

South Dakota Parents' Knowledge of Congenital Cytomegalovirus, Its Long-Term Health Effects, and Methods for Minimizing Exposure

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Abstract

Congenital CMV (cCMV) is acknowledged as one of the most common causes of nonhereditary sensorineural hearing loss and an important cause of neurodevelopmental delay in children. Despite the danger cCMV poses, many parents are unaware of the virus, its sequelae, mode of transmission, and preventative behaviors. The purpose of the study was to determine South Dakota parents' knowledge of cCMV, its sequelae, and ways to minimize exposure.

An electronic survey was used for data collection. Parents of children born in South Dakota from 2011 to 2018 were asked about their knowledge of CMV and cCMV, including common sequelae and ways to minimize exposure. Flyers were sent to randomly selected daycares and the link was posted on social media pages to advertise the electronic survey to South Dakota parents. After completing the survey, participants were directed to cCMV educational resources.

Respondents were more knowledgeable regarding the sequelae of cCMV rather than its transmission process or ways in which viral exposure can be minimized. Results show that there remains a need for cCMV awareness in South Dakota, particularly with a large focus on preventative measures.

Key Words: CMV, cCMV, sensorineural hearing loss, public awareness

Acronyms: CMV = cytomegalovirus, cCMV = congenital cytomegalovirus, CDC = Centers for Disease Control and Prevention, IRB = Institutional Review Board

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Cytomegalovirus (CMV) is common and typically harmless to the general public, but congenital cytomegalovirus (cCMV) poses a danger to babies when contracted in utero. Awareness of cCMV is lower than many other well-known congenital conditions, yet prevalence of cCMV is higher (Doutre et al., 2016). Preventing transmission is paramount and begins with awareness of the virus and how it is transmitted, which is why some states have created legislation aimed at increasing awareness and screening at birth. South Dakota does not have cCMV legislation and has the added challenge of unique rural geography, making dissemination of information at varying levels of healthcare difficult.

Cytomegalovirus belongs to the *Herpesviridae* family of viruses. After initial infections, all viruses of the *Herpesviridae* family remain latent within their host cells, with the possibility of reactivation. In individuals with a latent infection, the virus can reactivate without causing symptoms; however, during the reactivation period, the viral host will be actively shedding the virus, thus transmitting the infection. Initial infection of CMV occurs

through direct contact with the virus, typically through saliva and urine, with symptoms that mimic the common cold and likely go unnoticed. Congenital CMV contracted by a baby through the placenta, when the mother is actively infected with the virus during pregnancy, can cause serious and permanent risks.

According to the Centers for Disease Control and Prevention (CDC), the United States' prevalence rate for infants with cCMV is one in 200 children. Of infected newborns, about 10% are born with symptoms at birth, 10–15% are asymptomatic at birth but later develop hearing loss or other neurologic impairments, and the remaining 75%–80% will have no sequelae (Boppana et al., 2013; Kenneson & Cannon, 2007). What many do not realize is all infected newborns, with or without sequelae, will continue to shed and transmit the infection through bodily fluids for 18 to 30 months (Pati et al., 2016).

The most common diagnosis for a newborn infected with cCMV, symptomatic or asymptomatic, is sensorineural hearing loss (Naing et al., 2016). In addition, cCMV is acknowledged as the most common cause of

nonhereditary sensorineural hearing loss and an important cause of neurodevelopmental delay in children (Goderis et al., 2014; Kenneson & Cannon, 2007; Kimberlin et al., 2015). In addition to hearing loss, infants born with symptomatic cCMV often have more severe and permanent sequelae than infants born asymptomatic. Some sequelae can include neurologic delays, microcephaly, intracranial calcification, hyperbilirubinemia, motor defects, chorioretinitis, and seizures.

Despite the prevalence and danger cCMV poses for babies, many parents and medical providers are unaware of the virus, its sequelae, mode of transmission, and ways to minimize exposure. Awareness of cCMV was ranked the lowest by women when compared to other childhood conditions including the following: Spina bifida, Down syndrome, HIV/AIDS, sudden infant death syndrome, fetal alcohol spectrum disorder, congenital toxoplasmosis, congenital rubella syndrome, autism, Parvovirus B19, and Beta strep (Cannon et al., 2012; Doutre et al., 2016). Studies also reveal that medical providers have limited knowledge about cCMV and its dangers. The American College of Obstetricians surveyed a sample of OB/GYNs across the United States. Results revealed about half of the OB/GYNs surveyed were knowledgeable about how CMV is transmitted and preventative measures pregnant women can take, and 44% reported counseling their patients about preventing cCMV infection (Anderson et al., 2007; Fowler & Boppana, 2018).

The public health impact of cCMV is substantial, under-recognized, and is an issue worldwide due to its prevalence and the permanent sequelae (Binda et al., 2016). In an effort to reduce the prevalence and increase awareness, legislation to support cCMV screening and/or education has been enacted in 11 states, with additional states having proposed legislation. Five of the 11 states have specific laws regarding hearing-targeted testing for cCMV in infants (Doutre, 2015; National CMV Foundation, n.d.). South Dakota has no legislation for cCMV, but does have one hospital, Sanford Health, with a hearing-targeted cCMV screening protocol, which started April 29, 2013.

South Dakota is a conservative state that has historically opposed mandated healthcare policy. South Dakota's unique landscape of healthcare services adds to the challenge of disseminating information about cCMV, especially for pregnant mothers and families. Currently in South Dakota there are twenty-two hospitals, located in twenty counties, that offer labor and delivery services, meaning only 30% of counties in the state provide these services (South Dakota Department of Health - Birth report; South Dakota Department of Health - Metabolic screening program report, February 2018). Many mothers living in rural parts of the state must travel to receive services from a specialist in the management and care of pregnant women and babies, such as an obstetrician. However, due to the travel and associated costs, many mothers may seek prenatal care from another qualified medical provider (i.e., family practice physicians, pediatricians, nurse practitioners, or physician assistants), instead of a specialist located farther away in a larger

town. Therefore, not only do obstetricians in South Dakota need to be aware and knowledgeable about cCMV, but a wide range of medical professionals need to be able to counsel and educate mothers and families about cCMV.

The purpose of this study was to evaluate the knowledge of South Dakota parents and medical providers with regards to cCMV, its sequelae, and ways to minimize the risk of infection and transmission.

Method and Materials

Participants

Prior to data collection, approval to conduct the study was obtained from the Institutional Review Board (IRB) at the University of South Dakota. The target population included South Dakota parents and licensed medical providers who work with pregnant women and children, including medical doctors specializing in family medicine, obstetricians and gynecologists, pediatricians, nurse practitioners, and physician assistants. Participation was voluntary. Parents choosing to volunteer had to be current residents of South Dakota, and their child must have been born in the state. The total number of parent survey responses was 150. However, 15 respondents did not provide all the demographic information necessary to analyze data, and therefore their responses were not included in data analysis; 135 surveys had complete demographic information necessary for data analysis. Responses from the 135 participants who provided complete demographic information were included in data analysis. To estimate the total sample size needed, a G-power analysis with a moderate effect size of 0.25 and a power of 0.95 was completed a priori. Previous studies with similar focus did not report an effect size; therefore, a moderate effect size was selected. The estimate for total sample size was 210 participants (105 parent participants and 105 medical provider participants).

Participant Recruitment

Participants were recruited from within the state of South Dakota using emails and flyers sent to parent and tot groups, daycares, and various social media platforms. A list of licensed daycares was obtained online from the South Dakota Department of Social Services. For this study, the state of South Dakota was split into four regions as defined by the South Dakota Department of Health Public Health Preparedness and Response Team.

Five counties were randomly selected from within each of the four regions to be included in the survey. The daycares within these counties were then randomly rank ordered and called in order, smallest to largest. During each phone call, daycares were asked for their willingness to pass out information about the survey to the parents of the children in their care. If the daycare initially selected *did not agree to distribute information about the survey*, the daycare associated with the next value in rank order was contacted. In each phone call, the licensed daycare provider listed by the South Dakota Department of Social Services was requested as a point of contact.

The same script was used for each phone call, which

explained the reason for calling, described what would be asked of the daycare provider, and asked about their willingness to participate. If they agreed to participate, cover letters containing the survey link and investigators' contact information were provided and passed on to the parents. The cover letter purposefully did not specify cCMV; rather it generally stated that the study was seeking information from parents and healthcare providers on illness during pregnancy.

Medical providers were recruited via their state organizations, social media, and by contacting all large hospitals, critical access hospitals, rural health clinics, and healthcare networks in South Dakota. These individuals were asked to send out the cover letter (again not specifying cCMV), which contained the link for the survey. They were asked to distribute this cover letter to the providers in their organization or network. The contact information for all hospitals, critical access hospitals, and rural health clinics can be found on the South Dakota Department of Health website and was therefore considered public knowledge. However, not enough medical provider survey responses were obtained to perform statistical analysis for this population.

Survey Administration

A cross-sectional survey was used for this study to collect descriptive data from people across a geographically large and rural target population (see Appendix). The survey was conducted electronically using PsychData. Participants were given a link to this survey through cover letters provided to daycare providers and were to access the link using any internet accessible device. The survey took approximately five to seven minutes to complete. In the first section of the survey, demographic information was collected. The first demographic question for the parents asked for the child's date of birth. This allowed investigators to know whether the child was born before or after a hearing-targeted cCMV screening protocol was implemented by Sanford Health on April 29, 2013. Other demographic information collected included at which hospital the child was born and in which South Dakota county the family resided at the time of their child's birth.

The next section of the survey focused on questions related to the knowledge participants had regarding CMV and cCMV. Knowledge questions focused primarily on sequelae and ways to minimize exposure. Questions about other areas of knowledge, including the definition of cCMV, incident rate, and ways to identify cCMV, were included to look for trends. Participants were asked to answer the questions with respect to their youngest child and to the best of their ability, with all questions presented in closed-set, multiple-choice format. The last section of the survey was educational. Participants were provided links to websites and other materials where they could learn more about cCMV.

Results

A total of seven medical providers were surveyed, which is too small to provide statistically meaningful results. The distribution of respondents across South Dakota, in terms

of the county they resided in at the time of their child's birth, the county where birth occurred, and where the birthing hospitals are located, by county, in South Dakota is represented in Figure 1.

Respondents were asked to rank, using a Likert Scale, how knowledgeable they felt about ability to minimize their risk of exposure to CMV, cCMV sequelae (problems associated), and transmission from mother to baby. Responses can be seen in Figure 2. The most frequently selected answer for each of the three questions was *very unsure*.

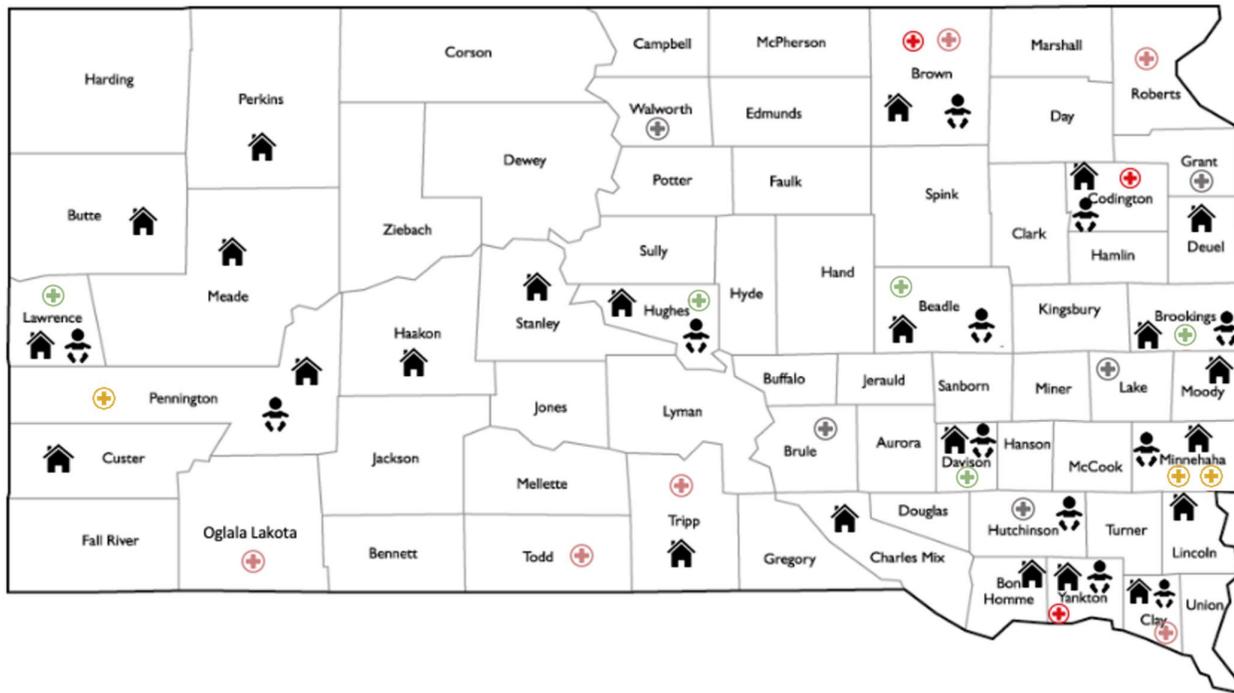
When respondents were asked where they had learned about congenital CMV, they most frequently answered (56%) that they had not learned about cCMV from anyone. The next most frequently answered response (18%) was *other*. Individuals who gave this response were often healthcare professionals from various fields (e.g., nursing, speech language pathology, audiology, physical therapy), a student of one of the aforementioned fields, or someone who worked with mothers and/or infants.

Respondents were asked 10 questions about their knowledge of cCMV and CMV; the first five questions pertained to the sequelae and the last five questions pertained to how to minimize risk of transmission (refer to Figure 3). For ease of analysis, please note that these 10 questions are listed as Questions 9–19 in the Appendix. In response to the questions about sequelae, respondents generally answered three of five questions correctly. Question 2, "Congenital CMV can be diagnosed no later than____," was frequently answered incorrectly, with the most commonly selected incorrect answer being "at birth". Question 3, "What is the most common problem associated with cCMV?" was answered incorrectly 60.0% of the time when the birth of the child was before 4/29/13 and 48.7% of the time when the birth of the child was after 4/29/13. The commonly selected incorrect answers were evenly spread across the following choices: "vision problems" (30% before, 18% after) and "seizures" (10% before, 18% after). The last five questions pertained to how to minimize risk of transmission. Respondents correctly answered question 6 ("All of the following activities are dangerous, as they may expose a mother to CMV and her unborn baby to cCMV, except____") and question 7 ("True or False: Changing a diaper exposes me to CMV through urine and fecal matter."). Question 8, "During which activity below is it most likely for a pregnant mother to be exposed to CMV?" was answered incorrectly about 70.0% of the time for birthdates before and after 4/29/13, with the most frequently selected incorrect answer being "scooping a cat's litter box" (40% before, 48% after). Question 9, "Children who are born with CMV will shed the virus for____," was answered incorrectly about 90% of the time for birthdates before and after 4/29/13, with the most frequently selected incorrect answers being "4–6 weeks" (50% before, 44% after) and "6–12 months" (30% before, 35% after). Question 10, "What is the incidence rate of cCMV occurrence each year?" was answered incorrectly 70% of the time before 4/29/13 and 76% after 4/29/13, with the most frequently selected incorrect answers being

Figure 1

Respondent Distribution Across Counties in South Dakota

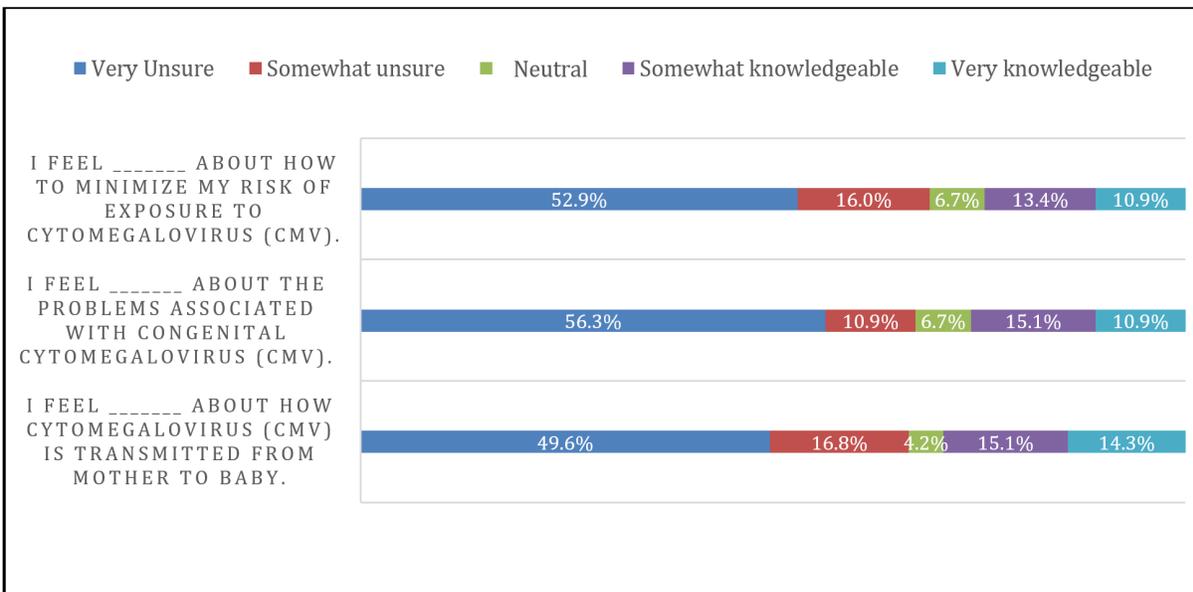
South Dakota County	Number of survey respondents residing in the county at the time of child's birth (🏠)	Number of survey respondent's babies born in the county (👶)	Hospitals with Birthing Services (births per year)	
			🟢 2000+ 🟡 300-499	🔴 500-1000 🟠 100-299 ⚪ 1-99
Beadle	1	1		🟢
Bon Homme	2	0		None
Brookings	7	4		🟢
Brown	1	1		🔴
Brule	0	0		⚪
Butte	3	0		None
Charles Mix	1	0		None
Clay	11	3		🔴
Codington	3	3		🔴
Custer	3	0		None
Davison	3	2		🟢
Deuel	2	0		None
Grant	0	0		⚪
Haakon	1	0		None
Hughes	8	9		🟢
Hutchinson	0	1		⚪
Lake	0	0		⚪
Lawrence	3	5		🟢
Lincoln	19	0		None
Meade	1	0		None
Minnehaha	28	64		🟡
Moody	1	0		None
Oglala Lakota	0	0		🔴
Pennington	27	34		🟡
Perkins	2	0		None
Roberts	0	0		🔴
Stanley	1	0		None
Todd	0	0		🔴
Tripp	1	0		🔴
Walworth	0	0		⚪
Yankton	2	4		🔴



Note. The distribution of respondents across South Dakota, the county they resided at the time of their child's birth, the county where birth occurred, and where the birthing hospitals are located, by county, in South Dakota.

Figure 2

Participant Responses to Questions about Cytomegalovirus (CMV) Transmission, Sequelae, and Exposure



Note. Respondents were asked how knowledgeable they felt about CMV transmission from mother to baby, congenital CMV sequelae (problems associated), and how to minimize risk of exposure. Respondents most frequently answered “very unsure”.

“1 in 550” (40% before, 27% after) and “1 in 1050” (20% before, 21% after).

Size of birthing facility and presence of protocol were analyzed (refer to Figure 4). A *large hospital* was considered any hospital that had 2000+ births a year. It did not appear that size of birthing facility had an effect on knowledge about CMV and cCMV. Next, the knowledge of those respondents whose birthing facility had an established hearing-targeted cCMV screening protocol was compared to the knowledge of those respondents whose birthing facility had no such protocol. Much like the size of the birthing facility, the presence of a protocol had no impact on respondents’ knowledge of CMV or cCMV.

Discussion

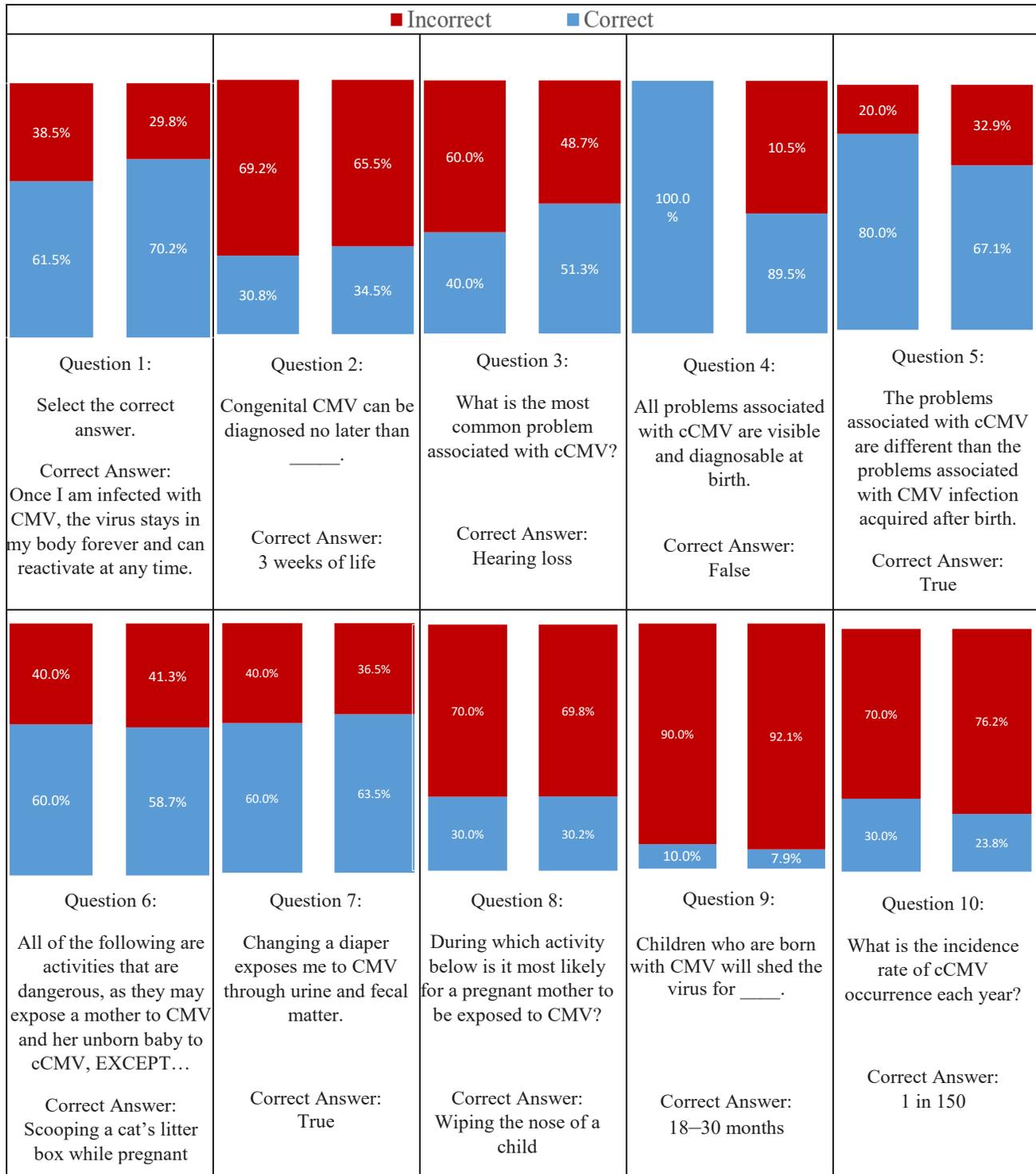
Respondents were able to correctly answer several questions about cCMV sequelae and ways to minimize exposure on the survey, despite overwhelmingly rating their confidence about the subject as *very unsure*. This finding is consistent with 56% of respondents reporting that they had “not learned about cCMV from anyone,” which is consistent with data from the 2015–2016 HealthStyles survey, that showed only 9% of women had heard about CMV (Doutre et al., 2016). It is clear that parents lack confidence in their knowledge about CMV, the problems associated with the virus, and how to minimize exposure. It was also interesting to observe that when parents did report having learned about cCMV, 18% reported learning about it from “other” and explained they were an employee or a student of the healthcare field. Therefore, it appears cCMV is important enough to be taught to future healthcare providers; however, it also appears the message is not being relayed to parents.

Respondents showed they were more knowledgeable about sequelae compared to their knowledge about minimizing exposure. When analyzing responses to the questions about minimizing exposure, there was confusion between cCMV and toxoplasmosis. This indicates there is confusion about how CMV is transmitted and therefore how to minimize risk of exposure. In Question 6, respondents were asked about activities that expose a mother to CMV and an unborn baby to cCMV. Approximately 60% of the time, respondents correctly responded that scooping a cat’s litter box did not put a mother or her baby at risk for becoming infected with CMV/cCMV. In Question 8, respondents were contradictory in their answer to Question 6; nearly 45% of respondents incorrectly answered that “scooping a cat’s litter box” was an activity that was the most likely to cause a pregnant mother to be exposed to CMV. This contradiction reveals there is work to be done when it comes to educating parents about CMV and how to minimize risk of exposure. Marshall and Adler (2009) estimate that every two years, an average of 80,000 pregnant women will be exposed to CMV from an infected child who attends daycare. Without a hygienic intervention, approximately half will become infected during pregnancy, with the majority of the infections being preventable. Educating parents about CMV, how it is transmitted, and ways to minimize exposure is imperative to reducing infection rates.

South Dakota has many small birthing facilities and only a few larger facilities. Results from this study suggest that birthing facility size does not impact parent knowledge of CMV and cCMV sequelae or how to minimize exposure to CMV and cCMV. There was also no difference between

Figure 3

Respondents' Knowledge about Sequelae (Questions 1-5) and How to Minimize Exposure and Transmission (Questions 6-10)

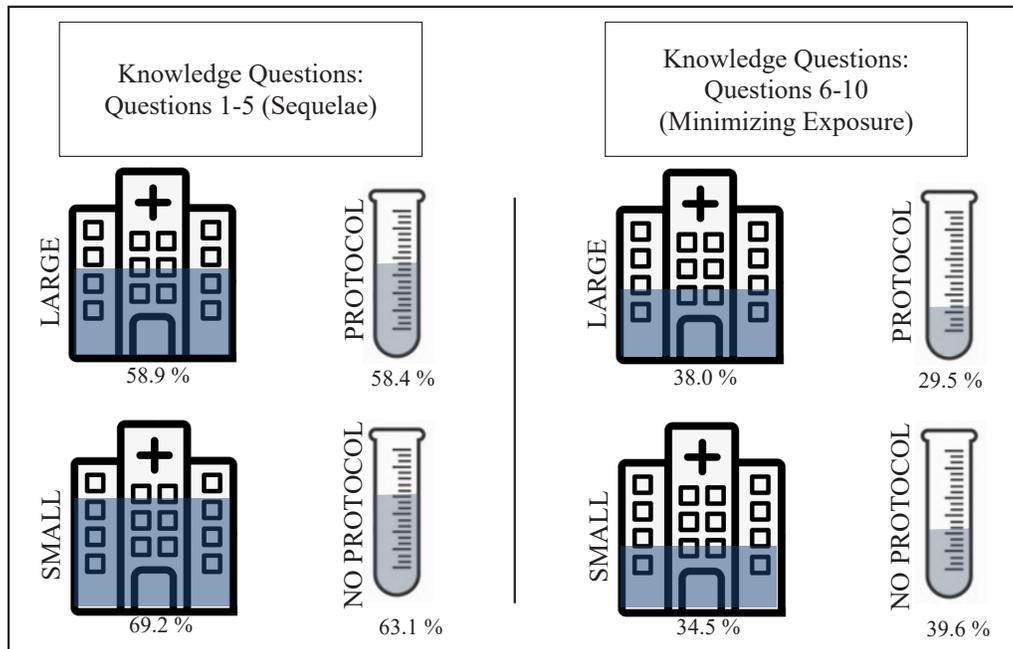


knowledge of sequelae and how to minimize exposure when comparing responses from parents whose infant was born at the hospital that has a hearing-targeted screening protocol to responses from parents whose infant was born at a hospital with no CMV screening protocol. With neither size nor screening protocol having an impact on knowledge, it likely means there will need to be a focused effort on cCMV awareness in South Dakota at all the prenatal clinics and birthing facilities.

Although the results obtained from this study are specific to South Dakota, they are in line with studies across the United States and the world that identify cCMV as having high prevalence yet low awareness and knowledge (Doutre et al., 2016; Marshall & Adler, 2009; Mazzitelli et al., 2017). The need for cCMV awareness is substantial, particularly with a large focus on preventative measures (Thackeray et al., 2017).

Figure 4

Cytomegalovirus (CMV) Knowledge at Large and Small Birthing Hospitals



Note. Knowledge of CMV and congenital CMV (CCMV) was analyzed at both large and small hospitals, along with knowledge at the hospital where there is a hearing targeted cCMV screening protocol.

References

- Anderson, B., Schulkin, J., Ross, D. S., Rasmussen, S. A., Jones, J. L., & Cannon, M. J., (2007). Knowledge and practices of obstetricians and gynecologists regarding cytomegalovirus infection during pregnancy – United States, 2007. *MMWR Weekly*, 57(3), 65–68. <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5703a2.htm>
- Binda, S., Pellegrinelli, L., Terraneo, M., Caserini, A., Primache, V., Bubba, L., & Barbi, M. (2016). What people know about congenital CMV: An analysis of a large heterogeneous population through a web-based survey. *BMC Infectious Diseases*, 16, 513. <https://doi.org/10.1186/s12879-016-1861-z>
- Boppana, S. B., Ross, S. A., & Fowler, K. B. (2013). Congenital cytomegalovirus infection: Clinical outcome. *Clinical Infectious Disease*, 57(Suppl. 4), S178–S181.
- Cannon, M. J., Westbrook, K., Levis, D., Schleiss, M. R., Thackeray, R., & Pass, R. F. (2012). Awareness of and behaviors related to child-to-mother transmission of cytomegalovirus. *Preventive Medicine*, 54, 351–357. <https://doi.org/10.1016/j.ypmed.2012.03.009>
- Centers for Disease Control and Prevention. (2018, June). Cytomegalovirus and congenital CMV infection. <https://www.cdc.gov/cmvi/index.html>
- Doutre, S. M. (2015). Reducing congenital cytomegalovirus infection through policy and legislation in the United States. *Microbiology Australia*, 162–164. <https://doi.org/10.1071/MA15058>
- Doutre, S. M., Barrett, T. S., Greenlee, J., & White, K. R. (2016). Losing ground: Awareness of congenital cytomegalovirus in the United States. *The Journal of Early Hearing Detection and Intervention*, 1(2), 39–48.
- Fowler, K. B., & Boppana, S. B. (2018). Congenital cytomegalovirus infection. *Seminars in Perinatology*, 42(3), 1–4. <https://doi.org/10.1053/j.semperi.2018.02.002>
- Goderis, J., De Leenher, E., Smets, K., Van Hoecke, H., Keymeulen, A., & Dhooge, I. (2014). Hearing loss and congenital CMV infection: A systematic review. *Pediatrics*, 134(5), 972–982. <https://doi.org/10.1542/peds.2014-1173>
- Kenneson, A., & Cannon, M. (2007). Review and meta-analysis of the epidemiology of congenital cytomegalovirus (CMV) infection. *Reviews in Medical Virology*, 17, 253–276. <https://doi.org/10.1002/rmv.535>
- Kimberlin, D. W., Jester, P. M., Sanchez, P. J., Ahmed, A., Arav-Boger, R., Michaels, M. G., Ashouri, N., Englund, J. A., Estrada, B., Jacobs, R. F., Romero, J.

- R., Sood, S. K., Whitworth, S., Abzug, M. J., Caserta, M. T., Fowler, S., Lujan-Zilbermann, J., Storch, G. A., DeBiasi, R. L., Han, J-Y., ... & Whitley, R. J. (2015). Valganciclovir for symptomatic congenital cytomegalovirus disease. *The New England Journal of Medicine* 372, 933–943. <https://doi.org/10.1056/NEJMoa1404599>
- Marshall, B. C. & Adler, S. P. (2009). The frequency of pregnancy and exposure to cytomegalovirus infections among women with a young child in day care. *American Journal of Obstetrics and Gynecology*, 200(2), 163.e1–163.e5. <https://doi.org/10.1016/j.ajog.2008.08.037>
- Mazzitelli, M., Micieli, M., Votino, C., Visconti, F., Quaresima, P., Strazzulla, A., Torti, C., & Zullo, F. (2017). Knowledge of human cytomegalovirus infection and prevention in pregnant women: A baseline, operational survey. *Infectious Diseases in Obstetrics and Gynecology*, 1–5. <https://doi.org/10.1155/2017/5495927>
- Naing, Z. W., Scott, G. M., Shand, A., Hamilton, S. T., van Zuylen, W. J., Basha, J., Hall, B., Craig, M. E., & Rawlinson, W. D. (2016). Congenital cytomegalovirus infection in pregnancy: A review of prevalence, clinical features, diagnosis and prevention. *Australian and New Zealand Journal of Obstetrics and Gynecology*, 56, 9–18. <https://doi.org/10.1111/ajo.12408>
- National CMV Foundation. *CMV Awareness*. <https://www.nationalcmv.org/default.aspx>
- National CMV Foundation. *Public Health Policy*. <https://www.nationalcmv.org/about-us/advocacy>
- Pati, S., Novak, Z., Boppana, S., Fowler, K., & Ross, S. (2016). Cytomegalovirus shedding in saliva and hearing loss in congenital cytomegalovirus (CMV) infection. *Open Forum Infectious Diseases*, 3, 654. <https://doi.org/10.1093/ofid/ofw172.517>
- South Dakota Department of Health, Office of Health Statistics. (2015). Birth Report. Pierre, SD: U.S.
- South Dakota Department of Health, Office of Health Statistics. (2018). Metabolic screening program report. February 2018. Pierre, SD: U.S.
- Thackeray, R., Magnusson, B. M., & Christensen, E. M. (2017). Effectiveness of message framing on women's intention to perform cytomegalovirus prevention behaviors: A cross-sectional study. *BMC Women's Health*, 17, 134. <https://doi.org/10.1186/s12905-017-0492-x>

Appendix
Parent Survey

IRB Approval effective from: 12/19/2017
IRB Approval not valid after: 12/18/2018
USD IRB

Date: December 12, 2017

Dear Parent:

You are invited to participate in a research study. The purpose of the study is to better understand parent knowledge about different metabolic, inherited, and genetic disorders at birth. We are inviting you to be in this study because you are the parent of a child born in South Dakota.

If you agree to participate, we would like you to complete a survey. The survey can be completed on any computer/device with Internet access and will take approximately 5 to 7 minutes. The types of questions you will be asked include where your child was born, where/if you learned about various metabolic, inherited, and genetic disorders during pregnancy, and your current knowledge of congenital metabolic, inherited, and genetic disorders.

We will keep the information you provide anonymous, however federal regulatory agencies and the University of South Dakota Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research.

Your responses will be anonymous to ensure that they cannot be linked to you. If we write a report about this study we will do so in such a way that you cannot be identified.

There are no known risks from being in this study, and you will not benefit personally. However, we hope that others may benefit in the future from what we learn as a result of this study.

All survey responses that we receive will be treated confidentially and stored on a secure server. However, given that the surveys can be completed from any computer (e.g., personal, work, school), we are unable to guarantee the security of the computer on which you choose to enter your responses. As a participant in our study, we want you to be aware that certain "key logging" software programs exist that can be used to track or capture data that you enter and/or websites that you visit.

Your participation in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you will not be penalized or lose any benefits for which you are otherwise entitled.

If you have any questions, concerns or complaints now or later, you may contact us at the number below. If you have any questions about your rights as a human subject, complaints, concerns or wish to talk to someone who is independent of the research, contact the Office for Human Subjects Protections at 605/677-6184. Thank you for your time.

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Appendix (cont.)
Parent Survey

- Please answer all questions to the best of your ability
 - All questions should be answered in regard to your YOUNGEST child
-

1. What is your child's date of birth (month/date/year)?
2. At what facility did you receive your prenatal care? (e.g. Avera Women's Clinic, Sanford Obstetrics and Gynecology Clinic, Black Hills Obstetrics and Gynecology Clinic)
3. In which South Dakota hospital was your child born? (Drop down)
 - a. Avera – McKennan (Sioux Falls)
 - b. Avera – Sacred Heart (Yankton)
 - c. Avera – St. Mary's (Pierre)
 - d. Avera – Queen of Peace (Mitchell)
 - e. Avera – St. Luke's (Aberdeen)
 - f. Avera – St. Benedict (Parkston)
 - g. Avera – Milbank Area Hospital
 - h. Brookings Hospital
 - i. Coteau Des Prairies Hospital (Sisseton)
 - j. Huron Regional Medical Center
 - k. Madison Community Hospital
 - l. Mobridge Regional Hospital
 - m. Pine Ridge IHS Hospital
 - n. Prairie Lakes Health Care (Watertown)
 - o. Sanford Aberdeen Medical Center
 - p. Sanford Chamberlin Medical Center
 - q. Sanford USD Medical Center – Sioux Falls
 - r. Sanford Vermillion Hospital
 - s. Rapid City Regional Hospital
 - t. Spearfish Regional Hospital
 - u. Rosebud IHS Hospital
 - v. Winner Regional Health Care Center
 - w. Other – Please Specify
4. In what South Dakota county did you reside at the time of your son or daughter's birth?
5. I feel _____ about how congenital CMV is transmitted from mother to baby.
 - a. Very Unsure
 - b. Somewhat Unsure
 - c. Neutral
 - d. Somewhat Knowledgeable
 - e. Very Knowledgeable
6. I feel _____ about the problems associated with congenital cytomegalovirus (CVM).
 - a. Very Unsure
 - b. Somewhat Unsure
 - c. Neutral
 - d. Somewhat Knowledgeable
 - e. Very Knowledgeable
7. I feel _____ about how to minimize my risk of exposure to cytomegalovirus (CMV).
 - a. Very Unsure
 - b. Somewhat Unsure
 - c. Neutral
 - d. Somewhat Knowledgeable
 - e. Very Knowledgeable

Appendix (cont.)

Parent Survey

8. I learned about congenital CMV from ____?
- Social media
 - A friend or family member
 - Medical provider
 - Online resource (not social media)
 - I have not learned about congenital CMV from anyone
 - Other (please explain)
- LOGIC (if c was selected)
- 8a). Which medical provider educated you the most regarding congenital CMV?
- Pediatrician
 - OB/GYN
 - Family Medicine
 - Nurse practitioner
 - Physician Assistant
 - Other (please specify)
- 8b.) Please specify when the medical provider informed you about congenital CMV.
- Pre-pregnancy
 - First trimester
 - Second trimester
 - Third trimester
 - Post pregnancy
 - My medical provider never talked with me about congenital CMV.
9. Select the correct answer
- Once I am infected with cytomegalovirus (CMV), I have immunity and will not be infected again.
 - Once I am infected with cytomegalovirus (CMV), the virus stays in my body forever, and can re-activate at any time.
 - Once I received the vaccine for cytomegalovirus (CMV), I will have immunity towards the virus, and will not be infected.
10. Congenital CMV can be diagnosed no later than ____.
- At birth
 - 3 weeks of life
 - 3 months of life
 - 3 years of life
11. What are the known problems associated with congenital cytomegalovirus (CMV)?
Select all that apply.
- Small head size
 - Autism
 - Vision Problems
 - Hearing Loss
 - Lung problems
 - Jaundice
 - Mental Disability
 - Facial abnormalities
12. What is the most common problem associated with congenital cytomegalovirus (CMV)?
- Vision Problems
 - Seizures
 - Hearing loss
 - Cerebral Palsy
13. All problems associated with congenital cytomegalovirus (CMV) are visible and diagnosable at birth.
- True
 - False

Appendix (cont.)

Parent Survey

14. The problems associated with congenital cytomegalovirus (CMV) are different than the problems associated with CMV infection acquired after birth.
 - a. True
 - b. False

15. All of the following activities are dangerous, as they may expose a mother to cytomegalovirus (CMV) and her unborn baby to congenital CMV, EXCEPT _____.
 - a. Sharing a cup or straw with a child
 - b. Scooping a cat's litter box while pregnant
 - c. Sharing a fork with your child
 - d. Picking up or playing with children's toys

16. Changing a diaper exposes me to CMV through urine and fecal matter.
 - a. True
 - b. False

17. During which activity below is it most likely for a pregnant mother to be exposed to CMV?
 - a. Scooping a cat's litter box
 - b. Touching an infected surface
 - c. Wiping the nose of a child
 - d. Getting bit by an insect

18. Children who are born with CMV will shed the virus for _____.
 - a. 4 - 6 weeks
 - b. 6 months – 12 months
 - c. 18 months – 30 months
 - d. 36 months – 42 months

19. What is the incidence rate of congenital CMV occurrence each year?
 - a. 1 in 50
 - b. 1 in 150
 - c. 1 in 550
 - d. 1 in 1050
 - e. 1 in 10,500
 - f. 1 in 30,500
 - g. 1 in 50,500

For more information about congenital CMV
Visit the following links:

National CMV Foundation

<https://www.nationalcmv.org/home.aspx>

Centers for Disease Control and Prevention

<https://www.cdc.gov/cm/overview.html>

Thank you!