An interdisciplinary clinic for children with arthrogryposis: Impact on clinicians and families

Noémi Dahan-Oliel¹,², Alexandra D. A. Vicente¹, Emily Lecker¹, Philippe Campeau¹,³, Frank Rauch¹,⁴, Reggie Hamdy¹,⁴
¹Shriners Hospitals for Children, Montreal, Quebec, Canada, ²School of Physical and Occupational Therapy, McGill University, Montreal, Quebec, Canada, ³Hôpital Ste-Justine, Montreal, Quebec, Canada, ⁴Faculty of Medicine, McGill University, Montreal, Quebec, Canada

Rationale: Children living with arthrogryposis multiplex congenita (AMC) have multiple needs requiring an interdisciplinary approach. Historically, children with AMC were seen by various healthcare professionals (HCP) at different visits, leading to fragmented care. An interdisciplinary clinic combining orthopedics, genetics, nursing, rehabilitation and social services was created to provide comprehensive care.

Objectives: To implement an interdisciplinary clinic for AMC; to identify families’ expectations at the clinic; and to measure clinicians’ and families’ satisfaction.

Method: Families were contacted prior to the clinic to set goals using the Canadian Occupational Performance Measure (COPM). A tracking sheet was used to document the COPM scores, and a personalized copy with this information was given to each family when they arrived for their visit to promote communication and ensure recommendations and intervention plans were linked with the goals. Family-centeredness of the clinic was evaluated using the Measure of Process of Care questionnaires completed by family members and clinicians.

Results: Ten families have established goals using the COPM. Overall, goals focused on self-feeding, maintaining mobility in the home, school and community and learning about equipment that could facilitate participation. Since each patient's goals and treatment plans are shared amongst clinicians and families, discordance was avoided, further streamlining patient care.

Conclusion: The use of the COPM to guide intervention planning in an acute care interdisciplinary clinic, and increase cohesiveness between clinicians and families is promising. This model can be used throughout organizations facing similar challenges of engaging patients and families, to provide comprehensive family-centered services.