

Overburden of family caregivers of elderly with depression: intervention strategies

Sobrecarga de cuidadores familiares de idosos com depressão: estratégias de intervenções

Sobrecarga de cuidadores familiares de ancianos con depresión: estrategias de intervenciones

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This is an integrative review that aimed to know the main coping strategies (psychological adaptation) to decrease the burden of family caregivers of older adults with depression, expressed in scientific production. The searches were done in Medline, Lilacs, Redalyc, Scielo and Pepsic with combinations of descriptors: caregiver, aged, depression, workload, psychological adjustment, in Portuguese, English and Spanish, considering the period from January 2014 to May 2019. The recovery consisted of 35 productions, categorized after by thematic similarities. The categories constructed were: *psychological strategies at the individual level* with 23 articles and *Coping strategies in the social sphere: Public Policies* with 12 articles. The main strategies to reduce the burden on family elderly caregivers, at the individual level, were: self-care behavior promotion, teaching relaxation techniques, conflict management and decision making, contributions to improve the social skills of the informal caregivers, and encouraging to spirituality as a protective factor for the elderly and families. In coping strategies related to the creation of Public Policies it was observed: formal support to caregivers, encouraging to social support, powerful implementation of the Family Health Strategy, implementation of Home Care in an organized way and home care service.

Descriptors: Caregivers; Aged; Depression.

Esta é uma revisão integrativa que teve por objetivo conhecer as principais estratégias de enfrentamento (adaptação psicológica) para diminuir a sobrecarga de familiares cuidadores de idosos com depressão, expressas nas produções científicas. As buscas ocorreram nas bases de dados Medline, Lilacs, Redalyc, Scielo e Pepsic, com combinações dos descritores: cuidador, idoso, depressão, carga de trabalho, adaptação psicológica, nos idiomas em português, inglês e espanhol, considerando o período de janeiro de 2014 a maio de 2019. Recuperou-se 35 produções, categorizados após por similitudes temáticas. As categorias construídas foram: *Estratégias psicológicas no âmbito individual* com 23 artigos e, *Estratégias de enfrentamento no âmbito social: Políticas Públicas* com 12 artigos. As principais estratégias para diminuir a sobrecarga dos familiares cuidadores de idosos, no âmbito individual foram: promoção de comportamento de autocuidado, ensino de técnicas de relaxamento, gestão de conflitos e tomada de decisões, contribuições a melhoria das habilidades sociais dos cuidadores informais, e o incentivo a espiritualidade como fator protetivo aos idosos e os familiares. Nas estratégias de enfrentamento relacionadas à criação de Políticas Públicas observou-se: suporte formal aos cuidadores, incentivo ao apoio social, implantação potentes da Estratégia Saúde da Família, implementação de Home Care de forma organizada e, serviço de atenção domiciliar.

Descritores: Cuidadores; Idoso; Depressão.

Esta es una revisión integral que tuvo por objetivo conocer las principales estrategias de enfrentamiento (adaptación psicológica) para disminuir la sobrecarga de familiares cuidadores de ancianos con depresión, expresadas en las producciones científicas. Las búsquedas ocurrieron en las bases de datos Medline, Lilacs, Redalyc, Scielo y Pepsic, con combinaciones de descriptors: cuidador, anciano, depresión, carga de trabajo, adaptación psicológica, en los idiomas en portugués, inglés y español, considerando el período de enero de 2014 a mayo de 2019. Se recuperaron 35 producciones, categorizadas después por similitudes temáticas. Las categorías construidas fueron: *Estrategias psicológicas en el ámbito individual* con 23 artículos y, *Estrategias de enfrentamiento en el ámbito social: Políticas Públicas* con 12 artículos. Las principales estrategias para reducir la carga de los familiares cuidadores de ancianos en el ámbito individual fueron: promoción de comportamiento de autocuidado, enseñanza de técnicas de relajación, gestión de conflictos y toma de decisiones, contribuciones a la mejora de las habilidades sociales de los cuidadores informales, y el incentivo a la espiritualidad como factor protector a los ancianos y a los familiares. En las estrategias de enfrentamiento relacionadas a la creación de Políticas Públicas se observó: apoyo formal a los cuidadores, incentivo al apoyo social, implantación potente de la Estrategia Salud de la Familia, implementación de Home Care de forma organizada y, servicio de atención a domicilio.

Descritores: Cuidadores; Anciano; Depresión.

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INTRODUCTION

The world is experiencing a phenomenon of aging population, which results in a substantial increase in the number of elderly in the overall population. In 1950, the elderly accounted for 8% of the population, being 202 million in number; in 2013, the percentage was 12% and reached 841 million. In 2050, it is estimated that this number will exceed 2 billion of older people in the world¹.

Among these illnesses, depression is currently the most common among the older adults² and with increased risk of morbidity and mortality³, considered as a public health problem, although there are few population studies on the prevalence of depression in Brazil⁴.

With the increasing number of elderly, it is necessary to expand the caregivers contingent. There are two main types: formal and informal caregivers. The caregiver is the one who is trained, attend courses, prepares to practice the care function and receives remuneration; the informal caregiver can be a relative, friend, neighbor, family, that and assumes responsibility with no training; these provide care for the older people at home⁵ and, most often with no pay.

The continuous exercise of the care task interferes in the lives of family caregivers, increasing its overload and causing physical, psychological and social problems. Thus, the depletion and exhaustion of caregivers, coupled with symptoms characteristic of those who suffer the burden can be resulting from continuous dedication, which leads the caregiver to leave their own needs to second plan⁶; that is why caregivers commonly complain about depression, stress, anxiety and overload⁷.

Public policies are still precarious and many caregivers find themselves alone in exercising this function, feeling helpless when facing the daily challenges. The family caregiver needs psychological counseling and social support, to find conditions to build some strategies that enhance their quality of life⁵.

That said, this study aimed to know the main coping strategies (psychological

adaptation) to decrease the burden of family caregivers of older adults with depression, expressed in scientific production.

METHOD

This is an integrative review which aimed to answer a central question, defined from the PICO method (P: participants, I: Intervention, C: comparison, O: result/outcome)⁸.

The main question was: What are the psychological adaptation strategies (coping) (O) that contribute to the overload reduction (I) of the family caregivers of older adults with depression (P)? In turn, the review was also based on the international form for studies in a systematic review and meta-analysis, the PRISMA - *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*⁹.

The search was conducted in the databases: MEDLINE, LILACS, REDALYC, SciELO and PePSIC. The search descriptors used were obtained in DeCS (Descriptors in Sciences Health), considering the Portuguese, English and Spanish languages. The operations were obtained by combinations of the following uniterms: (1) cuidador OR caregivers AND idoso OR aged OR anciano AND depressão OR depression OR depression; (2) cuidador OR caregivers AND idoso OR aged OR anciano AND adaptação psicológica OR adaptation, psychological OR adaptación psicologica OR coping; (3) cuidador OR caregivers AND idoso OR aged OR anciano AND carga de trabalho OR workload OR carga de trabajo; (4) cuidador OR caregivers AND idoso OR aged OR anciano AND jornada de trabalho OR work hours OR horas de trabajo. The descriptors: coping is a synonym for psychological adaptation and the uniterm overload corresponds to the workload and/or working hours.

In screening the inclusion criteria used were: a) articles published in Portuguese, English and Spanish; b) published in the last five years, a period from January 2014 to May 2019; c) Full-text and free access; d) which provided information to answer the guiding question or that addressed the issue tangentially. Exclusion criteria were: a) studies such as theses, dissertations, communications, monographs, reviews,

letters, editorials, news, books, chapters; b) repeated articles; c) articles out of the publication period established; and, d) articles that did not relate directly to the subject.

The survey in databases was held in May 2019. The first step is constituted by the reading of the titles of the articles identified, excluding those far from the subject proposed.

In the second step, the abstracts of the articles were read and productions selected in line with the subject and inclusion and exclusion criteria. This procedure was conducted by two independent judges, both graduated in psychology; disagreements were analyzed by a third judge.

Articles repeated were accounted once and the ones selected by the title and abstract were read in full. Once again, the criteria for inclusion and exclusion of full texts were applied. Articles retrieved and analyzed in full were the ones that directly answered the central question and addressed the issue tangentially.

The studies found were organized in an Excel spreadsheet, highlighting the articles retrieved the following aspects: title, year of publication, country, journal, objective, type of study, sample, instruments, main results and conclusions.

The presentation of the review is guided in PRISMA⁹ system recommendations. The selected articles were analyzed in full to the construction of the thematic categories, in order to answer the central question and the specific objective of the study.

Categories were constructed from the articles listed, which were arranged in charts and discussed in light of the productions related to the issue, as well as the discussion on gaps contributions.

RESULTS

A summary of the findings and methods used is summarized in Figure 1. Initially, 3,141 articles were identified and from these, 35 studies were selected for review, which answered the study proposal.

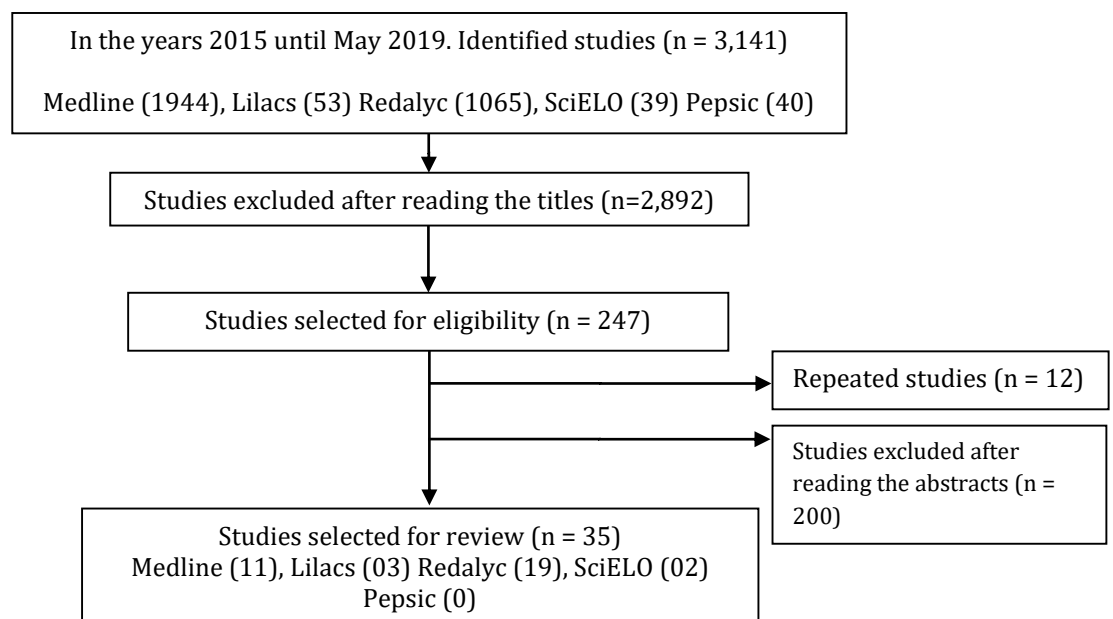


Figure 1. Selection process and identification of articles. 2019.

The origin of the researchers included as nationality: Brazil (22 articles), Singapore (2 articles), Spain (2 articles). The other countries had only one article each: the Netherlands, Australia, Sweden, Chile, Korea, Thailand, Belgium, UK, Philadelphia, Africa,

Cuba, Portugal, Mexico, Uruguay and Venezuela.

Periodicals with more publications were: *Revista Brasileira de Enfermagem* (03 articles) and, with two articles each - *Revista Brasileira de Geriatria e Gerontologia*, *Texto & Contexto em Enfermagem*, *Health and Quality*

of Life Outcomes, *Journal of Research Fundamental Care Online*.

Among the 35 articles retrieved, 57% were quantitative investigations, 28% qualitative and 14% quantitative and qualitative.

The qualitative studies used the interview¹⁰ as a tool, depth interview¹¹ as well, presented as a case study with semi-structured interviews with informal caregivers and elderly dependents¹² and case study with caregivers¹³ in addition to community operative group with the elderly, used instrument as a field diary¹⁴.

In quantitative studies caregivers were interviewed and the Zarit¹⁵ scale was used, as well a sociodemographic questionnaire, *the Zarit Caregiver Burden Interview form (ZBI)*, *the Geriatric Depression Scale (GDS)*, *frailty assessment*, according to the Phenotype of Fried¹⁶, *the Satisfaction with Life Scale*, *Instrumental Activities of Daily living (IADL)*, *Basic Activities of Daily Living (BADL)*, *Quality of life*: measured by the CASP 1926¹⁷ scale. And in quantitative and qualitative studies the same instruments were used in addition to *the Mini Mental State Examination (MMSE)*¹⁸.

The article of Aires et al. (2017), entitled "Depressive Symptoms of the elderly people and caregiver's burden in home care" fully answered the main question, referring to the coping strategies that minimize the burden on caregivers of patients with depressive symptoms¹⁹.

The terms elderly dependents that tangentially responded the objective appeared in 20% of the articles. Older people caring for the elderly was another topic that appeared in three studies and, in one of them the relationship between frailty, depressive symptoms and overload of elderly caregivers were investigated in the context of high social vulnerability¹⁶. The terms frail elderly were also evident, as in the article of Farjado, Linares, Canovas²⁰, which described the behavior of the group of elderly caregivers overload.

The categories defined were entitled: 1) Psychological strategies at the individual level, 2) Coping strategies in the social sphere:

Public Policies. In the first category, 23 articles were selected and, in the second, 12 articles.

DISCUSSION

Psychological coping strategies at the individual level

In this category, coping strategies in the psychological framework are presented. Interventions aimed at the formal and emotional support, in order to accommodate the anxieties and the health problems of the caregivers, are important and necessary, especially in order to minimize their overload²¹.

A study carried out in Portugal with 107 elderly caregivers found that a third of people who are dedicated to elderly care require specialized help to deal with the emotional stress, as well as this is a group that is at risk for the development of mental disorders, being important to conduct actions on diseases prevention and health promotion²².

In the prevention strategies, considering the overload for family taking care of the elderly, one must understand the feelings that go into overload as these livings oscillate between positive and negative, or that minimize or maximize overload and emotional distress. Among the positive experiences, moments of interaction between caregiver and elderly and maintenance of self-esteem stand out; and in the negative ones the abandonment of work to care, love life in the background, the commitment of social activities and leisure appear²³.

In another survey with 50 elderly caregivers, 25 care recipients and 25 health professionals, conflicts often involved in caregivers relations elderly, were: lack of support from other family members, financial problems, uncooperative behavior of the care receiver and conflicting opinions about affection²⁴.

The resources considered most useful to social skills: expression of positive feelings (expression for feelings of positive affect or consideration by another person), aggressiveness control (dealing with negative situations that require anger and aggression control) and discussion of the issues, these tasks also involve communication skills (get

information or have other people to stay with the elderly)²⁴.

One of the coping strategies proposed were the intervention programs to help professionals and caregivers to develop their social skills; such programs allow caregivers to take better care of themselves, reducing declines in their physical and emotional well-being²⁴.

A study conducted in Spain showed: 1) the importance of considering the coping strategies to assess elderly relatives caregivers, 2) the quality of life of caregivers is related to their coping strategies, 3) the quality of life can be aggravated by coping type avoidance and 4) the quality of life can be improved by activities focused on emotion and social support²⁵.

Such information is useful for clinical practice, in the development of interventions for family caregivers of elderly, seeking to promote the acceptance of the situation and seeking social support, such as: problem solving, benefit-finding and interventions, positive reappraisal, acceptance and control of dysfunctional thoughts, and interventions to strengthen social support²⁵.

Another protective intervention to family caregivers and the elderly likely to develop depression are the relationships with spirituality. Professionals should recognize the emotional and spiritual factors in the lives of individuals, aiming to provide comprehensive care and hope to the caregiver elderly, in order to prevent health problems and to promote quality of life and care²⁶.

Other study performed with informal caregivers in Thailand pointed out that spirituality was also seen as a positive intervention measure. In this research it was reported the negative impacts of care: emotional stress, financial struggles and concerns about the lack of knowledge¹¹. For the positive experiences: opportunities to show gratitude and accumulate Karma (performing good deeds with notions rooted in Buddhist teachings), affection by the care recipients, good relations with caregivers and encouraging general community in caring, understanding of suffering as part of managing the stress¹¹.

Other ways to provide relief to family caregivers of seniors are: provide timely information for effective self-care, relaxation techniques, communication, management of family conflicts and decision making, promoting quality of care²⁷. The workshops offer the caregiver learning about communication and management of emotions²⁷.

In caregiver-care dyad it is necessary to promote interventions with caregivers through training, counseling and support, as well as to propose self-care behavior to avoid caregiver burden, in addition to consolidating the social recognition of the informal caregiver, show their social contributions, encouraging them to take responsibility strategies and gender and intergenerational. Thus, the feminization of care is evident, and men should help more in the care process to the elderly²⁸.

A study carried out with 148 elderly caregivers showed that their satisfaction with family functioning depends on the quality of the exchange of support, which is more important than the amount of social partners involved in it and, it depends on reciprocity (give and receive support, caregiver and receiver), as being more important than the one-pointedness and the most important emotional support than the other types of support²⁹.

The adaptive capacity of the family, the affective bond strength, the opportunities for personal growth provide its members the ability to solve problems, as central elements to good family functionality²⁹.

The proposal to investigate the different interventions in short and medium term, such as the support groups, if they positively influence satisfaction with the elderly caregivers, even with the presence of negative factors, such as weakness and depression, is required. In this sense, further studies are needed for the production of theoretical subsidies to care strategies, as well as improving cognitive-emotional self-regulation strategies oriented to elderly family caregivers³⁰.

Coping strategies in the social sphere: Public Policies

In this category the main strategies suggested in the studies selected were: implementation of public policies aimed at the families of the elderly, intervention to caregivers and professionals within the Health Family Strategy (ESF) context, implementation of Home Care (HC), improvement of Department of Home Care (SAD) and highlighted the importance of support/social support to decrease the overload, and resilience strengthening.

The predominant gender, when it comes to informal caregivers, is female, the profile of a primary caregiver for the elderly are married women, middle-class, with elementary education and that takes care of a relative of first degree³¹.

A concrete way to reduce the burden on family caregivers is to provide social support and tasks division that can make care more balanced. The social support for caregivers of elderly above 65 years acts as a protective factor against loneliness, stress and depression, regardless of performing care tasks³¹.

Social support besides being a protective factor assists in strengthening the caregivers' resilience. There are two types of social support: emotional and instrumental, that can be offered by family and people close by or mental health services to help them sustain their caring role. Emotional social support is given when there is empathy, the availability to listen, which helps to relieve the accumulated emotional stress and anxiety associated with the elderly caregivers, especially with mental disease¹⁰.

The instrumental support can be offered through financial support, offering rest period for the caregiver to have time for himself, helping with household activities that can be from a family member or communities, institutions and services that offer mental health care for the elderly¹⁰.

In a review article it was pointed out the need to implement measures to promote social health, prevention and education that support the family caregivers of the elderly, and that health policy makers should establish

programs that improve social support for the not institutionalized elderly³¹.

Most of the time family caregivers consider insufficient the information and advice they receive, that is, they do not have people who can communicate and share their feelings and problems resulting from their care task. When the support and guidance are not available, there are direct consequences on the caregiver's health, leading them to depletion³².

A survey in Australia says how much the primary caregivers of an older family member with the disease mental constitutes a difficult task, which has consequence for the physical, emotional, social, financial health and for the wellbeing of caregivers; these should be encouraged to adopt coping strategies to strengthen their resilience¹⁰.

Therefore, it is important to direct public health policies that address the potential and limitations, providing an active aging and an attention that advantage the autonomy of the subjects involved, be it the elderly, caregivers or professionals. It also shows up weaknesses in the support actions to the families, developed by the FHS teams, especially those aimed at the caregivers¹⁵.

The state does not perform sufficient family support policies in the Unified Health System (SUS) and; the pension compensation is unequally distributed. Caregivers need attention by the state, since there is no guideline in law or regulation in the National Protection Policy for the Aged to guide the activity of family caregivers, leaving the subject without support³³.

A study in Cuba with 360 caregivers highlighted the urgency of drawing up care policies, in a broad approach, involving areas such as education, health services, social security, among others, because, although care is seen as a family responsibility, the task involves many factors, since the care action is multifactorial and interdisciplinary²⁰.

Public policies should identify the individual needs of support to caregivers before the illness of caregivers' family³⁴. Caring for the elderly should not lie solely on the family. Taking into account the burden and the costs are high, it is necessary the

support of the community and non-governmental institutions, as well as initiatives and social development projects that increase the support network to the community³².

A study carried out in Singapore with the elderly showed how much the social support mediates the association between resistance and caregiver burden; thereby, health professionals, especially those who offer support to caregivers, should promote and identify family members and friends to help in care, in order to minimize the caregiver overload²⁹.

In public policies aimed at the elderly caregiver under the FHS, it is important: the support groups that can improve the quality of life¹⁸, in addition to the training for informal caregivers, along with professionals³⁵.

Another survey conducted among professionals of a CAPS about the family of the elderly in psychic suffering, shows the need of creating reflective space on the care to this public, as well as overcoming the challenges of the link between family, user and mental health service. For that reason, it was emphasized the importance of formalization of care protocols to providing training courses for professionals and family³⁶.

Similarly, assessments of elderly caregivers should be performed for the early detection of problems that afflict and develop interventions to minimize their complaints and avoid the appearance of adverse outcomes¹¹. However, what happens is that very often the primary caregiver is not prepared for this role, and because of that, end up feeling insecure; home care requires a reorganization of health services, seeking to meet the needs of the population³⁷.

In a study of the views of family caregivers on a Care Service Household (SAD), it was highlighted the need for multi-professional staff conduct more visits, work in an integrated manner (especially in evaluation visits), build an individualized care plan and improve the training of professionals working in this space of care¹³. Especially by the fact that very often some people could not assume the role of caregiver, especially elderly people caring for the elderly (without

proper evaluation and training) and may incur ethical, human, social problems to be administered by SAD¹³.

The SAD must assess the family dynamics and the needs of caregivers; and health professionals should play a key role in interventions, in order to strengthen the family functioning and offer support³⁸.

Another possibility of interventions were: implementation of Home Care (HC), in an organized manner, which is a form of critical attention to the elderly care and its informal network³⁹. Health professionals can develop educational activities in the daily routine of home visits. The HC can guide and direct preventive measures and perform multidimensional assessment of the elderly and their caregivers⁴⁰.

A qualitative case study conducted in five European countries (Belgium, Netherlands, Luxembourg, France and Germany) states how much a single strategy of support cannot benefit all informal caregivers; so, adapted measures are necessary. The development of a coherent policy is a complex task but necessary¹².

Another strategy is the health education activities through operating groups, for older people linked to a local health unit, such as mental health groups in primary care aimed at the elderly and caregivers¹⁴.

Not only social support, but public policies, home care services and home care are interventions to help family caregivers. A research carried out in Africa (Ghana) points out the need to develop social protection programs, which should be expanded not only to the elderly but also to family caregivers of these elderly in vulnerability⁴⁰.

As it can be seen many concrete coping strategies were found; but, directed to the families of the elderly, only two studies have made specific mention of the elderly with depressive symptoms. Considering that these strategies tangentially answer the research question, it will have a significant contribution to seniors and family caregivers.

In a specific study with elderly people with depressive symptoms, which aimed to verify the prevalence of overload and factors associated to it in a poor and violent area of

Rio de Janeiro, among family caregivers, one verified that investigating and treating depression and dementia in the elderly, as well as providing support to their caregivers, can contribute to the effective management of the burden of the family caregivers, improving the quality of care and health of both of them⁴¹.

Therefore, whether the elderly with depressive symptoms or other mental disorders, when they are supported by care directly affects the caregivers who were less emotionally charged, which will contribute to the reduction in their subjective burden.

In this review, it is observed as a gap the low amount of research in elderly patients with depressive symptoms and their relationship with informal caregivers. Thus, follow-up studies of the possible associations among depressive symptoms, depression and caregivers' overload are suggested³⁹.

In this category, studies indicate the need for re-adjustment and reorientation of public policies that provide formal support to family caregivers^{23,42-44}. One proposes to establish preventive social programs to develop play areas for the elderly to support family caregivers and simultaneously benefit the quality of life for everyone⁴³. Health education groups, such as community, help and support groups, self-care teaching, and household consultations¹⁸. Also, the creation of public policies on the needs expressed by caregivers, ensuring coherent measures⁴⁴.

CONCLUSION

The main strategies to reduce the burden on elderly family caregivers, in the psychological context were: self-care behavior promotion, teaching relaxation techniques, conflict management and decision making, contributions to improved social skills of the informal caregivers, and encouragement to spirituality as a protective factor for the elderly and families.

Other coping strategies mentioned were related to the creation of public policies in the social sphere, such as providing formal support to caregivers, encouraging social support, powerful implementation of the HFS,

implementation of Home Care in an organized way and competent home care service.

However, while researches bring such contributions in terms of interventions, in most studies these strategies are mentioned superficially. There is no precise description of how to put them into practice. In most of the studies, it is suggested public policies implementation, but without mentioning more obvious practices, which can infer that there are still many gaps in the literature, both in international and national, in terms of effective interventions for elderly family caregivers.

The production on strategies to caregivers of patients with depression was reduced, so as to be included items that tangentially met the studies related to elderly and family caregivers by supporting important strategies.

Another limitation is the time factor, since the review was carried out over the past five years. Thus, the expansion of the time frame is suggested, selecting articles in other databases to identify whether there is an increased number of researches of elderly people with depressive symptoms, considering that this is a prevalent mental disorder in the elderly and therefore, scientific and social relevant.

On the other hand, the study showed how productions are referring the coping approach of elderly caregivers, subject to reflection and change of reality.

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CONTRIBUTIONS

Gabriela Souza Granero and **Álvaro da Silva Santos** participated in the desing of the study, data collection, writing and review. **Kelly Cristina Ramira Sousa, Carolina Peixoto Cintra** and **Mariana de Carvalho Casemiro** contributed to data survey and writing. **Luan Augusto Alves Garcia** and **Irma Helena Ferreira Benate Bomfim** participated in writing and review.

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