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Version: Accepted Version

Proceedings Paper:

Stones, S, Swallow, V, Milnes, L et al. (2017) Identifying the self-management needs of children with rheumatic and musculoskeletal diseases and their families: an exploratory sequential mixed methods study proposal. In: Rheumatology. British Society for Paediatric and Adolescent Rheumatology 2017, 04-06 Oct 2017, Sheffield, UK. Oxford University Press. Article no: kex356.033. ISSN: 1462-0324. EISSN: 1462-0332.

<https://doi.org/10.1093/rheumatology/kex356.033>

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Identifying the self-management needs of children with rheumatic and musculoskeletal diseases and their families: an exploratory sequential mixed methods study proposal

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Abstract

Background

For those diagnosed with long-term conditions in childhood, the skills needed to self-manage are not usually promoted until the child reaches adolescence. However, encouraging children with long-term conditions to adopt healthy self-management behaviours at the earliest opportunity is likely to positively influence their health and wellbeing. Several interventions have been developed for children with certain long-term conditions such as type one diabetes mellitus. However, this is not the case for children living with rheumatic and musculoskeletal diseases (RMDs).

Aims

Therefore, the aim of this study is to identify the self-management needs of children of primary school age (4 to 11 years old) living with RMDs to inform the specification of a future intervention to educate and empower children with RMDs and their families.

Methods

This study will employ an exploratory sequential mixed method design and will be conducted as three work packages. Young people and parents/carers have, and continue to guide this study, where they are involved in co-producing all aspects of the research. A realist synthesis will identify the contextual features and mechanisms underpinning interventions for children with long-term conditions, including asthma and type one diabetes mellitus, since there are many commonalities in the way that these long-term conditions are managed in childhood. This will inform a qualitative phase with children with RMDs, young adults with childhood-onset RMDs, and those involved in their care and education. These findings will inform the quantitative phase of the study, which will use Q-methodology to identify the preferred components and contents of a future self-management intervention.

Results

A previous literature review identified a lack of evidence about self-management of RMDs for children and their families, and of interventions available to support them. However, conceptualising self-management in children is a novel concept, where it is believed that the readiness of children to self-manage their health is heightened during periods of vulnerability, such as during early adolescence. By enabling and empowering children with RMDs at the earliest opportunity, there is scope to positively influence the way in which they learn about their condition(s) in an age- and developmentally-appropriate manner.

Conclusions

This study will contribute to the growing evidence-base regarding the self-management needs of children with RMDs. It will address the knowledge gap for self-managing childhood RMDs, by exploring the needs of all stakeholders involved in the care and education of children with RMDs. Taking a 360-degree view is expected to inform the specification for a novel intervention for children in the future, in addition to enlightening the wider community about the self-management needs of children with RMDs.