

Screening for Congenital Cytomegalovirus in North Carolina

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Introduction

The authors are full-time graduate students in UNC's Doctor of Audiology (AuD) program. They are conducting this investigation in conjunction with their participation as audiology trainees in the North Carolina LEND Program (Leadership Education in Neurodevelopmental and Related Disabilities). The findings reported here are part of an ongoing investigation and represent current work in progress.

Background

What is Cytomegalovirus (CMV)? CMV is a common virus related to the herpes family that affects people of all ages. More than half of adults over the age of 40 and 1 in 3 children by the age of five have been infected with CMV^{1,3,6}. Once a person is infected with CMV, the virus remains in the body for life and can reactivate. Most people with CMV infection have mild or no symptoms and may not even be aware they have been infected². If acquired after birth, there are few if any symptoms or consequences; however, if a mother acquires CMV infection during pregnancy, the infection can be passed through the placenta to the developing baby¹. *Congenital CMV (cCMV)* is present in 1 out of 200 babies in the US; 10% are symptomatic at birth and 10-15% are asymptomatic and may experience later onset of hearing loss or other neurological impairments^{2,3,6}.



What are the implications of cCMV for hearing and development? Congenital cytomegalovirus (cCMV) is the leading cause of non-genetic sensorineural hearing loss as well as other conditions including intellectual disability, cerebral palsy, and other neurodevelopmental disabilities^{1,3,4}. Congenital CMV related hearing loss can affect one or both ears and may cause progressive hearing loss over a period of months or years^{1,2}.

How is cCMV treated? Babies who show symptoms of congenital CMV can be treated with Valganciclovir, an antiviral agent. Antivirals may decrease the severity of hearing loss but require close monitoring for possible side effects^{1,3,6}.

What are the benefits of cCMV screening?

cCMV screening identifies babies who are likely to develop late onset cCMV-related hearing loss and who may require early intervention and/or medical treatment. To differentiate congenital and postnatally acquired infection, the screening needs to be performed within the first three weeks of life⁶.

What is the current status of cCMV screening in the US? Currently 13 states have legislative mandates to provide cCMV screening after a



failed hearing screen; many other states are considering legislation⁷. North Carolina does not have a legislative mandate but several hospitals in our state currently provide targeted cCMV screening via laboratory tests involving saliva, urine, or dried blood spots. In 2019 NC-EHDI created a CMV Workgroup that includes parent advocates, pediatric infectious disease and primary care physicians, audiologists,

research and public health stakeholders. The group's mission is to determine collaborative approaches to support the prevention and reduction of CMV infections in women and newborns, to ensure access to care for affected children, and to perform CMV-related outreach and education.

Purpose

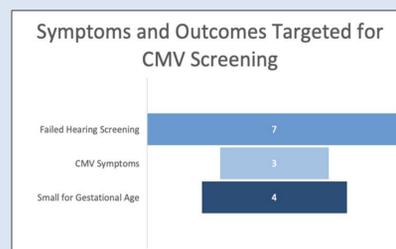
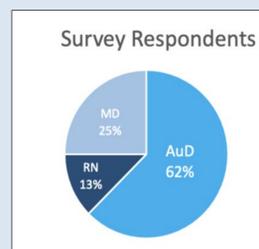
The purpose of this investigation is to study eight hospitals currently providing targeted cCMV screening in North Carolina to determine screening methods, outcomes, and challenges associated with this activity and to solicit their recommendations for hospitals considering implementation of a cCMV screening program.

Methods

In February 2022, an electronic survey (Qualtrics) was distributed to eight hospitals in North Carolina known to be providing cCMV screening based on an earlier study⁵. The invitation was directed to a specific individual at each hospital recommended by NC-EHDI staff. A member of the research team contacted prospective participants in advance to confirm their participation and to answer any questions related to the study. The survey included 12 questions based on preliminary planning with members of the NC-EHDI CMV Workgroup which included an audiologist and a physician with expertise in CMV. Specific areas of investigation included selection of babies for screening, screening method, timing and location, personnel involved, provider follow-up, and communication with families.

Preliminary Findings

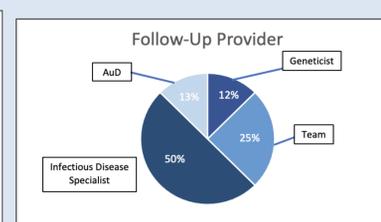
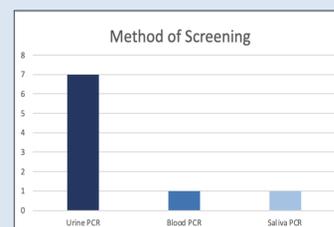
Key preliminary findings for this still ongoing investigation include the following:



- The length of time these screening programs have existed range from one to 12+ years

- Most hospitals conduct cCMV screening prior to discharge but in cases where this is not feasible screening is conducted at the first newborn visit.

- Nursing staff are the professionals most likely to collect the specimen for cCMV testing regardless of testing location.



- Benefits of targeted cCMV screening reported by these hospitals included: earlier detections of cCMV, education of the public, and timely referral for early intervention

- Challenges in screening protocol development reported by hospitals included:

- determining the appropriate screening timeline
- relaying and explaining results to the family
- coordinating next steps in care for the infant
- regulating sample collection in a timely manner
- cost of screening

Discussion

Our findings to date draw on the collective experience of eight hospitals in North Carolina currently providing targeted cCMV screening. The hospitals vary in size, institutional mission, geographic location, and years of experience with cCMV screening. The hospitals also vary in how babies are selected for screening, the screening method employed, and the providers involved in follow-up and communication with families. Several common themes also emerged from the comments of survey participants. An overarching theme is the importance of an interdisciplinary approach involving clinicians from multiple professional disciplines, each playing a unique and important role in the screening process from start to finish. There is also a belief that greater public education is needed regarding CMV and that cCMV screening is needed to facilitate early identification and treatment. The greatest challenges appear to be associated with timing of sample collection, communication and coordination with families regarding follow-up, and cost.



Future Directions

- The investigators are currently following up with participating sites to obtain additional information and clarification related to communicating results to families, next-steps in the referral process, and issues related to cost.
- We will conclude the current phase of this study in May 2022, when our findings will be presented to the NC-EHDI Advisory Committee and shared with the CMV Workgroup.



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