

# Understanding how children and young people with chronic non-cancer pain and their families experience living with pain, pain management and services: a meta-ethnography

Mayara Silveira Bianchim,<sup>1</sup> Line Caes,<sup>2</sup> Liz Forbat,<sup>3</sup>  
Abbie Jordan,<sup>4</sup> Jane Noyes,<sup>5</sup> Katie Thomson,<sup>1</sup>  
Ruth Turley,<sup>6</sup> Isabelle Uny<sup>7</sup> and Emma F France<sup>1\*</sup>

<sup>1</sup>Nursing Midwifery and Allied Health Professions Research Unit, Faculty of Health Sciences and Sport, University of Stirling, Stirling, UK

<sup>2</sup>Division of Psychology, Faculty of Natural Sciences, University of Stirling, Stirling, UK

<sup>3</sup>Faculty of Social Sciences, University of Stirling, Stirling, UK

<sup>4</sup>Department of Psychology and Bath Centre for Pain Research, University of Bath, Bath, UK

<sup>5</sup>School of Health Sciences, Bangor University, Bangor, Gwynedd, UK

<sup>6</sup>Freelance Researcher, Nursing Midwifery and Allied Health Professions Research Unit, Faculty of Health Sciences and Sport, University of Stirling, Stirling, UK

<sup>7</sup>Institute of Social Marketing, Faculty of Health Sciences and Sport, University of Stirling, Stirling, UK

\*Corresponding author [emma.france@stir.ac.uk](mailto:emma.france@stir.ac.uk)

Published July 2024

DOI: 10.3310/UTPM7986

## Plain language summary

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Health and Social Care Delivery Research 2024; Vol. 12: No. 17

DOI: 10.3310/UTPM7986

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## Plain language summary

Chronic pain lasting 3 months or more affects at least 8% of children in the UK. It causes difficulties with many aspects of children's lives including relationships, school attendance and use of National Health Services. In the UK, there are few specialist services and a lack of high-quality research for managing children's chronic pain.

Our study aimed to locate and pull together existing research on the experiences and views of children with chronic pain and their families. We wanted to find out how they think about and live with chronic pain, and their views and experiences of services and treatments, and what they want to achieve from them.

We conducted this study alongside children with chronic pain and their families, charities, healthcare professionals and academic experts. They helped us to conduct the study and to ensure our findings are relevant to children, families and the National Health Service.

We pulled together data from 43 studies that best answered our questions. We found that moderate and severe children's chronic pain that was not well managed affected the whole family, including their relationships and social lives. Families found it difficult to get help and a diagnosis from health services. Most families wanted a medical cure for pain. Families had long waits for answers and treatment but gradually realised there may be no cure, so they focused on living well with pain or gave up hope. Children and families from ethnic minority groups or with a learning disability experienced discrimination. Few studies focused on children under 5 years old, children with learning disabilities or experiences of services. Families need a pain management approach tailored to the whole family's needs involving schools, social care and health services. Our findings could improve treatment guidelines, training of health and social care professionals and service design and treatments.

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ISSN 2755-0079 (Online)

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This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

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## This article

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number NIHR128671. The contractual start date was in August 2020. The draft manuscript began editorial review in February 2023 and was accepted for publication in November 2023. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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