

Repositioning Parents at the Heart of Pain Communication in Pediatric Rheumatology

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DESCRIPTION

Chronic pain in childhood is not only a clinical condition but also a deeply personal and social experience. The study exploring parents' perspectives on pain communication in pediatric rheumatology brings much-needed attention to a critically under-researched area. It highlights that parents are not passive observers in healthcare interactions, but essential advocates and interpreters of their child's experience. This commentary delves into the core themes of the study and discusses their broader implications for practice, while advocating for a more structured integration of parental voices in pediatric pain communication.

One of the most compelling findings of the study is the active role parents assume in communicating about their child's pain. This isn't surprising when a child suffers from chronic musculoskeletal pain, particularly conditions like Juvenile Idiopathic Arthritis or Ehlers-Danlos Syndrome, it becomes an all-consuming reality for the family. Pain episodes affect sleep, mobility, mental health, school attendance and social life. Parents, therefore, become repositories of experiential knowledge. They can contextualize pain reports with behavioral changes, environmental factors, or treatment responses that a brief consultation can never fully capture. Yet, the study shows that this expertise often goes underutilized or, worse, ignored.

In their dual roles as both observers and caregivers, parents constantly negotiate how to best represent their child's pain to healthcare professionals. Some children rely heavily on their parents to translate their pain into language, while others downplay or conceal their symptoms out of fear of worrying their families. Parents must strike a delicate balance encouraging honest disclosure while protecting their child's emotional well-being. These nuances make it clear that any approach to pain communication that sidelines parents is not only incomplete but potentially harmful.

Parents highlight missed conversations on pain

Another theme that emerges powerfully is the inconsistency in healthcare professionals' approaches to pain communication.

Parents in the study reported that pain was not systematically discussed in every consultation and in some cases, was dismissed or minimized. This finding is both revealing and concerning. It reflects a systemic tension between clinical priorities and time constraints in busy outpatient settings, where pain may be perceived as a less urgent issue compared to disease activity or treatment response. However, to the families experiencing chronic pain daily, the absence of pain from clinical conversations can feel like a dismissal of their lived reality.

Importantly, parents did not merely highlight what was lacking. They articulated what constitutes effective pain communication: active listening, validating responses, personalized inquiries and consistency across the healthcare team. These "building blocks," as identified in the study, offer practical and achievable goals for clinical practice. If clinicians were to reliably and sensitively ask about pain and then act on that information it would not only validate the child's experience but also build trust with families. This can have cascading benefits, such as increased adherence to treatment and more open discussions about emerging symptoms or concerns.

What's striking is how often pain communication breaks down not because of poor intentions, but due to structural issues: short appointment times, limited training in pediatric pain management and a lack of interdisciplinary coordination. These are fixable problems, but they require institutional commitment. The study's findings suggest that we need a cultural shift in pediatric rheumatology, one that treats pain communication not as an optional sidebar but as a core component of every interaction.

Embedding pain assessment and parental partnership in care

This study has several important implications. Firstly, it challenges pediatric rheumatology departments to adopt structured protocols that ensure pain is routinely assessed and addressed. This could involve training clinicians in empathetic communication strategies, integrating standardized pain

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Received: 27-Jan-2025, Manuscript No. RCR-25- 37686; **Editor assigned:** 29-Jan-2025, PreQC No. RCR-25- 37686 (PQ); **Reviewed:** 12-Feb-2025, QC No. RCR-25- 37686; **Revised:** 19-Feb-2025, Manuscript No. RCR-25- 37686 (R); **Published:** 26-Feb-2025, DOI: 10.35841/2161-1149.24.15.444

Citation: Sarah D (2025). Repositioning Parents at the Heart of Pain Communication in Pediatric Rheumatology. Rheumatology (Sunnyvale). 15: 444.

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assessment tools and ensuring multidisciplinary teams (including psychologists and pain specialists) are available when needed. Secondly, it underscores the need to explicitly include parents in the clinical conversation not just as bystanders or informants, but as partners in care. Creating space for parental perspectives should be a standard part of consultation, especially when dealing with chronic and complex conditions.

CONCLUSION

In conclusion, this study illuminates the vital role that parents play in pediatric pain communication and calls for systemic

changes to better support that role. Chronic pain in children is a multifaceted challenge that demands equally multifaceted responses. Including parents not just as caregivers, but as communicative partners, is not just beneficial it is essential. To improve outcomes in pediatric rheumatology, we must listen more closely to the people who know these children best.