Parent-Reported Experiences with Health Care for Children with Inherited Metabolic Diseases in Canada: Results from a Multi-Centre Survey

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Results: 1. Participant Characteristics

Of the 1,455 children with IMD for whom data was obtained, 1,255 (86%) had parent-reported experiences. The mean age of participating parents was 44 ± 9 years, and median age was 42 (IQR: 32.47). A greater proportion of parents were female (69% vs 31%, p < .001) and 77% were married. Parents were predominantly white (93%; 7% other race). Most parents had a household income <$80,000 (63%); 20% reported an income of $80,000-$100,000.

3. Emergency Department & Hospital Care

Only 7% of parents reported that their child had been discharged from the ED in the year prior to completing the survey, and 20% reported that their child had been hospitalized within the past year. While 20% reported that they had visited the ED at least once in the past year, 35% reported that their child had been admitted to the hospital within the past year. Of the 40% of parents who had visited the ED in the past year, 41% reported that they had attended in person, while 59% reported that they had attended remotely via phone or video call.

4. Blood Laboratory & Pharmacy Care

Blood laboratory and pharmacy care were reported by 12% of parents. Of these parents, 97% reported that they had to travel to the blood laboratory (Figure 5). Of these parents, 44% reported that they were required to travel more than 2 hours to reach the blood laboratory. Of the 28% of parents who reported that they had to travel to the pharmacy, 45% reported that they were required to travel more than 2 hours to reach the pharmacy.

5. Care Coordination & Out-of-Pocket Expenses

Care coordination was reported by 6% of parents, with 8% of parents reporting that they had a coordinator who provided support to their child. Of these parents, 29% reported that they had been contacted by their coordinator more than once in the past year. Of the 38% of parents who reported that they had out-of-pocket expenses, 53% reported that they had been mandated to pay for medications, and 47% reported that they had been mandated to pay for transportation to the blood laboratory. Of the 42% of parents who reported that they had out-of-pocket expenses, 52% reported that they had been mandated to pay for medications, and 48% reported that they had been mandated to pay for transportation to the blood laboratory.