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## Introduction

- Paediatric chronic pain can have significant adverse effects on a multitude of domains in a child's life, with these effects also extending to their caregivers as well as their families.
- Caregivers of children with chronic pain can experience substantial disruptions and impacts to their live, manifesting in impaired psychological<sup>1</sup>, social<sup>2</sup> and physical<sup>3</sup> outcomes.
- Most studies in the field of paediatric chronic pain has explored isolated impacts of the caregiver's experience using quantitative measures. Qualitative approaches may offer unique, nuanced insights into the caregiver experience of paediatric chronic pain.

## Aims

- The purpose of this study was to holistically explore the caregiver's experience of paediatric chronic pain, as well as its impact on the caregiver's lives in various domains, such as the psychological, work, social and physical impacts, as well as any potential, positive aspects of the experience.

## Methods

### Research Question

To explore the impact of paediatric chronic pain on the caregiver

### Ethics Approval

Ethics approval was granted by the Sydney Children's Hospitals Network Human Research Ethics Committee (2020/ETH2788, 23 November 2020).

### Patient Recruitment

Participants were parents of children with chronic pain attending the Sydney Children's Hospital Chronic Pain Clinic in Australia. Purposeful recruitment ensured interviews captured a wide range of experiences.

### Interviews

Ten parents (eight mothers and two fathers) participated in semi-structured interviews, conducted online. Interview were audio-recorded and transcribed

### Caregiver Experience

The interviews inquired about the impact of the paediatric chronic pain on their psychological functioning, social life, work and finances, their parenting experience, physical health, as well as the positive aspects of the experience.

### Data Analysis

- Inductive thematic analysis was utilized. The process involved the identification and categorizing of codes and the development of preliminary overarching and sub-themes which were later refined, condensed and accompanied by relevant quotes.
  - Reliability coding was also undertaken by an independent researcher for 30% of the interviews

## Results

Thematic analysis of the semi-structured interviews asking caregivers of children with chronic pain about their experiences revealed **four (4) overarching themes**:

### The constant and all-consuming nature of the pain

- Caregivers described the constant effect of the paediatric chronic pain on themselves, as well as the family.
- They also experienced a range of emotions, such as sadness, guilt, frustration, anger, anxiety, and at times, depressive symptoms.
- Caregivers also characterised the nature of the pain to be all-consuming, affecting almost all aspects of their lives

*"It's an absolute constant, and the whole family feels it too" (Parent 8)*

*"I would say it's quite consuming. And it's something that you always aware of and something that you always thinking about" (Parent 1)*

### Dealing with uncertainty

- The caregiver experience of paediatric chronic pain was commonly fraught with an overwhelming sense of uncertainty, surrounding the child's health, diagnosis, pain, and their future.
- The inability to effectively manage their child's pain elicited feelings of disempowerment, hopelessness, and futility for the caregivers.

*"It was a big unknown to us. We had no idea what they were talking about" (Parent 5)*

*"I feel very anxious about it because I don't know what's going to happen... how she will be... how she'll cope." (Parent 1)*

### The Caregiver Experience of Paediatric Chronic Pain

### The importance of support and self-care

- Many caregivers underpinned the importance of strong support networks, supportive healthcare experiences and prioritising oneself in alleviating the negative impacts of the paediatric chronic pain experience
- Caregivers had the tendency to neglect their own self-care to take care of their child, which was inevitably detrimental to their health

*"Things really improved because we had more information on the pain and how it worked, looked like, and what it meant" (Parent 6)*

*"I haven't had a chance to think yet. I think I probably need to focus on myself and see how that's affected me" (Parent 5)*

### A revitalised view on relationships and life

- Although caring for a child with chronic pain was challenging, some caregivers also explored the positive aspects of the experience. These included stronger relationships with the child and support networks, a greater sense of optimism and gratefulness, as well as increased resilience

*"It does put things in perspective" (Parent 5)*

*"I think gives you gratitude; things that you would take for granted normally" (Parent 7)*

*"It has forged this special bond between him and me" (Parent 2)*

## Discussion

- This study was one of the first studies to explore the impact of paediatric chronic pain on caregivers in an Australian and New Zealand context and adds to the body of literature suggesting that families of children with chronic pain experience wide-reaching and multi-dimensional impacts, particularly on their caregivers. These results compliment the findings of our retrospective study well.
- The unpredictable, yet constant nature of chronic pain was identified as a significant contributing factor to the extensive impact of paediatric chronic pain on both the parent and the family.
- The sense of uncertainty commonly experienced by caregivers is particularly important, considering the emerging evidence of the adverse psychological ramifications associated with diagnostic uncertainty<sup>4</sup>.
- The importance of support in alleviating the negative effects of the experience emphasises the strong need for holistic, clinical interventions aimed at strengthening the caregiver's support networks, improving their healthcare experience and promoting their self-care.
- To date, there has been little research investigating or seeking to capitalise on any benefits associated with paediatric chronic pain in interventions and could be a fruitful direction for future research.

## Conclusion

Overall, these findings encourage increasing clinical attention towards the high-risk population of caregivers dealing with paediatric chronic pain, and the need for further studies into under-researched caregiver functioning dimensions and holistic family-centred interventions aimed at improving both caregiver and child outcomes.

## References

1. Faltyn, M., Cresswell, L. & Van Lieshout, R. J. Psychological problems in parents of children and adolescents with chronic pain: A systematic review and meta-analysis. *Psychology, Health & Medicine* **26**, 298-312 (2020).
2. Jordan, A., Eccleston, C., McCracken, L. M., Connell, H. & Clinch, J. The Bath Adolescent Pain - Parental Impact Questionnaire (BAP-PIQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of parenting an adolescent with chronic pain. *Pain* **137**, 478-487 (2008).
3. Campo, J. V. et al. Physical and emotional health of mothers of youth with functional abdominal pain. *Archives of Pediatrics and Adolescent Medicine* **161**, 131-137 (2007).
4. Neville, A., et al. Diagnostic uncertainty in pediatric chronic pain: Nature, prevalence, and consequences. *Pain Reports* **5**, e871 (2020).

## Acknowledgements

The authors would like to acknowledge the support of the Sydney Children's Hospital Chronic Pain Team.

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