Developing standards of care for patients with juvenile idiopathic arthritis

An opportunity to improve care and disseminate knowledge

This editorial refers to ‘BSPAR Standards of Care for children and young people with juvenile idiopathic arthritis’, by Karen Davies et al., doi:10.1093/rheumatology/kep460, on page 1406.

The recently published Standards of Care for Children and Young People with Juvenile Idiopathic Arthritis developed by the British Society for Paediatric and Adolescent Rheumatology (BSPAR) [1, 2] set a standard for specialty care to be emulated worldwide. Literature searches revealed only two other sets of guidelines [3, 4] for the treatment of juvenile idiopathic arthritis (JIA). One is a brief policy statement of services to be provided from the State of Wyoming in the USA. The other is a thorough set of recently published guidelines from the Royal Australian College of General Practitioners and the Australian National Health and Medical Research Council, intended for general practitioners who care for children with JIA. The Australian guidelines are based on a review of available literature with rating of the evidence presented for the diagnosis and management of JIA (including multidisciplinary care, pharmacological and non-pharmacological care).

The BSPAR guidelines begin with a well-articulated philosophy that sets the stage for the sections that follow. The philosophy emphasizes that these standards are but a minimum, and that empowering and involving patients and families in treatment plans and delivery of care are crucial, and that a holistic approach is the basis of care. While control of disease is stated as a major goal, surprisingly, remission of disease is not articulated as the over-riding goal of treatment for patients with JIA. Approaches and medications are now available to make remission of disease a reality for many, if not most, patients with JIA. The important new concept of remission of JIA should be widely publicized and made clear to everyone involved in the care of children with JIA.

The 17 sections of the Standards of Care that detail the elements of holistic care include:
- empowering patients with JIA and their carers;
- identification of JIA;
- referral to the paediatric rheumatology service;
- composition of the multidisciplinary team;
- access to investigations;
- access to treatment;
- monitoring of disease activity;
- regular review;
- ophthalmology screening;
- maintenance of bone health;
- pain management;
- paediatric orthopaedic surgery or hand surgery;
- care of adolescents with JIA;
- immunizations;
- inpatient management;
- outpatient services; and
- clinical networks and arrangements for shared care.

Without a doubt, identification of children with possible JIA is the initial key step and is challenging for most medical systems and countries, because physicians and nurses who care for children need better training and knowledge and access to care can be a huge barrier. A complete discussion regarding the issues of training and access to care has recently been published by Foster and Kimura [5] and Faller and Allen [6].

Importantly, clinicians should understand not only the signs and symptoms of possible JIA, but also the importance of early care (to avoid joint damage) in addition to the treatment successes that can be achieved with early aggressive treatment. The stated standard of being seen by a paediatric rheumatology team within 10 weeks of onset of disease symptoms and 4 weeks of the referral is ambitious and ideal, but probably difficult to achieve in most countries. Early, rapid referral requires not only well-trained general and family practice physicians, paediatricians, internists, orthopaedics and nurse clinicians, but adequate numbers of paediatric rheumatologists and teams to see these referred patients. Although the standard of early referral of children with potential JIA is a huge challenge worldwide, it is an important goal.

Disappointingly, these carefully developed standards do not clearly articulate the goal of achievement of inactive disease and remission, but rather have tight control. Medication combinations and approaches are available to achieve inactive disease and remission on medication and even remission off medication for many patients. Communicating the goal and reality of disease remission to patients, families, general practitioners, the medical community at large, governmental agencies, advocacy groups and the general public is crucial for changing treatment paradigms and improving rapid referral of patients with potential JIA.

These standards of care developed by the BSPAR are a thorough beginning and lay the ground work for what must quickly follow: specific algorithms of medication...
use coupled with benchmarks for disease control and identification of quality indicators. Additionally, access to participation in research investigations such as registries, observational studies, translational studies, protocol-based (standardized) care and treatment trials must be a key element and one of the philosophical pillars of the standards of care for children and young people with JIA. It is only through clinical research and continued assessment of standardized care that we will be able to identify the best treatment approach for each category of JIA and improve the long-term outcomes and health-related quality of life of patients with JIA.

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