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THE BURDEN OF INFORMAL CAREGIVERS OF THE DEPENDENT ELDERLY

A SOBRECARGA DOS CUIDADORES INFORMAIS DO IDOSO DEPENDENTE

LA CARGA DE LOS CUIDADORES INFORMALES DE ANCIANOS DEPENDIENTES

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ABSTRACT

Introduction: There is a significant number of people living at home whose health condition is characterized by self-care dependence. The care provided by family members often requires highly complex and intense knowledge and skills, and they are not prepared to adequately meet these needs. The care provided by a family member to an elderly dependent person can cause an intense overload to the family member. There is an emerging need to empower family members – family caregivers – as an essential resource in responding appropriately to the needs of dependent people. In these situations, it is essential to intervene with these caregivers, with the purpose of developing nursing interventions to help family members experience a healthy transition in their role as caregivers, helping them to provide quality care, but also to develop appropriate coping strategies to deal with the stress caused by the burden of caring.

Objective: To analyze the needs and skills of informal caregivers caring for dependent older people in self-care within the family context.

Methodology: Integrative literature review using the PICO mnemonic to compile the research question. We proceeded to search for articles on the EBSCOhost platform, selecting articles published between January 2010 and December 2022 in the MEDLINE complete and CINAHL complete databases. Four articles were selected and the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses – PRISMA method were followed.

Results: Most of the selected articles suggest there is scientific evidence that family caregiver burden exists. The identified nursing therapies were related to promoting awareness; promoting the use of support products; teaching, instructing and training techniques in the different domains of self-care; informing about community resources, namely home care services and day care centers; supervising the care provided in the different domains of self-care; and assessing housing conditions.

Conclusion: Informal caregivers who integrate dependent people in self-care need the health service to provide them with knowledge about the phenomenon of dependence in self-care within the family context. It is also essential that the planning of family preparation to take care of elderly dependent people in self-care is assumed by nurses as a professionalized practice, to promote the autonomy of these people and, at the same time, reduce the caregiver's burden.

Keywords: Caregiver; Caregiver Burden; Dependence in Self-care; Elderly; Family Member; Nursing Care.

RESUMO

Introdução: Existe um número significativo de pessoas em contexto domiciliário, cuja condição de saúde é caracterizada pela dependência no autocuidado. Estes cuidados prestados pelos familiares requerem, frequentemente, conhecimentos e habilidades de grande complexidade e intensidade, não estando os mesmos preparados para dar resposta adequada a essas necessidades. Os cuidados prestados por um membro de família a um idoso com dependência, podem originar uma sobrecarga intensa a esse familiar. Emerge a necessidade de capacitar os membros da família – familiares cuidadores – como recurso essencial nas respostas adequadas às necessidades dos utentes dependentes. Perante estas situações, torna-se crucial intervir junto destes cuidadores, com o objetivo de desenvolver intervenções de enfermagem de forma a ajudar os familiares a vivenciarem uma transição saudável no seu papel de cuidador, auxiliando-os a prestar cuidados de qualidade, mas também a desenvolver estratégias de coping adequadas para lidar com o stress causado pela sobrecarga do ato de cuidar.

Objetivo: Analisar as necessidades e capacidades dos cuidadores informais que cuidam de pessoas idosas dependentes no autocuidado em contexto familiar.

Metodologia: Revisão integrativa da literatura que utilizou a mnemónica PICO para compilar a pergunta de investigação. Procedeu-se à pesquisa de artigos na plataforma EBSCOhost, selecionando-se artigos publicados entre janeiro de 2010 e dezembro de 2022 nas bases de dados MEDLINE complete e CINAHL complete. Foram selecionados quatro artigos e seguiram-se as recomendações do método *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* – PRISMA.

Resultados: A maioria dos artigos selecionados sugerem existir evidência científica de que existe sobrecarga dos cuidadores familiares. As terapêuticas de enfermagem que se identificaram relacionam-se com: promover a consciencialização; promover o uso de produtos de apoio; ensinar, instruir e treinar técnicas nos diferentes domínios de autocuidado; informar sobre os recursos da comunidade, nomeadamente serviços de apoio domiciliário e centros de dia; supervisionar os cuidados prestados nos diferentes domínios de autocuidado e avaliar as condições habitacionais.

Conclusão: Os cuidadores informais que integram dependentes no autocuidado necessitam que o serviço de saúde lhes faculte o conhecimento sobre o fenómeno da dependência no autocuidado em contexto familiar. É também fundamental que o planeamento da preparação das famílias para tomar conta de idosos com dependência no autocuidado, seja assumido pelos enfermeiros como uma prática profissionalizada, no sentido de promover a autonomia destas pessoas e, simultaneamente, diminuir a sobrecarga do cuidador.

Palavras-chave: Cuidados de Enfermagem; Dependência no Autocuidado; Família; Idoso; Sobrecarga do Cuidador.

RESUMEN

Introducción: Hay un número importante de personas en casa cuyo estado de salud se caracteriza por la dependencia de los cuidados personales. Los cuidados que prestan los familiares suelen requerir conocimientos y habilidades muy complejos e intensos, y no están preparados para satisfacer adecuadamente estas necesidades. Los cuidados prestados por un familiar a una persona mayor dependiente pueden suponer una sobrecarga intensa para el familiar. Está surgiendo la necesidad de empoderar a los miembros de la familia – cuidadores familiares – como recurso esencial en la respuesta adecuada a las necesidades de la persona dependiente. En estas situaciones, es esencial intervenir con estos cuidadores, con el fin de desarrollar intervenciones de enfermería que ayuden a los familiares a experimentar una transición saludable en su papel de cuidadores, ayudándoles a proporcionar cuidados de calidad, pero también a desarrollar estrategias de afrontamiento adecuadas para lidiar con el estrés causado por la carga de cuidar.

Objetivo: Analizar las necesidades y capacidades de los cuidadores informales que atienden a personas dependientes en el contexto familiar.

Metodología: Revisión bibliográfica integradora utilizando la mnemotecnica PICO para compilar la pregunta de investigación. Se realizaron búsquedas de artículos en la plataforma EBSCOhost, seleccionando los artículos publicados entre enero de 2010 y diciembre de 2022 en las bases de datos MEDLINE complete y CINAHL complete. Se seleccionaron cuatro artículos y se siguieron las recomendaciones del método *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* – PRISMA.

Resultados: La mayoría de los artículos seleccionados sugieren que hay pruebas científicas de que se sobrecarga a los cuidadores familiares. Las terapias de enfermería identificadas están relacionadas con: promover la concienciación; promover el uso de productos de apoyo; enseñar, instruir y entrenar técnicas en los diferentes dominios del autocuidado; informar sobre los recursos comunitarios, concretamente los servicios de atención domiciliaria y los centros de día; supervisar los cuidados prestados en los diferentes dominios del autocuidado; y evaluar las condiciones de la vivienda.

Conclusión: Los cuidadores informales que integran a personas dependientes en el autocuidado necesitan que el servicio sanitario les proporcione conocimientos sobre el fenómeno de la dependencia en el autocuidado dentro del contexto familiar. También es fundamental que las enfermeras asuman la planificación de la preparación de las familias para cuidar a las personas mayores con dependencia en autocuidados como una práctica profesionalizada, con el fin de promover la autonomía de estas personas y, simultáneamente, reducir la carga del cuidador.

Descriptores: Cuidador, Familiar, Anciano, Dependencia en el Autocuidado, Carga del cuidador; Cuidados de enfermería

INTRODUCTION

Since the beginning of modern civilization, old age has been a concern of mankind, mainly because it is an unalterable process⁽¹⁾.

In 1970, average life expectancy at birth was 67.1 years, but by 2020 it would be 80.7 years⁽²⁾. In Portugal, people aged 65 and over represented 20.5% of the entire resident population⁽²⁾. The Portuguese aging index went from 27.5% in 1961 to 161.3% in 2019, which naturally produces a strong impact on society as a whole and demands adaptations and responses at several levels, namely from its support systems, such as health, social security, education, justice, and transportation⁽²⁾. According to the same source, this is an evident phenomenon that will worsen in the future, at least until 2050, that each person will have more years lived with the presence of multiple and complex chronic diseases (multimorbidity), which cause disabilities. This worsening of demographic aging will influence society from several perspectives, particularly with regard to health care and how it should be organized in order to provide care focused and specific to older people and closely involved with families and communities, ensuring equitable access and quality⁽³⁾.

Informal care is understood as the responsibility to provide care, support and assist the needs of dependent people, assumed by family, friends or neighbors, who do not receive any remuneration for the work performed and which aims to improve the well-being and health of the person cared for⁽⁴⁾. It is estimated that there are more than 125 million caregivers in Europe⁽⁵⁾, which reveals and justifies the increase in the elderly dependency rate, which in 1961 was 12.7% and in 2022 was 36.9%. In September 2019, Law no. 100/2019 was published in the Official Gazette, regulating the rights and duties of informal caregivers, as well as the person being cared for, and establishing support measures.

The informal caregiver is characterized as a person who assists and cares for a family member with some type of disease, disability or impairment, and this act of caring prevents the normal development of activities of daily living and social relationships of the family member providing care⁽⁶⁾.

These caregivers have needs at various levels, namely adapting the home environment to the person's needs, so as to ensure a safe and stimulating environment, as well as managing family, social and work relationships. In addition to these needs, informal caregivers often manifest physical, psychological, emotional, and socioeconomic overload⁽⁷⁾. In view of these situations, it is essential to intervene with these caregivers, with the purpose of developing nursing interventions to help family members experience a healthy transition in their role as caregivers, helping them to provide quality care, but also to develop appro-

priate coping strategies to deal with the stress caused by the burden of caring⁽⁶⁾. For this reason, it is essential that the families of these elderly people “be fully informed members of the care team and partners in establishing care plans”⁽⁸⁾.

According to Petronilho (2013)⁽⁹⁾, there is a significant number of people at home whose health condition is characterized by self-care dependence. This study shows that the need for health care is strongly associated with the person's own transition after an event that generates this dependence, as well as with the competence of the person and family members to manage this care for a significant period of time. This care provided by family members often requires knowledge and skills of great complexity and intensity, and they are not prepared to adequately respond to these needs⁽³⁾. According to the Portuguese Observatory of Health Systems OPSS (2015)⁽¹⁰⁾, there are approximately 110 thousand people dependent in self-care and health policies (based on cost containment principles, but also on humanistic principles), indicate that dependent people should be integrated in the home context⁽⁷⁾.

The elderly tend to strive to maintain their independence until the end of their lives, and family members are concerned with adapting to the dependency situation of one of their members. The onset of dependency in self-care triggers two transition processes. On the one hand, we have the transition process of the person affected by multimorbidity or aggravation of the consequences of aging, who becomes dependent. On the other hand, we have the transition of a family member to the role of Family Caregiver^(7,11,12).

Several factors have contributed to the importance of self-care as a focus of attention in the health area, particularly in Nursing⁽¹³⁾. As described above, nursing care is essential when there is a deficit between what the individual can perform (self-care action) and what needs to be performed to maintain the desired functioning (self-care need), constituting a self-care deficit⁽¹⁴⁾. Nurses are then an indispensable health resource in the evolution of adaptive processes to new health conditions of people (self-care agents)⁽⁹⁾.

Objective

To analyze the needs and abilities of informal caregivers caring for dependent elderly people in self-care in a family setting.

METHODS

Ethical aspects

The Ethics Committee was not asked for an opinion, as this was a secondary research study. When formulating the problem, the principles of clarity, objectivity and accuracy were carefully followed. The research path was designed so that the results would be relevant for nursing interventions and/or care practice and, in the case of the chosen topic, directed to a deeper analysis of the needs and skills of informal caregivers of dependent older people in self-care within the family context. The analysis of the data extracted from the selected studies was developed in line with the principle of respect for the results obtained in these investigations and by these researchers. The referencing of the authors took into account the compliance with the standards of good academic and scientific practices.

Study type

The nurse's clinical practice is always performed based on the most current scientific evidence and it is this aspect that translates Nursing care into quality care. This evidence-based practice encompasses a whole process of collection, interpretation, evaluation and implementation of clinical data important for professional decision-making.

The study in question is an Integrative Literature Review based on the need to implement quality care according to the most current scientific evidence. It comprises the following steps: (i) identification of the research question; (ii) search in scientific databases; (iii) definition of criteria for inclusion and exclusion of studies; (iv) selection of studies according to the defined criteria; (v) analysis of the selected articles; (vi) presentation and discussion of results; (vii) synthesis of the acquired knowledge.

Methodological procedures

As a methodological approach, the following steps were used to conduct this Integrative Literature Review: definition of the study's research question, definition of exclusion and inclusion criteria, introduction of descriptors into the databases, identification of studies in the databases, selection of studies after reading the title and abstract of the studies, thorough evaluation of the articles selected for this study, and finally, the analysis of the collected data.

In order to achieve the proposed objective, a research question was defined by applying the PICO mnemonic, which we intend to answer in this integrative literature review, in which “P” corresponds to population, “I” is intervention, “C” refers to comparison/control, and “O” is outcomes. The question outlined was as follows. In informal caregivers (P), which Nursing interventions (I) promote their empowerment (O)?

With the PICO question elaborated, a data collection on the topic under study was carried out during the month of October 2022 through the EBSCOhost platform, later selecting the MEDLINE complete and CINAHL complete databases. The descriptors used for the search were connected with the Boolean operators “AND” and “OR” in the following arrangement and order: “informal caregivers” or “family caregivers” and “overload”.

In order to limit the search, the following inclusion criteria were used: (i) full text; (ii) time period between January 2010 and December 2022; (iii) English, Spanish, and Portuguese; (iv) publications in peer-reviewed academic journals; and (v) population aged 65 years or more. The exclusion criteria considered were all duplicate articles and those that were not in line with the objective of this study, namely studies prior to 2010 and lack of relevant content. Studies with ambiguous methodology were also excluded.

For the selection of articles, the title and abstract of the articles were first read to check for concordance in the inclusion and/or exclusion, according to the previously defined criteria. If the title and abstract revealed interest or proved to be conclusive, the document was read in its entirety to minimize the loss of precious information for the development of the study. If the article proved to be relevant in terms of content, it was included in this study.

A total of 32 articles were selected in the initial search. After reading the titles and keywords, 27 articles were selected for full reading, of which 5 articles were excluded for being duplicates. In the end, 4 review articles were included. Figure 1⁷ shows how these results were arrived at using a PRISMA flow chart.

RESULTS

In order to meet the proposed objectives, several articles were read and their content was analyzed. The characteristics and main results obtained are summarized in Table 1⁷, in ascending chronological order of publication.

DISCUSSION OF RESULTS

This Integrative Literature Review summarizes the experiences of the informal caregiver of the dependent elderly, namely: the reasons for accepting the role; the difficulties; the coping strategies; the factors related to the burden and the sources of satisfaction that come from the act of caring.

The multiple factors that influence the increase of the burden on informal caregivers are: gender, age, level of kinship, level of education, housing situation, physical proximity and affective proximity⁽¹⁵⁾, in addition to the previously mentioned factors, the following factors were also listed: having more than one elderly person; increased amount/intensity of care; degree of dependence of the elderly; lack of knowledge about the evolution of the elderly's health status and/or techniques inherent to care; lack of collaboration of the elderly; social isolation; insufficient economic resources; family conflicts; lack of formal and informal support. Pereira and Filgueiras (2009)⁽¹⁶⁾, in addition to the previously mentioned causes, also mentioned the elderly's behavioral and cognitive changes and the impact on the caregiver's health.

Many of the informal caregivers end up accepting this role due to their financial condition, to the fact that the elderly do not consider being institutionalized and, also, due to the existence of several traditions and customs present in the families. Other reasons for accepting the role of caregivers are related to the fact that they see this role as an obligation/duty or simply as an act of charity.

According to the study developed by Araújo, Paul, and Martins (2010)⁽¹⁷⁾, the provision of informal care may cause a positive or negative impact on both the care recipient and the informal caregiver. With regard to the negative impacts, the most commonly mentioned are fatigue, stress, overload, non-acceptance of the elderly's state of dependence, feelings such as imprisonment, loneliness, sadness and guilt, problematic relationship with the elderly person, and difficulty in accepting the end-of-life of the elderly person. Regarding the positive impacts, the authors Given and Given (1991)⁽¹⁸⁾ highlight respect, self-esteem

and personal gratification as positive manifestations recognized by the informal caregivers. Personal gratification is related to the fact that informal caregivers perceive care provision as an act of reciprocity, of duty fulfilled and as a way to ensure that the elderly person is being well cared for, that they are able to help him/her and feel love for the person being cared for. Also with regard to the caregiver's benefits and sources of satisfaction, the results of the study by and Hogstel, Curry, and Walker (2005)⁽¹⁹⁾ highlighted 4 main benefits for the informal caregiver of an older person, namely appreciating the simple things in life; increasing the ability to resolve past conflicts and grief; developing personal strengths, increasing the acceptability of one's own aging; and having direct contact with the older person's full life, having fun and learning with him/her, while protecting him/her.

With regard to the difficulties experienced by the informal caregivers, the most mentioned were physical exhaustion, and they consider that emotional and psychological exhaustion is more depressing. They also reported that the fact of having become caregivers caused them constraints in their personal and professional life, for they have a conditioned life at home and a work overload, being unable to take vacations or enjoy a social life, for they have no possibility of being accompanied by the elderly caregiver or of leaving him/her alone, being sometimes forced to ask for help from others. Taking on the role of caregiver has led to limited freedom and professional and family losses. Informal caregivers are divided regarding the time they dedicate to themselves and to other family members, stating that they can only be with their children or grandchildren when they visit them at home.

The coping strategies that informal caregivers adopt when facing the feeling of overburden are: setting priorities, controlling emotions, facing life in stages, and remembering the good moments shared with the older person, always trying to highlight the positive aspects of the situation. Some authors also refer that religion and leisure activities are often invoked as coping strategies⁽²⁰⁾.

Santos (2008)⁽²¹⁾ remarked that, in addition to the coping strategies acquired by informal caregivers, there are two other factors that positively influence the resolution of the activities immersed in the care process, namely the previous experiences with other older people and the existence of formal and informal support. Mateus, and Fernandes (2019)⁽²²⁾ also mentioned that caregivers to overcome problems and obstacles resort to various types of strategies, for example, using venting with colleagues, activities such as painting, playing cards, etc.

With the emergence of Covid-19 and the pandemic, informal caregiver support ceased to exist, and consequently caregivers were left to perform all of the care for the elderly on their own. This may drive the emergence of psychological, physical, and biological problems as caregivers became more prone to overburdening than before the pandemic. As a strategy, the orientation of caregivers with a view to maintaining their physical and psychological health was adopted in the pandemic period.

Contributions to Nursing

Through the critical analysis of the articles about the experiences of the informal caregivers of the dependent elderly, we found that the nurse's intervention in promoting the empowerment of the caregiver/elderly dyad is of high importance.

Study limitations

In the design of this study, the use of studies before and after the Covid pandemic were found to be limitations, insofar as it was a conditioning factor of the results obtained, which provided two different views. The fact that only articles in Portuguese, English, and Spanish were considered was also a limiting factor in terms of the results obtained, as it led to the loss of other potentially important international research studies written in other languages.

FINAL CONSIDERATIONS

By developing this research we intended to analyze the burden of informal caregivers and which nursing interventions could contribute to the empowerment of this caregiver and, through this integrative literature review, it was possible to analyze some of the factors that influence the burden of informal caregivers.

The main factors related to the informal caregiver's burden are related to the sociodemographic characteristics, namely financial dependence, the degree of kinship, gender, physical and affective proximity, marital status, academic qualifications, and current employment situation, among others. They are also related to the caregiver's intrinsic factors, such as duty/obligation, gratitude/retribution. The family also has factors that influence the care, such as family tradition, and absence of another answer.

However, there are factors inherent to the elderly, such as the state of health, directly related to the degree of dependence of the elderly person; demands on the care provided and the rejection of institutionalization.

Due to the Covid-19 pandemic, informal caregivers of the dependent elderly have lost all the social support that was provided by the health services, and the entire process of caregiving has fallen on them, thus making them vulnerable to psychological illness and fear of the unknown, especially a disease that can cause several consequences.

There is still a need for nursing care planning combined with self-care, which requires the creation of a model of nursing care needs based on self-care. By assessing dependence in self-care, nurses plan and perform more rigorous interventions, assessing outcomes with greater effectiveness and, consequently, optimizing the recapacitation and autonomy of individuals.

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Authors' contributions

CF: Study design, data analysis, review and discussion of results.

CS: Study design, data analysis, review and discussion of results.

FS: Study design, data analysis, review and discussion of results.

LC: Study design, data analysis, review and discussion of results.

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MG: Study coordination, study design, data collection, storage and analysis, review and discussion of results.

AJ: Study coordination, study design, data collection, storage and analysis, review and discussion of results.

AC: Review and discussion of results.

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LL: Review and discussion of results.

All authors read and agreed with the published version of the manuscript.

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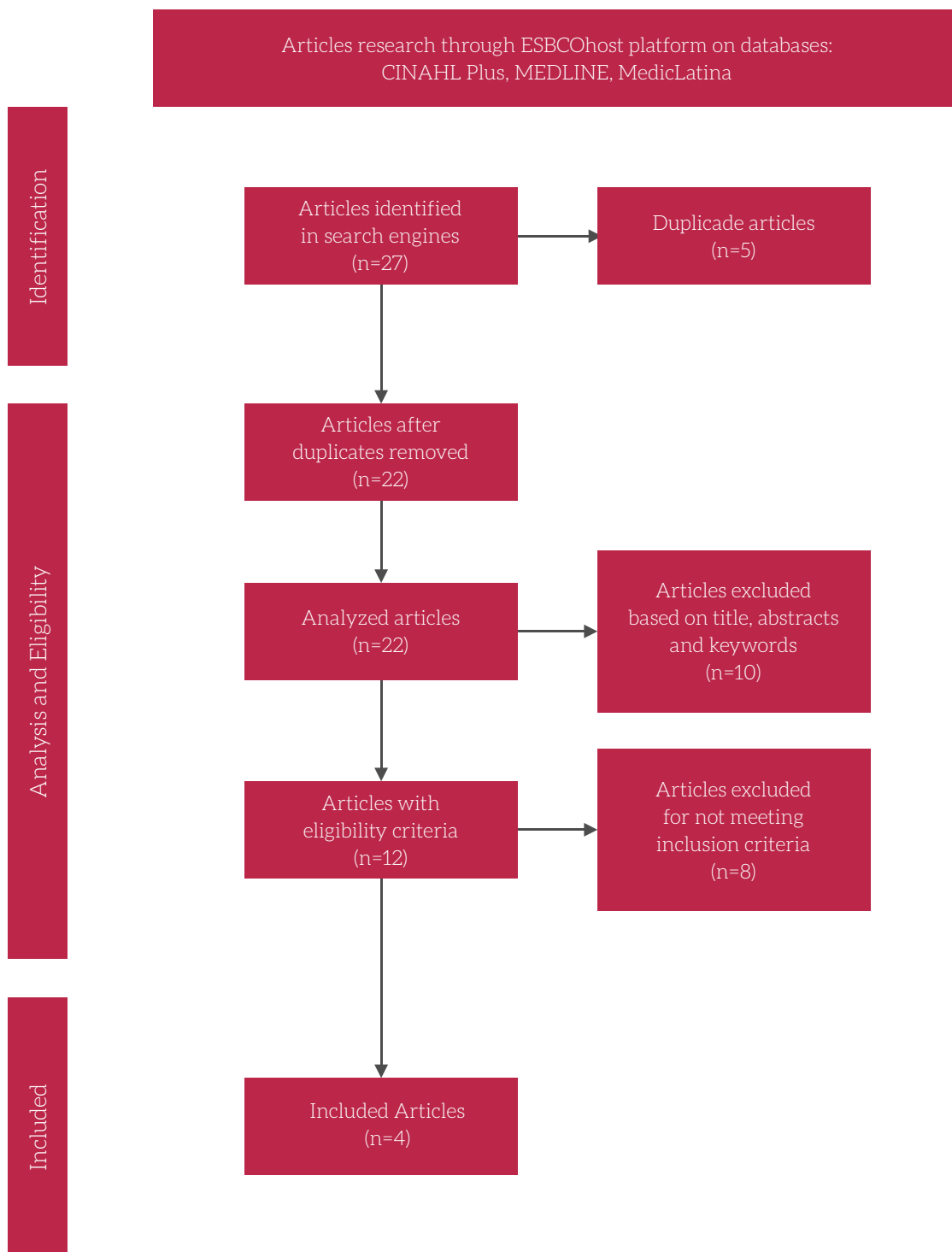


Figure 1 - 2020 PRISMA diagram for the presentation of the research methodology.⁵

Chart 1 - Identification of the studies and main results. →^κ

Authors/Year/Method	Objectives	Results
<p>Cruz, D C M; Loureiro, H A M; Silva, M A N C G M M; Fernandes, M M (2010)⁽²⁵⁾. The Experiences of the informal caregiver of the dependent elderly. Systematic literature review.</p>	<p>To describe the experiences felt by the informal caregiver, found in the available scientific production.</p>	<p>The main results found show some axes around which the experiences of the informal caregiver of dependent elderly people are built, namely: the reasons for accepting the role; the difficulties; the coping strategies; the factors related to the burden and the sources of satisfaction arising from the act of caring. With regard to the reasons for accepting the role of caregiver, this is based on four factors, namely: the degree of kinship (in most cases, those who have a higher burden are one of the members of the couple), gender (the one who has a higher burden is the female gender), physical proximity (those who have a higher burden are the ones who live with the elderly person), and affective proximity (established by the marital or filial relationship). In the study developed by Winter, Bouldin and Andresen (2010), the reasons that led the informal caregiver to accept this role revealed that it was related to financial dependence, family tradition or the fact that the elderly did not want to be institutionalized and their health condition, and, finally, factors involving the family and the community, i.e. availability of other caregivers and the (in)existence of financial and social sources.</p> <p>Simonetti and Ferreira (2008) referred to the fact that caregivers accept this role because they see it as a duty/obligation or simply an act of charity or gratitude/ retribution.</p> <p>With regard to the difficulties of the informal caregiver, Ekwall and Hallberg (2007) showed that the major difficulty that informal caregivers faced was the inherent demands of caring. In the study of Santos (2008), the most evidenced difficulties focused on the physical, psychological, social and financial dimensions. With regard to the physical dimensions, fatigue, illness or worsening of the elderly person's health condition emerged as obstacles to care provision. Simultaneously, the non-acceptance of the elderly's state of dependence, feelings such as loss of freedom, loneliness, sadness, and guilt; problematic relationship with the elderly, difficulty in accepting the end of life of the elderly, and increased stress also appear.</p> <p>Dissatisfaction with the responses of the formal network, the rejection of formal support by the elderly, the cost of the home help service and others expenses,</p>

Chart 1 - Identification of the studies and main results. ↔↔

Authors/Year/Method	Objectives	Results
<p>Cruz, D C M; Loureiro, H A M; Silva, M A N C G M M; Fernandes, M M (2010)⁽²⁵⁾. The Experiences of the informal caregiver of the dependent elderly. Systematic literature review.</p>	<p>To describe the experiences felt by the informal caregiver, found in the available scientific production.</p>	<p>associated with the lack of remuneration for the work. With regard to coping strategies, informal caregivers establish priorities, control their emotions, face life in stages, and remember the good moments shared with the older person, looking for positive characteristics of the situation. There are also authors who refer that caregivers invoke religious beliefs and perform leisure activities (Simonetti and Ferreira, 2008). Santos (2008) concludes that besides the coping strategies developed by the informal caregiver, there are two factors that facilitate the resolution of difficulties in the care process, which are previous experience with other elderly people and the existence of formal and informal support. Regarding the factors that induce the informal caregiver's burden, the following factors emerged from Andrade's study (2009): having more than one elderly person; increase in the amount/intensity of care; degree of dependence of the elderly; lack of knowledge on the evolution of the elderly's health condition and/or techniques inherent to care; the elderly's lack of cooperation; social isolation; resources insufficient economic; family conflicts; lack of formal and informal support; age of the caregiver and difficulty in accepting the role. Pereira and Filgueiras (2009), in addition to the causes listed above, also mentioned the behavioral and cognitive changes of the elderly, the caregiver's education and professional life; the impact of caring at the financial, labor, and social levels; and the impact on the caregiver's health. In the study of Ricarte (2009), female caregivers showed higher levels of burden (60.1%) than male caregivers (3.8%). He also found that caregivers aged 50-89 years (41%) are the group with the highest burden levels, as well as married caregivers (29.4%) and caregivers with less education (26.9%). This author also mentioned that the higher the level of dependence in the activities of daily living, the higher the level of burden, a relationship found in 28.1% of the caregivers in his sample, and the activity that most contributed to this effect was "bathing". Finally, regarding the benefits and sources of caregiver satisfaction, the results of</p>

Chart 1 - Identification of the studies and main results.↔↔

Authors/Year/Method	Objectives	Results
<p>Cruz, D C M; Loureiro, H A M; Silva, M A N C G M M; Fernandes, M M (2010)⁽²⁵⁾. The Experiences of the informal caregiver of the dependent elderly. Systematic literature review.</p>	<p>To describe the experiences felt by the informal caregiver, found in the available scientific production.</p>	<p>the study by and Hogstel, Curry and Walker (2005) highlighted 4 main benefits for the informal caregiver of an elderly person, these being appreciation for the simple things in life; increased ability to resolve past conflicts and hurts; development of personal strengths, increasing acceptability of one's own aging; and direct contact with the elderly person's full life, having fun and learning from them while protecting them.</p>
<p>Martins, J; Fonseca, C; Barbosa, M (2017)⁽³⁵⁾. The Characteristics of the Elderly Dependent and the Overload on the Informal Caregiver: A study in Belmonte. Quantitative cross-sectional study.</p>	<p>To assess how informal Caregiver burden is influenced by the sociodemographic characteristics and clinical status of the Elderly Dependents.</p>	<p>With regard to gender, Santos (2005) mentions that female informal caregivers have a greater physical, emotional and social burden. On the other hand, male informal caregivers recognize greater family support, greater satisfaction with the performance of the caregiver's role and with family care. Age is another factor that influences the burden of IC 's. According to Braithwaite and McGown (1993) younger caregivers show a greater ability to combat burden. On the other hand, older caregivers are more vulnerable and have higher levels of burden. On the other hand, Santos (2005) mentions that age is not a relevant factor that significantly changes the ICs' physical, emotional, and social burden. With regard to the degree of kinship, the informal caregivers who are spouses have a higher burden. This may be justified by the fact that spouses value more the situations of dependence, as well as their repercussions on the dynamics and quality of life of both, while daughters/daughters value the nuclear family and their work (Andrade, 2009a; Custódio, 2011; Garcia, 2009; Lage, 2007; Lemos, 2012; Loureiro, 2009; Pereira, 2008; Santos, 2008). In relation to the level of education, Santos (2005) considers that this characteristic is not relevant to affect the burden of informal caregivers, but Lage (2007) argues that informal caregivers with lower levels of education show higher levels of physical, emotional and social burden than those with higher levels of education. Riedel, Friedman, and Langerberg (1998) justify this fact by emphasizing that caregivers with higher levels of education value more the positive aspects related to their work and have an easier time dealing with the problems they face. The World Health Organization (2010) states that low levels of education are linked to poor health, more stress, and lower self-confidence. Thus, the fact that informal</p>

Chart 1 - Identification of the studies and main results. ←→↵

Authors/Year/Method	Objectives	Results
<p>Martins, J; Fonseca, C; Barbosa, M (2017)⁽³⁵⁾. As Características do Idoso Dependente e a Sobrecarga no Cuidador Informal: Um estudo em Belmonte. Quantitative cross-sectional study.</p>	<p>To assess how informal Caregiver burden is influenced by the sociodemographic characteristics and clinical status of the Elderly Dependents.</p>	<p>caregivers have a low level of education may make it more difficult for them to search for and acquire social resources that can provide them some support, thus increasing their burden. The IC's housing situation is another factor that affects their levels of burden. Thus, Farran (2004) argues that care practice is a stressful experience, particularly for those who live with the elderly.</p>
<p>Mateus, M N; Fernandes, S C B (2019)⁽²²⁾. Resilience in informal family caregivers of dependent elderly. Quantitative/qualitative cross-sectional study.</p>	<p>To evaluate the difficulties associated with the act of caring; to investigate what constraints are experienced in the personal life of the Informal Family Caregiver and to assess their level of resilience.</p>	<p>In the results of this article, there was a higher resilience capacity when children are the caregivers. The difficulties are related to physical, emotional/psychological wear and tear, being the limitation of freedom and the change in the family dynamics the major constraints in personal life. In this article, three methodologies were used: questionnaire surveys, in which it was found that the caregivers, in order to overcome the problems and obstacles, use several types of strategies, for example, by talking to colleagues, activities such as painting, playing cards, etc. One of the aspects that caregivers emphasize is the search for mental relief. Although physical exhaustion exists, caregivers consider emotional and psychological exhaustion to be more depressing. Results obtained after a semi-structured interview, in which the informal caregivers mentioned that becoming caregivers caused them constraints in their personal and professional lives, since they had a conditioned life at home and an overload of work. Regarding vacations, they can't enjoy that leisure time, because they have to take care of the family members. The fact of taking on the role of caregivers led to a limitation of freedom and to losses caused at the professional level, and these obligations of the act of caring imply changes in the family dynamics. Informal caregivers are divided regarding the time they dedicate to themselves and to other family members, stating that they can only be with their children or grandchildren when they are visited at home. They are unable to take vacations or enjoy a social life, since they are unable to accompany the elderly caregiver or leave him or her alone, and are sometimes forced to ask others for help. With the application of the Brief Resilience Coping Scale, results were verified for two groups: CIFR (informal family caregivers from rural areas), in which their resilience varied between 11 and 18 values, giving an</p>

Chart 1 - Identification of the studies and main results. ←→↵

Authors/Year/Method	Objectives	Results
<p>Mateus, M N; Fernandes, S C B (2019)⁽²²⁾. Resilience in informal family caregivers of dependent elderly.</p> <p>Quantitative/qualitative cross-sectional study.</p>	<p>To evaluate the difficulties associated with the act of caring; to investigate what constraints are experienced in the personal life of the Informal Family Caregiver and to assess their level of resilience.</p>	<p>average of 14. These results allow us to verify that 6 participants reveal a medium level of resilience, while 3 have a low level and only one has reached the strong level. These 3 are two men between the ages of 63 and 75, with a low level of education, a low monthly income, and have been providing care for more than 10 years. The average ability is highlighted by 4 women whose ages range from 44 to 69 years old and have a higher level of education than the previous group. Their average monthly income is higher. The strong resilience capacity belongs to a male CIFR, single, 52 years old, presenting a low level of education and providing care for 1 to 5 years, and has an average household income ranging from 750 to 1000 euros per month. CIFU (informal urban family caregivers), in which the resilience of the CIFU varies between 14 and 20 values, with an average of 16 values. These results allow us to see that 8 participants showed a medium level of resilience, while 2 showed a high strong level. The average resilience belongs to 6 women aged between 59 and 89 years old, with low educational attainment, an average monthly income between 750 and 1000 euros. Regarding the length of time they have been providing care, 3 have been doing it for 5 years, 1 between 6 and 10 years, and 2 for more than 10 years. A 68 year old divorced male CIFU and an 84 year old married CIFU show a strong resilience, a medium level of education and both have been providing care for between 1 and 5 years and have an average monthly income of over 1000 euros.</p>

Chart 1 - Identification of the studies and main results.^{←↵}

Authors/Year/Method	Objectives	Results
<p>Caparrol, A J S; Martins, G; Barbosa, G C; Monteiro, D Q; Alves, L C S; Gratão, A C M (2022)⁽²⁴⁾. Covid-19 Pandemic: Who Cares for Informal Caregivers of the Elderly? Reflection article.</p>	<p>To discuss critically and reflexively the impact of social isolation on informal caregivers and their families, facing the accumulation of functions that trigger physical and emotional overload, anxiety and stress symptoms on the health of this specific population, besides the difficulties faced by these individuals regarding the support that was provided by the health services and support orientations.</p>	<p>With the presence of COVID-19, many health services no longer provide support to the population at home, in order to protect the health of patients, their relatives, and health professionals.</p> <p>The support offered by the health services, after the pandemic, had several objectives such as making home visits in order to assess the health status of the user and to provide psychological support to the user's informal caregiver/family member.</p> <p>The social support network is composed of four distinct types of support: emotional support, which involves love and affection; instrumental support, which is the concrete aids such as material needs, practical and financial help; information support, which relates to advice, suggestions, and guidance; and social interaction, related to people with whom they can relieve stress and have fun.</p> <p>With the pandemic, this support no longer exists, and the caregivers are now performing all the care of the elderly alone. This fact can drive the appearance of psychological, physical, and biological problems, that is, these individuals became more prone to overload than before the pandemic. One of the strategies that have been adopted in this pandemic period of COVID-19, is to orient the caregivers, aiming at the maintenance of their physical and psychological health.</p>