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Factors facilitating the self- and shared-management of JIA by children, young people, their families, and professionals involved in their care: A realist evaluation

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Background:

Juvenile idiopathic arthritis (JIA) is a long-term condition, often requiring some element of lifelong management. Therefore, it is logical that children and young people are empowered to become competent at self-managing their health and wellbeing, while families are supported in their shared-management role during childhood, relinquishing control at age- and developmentally appropriate periods in their child's development. However, there are limited theoretical foundations underpinning optimal self- and shared-management support for children, young people and families living with JIA.

Objectives:

To explain the factors facilitating the self- and shared-management of JIA by children, young people, and their families, with professional support from healthcare professionals, third sector organisations, and education professionals.

Methods:

Guided by the Individual and Family Self-management Theory and the Shared Management Model, a three-stage realist evaluation was undertaken: 1) initial JIA self- and shared-management question theories were elicited from a document review, integrative review, and stakeholder insights [1]; 2) seven initial question theories were tested using qualitative research methods with 20 participants (young people, families, healthcare professionals, education professionals, and third sector representatives); 3) analysis of findings using a theory-driven approach to thematic analysis, in order to identify demi-regularities to extend or refute the initial question theories. The analysis drew on deductive, inductive, and retroductive reasoning.

Results:

There were six refined JIA self- and shared-management question theories: 1) meaningful and bespoke self-management support across the life course for children and young people with JIA; 2) recognised and valued shared-management support for the families of children and young people with JIA, with autonomy in mind; 3) individual healthcare plans as a shared management communication tool to facilitate optimal management of JIA; 4) consistent recognition, value, and encourage of self- and shared-management support from the paediatric rheumatology multi-disciplinary team and associated professionals; 5) child, young-person, and family-focused paediatric rheumatology care and support services across

the lifecourse; and 6) bespoke and inclusive approaches by education providers to enable children and young people with JIA to feel safe, supported, and able to fulfil their potential.

Conclusion:

There is an increasing recognition of the importance of self- and shared-management of JIA. However, there is a lack of an overall, cohesive approach to self- and shared-management between healthcare providers, education providers, and the third sector. Findings from this study illuminate the factors facilitating JIA self- and shared-management at individual, interpersonal, institutional and infrastructural levels. Further work is required to empirically test these refined question theories with interventions designed to enhance JIA care, education, and support.

References:

1. Stones et al. (2020). A realist approach to eliciting the initial programme theories for the self- and shared-management of juvenile idiopathic arthritis by children, young people, families and professionals involved in their care. *Pediatric Rheumatology* 18(Suppl 2): O062.

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