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Summary of patient/parent organisation services promoting self- and shared-management of JIA in the UK and Ireland

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Background:

Various patient/parent organisations provide information, education, and support services to children and young people with JIA and their families. Some organisations are JIA/uveitis focused, while others are umbrella rheumatic and musculoskeletal disease (RMD) organisations or have a broader remit to long-term conditions (LTCs). However, there are no summaries of such collective services offered in the UK and Ireland, which can add to confusion for children, young people, and families, while contributing to inconsistent signposting to services from healthcare professionals.

Objectives:

To summarise current and recent services promoting self- and shared-management of JIA by patient/parent organisations in the UK and Ireland.

Methods:

An electronic search of known patient/parent organisation platforms (website and/or social networking sites) was performed between August 2020 and January 2021. Materials provided at conference exhibitions since October 2016 were also reviewed. Services were identified, including their aims and further details, if available. These were then mapped by format (*e.g.*, educational, telemedicine, art therapy) and element (*e.g.*, informational videos, monitoring through self-report diaries, discussing art and related feelings), according to their mode of delivery (individual or group), adapted from Sattoe et al. (2015) [1].

Results:

Twelve patient/parent organisations in the UK and Ireland were identified (11 of which had some form of charity/company registration): seven were JIA-specific, one was uveitis-specific, two were RMD-focused, and two were LTC-focused. In total, 48 services were identified across the twelve organisations. Generally, group mode of delivery was more popular than individual mode of delivery. Of group-based services, educational and/or support sessions and residential/excursion programmes were the most frequently observed. Of individual-based services, educational sessions including written and visual information were predominant. No one organisation provided services across all formats and elements identified. There appeared to be a limited focus on goal setting, individual level skills training, and explicitly improving self-and/or shared-management capacity. Gamification techniques were notably absent, as was the use of psychotherapeutic approaches, such as cognitive behavioural therapy and motivational interviewing.

Conclusion:

Various services are offered by multiple patient/parent organisations with an interest in JIA across the UK and Ireland to promote self- and shared-management. However, no single organisation provides a comprehensive package of services to address the entire information, education, and support needs of children and young people with JIA, or their families. Furthermore, clarity of services offered across the sector is poor. Enhanced collaboration between organisations, together with a clearer focus on enhancing self- and shared-management of JIA across the lifecourse, may help to improve the offering to children, young people, and their families, so that they can more competently manage JIA.

References:

1. Sattoe et al. Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling* 2015; 98(6): 704-715.

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