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Addressing healthcare quality in juvenile idiopathic arthritis with a universal access program

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Editorial

Addressing Healthcare Quality in Juvenile Idiopathic Arthritis With a Universal Access Program

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In this issue of *The Journal of Rheumatology*, Concha, *et al*[1] describe the effects of the implementation, in 2010, of a national, legally mandated universal access program (Explicit Health Guarantees [GES]) for guaranteed juvenile idiopathic arthritis (JIA) diagnosis and treatment in Chile. The GES program guarantees that evaluation by a specialist takes place less than 30 days after referral from primary care, and that treatment must start no later than 7 days after confirmation of diagnosis. The authors report that this program led to earlier access to a pediatric rheumatologist and earlier JIA diagnosis. Diagnostic delay and time to evaluation by a pediatric rheumatologist were significantly reduced. Prior to GES, patients were evaluated and diagnosed 15 months after onset of symptoms vs 9 months post-GES. They found increased rates of treatment with biologic medications as well as increased magnetic resonance imaging (MRI) scans performed (9 vs 71). JIA remission rates, defined by Wallace criteria,[2] were found to be higher (29% vs 43%) and uveitis complications rates lower (45% vs 13%).[1]

The GES was implemented in Chile in 2005. A 2015 World Health Organization (WHO) report on the system demonstrated improved efficiency in the Chilean healthcare system.[3] The plan prioritizes and guarantees a number of issues or health conditions considered to be priorities (e.g., cancer, congenital heart diseases, high blood pressure, premature labor) based on people's needs. The target group with each health condition has the right of access, with a defined maximum time for the delivery of the service; the right to financial protection, which regulates the co-payment according to the type of health insurance that the beneficiary may have; and the right to quality, which means receiving health care that is guaranteed by a registered provider who is accredited according to the law. The funding source for GES was a 1% increase in value-added tax. GES impacts that are regularly reviewed by the country include the following: the frequency of health concerns that correspond to the ones that are guaranteed and the increase in use of services, indicating that the original prioritization was effective. Within the GES system, there has been a reduction in waiting times but not in the size of the queues (similar to non-GES pathologies). With regard to the quality of services, captured by self-report, there was no significant change for publicly insured beneficiaries. For privately insured beneficiaries, there has been an 8% improvement. Regarding the opportunities for services, publicly insured patients report reduced dissatisfaction, whereas privately insured beneficiaries report increased satisfaction. In terms of equity, there has been a 20% increase in coverage for the lowest 3 income quintiles.[3]

Providing high-quality care has been defined as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[4] Access to specialty rheumatology care was deemed important for future quality measure development by the American College of Rheumatology.[5] However, access to rheumatology care in the developing world, especially for children, has been faced with many challenges, including lack of awareness of arthritis and autoimmune diseases in childhood and limited access to pediatric rheumatology services.[6] The GES plan addresses several of the key aims for improvement described by the Institute of Medicine's framework for health care quality[4] (Table 1). JIA care was considered to be safe with the implementation of the GES program as it ensured access to ophthalmology care in all children with a diagnosis of JIA, thereby avoiding possible missed uveitis diagnosis. As a result, the rates of uveitis complications were significantly reduced, including a noticeable decrease in partial vision loss

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Table 1. Institute of Medicine framework for healthcare quality.[4]

Aims for Improvement	Definition
Safe	Avoiding harm to patients from the care that is intended to help them.
Timely	Reducing waits and sometimes harmful delays for both those who receive and those who give care.
Effective	Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
Efficient	Avoiding waste, including waste of equipment, supplies, ideas, and energy.
Equitable	Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.
Patient-centered	Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.

The 6 domains are available online[21]: Six Domains of Health Care Quality. Content last reviewed November 2018. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/talkingquality/measures/six-domains.html

from 36% to 4%. Similarly, effective care was achieved with improved access to MRI as evidenced by a significant increase in number of MRIs performed, likely facilitating earlier and more accurate diagnosis.

Timely access to pediatric rheumatology care for the diagnosis and treatment of patients with inflammatory arthritis is imperative to achieve optimal patient outcomes.[7] The contrary is also true—a delay to diagnosis is associated with poorer outcomes.[8] The Wait Time Alliance (WTA) of Canada[9] benchmarks for arthritis care for patients with suspected systemic-onset JIA (7 days) and nonsystemic JIA (4 weeks) have been assessed and are being achieved in 1 provincial Canadian cohort.[7] With the GES system in place, these targets are also being met; however, the wait lists remain long. Patients are being evaluated at a mean of 9 ± 4.2 months after onset of symptoms.[1] A Canadian JIA inception cohort registry reports diagnosis at a median of 14.6 weeks (IQR 8.3–38.3) from symptom onset.[10] The British Society for Pediatric and Adolescent Rheumatology (BSPAR) standards of care (SOC) for children with JIA guidelines suggest < 10 weeks.[11] Alternate clinical networks and pathways to referral are areas of future work to improve timely access. A formal evaluation of the Canadian WTA benchmark for ideal time to first uveitis screening by eye care provider for oligoarticular, psoriatic, RF-negative, or undifferentiated JIA (4 weeks) has not been reported. Similarly, Concha, *et al*[1] do not comment on time to first ophthalmic examination but rather report on decreased uveitis-related complications. It will be important in future work to evaluate this measure of timely access to ophthalmic assessment, diagnosis, and care, which should ideally occur < 6 weeks from the time of JIA diagnosis.[12]

Equitable care is also a key mandate of the GES. The program is free for people with low socioeconomic status who have public insurance. For those with public insurance but middle socioeconomic status, GES covers 90% of costs, and for the privately insured population, 80% of costs are covered by insurance. The BSPAR SOC for children with JIA include access to a full multidisciplinary team (MDT; Figure 1), the members of which have appropriate skills and experience for managing children with arthritis.[11] Evaluation of the practice in the UK against the SOC demonstrated variability, with only 59% (184/311) of patients assessed by a specialist nurse at < 4 weeks and 45% (141/311) assessed by a physiotherapist by < 8 weeks. All centers had access to a nurse specialist and physiotherapist. Most had access to an occupational therapist (8/10) and a psychologist (8/10).[13] Concha, *et al*[1] report that the majority of patients who need rehabilitation attend a not-for-profit organization. Hence, patients before and after GES have access to rehabilitation (physiotherapy and occupational therapy) regardless of their income or treatment guarantees. It is not clear if these are practitioners have expertise in JIA of if patients have access to other members of the MDT. Both in the developed and developing world, optimizing access to the MDT and delivery of equitable care close to home, where possible, are future goals.

When JIA was added to the GES, access for life, even after transition to adult medicine, was guaranteed. In their report, Concha, *et al*[1] do not report on the type of healthcare providers following these patients nor patient outcomes after the transition period. The importance of ongoing access to care after transition is highlighted in the European Alliance of Associations for Rheumatology recommendations for the transitional care of young people with juvenile-onset rheumatic diseases.[14] Considering that pediatric-onset rheumatic disease can be more severe than adult-onset disease, it is critical that optimal care continues across the transition period into early adulthood.[15,16] For patients with JIA, the transition period has been associated with increased risk for poor symptom and disease control, morbidity, and mortality.[17,18,19,20] The transition period is therefore a critical time to ensure that patients are engaged in their care, have adequate access to health care, and understand the

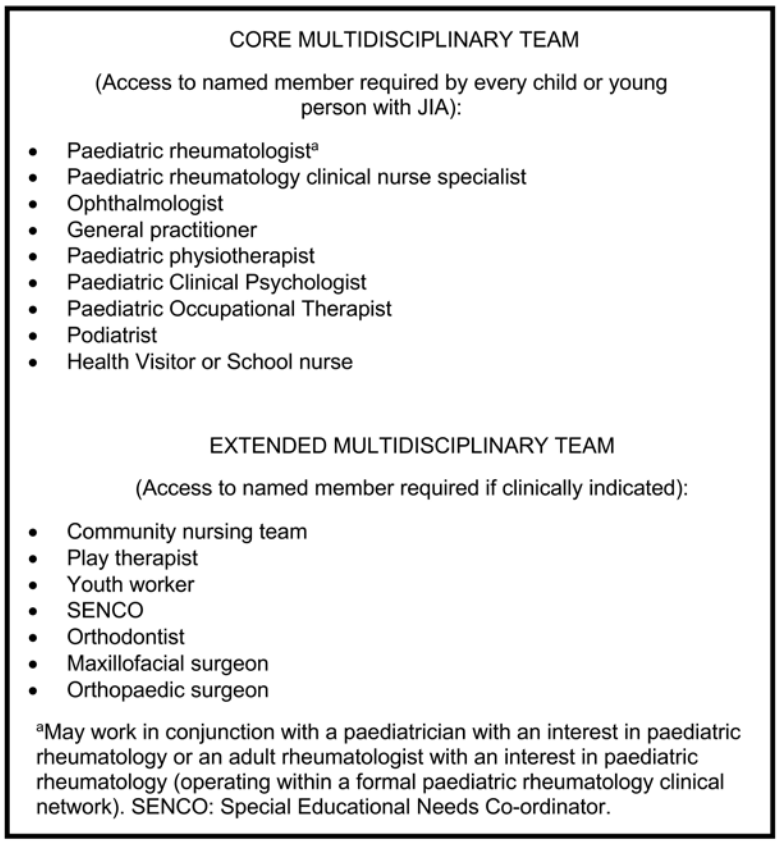

Figure 1. Essential members of the pediatric rheumatology multidisciplinary team. Reprinted from Davies K, *et al*; on behalf of the British Society of Paediatric and Adolescent Rheumatology[11] by permission of Oxford University Press. JIA: juvenile idiopathic arthritis.

increasing expectation for them to manage their own care. The next steps in evaluation of the GES, in addition to guaranteeing access for life, should involve ensuring that patients with JIA are best equipped to succeed after their transition to adult care. This includes optimizing self-management skills, preparing them for the differences between pediatric and adult health systems, and supporting them through the many other life transitions they will be experiencing.

As described by the authors[1] and as evidenced by the WHO report,[3] implementation of the GES system for JIA has resulted in improved access to safe, timely, equitable, and effective care, with improved medication access and decreased uveitis complications, as well as access across the continuum of aging in a developing country. As the authors note, during this time, awareness of JIA has undoubtedly increased as a result of this program, as has the socioeconomic development in Chile, and both may have affected the results to appear more favorable. Further, patients included in this study were from a private hospital network; patients seen at public hospitals likely have additional and greater difficulties in access to diagnosis and therapy due to hidden access barriers such as geographic distance and cost of transportation. Timely access to initial and ongoing ophthalmic care by a provider with expertise in uveitis and access to a full MDT with expertise in JIA remain important unmet needs in both the developing and developed world.

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