



REVISIONES

Nursing interventions to reduce the overload on informal caregivers. Systematic review of clinical trials

Intervenciones enfermeras para disminuir la sobrecarga de cuidadores informales.
Revisión sistemática de ensayos clínicos

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ABSTRACT:

Background: Informal caregivers are usually family members, which lead to dependence of the patient on the caregiver. This may result in disturbances to the caregivers' quality of life. Address the negative effects of informal caregiving, several types of interventions have been reported to be effective in reducing medical visits by both informal caregivers and the patients in their care

Aim: Examine the effectiveness of existing nursing interventions designed to reduce the overload of the informal caregiver of people with chronic illness.

Methodology:

Design: Systematic review

Data Sources: Databases including Pubmed (MEDLINE), Embase, The Cochrane Library and CINAHL were searched using keywords about nursing interventions in family caregivers. Articles published between 2014-2019 were retrieved and underwent data analysis and knowledge synthesis.

Review method: Two reviewers independently selected studies. Quality appraisal was based on PRISMA statements appraisal checklist. Synthesis was narrative.

Results: Ninety-five studies were examined in their entirety, with seventy-seven being discarded as not providing results or not related to reducing overload. The final count of articles included in this review

was eighteen which were all randomised clinical trials. Seven were categorized as technology-based interventions; two as self-help manuals; one as a physical activity-based intervention; and eight as group or individual psychoeducational therapy.

Conclusions: Analysis of the different studies shows effectiveness in reducing symptoms such as stress, anxiety, depression or even unmet needs. The interventions that were found to be most effective in reducing caregiver overload were home care visits and psychoeducational interventions, both individual and group.

Keywords: Caregiver; Interventions; Clinical trials; Nurse

RESUMEN:

Introducción: Los cuidadores informales suelen ser miembros de la familia de un paciente, que conducen a la dependencia del paciente del cuidador. Esto puede resultar en perturbaciones en la calidad de vida de los cuidadores. Para abordar los efectos negativos de la atención informal, existen varios tipos de intervenciones eficaces para reducir las visitas médicas tanto de los cuidadores informales como de los pacientes a su cargo.

Objetivo: Examinar la eficacia de las intervenciones de enfermería existentes diseñadas para reducir la sobrecarga del cuidador informal de personas con enfermedad crónica.

Metodología:

Diseño: Revisión sistemática

Fuentes de datos: Bases de datos como Pubmed (MEDLINE), Embase, The Cochrane Library y CINAHL fueron buscadas usando palabras clave sobre intervenciones de enfermería en cuidadores familiares. Los artículos publicados entre 2014-2019 fueron recuperados y sometidos a análisis de datos y síntesis de conocimientos

Método de revisión: Dos revisores seleccionados de forma independiente. La evaluación de la calidad se basó en la lista de verificación de evaluación de declaraciones prisma. La síntesis es narrativa.

Resultados: Noventa y cinco estudios fueron examinados en su totalidad, y setenta y siete fueron descartados por no proporcionar resultados adecuados. El recuento final de artículos incluidos en esta revisión fue de dieciocho que fueron todos ensayos clínicos aleatorizados.

Conclusiones: El análisis de los diferentes estudios muestra eficacia en la reducción de síntomas como estrés, ansiedad, depresión o incluso necesidades insatisfechas. Las intervenciones más eficaces para reducir la carga del cuidador fueron las visitas domiciliarias y las intervenciones psicoeducacionales, tanto individuales como grupales.

Palabras clave: Cuidador; Intervenciones; Ensayos clínicos; Enfermera.

INTRODUCTION

The increase in life expectancy and the reduction in the birth rate in Europe has resulted in an aging population in general and a higher prevalence of chronic diseases⁽¹⁾. This current demographic situation leads to an increase in the need for care of dependent elderly people, with family caregivers (known as informal caregivers) being the main caregivers in charge of covering the daily and instrumental activities of daily living. This produces a social, economic and physical burden on these caregivers.

For informal caregivers, performing this care is a source of chronic stress that can have serious consequences on their physical and mental health⁽²⁻⁵⁾. A meta-analysis by Pinquart et al.⁽⁴⁾ showed that informal caregivers have significantly higher levels of anxiety and depression than non-caregivers, as well as poorer physical health.

According to the literature, interventions aimed at reducing overload in informal caregivers of older adults with chronic pathologies show efficacy in the reduction of medical consultations both for these caregivers and for the patients under their care. In addition, greater access to treatment, a reduction in total contact time with the health

system and improvements in the cost-effectiveness of treatment have been observed in patients ⁽⁶⁾.

Due to the close contact between informal caregivers and patients, knowledge about the disease and the prevention of prevalent chronic diseases increases, generating changes in attitudes towards health and disease ⁽⁷⁾.

One of the priorities for public health managers should be to reduce the level of burden of informal caregivers, making interventions and offering more of the existing services to improve the caregiver's quality of life ⁽⁸⁾.

For this reason, this review aims to provide an overview of the interventions carried out to date for this purpose and to analyze the results obtained.

OBJECTIVE

To examine the effectiveness of the existing nursing interventions designed to reduce the load on the informal caregivers of people with chronic illnesses.

METHODOLOGY

Design

A systematic review was carried out of the clinical trials found in the literature following the parameters of composition and organization for studies of this kind in conformity with the guidelines of the PRISMA ⁽⁹⁾.

The review was registered in PROSPERO with registry number CRD42020175142.

Search outcomes

The sources used to carry out this research were Pubmed (MEDLINE), Embase, The Cochrane Library and CINAHL. The search strategy used was "nursing intervention AND informal caregiver".

Original studies were included with the following inclusion criteria: (a) experimental research design (randomized controlled trials and clinical trials); (b) published in English or Spanish; (c) published between January 2014 and December 2019 (d) participants: informal caregivers of patients c) intervention: nursing interventions to reduce overload in informal caregivers; d) outcome measure: health-related quality of life, levels of depression and anxiety of informal caregivers.

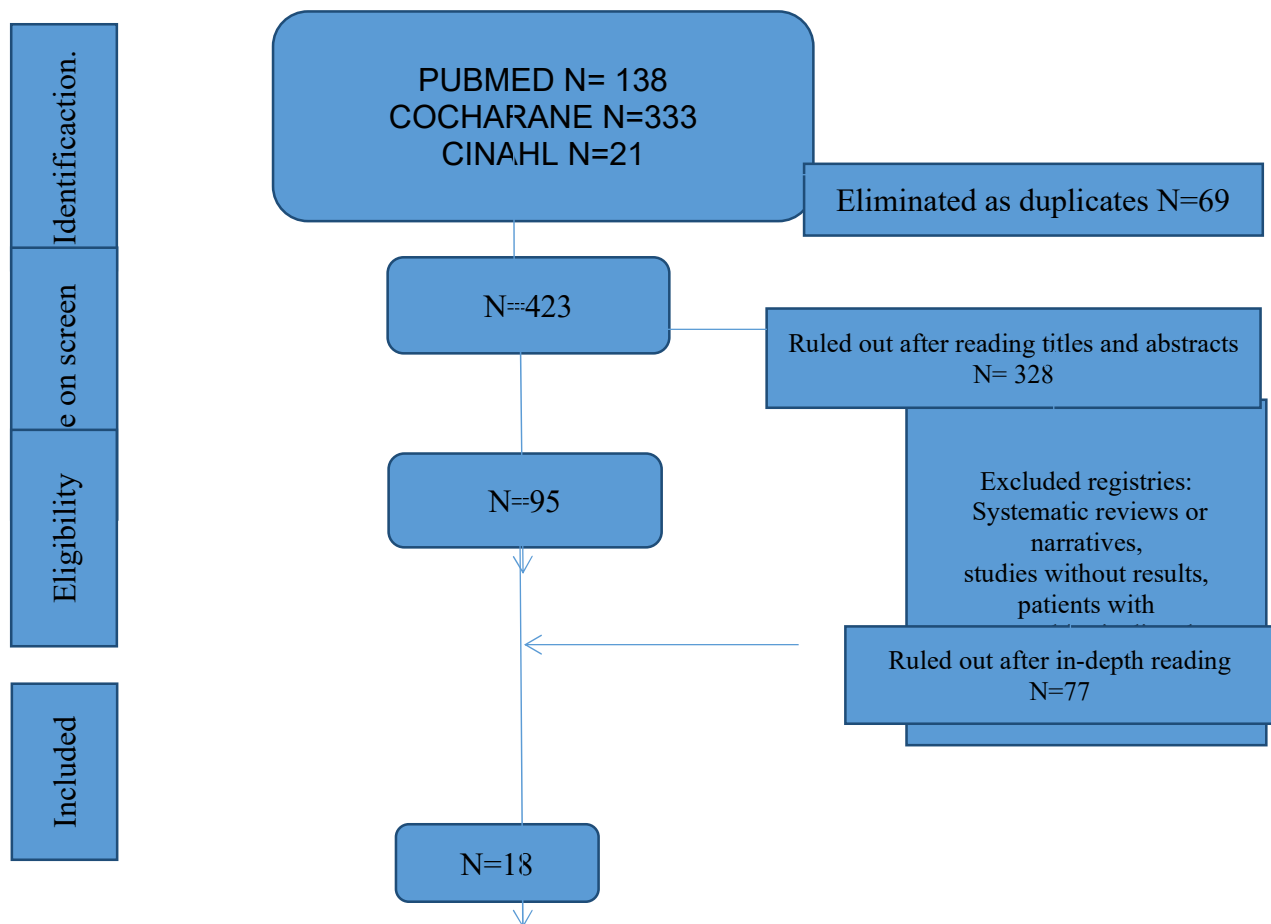
Studies on caregivers of patients with neuropsychiatric pathology were excluded.

PRISMA recommendations were followed to inform the search process ⁽⁹⁾.

Two reviewers performed an independent title and abstract assessment of each article for article selection. A third reviewer was present to resolve disagreements. The PRISMA flow diagram shown in Figure 1 details the processes involved in study selection. Based on the database searches, we identified 492 records, of which 69

duplicates were removed. Of the remaining 423 records, a selection was made after reading the title and abstract, which conditioned the exclusion of 328 records (those articles with content unrelated to the research or meeting exclusion criteria were excluded). Ninety-five studies were examined in their entirety and 77 were discarded because they did not provide results or were not related to the reduction of overload. The final count of articles included in this review was 18 (Fig 1).

Figure 1. Flowchart of the review



Quality assessment

Assessing the risk of bias is one of the problems that can arise in the course of any systematic review. To assess this risk and the quality of the randomized clinical trials found, the Jadad scale has been used ⁽¹⁰⁾.

This scale is based on analyzing three quality criteria within a study: randomization, blinding and liability (dropout and withdrawals), and assigning a certain score to the studies according to whether the different criteria are met.

Taking this scale into account, we assigned 1 point if randomization was mentioned and 1 additional point if the randomization method was appropriate. In addition, we deducted 1 point if the randomization method was inappropriate. Regarding blinding, we assigned 1 point if blinding was mentioned, 1 additional point if the blinding method was appropriate, and again deducted 1 point if the blinding method was inappropriate.

Finally, we assigned 1 point if there was a description of loss to follow-up and dropouts from the study.

The Jadad scale performs a ranking from 0 to 5; if the Jadad score is ≥ 3 points, the trial is considered a high-quality investigation, whereas if the Jadad score is ≤ 2 points, the study is considered of low quality ⁽¹⁰⁻¹²⁾.

Extraction and analysis of the data

For the extraction of data from the studies that we found, we analyzed the following independently: a) basic characteristics of the article (year, author, and research design), b) characteristics of the study sample, c) type of intervention, and d) comparative results.

Synthesis of the data

We decided to use an analysis of the narrative to describe the results of the systematic review based on the highest level of evidence, including only randomized clinical trials (RCT). This technique was chosen instead of a quantitative meta-analysis of the dynamics of the interventions because the duration and follow-up times with patients varied from one study to another. Also, the number of studies with consistent results that were found and included limited the possibility of carrying out a meta-analysis.

RESULTS

The methodological quality of the 18 articles found with the application of the Jadad scale was determined. Thirteen studies were rated as high quality (score >3) and five as low quality (score <2) (Table 1).

Table 1. Jadad classification.

Author	Is the study described as randomized?	Is the method used to generate the randomization sequence identified, and is it appropriate?	Is the study identified as double blind?	Is the masking or blinding method identified, and is it appropriate?	Is there mention of those lost in follow-up and those who dropped out?	Score
Gabriel and Mayers (2019)	1	1	0	0	0	2
Moskowitz et al. (2019)	1	1	0	0	1	3
Cuthbert et al. (2018)	1	1	1	1	1	5
Heckel et al. (2018)	1	1	0	1	1	4
Kales et al. (2018)	1	1	1	1	1	5
Chiang et al. (2017)	1	1	0	1	1	4
Doris SF Yu. (2016)	1	1	0	0	0	2

Hendrix et al. (2016)	1	1	1	1	1	5
Nejad et al. (2016)	1	1	1	1	1	5
Núñez-Naveira et al. (2016)	1	1	0	0	1	3
Aoun et al. (2015)	0	1	0	0	0	1
Bakas et al. (2015)	1	1	0	1	1	4
Gallagher et al. (2015)	1	1	0	0	0	2
McCann et al. (2015)	1	1	1	1	1	5
Tanner et al. (2015)	1	1	0	0	0	2
Rodríguez-Gonzalo et al. (2015)	1	1	1	1	1	5
Pfeiffer et al. (2014)	1	1	0	0	1	3
Schulz et al. (2014)	1	1	0	0	1	3

Description of the studies included

The eighteen studies analyzed were carried out in Australia (n=3), the United States (n=7), Asia (n=4), Africa (n=1), Europe (n=2), and Canada (n=1).

The shared goal of all the studies analyzed was to assess the impact of interventions on informal caregivers. The variables treated included caregiver load, depression, anxiety, anguish, caregiver skills, and well-being.

In all of the studies the control group received normal care.

Characteristics of the interventions

Almost all the interventions were designed to acquire knowledge about care and self-care, as well as to identify unsatisfied needs, using information and communication technologies (n=8).

A number of different tools were used to carry out the studies. These included online platforms and applications (n=2)^(13,14), telephone contact (n=3)⁽¹⁵⁻¹⁷⁾, home visits (n=1)⁽¹⁸⁾, a combination of telephone contact and home visits (n=2)^(19,20), attendance of psychoeducational sessions (n=6)⁽²¹⁻²⁶⁾, distribution of a self-help manual (n=2)⁽²⁷⁾, reading of a photocomic book (N=1)⁽²⁸⁾, information on the instruments used to monitor patients in intensive care (n=1)⁽²⁹⁾, and physical exercise (N=1)⁽³⁰⁾.

Results of the nursing interventions

For a better analysis, the interventions found and the outcome measures of each study will be described in different sections.

Interventions based on information and communications technology

We found a total of 7 studies that may be classified into this category.

In the study of Núñez-Naveira et al.⁽¹⁴⁾, they used a mobile application called “UnderstAID” which was accessible with any device connected to the internet. The app included a learning section with information about pathologies, how to provide care, and tools for self-care. The app provided caregivers the opportunity to use a calendar to record visits and daily tasks, as well as offering an interactive network to maintain contact with other caregivers.

Moskowitz et al.⁽¹⁶⁾ carried out an online intervention, designed to teach caregivers about positive emotional regulation. In the same line, Kales et al.⁽¹³⁾ also developed a platform to provide information, establishing a system to delivery daily messages intended to encourage caregivers to communicate and seek support when needed.

The intervention of Bakas et al.⁽¹⁵⁾ was based exclusively on telephone calls. Prior to this the participants were given an informative leaflet and a resource guide with a verification checklist. And in the study of Heckel et al.⁽¹⁹⁾, 3 calls were made to provide support and information from a cancer council.

Other studies combined telephone contact with home visits. Pfeiffer et al.⁽¹⁷⁾ offered an intervention with home visits and telephone follow-up. The aim of the visits was to fashion an individualized plan to identify the unsatisfied needs of the caregivers regarding information and training. Using the same methodology, Tanner et al.⁽²⁰⁾ made 2 home visits, to determine unsatisfied needs of the caregivers with the aim of prioritizing these and creating an individualized care plan. The first visit was followed by monthly calls to maintain the commitment of the care team. The frequency and intensity of additional contacts were determined by need and the families.

The results of two other studies Heckel et al. and Tanner et al.^(19,20) showed no effect on caregiver overload, nor were there statistically significant differences in comparison with the control groups in terms of overload, depression, or quality of life. However, in comparison to the control groups there was a reduction in the unsatisfied needs of the caregivers.

The research carried out by Heckel et al.⁽¹⁹⁾ on caregivers at risk of depression, the intervention did have a positive effect on caregiver self-confidence.

In contrast, in the studies of Bakas et al., Moskowitz et al., Núñez-Naveira et al., and Pfeiffer et al.⁽¹⁴⁻¹⁷⁾ there was a significant reduction of both depression and anxiety.

In the study of Kales et al.⁽¹³⁾, the caregivers showed a reduction in the level of anguish. However, for the items of caregiver stress, depression, load, and communication there were no relevant differences between the groups.

Self-help manuals

There were two studies that fell into this category. The first, carried out by McCann et al. ⁽²⁷⁾, caregivers were given a written manual based on self-help principles. The effectiveness of the guided self-help manual, derived from cognitive behavioral therapy, in reducing emotional expression of depression by caregivers was assessed, showing a general improvement in comparison to the control group that received standard support.

In the study of Gallagher-Thompson et al.⁽²⁸⁾ a photocomic book was distributed to a Hispanic population in the United States, which depicted characters going through difficult circumstances and presenting the reader with coping skills and approaches to solving problems, so as to improve depression and relieve stress. The results demonstrated that the material was perceived by the target group as supportive.

Group psychoeducational intervention

The 6 studies included in this category showed similarities in objectives and methodologies, providing information and training to the caregivers through psychoeducational programs^(21,22,24-26,) In some cases, they also complemented the sessions with telephone follow-up⁽²³⁾.

In general, psychoeducational interventions reduced the caregivers' overload and improved their quality of life, in comparison to the control group⁽²¹⁻²⁴⁾. Other variables that showed improvement included mourning⁽²⁴⁾, attention to hygiene, and mobility⁽²⁵⁾. However, in the study of Rodríguez-Gonzalo et al.⁽²⁵⁾ the variables of overload, physical and mental health, and social problem-solving abilities did not improve.

There is some controversy regarding depression, as in one of the studies a reduction at 6 months and 12 months was followed by no measurable improvement at 18 months⁽²⁴⁾.

Yu ⁽²⁶⁾ carried out a study on the use of a case-management model (HSC-CM). The intervention focused on 3 components of service: exhaustive assessment to identify caregiver needs, case management to provide coordinated, uninterrupted care, and education based on a personalized multidisciplinary group to cover the needs of the caregiver. The results demonstrated a significant improvement in the overload index of the caregivers, their vitality, their social role, and their general well-being.

Another methodological focus was that used in the study of Hendrix et al.⁽²²⁾. The authors used a protocol (Enhanced-CT) to measure the engagement of informal caregivers in a single session. They worked with two components: the management of patient symptoms and caregiver stress. For the first component, a nurse provided training on strategies for symptom management. If the patient had no active symptoms, the discussion focused on their prevention. The nurse also provided training on care-providing techniques if needed, and encouraged the caregivers to identify and discuss areas of homecare that they found troubling. The results showed short-term improvement in caregiver stress and preparedness for care, but not in psychological well-being. In the other study combining education with telephone follow-up, there was seen to be an improvement in the caregivers' overload index ⁽²³⁾.

Individual psycho-educational intervention

We examined two articles reporting individualized psycho-educational interventions.

In the Chiang et al.⁽²⁹⁾ study, information was provided to the caregivers on techniques and instruments used with patients to maintain their clinical stability in the intensive care unit setting. This individual psycho-educational therapy obtained results that included lower scores on the DASS scale of depression and anxiety.

The study carried out by Aoun et al.⁽¹⁸⁾, in contrast, involved nurses making two home visits to speak with the caregivers so as to identify the areas in which they needed the most support. In this manner they determined the greatest needs and agreed upon actions and solutions and put a joint action plan in place. In this study the intervention group showed a significant reduction in overload after the support received in the home visit.

Physical activity intervention

In the only study found using this kind of intervention, that of Cuthbert et al.⁽³⁰⁾, the physical activity program for caregivers involved attending an exercise class twice a week. Improvements were seen not only in physical health, but also in anxiety, depression, and quality of life.

DISCUSSION

The aim of this review was to identify and determine the effectiveness of existing nursing interventions designed to reduce the overload on informal caregivers of patients. Family care is seen more and more as an important informal care resource in many parts of the world. Nevertheless, the care of patients can be a physical and mental drain on the caregivers, causing important deterioration in their health⁽²⁶⁾. In this line, it should be borne in mind that while the overload may be measured in objective terms, quality of life is a subjective perception of well-being^(15,21).

Although there is extensive literature on support for the caregiver, there is a scarcity of evidence-based data on the practice. There has been little focus on comprehensive evaluation of the caregiver, case management, and group activities that have shown a potential benefit in reducing caregivers' load, improvements in quality of life, and general health and functioning⁽²⁶⁾.

It was the two-pronged interventions that had the greatest effect. The data show an increase in effectiveness with the integration of additional protocols backed by evidence, such as mourning, meditation, and strategies to relieve stress⁽²⁰⁾. Some studies have demonstrated the effectiveness of follow-up phone calls in helping caregivers with the skills and knowledge that they have previously acquired in workshops or individual sessions^(23,26).

Some of the results of the studies analyzed suggest even culturally-derived interventions may be useful, as was the case with the photocomic project. This tool has proved effective in Hispanic communities in the United States in reducing depressive symptoms, allowing even those with limited reading skills to benefit from the content⁽²⁸⁾.

It has also been demonstrated that the continuity of care is further optimized when case managers (nurses or social workers) establish a long-term relationship, thereby coming to better understand the caregivers' situation⁽²⁶⁾. However, Hendrix et al.⁽²²⁾ warn of the need for additional time to allow the professionals to put this into practice, which involves as a consequence a new test of the workload, given that many caregivers speak of the importance of devoting time to discussing their needs and practicing their acquired caregiving skills.

In summary, our findings lend support to the idea that interventions carried out in conjunction with active care can benefit the caregivers, even in their subsequent mourning⁽³⁰⁾.

CONCLUSIONS

This article provides information about the various types of interventions that have been carried out in order to reduce the overload of informal caregivers.

The analysis of the studies presented here demonstrates effectiveness in reducing symptoms such as stress, anxiety, depression, and even unsatisfied needs. The most effective studies in reducing the excessive load on caregivers are those with home visits and the psychoeducational programs, both for individuals and for groups.

It would be useful to conduct further research in order to develop and implement a nursing program aimed at lowering the caregiver burden and not merely at improving the caregiver's health.

The implications of this research from a theoretical perspective lie in offering a basis upon which to build and carry out future research aimed at establishing nursing protocols designed to lower the load, depression, and anguish of the caregiver. In addition, this study could point the way to future lines of research such as identification of the ideal informal caregiver profile in relation to the ill family member under his or her care, and the risk factors associated with the success or failure of new interventions aimed at improving the quality of life of both the caregiver and the patient.

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