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Improving Care Delivery and Outcomes in Pediatric Rheumatic Diseases

Julia G. Harris, MD¹, Catherine A. Bingham, MD², and Esi M. Morgan, MD, MSCE^{3,4}

¹Children's Mercy - Kansas City, Kansas City, MO

²Penn State Hershey Children's Hospital, Hershey, PA

³James M. Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

⁴University of Cincinnati College of Medicine, Cincinnati, OH

Abstract

Purpose of review—To highlight efforts in pediatric rheumatology related to optimizing the care provided to patients with pediatric rheumatic diseases and describe various approaches to improve health outcomes.

Recent findings—Recent studies report low rates of remission, frequent occurrence of comorbidities, disease damage, and decreased health-related quality of life in pediatric rheumatic diseases. Pediatric Rheumatology Care and Outcomes Improvement Network is a quality improvement learning network that has demonstrated improvement in process of care measures through use of a centralized patient registry, and interventions including pre-visit planning, population management, shared decision making, and patient/parent engagement. A pediatric rheumatology patient-powered research network was established to enable patient and caregiver participation in setting research priorities and to facilitate data sharing to answer research questions. Quality measure development and benchmarking is proceeding in multiple pediatric rheumatic diseases.

Summary—This review summarizes the current efforts to improve care delivery and outcomes in pediatric rheumatic diseases through a learning health system approach that harnesses knowledge from the clinical encounter to serve quality improvement, research and discovery. Incorporating standard approaches to medication treatment plans may reduce variation in care. Including the patient voice to design of research studies brings focus on more patient relevant outcomes. (See Video, Supplemental Digital Content 1).

Corresponding author: Esi M. Morgan, MD, MSCE, Associate Professor of Pediatrics, Division of Rheumatology, James M. Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, MLC 4010, Cincinnati, OH 45229, Phone: 513-636-7212, esi.morgan_dewitt@cchmc.org.

Conflicts of Interest

None of the authors has any commercial or financial conflict of interest. The authors are all members of PR-COIN and CARRA networks. Dr. Morgan and Dr. Bingham are members of the PR-COIN Steering Committee.

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Keywords

Quality improvement; healthcare delivery; patient outcome assessment; rheumatology; pediatric

Introduction

Improving care delivery and outcomes for patients with pediatric rheumatic diseases is imperative. Many pediatric rheumatic diseases persist into adulthood, with negative sequelae from the disease or its treatment [1]. A recent cohort study of juvenile idiopathic arthritis (JIA) patients reported 50% with non-polyarticular categories of disease achieved remission within 5 years of diagnosis; however, far fewer polyarticular JIA patients attained remission (zero to 14%) [2•]. Long-term studies report that 40–68% of JIA patients are in remission after 17 to 30 years of follow-up [3,4•], and patients can suffer significant functional limitations and decreased health-related quality of life [3,5]. Childhood-onset systemic lupus erythematosus (cSLE) is typically more severe than adult-onset SLE [1,6] and was found to be an independent predictor of increased mortality [7]. Patients with cSLE also have decreased health-related quality of life including limitations in social capacities and restricted life goals [8•,9]. Juvenile dermatomyositis (JDM) leads to calcinosis in approximately one-third of patients [10], and 90% of patients had evidence of damage at a mean follow-up of 4.2 years [11]. Given therapeutic advances, these outcomes are disappointing. Why aren't more patients achieving disease remission?

Following the reports of suboptimal care from the Institute of Medicine's Committee on the Quality of Healthcare in America, there has been increased focus by health care institutions and the public on quality of care [12,13]. In addition to gaps in health care for children in the United States [14], the quality of care specific to rheumatic diseases has also been inadequate [15,16]. Organizations like the American College of Rheumatology (ACR) and the American Board of Pediatrics have supported efforts to improve the care provided to patients with rheumatic conditions, including children [14,17]. One such effort has been the development of quality measures to aid in quality improvement efforts and quality-focused research [17]. An emerging successful infrastructure for improvement of health outcomes is establishment of collaborative improvement networks that engage health care teams, patients, and researchers, contribute data into shared registries, and utilize quality improvement methods to accelerate and spread improvement [14,18]. Pediatric collaborative improvement networks have shown significantly improved health outcomes and have served as models for other subspecialty network development [19]. The approach is that of a learning health system, in which data gathered from point of care is applied for purposes of quality improvement as well as health services and comparative effectiveness research (CER).

Health outcomes research provides insight into challenges faced by patients with pediatric-onset rheumatic diseases [20,21•]. Incorporating patient-reported outcomes data into clinical decision making and research puts the focus on aspects of health relevant to patients. In employing quality improvement approaches in health care, selecting quality indicators that have a measurable impact on patient relevant outcomes requires careful determination.

Pediatric Rheumatology Learning Network

Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN), established in 2011, is a growing network of care centers (currently 17 in United States and Canada) with the mission to improve outcomes of care in JIA using a learning network approach [22]. PR-COIN utilizes a centralized patient registry and interventions proven to improve chronic illness care [23] including pre-visit planning, population management, self-management, as well as shared decision making and patient/parent engagement (Table 1) [28]. Teams track performance on quality measures, including five outcome measures and eleven process measures that were adapted from a publication from 2011 [29], for the purposes of analysis to guide improvement activities. Both site specific and aggregate data is analyzed monthly via statistical process control charts, allowing PR-COIN to audit and give feedback on performance over time. Improvement science methods employed include developing key driver diagrams with time bound goals, process mapping, and failure mode and effects analysis (FMEA). The Model for Improvement is used in planning tests of change and highlights three key questions: what are we trying to accomplish?; how will we know that a change is an improvement?; and what changes can we make that will result in improvement [25]? Tests of change can be done with plan-do-study-act cycles, a framework used to perform rapid cycle improvement. Successes and failures are shared via monthly action period calls, biannual face to face learning sessions, PR-COIN website, newsletter, and webinar learning labs such that learning can be spread more rapidly. Certain PR-COIN sites have mapped data captured in the electronic medical record to the central network patient registry for more efficient data entry into the registry, and currently a SmartForm is being developed to facilitate this process (Epic Systems Corporation, Verona, WI, USA). Linking the electronic medical record to improvement network registries can ease the burden of data entry and further improve care by utilizing an automated report system [30].

Population management (PM) is an intervention that enables overview of characteristics of all patients in the registry at a population level. PR-COIN employs an automated reporting function linked to the registry with an electronic tool that allows identification of groups of patients and drill down to individual patients based on criteria included in the registry (demographic characteristics, clinical features, disease status, medication used) [31]. The PM tool allows individual sites to identify high-risk patients and can be used to generate care gap reports, such as patients not in compliance with quality measures or those lost to follow-up. Acting on this data allows PR-COIN sites to target efforts to close gaps in care across their patient population.

Pre-visit planning (PVP) is another intervention proven to improve quality of care [32,33]. PVP is the act of systematically preparing for a patient visit by verifying compliance with identified recommended processes of care (e.g. performance of toxicity monitoring labs), identifying areas of need, risk, or gaps in care. PVP allows for the healthcare team to more efficiently conduct the clinic visit and free up time to focus on priority needs of the patient.

PR-COIN has also conducted an initiative to enhance Shared Decision Making (SDM) [34,35]. SDM is a process where a provider shares medically reasonable treatment options, and the patient/parent has the opportunity to guide the conversation, considering his/her

goals and preferences. In PR-COIN, JIA medication treatment choice cards were developed to facilitate discussion about different medication attributes of importance to patients to arrive at informed treatment decisions in alignment with patient goals. Engaging patients and families is an increasingly recognized component for quality improvement in healthcare that is patient centered [27•]. PR-COIN has formed a parent leadership roundtable, Facebook page, parent attendance at action period calls, and robust parent presence at learning sessions. Parents set 90 day goals, hold positions at leadership level and on PR-COIN subcommittees, and contribute novel talent and skills to the network [36]. Through patient/parent engagement, PR-COIN is striving to foster co-production of network activities whereby health care teams and patients/families can work together to produce more desirable outcomes for children with JIA.

Development of a cSLE learning network is underway with plans to build on PR-COIN's successful model, the established infrastructure, and common membership. The preliminary global aim of this collaborative is to promote comprehensive patient- and family-centered care to ensure survival, prevent organ damage, and optimize health-related quality of life in all cSLE patients through optimal disease control and co-morbidity management [37]. Focus groups have been held at PR-COIN learning sessions in preparation for a design phase before launching a cSLE initiative.

Pediatric Rheumatology Research Organizations

There are several research organizations in the field of pediatric rheumatology that allow for multi-center collaboration. The Pediatric Rheumatology Collaborative Study Group is a large North American organization that has a primary aim of conducting high quality clinical trials of therapeutic agents in children with rheumatic diseases [38]. A similar collaborative based out of Europe with international membership is the Paediatric Rheumatology International Trials Organization (PRINTO) [39,40]. In addition to medication studies, PRINTO has focused on patient and family education with creation of a website, research training, and development of an auto-inflammatory disease registry [40]. The Childhood Arthritis and Rheumatology Research Alliance (CARRA) is a North American organization with large representation that has a mission to conduct collaborative research to prevent, treat and cure pediatric rheumatic diseases [41]. This organization has a patient registry and several disease-specific work groups. The Paediatric Rheumatology European Society has members throughout Europe and the Middle East with committees focusing on education, clinical affairs, research, allied health professionals, and trainees [42]. There are several other pediatric rheumatology organizations including Pediatric Vasculitis Initiative, FMF Arthritis Vasculitis and Orphan disease Research in Paediatric Rheumatology, Canadian Alliance of Pediatric Rheumatology Investigators, British Society for Paediatric and Adolescent Rheumatology (BSPAR), and German Society of Pediatric and Adolescent Rheumatology. The research performed by these networks is anticipated to ultimately improve treatment. However, without coordinated effort to change practice and implement best evidence care, there is a significant lag for research findings to become part of clinical practice and wide variability in uptake [43].

Patient-Powered Research Networks

The Patient-Centered Outcomes Research Institute (PCORI) was developed in 2010 through the Affordable Care Act to fund comparative clinical effectiveness research [44]. PCORI has funded development of “patient-powered research networks” that bring together patients/ caregivers and researchers to advance patient-centered CER [45]. These networks allow patients and their families to generate data, contribute information, prioritize research questions, and assume leadership roles. In 2013, with funding from PCORI, the Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) came together to develop a patient-powered research network in pediatric rheumatology [46]. Consortium members include caregiver representatives, CARRA, PR-COIN, the Arthritis Foundation, and the Lupus Foundation of America, with CureJM Foundation joining as a collaborating member in a second phase (2015–18) [47] to continue efforts on building an optimal patient-centered research structure.

Consensus Treatment Plans

Consensus treatment plans (CTPs) are structured guidelines developed from prevalent practice, and agreed upon by clinical experts, that describe different therapeutic approaches to diseases that have a low prevalence or deficient evidence-based practices as in most pediatric rheumatic diseases. CTPs facilitate CER in clinical settings by providing case definitions, recommended collection of data elements at defined visit intervals, and reducing variability in care [48]. Due to paucity of clinical trial data or head-to-head medication studies in pediatric rheumatic diseases, CARRA has developed CTPs based on collaborative surveys and expert opinion. The initial treatment of moderately severe JDM was the first CTP published by CARRA in 2010, which was prompted after a collaborative survey reported considerable treatment variation [49,50]. A subsequent CTP developed protocols for the entire JDM treatment course [51]. CTPs for induction therapy of newly diagnosed proliferative lupus nephritis in cSLE were published in 2012 [52]. Two different CTPs have been developed for JIA - one in new-onset systemic JIA [53] and another on new-onset polyarticular JIA [54•]. Lastly, CARRA developed standardized treatment plans for juvenile localized scleroderma, in addition to clinical assessment and treatment response criteria using consensus methodology [55].

Similarly, a European project organized by PRINTO, “Single Hub and Access point for paediatric Rheumatology in Europe” (SHARE), is trying to combat the lack of evidence-based guidelines and substantial variation in care of patients with pediatric rheumatic diseases [56]. The first phase of this project included circulation of surveys to PRINTO centers to establish current clinical practices with future plans to develop international best practices from this survey and from the literature.

Quality Measures

Quality measures represent the minimum standards of care and are “mechanisms that enable the user to quantify the quality of a selected aspect of care by comparing it to an evidence-based criterion that specifies what is better quality” [57]. Quality measures are developed

from evidence and expert opinion and ideally have three properties: importance, scientific soundness, and feasibility [56]. There are three different types of quality measures - structural, process, and outcome measures - with most quality measures being process of care measures given these are actionable items that respond quicker to change [17,58].

Quality measures, also known as quality indicators, have been created for rheumatic conditions including SLE and analgesic use [15,59–62], with the ACR endorsing measures in rheumatoid arthritis, gout, and glucocorticoid-induced osteoporosis [63]. Development of many of these measures involved a 3-step approach: literature review, selection of quality measures based on impact or extensive recommendation, then creation of “if-then-because” statements to reflect the population, process of care measure, and impact on outcomes [59]. A similar method was used to generate quality measures for JIA by Lovell, *et al.* in 2011, which also included timing of assessments, acceptable assessment tools, and performance goals [29]. Twelve JIA quality measures were proposed under four domains: disease control, safety monitoring, assessment of self-efficacy and patient/parent satisfaction, and access to care.

PR-COIN adapted these JIA quality measures to track the following process of care measures: measurement of active joint count, arthritis-related pain, physician global assessment of disease activity, health-related quality of life, and physical function; screening for uveitis, medication toxicity, and tuberculosis; and medication counseling [64]. PR-COIN also monitors and tracks JIA outcome measures: clinical inactive disease [65], clinical remission, clinical Juvenile Arthritis Disease Activity Score (JADAS) [66•], no or mild pain level, and optimal physical functioning.

Prior to development of the JIA quality measures in the United States, BSPAR generated ‘standards of care’ for JIA that were first published in 2009 [67]. These were complemented by a joint effort of BSPAR and the Arthritis and Musculoskeletal Alliance to create 44 standards of care for children and young people with JIA [68].

In 2011, Brunner, *et al.* advocated for a comprehensive management plan for cSLE and highlighted clinical and laboratory disease surveillance measures, health maintenance, and education [69]. Twenty-six quality indicators for cSLE were developed with international input in 2013 amongst 9 domains: laboratory testing around time of diagnosis, general prevention, lupus nephritis and hypertension management, medication management, bone health, ophthalmologic surveillance, cardiovascular risk factor education, pregnancy, and neuropsychiatric manifestations [70]. The CARRA JDM Quality Measures Workgroup is also working on establishing quality measures for JDM, taking into consideration patient-reported and patient-centered measures [71].

Benchmarking and Improvement of Quality Measures

Benchmarking of quality measures is important to determine ease of measurement in clinical practice and to obtain performance data. Ten centers in the United Kingdom performed retrospective reviews on a total of 428 JIA patients to benchmark the BSPAR and the

Arthritis and Musculoskeletal Alliance standards of care [72]. Percent of patients fulfilling this minimal level of care ranged from 15 to 99%.

Initial benchmarking of cSLE quality indicators demonstrated variability in care of the seven contributing sites - 4 in the United States, 2 in Brazil, and 1 in India [73]. Retrospective review assessed 483 cSLE patients, and large centers had a higher performance in satisfying the quality indicators overall versus small centers. Example performance on select quality measures is as follows: education on sun avoidance 54–99%, prescription of antimalarial therapy 75–100%, bone mineral density testing if patient received chronic systemic steroids 7–90%, and annual eye exam if on antimalarial therapy 72–96%.

PR-COIN has gone beyond benchmarking and is tracking quality measures over time. There are currently over 3,000 JIA patients and over 15,900 encounters in PR-COIN's clinical registry [37]. Two quality measures - documentation of complete joint count and measurement of arthritis-related pain - are meeting or exceeding initial goals [64]. In addition, PR-COIN has improved six process of care measures: measurement of functional ability, monitoring medication toxicity labs, documentation of complete joint count, initial medication counseling for new medications, annual medication counseling, and measurement of health-related quality of life [22,64]. Many individual sites are also improving quality measures.

Conclusion

Improving care delivery and outcomes is essential in pediatric rheumatology given persistence of diseases into adulthood and the gap between recommended care and the care actually received. Research is important, but quality improvement efforts, especially through a learning health network approach, can revolutionize clinical practice.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Points

- Outcomes improvement is accelerated in the context of a networked learning health system approach using data and shared best practices to drive clinical care, quality improvement, and research.
- Research is important to evidence generation, and quality improvement networks are instrumental for reliable translation of research into clinical practice.
- Partnership between patients/families and health care teams is likely to accelerate improvement in care delivery and patient relevant outcomes for children with rheumatic diseases.
- Benchmarking is useful to understand system performance but improvement requires planned intervention, tests of change, and learning from the results.

Table 1

Healthcare quality improvement concepts and terms.

Learning health care system [24]	Links personal and population data to researchers and practitioners, dramatically enhances the knowledge base on effectiveness of interventions and provides real-time guidance for superior care in treating and preventing illness
The Model for Improvement [25]	A guiding approach to improvement projects and tests of change based on three fundamental questions: <ol style="list-style-type: none"> 1 What are we trying to accomplish? 2 How will we know that a change is an improvement? 3 What changes can we make that will result in improvement?
Pre-visit planning	The act of systematically preparing for an efficient quality patient visit by gathering necessary information, assessing compliance with recommended processes of care and identifying gaps in care
Population management	An intervention that enables overview of characteristics of all patients in the registry, subpopulations, and individual patients; facilitates identification of care gaps and high risk patients for proactive care
Shared decision making	Providers and patients contribute jointly in the process of medical decision making; providers share best evidence about treatment options; patients/caregivers have the opportunity to include in the conversation treatment attributes that are important to them and to make informed decisions that suit their goals and preferences.
Self-management [26]	The ongoing process by which an individual with a chronic illness or condition and his/her family engage in the following tasks: <ul style="list-style-type: none"> - Medical management – managing symptoms and promoting health - Emotional management – managing emotions commonly experienced - Role management – managing the impact of illness on functioning, interpersonal relationships, and life roles
Plan-Do-Study-Act cycles (PDSA) [25]	Framework for an efficient trial-and-learning methodology to help develop tests, analyze results, and implement effective changes
Key driver diagram	A visual that lays out specific project aims, key drivers or determinants of achieving the desired aim, and planned interventions to test and move the corresponding driver(s) to achieve the aim
Process mapping [25]	A visual picture of a process being studied to understand how the current process or system works (e.g. flow diagram)
Failure mode and effects analysis(FMEA) [25]	Systematic, proactive method of identifying and preventing product and process problems before they occur by using a standardized approach to analysis that includes review of function, failure modes, failure causes, and failure consequences
Co-production [27•]	Patients/families and healthcare team partnering to design, commission or produce a common desired service, object or outcome
Quality measure	A means to assess performance of an individual or organization on important processes or outcomes
Benchmarking	Comparing individual results and performance on quality measures against best practices in the field