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Can we implement the new research agenda for mental health?

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Children and young people with rheumatic diseases face considerable challenges to their mental health, yet the research guiding prevention and intervention strategies is limited. A new research agenda provides an important step forward by highlighting important issues, but can these research priorities be addressed within the paediatric rheumatology health-care context?

Refers to Rubinstein, T. B. et al. Prioritized agenda for mental health research in pediatric rheumatology from the Childhood Arthritis and Rheumatology Research Alliance Mental Health Workgroup. J. Rheumatol. <https://doi.org/10.3899/jrheum.190361> (2020).

The management of childhood rheumatic diseases is complex; optimal quality care involves a multi-disciplinary approach covering a diverse range of professional practices, knowledge domains and skills, including medicine, nursing, physiotherapy, occupational therapy, social work, psychology and school liaison¹. Arguably, responsibility for the emotional wellbeing of these young patients is shared by all members of the rheumatology team; however, there is currently little clear evidence about long-term outcomes on which to base clinical practice. Psychological distress functions as an outcome of disease as well as a contributor to the broader health of that individual².

The new agenda from the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Mental Health Workgroup³, which outlines five broad priority domains of mental health research, is to be welcomed. As well as orientating researchers towards important gaps in our current knowledge and practice, it provides a timely reminder to everyone involved in commissioning health services of the need to keep psychological wellbeing at the heart of care provision. However, it is important to consider the research and health-care context within which this new research agenda sits.

Research involving children and young people with chronic conditions faces very specific challenges, not least those that arise as a result of the major physical, intellectual, emotional and social changes that occur during childhood and adolescence. These challenges are seen most clearly when trying to interpret data from longitudinal cohort studies;

arguably, one of the strongest methods available for paediatric rheumatology research. Additional methodological challenges relating to data collection from younger individuals include the use of proxies such as parents, who report on behalf of children but who are only able to provide partial representations of the child's wellbeing⁴, and a lack of data collection tools that are appropriate for the developmental stage of the child or young person. Even if these issues can be addressed, there is still a need to establish and maintain research cohorts large enough to develop robust, predictive models that can take account of the many other influences on health outcomes.

Acquiring a sufficiently large cohort is particularly challenging for rare rheumatic diseases and is further complicated when varied or complex treatment pathways need to be accounted for.

The first priority set out by the CARRA research agenda³ is to “determine the prevalence and incidence of mental health disorders in pediatric patients with rheumatological disease”. Although some literature is available on the prevalence and incidence of psychological distress in young people with rheumatic diseases, it is of limited quality and quantity. Existing studies are predominantly cross-sectional, rather than longitudinal, and tend to include individuals with only the more common inflammatory rheumatic diseases such as juvenile idiopathic arthritis (JIA). Even within JIA research, limitations include a failure to link the incidence of mental distress with the rarer sub-types of JIA, where differences might be expected to arise. Characterizing the breadth of conditions is as important as characterizing the range of symptom severity within conditions and how they might or might not be associated with psychological distress. For example, paediatric rheumatology encompasses the treatment and management of inflammatory conditions, such as JIA, but also non-inflammatory conditions, such as hypermobility, complex regional pain syndromes and chronic back pain⁵. Research into psychological outcomes across inflammatory and non-inflammatory conditions will be crucial for the identification of those mechanisms that are specific to inflammatory processes, as well as those that are associated with symptoms common to all conditions, such as persistent pain or fatigue.

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“Importantly, mental health screening tools are not substitutes for conversations about mental health”

The routine capture of psychological data, which would require consensus building across both the research and clinical communities in terms of which variables to collect and when, would be one way to start to address the considerable gaps in our understanding of psychological wellbeing in childhood rheumatic diseases. In paediatric rheumatology research, consensus is already being achieved about data collection for physical aspects of disease⁶. The emergence of new mobile and electronic health data collection methods will greatly enhance the availability of data for both research and clinical use.

Digital tools are often more acceptable to children and young people and less demanding than interviews or paper-based questionnaires⁷. Such tools might reduce the need for proxy reporting by parents or clinicians, as children as young as 5 years of age are able to directly provide data using digital tools. Furthermore, remote data collection frees up precious clinical consultation time.

Screening forms another important domain in the CARRA research agenda³. In practice, screening for mental health disorders in paediatric rheumatology varies considerably; some services use specific screening tools whereas others take a more general psychosocial interview approach⁸. Whether either approach has advantages in terms of prevention or identification of mental illness, or of other disease outcomes, is presently unclear. Importantly, mental health screening tools are not substitutes for conversations about mental health, and an approach that combines these methods might prove to be best.

Health-care professionals working in paediatric rheumatology are uniquely placed to postulate potential links between physical manifestations of the rheumatic disease and substantial changes in the psychological wellbeing of their patients; such changes are less likely to be picked up using generic mental health screening tools.

The nomenclature around mental health varies considerably between that used in the research literature and that used in clinical settings. Sometimes psychological distress is viewed as part of a broader concept, such as health-related quality of life⁹, and at other times specific disorders such as anxiety or depression are considered to be potential comorbidities of the rheumatic disease itself¹⁰. Again, further consensus development around routine data capture would be beneficial; however, clarity is also needed about whether the focus should be on screening alone, or whether the research remit should be broadened to consider the prevention of psychological distress. With regards to prevention, the CARRA research agenda³ refers to “adjustment and coping interventions”, rather than suggesting an explicit focus on the psychological processes that might contribute to the development of poor mental health for children and young people with rheumatic diseases. However, for such adjustment and coping interventions to be successful, relevant behavioural, cognitive or other psychological targets need to first be identified.

Overall, the CARRA prioritized agenda for mental health research in paediatric rheumatology³ provides an important steer for the research community. We need a research evidence base that will guide the development of interventions, not only to address the unmet mental health needs of young people with rheumatic diseases, but also to enhance management approaches that prevent mental illness and promote psychological resilience.

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Competing interests

The authors declare no competing interests.