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(REVIEW ARTICLE)

Quality of life of children with juvenile rheumatoid arthritis and the role of the school nurse

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Abstract

Introduction: Juvenile Idiopathic Arthritis (JIA) can significantly impact children's quality of life by restricting their participation in everyday activities and affecting their psychosocial development. School nurses can provide education and counseling to children with JIA and their families regarding the disease, its symptoms, and management strategies, affecting their quality of life (QoL) positively.

Aim: The aim of the review was to explore the role of the school nurse in improving the quality of life of children with JIA. Additionally, the study sought to map the existing literature on this topic and identify potential research gaps.

Methodology: For the purposes of this study, a scoping review methodology was adopted. The literature search was conducted across academic databases using the keywords "juvenile idiopathic arthritis", "quality of life", "school nurse", "intervention", and "psychosocial support".

Findings: A total of 139 studies were identified, however only two studies met the inclusion criteria. Parents reported that their experiences with school nurses were largely supportive, although there was some variation among nurses and across school levels. Some adolescents described greater support and less stigma from school nurses when they were younger, while others noted improvements as they grew older. The availability of the school nurse emerged as a critical factor for children with JIA. The nurse's role extended beyond medical care to include psychological support and the enhancement of the child's sense of safety within the school environment.

Conclusions: JIA negatively affects children's quality of life, while the school nurse can play a significant role in supporting and enhancing it. However, a clear gap was identified in the existing literature regarding the contribution of the school nurse, highlighting the need for further research.

Keywords: Juvenile Idiopathic Arthritis; Quality of Life; School Nurse; Intervention; Psychosocial Support

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1. Introduction

Rheumatoid arthritis (RA) is a chronic autoimmune disease characterized by inflammation of the joints, causing pain, stiffness, and limited mobility [1]. Although RA is typically associated with adults, it can also affect children, manifesting as Juvenile Idiopathic Arthritis (JIA). JIA can significantly impact children's quality of life by restricting their participation in everyday activities and affecting their psychosocial development [2].

Juvenile Idiopathic Arthritis (JIA) is a chronic inflammatory disease that affects the joints and represents the most common rheumatic disorder of childhood. The terminology used for chronic arthritis in children has evolved over time

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from “juvenile chronic arthritis” and “juvenile rheumatoid arthritis” to the currently accepted term “Juvenile Idiopathic Arthritis,” established in 1995. JIA is characterized by joint pain, swelling, and stiffness, and it is diagnosed when arthritis persists for at least six weeks in individuals under the age of sixteen. The condition occurs slightly more frequently in girls. Unlike adult rheumatoid arthritis, which is lifelong and progressive, children with JIA may experience remission as they grow older. However, the disease can interfere with bone growth and development in a growing child, making early diagnosis and intervention critically important [3] (Okamoto et al., 2019). Quality of Life (QoL) is a multidimensional construct that includes physical, psychological, social, and environmental dimensions [4] (Sosnowski et al., 2017). For children living with JIA, QoL is influenced by several factors, such as disease severity, the impact of symptoms on daily functioning, treatment effectiveness, and psychosocial adjustment [2].

School nurses can provide education and counseling to children with JIA and their families regarding the disease, its symptoms, and management strategies. The nurse can also help children develop essential self-management skills, such as pain control, medication adherence, and the incorporation of appropriate physical exercise into daily routines. Furthermore, the school nurse can collaborate with teachers and school staff to ensure that children with JIA receive the necessary support and accommodation within the educational environment [5].

More specifically, school nurses play a key role in the early recognition of JIA symptoms, referral to specialized rheumatologists, and continuous monitoring of the disease’s progression. In addition, nurses can assess the child’s quality of life, provide education to the child, family, and teachers about the condition, and offer psychosocial support aimed at reducing pain, improving mobility, and managing fatigue [6].

Collaboration with other healthcare professionals allows for a comprehensive and multidisciplinary approach, ensuring that the child’s needs are addressed holistically. The nurse also contributes to the creation of a supportive and inclusive school environment, promoting awareness within the school community and fostering understanding and empathy among peers and educators. Ultimately, school nurses’ involvement enhances social inclusion and facilitates the child’s overall adaptation and well-being in the school setting [7]. The aim of the review was to explore the role of the school nurse in improving the quality of life of children with JIA. Additionally, the study sought to map the existing literature on this topic and identify potential research gaps.

2. Methods

This study adopts the methodology of a scoping literature review to thoroughly investigate the central phenomenon concerning the quality of life of children with rheumatoid arthritis and the role of the school nurse in improving it. The scoping review approach was selected as the most appropriate method for this purpose, as it allows for a broad and systematic mapping of existing literature, the identification of key concepts and themes, and the detection of gaps in current research [8].

To ensure methodological rigor and transparency, the review was conducted in accordance with the PRISMA-ScR guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews). Adhering to the PRISMA-ScR standards contributes to the structured organization and presentation of findings, thereby facilitating their evaluation and interpretation.

The PRISMA-ScR framework is an extension of the original PRISMA statement, specifically designed for reporting systematic and scoping reviews. It provides a detailed checklist of items organized into seven sections that encompass all stages of a scoping review from the title and abstract to the discussion. This checklist assists researchers in reporting their methodology and findings with clarity and completeness, enhancing the overall reliability, transparency, and reproducibility of the review [8].

To ensure the validity and relevance of the findings, the study was delimited by specific inclusion and exclusion criteria for the research papers examined. Specifically, studies published in English or Greek were included in order to guarantee accessibility and accurate evaluation by the researchers.

In terms of study type, empirical research studies providing data on the quality of life of children with rheumatoid arthritis and the role of the school nurse were accepted. Studies that did not meet these criteria such as reviews, case studies, or papers unrelated to the specific research questions were excluded from the analysis.

The literature search was primarily conducted in three major electronic databases: PubMed, Scopus, and CINAHL. These databases were selected due to their extensive coverage of peer-reviewed journals in the fields of health sciences and education.

The search strategy was based on combinations of carefully selected keywords, including "juvenile idiopathic arthritis," "quality of life," "school nurse," "intervention," and "psychosocial support." Boolean operators (AND, OR) were used to enhance the precision and efficiency of the search and to ensure the retrieval of the most relevant studies [9].

3. Results

The stages of identification, screening, eligibility, and inclusion of the studies, as well as the number of studies that were included or excluded at each stage, are as follows:

3.1. Stage 1: Identification

A comprehensive search was conducted across various databases, including PubMed, Scopus, CINAHL, and other relevant sources. In total, 139 studies were identified at this stage.

3.2. Stage 2: Screening

- Eight duplicate studies were removed.
- A total of 106 studies were excluded based on their titles and abstracts, as they did not meet the inclusion criteria.
- Subsequently, 25 studies were retained for full-text assessment.

3.3. Stage 3: Eligibility

Out of the 25 full-text studies reviewed, 23 were excluded after detailed evaluation.

3.4. Stage 4: Inclusion

Finally, two studies were included in the scoping review.

The figure below presents the flow diagram of the study selection process, according to the PRISMA-ScR method (*Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews*). The diagram illustrates the stages of identification, screening, eligibility, and inclusion of the studies, as well as the number of studies that were included or excluded at each stage (Figure 1).

In an empirical study conducted by Wakefield et al. (2023), the authors explored the social stigma associated with pain in adolescents with Juvenile Idiopathic Arthritis (JIA). The study involved 16 adolescents aged 12 to 17 years and 13 parents. Four focus groups were conducted, two with adolescents and two with parents, and the data were analyzed using qualitative content analysis. The findings revealed that adolescents with JIA experienced pain-related stigma, mainly from peers, teachers, and physical education instructors, but rarely from family members. The key categories of stigma identified included felt stigma, internalized stigma, anticipated stigma/concealment, and factors contributing to pain-related stigma. A common stigmatizing experience was the perception by others that the adolescent was "too young to have arthritis." Overall, the study indicated that adolescents with JIA face social stigma associated with pain in certain social contexts. Diagnostic certainty was found to contribute to greater support from healthcare providers and families. The authors suggested that future studies should examine the impact of pain-related stigma across various pediatric pain conditions. Parents reported that their experiences with school nurses were largely supportive, although there was some variation among nurses and across school levels (elementary, middle, and high school). Some adolescents described greater support and less stigma from school nurses when they were younger, while others noted improvements as they grew older [10].

In another study by Nabors et al. (2007), researchers examined school support and functional outcomes among children with juvenile rheumatic diseases. The study included 82 children aged 6 to 18 years, 75% of whom had JIA. Children completed the *"How Is School?"* questionnaire, while parents provided information regarding the child's illness and family functioning. The results demonstrated that positive family functioning was associated with a reduced need for school-based support from nurses, teachers, and peers. The availability of the school nurse emerged as a critical factor for children with JIA. The study highlighted the importance of consistent and reliable access to a school nurse, especially during periods of pain exacerbation or symptom flare-ups. The absence or limited presence of a school nurse was linked to feelings of insecurity and anxiety among children. The nurse's role extended beyond medical care to include psychological support and the enhancement of the child's sense of safety within the school environment. Peer support was also found to be important for children, regardless of the level of family support. The study emphasized the need for individualized care plans in schools tailored to each child's needs. Furthermore, the researchers stressed the significance of school nurse support, particularly during painful episodes experienced by the children [5].

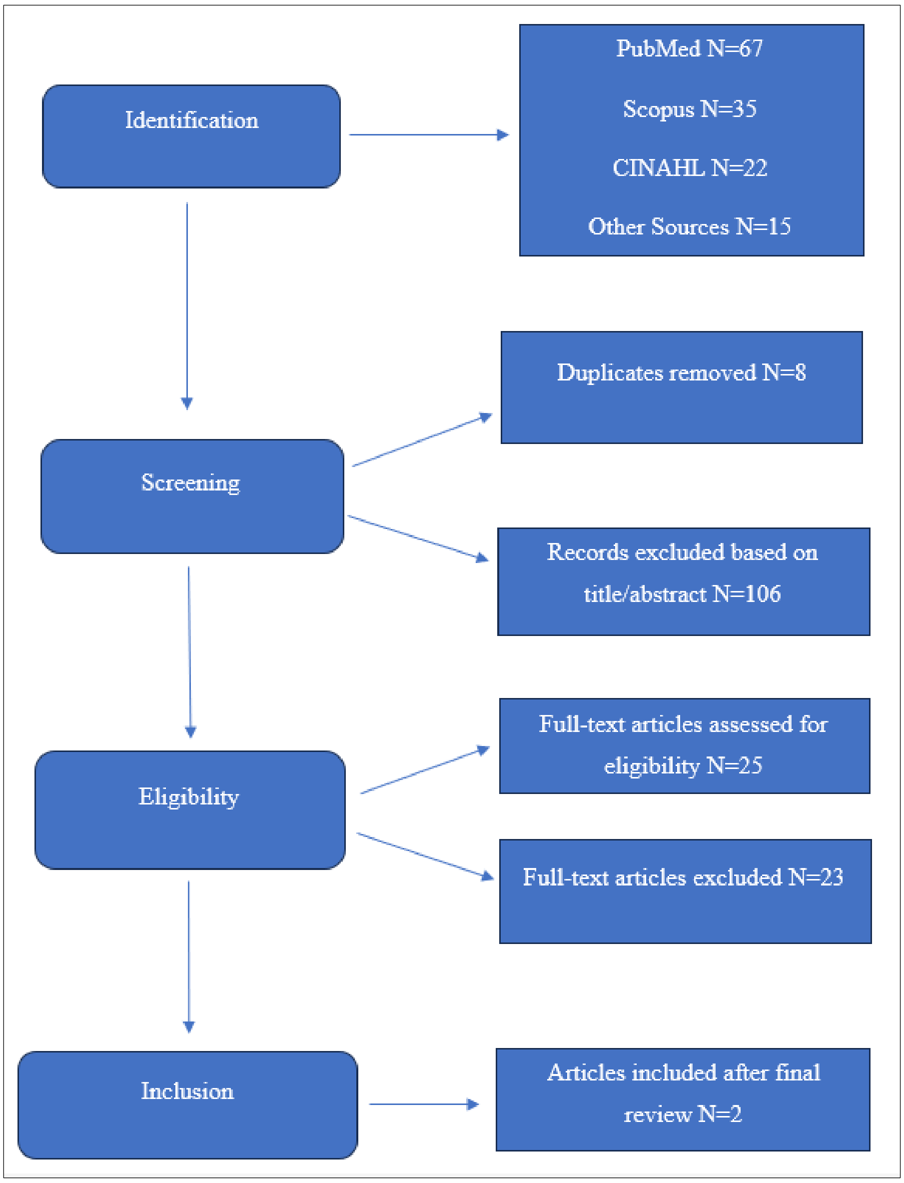

Figure 1 Flow diagram of the study selection process, according to the PRISMA-ScR method

The two studies included in this scoping review address different aspects of Juvenile Idiopathic Arthritis but provide valuable insights into the quality of life of affected children and the role of the school nurse. The first study, Wakefield et al. (2023), employed qualitative design and focused on the experiences of stigma among adolescents with JIA, involving 16 adolescents and 13 parents [10]. The second study, Nabors et al. (2007), used a quantitative approach and examined school support among 82 children and their parents [5]. Both studies were conducted in the United States. While the first utilized focus groups and qualitative analysis, the second relied on questionnaires and statistical evaluation.

The table below presents a summary of the extracted information from these two studies (Table 1).

Table 1 Summary of the extracted information from the two studies

Reference	**Wakefield et al. (2023) [10]**	**Nabors et al. (2007) [5]**
Authors	Emily O. Wakefield, Vaishali Belamkar, Ashley Sandoval, Rebecca M. Puhl, Barbara Edelheit, William T. Zempsky, Hannah A. Rodrigues, & Mark D. Litt	Laura A. Nabors, Emily A. Iobst, Jason Weisman, Barbara Precht, Peter Chiu, & Hermine Brunner
Publication year	2023	2007
Title	Does Diagnostic Certainty Matter?: Pain-Related Stigma in Adolescents with Juvenile Idiopathic Arthritis	School Support and Functioning for Children with Juvenile Rheumatic Diseases
Research method	Qualitative	Quantitative
Sample	16 teenagers (12-17 years old) having JIA and 13 parents	82 children (6-18 years old) having JIA with comorbidity
Methodology	Focus groups, qualitative content analysis	Questionnaires, statistical analysis
Basic results	Adolescents with JIA experience pain-related stigma, mainly from peers and teachers. Diagnostic certainty may help reduce stigma.	Positive family functioning is associated with a reduced need for school support. The availability of a school nurse is crucial.

4. Discussion

The present scoping literature review aimed to investigate the quality of life of children with Juvenile Idiopathic Arthritis (JIA) and the role of the school nurse in improving it. The review showed that JIA can significantly affect children's quality of life, causing physical, psychological, and social difficulties. Children with JIA may experience pain, fatigue, joint stiffness, and limited mobility. The symptoms of the disease can negatively influence their ability to participate in everyday activities such as play, sports, and school attendance.

Moreover, JIA can have a negative impact on children's mental health, leading to anxiety, depression, and low self-esteem. These findings are consistent with previous research indicating that JIA can substantially affect children's quality of life. For example, a study by Martini et al. (2022) found that children with JIA reported a lower quality of life compared to healthy peers, particularly in areas such as physical pain, fatigue, and social functioning [11]. Similarly, a study by Giancane et al. (2016) showed that JIA negatively influences children's mental health, increasing the risk of developing anxiety and depression [2].

The review also emphasized the important role of the school nurse in supporting children with JIA and improving their quality of life. The school nurse can provide education and counseling to children and their families regarding JIA, its symptoms, and management strategies. The nurse can also help children develop self-management skills, such as pain control, medication adherence, and regular exercise. Additionally, the school nurse can collaborate with teachers and school staff to ensure that children with JIA receive the necessary support within the school environment [5], [10].

Limitations of the study

Although this scoping review provides valuable insights into the quality of life of children with Juvenile Idiopathic Arthritis (JIA) and the role of school nurses, some limitations must be acknowledged.

First, the limited number of eligible studies—only two that met the inclusion criteria—restricts the generalizability of the findings. This small evidence base makes it difficult to draw firm conclusions or identify causal relationships between nursing interventions and quality-of-life outcomes. Second, the heterogeneity of the included studies in terms of research design (qualitative vs. quantitative), sample size, and population characteristics may have affected the comparability of results. The differences in methodologies and outcome measures across studies could lead to variability in the reported findings. Third, the language restriction to English and Greek publications may have excluded relevant studies published in other languages, introducing potential publication bias. Likewise, the database selection (PubMed, Scopus, and CINAHL) might have omitted studies indexed in other specialized databases. Fourth, as with any literature-based review, the results depend heavily on the accuracy and completeness of the reported data in the primary studies. Any methodological weaknesses, biases, or missing data in those studies may have influenced the overall synthesis.

Future research should expand the scope to include a greater number of studies, apply systematic review methods with quality assessment tools, and explore longitudinal and intervention-based designs to further clarify the impact of school nursing on children with JIA.

5. Conclusion

The present scoping literature review, focusing on the quality of life (QoL) of children with Juvenile Idiopathic Arthritis (JIA) and the role of school nurses, highlights important findings regarding their support within the school environment. JIA, as a chronic rheumatic condition, can severely affect children's daily lives and participation in activities. Beyond its physical manifestations, it often burdens children's mental health—leading to anxiety, depression, and low self-esteem—and hinders their social adjustment.

Within this challenging context, the role of school nurses emerges as crucial. Through specialized knowledge and daily presence, the school nurse can assume a multifaceted role: providing clinical support (early detection, monitoring, and assistance in treatment management), offering education and counseling to children and their families on self-management of the disease, and collaborating with teachers and school staff to create a supportive and accessible educational environment that promotes social inclusion. The school nurse's responsibilities also include raising awareness within the school community and adapting school conditions to meet the specific needs of each child.

Nevertheless, this review revealed a clear research gap. The role of school nurses in supporting children with JIA rarely constitutes a primary focus of existing studies. This finding underscores the urgent need for future research dedicated specifically to this area. Future investigations should explore the effectiveness of targeted nursing interventions in improving quality of life, examine the experiences of both children and nurses, and identify the practical challenges encountered in everyday school settings.

Compliance with ethical standards

Disclosure of conflict of interest

The authors declare no conflict of interest.

Statement of ethical approval

This article is a scoping review of previously published studies and does not involve any new studies with human participants or animals performed by the authors. Therefore, ethical approval was not required.

Statement of informed consent

Informed consent was not required as no human participants were directly involved.

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