



**INTERVENÇÕES PARA OS CUIDADORES DE PESSOAS INTEGRADAS NUM PROGRAMA DE REABILITAÇÃO CARDÍACA:
PROTOCOLO DE SCOPING REVIEW**

**INTERVENTIONS FOR FAMILY MEMBERS OR CAREGIVERS OF PATIENTS TAKING PART IN A CARDIAC REHABILITATION
PROGRAM: SCOPING REVIEW PROTOCOL**

**INTERVENCIONES PARA CUIDADORES DE PERSONAS INTEGRADAS EN UN PROGRAMA DE REHABILITACIÓN CARDÍACA:
PROTOCOLO DE REVISIÓN DE ALCANCE**

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RESUMO

Introdução: A Reabilitação Cardíaca (RC) é um programa multifactorial, geralmente composto por exercício físico estruturado, apoio psicológico e educação para promover mudanças positivas no estilo de vida de pessoas com doença cardíaca. A maioria dos estudos define que é importante envolver a família (cuidadores) após o diagnóstico de doença cardíaca para garantir o sucesso do tratamento, e na RC não é diferente. Não sendo um objetivo implícito no cariz de prevenção secundária da RC, percebe-se que algumas das intervenções incluídas no programa podem ter um impacto positivo para os cuidadores. É fundamental compreender quais as intervenções da RC que podem ser utilizadas para promover o papel do cuidador e a sua saúde.

Objetivo: Mapear as intervenções dirigidas ao cuidador das pessoas com doença cardíaca, em programa de RC, promotoras do seu papel e da sua saúde.

Métodos: Scoping Review orientada pela metodologia proposta pelo Joanna Briggs Institute para a realização de Scoping Reviews. Dois revisores independentes avaliarão a relevância dos artigos, a extração e síntese dos dados. Serão considerados para inclusão nesta revisão estudos escritos em inglês, espanhol e português, publicados a partir de 1950, pesquisados nas seguintes fontes bibliográficas: CINAHL Complete (Via EBSCO) ; PubMed; Scopus; SciELO; Cochrane Library; PEDro; DART-Europe; OpenGrey e RCAAP.

Resultados: Com a realização desta scoping review prevemos incluir diversos estudos que demonstrem inequivocamente a existência de intervenções do programa de RC, com impacto positivo e facilitador na saúde e papel do cuidador de pessoa com doença cardíaca.

Conclusão: Este protocolo de revisão sistemática prevê mapear as intervenções dirigidas ao cuidador da pessoa com doença cardíaca, demonstrando a mais-valia das mesmas serem integradas nos programas de RC.

Palavras-chave: reabilitação cardíaca; cuidador; papel; saúde

ABSTRACT

Introduction: Cardiac Rehabilitation (CR) is a multifactorial program, usually composed of structured physical exercise, psychological support and education to promote positive changes in the lifestyle of people with different heart diseases. Most studies define that it is important to involve the family (caregivers) after the diagnosis of heart disease to guarantee the treatment's success, and CR is no different. Not being an implicit objective of secondary prevention of CR, some of the interventions included in CR can positively impact caregivers. Therefore, it is essential to understand which interventions can be used to promote the role of caregiver and their health.

Objective: Map which interventions have been implemented that support caregivers of patients with the cardiac disease taking part in a cardiac rehabilitation program, in their role and health.

Methods: Scoping Review guided by the methodology proposed by the Joanna Briggs Institute for conducting Scoping Reviews. Two independent reviewers will evaluate the relevance of the articles, the extraction and synthesis of the data. Studies written in English, Spanish and Portuguese, published after 1950, will be considered for inclusion in this review, researched in the following bibliographic sources: CINAHL Complete (Via EBSCO); PubMed; Scopus; SciELO; Cochrane Library; Pedro; DART-Europe; OpenGrey and RCAAP .

Results: With this scoping review, it's proposed to include several studies that unequivocally demonstrate the existence of interventions with a positive and facilitating impact on health and the role of caregivers of people with heart disease in CR programs.

Conclusion: This systematic review protocol provides mapping interventions to the caregiver of people with heart disease, demonstrating the added value of being integrated into CR programs.

Keywords: cardiac rehabilitation; caregiver; role; health

RESUMEN

Introducción: La Rehabilitación Cardíaca (RC) es un programa multifactorial, generalmente compuesta por ejercicio físico estructurado, apoyo psicológico y educación para promover cambios positivos en el estilo de vida de personas con diferentes enfermedades cardíacas. La mayoría de los estudios definen que es importante involucrar a la familia (cuidadores) después del diagnóstico de enfermedad cardíaca para garantizar el éxito del tratamiento, y la RC no es diferente.

Al no ser un objetivo implícito en la naturaleza de la prevención secundaria de la RC, es evidente que algunas de las intervenciones incluídas en la RC pueden tener un impacto positivo para los cuidadores. Por tanto, es fundamental comprender qué intervenciones se pueden utilizar para promover el papel del cuidador y su salud.

Objetivo: Mapear las intervenciones dirigidas al cuidador de personas con enfermedad cardíaca, en un programa de rehabilitación cardíaca, promoviendo su rol y su salud.

Métodos: Scoping Review guiada por la metodología propuesta por el Instituto Joanna Briggs para la realización de Scoping Reviews. Dos revisores independientes evaluarán la relevancia de los artículos, la extracción y síntesis de los datos. Los estudios escritos en inglés, español y portugués, publicados después de 1950, serán considerados para su inclusión en esta revisión, investigados en las siguientes fuentes bibliográficas: CINAHL Complete (Vía EBSCO); PubMed; Scopus; SciELO; Biblioteca Cochrane; Pedro; DART-Europa; OpenGrey y RCAAP.

Resultados: Con esta revisión de alcance, prevemos la inclusión de varios estudios que demuestren de manera inequívoca la existencia de intervenciones con un impacto positivo y facilitador en la salud y el rol de los cuidadores de personas con cardiopatía en los programas de RC

Conclusión: Con esta revisión de alcance, prevemos la inclusión de varios estudios que demuestren de manera inequívoca la existencia de intervenciones con un impacto positivo y facilitador en la salud y el rol de los cuidadores de personas con cardiopatía en los programas de RC.

Palabras Clave: rehabilitación cardíaca; cuidador; papel; salud

INTRODUCTION

Cardiac Rehabilitation (CR) is a preventive and multi-component program generally composing of structured exercise training, psychological support and education to promote positive lifestyle changes (Wingham et al., 2019). CR consists of three phases and is shown to reduce mortality, hospitalisation, health care, and to improve exercise capacity, quality of life and psychological wellbeing. Core components in cardiac rehabilitation include patient assessment, physical activity counselling, exercise training, diet/nutritional counselling, risk factor control, patient education, psychosocial management and vocational advice (Wingham et al., 2019; Sumner, Harrison, & Doherty, 2017).

Outcomes assessment can be broadly divided into health outcomes (morbidity, mortality, health-related quality of life), clinical outcomes (e.g., improvements in risk factors, in functional capacity and in psychosocial measures), behavioural outcomes (e.g., an appropriate response to symptoms, improvements in diet and physical activity) and service outcomes (e.g., patient and staff satisfaction, access and utilisation of services, patient healthcare utilisation and other financial and economic outcomes) (Bäck, Hansen, & Frederix, 2017; Novo et al., 2020; Sumner et al., 2017).

Cardiac rehabilitation is designed to improve cardiovascular health if a patient has experienced a heart attack, heart failure, heart surgery and assistance devices (Uithoven, Smith, Medina-Inojosa, Squires, & Olson, 2020). Nowadays, interventions and health outcomes of people with heart disease in CR program are recognised. Most of the studies define that it's important to involve family (caregivers) after the diagnosis of heart disease to guarantee the success of treatment, and CR is not different. They contribute substantially to patient's management of and recovery from cardiovascular disease (Bouchard et al., 2020). When the patient takes part in a cardiac rehabilitation program, the team involves his caregiver to enhance the health outcomes for the person, impacting the family.

It must be realised that a caregiver's role due to the physical and emotional overload, associated or not with the sharing of risk factors (smoking, sedentarism, others) increases, for example, the risk of developing heart disease in the caregiver.

Caregiving demands have been frequently related to a heavy burden role, decreasing the quality of life with physical and mental exhaustion, such as depression and anxiety and other physical health conditions. Some CR interventions seem to be a crucial step to improve patients' evolution, helping them understand the influence of psychobiological risk factors and building strategies to control daily stress, so some interventions can be used in caregivers (Lang et al, 2018).

In addition to its role's, in some cardiac diseases, there is a genetic/hereditary component, and risk behaviours are often shared between cohabitants. For example, a sedentary lifestyle is one of the worrying cardiovascular risk factors shared by patients and caregivers. Still, the exercise component works as the primary prevention of cardiovascular disease for caregivers (Fletcher et al., 2018).

It is essential to understand which cardiac rehabilitation programs interventions can also be used to improve the caregivers' role and health.

What is known is that are a lot of different interventions of cardiac rehabilitation programs that help caregivers in different contexts and, in studies like Lang et al. (Lang et al., 2018), Wingham et al. (Wingham et al., 2019) Erlinda and Michael (The & Jarrett, 2019). However, information on implemented and evaluated interventions, their characteristics, contexts of application, and the population is dispersed in the literature, making it challenging to construct precise questions on the effectiveness of those interventions and, consequently, to conduct a systematic review.

This scoping review's primary purpose is to map which interventions have been implemented that support caregivers of patients with cardiac disease taking part in a cardiac rehabilitation program in their role and health.

A preliminary search on databases (JBI Database of Systematic Reviews and Implementation Reports, Cochrane Database of Systematic Reviews, Academic Search Complete, CINAHL Complete, Communication Source, PsycARTICLES, PsycINFO, and PubMed) revealed no existing scoping or systematic reviews (published or in progress) of Cardiac Rehabilitation Interventions in Caregivers of the patient with cardiac disease.

This scoping review is part of a research project that may increase cardiac rehabilitation nurses' response to the patient and caregivers who have cardiac disease.

As the evidence in this area is dispersed, four guiding research questions were constructed:

1. What interventions are implemented and evaluated to provide support to caregivers of patients taking part in a cardiac rehabilitation program, in their role and promote their health?
2. What are the characteristics (duration, dose and frequency) of those interventions?
3. Which contexts (hospital, primary care, home) are the interventions implemented and evaluated?
4. Which populations (for example, caregivers of patients with heart failure, caregiver of patients with coronary disease, taking part in a cardiac rehabilitation) are interventions implemented and evaluated?

1. METHODS

This protocol of scoping review was guided by the methodology proposed for Joanna Briggs Institute for the conduct of scoping reviews (M. D. J. Peters et al., 2015; M. Peters et al., 2015), and purpose to examine and map cardiac rehabilitation interventions implemented and evaluated to promote caregiver role and help the caregiver health. According to the Joanna Briggs Institute, "scoping reviews undertaken with the objective of providing a map of the range of the available evidence can be undertaken as a preliminary exercise prior to the conduct of a systematic review." (M. D. J. Peters et al., 2015, p. 6)

Articles will be analysed based on the following inclusion criteria:

Participants

This scoping review will consider all studies that focus on caregivers of patients with medical or surgery heart disease, assisted by cardiac rehabilitation teams.

Concept

This scoping review will consider all studies that focus on interventions implemented to the caregiver of patients taking part in cardiac rehabilitation.

This scoping review will consider all studies that address cardiac rehabilitation interventions implemented and have the role and the health of caregivers into account (for example, education, counseling, exercise, health advice).

Context

This scoping review will consider all interventions implemented in all the contexts. This will include specifically hospital, primary care, home, cardiac rehabilitation centre, ambulatory.

Types of sources

This scoping review will consider quantitative, qualitative and reviews studies. Quantitative designs include any experimental study designs (including randomised controlled trials, non-randomised controlled trials, or other quasi-experimental studies, including before and after studies) and observational designs (descriptive studies, cohort studies, cross-sectional studies, case studies and case series studies).

Qualitative designs include any studies that focus on qualitative data such as, but not limited to, phenomenology, grounded theory and ethnography designs.

Reviews study include any Systematic Reviews.

Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilised in this review. An initial limited search of Pubmed was followed (oct 2020) by analysing the text words contained in the title and abstract and of the index terms used to describe the articles.

Search	Query	Records retrieved
#1	((Cardiac rehabilitation[Title/Abstract]) OR ((rehabilitation interventions[Title/Abstract]) OR (rehabilitation intervention[Title/Abstract]))) AND ((heart disease[Title/Abstract]) OR (heart surgery[Title/Abstract])) AND ((caregiver[Title/Abstract]) OR (caregivers[Title/Abstract]))	7
#2	((Cardiac rehabilitation[Title/Abstract]) OR ((rehabilitation interventions[Title/Abstract]) OR (rehabilitation intervention[Title/Abstract]))) AND ((heart disease[Title/Abstract]) OR (heart surgery[Title/Abstract])) AND ((caregiver[Title/Abstract]) OR (caregivers[Title/Abstract])) Filters: English, Portuguese, Spanish	6

A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English, Spanish and Portuguese will be considered for inclusion in this review. Studies published since 1950 will be considered for inclusion in this review to capture how rehabilitation interventions implemented and evaluated to provide the caregiver role because it is the data when are developed cardiac rehabilitation programs. The databases to be searched include: CINAHL Complete; PubMed; Scopus; SciELO; Cochrane Library; PEDro. The search for unpublished studies will include: DART-Europe; OpenGrey; RCAAP . Initial English language keywords to be used will be: (Cardiac rehabilitation) OR (rehabilitation interventions) AND (caregiver) AND (heart disease) OR (heart surgery) AND (role).

Information sources

Study selection

Articles searched will then be assessed for relevance to the review, based on the title and abstract's information, by two independent reviewers. The full article will be retrieved for all studies that meet the inclusion criteria of the review. If the reviewers have uncertainties about a study's relevance from the abstract, the full article will be retrieved. Based on full texts, two reviewers will examine independently whether the studies conform to the inclusion criteria. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Studies identified from reference list searches will be assessed for relevance based on the study's title and abstract.

Data extraction

Data will be extracted from papers included in the review using a charting table aligned to this research's objective and question, as indicated by the methodology for scoping reviews developed by the Joanna Briggs Institute (The & Jarrett, 2019). A data extraction instrument was developed (Appendix II); however, this may be further refined for use at the review stage. Two reviewers will extract data independently. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The two reviewers, independent of each other, will chart the "first five to ten studies using the data charting form and meet to determine whether their approach to data extraction is consistent with the research question and purpose", as suggested by Levac, Colquhoun and O'Brien (Levac, Colquhoun, & O'Brien, 2010, p. 6). Besides, if it is necessary, primary authors will be contacted for further information/clarification of the data, as suggested by Arksey and O'Malley's framework (Arksey & O'Malley, 2005).

Data presentation

The extracted data will be presented in diagrammatic or tabular form in a manner that aligns with this review's objective. A descriptive summary will accompany the tabulated and/or charted results and will describe how the results relate to the reviews objective and question. A summary of each article will include the author(s), year of publication, country of origin, purpose, population, sample size, methodology, concepts of interest and key findings relating to the review questions. For question 1 and 2 the tables and charts may include data indicated in Table 2:

Interventions of Cardiac Rehabilitation programs that support caregivers	Educational Intervention	Emotional support	Exercise Training	Others
Type of intervention				
Duration of intervention				
Frequency of intervention				

For question 3, the tables and charts may include data indicated in Table 3:

Interventions of Cardiac Rehabilitation programs that support caregivers	Educational Intervention	Emotional support	Exercise Training	Others
Hospital				
Primary Care				
Home				
Ambulatory				
Rehabilitation Center				
Others				

For question 4, the tables and charts may include data indicated in Table 4:

Interventions of Cardiac Rehabilitation programs that support caregivers	Educational Intervention	Emotional support	Exercise Training	Others
Caregivers of patients with heart disease				
Caregiver of patients submitted a heart surgery				
Others				

2. RESULTS

It's the objective of this scoping inclusion of several studies that describe interventions in cardiac rehabilitation programs, aimed to caregivers of people with heart disease.

An initial researched describe cardiac rehabilitation impact on caregiver outcomes, improve their confidence to support self-management, and be perceived to help maintain their role as caregivers (Wingham et al., 2019). Interventions like physical activity, educational intervention, resuscitation-retraining program, psychological intervention are described (Wingham et al., 2019 (Gonzalez-Salvado, et al., 2019), Sommaruga M., et al., 2018). Home-based appears most referenced.

3. DISCUSSION

It's important to recognise if caregiver role has impact in the caregivers health and what interventions will prevent or treat that effects. At the same time, some caregivers share cardiovascular risk factors, so it's essential to prevent them. Exercise and psychology intervention could help caregivers in this role but can help their health, and some preliminary studies prove this. Simultaneously, when we reflected on caregiver's of people with heart disease, we see that sometimes they have the same cardiovascular risk factors, so one component of CR is educational intervention can be used to help caregivers.

CONCLUSION

Therefore, this map will identify relevant issues to help advance evidence-based health care, develop knowledge, identify possible gaps and inform systematic reviews. Besides, this mapping will help inform the development of the appropriate and effective intervention(s) for caregivers of patients with heart disease to provide them with comfort and help other levels of studies.

REFERENCES

- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Bäck, M., Hansen, T. B., & Frederix, I. (2017). *Cardiac rehabilitation and exercise training recommendations. Cardiac rehabilitation: rationale, indications and core components*. Retrieved from <https://www.escardio.org/Education/ESC-Prevention-of-CVD-Programme/Rehabilitation>
- Bouchard, K., Brownrigg, J., Quinlan, B., Bilodeau, J., Higdon, G., & Tulloch, H. (2020). Supporting the Health and Well-being of Caregivers. *The Journal of Cardiovascular Nursing*, 35(3), 268–272. <https://doi.org/10.1097/JCN.0000000000000678>
- Fletcher, G. F., Landolfo, C., Niebauer, J., Ozemek, C., Arena, R., & Lavie, C. J. (2018). Promoting Physical Activity and Exercise: JACC Health Promotion Series. *Journal of the American College of Cardiology*, 72(14), 1622–1639. <https://doi.org/10.1016/j.jacc.2018.08.2141>
- Lang, C. C., Smith, K., Wingham, J., Eyre, V., Greaves, C. J., Warren, F. C., ... REACH-HF investigators. (2018). A randomised controlled trial of a facilitated home-based rehabilitation intervention in patients with heart failure with preserved ejection fraction and their caregivers: the REACH-HFpEF Pilot Study. *BMJ Open*, 8(4), e019649. <https://doi.org/10.1136/bmjopen-2017-019649>
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(1), 69. <https://doi.org/10.1186/1748-5908-5-69>

- Novo, A., Delgado, B., Mendes, E., Lopes, I., Preto, L., & Loureiro, M. (2020). *Reabilitação cardíaca - evidência e fundamentos para a prática*. Loures: Lusodidacta.
- Peters, M. D. J., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-Based Healthcare*, 13(3), 141–146. <https://doi.org/10.1097/XEB.0000000000000050>
- Peters, M., Godfrey, C., McInerney, P., Soares, C., Khalil, H., & Parker, D. (2015). *Methodology for JBI scoping reviews. The Joanna Briggs Institute reviewers' manual* (pp. 1–24). pp. 1–24. Adelaide (Australia): The Joanna Briggs Institute, The University of Adelaide.
- Sumner, J., Harrison, A., & Doherty, P. (2017). The effectiveness of modern cardiac rehabilitation: A systematic review of recent observational studies in non-attenders versus attenders. *PLOS ONE*, 12(5), e0177658. <https://doi.org/10.1371/journal.pone.0177658>
- The, E., & Jarrett, M. J. (2019). Impact of intensive basic life support training as part of cardiac rehabilitation program: Targeting family versus non-family bystanders. *European Journal of Preventive Cardiology*, 26(8), 793–794. <https://doi.org/10.1177/2047487319830486>
- Uithoven, K. E., Smith, J. R., Medina-Inojosa, J. R., Squires, R. W., & Olson, T. P. (2020). The Role of Cardiac Rehabilitation in Reducing Major Adverse Cardiac Events in Heart Transplant Patients. *Journal of Cardiac Failure*, 26(8), 645–651. <https://doi.org/10.1016/j.cardfail.2020.01.011>
- Wingham, J., Frost, J., Britten, N., Greaves, C., Abraham, C., Warren, F. C., ... Taylor, R. S. (2019). Caregiver outcomes of the REACH-HF multicentre randomised controlled trial of home-based rehabilitation for heart failure with reduced ejection fraction. *European Journal of Cardiovascular Nursing*, 18(7), 611–620. <https://doi.org/10.1177/1474515119850011>
- Chauvet-Gelinier, J. C., & Bonin, B. (2017). Stress, anxiety and depression in heart disease patients: A major challenge for cardiac rehabilitation. *Annals of physical and rehabilitation medicine*, 60(1), 6–12. <https://doi.org/10.1016/j.rehab.2016.09.002>
- Sommaruga, M., Angelino, E., Della Porta, P., Abatello, M., Baiardo, G., Balestroni, G., ... Pierobon, A. (2018). Best Practice in Psychological Activities in Cardiovascular Prevention and Rehabilitation: Position Paper. *Monaldi Archives for Chest Disease*, 88 (2). <https://doi.org/10.4081/monaldi.2018.966>