Systematic Reviews

PROTOCOL

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Caregiver experiences and needs in pediatric rheumatic disease: a mixed-methods systematic review protocol

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Abstract

Introduction Understanding the genuine experiences and requirements of caregivers and implementing targeted interventions can have a positive impact on the physical and mental well-being of caregivers with children diagnosed with rheumatic diseases, ultimately reducing their burden and enhancing their quality of life. While there has been a gradual increase in research in this area in recent years, there remains a gap in the evidence that comprehensively and systematically reflects the actual experiences and needs of caregivers. We will employ a mixed-methods approach to evaluate the real-life experiences and requirements of caregivers for children diagnosed with rheumatic diseases to provide insights for both research and clinical interventions.

Methods and analysis All types of studies (quantitative, qualitative, and mixed-methods) involving caregivers of children aged 0 to 18 with rheumatic diseases will be included. We will conduct a comprehensive search across multiple databases, including MEDLINE (PubMed), Embase (Ovid), PsycINFO (Ovid), CINAHL (EBSCO), Cochrane Central Register of Controlled Trials (CENTRAL), CNKI, WanFang, and VIP, as well as the grey literature, to identify primary studies published in either English or Chinese since 2000. Two independent reviewers will conduct the selection process and cross-check the data extraction. The focus of interest will be on understanding the experiences and needs of caregivers for pediatric rheumatic disease patients. In our systematic review, we will employ the 2018 version of the Mixed Methods Assessment Tool (MMAT) to evaluate study quality, and we will apply a convergent integration approach to synthesize the data.

Ethics and dissemination Ethical approval is not needed, as no primary data will be collected. The results will be made available through a peer-reviewed publication.

Systematic review registration PROSPERO 42023465302

Keywords Rheumatic diseases, Child, Caregivers, Experiences, Health services needs and demand

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Strengths and limitations of this study

Two reviewers will independently screen eligible studies for inclusion, extract data, and evaluate study quality, thereby preventing personal bias. Disputes between the reviewers will be resolved by consulting a third reviewer. This systematic review will be conducted in accordance with the Briggs Institute methodology for Mixed Systems Review methodology to ensure a high level of rigor.

The study has two main limitations. First, converting quantitative studies to qualitative descriptions may lead to data loss and affect outcome reliability. To address this, we will involve a third researcher to independently analyze the studies and compare results with the initial researchers, with final decisions made through team discussions. Second, the findings depend on the available data from included studies, which may not fully reflect the original data. We will trace the original data and contact authors if necessary to verify reliability. If data authenticity remains in doubt, the research team will decide on the inclusion of the study.

Introduction

Pediatric rheumatic diseases constitute a diverse spectrum of autoimmune disorders that primarily affect children, including juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), and juvenile scleroderma [1]. These conditions often manifest with intricate clinical features, such as joint inflammation, musculoskeletal pain, skin rashes, and, at times, systemic involvement [2]. A key hallmark of these diseases is their protracted and relapsing nature, posing substantial challenges to both affected children and their families. In recent years, significant progress has been made in comprehending the immunopathological mechanisms underlying pediatric rheumatic diseases. These advancements have facilitated the development and widespread adoption of biopharmaceutical treatments, earning recognition for their effectiveness in managing symptoms and mitigating disease progression among affected children. However, caregivers who shoulder the responsibility of caring for children with rheumatic diseases encounter formidable obstacles [2].

Frequent hospital visits, coupled with the financial burdens of treatment and medication, impose significant strains on families. Indirect costs, such as the need for parents to take time away from work to care for their child during flare-ups and disruptions in the child's education due to missed school days, compound the economic challenges faced by caregivers [2–4]. Beyond financial challenges, it is crucial to recognize that pediatric rheumatic diseases transcend the realm of physical symptoms. The impact on both children and caregivers is substantial, as children may contend with a wide range of emotions, including frustration, sadness, or isolation, stemming from the variable and often unpredictable nature of their condition [3, 5]. These emotional struggles can disrupt social interactions and educational pursuits, thereby influencing the trajectory of a child's upbringing [3, 5].

The unpredictability of disease flares and the requisite diligence in disease management have the potential to disrupt daily routines, curtail social connections, and contribute to emotional stress for both pediatric patients and their caretakers, who are often parents or family members [6]. Such caregivers bear witness to their child's struggles and may grapple with a sense of helplessness. The emotional toll on caregivers may manifest as anxiety, depression, or stress, jeopardizing their well-being and their capacity to deliver optimal care. Caregivers also confront practical challenges in managing pediatric rheumatic diseases, encompassing responsibilities such as coordinating medical appointments, administering medications, and ensuring adherence to treatment regimens [3, 7, 8]. As children with rheumatic conditions transition into adolescence and adulthood, the caregiving dynamic undergoes transformation [9]. This period of transition introduces uncertainties regarding the child's ability to assume greater responsibility for their health and the extent of continued caregiver involvement, highlighting the importance of a well-coordinated healthcare transition plan [10].

To enhance the management of childhood rheumatic disorders, healthcare professionals have implemented a multifaceted approach to support caregivers [11, 12]. These strategies are designed to provide comprehensive assistance, enabling caregivers to effectively address the unique needs of their young patients. Healthcare experts leverage various resources, including online platforms and educational materials, to offer practical guidance that aids caregivers in gaining a deeper understanding of rheumatic diseases in children. This educational component covers essential aspects such as the etiology, symptoms, treatment options, and medication management associated with these conditions [13]. By enhancing caregivers' health literacy through practical education, they are better equipped to assist children in managing their diseases. In addition to education, experts develop intervention plans with a family-centered focus, aiming to bolster family resilience and adaptability, ultimately maximizing positive outcomes for patients. These interventions may encompass psychological support, coping strategies training, family counseling, and the establishment of supportive social networks [8, 12–16].

While qualitative systematic assessments have been conducted on caregivers of children with juvenile idiopathic arthritis (JIA), these studies have primarily focused

on the emotional well-being of the child, with limited attention directed toward understanding the needs and experiences of caregivers [17, 18]. Furthermore, the qualitative nature of the included studies introduces inherent limitations related to objectivity and comprehensiveness [6, 17]. A systematic analysis has underscored that family carers' supportive care requirements remain unmet, particularly in terms of access to critical information (e.g., treatment options, lifestyle recommendations) and health care services (e.g., emotional support, experiences with health care services) [19]. These factors intersect with caregiver experiences Addressing these unmet needs is imperative to ensure the holistic well-being of both young patients and their families.

Existing systematic reviews focusing on children with rheumatic diseases underscore the complex clinical nature of these conditions, their impact on both children and caregivers, and the advancements in therapeutic approaches [20–22]. However, no systematic review has been conducted exclusively examining the experiences and needs of caregivers in pediatric rheumatic disease yet [23, 24]. To bridge this knowledge gap, our review will focus on parents, family caregivers, or legal guardians of children aged 0–18 years who were diagnosed with pediatric rheumatic diseases. The term "family caregivers" encompasses parents (both mother and father), grandparents, uncles, aunts, and individuals residing in the same household as the child, all of whom assume the role of guardians. We will investigate the emotional and behavioral responses exhibited by these caregivers during various phases of their child's diagnosis, encompassing emotions such as anxiety, fear, confidence, stigma, and feelings of burden [3]. Additionally, we will explore corresponding actions such as reducing panic, providing support, requiring overmedicalization, or adopting a sense of control. We will specifically examine the information needs of caregivers, including the type, content, subject matter, quantity, frequency, and mode of delivery of information needed to effectively support and manage their children's health conditions.

In summary, this comprehensive review aims to provide a thorough exploration of the experiences and requirements of caregivers responsible for the well-being of children with pediatric rheumatic diseases. Acknowledging the intricate nature of caregiving demands and the evolving needs of these caregivers is of paramount importance. The implementation of effective and timely interventions, complemented by robust support systems and personalized resources, is essential for mitigating the psychological and emotional strains endured by caregivers. Addressing these multifaceted challenges and delivering holistic care empowers healthcare professionals to assume a pivotal role in augmenting the overall quality of life and prognosis for children grappling with rheumatic diseases, as well as their dedicated caregivers.

Methods and analysis

Design

The protocol and research questions were developed collaboratively by a team of healthcare professionals, including nurses specializing in rheumatology care, rheumatologists, rehabilitation therapists, evidence-based medicine experts, and patients and their families. The research questions will be addressed through a combination of qualitative and quantitative studies, and their findings will be integrated using the convergent integration method [25]. The literature selected for this study will be systematically evaluated in accordance with the JBI guidelines for mixed-method systematic reviews [25]. Abbreviations of technical terms will be defined upon their initial use, and the writing will employ clear and concise language with a logical progression of information. Grammatical accuracy will be rigorously maintained, and the study's mixed-methods evaluation process will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol (PRISMA-P 2015) guidelines [26]. The protocol is registered in the International Prospective Register of Systematic Reviews (PROSPERO CRD 42023465302). Furthermore, the review will avoid biased language, embellishments, and unnecessary filler words.

Inclusion criteria

Participants

The participants will be parents, family carers, or legal guardians of children (0–18 years old) with rheumatic diseases, including JIA, SLE, JDM, and juvenile scleroderma [27]. The term "familial caregivers" encompasses individuals such as parents (both mother and father), grandparents, uncles, aunts, and any other individuals residing in the same household as the child [28]. These caregivers assume the role of guardians and are responsible for the child's overall care and well-being.

Adolescents aged 10 to 19 with pediatric rheumatologic diseases will also participate. This demographic possesses distinct needs and experiences that significantly affect caregivers during adolescence. Therefore, their inclusion will enhance reviewers' comprehension of caregivers' experiences and needs during this crucial developmental phase.

Exclusion criteria

The literature related to the experiences and needs of professional caregivers, including doctors, nurses, rehabilitators, and other healthcare professionals, will not be incorporated into this research.

Phenomena of interest

The phenomena of interest are the experiences and needs of caregivers for pediatric rheumatic disease patients. Within this context, the concept of "experience" refers to the emotional and behavioral responses exhibited by parents during the initial phases of their child's diagnosis or at various points following the diagnosis. These responses encompass a range of emotions, including anxiety, fear, confidence, stigma, and feelings of burden, as well as corresponding actions such as reducing panic, providing support, requiring overmedicalization, or adopting a sense of control [3, 5]. On the other hand, the term "needs" refers to the specific requirements of parents in terms of information. This includes the type, content, subject matter, quantity, frequency, and mode of delivery of information that parents either require or desire to effectively support and manage their children's health conditions [19, 28].

Context

This review will consider studies from any geographic location globally.

Types of studies

The selected studies will encompass a variety of research methodologies, including observational studies and qualitative or mixed-method studies employing approaches such as phenomenological, grounded theory, and ethnographic. Additionally, this review will include baseline data obtained from intervention studies, such as educational interventions and mHealth management interventions, aimed at influencing the management practices of parents caring for children with rheumatic diseases and investigating their experiences and information requirements. Case reports, practice guidelines, case series, conference abstracts, expert opinions, and book chapters will not be included in this review.

Search strategy

Our comprehensive search strategy is designed to encompass both published and unpublished studies. It will focus on identifying qualitative and quantitative studies conducted in both English and Chinese languages. To achieve this, we have structured a three-phase search process in accordance with the recommended approach by JBI. In the initial phase, we will establish index terms based on a preliminary search of the PubMed and CINAHL databases. The search strategy will combine key terms "Rheumatic diseases", "Child", "Caregivers", "Experiences", and "Health Services Needs and Demand", and their variations retrieved by Mesh. The search dates will be from 2000 to the present. Subsequently, we will implement a tailored search strategy across various databases, including MEDLINE (PubMed), Embase (Ovid), PsycINFO (Ovid), CINAHL (EBSCO), Cochrane Central Register of Controlled Trials (CENTRAL), CNKI, WanFang, and VIP. Furthermore, we will conduct additional searches for grey literature on Web of Science and ProQuest, focusing on dissertations and theses. Finally, we will search the reference lists of articles that meet our inclusion criteria to identify any additional pertinent studies. The full search strategy is available in Supplementary information 1: Appendix 1.

Study selection

The selection process will be carried out by two independent reviewers who will cross-check the data extraction. Initially, we will utilize EndNote X9 document management software to eliminate duplicate documents and sources that are not aligned with the study's focus, lack relevant qualitative or quantitative measures, or are not primary sources. The software will be used to screen titles and abstracts, ensuring that only relevant materials are included in the study. A meticulous review of the full documents will be conducted to confirm that the appropriate literature is incorporated. Any disagreements will be discussed between two reviewers, and if necessary, a third reviewer will be consulted to resolve disagreements. Our search strategy and selection process will be thoroughly documented using a PRISMA flow diagram [29], which will provide the rationale for excluding any literature.

Assessment of risk of bias

Two reviewers will evaluate the methodological rigor of selected studies using the 2018 version of the Mixed Methods Assessment Tool (MMAT) [30]. The evaluation will include qualitative, cross-sectional, and cohort studies. Any resulting discrepancies in assessments will be resolved by a third reviewer serving as an adjudicator for a final decision. The quality scores of each study will be calculated by aggregating affirmative responses to the relevant MMAT criteria. The criteria are categorized as "yes," "no," or "cannot." Studies that meet less than 4 out of 5 MMAT criteria will be categorized as low quality, whereas studies that meet 4 or more out of 5 MMAT criteria will be considered high quality [31]. If necessary, missing or additional study data will be requested from the authors for further clarification. Any disagreements between reviewers will be resolved through discussion or by consulting a third reviewer. Data extraction and synthesis will be conducted for all studies, regardless of their methodological quality assessment. The findings of the study quality evaluation will be presented in both written and tabular formats.

Data extraction

Qualitative and quantitative data will be extracted from the included studies using the JBI Mixed Methods Data Extraction Form [32]. This form is a crucial link between primary studies and systematic reviews. It allows for the evaluation, exploration, summarization, and presentation of evidence. The language will be formal, value-neutral, and free from biased language, ornamental language, and filler words. The text will be grammatically correct and follow a logical progression with causal connections between statements. The development, testing, and use of the form are vital stages in the systematic review process. We also will indicate the initials of the authors and the year to represent the studies in the form. Two independent reviewers will conduct initial testing of the data extraction form. Abbreviations for technical terms will be explained when first used. Citations will be consistent, and quotes will be clearly marked. Following the testing phase, the two reviewers will discuss whether any modifications to the extraction form are needed. If modifications are deemed necessary, the entire team will provide input. Both reviewers will use a standard data extraction form for their respective extraction processes. If any discrepancies arise, a third reviewer will mediate and reach a consensus. The process of extracting data will cover a wide range of aspects. The information extracted will include the following:

-Author details.

-The study's geographic location.

-Study design and analysis method.

-Information about the study group (including the types of disease, therapeutic schedules, sociological traits, and sample size).

-Contextual factors (including the levels of household income, social support networks, medical insurance, and culture).

-Phenomena that are the focus of interest.

-Foremost findings.

Data transformation

Data conversion is crucial in ensuring research objectivity and precision, specifically when concurrently integrating quantitative and qualitative findings. This involves translating quantitative data into narrative descriptions, deliberately intended to enhance objectivity, and transforming it into textual descriptors or narrative interpretations of the quantitative results, in direct alignment with the review questions. JBI recommends this approach due to its lower error susceptibility compared to quantification, which entails assigning numerical values to qualitative data [31]. Utilizing structured data extraction forms, relevant quantitative data are systematically extracted, including findings obtained from descriptive statistical analyses. To provide an example, let us conduct a cross-sectional study that examines the existing family burden in children with rheumatic diseases and the factors that lead to it. In this scenario, the factors that contribute to the family burden are expressed descriptively, making the integration process clear and consistent. We also will add charts alongside the narrative descriptions in quantitative summaries to bring clarity and depth to the information, making the overall integration much stronger.

Data synthesis

The convergent integration method will be utilized to synthesize both quantitative and qualitative data [33]. We anticipate encountering diversity in pediatric rheumatologic diseases, treatments, as well as socio-economic and cultural contexts across the included studies. We will account for this heterogeneity in our analyses to comprehend how these factors interact with caregiver experiences. If the available data permits, we will categorize the studies based on key characteristics such as disease type, treatment modality, cultural background, household income levels, and others. We will determine which studies are sufficiently similar to facilitate a synthesis of our findings through group discussions. The quantitative data will be transformed into textual or narrative descriptions, while the qualitative data will undergo thematic analysis using NVivo software [34]. For the qualitative data, an inductive coding approach will be employed, assigning one or more codes to each line of text based on its meaning and content. The codes will be organized into themes and subthemes, and the process will be continued until no new themes are evident from the data. The analysis will be reviewed comprehensively by a second reviewer to ensure reliability. Any discrepancies in interpretation will be resolved through consultation with a third reviewer. The reviewer will thoroughly revisit the collected data repeatedly and objectively identify themes based on the data's connotations. This rigorous process will result in the creation of the final integrated findings. During the integration process, a continuous comparison of qualitative and quantitative data will be conducted until no additional themes are discovered. The synthesis of themes and subthemes will undergo a final review and validation by a reviewer proficient in both quantitative and qualitative research methods.

Though a third reviewer will be designated for adjudicating differences, a formal consensus-building approach could be beneficial. We will hold regular team discussions to streamline the review process and reduce potential reviewer bias.

Discussion

This protocol outlines a systematic review encompassing both published and unpublished quantitative, qualitative, and mixed-methods studies. Its aim is to comprehensively explore the experiences and needs of caregivers responsible for children with pediatric rheumatic diseases. This endeavor represents a significant advancement in addressing the holistic needs of both patients and their families. Through the utilization of a convergent integration approach to synthesize qualitative and quantitative evidence, the review will provide a thorough report on caregiver experiences and requirements, thereby informing researchers and policymakers. The evidence derived from this systematic review will support the development of intervention strategies and policies tailored to meet caregivers' needs. By publishing the research plan, we enhance clarity regarding the retrieval strategy and mitigate the risk of bias. Any modifications to this protocol will be documented in the published systematic review.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s13643-025-02788-1.

Additional file 1. Appendix 1: Search strategy

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Authors' contributions
Yuxuan Xiang played a pivotal role throughout all phases of this review, encompassing program development, project coordination, and manuscript drafting. Xiangwei Yang provided overarching guidance, contributed to program development, conducted the final review of the manuscript, and provided funding for the project. Ru Ding, Yuan Bixia, and Jing Wu actively participated in the conceptualization of the review, as well as in the drafting and editing of the manuscript. Rongmei Lu assumed the role of an expert in reviewing the mixed-methods system, offering valuable insights into the methods and tools to be employed. The final version of this manuscript underwent a comprehensive review and received unanimous approval from all authors.

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Data Availability
This research programme has been made available to the public as a preprint on Research Square, accessible via the following URL: https://doi.org/10.21203/rs.3.rs-3582765/v1. It is important to note that any modifications made to this programme will be clearly indicated.

Ethics approval and consent to participate
Secondary data analysis does not require ethical approval. The results of the study will be published in a peer-reviewed journal.

Competing interests
The authors declare that they have no conflicts of interest.

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