

The father's involvement in the care of a child with a serious illness: A scoping review protocol

A participação do pai no cuidado ao filho com doença grave: Um protocolo de revisão de escopo

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ABSTRACT

Objective: To present a protocol for a scoping review to map and describe the studies available in the scientific literature regarding the presence and involvement of the father in the care of a child with a serious illness. **Method:** The protocol follows the methodology proposed by the Joanna Briggs Institute (JBI) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses – Extension for Scoping Reviews (PRISMA-ScR) guidelines for reporting review protocols. Our guiding question was: "How does father involvement in the care of a critically ill child occur?". A detailed search strategy using the Population, Concept, and Context (PCC) strategy will be conducted on CINAHL, Embase, Scopus, Web of Science, SciELO, PubMed, and Virtual Health Library (BVS). For gray literature searches, Google Scholar and the Catalog of Theses and Dissertations of the Coordination of Superior Level Staff Improvement (CAPES) will be used. Two independent reviewers will select search results based on title and abstract information. They will then read the full studies by considering the eligibility criteria and extract relevant information for the review of this protocol by using a standardized form. The results will be presented as tables, flowcharts, figures, and narrative and descriptive summaries.

Keywords: Father; Father-Child Relationships; Paternal Behavior; Childcare; Catastrophic Illness.

RESUMO

Objetivo: Apresentar um protocolo de revisão de escopo para mapear e descrever os estudos disponíveis na literatura científica acerca da presença e participação do pai no cuidado ao filho com doença grave. **Método:** O protocolo seguirá o método proposto pelo *Joanna Briggs Institute* (JBI) e as diretrizes do *Preferred Reporting Items for Systematic reviews and Meta-Analyses – Extension for Scoping Reviews* (PRISMA-ScR) para relato de protocolos de revisão. Nossa pergunta norteadora foi "Como ocorre a participação do pai no cuidado ao filho com doença grave?". Será utilizada uma estratégia de busca detalhada empregando a estratégia PCC (população, conceito e contexto) nas bases de dados CINAHL, Embase, Scopus, *Web of Science*, SciELO, PubMed e Biblioteca Virtual em Saúde (BVS). Para busca de literatura cinzenta, serão utilizados o *Google Acadêmico* e Catálogo de Teses e Dissertações da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES). Dois revisores independentes selecionarão os resultados da busca por meio da informação do título e resumo. Em seguida, realizarão a leitura dos estudos na íntegra, considerando os critérios de elegibilidade, e extrairão, por meio de um formulário padronizado, as informações pertinentes à revisão a qual esse protocolo se propõe. Os resultados serão demonstrados na forma de quadro, fluxograma, figuras, resumo narrativo e descritivo.

Descritores: Pai; Relações Pai-Filho; Comportamento Paterno; Cuidado da Criança; Doença Catastrófica.

INTRODUCTION

Over time, the role of the father has evolved from that of a mere financial, disciplinary pillar of the family to that of a provider of love and a participant in the education of the children. The contemporary father wants to be involved in the family routine and the daily life of the children, showing interest in caring, protecting, and transmitting teachings, values, and affection as well as redefining fatherhood and becoming a protagonist in the education of the children⁽¹⁻²⁾. Today's man, engaged in parenthood, has begun to show interest in participating in the education of his children and in deepening the father-child relationship emotionally; however, he still faces obstacles dictated by the contradictory norms of a society steeped in traditional values, where parenthood is encouraged and associated with the maternal figure, placing the father in a supportive role to the mother⁽³⁻⁴⁾.

The contemporary father has been educated and socialized within masculinized norms that do not include the act of caregiving. Faced with a child's illness, the paternal figure returns to the role of family provider, creating a conflict between the current conception of fatherhood and the retrograde social ideology of manhood⁽⁵⁻⁶⁾. The importance of the father's involvement in the child's care is recognized in the scientific literature, as it has a significant impact on the child's development and social construction. Thus, the father is crucial in caring for the sick child, contributing to the well-being and improvement of the child's care⁽⁷⁾.

However, there is no consensus in the literature on the active involvement of fathers in the care of sick children. Studies show that the father plays his role based on the traditional gender concept, with predetermined sociocultural and stereotyped functions. Scholars claim that there is a distinction between the roles of father and mother, which leads to limited paternal involvement in the care of the sick child. As a result, the father perceives his presence and the exercise of fatherhood as of little importance^(1,8-11). There is no precise legal definition of a serious illness, but rather a list of illnesses that are considered serious by law. Thus, a serious illness is considered to include a wide variety of conditions classified according to their severity; therefore, the greater the severity of a disease, the greater its capacity to seriously affect the health of those who suffer from it. They are characterized by a progressive and persistent development, with a potential risk of causing

disability, dependence on care, and a threat of death⁽¹²⁻¹⁴⁾.

Regarding the father's involvement during the child's treatment and rehabilitation, one study found that the father's involvement in the care of the sick child is minimal or even absent during this process⁽¹⁵⁾.

The development of this protocol arose from the circumstances described above, as it is justified by the need to deepen knowledge about the father's involvement in the care of a child with a serious illness. It is crucial to map the available evidence on this subject since gaps in knowledge can be observed in studies that discuss the presence and participation of the father in the care of a child with a serious illness. Although there has been a recent interest in the paternal figure, little is known about how the father experiences, perceives and performs his role in fatherhood in this context. Therefore, this study aimed to present a scoping review protocol to map and describe the studies available in the scientific literature regarding the presence and involvement of the father in the care of a child with a serious illness.

METHOD

This is a scoping review protocol designed to explore research concepts, map studies, clarify and synthesize scientific evidence, and identify existing research gaps⁽¹⁶⁾. The protocol was developed following the Joanna Briggs Institute (JBI) guidelines and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Extension for Scoping Reviews (PRISMA-ScR)⁽¹⁶⁻¹⁷⁾. The protocol has been registered with the Open Science Framework (OSF) and is available at <https://osf.io/5fzrg/> (DOI 10.17605/OSF.IO/5FZRG).

The following five steps were taken to develop this protocol⁽¹⁸⁾:

First step

The research question was formulated according to the PCC acronym (where p = population; c = concept; and c = context) (Figure 1).

Figure 1 – PCC strategy to be used in the scoping review. Londrina, PR, Brazil, 2023

PCC		Description
P	Population	Father
C	Concept	Studies on paternal care
C	Context	Childcare; Serious or catastrophic illness

According to this strategy, the research question was developed: "How does the father participate in the care of his child with a serious illness?"

Second step

Identification of relevant studies: includes the selection of databases, the formulation of search strategies using descriptors and Boolean operators, and the definition of inclusion and exclusion criteria. The following databases will be searched CINAHL (Cumulative Index to Nursing and Allied Health Literature), Embase (Excerpta Medica dataBASE), Scopus, Web of Science, SciELO (Scientific Electronic Library Online), PubMed, and Virtual Health Library (BVS). For gray literature searches, Google Scholar and the Catalog of Theses and Dissertations of the Coordination of Superior Level Staff Improvement (CAPES) will be used. The search strategies will be adapted to the specificities of

each database. The "advanced search" function will be used in the first stage of the search for studies, using MeSH (Medical Subject Headings) and DeCS (Descritores em Ciências da Saúde) descriptors and the Boolean operators AND and OR. For the search in the CAPES Theses and Dissertations Catalog, a single-term search strategy will be used, as well as cross terms without Boolean operators. The strategy will include the following crossed terms:

1. Descritores em Ciências da Saúde (DeCS): Pai AND Relações Pai-Filho OR Comportamento Paterno AND Cuidado da Criança AND Doença Grave.

2. Medical Subject Headings (MeSH): Fathers AND Father-Child Relations OR Paternal Behavior AND Child Care e Critical Illness.

The uncontrolled descriptors "sick child" and "father care" are also used in the search. The search strategy adopted for each database is detailed in Figure 2.

Figure 2 – Elaboration of the search strategy in the various databases/portals. Londrina, PR, Brazil, 2023

Databases	Search strategy
BVS	#1 Pai AND Relações Pai-Filho OR Comportamento Paterno AND Cuidado da Criança AND Doença Grave; #2 Pai AND Cuidado da Criança AND Doença Grave; #3 Pai AND Cuidado da Criança AND "Filho doente"; #4 Comportamento Paterno AND Filho Doente AND Doença Grave
CINAHL	#1 Fathers AND Father-Child Relations OR Paternal Behavior AND Child Care AND Critical Illness; #2 Fathers AND Child Care AND Critical Illness
PubMed	#1 Fathers AND Father-Child Relations AND Child Care AND Critical Illness; #2 Fathers AND Child Care AND Critical Illness; #3 Paternal Behavior AND Child Care AND Critical Illness; #4 Paternal Behavior AND "Sick Child" AND Critical Illness; #5 Paternal Behavior AND "Sick Child"
Embase	#1 Father AND Father child relation OR Paternal Behavior AND Child Care AND Critical Illness; #2 Father AND Child Care AND Critical Illness; #3 Father child relation OR Paternal Behavior AND Child Care AND "Sick Child"; #4 Father child relation OR Paternal Behavior AND "Sick Child"; #5 Father AND Child Care
Scopus	#1 Fathers AND Father-Child Relations AND Child Care AND Critical Illness; #2 Father AND Child Care AND Critical Illness; #3 Paternal Behavior AND "Sick Child"
Web of Science	#1 Fathers AND Father-Child Relations OR Paternal Behavior AND Child Care AND Critical Illness; #2 Fathers AND Child Care AND Critical Illness; #3 Paternal Behavior AND "Sick Child"; #4 Fathers AND Child Care AND "Sick Child"
SciELO	#1 Fathers AND Father-child relation OR Paternal Behavior AND Child Care AND Critical Illness; #2 Fathers AND Child Care AND Critical Illness; #3 Father-child relation AND "Sick Child"; #4 Fathers AND "Sick Child" AND Critical Illness; #5 Fathers AND Child Care; #6 Fathers AND "Sick Child"
Google Acadêmico	#1 Pai AND Relações Pai-Filho OR Comportamento Paterno AND Cuidado da Criança AND Doença Grave
CAPES	#1 "Cuidado do Pai"; #2 "Filho Doente"; #3 Relações Pai-Filho; #4 Comportamento Paterno

The established eligibility criteria will be applied during the study selection process to ensure that only studies suitable for the scope of the review are included in the analysis. These criteria are fundamental to obtaining a high-quality review based on significant evidence on the topic of the father's presence and involvement in the care of a child with a serious illness.

To be included in the review, studies must be published in databases and gray literature that focus on the father as a population and address the concept of paternal behavior, father-child relationship, and paternal involvement in the care of the child in the context of serious or catastrophic illness.

Articles of any methodological design will be selected, and published in Portuguese, English, and Spanish, without time limit, available in full and free electronically, as well as dissertations and theses that answer the research question. Editorial studies, response letters, and opinion articles will be excluded. Duplicate documents will be considered as lost documents and will be counted only once.

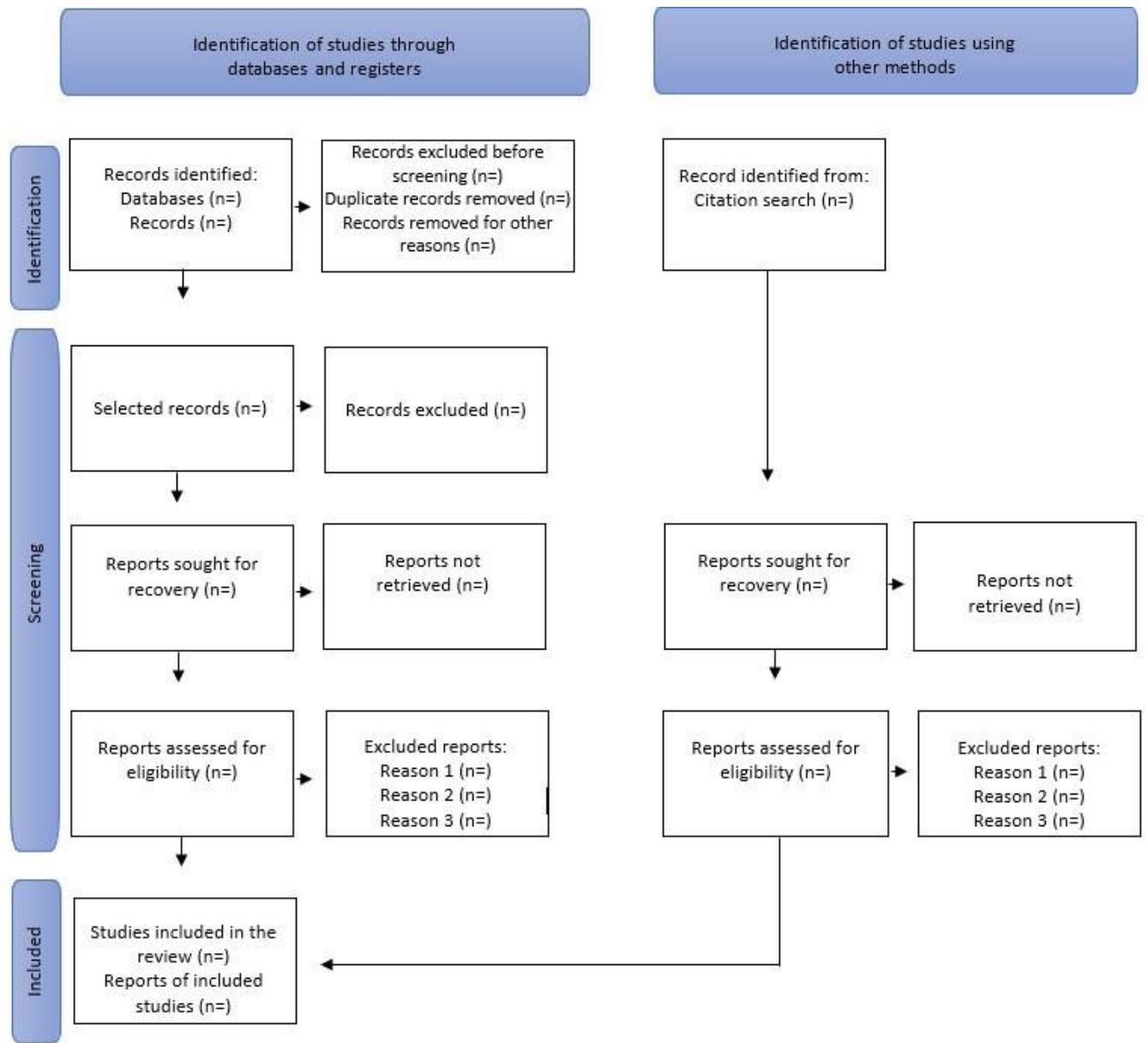
Third step

Selection and initial assessment of studies: will be carried out by two independent reviewers who will first carefully read the title and abstract of each retrieved material. Shortly the-

reafter, eligible studies according to the established inclusion and exclusion criteria will have their data exported to a Microsoft Excel spreadsheet for subsequent grouping and removal of duplicates. Finally, the reviewers will read the studies in full, applying the inclusion criteria again for later data extraction. To identify additional studies, a search of the reference lists of all studies meeting the eligibility criteria will be performed. The studies selected in this new search will be assessed similarly to the other studies, as described above. If there are additional studies, they will be listed separately and identified in the presentation of the results. In case of disagreement between the two reviewers during the study selection process, the material will be retrieved and forwarded to a third reviewer with expertise in the topic, who will provide the final opinion. To ensure transparency and quality, the search and study selection process will be described using a flowchart adapted from PRISMA-ScR⁽¹⁹⁾ (Figure 3), which will present the quantitative results from each database, with reasons for excluding studies and the total number of studies included for data analysis and synthesis.

The entire process of study selection and evaluation is performed manually by the authors using Microsoft Excel, as mentioned above; no reference management software is used.

Figure 3 – Study selection flowchart. Londrina, PR, Brazil, 2023



Source: PRISMA-ScR flowchart adapted from Page *et al.*, 2021.

Fourth stage

The extracted data will be analyzed and categorized to identify patterns, trends, and gaps in the existing literature. The analysis will be performed by two independent reviewers using the data extracted from the selected studies. A guideline developed by the reviewers will be

used to guide the systematization of information from the studies included in the scoping review (Figure 4). The data collection instrument will be evaluated by the reviewers prior to the start of the extraction through a pilot test. The instrument may be reformulated at any time during the research as needed during the data extraction process. This will be detailed in the scoping review.

Figure 4 - Scoping review data extraction tool. Londrina, PR, Brazil, 2023

Data from the selected studies	Description
ID	Orderly identification of the study
Authors	Surname/Name (Vancouver style)
Year of publication	Year the study was published
Title	Original study title
Type of publication	Article, thesis, or dissertation
Country of origin	Country where the study was conducted
Journal	Name of the journal
Type of study	Methodology
Study objective	The study's main objective
Main results and considerations	Synthesis of the evidence on the presence and participation of the father figure in the care for a child with a serious illness

Fifth step

The final presentation of the data will be both written and visual. The presentation will use figures, tables, flowcharts, and other visual resources to facilitate the visualization and understanding of the results. Correspondingly, a critical analysis of the results will be conducted, which will be presented in a descriptive, reflective manner of the evidence found by considering the aim of the review.

Ethical considerations

A scoping review will be conducted by ethical principles and applicable methodological guidelines. A rigorous and systematic work will be carried out to identify, select, and analyze previously published studies, respecting good practices in scientific research, such as citation norms and referencing all materials found. The review will be based on the analysis of publicly available data and will not directly involve the participation of human subjects; therefore, there is no need for analysis by an ethics committee.

Expected results

The results of this review are expected to enable discussion, dissemination, and systematization of knowledge on the topic. In addition, the review is hoped to provide an expanded view of the topic by identifying and mapping the studies available in the literature, identifying gaps in existing knowledge, and providing recommendations for future research.

In addition, the findings may provide valuable information to health care professionals, researchers, and policymakers who seek to increase awareness of fatherhood, promote positive paternal involvement, and improve the well-being of children and families in these challenging circumstances.

CONFLICT OF INTERESTS

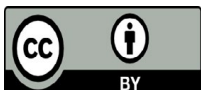
The authors have declared that there is no conflict of interests.

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Project design: Silva RS da, Zani AV
Data collection: Silva RS da, Coppo CB, Zani EM, Zani AV
Data analysis and interpretation: Silva RS da, Coppo CB, Zani EM, Zani AV
Writing and/or critical review of the intellectual content: Silva RS da, Coppo CB, Zani EM, Zani AV
Final approval of the version to be published: Silva RS da, Coppo CB, Zani EM, Zani AV
Responsibility for the text in ensuring the accuracy and completeness of any part of the paper: Silva RS da, Coppo CB, Zani EM, Zani AV



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