

# Exploring the experiences of family caregivers with low income accessing health care services for children with inborn errors of metabolism

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## INTRODUCTION

**Inborn errors of metabolism (IEMs)** are a diverse group of genetic conditions that occur in up to 1 in 800 newborns

- IEMs require ongoing medical and/or dietary management, with some having serious complications despite appropriate treatment
- IEMs have an impact on family physical, emotional, social, and financial wellness

## RESEARCH QUESTION

*“What are the lived experiences of family caregivers with low-income accessing care for their children with IEMs in Manitoba?”*

## METHODS

- Individual interviews** were conducted with eight family caregivers of children with IEMs who access care in Manitoba
- Factors that facilitate and cause difficulties in accessing care were explored using a semi-structured interview guide, with a focus on how **income** may impact access to care
- Constructivist grounded theory** was used to generate a theory to explain these study participants' experiences of caregiving
- Recommendations** were made to improve access to metabolic care in Manitoba

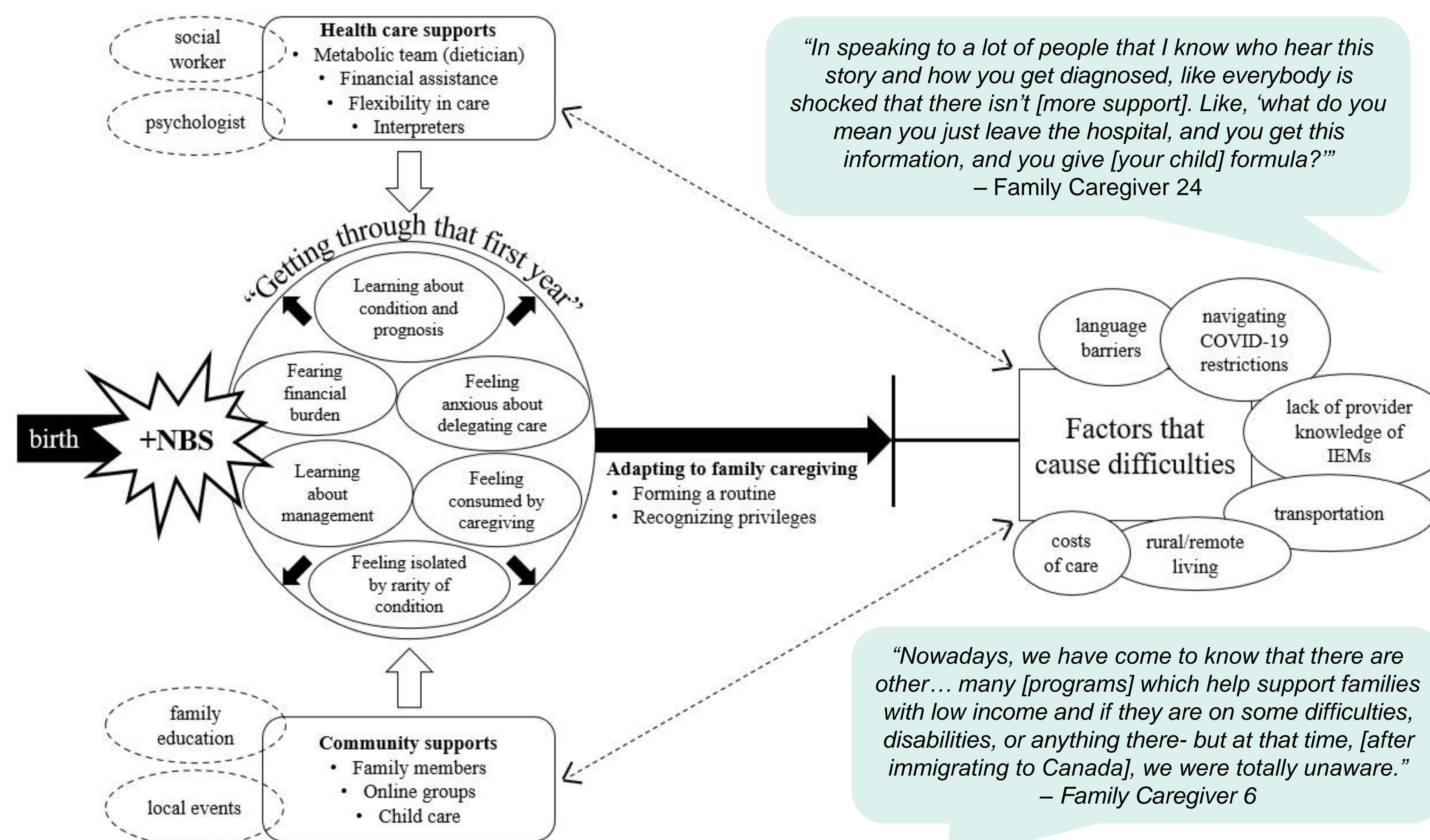
## RESULTS

- Caregiving was reported to be **overwhelming** and **consuming** especially throughout the first year following a positive newborn screen
- Participants expressed that they were lacking **psychosocial support** as well as assistance with navigating **financial resources**

Demographic Characteristics of Interview Participants (N=8)

<b>Age (years)</b>	20 – 29	4 (50%)	<b>Annual Household Income (\$)</b>	< 30,000	2 (25%)
	30 – 39	1 (13%)		30,000 – 49,000	0 (0%)
	40 – 49	3 (38%)		<b>50,000 – 99,999</b>	<b>3 (38%)</b>
<b>Gender</b>	Two Spirit	1 (13%)	100,000 – 149,999	1 (13%)	
	Man	1 (13%)	150,000 +	1 (13%)	
	<b>Woman</b>	<b>6 (75%)</b>	No response	1 (13%)	
<b>Ethnicity</b>	First Nations	1 (13%)	<b>Distance to Tertiary Care</b>	<b>&lt;30 minutes</b>	<b>4 (50%)</b>
	Metis	1 (13%)		30 minutes – 1 hour	0 (0%)
	<b>European origins</b>	<b>3 (38%)</b>		1 – 1.5 hours	2 (25%)
	Asian origins	1 (13%)		1.5 – 2 hours	1 (13%)
	Other	2 (25%)		> 2 hours	1 (13%)

Theoretical Model: The Experience of Family Caregiving for Children with IEMs



## RECOMMENDATIONS

- Provide formal **psychosocial support**
  - By integrating a psychologist with the metabolic team
- Offer support in navigating **financial resources**
  - By integrating a social worker with the metabolic team
- Deliver **education to family members**
  - By forming an education team to offer support via in-person and virtual group family education appointments
- Organize **local community events**
  - To raise awareness of IEMs and to connect families with similar IEMs
- Increase **flexibility** in care
  - By continuing to provide virtual care as an option and by expanding the amount of caregiving that can be performed at home

## FUTURE DIRECTIONS

Future studies should consider exploring:

- Experiences of adults with low income** accessing their own IEM-related care
- Indigenous perspectives** on family caregiving for children with IEMs
- Immigrant and refugee experiences** of family caregiving for children with IEMs

## ACKNOWLEDGEMENTS

