

## NECESSIDADES DOS FAMILIARES CUIDADORES DA PESSOA COM AMPUTAÇÃO DO MEMBRO INFERIOR: PROTOCOLO SCOPING REVIEW

## NEEDS OF FAMILY CAREGIVERS OF THE PERSON WITH LOWER LIMB AMPUTATION: SCOPING REVIEW PROTOCOL

## NECESIDADES DE LOS CUIDADORES FAMILIARES DE LA PERSONA CON AMPUTACIÓN DE MIEMBRO INFERIOR: PROTOCOLO SCOPING REVIEW

Diana Rodrigues<sup>1,2,3</sup>  <https://orcid.org/0000-0002-7602-1313>

Sofia Castanheira<sup>4</sup>  <https://orcid.org/0000-0003-2359-1651>

Luís Carvalho<sup>3,4</sup>  <https://orcid.org/0000-0003-1017-4787>

Cristina Barroso<sup>3,4</sup>  <https://orcid.org/0000-0002-6077-4150>

<sup>1</sup> Instituto de Ciências Biomédicas Abel Salazar da Universidade do Porto, Porto, Portugal

<sup>2</sup> FCT – Fundação para a Ciência e Tecnologia, Lisboa, Portugal

<sup>3</sup> CINTESIS – Centro de Investigação em Tecnologias e Serviços de Saúde, Porto, Portugal

<sup>4</sup> Escola Superior de Enfermagem do Porto, Porto, Portugal

Diana Rodrigues - dianfr@gmail.com | Sofia Castanheira - sofiamcastanheira@gmail.com | Luís Carvalho - luiscarvalho@esenf.pt |  
Cristina Barroso - cmpinto@esenf.pt



### Corresponding Author

*Diana Rodrigues*

Rua Dr. Sérgio Vieira de Melo, 58 2º Esq  
4420-623 – Gondomar – Portugal  
dianfr@gmail.com

RECEIVED: 14<sup>th</sup> November, 2022

REVIEWED: 28<sup>th</sup> December, 2022

ACCEPTED: 19<sup>th</sup> January, 2023

PUBLISHED: 28<sup>th</sup> March, 2023

## RESUMO

**Introdução:** A amputação do membro inferior provoca grande impacto físico e funcional. O impacto com a nova realidade ocorre principalmente no regresso ao domicílio, onde os familiares cuidadores assumem um papel fundamental. A transição para o papel de cuidador envolve sentimentos e necessidades múltiplas, pelo que a identificação das suas necessidades é fundamental para que a transição para esse novo papel seja saudável.

**Objetivo:** Mapear as necessidades dos familiares cuidadores da pessoa com amputação do membro inferior.

**Métodos:** Scoping review de acordo com metodologia Joanna Briggs Institute. Serão usadas as bases de dados: MEDLINE Complete (EBSCO), CINAHL Complete (EBSCO), Medclatina (EBSCO), Science Direct (EBSCO), Scielo (EBSCO), Academic Search Complete (EBSCO), OpenAire (EBSCO), Scopus, Web of Science e Trip. Para literatura cinzenta será utilizado o RCAAP (via EBSCO) e o Google Scholar. A revisão considerará os estudos que incluam as necessidades dos familiares cuidadores da pessoa com amputação do membro inferior no regresso a casa. Estudos em português, inglês e espanhol serão incluídos. A análise da relevância dos estudos, extração e síntese dos dados será realizada por dois investigadores independentes, um terceiro investigador será incluído em caso de discordância.

**Resultados:** Com os dados recolhidos pretende-se efetuar a listagem das necessidades dos familiares cuidadores da pessoa com amputação do membro inferior.

**Conclusão:** Com esta revisão espera-se sintetizar o conhecimento sobre as necessidades do cuidador da pessoa com amputação do membro inferior e identificar eventuais lacunas existentes na área referida.

**Palavra-chave:** amputação; cuidadores; determinação de necessidades de cuidados de saúde; família; enfermagem

## ABSTRACT

**Introduction:** Lower limb amputation has a great physical impact, with functional limitations and increased dependence on daily living activities that generate changes in the quality of life of the amputee and family. Support and care to the amputee are provided by the family caregiver, who experiences multiple feelings and needs in the transition to their new role. Identification of these needs is fundamental the creation of appropriate nursing interventions.

**Objective:** To map the needs of family caregivers of the person with lower limb amputation.

**Methods:** Scoping review according to the Joanna Briggs Institute methodology. The following databases will be used: MEDLINE Complete (EBSCO), CINAHL Complete (EBSCO), Medclatina (EBSCO), Science Direct (EBSCO), Scielo (EBSCO), Academic Search Complete (EBSCO), OpenAire (EBSCO), Scopus, Web of Science and Trip. For grey literature, RCAAP (via EBSCO) and Google Scholar will be used. The review will consider studies that include the needs of family caregivers of the person with lower limb amputation in returning home. Studies in Portuguese, English and Spanish will be included. Analysis of the relevance of the studies, extraction and synthesis of the data will be carried out by two independent researchers, a third researcher will be included in case of disagreement.

**Results:** The collected data will be used to identify the needs of family caregivers in providing care to persons with lower limb amputation.

**Conclusion:** With this review, we expect to synthesize knowledge about the needs of the caregiver of a person with lower-limb amputation or to identify existing gaps in this area.

**Keywords:** amputation; caregivers; family; needs assessment; nursing

## RESUMEN

**Introducción:** La amputación de miembros inferiores causa un gran impacto físico y funcional. El impacto con la nueva realidad se produce principalmente al volver a casa, donde los cuidadores desempeñan un papel fundamental. La transición al papel de cuidador familiar implica sentimientos y múltiples necesidades, por lo que la identificación de sus necesidades es esencial para una transición saludable a este nuevo papel.

**Objetivo:** Mapear las necesidades de los cuidadores familiares de la persona con amputación de miembro inferior.

**Métodos:** Revisión de alcance según la metodología del Instituto Joanna Briggs. Se utilizarán las siguientes bases de datos: MEDLINE Complete (EBSCO), CINAHL Complete (EBSCO), Medclatina (EBSCO), Science Direct (EBSCO), Scielo (EBSCO), Academic Search Complete (EBSCO), OpenAire (EBSCO), Scopus, Web of Science y Trip. Para la literatura gris, se utilizará RCAAP (a través de EBSCO) y Google Scholar. La revisión considerará estudios que incluyan las necesidades de los cuidadores familiares de la persona con amputación de miembros inferiores en el retorno al hogar. Se incluirán estudios en portugués, inglés y español. El análisis de la pertinencia de los estudios, la extracción y la síntesis de los datos serán realizados por dos investigadores independientes, incluyéndose un tercer investigador en caso de desacuerdo.

**Resultados:** Con los datos recogidos, pretendemos enumerar las necesidades de los cuidadores familiares de la persona con amputación de miembros inferiores.

**Conclusión:** Con esta revisión, esperamos sintetizar el conocimiento sobre las necesidades del cuidado de la persona con amputación de miembro inferior e identificar posibles lagunas en esta área.

**Palabras clave:** amputación; cuidadores; enfermería; evaluación de necesidades; familia

## INTRODUCTION

Lower limb amputation is a loss that affects and changes several parameters of a patient's life, representing a challenge for him/her, the family, and the health professionals involved in the care process. Family caregivers are confronted with their family members' clinical situations and the changes they bring about, which may hinder their ability to cope with and manage the situation (Areia et al., 2020).

After lower limb amputation, most people face stressful situations such as phantom pain, loss of functional independence, and changes in body image (Couture et al., 2012). The loss of physical, psychological, or intellectual autonomy caused by the disease and worsened by the amputation makes it impossible for the person to perform activities of daily living independently, thus compromising self-care and making them dependent on someone else to perform their activities of daily living.

Within a family, when a situation of illness with dependence on sick member arises, there is a need to make changes in the activities of daily living, and the role of caregiver is usually assumed by women, maids, or unemployed, single women who live with the dependent person. Taking on a new role is associated with multiple feelings and needs that may be antagonistic and contradictory regarding the competence, tension, and conflict that may be associated (Fernandes & Angelo, 2016).

Meleis et al. (2015) found that caring for a dependent person in a family has become increasingly common. The role of family caregivers arises when there is a change in the health condition of a family member, initiating a transition process within the family itself. This implies that a family member who assumes the role of caregiver will experience a situational type of transition, where changes will occur in the life of the person who becomes dependent, as well as in the life of the family caregiver, requiring learning and the acquisition of new skills. The same author defines transition as a change in health status, in the form of relationships, and in the abilities and hopes that will cause changes in the needs of individuals.

The needs of caregivers vary according to the transition stage they are in, and the assessment of these needs should be done taking into consider all areas of caregiving, family relationships, physical self-care, emotional, and practical needs (Shaw et al., 2016).

For an informal caregiver to feel empowered to care for the other, they must have knowledge about the illness of the person being cared for and acquire new skills for caregiving. Caregivers have their own potential and needs, which makes them unique (Castro et al., 2016). In the process of caring for dependent people, caregivers' needs should be identified by considering their individual needs and those of the person being cared for (Antunes & Marques, 2017).

Caregivers show a set of needs that should be considered a focus of attention for nursing interventions (Melo et al., 2014). Caregivers assume multiple responsibilities and may generate overload, particularly when their needs are not adequately met (Tsai et al., 2015). The identification of family caregivers' needs as early as possible is essential for nurses to develop interventions that empower caregivers in their role. Teixeira et al. (2017) found that empowerment and early intervention with family caregivers represent benefits for caregivers, persons cared for, and health systems, thereby promoting cost reduction and health gains. Caregivers are more vulnerable when they lack support, which has detrimental effects on individual, family, social, and economic levels.

The objective of this scoping review is to map the needs of family caregivers of the person with lower limb amputation. A preliminary search of the JBI Evidence Syntesis, Medline, and Cinahl databases was performed, and no published or developing reviews on the topic under study were identified.

This scoping review, intends to answer the following question: What are the needs of family caregivers of the person with lower limb amputation?

## 1. METHODS

The present study was developed according to the scoping review methodology used to elaborate the mapping of concepts, sources, and evidence available in each research area and to identify possible gaps in knowledge concerning the topic under study. The development of this review protocol followed the recommendations of the Joanna Briggs Institute (Peters et al., 2020).

To ensure transparency and rigor, the study will be conducted according to the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for Scoping Reviews (Prisma-ScR) Checklist (Tricco et al., 2018).

This scoping review protocol is registered in Open Science Framework (<https://osf.io/wu82x>).

The protocol has not been submitted to or published in any journal.

### 1.1 Inclusion criteria (CCP)

To develop the research question of this scoping review, the Population, Concept, Context (PCC) strategy was used, following the Joanna Briggs Institute guidelines (Peters et al., 2020).

### 1.2 Participants

This scoping review will include family caregivers of persons with lower limb amputation, only studies whose family caregivers are over the age of 18 will be included.

### 1.3 Concept

This scoping review will include all studies that report the needs of family caregivers of persons with lower limb amputation. All type of family caregivers' needs will be included as concepts. Studies that do not refer to the needs of family caregivers and those that refer only to the needs of the amputee will be excluded.

### 1.4 Context

This review will include studies involving family caregivers' inpatients discharged to their homes.

### 1.5 Types of studies

Regarding the type of evidence, quantitative and qualitative studies, primary studies, systematic reviews, gray literature (books, theses, dissertations, and guidelines), published in indexed sources, that answer the research question will be included. Other types of text, including opinion papers and reports, will be considered in this review. Study protocols will be excluded.

Only studies written in Portuguese, English, and Spanish, with no limit of research time interval, will be included in the review.

### 1.6 Search Strategy

The search strategy used will be the three-step strategy proposed by the Joanna Briggs Institute (Peters et al., 2020), to find published and unpublished studies that answer the review question. An initial limited search of CINAHL Complete (EBSCO) and MEDLINE Complete (EBSCO) databases was conducted to identify index terms and keywords contained in title and abstract of the articles found. In the second stage, the index terms and keywords identified in the initial review results will be combined in a full search strategy adapted for all databases included. The search strategy will aim to locate both published and unpublished studies in peer-reviewed databases and in grey literature sources. The search strategy will be refined with the help of a librarian. Table 1 shows a full search strategy for MEDLINE complete (EBSCO) database.

**Table 1** – Search strategy for MEDLINE complete (EBSCO) database

Database	Query	Results obtained
Medline complete (EBSCO)	TI ( (Caregiver* OR "Care Giver*" OR "Carer*") AND ("Lower Extremit*" OR "Lower Limb*" OR "Membrum infer*") AND ("Amputat*") ) OR SU ( (Caregiver* OR "Care Giver*" OR "Carer*") AND ("Lower Extremit*" OR "Lower Limb*" OR "Membrum infer*") AND ("Amputat*") ) OR AB ( (Caregiver* OR "Care Giver*" OR "Carer*") AND ("Lower Extremit*" OR "Lower Limb*" OR "Membrum infer*") AND ("Amputat*") )	38

Search strategies of all included databases will be presented in the final report. The databases to be searched included: MEDLINE Complete (EBSCO), CINAHL Complete (EBSCO), Mediciatrina (EBSCO), Science Direct (EBSCO), Scielo (EBSCO), Academic Search complete (EBSCO), OpenAire (EBSCO), Scopus, Web of Science and Trip. Grey literature to be searched includes Open Access Scientific Repositories of Portugal - RCAAP (via EBSCO) and Google Scholar.

In the third step, a search and analysis will be performed using the reference list of all included studies, so that potential studies can be identified as potential to be added to the search.

### 1.7 Study selection

Following the full search, all citations results will be uploaded into reference manager software Mendeley Desktop (version 1.19.8.) and duplicates will be removed. Study selection will be developed in two stages. In the first stage, titles and abstracts will be screened by two independent researchers against the inclusion criteria to determinate the relevance of the study. The full article of selected studies will be reviewed against the inclusion criteria by two researchers to verify their relevance to the review. The reasons of exclusion of the full-text papers that did not meet the inclusion criteria will be recorded and reported in this scoping review. Any disagreements that arise between researchers at each stage of the selection process will be resolved through discussion or by third researcher. Since this is a scoping review, the methodological quality of the selected studies will not be analyzed (Peters et al., 2017). The results of the study selection will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Page et al., 2021).

### 1.8 Data Extraction

Data will be extracted from included studies in the scoping review by two independent researchers. Using a data extraction tool developed by the researchers based on standardized data extraction tool from Joanna Briggs Institute. The tool is shown in Table 2.

**Table 2** – Data extraction grid

Data extraction	1	2	3
Author(s)			
(year)			
Country			
Objective/Research question			
Population / Sample			
Methodology (Methods)			
Identified needs			
Study context			
Main conclusions			
Other comments			

The data extraction tool may need some refinements during the data extraction process and according to the needs observed by the researchers. The relevant data extracted from the articles included in the review will be extracted by two independent researchers and grouped according to the established categories. If questions arise or additional information is needed, the first author of the studies will be contacted.

In case of disagreement between the researchers regarding the included studies, a third researcher will be consulted.

### 1.9 Data synthesis

Extracted data will be presented in narrative format and presented in charts and/or graphs to facilitate understanding, according to the purpose of the review. This step will be developed by two independent researchers, in case of disagreements a third researcher will be included.

To answer the aim and the research question “what are the needs of family caregivers of the person with lower limb amputation?”, the following data will be analyzed (Table 3).

**Table 3** – Data synthesis grid

Study(Author, year)	Sample	Identified needs	Study context	Main Conclusions

## 2. RESULTS

In this step, will be presented the characteristics of the studies included in this review about the needs of family caregivers of the person with lower limb amputation in the context of discharge to home. The results obtained may provide data to identify the most emerging needs of the family caregivers in caring for the person with lower limb amputation.

Caregivers face constant challenges; to experience a transition to the new role in a healthy way, they need to organize and prepare themselves adequately. To maintain an adequate level of health and well-being ensuring continuity of care of a dependent person, is important to coordinate with health professionals, particularly nurses, to meet their needs (Melo et al., 2014).

The process of care provision is dynamic, complex, and arduous, with variations in terms of feelings and needs of both caregivers and care recipients (Sarmiento et al., 2010).

This review aims to identify possible gaps in the literature and research on the intended theme, by determining which areas require a deeper or more complete analysis.

## CONCLUSION

To awaken the caregiver's interest in learning, it is important to know the needs so that the problems or cases are well aligned with reality. Health promotion should focus not only on the physical aspects of the disease, but also on the empowerment of the person to become an active agent in managing their health and that of the person they care for. In this context, it is essential to identify needs that go beyond disease deviations (Freire et al., 2021).

With this review, we expect to synthesize the knowledge on needs of family caregivers of people with lower limb amputation, contribute to the knowledge on the topic and indicate gaps in the area, thus highlighting the need for further clinical research.

## REFERENCES

- Antunes, P. F., & Marques, P. A. O. (2017). Transition to the family caregiver role in Portugal. *Porto Biomedical Journal*, 2(6), 254-259. <https://doi.org/10.1016/j.pbj.2017.05.002>
- Areia, N., Major, S., Fonseca, G., Oliveira, V., & Relvas, A. P. (2020). Prevalence and predictors of psychological morbidity in family relatives of terminally ill cancer patients. *Psicologia, Saúde & Doença*, 21(01), 169-175. <https://doi.org/10.15309/20psd210125>
- Castro, L., de Souza, D. N., Pereira, A., Santos, E., Lomeo, R., & Teixeira, H. (2016). Competências dos cuidadores informais familiares no autocuidado: autoestima e suporte Social. *CIAIQ2016*, 2. <https://proceedings.ciaiq.org/index.php/ciaiq2016/article/view/892>
- Couture, M., Desrosiers, J., & Caron, C. D. (2012). Coping with a lower limb amputation due to vascular disease in the hospital, rehabilitation, and home setting. *International Scholarly Research Notices*, 2012, e179878. <https://doi.org/10.5402/2012/179878>
- Fernandes, C. S., & Angelo, M. (2016). Cuidadores familiares: o que eles necessitam? Uma revisão integrativa. *Revista da Escola de Enfermagem da USP*, 50, 0675-0682. <https://doi.org/10.1590/S0080-623420160000500019>
- Freire, R. M. A., Martins, T., Peixoto, M. J., Puga Machado, P. A., & Vilela, C. (2021). Programas de intervenção para familiares cuidadores de pessoas dependentes. *Autocuidado: Um Foco Central da Enfermagem*, 59-70. <https://doi.org/10.48684/sxd1-y587>
- Khalil, H., Peters, M. D., Tricco, A. C., Pollock, D., Alexander, L., McInerney, P., Godfrey, C. M., & Munn, Z. (2021). Conducting high quality scoping reviews-challenges and solutions. *Journal of Clinical Epidemiology*, 130, 156-160. <https://doi.org/10.1016/j.jclinepi.2020.10.009>
- Meleis, A. I. (2015). Transitions theory. *Nursing theories and nursing practice*, 4, 361-380.
- da Costa Melo, R. M., dos Santos Rua, M., & de Brito Santos, C. S. V. (2014). Necessidades do cuidador familiar no cuidado à pessoa dependente: uma revisão integrativa da literatura. *Revista de Enfermagem Referência*, 4(2), 143-151. <https://doi.org/10.12707/RIV14003>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., ... Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical research ed.)*, 372, n71. <https://doi.org/10.1136/bmj.n71>
- Peters, M. D., Godfrey, C., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2017). Scoping reviews. *Joanna Briggs Institute reviewer's manual*, 2015, 1-24.
- Peters, M. D., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Khalil, H. (2020). Chapter 11: scoping reviews (2020 version). *JBI manual for evidence synthesis*, JBI, 2020. <https://doi.org/10.46658/JBIMES-20-12>
- Peters, M. D., Godfrey, C., McInerney, P., Khalil, H., Larsen, P., Marnie, C., ... & Munn, Z. (2022). Best practice guidance and reporting items for the development of scoping review protocols. *JBI evidence synthesis*, 20(4), 953-968. <https://doi.org/10.11124/JBIES-21-00242>
- Sarmento, E., Pinto, P., & Monteiro, S. (2010). *Cuidar do idoso: Dificuldades dos familiares*. Formasau.
- Shaw, J. M., Young, J. M., Butow, P. N., Badgery-Parker, T., Durcinoska, I., Harrison, J. D., Davidson, P. M., Martin, D., Sandroussi, C., Hollands, M., Joseph, D., Das, A., Lam, V., Johnston, E., & Solomon, M. J. (2016). Improving psychosocial outcomes for caregivers of people with poor prognosis gastrointestinal cancers: A randomized controlled trial (Family Connect). *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 24(2), 585-595. <https://doi.org/10.1007/s00520-015-2817-3>
- Teixeira, A., Alves, B., Augusto, B., Fonseca, C., Nogueira, J., Almeida, M., & Nascimento, R. (2017). Medidas de intervenção junto dos cuidadores informais. *Documento Enquadrador, Perspetiva Nacional e Internacional*. Lisboa: Gabinete de Estratégia e Planeamento do MTSSS. [http://cuidadores.pt/sites/default/files/documentos/Doc\\_CI\\_PDF](http://cuidadores.pt/sites/default/files/documentos/Doc_CI_PDF)
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, 169(7), 467-473. <https://doi.org/10.7326/M18-0850>
- Tsai, P. C., Yip, P. K., Tai, J. J., & Lou, M. F. (2015). Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. *Patient preference and adherence*, 9, 449-457. <https://doi.org/10.2147/PPA.S77713>