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## INTRODUCTION

- **Family-centred care** in pediatrics engages children and their families as integral members of healthcare teams<sup>1,2</sup>
- Limited evidence<sup>3-5</sup> exists about aspects of healthcare that are most important to the experiences of children with rare inherited metabolic diseases (IMDs) and their family caregivers
- To inform improvements, we also need to understand provider perspectives about barriers to, and facilitators of, family-centred healthcare delivery
- **Objective:** to describe caregiver and healthcare personnel perceptions of challenges in receiving and delivering family-centred healthcare for young children with IMDs in Canada

## METHODS

- **Study #1 – Qualitative interviews with caregivers**  
Participants were recruited from a broader cohort study:
    - Cohort study: caregivers (parents) of children ≤12 years old with an IMD were recruited through 1 of 11 participating Canadian pediatric metabolic centres
    - This interview study: a diverse sample (across child age, sex, metabolic centre, IMD) of cohort participants who rated one of their child's recent healthcare encounters as either unsatisfactory or extremely satisfactory
  - **Study #2 – Qualitative interviews with healthcare personnel**  
Participants:
    - Diverse sample across roles of providers, administrators and decision-makers involved in pediatric IMD care in Canada
    - Recruited from investigator networks and snowball sampling
- Data collection:** One-on-one, semi-structured video or telephone interview about a single care encounter  
**Analysis:** Qualitative thematic analysis
- Data collection:** One-on-one, semi-structured video or telephone interview about challenges, resources, and needs related to important themes identified in Study #1  
**Analysis:** Qualitative framework analysis<sup>6-8</sup> (in progress)

## RESULTS: PARTICIPANT CHARACTERISTICS

Study #1: Caregivers (n=20)		Study #2: Healthcare personnel (n=32)	
<b>Child age</b>		<b>Role</b>	
0-3 years	10	Metabolic physician	9
4-6 years	2	Metabolic dietitian	4
7-9 years	5	Emergency dept clinician	4
10-12 years	3	Metabolic nurse	2
<b>IMD clinical trajectory*</b>		Family physician	2
Acute & episodic	8	Pharmacist	2
Multi-system & progressive	7	Genetic counsellor	2
Chronic & non-progressive	5	Social worker	2
<b>Setting of encounter of interest</b>		Complex care team personnel	2
Metabolic clinic	7	Decision-maker / non-clinical	3
Emergency dept or inpatient	6	<b>Gender identity: woman</b>	25
Non-metabolic outpatient	3	<b>Province of practice</b>	
Blood laboratory	2	Ontario	12
Other setting	2	Quebec	7
		Alberta	6
		Nova Scotia	5
		Manitoba	2

\*Children's IMD diagnoses were grouped into 3 typical clinical trajectories by clinician investigators on the team

## RESULTS: KEY CARE CHALLENGES & STRATEGIES (PRELIMINARY)

### Overview

- Caregivers in Study #1 described a range of challenges experienced during healthcare encounters
- Three main categories of challenges became the topics discussed with healthcare personnel in Study #2
- We present one main issue for each category, from caregiver and personnel perspectives

### Challenges experienced by families

- (1) Unsatisfactory care coordination
- (2) Lack of familiarity with IMDs in some settings
- (3) Poor provider-family communication

### 1 Unsatisfactory care coordination Main issue: Perceived lack of information sharing between care providers

**Caregivers:** In the absence of information sharing, caregivers described taking on the role of "care managers".

"I find that frustrating in a lot of the clinics. 'So, what are her medications?' I was here three weeks ago [...]. I know she has a whole file from Complex Care (...) **Why are we going through half an hour of all her things?'** Parent of child 1-3 yrs old with multi-system & progressive IMD

"It's just me having to relay information and **I am not always confident that I am able to relay it as clearly as a physician might be able to relay it** (...) it would probably be a lot more effective if [eye doctor] just passed that information along herself." Parent of child 7-9 yrs old with acute & episodic IMD

### 2 Provider unfamiliarity with IMDs Main issue: Failure to implement child's emergency protocol

**Caregivers:** difficult interactions with providers unfamiliar with IMD-related care at emergency department (ED) & inpatient care

- Described providers who did not connect with metabolic clinic despite requests and/or did not listen to caregiver expertise

"**It's always a struggle, yes. They don't look at the letters.** It's even sometimes quite a challenge to get them to phone the pediatrician, when we have a protocol letter that they refuse to read that says, 'Call me if this kid presents.'" Parent of child 1-3 yrs old with acute & episodic IMD

**Personnel:** Identified lack of formal mechanisms for sharing information with other providers

- Especially between hospital & community settings
- Metabolic team members: described feeling responsible for information sharing
- Strategies used: multidisciplinary meetings, joint appointments, team protocols, outreach

"...instead of feeling that I was involved as a team member, I felt I was sort of an outside onlooker (...) For example, when the family travelled, how are they going to look after their child? (...) **I didn't know who to ask.**" Family physician

"When I ... talk to them [primary care providers] on the phone for the first time, I always say, 'Please ... call me if you have questions (...) **there's no question that is not a good question and there is no time that is not a good time.**'" Metabolic physician

**Personnel:** described differences in procedures between pediatric EDs and non-pediatric EDs

"...**there's just discomfort with children [at smaller hospitals]. That discomfort is really compounded if there is a patient who has a metabolic disorder,** and that's across all healthcare professionals [in the ED] (...) the lack of familiarity and the lack of comfort puts the child at increased risk that those even basic things will be missed." Emergency physician

### Metabolic team strategies to address:

- Protocol letters developed with ED team feedback
- Education and outreach for local hospitals
- Advance pharmacy preparation
- Coaching of families

## RESULTS (CONTINUED)

### 3 Poor provider-family communication Main issue: communication outside of appointments

**Caregivers:** described uncertainty about *whether* they could reach out to their key providers or *whom* to contact with questions

- Uncertainty most present in early childhood, where there may be steep learning curve about care for the child

"I am normally the one who reaches out (...) It would be nice to have more of a schedule (...) **I feel like I don't know what I'm doing. I just wish I could maybe have more check-ins** for that because I feel like I'm just failing." Parent of child 1-3 yrs old with chronic & non-progressive IMD

**Personnel:** described observing this uncertainty and feeling concerned about families seen or heard from infrequently

- Described strategies for communicating with families between visits:
  - explicitly encouraging contact
  - active outreach to families
  - creating opportunities for contact

"...when [families with infants] come in for their blood work, **I ask them to swing by the clinic (...) I will squeeze them [in] whenever they show up** (...) and answer any questions that might have come up." Metabolic dietitian

## DISCUSSION

- Caregivers described important **challenges to family-centred pediatric IMD care**, and negative impacts
- Healthcare personnel **corroborated these challenges** important to families and described **resources & strategies used** to address them
  - However, efforts are often self-initiated and time-consuming
  - Not all providers able to use these self-initiated strategies, potentially contributing to care inequities and provider burnout
  - System solutions needed beyond individual efforts
  - Strategies also challenged by heterogeneity of IMDs and of family needs
- Limitations:
  - Caregiver interviews: Families who did not speak English were excluded from the cohort study due to the constraints of the data collection tools
    - These families likely face additional barriers that need to be identified and addressed to ensure equitable family-centred care
  - Personnel interviews: We were unable to recruit personnel working in some important settings (community ED personnel, blood laboratory staff) settings

**Conclusion:** Integrating parent and personnel perspectives provides a rich understanding of current challenges to family-centred care for IMDs in children. Our findings may inform scalable interventions to address important gaps in care.

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