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EDITORIAL

The role of shared decision making in pain management for juvenile idiopathic arthritis. The JIA Option Map

O papel da tomada de decisão compartilhada no tratamento da dor na artrite idiopática juvenil. O mapa de opções da AIJ

Karine Toupin-April[1], Juliana Barcellos de Souza[2]

Guideline recommendations for pain management involve person-centered care and evidence-based practice (EBP) in an interprofessional team. EBP integrates the best available evidence, as well as clinical expertise (professional judgment), client values/goals, and the context, including resources[1]. It is important to ensure the use of effective, safe, and feasible interventions that align with each person's goals and health care providers' (HCPs) expertise. Pain management is also most effective when provided by various HCPs, including physicians, nurses, physiotherapists, occupational therapists, psychologists, and others using interprofessional collaboration[2].

Shared decision making (SDM) is also key to facilitating patient-centered care and EBP in chronic conditions[3,4] by allowing for optimal communication of each person's values and goals. Using SDM and EBP in an interprofessional manner can be difficult in clinical practice. There is a need for specialized HCPs trained in pain management to access, understand, and communicate up-to-date scientific evidence and to effectively engage patients in SDM[5-7].

To reach this goal, groups of researchers, HCPs, patients, and family members have collaborated to develop various interventions. Effective SDM interventions include patient decision aids (PDAs) and decision coaching[8,9]. PDAs are tools that provide evidence-based information on treatment options, help clarify values and preferences, and support decision-making. They can be simple or more complex for various treatment options, and linear or interactive by showing personalized information to each user using web platforms. Decision coaching is a non-directive approach to help people make decisions that are consistent with their own values and preferences. Decision coaching is often combined with PDAs for optimal results. There are many PDAs for a wide range of chronic conditions, such as chronic pain. One such tool for juvenile idiopathic arthritis (JIA) is the JIA Option Map, an interactive web-based PDA that was developed by a team of researchers, HCPs and patients[10-12]. This editorial presents the process of creating the JIA Option Map.

JIA is a chronic autoimmune condition that begins before 16 years old. Young people with JIA report symptoms such as joint pain, stiffness, swelling, fatigue, anxiety, or depression. It is challenging for families to access reliable information and choose between various symptom management strategies beyond traditional disease-modifying antirheumatic drugs (DMARDs) and biologics.

Since 2016, the Choice Research Lab (www.choiseresearchlab.ca) has engaged young people with JIA, HCPs and researchers to build a PDA to help choose among JIA pain management approaches following the International Patient Decision Aids Standards (IPDAS) systematic development process[13]. The team conducted a literature review and interviews to assess decision-making needs of young people with JIA, which included a need to improve decision-making for pain management[14,15]. The team used a systematic review to summarize the benefits and risks of pain management approaches and a series of consensus meetings to agree on the content and format of the JIA Option Map. The team then built a paper version of the PDA and a web application and assessed its usability and acceptability[10].

The original JIA Option Map was developed exclusively for pain management, the most common symptom among young people with JIA. It aims to help adolescents and young adults, as well as parents and caregivers to facilitate SDM by providing information on a wide range of pain management approaches in JIA, by clarifying patients' values and preferences and by helping them choose the best approaches. The app has six steps. Step 1 assesses pain and use of approaches for JIA. Step 2 assesses young people's values and preferences. Step 3 presents a few pain management approaches based on the pain location and values and preferences. Young people can also view all options if they wish (about 40 options).

Treatment options are divided into six categories: (1) splints, orthotics, and other devices; (2) physical activities; (3) physical treatments; (4) psychological, spiritual, and educational approaches; (5) pain medications; and (6) nutrition. The app provides evidence-based information on benefits and risks, and a few practical recommendations and links to websites and apps for each approach. Young people can select their favorite approaches to review them again next time they use the app. Step 4 asks them to make a plan to follow. Step 5 allows people to track their pain over time to see if approaches are helpful. Step 6 shows a summary of all the information entered in the app so that people can discuss it with their HCPs to facilitate SDM.

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[1] Universidade de Ottawa, Hospital Infantil do Leste de Ontário, Institute du Savoir Montfort, Ottawa, Canadá.
[2] Universidade do Estado de Santa Catarina, Florianópolis, SC, Brasil.

Correspondence to:
Karine Toupin-April
ktoupina@uottawa.ca

The app showed good usability and acceptability[10-12]. Adolescents and young adults with JIA and parents found it easy to use. They appreciated the wide range of pain management approaches with evidence-based summaries, as well as links to online resources and interactive features to track pain over time. They all felt that the app would help them learn about new treatment options and their associated pros and cons. Most found the app would be helpful in making decisions based on what matters most to them. However, some mentioned the need to add treatment options for symptoms other than pain, and tips to help people participate in daily activities. They also suggested preparing HCPs to use the app with their patients.

The team has recently been expanding the app to include approaches to manage not only pain but other symptoms like fatigue, stiffness, anxiety, stress and depression[16]. To do this, the research team conducted surveys and consensus meetings, following by a systematic review of the evidence to add approaches to manage these other symptoms.

Overall, the app shows strong potential to improve decision-making among young people with JIA. Young people's involvement in the research team and as research participants, as well as that of HCPs from various professions, were crucial to the success of this endeavor.

Future research will focus on testing the effectiveness of the JIA Option Map in promoting effective decision-making in JIA. When thoroughly tested, the JIA Option Map may serve as a viable tool to help young people with JIA and their families make informed and personalized decisions in clinical settings, which may help to empower them and self-manage their symptoms for optimal health outcomes.

These findings reinforce the importance of HCPs helping people make the best decisions possible to manage symptoms such as pain. Each person deserves to be informed about a wide range of treatment approaches including physical, psychological and nutritional approaches, and their characteristics such as benefits and risks, according to up-to-date scientific evidence. Since there is no "one size fits all" method to managing pain, they should also consider what matters most to patients when choosing approaches. This will help ensure their commitment to following optimal approaches for better health outcomes. Finally, using SDM for chronic conditions is an interactive and long-term process that can facilitate a good therapeutic relationship based on transparency, respect and trust and can lead to empowerment of people with chronic conditions.

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