some characteristics were strongly correlated with caregiver burden, such as demented elderly behavioral disorders \(p<0.001\), dependency \(p=0.003\), onset of symptoms \(p=0.016\) and of care giving \(p<0.001\), previous diagnosis \(p=0.016\), and co-residency \(p=0.002\)^4. It is common to find significant positive correlation between the presence of severe behavioral manifestations in demented elderly individuals and high levels of caregiver burden^7.

Behavioral manifestations in demented elderly individuals are manifested as disorientation, aggressiveness, skin drought, urinary incontinence, disturbances in the family relationship, which is among the mostly harmful, and increase caregiver burden^6. In addition to increased care burden, these behavioral manifestations contribute to sleep disruptions in caregivers’ lives, as well. Another study revealed that 63% of caregivers’ spouses reported sleep disruptions due to the nocturnal behavior of the
recipients of their care. Poorer caregiver sleep quality was associated with higher frequency of nocturnal disruptions by the care recipients.9

Another review of studies investigating the association between behavioral problems in patients with dementia and the burden of caregivers reported that all studies indicated that behavioral disturbances are an important cause of burden, although there was little consistency in the definition of “behavioral disturbances”10.

When comparing groups of caregivers of demented elderly and caregivers of non-demented elderly, the first is more likely to have ‘pathological stress’ than the control group, and also presenting significantly more anxiety and hopelessness11. Caregivers of patients with more severe depression and patients who reported that they had symptoms for longer periods reported more burden. Caregivers who perceived more Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and behavioral and mood problems in patients also reported more burden. Another study conducting a multivariate analysis revealed that caregivers’ emotional distress and patients’ behavior and mood problems were independently associated with burden scores12.

The burden upon caregivers may be considered to be a result of the personality and behavior changes in each stage of dementia that these observe in their loved ones. As expected, it was revealed that the greater the degree of dementia, the greater the interference in the caregivers’ lives tended to be. As the disease progresses, individuals need more and more supervision and care13.

Many studies in the literature also show that the characteristics of caregivers influence caregiver burden. Gender influences kinship roles and perceptions of caregiver burden. Some studies have found that female caregivers tend to report more health problems and depressive symptoms than male caregivers9,12,14. The results of one study, however, found that there are no significant differences in the burden level with regard to gender or age. These could be related to sample size and the authors suggest further exploring these issues in future studies7.

Age may also influence caregiver burden. One study demonstrated that younger relatives reported more burden than older ones. Caregivers that were children of patients reported more burden than caregivers who were spouses or had other relationships with patients12. Other socio-demographic characteristics of relatives were not statistically associated with burden (education, job, income, living with patient, number of hours of contact per week), nor was the number of physical problems reported by relatives positively associated with relatives’ burden12.

Another important factor reported in the studies is related to caregiver knowledge concerning the disease. When caregivers did not adequately understand the several potential manifestations of the dementia, caregiver exhaustion and family conflicts are more likely to happen8. Family caregivers need not only receive education regarding the disease but should also receive regular home visits from health professionals in order to better deal with more idiosyncratic problems, such as certain types of behavior. This is an essential requirement for satisfying the needs of both demented elderly people and their caregivers. Groups supporting the family and the caregivers of elderly individuals with Alzheimer’s are rich knowledge resources that deserve attention from and participation with health professionals, especially nurses15.

Finally, the results of another study contribute to understanding the costs involved in caring for elderly individuals with dementia and the impact of this type of care on family income, such as caregiver burden. In the group studied, the monthly family income was greater than or equal to five times the minimum wage in 62.4%
of cases. This corresponds to an annual family income of US$ 3,967.00. The findings suggest that the financial impact of caring for an elderly person with dementia is considerable, compromising an average of 66% of the family income. The expenditure may reach 75% of family income in cases of patients in the initial stages, 62% at advanced stages, and approximately 80% when the dementia is associated with another chronic disease

**Experiences of caregivers**

Six articles addressed the experience of caring for an elderly demented relative. Some studies investigated the caregivers’ personalities and how these influenced the activity of caring and also the decision of choosing someone to provide care for the patient.

Caregivers are resolute people who try to solve problems. They perform many tasks at the same time and feel like they are the best ones to do what they do. These characteristics are mainly perceived in female caregivers. In general, caregivers do not ask for help because they either believe they are the most capable to provide care or because they think that others should realize they are in need without being asked. Taking care of a demented elderly relative elicits many contradictory feelings in a short period of time: love and anger, patience and intolerance, affection, sadness, irritation, loss of heart, punishment, defiance, unreliability, pessimism, solitude, doubts concerning how to provide care, fear of becoming sick as well, fear that the patient is suffering, fear that the patient will die. The most common feeling was guilt, especially when the demented relative is suffering.

In the most of analyzed studies, women accounted for the majority of caregivers which contributes to the fact that in Brazil the role of caring is culturally and socially attributed to women. Women first care for their children, then for their parents, and finally for their husbands. Caregivers are usually in the adult age group, in which women have several social roles, such as working outside of the home, in addition to caring for their elderly parents and/or husbands. This phenomenon is expected since in Brazil women live longer than men, and, by the time they are affected with dementia, most of them are already widows. This fact explains some conflicts in family relationship because arrangements have to be made at the level of the family core and problems sometimes may reflect a lack of willingness to provide care when electing a caregiver is based on care needs.

Consequently, those who are chosen to play the caregiver role, usually do not know how to deal with the situation since most of them do not understand the symptoms and consequences of such a disease affecting the health of the elderly individual and that of their own. Most caregivers do not feel comfortable with the situation, either because they do not have enough family support or because there is no better clinical prospect or for other reasons. This is so even when they are interested in learning how to deal with these individuals and to practice self-care.

Even though there have been changes in the roles of family members, when one family member becomes sick and can no longer fulfill the caregiver role, the family becomes unbalanced and a crisis is triggered, which requires it to reorganize (such as when a daughter who cares for her the mother gets a job or starts to dedicate time to her husband or children that would otherwise be dedicated to the patient). The situation may be aggravated because the care provided to demented patients can last many years, making negotiations within the family concerning who should provide care become even more complex.
In a study conducted with five female caregivers of five elderly individuals with dementia, the authors concluded that being the main caregiver of an elderly individual with dementia is a challenge, especially when one does not receive family or social support. Caregivers become fragile, as well, due to their advanced age; they become physically and emotionally stressed and are required to provide such care because they have no other option, though they attempt to be patient, tolerant, affectionate and respectful. It is essential that caregivers are understood and supported during the caring process.

At the present, support networks are still insufficient to provide adequate support to elderly Brazilian individuals and their families. The need for comprehensive healthcare models for physically and mentally dependent elderly people should be voiced by the diverse sectors of society, aiming to achieve the goals of the Brazilian National Policy for the Elderly and the Program of Family Healthcare. There is an urgent need for interdisciplinary interventions that facilitate the daily lives of caregivers with regard to caring for demented elderly individuals at home, according to the needs of the family.

**Caregiver burden instrument and definition**

Only one article used an evaluation instrument, the Brazilian version of the Zarit Burden Interview (ZBI). The ZBI is a 22-item scale assessing the degree to which caregivers perceive their health, personal and social life, finances and emotional well being, and how they are affected as a result of providing care to a relative. Caregivers were asked how frequently they presented each of the 22 items; answers ranged from “never” to “always”. A total score was obtained by summing all items (scores range from 0 to 88); higher scores indicate more burden.

This study revealed that this instrument is easy to administer to the caregivers of dementia patients. It also proved to be reliable, with overall reliability rates that were comparable to those of previous studies. This is supported by the fact that the profile of the studied caregivers was similar to that of the original study. The Brazilian version of ZBI is a reliable instrument to be used as a measure of caregiver burden related to dementia. The rate of reliability proved to be comparable to the original version and is a useful instrument to be applied both in research and clinical practice.

Another study addressed the definition of burden, specifically the definition of subjective burden. Objective burden of informal care giving refers to the amount of time spent in care giving, the caregiver’s tasks that are performed and potential financial problems. Subjective burden refers to how the informal caregiver perceives the impact of the objective burden related to care giving.

The caregivers of patients with Alzheimer’s disease present high levels of subjective impact. The impact level depends on factors such as caregivers’ level of education and the patients’ degree of dependence. Caregivers who present greater level of subjective impact have a higher level of education, as well as those who take care of bedridden patients. The subjective impact of AD in caregivers was deemed significant and subject to various factors such as caregivers’ educational level and the patients’ level of dependence.

Explaining the subjective burden of care and understanding what elements contribute to it are important lines of research. Only one paper in this review focused on this topic. If the aim of healthcare is to preserve and restore health, it seems logical that the health of caregivers, as well as that of patients, should be preserved.
CONCLUSION

This review reveals that the situation of constantly providing care to elderly individuals with dementia poses important burden risks to Brazilians caregivers. Therefore, providing psychological and social support to caregivers is essential. Further research is needed to more deeply evaluate symptoms of subjective burden in caregivers providing care to the demented elderly population, and also to focus on the effective use of the resources, such as social support and coping strategies, used by caregivers when facing the task of caring for a relative with dementia.

This study provided a better understanding of caregiver burden experienced by those caring for elderly individuals with dementia in Brazil. The Brazilian government and city health services, universities, non-governmental organizations and other agencies and networks urgently need to organize in order to devise formal and informal intervention proposals directed to informal caregivers.

REFERENCES