The day-to-day experiences of caring for children with Osteogenesis Imperfecta (OI)

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INTRODUCTION

- OI caregivers often face unique parenting challenges: increased homecare needs, social isolation, lack of OI information, and/or difficulties accessing treatment [1, 2].
- Literature gap: 0 studies focusing specifically on minutiae of day-to-day OI care
- Understanding daily experiences and challenges of caregivers with unique needs = better clinical supports and policies for caregivers, patients, & families
- Purpose: To explore the day-to-day experiences of caregivers who are caring for children with OI

METHODS

- Qualitative description
- Secondary analysis
- Adult family caregivers (mostly parents) of children with OI being treated at the study site were interviewed, 15-90 minutes per individual interview
- Data were thematically analyzed

RESULT

Sample
- n = 18 caregivers from 14 families
- 13 women, 5 men; 16 parents, 2 legal guardians
- Residential region (14):
  - 8 Quebec, 3 other Canadian provinces, 3 International
- Age range: 24 – 57 years old
- Child’s OI Types: I (3), III (4), IV (6), VI (1)

Accessing OI information and treatment is difficult, especially for caregivers who live far away. Clinicians should research and develop home-care treatment strategies to support caregivers during challenging periods.

- Ex. Home splint kits, Online tools
- Policymakers should ensure day-to-day community supports are truly accessible and usable
  - Ex. Wheelchair ramps cleared of snow, adapted buses with accessible routes

IMPLICATIONS

- Results showcase what being a caregiver for a child with OI involves on a day-to-day basis
- Confirms the limited previous research on day-to-day OI caregiving experiences [1,2], adding a more detailed visualization of minutiae of day-to-day care
- Recommendations include suggestions for future clinical, policy, and research endeavours to better support family caregivers of children with OI

THEMES

Regular day-to-day routines and activities:
- Morning routines = most challenging (many ADLs, time restriction, must not forget mobility aids/medications). Adapted bus services not always accessible/usable.
- Evening routines = more relaxed. Dinner at home. Low impact activities (ex. swimming, art lessons). Physiotherapy, occupational therapy.
- Facilitating child’s mobilization = common activity for families with OI. Ex. Transfers from wheelchair.

Long-term Strategies to support day-to-day care:
- Managing the environment
  - “It’s really just managing the environment more than the kid... [The] environment is our responsibility.”
    (Mother, Family 1, Type IV)
- Coordinating care and respite
  - “Dealing with OI is most likely all the time, how are we going to do things? You know? How are we going to surpass this limitation?”
    (Mother, Family 5, Type III)

CONCLUSIONS

- Coordinating care and respite
- Results showcase what being a caregiver for a child with OI involves on a day-to-day basis
- Long-term strategies to support day-to-day care:
  - Managing the environment
    - “It’s really just managing the environment more than the kid... [The] environment is our responsibility.”
      (Mother, Family 1, Type IV)
  - Coordinating care and respite
    - “Dealing with OI is most likely all the time, how are we going to do things? You know? How are we going to surpass this limitation?”
      (Mother, Family 5, Type III)

Disclosure

The authors have no conflicts of interest to report. This work was generously supported by the Tunis Shriners, the Newton Foundation, Scotiabank®, and the McGill University Ingram School of Nursing Summer Bursary Programs of 2018 and 2019. Dr. Tsimicalis is supported by a Chercheur-Boursier Junior 1 from the Fonds de Recherche Québec-Santé (Quebec Medical Research Council). Ms. Castro is supported by a Fonds de Recherche Québec-Santé Formation de Doctorat (doctoral research award). Acknowledgements: Several Shriners clinicians and caregiving stakeholders also provided invaluable feedback on the interview guides (Johanne Brunelle, RN; Sylvie-Anne Plourde, RN; Catherine Dubé, BSW; Trudy Wong, MSW; Mary Curtin, BA; Maria Caruso, BA, DipEd, CertSpEd; Marie Donato, BA, DipEd, CertEd; and Angela Gugliotti, BA). Ms. Guylaine Bédard designed this poster. Finally, this study could not have been conducted without the caregiver participants who took time to share their knowledge and expertise. Selected references: (others in preprint) [1] Doglia KJ, Rauch F, Tri G, et al. Shaping and managing the course of a child’s disease: parental experiences with osteogenesis imperfecta. Disabil Health J 2014;7(3):343-9. PMID: 24947576Online First: 2014/06/21. [2] Bernehall CI, Brodin J. What families with children with brittle bones want to tell. Child Care, Health and Development 2002;28(4):309-15. PMID: 12211190 Online First.