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Original Article

Quality indicators for care in juvenile idiopathic arthritis

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Objective: To develop a set of quality indicators (QIs) tailored to improve the care provided to children with juvenile idiopathic arthritis (JIA) in countries across the Asia-Pacific region.

Methods: An adaptation of the Research and Development Corporation (RAND)/University of California, Los Angeles (UCLA) Appropriateness Method (RAM) was used. An initial set of 32 QIs was developed after a systematic search of the literature. These were presented to members of a Delphi panel composed of pediatric rheumatologists and other relevant stakeholders from the Asia Pacific League of Associations for Rheumatology Pediatric Special Interest Group (APLAR-Pediatric SIG). After each round, the mean scores for validity and reliability, level of disagreement, and median absolute deviation from the mean were calculated.

Results: The panelists were presented with 32 QIs in two rounds of voting, resulting in the formulation of a final set of 22 QIs for JIA. These QIs are categorized within six domains of care, including access to care, clinical assessment, medications and medication monitoring, screening for comorbidities, counseling, and self-efficacy and satisfaction with care.

Conclusion: These QIs have been developed to evaluate and improve the quality of care provided to children with JIA, aiming to enhance health outcomes and ensure that healthcare services are tailored to the unique needs of this patient population.

Keywords: Juvenile idiopathic arthritis, Quality indicators, Outcome, Asia-Pacific region

INTRODUCTION

The International League of Associations for Rheumatology (ILAR) coined the term "juvenile idiopathic arthritis" (JIA) in 1995 to describe a heterogeneous group of chronic, inflammatory arthritides of unknown origin with onset in childhood

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prior to the age of sixteen. The ILAR subsequently classified JIA into seven categories based on the clinical, serological, and genetic features in the first six months of disease onset [1,2]. JIA is the most prevalent rheumatic disease affecting the pediatric population, with a pooled prevalence of 20.5 per 100,000 population (range 3.8~400) [3]. Furthermore, it is the most prevalent disease encountered in the pediatric rheumatology clinic [4-7]. JIA has a profound influence on patients' lives and those of their caregivers. Affected children may experience compromised physical function, impaired vision, and a reduced overall quality of life. The introduction of innovative therapeutic agents in recent decades has markedly enhanced the prognosis of this condition. However, improper treatment and disease management may precipitate irreversible joint damage and permanent disability [8].

Over the past few decades, there has been an increasing interest in the betterment of quality and safety in healthcare. A widely accepted definition of quality in healthcare is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and care consistent with current professional knowledge" [9]. The Donabedian model of quality is a conceptual framework that describes three dimensions of care that can be evaluated: structure, process, and outcome [10].

The Institute of Medicine has established six domains of healthcare quality, including timely, patient-centered, safe, effective, efficient, and equitable care [11].

Quality measures (QMs) are metrics used to quantify and assess healthcare provision and performance with the goal of providing high-quality healthcare. QMs are derived from quality indicators (QIs), which are statements about best practices associated with high-quality care and frequently represent minimum standards of care. Typically, QIs are presented in the following format: IF (a clinical statement or scenario), THEN (a clinical action), whereas QMs are reported as a percentage representing a quality or performance measure. Both QIs and QMs are frequently utilized in quality improvement initiatives and benchmarking to evaluate and enhance the quality of care provided to patients. Their use can help identify areas for improvement, track progress over time, and ultimately enhance the quality of healthcare delivery. Measures of care for patients with JIA have been published in the United States (US), Canada, and the United Kingdom (UK) [12-15]. They have yet to be reported from the Middle East and North Africa or the Asia-Pacific regions. Given the cultural, socioeconomic, epidemiological, and resource-related variations, there is a need for QIs for care in JIA in these regions. These indicators can guide targeted interventions, resource allocation, and research initiatives, resulting in better outcomes and patient-centered care for JIA patients in these areas. Furthermore, cross-regional collaboration and harmonization can promote shared learning and improve the global JIA care quality. This multi-national collaborative study aimed to achieve consensus for a set of evidence based QIs centered around the care of children with JIA in these diverse ethnic regions.

MATERIALS AND METHODS

An adaptation of the Research and Development Corporation (RAND)/University of California Los Angeles (UCLA) Appropriateness Method (RAM) was used to establish the QIs for JIA.

In accordance with RAM, this study involved a multi-step process that included a systematic literature review, items development, assembly of an expert panel, and rating of items until a consensus was reached.

Systematic literature review

Four electronic databases, Cochrane Library, Web of Science, Scopus, and MEDLINE through PubMed, were systematically searched for relevant peer-reviewed publications through June 25, 2022. Additionally, reference lists of identified records were searched for relevant sources. Where applicable, Keywords, Topics, and MeSH Terms were used to expand the search (Supplementary Material 1).

Studies published in English on QIs, QMs, standards of care, clinical practice guidelines, and expert consensus related to JIA were included. In the case of quality studies, only those that adhered to a consensus approach and were supported by scientific evidence were included. Furthermore, only guidelines published within the last 5 years were considered during the QIs' development. By limiting the scope to more recent guidelines, we aimed to ensure that the indicators were based on the most current and relevant evidence.

Exclusion criteria included studies involving adult patients, inflammatory arthritides other than JIA, and those focusing on specific JIA-related comorbidities such as macrophage activation syndrome. In addition, reviews, case reports, editorials, opinions/views, abstracts-only, and studies published in languages

other than English were excluded. Initially, titles and abstracts were screened, then eligibility was decided upon after a full-text review. Records were screened independently by two reviewers (HA and RA). Disagreement was resolved by reconciliation or consultation with a third reviewer (SMA).

Items development

A working group (SMA, KK, RJ, HA, RA) was formed to extract items related to quality care in JIA and rephrase them into QIs using the IF-THEN format. Working group members were selected based on their expertise in the care of children with JIA (SMA, KK, RJ, TA) and for overall project management (HA and RA).

Delphi panel members

An expert panel of 12 pediatric rheumatologists from 12 countries from the Middle East, North Africa, and the Asia-Pacific region was assembled. Panelists were members of the Asia Pacific League of Associations for Rheumatology, Pediatric Special Interest Group (APLAR- Pediatric SIG) and were selected based on their experience in managing children with JIA. All members accepted the invitation to participate in the Delphi panel. Other stakeholders included a general pediatrician and 2 pediatric physiotherapists involved in caring for patients with JIA, as well as a parent of a child with JIA. This study was approved by the Ethics Committee of the Research Affairs Council at King Faisal Specialist Hospital and Research Center, Riyadh under the Study protocol RAC No. 2231126.

Rating of items

In the first round of rating, panelists were emailed an electronic link to an online survey listing the 32 QIs. As part of the evaluation process, the Delphi panelists were urged to reflect on the evidence for each QI and requested to provide any relevant feedback or comments. Furthermore, they were requested to evaluate each QI using a 9-point scale. Firstly, they were asked to rate each QI based on its validity and, secondly, based on its feasibility. In the given scale, a value of one indicates that the QI is not considered valid or feasible, while a value of nine indicates that the QI is deemed highly valid or feasible. Disagreement was defined according to the criteria outlined by RAM as four or more panelists rating in the extreme values of 1~3 or 7~9. The mean absolute deviation from the mean was calculated as well. These measures were used to facilitate discussion and refine the QIs. Candidate QIs were excluded after this round if they had a low mean validity score (lower than 6 on the 9-point scale).

In the second round, the Delphi panelists were presented with specific QIs from the first round that had notable disagreements in validity or feasibility or had a mean absolute deviation of one or more in their validity or feasibility score. Through an exhaustive review of the voting results, feedback, and comments from the Delphi panelists, the working group was able to refine and consolidate the set of QIs to their final and optimal form. This process guaranteed that the QIs presented were valid, feasible, and relevant for healthcare providers in pediatric rheumatology.

RESULTS

Systematic literature review

A systematic search of the Cochrane Library, Web of Science, Scopus, and MEDLINE through PubMed yielded 565 records. However, only 14 records were included in the final literature review (Supplementary Material 2).

Items development

Initially, 109 QIs were extracted by two independent researchers (HA and RA). The collated QIs were reviewed collectively, and duplicate and irrelevant QIs were excluded. Furthermore, QIs deemed under the control of healthcare providers other than pediatric rheumatologists were excluded. After receiving feedback from experts in the working group, the input was used to refine the final set of QIs. The result was a comprehensive set of 32 QIs deemed suitable for presentation to the Delphi panel members, along with their level of evidence (Supplementary Material 3). These QIs were classified under six domains: access to care, clinical assessment, medications and medication monitoring, screening for comorbidities, counseling, and finally, self-efficacy and satisfaction with care.

Delphi panel members

All 12 panelists participated in the first round of rating the QIs, while 11 of the 12 panelists participated in the second round. Feedback and comments from the other four stakeholders were considered throughout the process of QIs development.

Rating of items

The results of the initial rating can be found in Supplementary Material 4. All 32 QIs received a median score of over 6 for

both validity and feasibility. However, there was disagreement regarding the validity of QI-10, which led to its removal from the set. The panelists were presented with 8 QIs from the first round. These QIs had a median absolute deviation of one or more in their validity, feasibility, or both. The scores from the second round were similar to those of the first round, as shown in Supplementary Material 4 .

After the two rounds, 31 QIs remained. After deliberation and further discussion, the working group agreed to remove two QIs (QI 22 and QI 27) due to anticipated difficulties in converting

Table 1. Final set of quality indicators for juvenile idiopathic arthritis

Domain 1: Access to care
IF a patient is referred with possible juvenile idiopathic arthritis (JIA), THEN they should be seen by a pediatric rheumatologist within four weeks from the date of referral.
Domain 2: Clinical assessment
IF a patient has JIA, THEN a parent's or patient's global assessment of disease activity using a valid and reliable age-appropriate tool should be performed at the first visit and repeated at each subsequent visit.
IF a patient has JIA, THEN a physician's global assessment of disease activity using a valid and reliable age-appropriate tool should be performed at the first visit and repeated at each subsequent visit.
IF a patient has JIA, THEN a full active joint count should be performed at the first visit and repeated at each subsequent visit.
IF a patient has JIA, THEN an assessment of functional ability using a valid and reliable age-appropriate tool should be performed at the first visit and repeated every 6 months.
IF a patient has JIA, THEN an assessment of the health-related quality of life using a valid and reliable age-appropriate tool should be performed at the first visit and repeated every 6 months.
IF a patient has JIA, THEN antinuclear antibody, rheumatoid factor, anti-cyclic citrullinated peptide, and HLA-B27 should be performed as appropriate at the first visit and repeated for confirmation as indicated.
Domain 3: Medication & medication monitoring
IF a patient has JIA, THEN medications should be chosen according to published clinical practice guidelines and local availability.
IF a patient has JIA, THEN a valid and reliable age-appropriate tool to measure disease activity should guide treatment decisions to facilitate a treat-to-target approach.
IF a patient with JIA is on methotrexate, THEN folic/folinic acid should be prescribed.
IF a patient with JIA is on hydroxychloroquine, THEN baseline retinal screening should be performed and repeated yearly.
IF a patient has JIA, THEN screening for tuberculosis should be performed prior to initiating treatment with a biologic DMARD and repeated whenever there is a concern for exposure.
IF a patient with JIA is on disease-modifying antirheumatic drugs, THEN baseline screening and monitoring should be done according to published guidelines and manufacturer's recommendations.
Domain 4: Screening for comorbidities
IF a patient has JIA, THEN ophthalmic screening for uveitis should be performed according to published clinical practice guidelines.
IF a patient has JIA, THEN monitoring growth (height, weight) should be performed at the first visit and repeated at each subsequent visit.
IF a patient has JIA, THEN screening and monitoring for osteoporosis (particularly if they are on corticosteroid therapy) via bone profile, vitamin D level, and bone density should be part of routine clinical assessment.
IF a patient has JIA, THEN monitoring mental health and well-being should be part of routine clinical assessment.
Domain 5: Counselling
IF a patient has JIA, THEN the immunization status should be reviewed and optimized at diagnosis and annually thereafter in line with local immunization schedules.
IF a patient with JIA is engaging in high-risk behaviors that are detrimental to their health, THEN counselling should be provided at each visit (if not annually).
IF a female patient (of childbearing age) has JIA, THEN counselling regarding appropriate contraception while on potentially teratogenic medications is performed at least yearly.
Domain 6: Self-efficacy and satisfaction with care
IF a patient has JIA, THEN an assessment for self-efficacy using a valid and reliable tool should be performed within 6 months of the first visit and then every 6 months.
IF a patient has JIA, THEN an assessment of the satisfaction with care provided should be obtained within a year of the first visit and repeated yearly.

them into QMs. Out of the remaining 29 QIs, 8 (QI 13-19 and QI 21) were consolidated into one QI to allow for similarity in the breadth and width of the final set of QIs. Ultimately, a total of 22 QIs for JIA were approved (Table 1).

DISCUSSION

This work defines a comprehensive set of QIs for the care of pediatric patients with JIA. This set has been developed based on a rigorous and comprehensive methodology encompassing multiple phases and varied input from international experts who are members of the APLAR-Pediatric SIG and specialize in the care of JIA patients, and stakeholders, as well as by incorporating the latest scientific evidence. Through this process, 22 QIs have been identified, covering six domains of care: access to care, clinical assessment, medication and medication monitoring, screening for comorbidities, counseling, and self-efficacy and satisfaction with care. These QIs serve as an initial instrument for evaluating healthcare quality in patients with JIA.

In the field of pediatric rheumatology, it is imperative to assess the quality of care provided to patients. By doing so, we can ensure that patients receive appropriate care, leading to improved patient outcomes [16,17]. Additionally, evaluating healthcare quality can aid in the allocation of healthcare resources. Therefore, healthcare providers are encouraged to adopt optimal practices and improve patient outcomes by measuring quality. Lovell et al. [12] introduced a set of 12 QMs that focus on the process of care in JIA in the US. Each QM provides a clear statement outlining the specific assessment, including guidance on when and how frequently it should be performed. They also offer recommend tools or methods to facilitate the assessment, along with initial performance goals for each QM [12]. In the UK, an additional 11 service-related JIA QMs were published, encompassing 32 data items for national audit process [14]. To enhance JIA care in Canada, Barber et al. [13] proposed 10 key performance indicators.

JIA has been associated with significant disparities in healthcare outcomes among different demographic populations [18]. The potential implications of implementing JIA QIs in clinical practice will be influenced by several technical attributes, including, among other factors, their acceptability, validity, feasibility, and reliability. Therefore, further research to delineate these characteristics is a crucial step in validating the QI set. Furthermore, the extent of the impact these QIs will have on JIA care will depend primarily on the level of their adoption. Innovative research methodologies and more extensive databases of patients or administrative records may be necessary to conduct quality measurement endeavors successfully.

It is essential to acknowledge that the QIs presented in this context represent the current scientific evidence and professional consensus in the field of JIA. Therefore, it is necessary to note that these QIs are not intended to remain fixed, and a revision may be necessary as new evidence emerges. Furthermore, it is imperative to acknowledge that QIs signify a baseline level of care deemed acceptable rather than serving as benchmarks for optimal practices or as directives for patient treatment. Additionally, it is challenging to encompass all elements of care for patients diagnosed with JIA, including distinct disease subtypes and complications, such as uveitis and macrophage activation syndrome. Finally, high-quality evidence for various aspects of JIA is limited. As a result, we have included studies with variable levels of evidence and expert consensus to address the knowledge gaps in JIA [19-28].

In summary, a set of QIs for JIA has been developed using a validated approach known as the RAND/UCLA Appropriateness Method, with necessary modifications. We anticipate that the availability of QIs will facilitate the involvement of researchers and organizations in endeavors related to measuring the quality of care in JIA. Further research in this field has the potential to impact health outcomes in JIA by providing the foundation for clinical trials and policy interventions aimed at enhancing quality.

CONCLUSION

A comprehensive set of 22 QIs has been devised specifically for pediatric patients diagnosed with JIA, with a strong emphasis on their applicability within clinical settings. The selection of these indicators was conducted with meticulous attention to their scientific validity and feasibility, rendering them suitable for the assessment of care quality for patients diagnosed with JIA. Healthcare providers can strive to enhance the quality of care for patients with this condition by employing these QIs. Furthermore, the utilization of these indicators can be employed within the framework of health policies in order to establish a uniform standard of care and enhance patient outcomes for patients with JIA.

SUPPLEMENTARY DATA

Supplementary data can be found with this article online at https://doi.org/10.4078/jrd.2023.0071

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CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

AUTHOR CONTRIBUTIONS

Hend Alkwai: data curation and formal analysis (equal); writing - original draft preparation (lead). Reem Alshammari: data curation and formal analysis (equal). Reem Abdwani, Muna Almutairi, Raed Alzyoud, Thaschawee Arkachaisri, Sumaira Farman, Soad Hashad, Rebecca James, Khulood Khawaja, Hala Lotfy, Swee Ping Tang, and Soamarat Vilaiyuk: conceptualization (equal); methodology (equal); writing - review and editing (equal). Sulaiman M Al-Mayouf: conceptualization (lead); data curation and formal analysis (equal); methodology (equal); supervision (lead); writing-original draft preparation and review and editing (equal). All authors approved the final version and take full responsibility for the integrity and accuracy of all aspects of the work.

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