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Corresponding author:

Matías Correa Casado

mcc249@ual.es

Author Affiliation:

Department of Nursing,
Physiotherapy and Medicine,
University of Almeria, 04120
Almeria, Spain.

Health programmes for older adults who are the primary family caregivers for their partners: a scoping review

Chica-Pérez, A; Martínez-Sola, L; Correa-Casado, M; Fernández-Sola, C; El-Marbouhe-El-Faqyr, K; Hernández-Padilla, JM.

ADMINISTRATIVE INFORMATION

Support - University of Almería.

Review Stage at time of this submission - The scoping review has been completed but is not yet published.

Conflicts of interest - None declared.

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Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 10 December 2024 and was last updated on 10 December 2024.

INTRODUCTION

Review question / Objective The objective of this scoping review was to examine and map health programmes that have been implemented and evaluated with the aim of improving the health of older adults who assume the role of primary family caregiver for their partner. Therefore, the study aimed to answer the following research questions:

- What programmes have been implemented and evaluated to improve health?
- What are the characteristics (duration and frequency) of these programmes?
- What was the main health condition of the people receiving informal care?
- What are the outcome domains of these interventions (physical, cognitive, social or emotional)?

- What outcomes are assessed in studies that have implemented and evaluated these programmes?

Background Adopting a family caregiving role has an impact on the biopsychosocial health of older adults (i.e. people aged 65 and above) [1]. A family caregiver is defined as a person who provides unpaid care to a relative related by blood or marriage [2]. It is estimated that between 5-21% of the global population are family caregivers [3], while available data indicate that 13% of the population in Spain assumes this role [4]. In the case of dependent older adults, the available evidence suggests that it is primarily their partners who assume the role of primary family caregiver [1,5-10]. This duty is known to be a risk factor for the development of numerous health problems [11] and is associated with fatigue and burnout [12]. In addition, the health status of family caregivers is further affected in the case of older adults [13],

who perceive accessing health services as a frustrating and exhausting process [14,15]. In this context, it is important for health professionals to design, implement and evaluate the effects of specific interventions to improve the health and support offered to older adults who take on the role of primary family caregiver for their partners [6].

In general, family caregiving is associated with higher levels of depression [16] and poorer quality of life [17]. In the case of older adults, this role is linked to an increased likelihood of experiencing pain [18], greater mental health impairment [19] and reduced quality of life [20]. Anxiety, depression and caregiver burden are the main factors contributing to the deterioration of older adult family caregivers' quality of life [17]. Moreover, the increased risk of hospitalisation among older adults [21] is an added stress when they assume the role of primary family caregiver [22]. Furthermore, the scarcity of support services for older adult primary family caregivers, as well as the difficulties they face in navigating the health care system [14], may lead them to seek help less frequently [23,24].

The available evidence suggests that numerous interventions have been implemented and evaluated worldwide with the aim of improving the biopsychosocial health of family caregivers [8,25-27]. However, most of these interventions were not designed with the caregiver's age in mind, which could be a determining factor in their health status [28]. Although some authors suggest that specific health programmes could improve the quality of life of older adult family caregivers [29], no literature reviews have been found to assess the scope of these programmes.

Rationale The increasing prevalence of family caregiving, especially among older adults, underscores the importance of addressing the health challenges faced by primary caregivers. Family caregivers, particularly those caring for dependent older adults, often experience significant biopsychosocial strain, which can lead to a deterioration in their health and quality of life. Given that older adults are more likely to assume caregiving roles for their partners, this group faces heightened risks such as physical and mental health issues, caregiver burden, depression, anxiety, and social isolation. Furthermore, the lack of specialized support services and the barriers within healthcare systems make it difficult for these caregivers to access the help they need.

Despite the recognition of the negative impact caregiving can have on the health of older adults, most interventions to support them do not specifically cater to their unique needs. While

general health programs have been implemented worldwide to improve caregiver health, few are tailored to older adults, and none have comprehensively reviewed the existing interventions targeting this population. The rationale for this scoping review is to fill this gap by identifying and mapping health programs specifically designed for older adults who are primary family caregivers. By examining the characteristics and outcomes of these interventions, this review will provide valuable insights into the effectiveness of targeted programs aimed at improving the health and well-being of older adult family caregivers. This research will help inform future interventions, policies, and healthcare strategies to support this vulnerable group and enhance their overall quality of life.

METHODS

Strategy of data synthesis To select the studies, a comprehensive search was carried out between December 2023 and March 2024 using a three-phase process. In the first phase, an initial search was conducted in the following databases: MEDLINE (via PubMed), Cochrane, EMBASE, CINAHL, Web of Science and SCOPUS. Keywords in titles and abstracts of the main articles were also identified in this phase. In the second phase, the keywords were combined with the natural language found in the first phase. For this purpose, the Boolean operators OR and AND were used and a comprehensive search strategy was designed. Finally, in the third phase, the search strategy was adapted for each database. The MeSH terms used were “aged”, “caregiver” and “health promotion”. The combination of natural language and MeSH keywords resulted in the following search strategy used for PubMed: ((elderly) OR (older adults) OR (aged) OR (older) OR (olders) OR (aged) AND ((care-giver) OR (caregivers) OR (carer) OR (caregivers)) AND ((spousal) OR (spouse) OR (partner) OR (couple)) AND ((intervention) OR (interventions) OR (program*) OR (programme) OR (health programme) OR (health programme) OR (health promotion))). This search strategy was used as a guide for the rest of the databases with the following modifications.

Eligibility criteria In line with the JBI methodology for scoping reviews [30], the PCC methodology (P: participants, C: concept, C: context) was applied to define the inclusion criteria:

- Participants: studies focusing on older adults with a mean age of 65 years or above who

undertake the role of primary caregiver for their partner.

- Concept: studies involving programmes/ interventions implemented and evaluated to improve their health.
- Context: studies conducted in community settings.

This review included quantitative, qualitative and mixed methods studies. In terms of language, studies published in English and Spanish were considered for inclusion. Articles were excluded if the health programmes had not been implemented or if they did not determine the characteristics of the programmes or the results obtained. Studies whose publication date exceeded 10 years were also excluded.

Source of evidence screening and selection

The article selection process was carried out in several phases. In the initial identification phase, articles were extracted from various databases. During the screening phase, duplicate articles and those written in a language other than English or Spanish were manually removed. In the next phase, articles not related to the topic based on their title and/or abstract were excluded. In the eligibility phase, two reviewers from the research team independently assessed the remaining articles, excluding those that did not provide full-text access or were published more than 10 years ago, as well as others that did not meet the eligibility criteria. Ultimately, articles that met all the established requirements were included. This process of article selection is reflected in the flowchart.

Data management Two researchers separately extracted the data from the studies included in the review. The methodology proposed by JBI [30] was followed taking into account the objectives and research questions of the review. A data extraction table was created with the following headings: author, year and country, type of design, study objective, population, main health condition of care recipient, intervention, duration of study and follow-up, study variables and assessment tools, and finally, main results. The method followed for data extraction was tested with one of the articles selected for inclusion in this scoping review. The reviewers did not find any discrepancies in the data extracted nor encounter any problems in the extraction process. Therefore, the two reviewers used this method to extract data from all of the records. Lastly, a third peer reviewer confirmed the accuracy and integrity of the previously extracted data. A summary of the main data extracted can be found in Table 1.

Language restriction In terms of language, studies published in English and Spanish were considered for inclusion.

Country(ies) involved Spain.

Keywords aged; caregivers; health promotion; partner; programmes.

Contributions of each author

Author 1 - Anabel Chica Pérez.

Email: acp819@inlumine.ual.es

Author 2 - Lucía Martínez Sola.

Email: lms740@inlumine.ual.es

Author 3 - Matías Correa Casado.

Email: mcc249@ual.es

Author 4 - Cayetano Fernández Sola.

Email: cfernand@ual.es

Author 5 - Karim El Marbouhe El Faqyr.

Email: eek918@ual.es

Author 6 - José Manuel Hernández Padilla.

Email: j.hernandez-padilla@ual.es