

Profile of Pediatric Chronic Pain Patients: A Survey of Caregivers in the United States

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Introduction

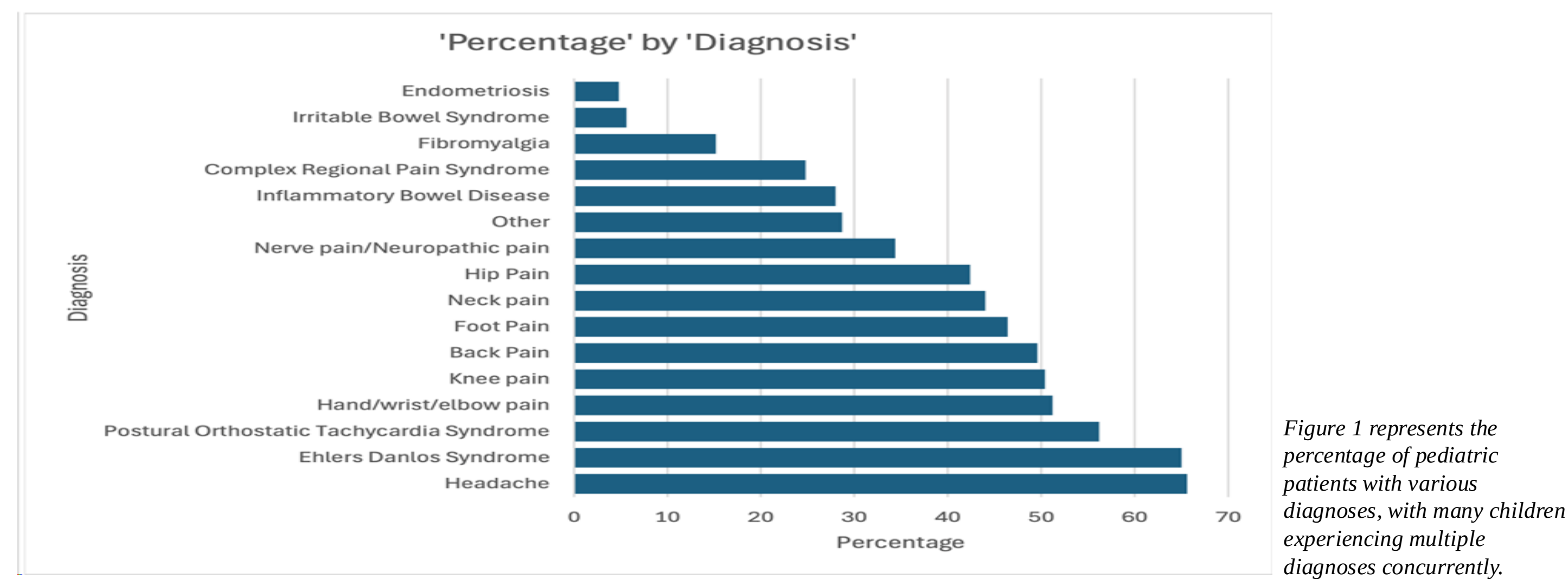
Chronic pain is an underemphasized, invisible illness, especially amongst children. Up to 43% of school aged children in the United States report recurrent or chronic pain that results in significant personal, societal and health care costs.

The primary objective of this study was to assess the demographics and describe characteristic profile, challenges and needs of the pediatric chronic pain patients from their caregivers' perspectives. This patient profile was intended to serve as a surrogate for evaluating the unique challenges, needs and desires of this vulnerable patient population and their caregivers.

Aim

Assess the demographics, characteristics, challenges, and needs of pediatric chronic pain patients from caregivers' perspectives, creating a profile to represent this vulnerable population and their caregivers.

Patient Demographic Information



The most common diagnoses included Ehlers-Danlos Syndrome and headaches, followed by musculoskeletal pains, and abdominal pain. Over 50% of pediatric pain patients endured 3 or more pain diagnoses concurrently. From the patients whose caregivers completed the survey, over 70% experienced daily pain scores above 5/10, with the majority having endured chronic pain for >75% of their lives.

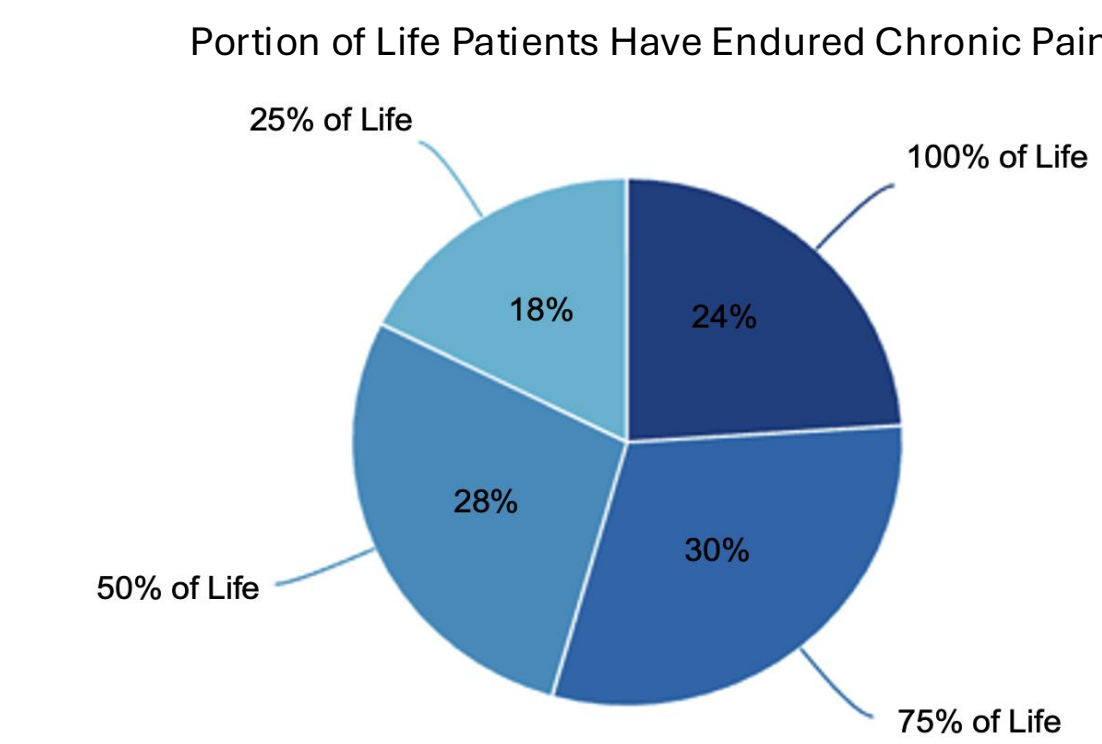


Figure 2 represents the portion of their lives that the pediatric patients of the caregivers involved in this study have endured chronic pain.

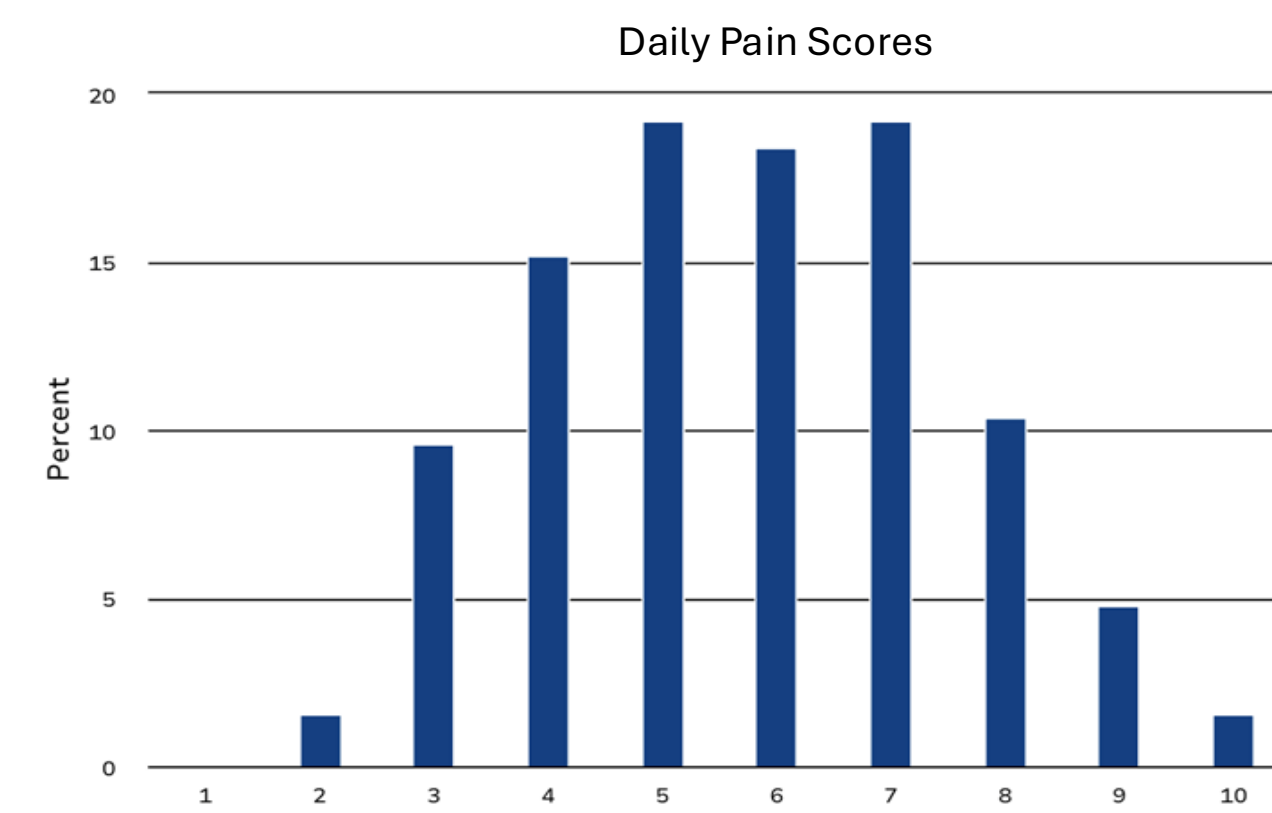
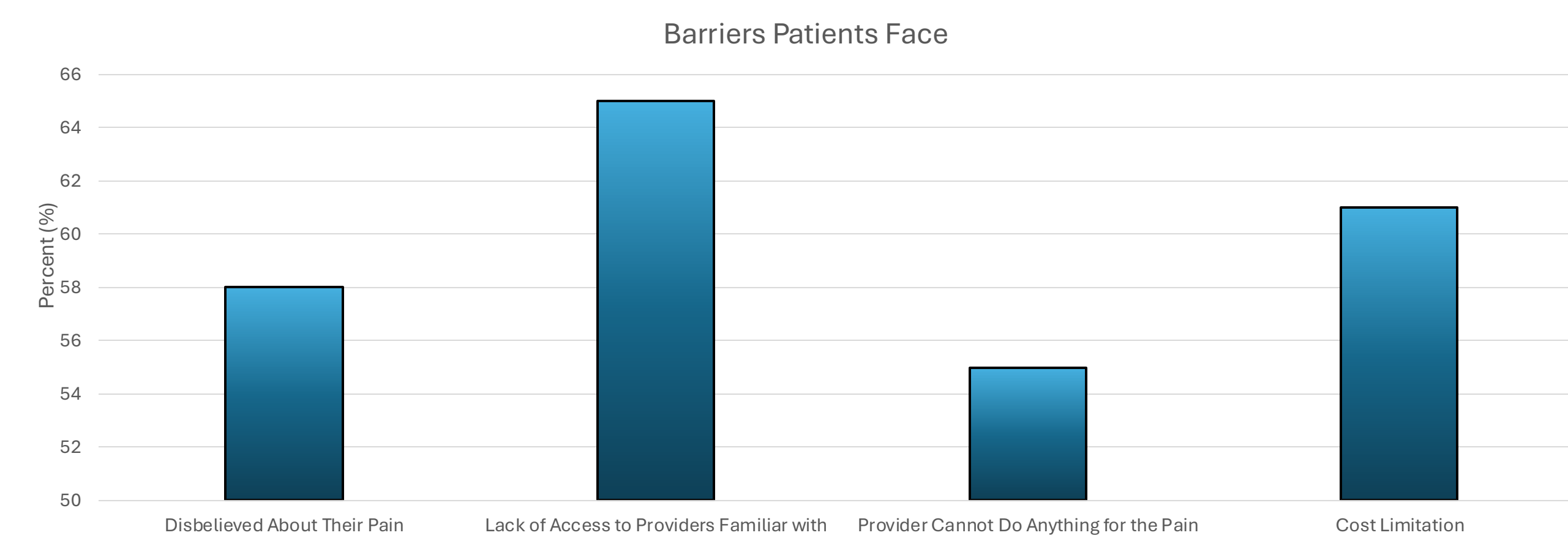


Figure 3 represents the daily pain scores of the pediatric patients of the caregivers involved in this study.

Results – Patient and Caregiver Challenges



Caregivers reported several barriers to treatment including limited access to pain care by a pain specialist, where patients' pain was predominantly being managed by their primary care provider. Patients often faced being disbelieved about their pain, lacked access to providers knowledgeable about their specific diagnosis and its management, and were told that provider could not do anything more for their pain beyond general advice resulting in patients feeling invalidated, undervalued, overlooked, and demoralized.

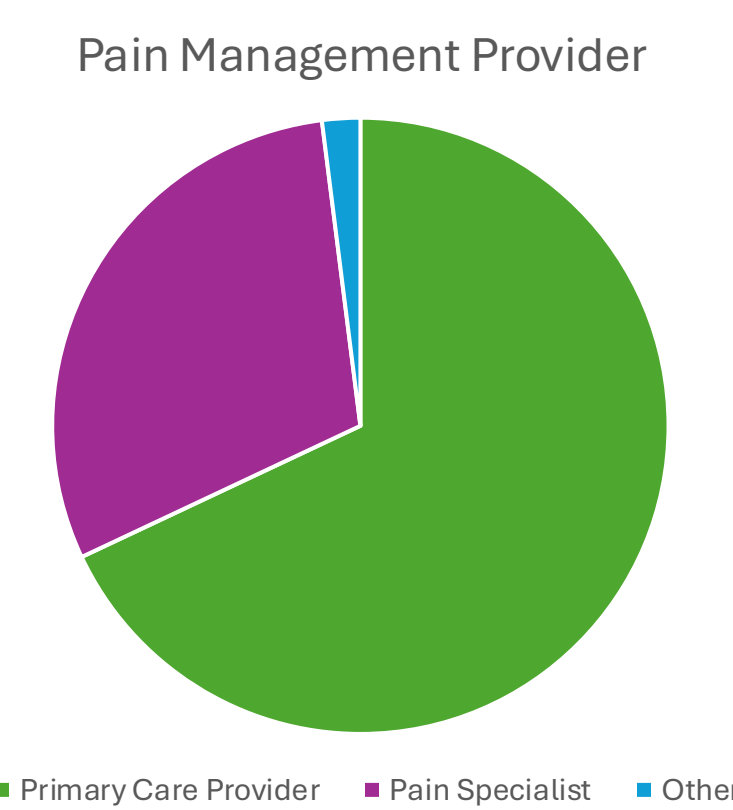


Figure 5 represents the primary pain management provider for pediatric pain patients represented by the caregivers in the survey.

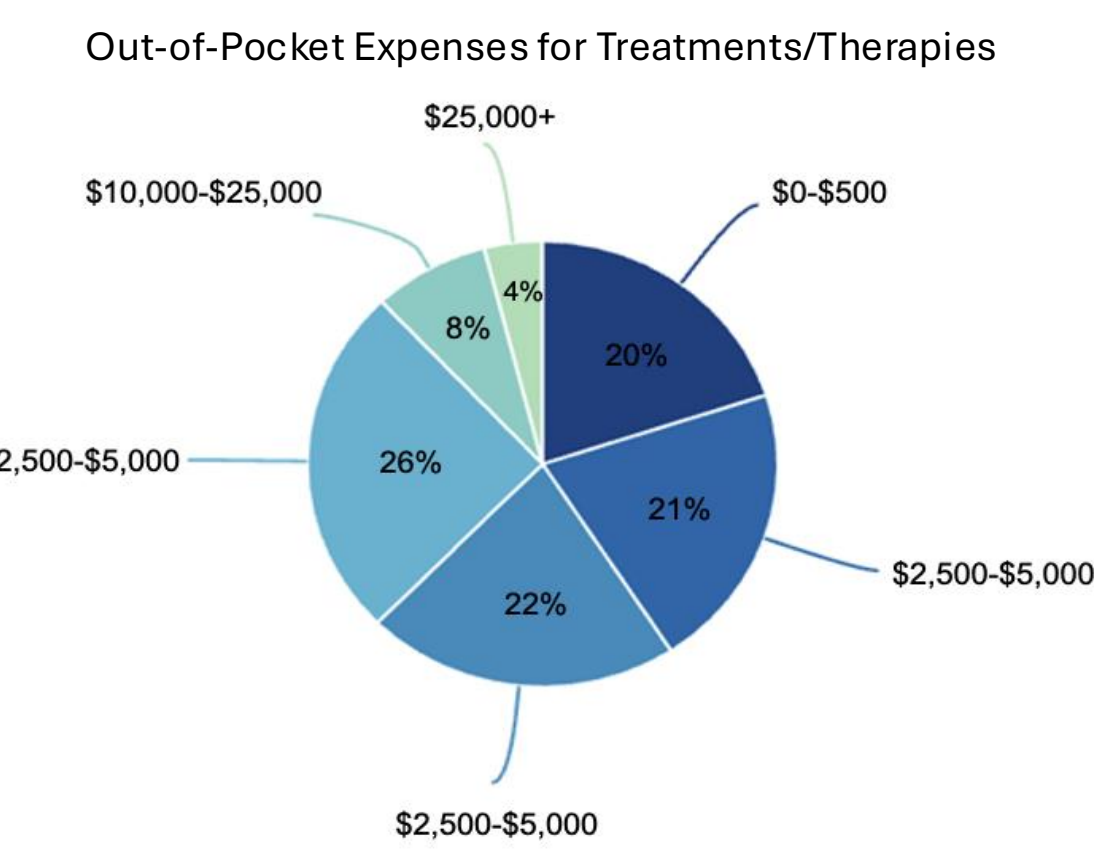


Figure 6 represents the amount of out-of-pocket expenses caregivers had to contribute to their child's pain-related therapies and treatments each year.

The majority of caregivers encountered treatment limitations for the pediatric patients they are responsible for due to cost resulting in needing to forego some recommended treatments or therapies. For the treatments and therapies they were able to undergo, patients, caregivers, and their families encountered significant out-of-pocket expenses, with some paying upwards of \$25,000 per year.

Conclusion

Pediatric chronic pain is common and burdensome to both the patients and their families. Pediatric chronic pain patients lack sufficient access to trained healthcare professionals and appropriate treatments, with primary care physicians playing a pivotal role in pain care.

A careful analysis of the burden of pediatric chronic pain, barriers to adequate and effective treatment modalities and increased investment into appropriate pharmacological and non-pharmacological treatments are needed.

Careful understanding of the characteristics, profile of pediatric pain patients, their challenges, needs and desires is imperative in provision of appropriate care and the consequent reduction in the personal, societal and healthcare burden.

References

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Acknowledgements

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Methods

Data Collection

- Survey questions explored demographics, associated diagnoses, unique challenges, and barriers to treatment faced by the children living with chronic pain and their caregivers

Analysis

- At the end of the 6 weeks the survey results were tabulated
- Simple statistical analysis for both quantitative and qualitative responses was conducted

Participant Selection

- Electronic survey sent using social media and/or email to 200 caregivers of pediatric chronic pain patients who participated in the US Pain Foundation's Pediatric Pain Warrior program