

# The Lived Experiences of Caregivers of Children With Congenital CMV Receiving Healthcare in a Remote and Rural Area of Northern Canada

Laija Beaulieu & Dr. Helle Møller

Lakehead University, Master of Arts in Social Justice Studies, Thunder Bay, Ontario, Canada



## INTRODUCTION

- Congenital cytomegalovirus (cCMV) is the most common non-genetic and preventable cause of hearing loss and birth defects in infants which may cause life-long healthcare and affects more children than several better-known childhood disabilities, such as Down Syndrome, spinal bifida, Fetal Alcohol Syndrome (FAS), and toxoplasmosis (Cannon, 2009; Cannon & Davis, 2005; CMV Canada, n.d.; Colungnati et al., 2007).
- In 2019, Ontario was the first province in Canada to include CMV as part of its universal newborn screening. Since then, Saskatchewan has followed suit in 2022 and Alberta announced their support for cCMV screening in August 2023 (CMV Canada, 2022; CMV Canada, 2023; Newborn Screening Ontario, n.d.).
- The remote and northern regions of Ontario have poorer access to healthcare and are behind in provincial averages in the quality of health and healthcare largely due to the distance between communities, as well as challenges with the recruitment and retention of health professionals (Health Quality Ontario, 2017; Montour et al., 2009). These combined challenges impact the ability to offer care for those who are affected by many health concerns, including the generally small CMV population particularly as awareness and knowledge about the condition are very limited (Benou et al., 2022).
- The research took place in Thunder Bay which has a population of approximately 100,000 people in Northwestern Ontario and is often referred to as a hub that serves several remote northern areas.
- One of the authors, Laija Beaulieu, has a son with cCMV and she wishes to further understand other caregivers' experiences and perspectives on CMV healthcare services, as well as the delivery of CMV healthcare while living in a remote area of Northwestern Ontario.



## ANALYSIS

- All participants lived in the Thunder Bay area, please refer to "Table 1" for participant characteristics.
- There was a total of 4 participants in this research project which consisted of 3 in-person semi-structured interviews that took place during July 2023 in Thunder Bay, Ontario, Canada.
- One interview consisted of a husband and wife while the other two interviews were a mother and a step-father, all of whom have a child with cCMV. One interviewee had a child who was part of universal screening for CMV at birth (universal newborn screening for CMV commenced in Ontario in 2019) while the other interview participants did not receive a cCMV diagnosis until their children were 2-6 years old.
- Transcripts were analyzed using thematic analysis to identify meaningful patterns or themes, as well as subthemes that were associated with the research questions. The stages of analysis included initial coding, searching for themes, creating subthemes, reviewing themes and subthemes, as well as defining and naming themes and subthemes.
- NVivo 14 computer software was utilized to manage the data.

Table 1 Participant Characteristics

	N	Total	%
<b>Participant's gender</b>			
Female	2	4	50%
Male	2	4	50%
<b>Age of child at time of interview</b>			
0-10	1	3	33%
11-15	1	3	33%
16-20	1	3	33%
<b>Age of child when diagnosed with congenital CMV</b>			
0-2	1	3	33%
2-4	2	3	66%
<b>Severity of congenital CMV</b>			
Hearing loss (unilateral or bilateral)	2	2	100%
Vision disturbances	1	2	50%
Seizures (diagnosed by MRI imaging of brain)	2	2	100%
Memory and cognitive dysfunction	2	2	100%
Developmental delay	2	2	100%
Motor and balance difficulties	1	2	50%
Unknown (at time of interview)	1	3	33%

## RESULTS

Table 2 Themes and Subthemes

Themes	Subthemes
Distress associated with diagnosis of congenital CMV	Dismay of Diagnosis Lack of information and direction from professionals Contemplate circumstances of CMV infection
Facilitators associated with coping with congenital CMV diagnosis	Acknowledge what could have been with CMV but was not Staying positive and self-assurance to conquer future obstacles Receiving diagnosis Social and community support
Burdens connected with caring for a child with congenital CMV	Difficulties navigating educational, social, and health aspects Guilt and fear of being blamed Fear for child's future and independence in adulthood Struggle with negative emotions and uncertainty CMV encompasses all aspects of life Parental responsibility to advocate for services Lack of guidance and support from medical professionals Effects on family dynamics and support systems
Difficulties associated with accessing/receiving CMV-related healthcare	Parental responsibility to advocate for assistance Lack of awareness and support from professionals Lack of awareness and services in community
Facilitators associated with accessing/receiving CMV-related healthcare	Support from family and community Receiving diagnosis
Barriers to CMV-related healthcare living in a remote and rural area	Disorganized pathways to healthcare and support Long waitlists and lack of specialists which requires referrals Referrals cause long distance travel Travel causes financial strains Personal obligations and circumstances prevent travel
Valuable support strategies	Raising awareness and educating caregivers/community Screening for CMV One primary professional community contact

- There were 7 main themes that were found with several subthemes, please refer to "Table 2."
- Delays in having a diagnosis of cCMV are connected with caregiver distress, as well as delays in childhood interventions (i.e., cochlear implants, speech services, etc.). Lack of information and knowledge about CMV, as well as direction with services and support among professionals can exacerbate caregiver distress.
- Caregivers experienced difficult emotions upon diagnosis which led to anxiety, distress, and a sense of feeling helpless. Mothers noted continual guilt and fear of being blamed for their children contracting CMV in utero. Fear and anxiety for children's future increases with their age, as well as uncertainty for the children's ability to be independent in adulthood.
- Facilitators associated with coping with a cCMV diagnosis were: being appreciative of the possible health and developmental consequences of cCMV that their children did not have, self-assurance they will conquer whatever future obstacles come their way, and leaning on family and social networks. When children were diagnosed with cCMV through newborn screening, caregivers appreciated being set up with an initial childhood audiologist and pediatrician. However, lack of information and direction from medical professionals acted as a barrier even with CMV screening at birth.
- Barriers to CMV-related healthcare living in a remote and rural area were: lack of guidance, disorganized pathways to services and support, long wait times for specialists, and lack of specialists in their community which lead to referrals. The referrals lead to multiple long-distance travels (over 1,000 kilometres or 621 miles) which may lead to financial strain and difficulty with being able to attend appointments due to personal circumstances (finding care for other children, family pets, etc.).
- Valuable support strategies were: raising awareness, providing information to educate caregivers and the wider community, screening for cCMV at birth, and implementing one primary community contact who could guide caregivers with support groups, financial assistance programs (i.e., travel grants, disability tax credit, etc.), special education information, CMV information, and all the potential life-long services the children may require.

## CONCLUSION

- There is a need to increase awareness among community professionals to provide information, better support, and direction for families caring for children with cCMV.
- There is a strong desire to have one main point of contact to streamline support for caregivers, as well as assist with the long-term consequences of cCMV as it is a life-long condition where difficulties may not be recognized until the child reaches school age.
- CMV screening at birth was valued and having an early diagnosis assisted with a gap in healthcare interventions which may cause unnecessary health and developmental delays (for example, cochlear implants may be implanted at an earlier age which limits speech and language delay, etc.).
- The more rural and remote the area caregivers live in, the more difficult and burdensome it is to access and receive care which ultimately affects children's health and development.

## OBJECTIVE

- The goals of this research project are:
  - To understand the lived experiences of caregivers with children who have cCMV and what barriers and gaps in healthcare they may have experienced living in remote and Northern Ontario.
  - To inquire what services and/or programs families would like to have in regard to CMV healthcare.
  - To start to develop a body of research on this topic as there is none to date that focuses on parental perspectives in Canada.
- The questions guiding this research project are:
  - What are the participants' lived experiences as caregivers with a child who has been affected by cCMV?
  - What are the participants' experiences with accessing and receiving CMV healthcare in Northwestern Ontario, as well as the wait times to see healthcare professionals?
  - Were there any barriers to CMV healthcare that participants faced that were due to living in a remote and rural northern area of Ontario?
  - What CMV services and/or programs would caregivers of children with cCMV feel could be beneficial in Northwestern Ontario?

## METHODS

- A phenomenological framework was used for this research project. Phenomenology is a qualitative research approach that focuses on the study of an individual's lived experiences. Phenomenology aims to privilege participants' viewpoints which demonstrates respect for each as the expert of their own life which makes phenomenology empowering as it provides access to the viewpoints of those who may be otherwise marginalized or unheard to promote social and systemic change (Dollarhide et al., 2019).
- Conduct semi-structured in-person interviews with caregivers who have children with cCMV who have accessed CMV healthcare services in Northwestern Ontario.

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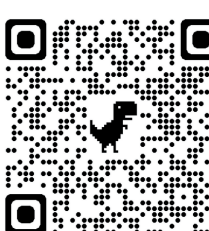
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Lakehead University Research Ethics Board (REB)  
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