

RESEARCH ARTICLE

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Digital health tools in juvenile idiopathic arthritis: a systematic literature review

Jordi Anton^{1,2*} , María Montoro³ , Estíbaliz Loza⁴ , Teresa Otón⁴ , Susan Ramirez³ and Diego Benavent⁵

Abstract

Background Nowadays, digital health technologies, including mobile apps, wearable technologies, social media, websites, electronic medical records, and artificial intelligence, are impacting disease management and outcomes. We aimed to analyse the characteristics and use of digital health tools in juvenile idiopathic arthritis (JIA).

Methods We conducted a systematic review (SR) to identify articles examining the characteristics, use, and outcomes (feasibility, usability, and effectiveness) of digital health tools in JIA patients. A sensitive search strategy was performed in Medline, Embase, and Cochrane databases until December 2022 (later updated to March 2024). Two reviewers independently selected the studies and collected the data, including study quality. A descriptive analysis was performed.

Results A total of 21 studies were included, one SR, six randomised controlled trials, four observational studies, four validation studies, one discovery and verification study, and five qualitative studies. Study quality was generally moderate. Most studies focused on patients with JIA (especially young people), but also on parents and health care professionals. Different digital health technologies were investigated, like websites, mobile apps, wearables, and telemedicine. The main objectives of the tools were self-management, symptom and quality of life monitoring, physical activity tracking, disease knowledge improvement, and medication monitoring. Different themes and contents were usually included in the same digital health tool, such as psychological health, lifestyle, intimacy, or shared decision-making. Tool development and validation processes were poorly or not at all described, and data regarding regulatory compliance, security, or privacy were scarce.

Conclusions There is significant variability in the type, characteristics, objectives, and contents of digital health tools for JIA. They still show limitations and gaps, thus highlighting the need for better critical assessment and reporting.

Keywords Digital health tools, Juvenile idiopathic arthritis, Systematic review

Background

Juvenile idiopathic arthritis (JIA) is the most common paediatric rheumatological disease, affecting approximately 1 in 1,000 children [1]. JIA influences the development of patients and restricts their social interactions, isolating them from their peers, and potentially negatively impacts health-related quality of life (HRQL) [2, 3]. JIA encompasses a group of heterogeneous disorders with seven subtypes. Each subtype presents different phenotypes, symptoms, and disease progression, requiring distinct treatment approaches [4]. JIA treatments aim

*Correspondence:

Jordi Anton

Jordi.anton@sjd.es

¹ Department of Paediatric Rheumatology, Hospital Sant Joan de Déu, Barcelona, Spain

² Department of Surgery and Medical-Surgical Specialties, Obstetrics, Gynaecology and Paediatrics, Medicine and Health Sciences School, Universitat de Barcelona, Barcelona, Spain

³ Pfizer Medical, Madrid, Alcobendas, Spain

⁴ Instituto de Salud Musculoesquelética, Madrid, Spain

⁵ Department of Rheumatology, Hospital Universitari de Bellvitge, L'Hospitalet de Llobregat, Barcelona, Spain



to control the disease, prevent long-term articular and extra-articular damage as well as physical disability, and maintain patients' growth and development, quality of life, and social participation [5–7]. Therefore, to achieve these goals, JIA management should be multidisciplinary and multifactorial.

Parental involvement in JIA management is vital. Both JIA treatment and treatment strategy should be based on shared decisions between the parents/patient and the paediatric rheumatology healthcare team [5–7]. However, parenting JIA children presents many challenges, including dealing with the child's physical (*e.g.*, pain and fatigue) and emotional (*e.g.*, stress, anxiety, and depression) symptoms, managing medication, medical visits, or impact on schooling [8]. At the same time, there might be other related issues, such as time off work, costs, concerns, and uncertainty about the future [9, 10].

On the other hand, paediatric rheumatology is no exception to the impact of digital health technologies, such as mobile apps, wearable technologies, social media, websites, electronic medical records, or artificial intelligence (AI). Digital health technologies provide a real opportunity to improve several aspects of JIA management, for example access to healthcare services and diagnosis, patient monitoring, self-management, adherence, and positive health behaviours [11]. Moreover, studies have suggested that many children with JIA are experienced users [12, 13]. Other potential benefits include data collection for clinical and research purposes, improvement of the communication with healthcare providers, as well as parent satisfaction and confidence [14, 15]. Although the interest and research in digital health technologies have increased in recent years, these technologies are still at an early development stage.

Based on the above, we carried out a systematic review (SR) to analyse the types, characteristics, feasibility, usability, and effectiveness of digital health tools in JIA patients. These results might help to develop and implement digital health tools and eventually improve JIA outcomes.

Methods

An SR was performed based on the recommendations of the Cochrane Collaboration and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) [16, 17], which followed the Good Clinical Practice regulations. First, a review protocol was generated. We aimed to review and analyse the characteristics and use of digital health tools in JIA.

Search strategy and selection criteria

Studies were identified using sensitive search strategies in the main medical databases. For this purpose, an expert

librarian checked the search strategies. Terms related to disease and digital health tools were used as search keywords, with a controlled vocabulary, specific MeSH headings, and additional keywords (see Tables S1–S3 of the supplementary material). The following bibliographic databases were screened up to December 2022 (later updated to March 2024): Medline (PubMed), Embase, and the Cochrane Library. References were managed in Endnote X20 (Thomson Reuters). Finally, a manual search was performed by reviewing the references of the included studies, as well as all publications and other information provided by the authors.

Studies were eligible if they met the following inclusion criteria: 1) articles that included patients with JIA, parents, or health care professionals; and 2) articles involving digital health tools (including mobile apps, wearable technologies, social media, websites, electronic medical records, or artificial intelligence), any comparator, and outcomes related to the interventions (feasibility, usability, and effectiveness). There were no restrictions regarding digital tool types or intervention characteristics. We selected SRs, randomised controlled trials (RCTs), observational studies, and qualitative research in English, French, or Spanish.

Study screening and data collection

Two reviewers (EL and TO) independently screened the titles and abstracts of the retrieved articles. They collected data from the included studies using ad hoc standard forms. In case of discrepancy in either process, a third reviewer helped to settle the issue. To assess study quality, we used the Ameasurement Tool to Assess Systematic Reviews (AMSTAR2) [18] for SRs, the Jadad score [19] for RCTs, the Newcastle–Ottawa Scale (NOS) [20] for observational studies, the Quality Assessment Diagnostic Accuracy Studies (QUADAS-2) [21] for validation studies, and the method proposed by Hawker and colleagues [22] for qualitative articles. Evidence tables were then generated.

Data analysis

A descriptive analysis was performed. Categorical variables were expressed as numbers and proportions (%), while continuous variables were expressed as means and standard deviations.

Results

The search led to the identification of 3,716 articles, of which 516 were duplicates (Fig. 1). After the first selection process, 3,175 articles were excluded, and seven more after a detailed review of the remaining 25 studies [23–29] (see Table S4 of the supplementary material). Finally a total of 21 studies we included (3 of them from

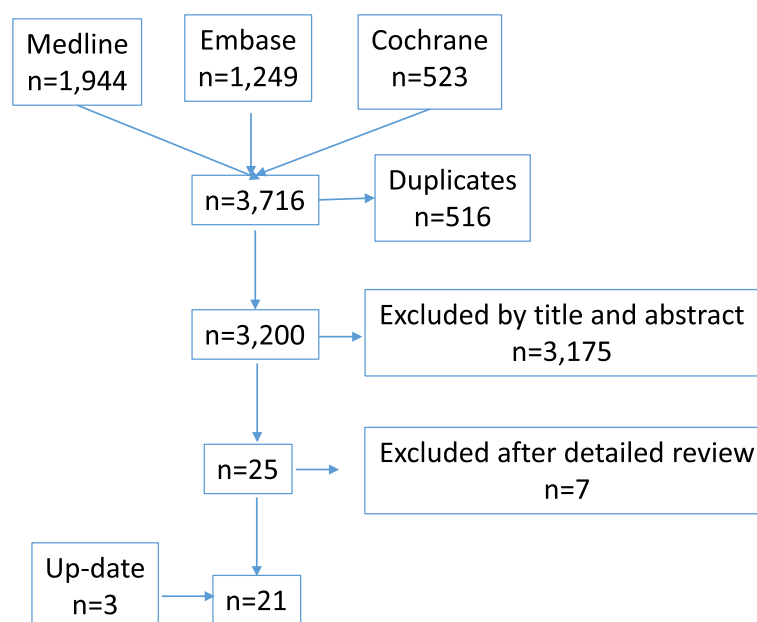


Fig. 1 PRISMA flowchart

the 2024 up-date) [11, 14, 15, 30–47]. Tables S5 and S6 of the supplementary material depict the main characteristics and results reported in the included studies.

There was a great variability among studies. They were published between 2013 and 2024 by teams from the Netherlands [30, 33, 34], Australia [11, 31], United Kingdom [14, 15, 38, 39, 43], United States of America [32], Iran [36], Canada [35, 37, 44, 45, 47], China [40, 41], Ireland [42], and Chile [46]. We found one SR [31], six RCTs [14, 30, 32, 37, 44, 45], four observational studies [11, 34, 35, 46], four validation studies [33, 36, 40, 41], one discovery and verification study [43], and five qualitative studies [15, 38, 39, 42, 47]. Study duration ranged from 4 weeks [11] to 12 months [14, 32, 45]. The overall study quality was considered moderate (see Table S5 of the supplementary material).

Regarding the baseline characteristics of JIA patients, although their ages varied from 1 to 19, many were young people with different JIA types. Most patients were females (from 42 to 90%), and the most common JIA subtype was oligoarthritis, followed by polyarthritis. Disease activity or severity level was reported in some studies using different measures [32, 34, 35], and, in general, was moderate to low. Only two studies reported data relating to access to and use of digital technologies in daily life, which was high ($\geq 95\%$) [30, 46].

In this SR, different digital health technologies were examined, like websites ($n=9$, 43%) [11, 14, 15, 30, 32, 34, 42, 45, 47], mobile apps ($n=7$, 33%) [11, 15, 33, 37–39], wearable technologies ($n=1$, 5%) [35], AI ($n=4$,

19%) [36, 40, 41, 43], and telemedicine ($n=2$, 10%) [44, 46]. Three studies used different digital tool types in the same intervention [11, 15, 32]. Intervention durations were highly variable. The target of most digital health tools were JIA patients [11, 15, 31–37, 39–47], but also their parents [14, 32, 34, 39, 42, 45, 47] and health care professionals [15, 31, 32, 34, 38, 42, 45, 47]. Nevertheless, the development and validation processes of digital health tools were poorly or not at all described. Data regarding regulatory compliance, security, or privacy were scarce [11, 14, 34, 37, 44, 45].

The outcomes of the included studies reflected the different development stages of the intervention (feasibility, usability, and effectiveness). Although feasibility was analysed in many studies [11, 15, 30, 31, 34, 35, 37, 38, 42, 44], few dimensions were examined or reported. Feasibility was assessed, for example, by analysing the tool's errors or malfunctions [11, 35], participant accrual/attrition rates, or user experience (including acceptability) [15, 30, 34, 37, 38, 42, 47]. However data were scarce regarding to the digital tools interoperability, compatibility, support and training, or legal and regulatory feasibility. Data on usability of digital health tools were scarce [15, 31, 37, 44], and effectiveness was frequently analysed by assessing the corresponding concept, as detailed below, through a wide measure range [14, 30–34, 36, 37, 39–41, 43–47]. For example, HRQoL was evaluated with validated questionnaires like the Pediatric Quality of Life Inventory (PedsQL) [32] or generic HRQoL scores [34]. Only three studies

assessed patient safety [31, 32, 43]. See supplementary material for more information.

The main objectives of the digital health tools were self-management [15, 30–32, 37, 42, 44, 45], symptom monitoring [11, 31, 37–39, 47], HRQoL monitoring [33, 34], physical activity tracking [11, 35], disease knowledge improvement [14], and medication adherence [11]. However, almost all digital health tool interventions addressed other themes and contents, reflecting their multifaceted nature (see Table 1), like psychological health, lifestyle, disease knowledge, school/work issues, personal and social relations, intimacy, or shared decision-making. Regarding articles involving AI, the main objectives were JIA diagnosis and trajectory [36, 43], as well as treatment response prediction (for methotrexate and etanercept) [40, 41].

Finally, the effectiveness of digital health tools was generally positive, although preliminary and substantially variable.

Discussion

Digital health technologies might offer several benefits in the management of JIA patients. Integrating digital health technologies into clinical practice might improve care access, patient monitoring, adherence to treatments, or self-management skills [11]. In this SR, we analysed the characteristics and use of digital health tools in patients with JIA.

One of the main conclusions of this SR is the significant variability in study designs and types, characteristics of digital health tools, and interventions or outcome measures, which limited the analysis, interpretation, and comparability of results. We must mention that many of the included articles were short-term, proof-of-concept studies with small sample sizes requiring further validation. This is in line with the results reported in adult rheumatology [48]. Therefore, more research is needed to evaluate the real effect and define the role of digital health technologies in rheumatology. However, as we have explained, the main target of digital health tools is the JIA patient, whereas, in adults with rheumatic diseases, the rheumatologist is often the main target [48]. In this context, we would also like to comment on the role and contribution of qualitative research, which is scarce in this field. Qualitative research approaches can provide rich, nuanced insights into the impact of digital tools on patients with JIA and their parents [49]. These approaches focus on understanding experiences, perceptions, and emotions, which are especially important when exploring complex, personal, and sometimes transformative experiences like those related to managing a chronic illness such as JIA. These studies can complement the results of qualitative research.

Most digital health tools were created with a main general purpose (*e.g.*, self-management) but contain several modules with different contents and themes covering other domains (multiplicity). This might affect tool feasibility as the content and/or the interaction needed to obtain a benefit might be excessive. Thus, it is important to balance objectives, contents, and interactions to be as efficient as possible. In this context, at least for educational purposes, the scope and target of digital health tools can be expanded to others, like teachers or general paediatricians.

On the other hand, digital health tool uptake might be hindered by JIA subtype, disease control, or patient age. For instance, adolescents and young adults could represent an important barrier. We did not find any related data in this SR. However, in the literature on adult patients, the dropout rate when using digital tools has been reported as constant and important [50]. Factors like disease activity have been associated with tool use [51], as tool adherence was greater in patients with higher disease activity. Further research will help identify the JIA sub-populations that could benefit most from digital health tools. Still, it will also enable us to define usage patterns (*e.g.*, in the event of a flare-up or pain) and implementation strategies to increase uptake. This might also contribute to intervention efficiency (*e.g.*, by providing meaningful data).

Another point to comment on is usability. Although children and young people are experienced users of digital technologies [12, 13], our SR had little or no description of digital literacy and competence, and current digital technology use was not properly explored. Complex tools might discourage patients, parents, and healthcare providers from using them. Therefore, user-friendly designs and interfaces or gaming can enhance usability and, eventually, digital tool use. Educational activities, including comprehensive training for patients, parents, and healthcare providers in the use of digital health tools, technical support, and user guides, could be very beneficial in increasing the uptake of these tools.

Finally, we would also like to highlight the need for standardised reporting of studies on digital health tools. For this purpose, a multidisciplinary team including patient associations, healthcare providers, regulatory/ethics experts, methodologists, and information technology engineers would be necessary. Pilot studies assessing the benefit of these tools and the decisions made with the information provided by them compared with usual care may also be necessary.

Apart from these considerations connected to tool development and validation, we would like to comment on several aspects of their daily life implementation.

Table 1 Themes and contents covered in each digital health tool intervention/s across included studies. The main objective/s are highlighted

Study	Pain / symptoms monitoring	Self- manag	Mood/ psychol	Diet, healthy lifestyle	Physical activity / function	Disease knowledge	School / work	Friends, family, communication	Relations, intimacy	Medication	Diagnosis	HRQoL monitoring	Setting goals	Shared decision making
Ammer- laan_2017 [30]	X	X			X			X				X		
Butler_2024 [11]	X				X					X				
Cai_2017 [15]	X	X	X		X		X			X				
Connelly_2019 [32]	X	X		X	X			X		X		X		
Doeleman_2021 [33]												X		
Haverman_2012 [34]					X							X		
Heale_2018 [35]					X									
Kian Ara [36]											X			
Lalloo_2021 [37]	X	X				X							X	
Lee_2019 [38]	X													
Lee_2020 [39]	X													
Mo_2020 [40]										X				
Mo_2019 [41]										X				
Mulligan_2022 [14]						X								
O'Sullivan_2018 [42]	X	X	X	X	X	X	X	X	X	X		X		X
Shoop-Wor- rall_2024 [43]														
Stinson_2016 [44]		X		X	X			X				X		X
Stinson_2020 [45]	X	X	X	X	X	X	X	X	X	X		X		
Toupin- April_2020 [47]	X	X	X	X	X	X				X			X	X

Abbreviations: HRQoL, health related quality of life

The use of digital health tools might raise privacy and security concerns, especially for parents. Ensuring that patient data is securely stored and transmitted is critical. The confidentiality of sensitive health information should always be guaranteed as well. Currently, different regulatory bodies like the European Medicines Agency (EMA) and national competent authorities regulate this use. They make sure that these tools can deliver on their promise to improve healthcare outcomes while maintaining the highest safety, efficacy, and security standards. The tools should be clear about this to avoid any concerns, and patients/parents should be informed accordingly.

Implementing digital health tools, especially those designed to monitor diseases or treatments, might also present technical challenges. If this information is not embedded in the electronic medical records, it might not be useful. Integrating new digital tools into existing healthcare information systems may be difficult and/or lead to interoperability issues. Moreover, depending on the tool, or even the country, there might be copyright issues and/or limited or conditional access (payment). Thus, exploring this context to prevent or resolve technical problems is vital. This is also important for exporting/translating experiences/digital health tools across centres and even countries.

Conclusion

In summary, there are major deficiencies and challenges that need to be addressed by research before these tools will become meaningful, safe and ethically robust. Therefore, further research into the use of digital health tools in the field of JIA is critical. JIA patients may benefit from adopting digital health technologies to better understand the disease characteristics and progression, adherence to treatment, and the impact on patient's quality of life. It may also facilitate clinical decisions and improve patient self-management and parental confidence. Healthcare providers and health systems could also benefit from using digital health technologies by accessing real-time meaningful data. In-depth research is needed before further daily practice recommendations can be given.

Abbreviations

AI	Artificial intelligence
AMSTAR	A measurement Tool to Assess Systematic Reviews
EMA	European Medicines Agency
HRQL	Health-related quality of life
JIA	Juvenile idiopathic arthritis
NOS	Newcastle-Ottawa Scale
PedsQL	Pediatric Quality of Life Inventory
PRISMA-P	Systematic Reviews and Meta-Analyses Protocols
QUADAS	Quality Assessment Diagnostic Accuracy Studies
RCTs	Randomised controlled trials
SR	Systematic review

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12969-025-01094-3>.

Additional file 1.

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None.

Authors' contributions

DB: Conceptualization, correcting original draft, approval of final version of manuscript. MM: Conceptualization, correcting original draft, approval of final version of manuscript, supervision. SR: Correcting original draft, approval of final version of manuscript. TO: Data collection, correcting original draft, approval of final version of manuscript. EL: Data collection, writing original paper, agreement to be accountable for all aspects of the work.

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Data availability

Not applicable.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

All authors read and approved the final manuscript and gave their consent for publication.

Competing interests

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