

October 2025

Vol. 27 No. 3

<https://pediatric-pain-letter.org/>

Editor: Deirdre E. Logan, PhD, deirdre.logan@childrens.harvard.edu

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Commentary

Family Engagement with a Pediatric Chronic Pain Service

Jasmine Bagnall and Tiina Jaaniste

Healthcare engagement entails the active participation of patients and family members as essential, invested members of the healthcare team (Pomey et al., 2015), marking a shift away from the narrower behavioral concept of adherence to healthcare professional (HCP) directives. There is growing recognition of the importance of healthcare engagement (Barello et al., 2015; Marzban et al., 2022; Teela et al., 2023), with one author going so far as to say that patient engagement is “the blockbuster drug of the century” (Chase, 2012). Patient and family engagement in the context of attending a pediatric chronic pain service is likely critical to the successful implementation of an interdisciplinary program. However, there remain many gaps in our knowledge of how best to engage families attending pediatric chronic pain services. This review synthesizes available literature to provide a working definition of family healthcare engagement. We then examine the role of patient and family engagement in pediatric chronic pain management, exploring potential impacts of engagement, and current clinical strategies that promote patient and family engagement. We conclude with consideration of future clinical and research directions.

Definition of Family Health Engagement

There has been a lack of clarity in how the term healthcare engagement is used. Drawing on the conceptual literature in this field, we propose that family healthcare engagement may be defined as a

multidimensional construct involving active participation of patients and families in their healthcare, as invested team members (Pomey et al., 2015), with critical knowledge about their healthcare needs (Carman et al., 2013; Castro et al., 2016; Cené et al., 2016). Healthcare engagement is a dynamic, co-constructed process (Bright et al., 2015), encompassing cognitive, emotional, and behavioral dimensions (Barello et al., 2019; Barello et al., 2015; Di Tosto et al., 2023), enabling collaboration with bidirectional knowledge sharing and shared decision-making about goals of treatment and approaches used (Clavel et al., 2021). These interrelationships are embedded in a broader organizational context within the healthcare setting (Sieck et al., 2023). Improved conceptual clarity is essential to advance the field, both for assessing family healthcare engagement and developing interventions to optimize it.

Family Engagement in the Context of Managing Pediatric Chronic Pain

Effective healthcare engagement must be developmentally-informed and family-centered. As adolescents gain cognitive, social, and emotional skills, they increasingly take responsibility for managing general aspects of their healthcare (Beacham & Deatrick, 2013; Christie et al., 2014). However, adolescents with chronic health conditions, such as chronic pain, commonly rely on parents to handle logistics related to appointment scheduling, transport, and ensuring availability of medications (Beacham & Deatrick, 2013). Moreover, parents of

adolescents are typically integrally involved in pediatric chronic pain programs (McGurgan & Wilson, 2025; Rook & Gauntlett-Gilbert, 2016), providing emotional support, serving as coping coaches (Guite et al., 2018a; Guite et al., 2018b) and potentially adjusting their own responses to the child's pain (Levy et al., 2010; Palermo et al., 2014).

Attention to the triadic relationship between patients, parents, and HCPs is essential for fostering collaboration and helping shape treatment goals and care decisions, thus optimizing family engagement. Barriers to effective family engagement may stem from varied issues, as shown in Figure 1. Various patient and family factors may impede effective family engagement with services, including demographic (e.g., distance to service), cognitive (e.g., low perceived value of program), affective (heightened negative affect), and broader biopsychosocial (e.g., family tensions) factors. Figure 1 shows how these patient and family factors

sit within the context of various potential HCP factors that may also impact on the family's engagement with the service, such as HCP communication skills and level of experience. All these factors are embedded within broader organizational factors, such as organizational flexibility, coordination between treating HCPs, and organizational time pressures.

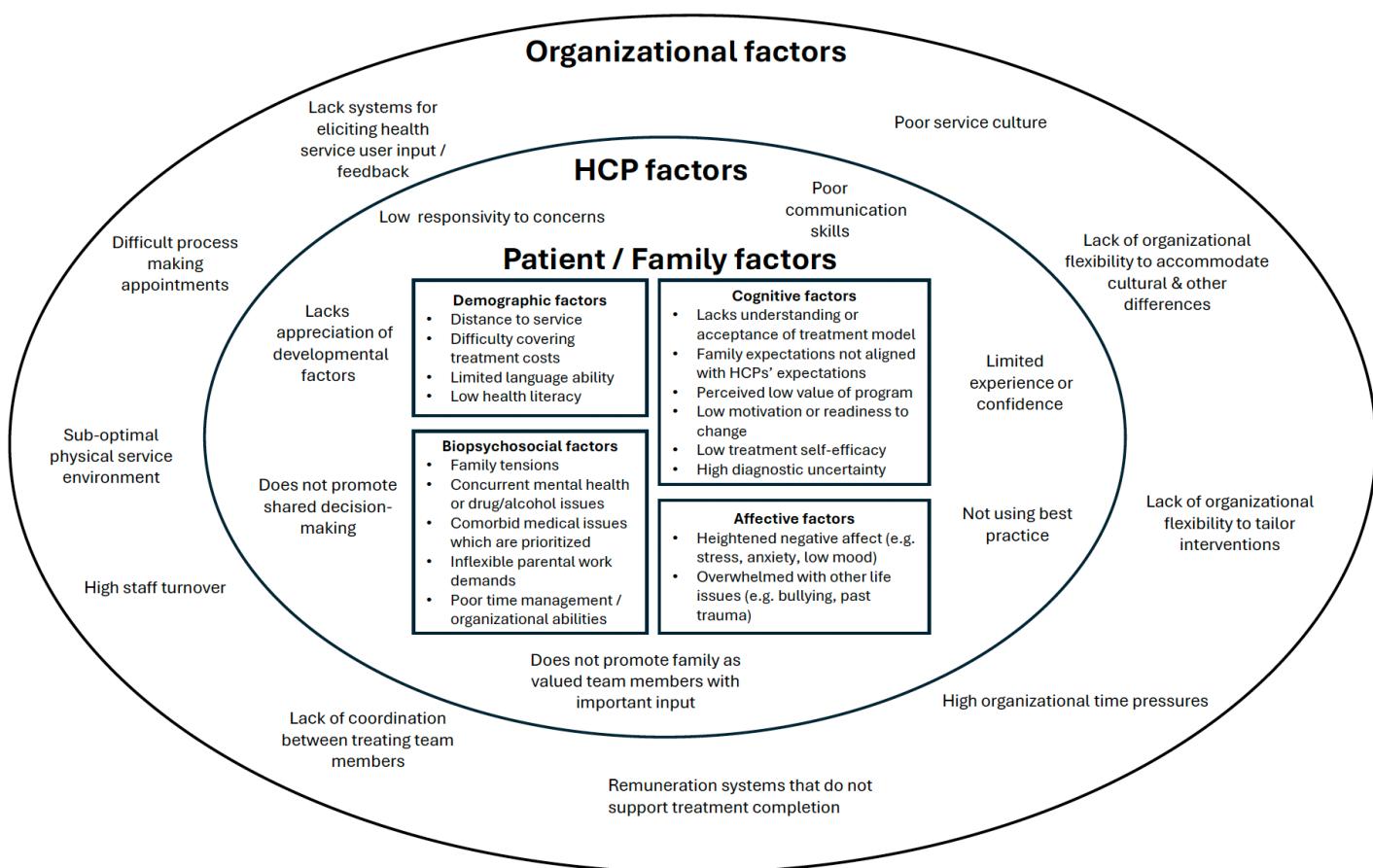


Figure 1. Potential barriers to family engagement with a pediatric chronic pain service.

Potential Impacts of Greater Patient and Family Engagement

Greater healthcare engagement has been found to improve patient health outcomes and increase healthcare system efficiency (Marzban et al., 2022). Increased engagement is also correlated with service quality and patient satisfaction (Alkhatib et al., 2024; Çakmak & Uğurluoğlu, 2024; Keelson et al., 2024). High-quality care encourages engagement; engaged patients also enhance care by communicating their needs which enables better-tailored interventions (Cote et al., 2004).

Engagement can result in greater confidence to manage chronic conditions (Christie et al., 2014), increased treatment adherence (Keelson et al., 2024; Mosen et al., 2007), and increased use of self-management strategies (Mosen et al., 2007; Sharma et al., 2018). Engaged patients have been found to have better quality of life, better functioning, and utilize more preventative health behaviors (Keelson et al., 2024). Conversely, disengaged families may not implement recommendations such as behavioral and lifestyle changes (D'Arrigo et al., 2020). Ultimately, families not adequately engaged with a service may be more likely to drop out before receiving a full intervention (Tiong et al., 2025), but data is lacking.

Patients with higher engagement have been found to have lower per capita healthcare costs and lower emergency department presentations and hospital admissions (Greene et al., 2015). Furthermore, greater healthcare engagement supports improvements in service delivery (Marzban et al., 2022) and patient safety (Alkhatib et al., 2024).

Current Family Engagement Interventions

As shown in Figure 1, family healthcare engagement is influenced by patient and family, HCP, and organizational factors (Schmied et al., 2023; Wild et al., 2020). Current engagement interventions include various clinical strategies, information technology initiatives, and organizational policy approaches.

Clinical Strategies

Strategies that promote parental involvement in adolescent chronic pain treatment (e.g., through education and instruction in coping strategies) have been found to enhance parental psychosocial well-being (Palermo et al., 2016) and patient functioning (Palermo et al., 2016; Russell et al., 2020). It is not well understood by what mechanism patients benefit from parent interventions. Given the crucial role that parents have in facilitating their child's access to chronic pain services, it is possible that parents who are better supported are likely to have greater capacity to engage and support patient engagement with the service.

Person-centered communication has been found to be integral to the relationship between patients and HCPs, and to successful patient engagement with their healthcare more broadly (Çakmak & Uğurluoğlu, 2024). At least 16 observational tools have been developed to identify provision of person-centered care (Ekman et al., 2020). Such tools may provide feedback and train HCPs in the provision of person-centered care, thus promoting family engagement. Approaches to promote shared decision-making have also been used to enhance child and family engagement (Nagra et al., 2024), and applied to various pediatric chronic contexts (Baweja et al., 2021; Hubner et al., 2018; Nagra et al., 2024). To date there has been little work on approaches that promote shared decision-making specifically in the pediatric chronic pain context among patients, parents, and HCPs.

Motivational interviewing (MI) can be utilized by HCPs to address patient ambivalence and readiness to change (Bean et al., 2019) and has been successfully applied to pediatric chronic pain contexts (Forgács-Kristóf et al., 2024; Smith & Logan, 2022). Studies with adults living with chronic pain have found MI to increase short-term adherence to interventions (Alperstein & Sharpe, 2016), although data on engagement is lacking.

Health Information Technologies to Promote Engagement

The use of health information technology initiatives to promote healthcare engagement is a burgeoning field (Wang et al., 2025), with initiatives including accessible electronic medical records, various telehealth uses, mobile health apps, and SMS texting. A systematic review, with 54 included studies, found that patient access to their electronic health records improved self-reported levels of engagement or activation related to self-management (Tapuria et al., 2021). Comparable data is lacking in the pediatric healthcare context (Hagström et al., 2022).

Another form of technology used to promote patient and family engagement is telehealth, such as delivered via video calls, enabling patients and families to engage with services when face-to-face attendance is difficult (e.g., due to distance or illness). Numerous articles highlight strategies for optimizing engagement via telehealth modalities for adult pain (Cerda et al., 2024; Tauben et al., 2020) and pediatric chronic pain (D'Alessandro et al., 2020; Richardson et al., 2021) contexts.

Mobile health apps like WebMAP Mobile™ (Palermo et al., 2020), Pain Squad (Tutelman et al., 2018) and others, support engagement through features like daily tracking of pain intensity and function, education and reminders about coping strategies, and in some cases access to real-time advice (Richardson et al., 2020). Implementation of gamification strategies can optimize engagement, as they promote strategic thinking, incorporate a feedback system, and provide gaming incentives for self-management (Miller et al., 2016; Nasir et al., 2022).

SMS texting has been used to encourage adherence and engagement with adult chronic pain interventions (Armfield et al., 2024), and in the context of various adolescent chronic health conditions (Badawy et al., 2017; Galvin et al., 2025). Issues of optimal timing and frequency of messages remain poorly understood (Armfield et al., 2024).

Health Service User Involvement in Organizational Planning and Policy

There is growing recognition of the value of user involvement in health service development, delivery, and evaluation (Forbat et al., 2009; Teela et al., 2023), potentially helping shape services to be easier for future healthcare users to engage with. Health service users are also increasingly involved in focus groups and other co-design approaches to contribute to healthcare provider education and policy development (Bombard et al., 2018).

Future Directions

Improved tools are needed to assess family engagement in the context of pediatric chronic pain management. In recent decades there has been a shift to a more patient-centered focus on engagement and less paternalistic assessment of adherence to HCP directives (Clavel et al., 2021). The shift to a more dynamic, co-constructed process of engagement requires more nuanced self-report measures of assessment. Longitudinal research is also needed to examine how engagement changes over time, and factors that may impact it. If engagement measures are found to be predictive of subsequent treatment attrition, this highlights the need for developmentally appropriate clinical interventions, targeting patients as well as their caregivers, to promote better family engagement in the pediatric chronic pain context.

Given the multi-dimensional nature of engagement, where low levels of engagement may be associated with cognitive, affective or behavioral factors, it may be fruitful to tailor clinical interventions to specific factors. For example, affective interventions may support patients or caregivers with low engagement due to depressed mood. In contrast, those who believe only medical treatments can relieve pain may benefit from psychoeducation to address their cognitions prior to successful engagement with services providing biopsychosocial interventions.

To date the pediatric chronic pain literature addressing family engagement has almost

exclusively focused on patients and their parents. Future research may also benefit from an investigation of the role of siblings.

Conclusions

Family engagement in the context of pediatric chronic pain management is of critical importance, and likely to lead to more favorable treatment outcomes. Despite the potential impacts healthcare

engagement may have on patient experience and outcomes, the full benefits have not yet been fully actualized. Further work is needed in the pediatric chronic pain context to better understand family engagement and to establish family, HCP, and organizational approaches to promote family engagement with pediatric chronic pain services.

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