The Role of a State Public Health Initiative in Shaping Provider Knowledge, Beliefs and Practices

A Mixed Methods Study of a Cytomegalovirus Prevention Program

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This document was submitted as a dissertation in July 2023 in partial fulfillment of the requirements of the doctoral degree in public policy analysis at the Pardee RAND Graduate School. The faculty committee that supervised and approved the dissertation consisted of Dr. Stephanie Rennane (chair), Dr. Julia Bandini and Dr. Stephanie Browning McVicar.

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Abstract

Congenital cytomegalovirus (cCMV) is the leading cause of viral birth defects and developmental delays in newborn infants in the U.S., infecting an estimated 0.4-0.8% of babies. While there is no cure for CMV, there are hygiene measures that can potentially reduce the risk of infection. The aim of this dissertation is to explore the impact of Utah’s public health education intervention to increase pregnancy care provider awareness of cCMV preventative hygiene measures, knowledge, and counseling behaviors through a comparison to a similar comparison state without an intervention (Nevada). This observational study employed a mixed methods approach that utilized surveys and semi-structured interviews to explore: 1) What are the cCMV prevention counseling practices and knowledge among pregnancy care providers in Utah and Nevada? 2) What are providers’ perceptions of barriers to educating patients about cCMV?

Pregnancy care providers (OB/GYNs, Maternal Fetal Medicine Physicians, Midwives, Family Medicine Physicians, Nurse Practitioners) in Utah and Nevada were surveyed (Utah n=110, Nevada n=68) and interviewed (Utah n=15, Nevada n=1). I performed descriptive statistical analysis of survey results and thematic analysis of the semi-structured interviews. Survey results showed that Utah pregnancy care providers were 16% more likely to counsel their patients regarding cCMV (p<0.05) when compared to providers in Nevada. Providers in Utah who received cCMV public health initiative materials were 26% more likely to provide patient cCMV counseling (p<0.01) than those in Utah who did not receive the materials. Providers in the interviews reported that a lack of cCMV treatment options created uncomfortable conversations around cCMV counseling with patients. Additionally, providers perceived cCMV preventative measures especially for mothers of small children as unrealistic with the potential to create unnecessary maternal anxiety and guilt.

Based on findings from my study, this public health approach offers a potential partial solution to increasing patient cCMV counseling. Several barriers were identified that inhibit providers from counseling their patients regarding cCMV preventative measures. Further work is needed to reduce systemic barriers in parallel with any potential public health efforts to increase cCMV preventative counseling by pregnancy care providers for women of childbearing age.
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Abbreviations

ACOG  American College of Obstetricians and Gynecologists

ccMV  Congenital Cytomegalovirus

CME  Continuous Medical Education

CMV  Cytomegalovirus

CNM  Certified Nurse Midwife

CPM  Certified Professional Midwife

DIKW  Data, Information, Knowledge, Wisdom

DO  Doctor of Osteopathy

LM  Licensed Midwife

MD  Medical Doctor

MFM  Maternal Fetal Medicine

NP  Nurse Practitioner

OB/GYN  Obstetrician/Gynecologist

PA  Physician Assistant

UDOH  Utah Department of Health

TORCH  Toxoplasmosis, Other (Syphilis, Hepatitis B), Rubella, Cytomegalovirus, Herpes
Chapter 1. Introduction

General Aims, Objectives, and Policy Relevance

Pregnancy care providers interact with women at critical times in fetal development, both pre and post conception, creating opportunities to reduce the development of congenital defects through preventative counseling. For some conditions that have less public awareness, providers might be the only source of vital prevention information for women of childbearing age (Johnson et al., 2006). But what if these lesser-known conditions also have limited awareness among pregnancy care providers? Dissemination and implementation of best practices in provider populations has been a noted issue in healthcare (Brownson et al., 2012; Grant et al., 2003; Balas and Boren, 2000). One potential approach to increase provider awareness of preventative counseling for congenital conditions is through public health education and awareness campaigns. Examining a public health education and awareness initiative around congenital Cytomegalovirus, a potentially preventable congenital condition, offered a unique case for exploring how a state-wide education and awareness campaign impacted provider behavior (CDC, n.d.).

Congenital Cytomegalovirus (cCMV) is the leading cause of viral birth defects and developmental delays in newborn infants in the U.S., infecting an estimated 0.4-0.8% of the 4 million babies born each year (CDC, n.d.). There are many possible symptoms of cCMV at birth including hearing loss, microcephaly, and growth retardation (CDC, n.d.). Over time, 50-80% of symptomatic cCMV babies will go on to develop long-term, neurological sequelae including intellectual and developmental disabilities, epilepsy, cerebral palsy and even death (Thackeray, 2014). A cCMV diagnosis can also lead to significant costs to both the public and families over the lifetime of the child (Gantt et al., 2016). These costs can include expenses related to health care, adaptive equipment, special education, therapy, and parental loss of income due to caregiving (Marsico and Kimberlin, 2017). Because so many cases go undiagnosed, there is uncertainty regarding the true number of symptomatic cCMV cases and a wide range of estimates in cost-of-illness (COI) studies for patients who have received a diagnosis (Grosse et al., 2021). A 2001 study estimated the societal cost of cCMV in the U.S. as nearly $4 billion per year in 1995 dollars, or $6.6 billion in 2018 dollars (Lawrence, 2001).

cCMV is potentially preventable through hygiene measures including handwashing after contact with saliva or urine of young children as well as avoiding the sharing of utensils or kissing young children on the mouth (CDC, n.d.). Despite published studies that identify the potential for hygiene practices to help reduce the number of cCMV cases, very few U.S. practitioners educate women of childbearing age about these practices (Billette de Villemeur, 2020) (Cannon, 2005). Additionally, there are no national guidelines for cCMV prevention and
little public awareness of the disease. While nine states have active legislation requiring cCMV prevention through education and awareness, only Utah had accompanied funding for education (National CMV Foundation, n.d.). This piecemealed approach has led to limited cCMV prevention policies across the U.S. For example, a 2016 survey of U.S. adults found that only 6.7% were aware of cCMV (Tastad, 2019).

Utah’s CMV Public Health Initiative went into effect on July 1, 2013. The initiative directed the Utah Department of Health (UDOH) to create a public education program around cCMV. The educational program targeted pregnant women and women who may become pregnant on the occurrence, transmission, risks, and prevention measures for cCMV. For this public health education campaign, brochures and fliers were sent statewide to pregnancy care (OB/GYNs, Family Medicine Physicians, Maternal Fetal Medicine Physicians, Pediatricians and Midwives) providers to share with their patients. Other efforts included public service announcements at largely attended public events, billboards, and mass transit advertisements. UDOH also presented in-person presentations to educate several groups including nursing and nurse practitioner students, medical students, and residents.¹ Funding for the educational efforts (which will be referred to as the “intervention” henceforth) was cut in July 2020 due to COVID-19 budget impacts prohibiting further large-scale public health awareness campaigns.

Multiple studies have identified the lack of awareness of cCMV amongst the general population and the potential for education and awareness initiatives to reduce cCMV transmission (Vauloup-Fellous et al., 2009). Yet, to date Utah is the only state to implement a wide-scale public education campaign in the U.S. (National CMV Foundation, n.d.). The aim of this observational study is to explore the impact of Utah’s education and awareness intervention on pregnancy care provider cCMV knowledge and counseling practices. Using a mixed-methods approach, my dissertation compares cCMV provider counseling practices post-intervention in Utah to a demographically similar state without an intervention to target cCMV awareness. This study aims to inform policy makers and public health stakeholders regarding:

- Current provider cCMV knowledge and counseling practices across two states with and without a public health intervention.
- The barriers perceived by pregnancy care providers to counseling their patients regarding CMV infection prevention that could impact a similar intervention’s effectiveness.

While this study focuses on exploring how a state-wide cCMV initiative shaped pregnancy care provider knowledge and practices, there are broader implications for this work. Legislation

¹ Other efforts included in person education sessions of Early Intervention providers, Home Visiting providers, Early Head Start, Head Start, local health departments staff, hospitals, audiologists, graduate students, WIC offices, community health centers, Grand Rounds, Tribal Leaders, women’s health fairs, prenatal classes, and social media.
has been viewed in the advocacy world as a tool for altering provider practices. But is legislation and a resulting public health campaign effective at increasing pregnancy care provider preventative counseling? Are there other perceived barriers at play that diminish their effectiveness? I examined knowledge and counseling behaviors as well as provider perceived barriers to patient counseling.

**Research Design**

To explore the impact of Utah’s public health initiative, I examined two research questions:

1. What are the cCMV prevention counseling practices and knowledge among pregnancy care providers in Utah and Nevada?
2. What are providers’ perceptions of barriers to educating patients about cCMV?

For a comparison state, I prioritized one that was a neighboring state that had a similar population size without a cCMV intervention for comparison with Utah. UDOH recommended Nevada as a culturally similar state for comparison. Other regional neighboring states considered were Wyoming, Idaho, and Colorado. Colorado had already enacted cCMV education and awareness legislation and Wyoming and Idaho had much smaller population sizes (579k and 1.9M respectively) (U.S. Census Bureau, 2022). Table 1.1 provides a comparison of the two states on several dimensions. While Utah and Nevada have similar population sizes (~3.4 million in Utah and ~3.2 million in Nevada) there are differences between the two states that should be noted (U.S. Census Bureau, 2022). Utah has ~12,000 more live births a year than Nevada but a smaller population of OB/GYN physicians perhaps because nearly double (8% vs 4%) of Utah’s births are attended by a Nurse Midwife (U.S. Bureau of Labor Statistics, 2020; March of Dimes, 2022; Georgetown University, 2019). Midwives belong to a different professional organization than OB/GYNs that could have impacted their cCMV counseling practices outside of the public health intervention. Additionally, Nevada spends less per person on public health ($51/person) than Utah ($81/person) and 3% more women in Nevada report not having a personal health provider compared to Utah (America’s Health Rankings, 2022; ; Kaiser Family Foundation, 2021). Nevada has more medical schools (n=2) than Utah (n=1), but Utah has more cCMV research (n=6 clinical trials) versus Nevada (n=0 clinical trials) (clinicaltrials.gov, 2023). Utah’s past and current CMV research could have exposed providers in the state to cCMV outside of the public health education campaign, indirectly increasing awareness of cCMV in the state.

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Table 1.1 Comparing Utah and Nevada

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Utah</th>
<th>Nevada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Estimate (2022)</td>
<td>3,380,800</td>
<td>3,177,772</td>
</tr>
<tr>
<td>Female persons, percent</td>
<td>49.4%</td>
<td>49.6%</td>
</tr>
<tr>
<td>White alone</td>
<td>77.2%</td>
<td>46.6%</td>
</tr>
<tr>
<td>Live births in 2020</td>
<td>45,702</td>
<td>33,653</td>
</tr>
<tr>
<td>OB/GYN Physicians</td>
<td>n=230</td>
<td>n=305</td>
</tr>
<tr>
<td>Medical Schools</td>
<td>n=1</td>
<td>n=2</td>
</tr>
<tr>
<td>Percent of Births Attended by Nurse Midwives</td>
<td>8.04%</td>
<td>3.96%</td>
</tr>
<tr>
<td>Public Health Funding 2018-2019 ($ per person)</td>
<td>$81</td>
<td>$50</td>
</tr>
<tr>
<td>Women Who Report Having No Personal Health Care Provider</td>
<td>13%</td>
<td>16%</td>
</tr>
<tr>
<td>CMV Clinical Trials</td>
<td>n=6</td>
<td>n=0</td>
</tr>
</tbody>
</table>


To address the first research question, I predominantly relied on a cross-sectional, self-administered survey I fielded to identify cCMV knowledge and counseling practices among pregnancy care providers in Utah and Nevada, and to examine differences in counseling behavior between providers in Utah who did and did not receive materials from UDOH. The cross-sectional nature of this study limits the ability to perform a causal analysis as no data was collected pre-intervention. The survey included questions related to:

- How providers learned about cCMV
- If providers received any education or training from UDOH
- Factors involved when providers don’t education patients regarding cCMV
- How frequently providers educate patients about cCMV risks and consequences
- How providers educate their patients

To address the second research question, I predominantly relied on semi-structured interviews to explore barriers, attitudes and beliefs surrounding cCMV patient education and knowledge among pregnancy care providers. Interview questions focused on provider cCMV knowledge, how providers inform and educate patients about cCMV prevention measures and reasons for not discussing cCMV with patients. While surveys were used to predominantly address RQ1 and semi-structured interviews for RQ2, there were areas of overlap. For example, there was a question in the survey that asked providers about why they don’t counsel their patients regarding cCMV. Additionally, interview participants discussed their knowledge of cCMV preventive measures. I was only able to recruit one pregnancy provider to interview in Nevada, so I was unable to compare interview findings between the two states.

Lastly, to integrate my findings across research questions, I applied the Data, Information, Knowledge, and Wisdom (DIKW) Pyramid to serve as a framework (Figure 1.1). The DIKW hierarchy, first known to be cited in Ackoff’s 1989 paper, “From data to wisdom,” was initially...
used in knowledge and information science to explain the structure and flow from data to action (wisdom) (Ackoff, 1989). Outside of information science, the pyramid has been applied in healthcare specifically in the field of nursing informatics. With vast amounts of electronic healthcare record data (EHR) available, Artificial Intelligence (AI) has been used to create dashboards for clinical decision support to augment decision making by healthcare providers. Illustrating these systems within the DIKW pyramid helps nurses to visualize that these systems are built upon multiple layers and to be alert if they notice discrepancies in the tool. Additionally, the DIKW pyramid enables nursing leaders to strategically evaluate the relationship between AI and clinical decision support. (Cato et al., 2020).

**Figure 1.1 Data, Information, Knowledge, and Wisdom Pyramid Applied to Utah’s cCMV Public Health Initiative**

![Diagram](Image)

The pyramid is constructed of four layers that build upon each other with data serving as the foundation. As the levels of the pyramid progress upwards, data is ultimately transformed into wisdom (Ackoff, 1989). Starting at the bottom, the data layer is a collection of facts and symbols that represent properties of objects, events, and their environment (Rowley, 2007). Data is a product of observation, a record of what has already happened (Allen, 2017). Additionally, data is considered true, taken as fact but does not provide context (Frické, 2009). Rowley points out, “definitions are largely in terms of what data lacks; data lacks meaning or value, is unorganized and unprocessed. They lay the foundations for defining information in terms of data” (Rowley, 2007). A simple example of data and data acquisition is an unmanned weather station that continuously records temperatures – the temperature recorded by itself has no context. This comprises data (Frické, 2009).

Moving on to the next layer, information is often defined in its relation to data. Information is data that has been organized, structured, processed and/or formatted. Through this process, data
is given relevance for a specific purpose, providing meaning and value (Rowley 2007). Information typically addresses questions that begin with such words as who, what, and when. Information consists of relevant data but can also be aggregated or inferred from data as well (Frické, 2009). Using the unmanned weather station example, if someone wanted to know the average temperature for the month of June, the temperature data could be aggregated and an average calculated, creating information.

Next, knowledge is understanding how to apply information. “Knowledge is data and/or information that have been organized and processed to convey understanding, experience, accumulated learning, and expertise as they apply to a current problem or activity,” (Turban and Rainer, 2005). While data and information can come from humans or machines, knowledge is thought to come from the human mind, an individual’s understanding of information (Rowley, 2007). Knowledge in the DIKW application is knowing how (tacit knowledge) versus knowing what (explicit knowledge) (Awad and Ghaziri, 2004). An individual can know what a bicycle is but knowledge for this context is having the individual skill to know how to ride a bicycle.

Lastly, wisdom is knowledge applied into action. “Wisdom is the ability to act critically or practically in any given situation. It is based on ethical judgement related to an individual’s belief system,” (Jashapara, 2005). Wisdom isn’t just the accumulation of knowledge but knowing how to act in accordance with that knowledge (Frické, 2009). When compared to the other layers, wisdom is less defined in the literature, seen as a more abstract concept when compared to data, information, and knowledge (Rowley, 2007). While knowledge is knowing how to ride a bicycle, wisdom is being aware of the nuances of riding like being cautious in busy areas and using precautions when it is dark. Wisdom comes from aggregating and exercising knowledge.

Figure 1.1 illustrates the translation of the layers to this specific application of Utah’s cCMV public health initiative. For this application, I define the data layer as the existing body of global cCMV research which includes cCMV published studies regarding prevention, outcomes, and treatment.

A May 15, 2023, a PubMed search on congenital Cytomegalovirus identified 3,715 published articles since 1947.

Moving up, knowledge refers to knowledge at the individual provider level and consists of their
understanding of cCMV including preventative measures, sequelae, symptoms, and treatment. Lastly, wisdom represents an individual provider’s actions, their cCMV preventative counseling practices with their patients. While this pyramid has been used previously in healthcare, this, this is the first empirical study to apply the framework to health education. This study therefore offers a novel approach to understanding the dissemination from a public health education campaign to provider knowledge and ultimately to provider actions (Cato et al., 2020; Matney et al., 2011). Using this simple framework helped to visualize the bigger process and locate barriers that prevent providers from counseling their patients regarding cCMV.

Overall, this study found significant statistical and practical differences between the survey population of providers in Utah and Nevada regarding counseling patients regarding cCMV. Additionally, providers in Utah who received materials from UDOH were more likely to counsel patients regarding cCMV preventative measures than providers in Utah who did not receive cCMV materials. Despite these results, providers in Utah were more likely than providers in Nevada to cite being uninformed about cCMV as a reason for not providing counseling, suggesting there are barriers when trying to move providers from information to knowledge to wisdom. Provider interviews identified several barriers to provider cCMV preventative counseling including provider lack of awareness of cCMV, perceptions that preventative measures were unrealistic and would cause unnecessary maternal anxiety and guilt, perceptions that cCMV hygiene measures fell under standard hygiene counseling and a lack of treatment options made providers feel uncomfortable talking to their patients about cCMV.

Based on these findings, I present four possible mechanisms to increase provider counseling: 1) invest in further research to evaluate the effectiveness of cCMV preventative education, 2) address inconsistencies in professional guidelines regarding cCMV counseling, 3) consider supplemental approaches to a public health campaign to increase provider knowledge, and 4) utilize key individuals as trusted insiders to promote knowledge and implementation among other providers. I utilized the key individual approach to increase provider survey responses and found that recruitment coming from someone inside the organization increased overall provider participation. Similarly, using key individuals to spread a public health campaign offers a potential way to increase provider buy-in and adoption.
cCMV is a potentially preventable public health crisis (Ross et al., 2009). Responsible for an estimated 400 deaths and 8,000 permanent disabilities in children annually, cCMV is still largely overlooked in public health (Cannon, 2005). Congenital CMV occurs when CMV is transferred in utero from a mother to her fetus (CDC, n.d.). Women who undergo their first CMV exposure during their first trimester of pregnancy are at the highest risk for delivering babies with long-term sequelae (Faure-Bardon et al., 2019). For pregnancies that transfer CMV in utero during the first trimester, 30-35% of these newborns develop neurological sequelae, and 25% will suffer from permanent hearing loss (Leruez-Ville and Ville, 2020).

Generally, approaches to prevent and mitigate cCMV fall into four different phases: pre-pregnancy, prenatal, birth, and newborn. These phases can be divided between preventing infection and diagnosing and treating cCMV (Figure 2.1).

Historically, infection prevention strategies for women who are pregnant or might become pregnant have focused on four main approaches:

- Increasing cCMV awareness and educating women about the transmission and risk of cCMV
- Performing seronegative screening for women to find out if they have previously contracted CMV (primary infection)
- Vaccinating women for CMV when and if a vaccine becomes available
- Administering antivirals if a woman contracts CMV while pregnant

The main approach to reducing cCMV infections is to educate women regarding prevention measures to help reduce the risk of CMV infection while pregnant. The CDC lists ways to lessen risk of CMV infection by, “reducing contact with saliva and urine from babies and young
children.” (CDC, n.d.) Young children shed high amounts of CMV through their urine and saliva. Pregnant women can avoid getting their child’s saliva in their mouth by not sharing food, utensils or kissing on the mouth. Also, pregnant women should thoroughly wash their hands after changing all diapers (CDC, n.d.).

Seronegative screening has limitations. Women who have previously contracted CMV are still at risk of secondary CMV infection which can pass in-utero to their baby (1.1-1.7% transmission rate to the fetus (Lazzarotto et al., 2011). While the transmission rate for cCMV is lower for a secondary CMV infection than for a primary CMV infection (30-35% transmission rate to the fetus), because of the high number of adults who have been previously infected with CMV, non-primary infections account for nearly two thirds of infants infected with CMV (Marsico, 2017). The development of a CMV vaccine has proven challenging with no FDA approved vaccine currently available (Schleiss and Diamond, 2020).

Anti-viral medications administered during pregnancy have been shown to have no impact and are not currently recommended (Avery, 2021).

The diagnosis and treatment phase typically happen after birth once in-utero infection has occurred. Babies are identified either through newborn screening or once they display symptoms (Grosse et al., 2017). Screening approaches include both targeted screening that tests newborns who fail the newborn hearing screening or universally, including cCMV in the newborn screening panel (Beswick et al., 2019). Antiviral treatments exist for symptomatic babies who are identified early, typically within the first 30 days of life (Acosta et al., 2020). These treatments can work to stop the virus from causing further hearing loss and neurological damage (Kimberlin et al., 2015). Early intervention and follow up are important for providing developmental services for cCMV infected children (Marsico, 2017).

This research will focus specifically on cCMV awareness and education occurring during the infection prevention phases. While diagnosis and treatment are also critical phases, cCMV policies that work to prevent congenital infections entirely can help reduce the overall public health impact of the disease.

**cCMV Awareness and Education**

Pregnant women are commonly infected by exposure to young children who shed high loads of the virus through their urine and saliva (CDC, n.d.). Pregnant mothers are constantly at risk – mothering is hands on and intimate contact with children’s saliva and even urine is inevitable. Despite the challenges, one study in France showed that educating women of childbearing age on proper hygiene and cCMV risks can help reduce infection transmission (Vauloup-Fellous, 2009).

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4 Several scientific challenges have precluded an approved CMV vaccine including limited relevant animal models, unknown immune correlate of protection, re-infection reactivation, unclear role of anti-gB antibodies to control infection, CMV is not a classical viremia and non-standardized immunologic assays and diagnostics. (Cristina Cassetti, 2018).
Other pregnancy risks that depend on behavior change to protect neonatal health are included in pregnancy education like avoiding alcohol, sushi, and cat litter, but very few pregnancy care providers in the U.S. include cCMV in their patient education (Schaefer, 2020).

The lack of education regarding cCMV has led to a general lack of awareness of the virus among the U.S. population (Jeon et al., 2006). Despite the high incidence levels, CMV has lower awareness than many other neonatal conditions that are typically less frequent (Doutré, 2016). Figure 2.2 shows the results of a 2016 study that utilized data from the 2015 and 2016 HealthStyles™ surveys to evaluate awareness of varying childhood conditions among U.S. adults. The study found that in comparison to other childhood conditions, cCMV had the lowest level of awareness (6.7%) but tied for the highest number of U.S. annual incidence (6,000) (Doutré, 2016). Down syndrome, which tied cCMV for U.S. annual incidence, had the second highest level of awareness (85.4%) (Doutré, 2016).

**Figure 2.2 U.S. adult awareness of childhood conditions with approximate annual U.S. incidence of disability due to each condition**

![Graph showing U.S. adult awareness of childhood conditions with approximate annual U.S. incidence of disability due to each condition](image)

*Source: (Doutré, 2016)*
Previous Awareness and Education Studies

There are several studies that have evaluated knowledge of cCMV in the U.S. Prior studies have used a variety of different sampling criteria (e.g., women of childbearing age or all women) and have shown a range of levels of awareness around cCMV (7-33%) (Benou et al., 2021; Doutré; 2016). One of the first studies conducted in the U.S. in 2006 (Jeon et al., 2006) surveyed cCMV awareness among women of childbearing age across 7 different U.S. locations including Georgia, Alabama, Ohio, Utah, Virginia, Illinois, and Texas. This study included women who were recruited from pediatric and OB/GYN clinics, a student union center, and medical school. Out of the 643 women surveyed, 22% had previously heard of cCMV. There was no significant difference found in cCMV awareness by income or race/ethnicity but on average, women with higher levels of education had increased awareness of cCMV (p<.0001). Knowledge of hygiene measures to reduce the risk of CMV infection among participants who were aware of cCMV was low with most respondents unable to correctly identify symptoms of cCMV (Jeon et al., 2006).

In 2017, Tastad et al. conducted a survey of 726 women at the Minnesota State Fair to evaluate awareness of cCMV and attitudes toward screening. The study compared awareness between women ages 18-44 who had been pregnant within the past 10 years with women in the same age range who had had never been pregnant. Women who were pregnant more than 10 years ago were excluded. Only 20% of women had heard of cCMV and there was no significant difference in knowledge between never pregnant and recently pregnant women, highlighting the lack of cCMV education during pregnancy (Tastad, 2019).

A 2020 study assessed pregnant women’s knowledge of cCMV before and after an educational intervention – a cCMV educational handout which contained information from the CDC, Society of Maternal Fetal Medicine, and American College of Obstetricians and Gynecologists (ACOG). Participants completed a survey questionnaire prior to receiving the educational material to determine baseline knowledge. After the material was given to the study participant at their prenatal visit, they were instructed to review the materials on their own and a second questionnaire was administered at their next follow up appointment. A total of 215 women completed pre and post questionnaires revealing that 33% of women had previously heard of cCMV while 75% indicated an awareness of cCMV after education. When asked about their satisfaction with the education they received at the end of the study, the majority (96%) of women were satisfied, and 98% responded that they thought more women should receive the educational handout as part of standard prenatal care. These results highlight attitudes of pregnant women and the desire to know about potential pregnancy risks from cCMV (Schaefer, 2020).

Other developed countries have conducted similar surveys with different results. Results from Italy and France show higher levels of awareness when compared to U.S. study results. A 2011 survey in France that sampled pregnant women receiving prenatal care at two obstetrics clinics showed that 60% of women had heard of cCMV while 72% of those who had heard of cCMV knew that hygiene measures could help prevent infection (Cordier, 2012). In Italy, a
survey conducted in 2015 of men and women affiliated with Milan University (students, administrative staff, teaching staff) found that out of the 10,190 responses, 56% had heard of cCMV previously. Only 32% of respondents were aware that the virus could result in congenital sequelae. The study concluded that even among a highly educated group (45.4% were Bachelor or Master graduates) there was a limited and confused awareness of cCMV infection (Binda, 2016). When compared to the U.S., both France and Italy showed higher levels of cCMV awareness. Overall, studies in both the U.S. and other developed countries have reported low levels of awareness of cCMV in women.

**Current CMV Education and Awareness Practices in the United States**

**Legislation**

cCMV policy adoption in the United States to date has largely resulted from individual advocates working to implement policy at the state government level. Nine states currently require the state to provide public and professional education on cCMV to women of childbearing age, pregnancy care providers and at-risk workers, while one state only requires education for women of childbearing age5. Of these 10 states, only Utah provided state-level funding for these efforts. States that have passed cCMV legislation without appropriations typically rely on posting information regarding cCMV on their public health websites to fulfill their obligation. cCMV legislation is a newer trend with a cluster of legislation passed from 2013 to 2018. Interestingly, around this time, four other states also introduced legislation for cCMV education but were never passed (Table 2.1) (National CMV Foundation, n.d.).

<table>
<thead>
<tr>
<th>Year</th>
<th>State</th>
<th>Passed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>Utah</td>
<td>Yes</td>
</tr>
<tr>
<td>2015</td>
<td>Texas</td>
<td>Yes</td>
</tr>
<tr>
<td>2015</td>
<td>Hawaii</td>
<td>Yes</td>
</tr>
<tr>
<td>2016</td>
<td>Tennessee</td>
<td>Yes</td>
</tr>
<tr>
<td>2016</td>
<td>Illinois</td>
<td>Yes</td>
</tr>
<tr>
<td>2017</td>
<td>New York</td>
<td>Yes</td>
</tr>
</tbody>
</table>

5 At risk workers are individuals working with young children who shed high loads of CMV. (Occupational Safety and Health Administration, n.d.)
<table>
<thead>
<tr>
<th>Year</th>
<th>State</th>
<th>CMV Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017</td>
<td>Idaho</td>
<td>Yes</td>
</tr>
<tr>
<td>2017</td>
<td>Iowa</td>
<td>Yes</td>
</tr>
<tr>
<td>2017</td>
<td>Maine</td>
<td>No</td>
</tr>
<tr>
<td>2018</td>
<td>Colorado</td>
<td>Yes</td>
</tr>
<tr>
<td>2018</td>
<td>California</td>
<td>No</td>
</tr>
<tr>
<td>2019</td>
<td>Pennsylvania</td>
<td>No</td>
</tr>
<tr>
<td>2019</td>
<td>Michigan</td>
<td>No</td>
</tr>
<tr>
<td>2021</td>
<td>Minnesota</td>
<td>Yes</td>
</tr>
</tbody>
</table>

SOURCE: (National CMV Foundation, n.d.)

American College of Obstetricians and Gynecologists

ACOG, founded in 1951, is the leading professional membership organization for Obstetricians and Gynecologists in the U.S and currently includes more than 60,000 members. Part of ACOG’s responsibility is to produce best practice guidelines and educational materials that aid in improving women’s health (ACOG, undated). Regarding CMV, starting in 2000, ACOG encouraged infection control practices like hand hygiene to help decrease in-utero infection and recommended that OB/GYNs counsel pregnant women on preventative practices like cautious handling of CMV-infected articles (ACOG, 2000). In 2007, ACOG conducted a nationally representative survey of OB/GYNs to determine both CMV knowledge and practices. The survey found that 90% of OB/GYNs knew that proper hand hygiene could reduce the risk of infection but only 44% counseled their patients on ways to prevent CMV infection (CDC, 2007).

Despite previously recommending patient education on CMV prevention practices, in 2015 ACOG updated their guideline to no longer recommend patient counseling to reduce the risk of CMV infection (ACOG, 2015). The Vice President of ACOG at the time, Dr. Christopher Zahn, said that “doctors needed to focus on conditions with proven interventions and let patients dictate the discussion” (Saint Louis, 2016). Dr. Zahn also indicated that conversations during pregnancy are patient driven with too many topics to discuss during patient visits (Saint Louis, 2016).

Utah’s cCMV Public Health Initiative

In 2013, Utah passed legislation H.B. 81 UCA 26-10-10, “Cytomegalovirus Public Health Initiative” that directed the Utah Department of Health (UDOH) to establish a public education program around CMV infection and to screen babies who fail the newborn hearing screening test(s) for CMV within 21 days of age and to inform the parents regarding birth defects caused
by cCMV and available methods of treatment. The bill was chiefly sponsored by Representative Ronda Rudd Menlove whose granddaughter was diagnosed with cCMV. The bill went into effect on July 1, 2013, with an annual State General Fund appropriation of $30,800; a $4,000 State General Fund appropriation was given for UDOH expenses in preparation for the state fiscal year (SFY) 2014 mandate start date (Menlove, et al., 2013). The appropriation was to fund a 0.5 full time equivalent educator and educational materials. In SFY 2015, an additional $40,000 was secured by Representative Menlove from the State General Fund to help with additional expenses incurred from planning and hosting in Salt Lake City the first National Congenital CMV Public Health & Policy Conference. The $70,800 appropriation remained until the funding was removed beginning SFY 2021 (7/1/20) due to state COVID-19 budget cuts with the sentiment that the programs’ educational goal had been achieved, but without any evaluation of the state public health initiative.

H.B. 81 UCA 26-10-10 required the public education program to inform pregnant women and women who may become pregnant of the following (Menlove, et al., 2013):

- Incidence of CMV
- Transmission of CMV to pregnant women and women who may become pregnant
- Birth defects caused by cCMV
- Methods of diagnosing cCMV
- Available preventative measures

Additionally, H.B. 81 dictated that UDOH provide these materials to childcare programs, school nurses, health care facilities, health educators, religious organizations offering children’s programs and health care providers caring for pregnant women (Menlove, et al., 2013). During the seven years of the cCMV Public Health Initiative, UDOH distributed brochures and educational materials to the various groups, conducted large scale community public awareness campaigns, local and statewide presentations, and still includes information regarding cCMV on their website, in their educational materials and presentations (Utah Department of Health, n.d.). Some of the UDOH efforts to spread cCMV awareness was through their large-scale public health awareness campaign (McVicar, 2021) (See Figure 2.3).
Policy Implications

This dissertation contributes to the larger body of cCMV research by exploring the effects of a state-level public health solution to reduce cCMV infection through provider education. Additionally, this study identifies barriers surrounding cCMV patient counseling culture that could impact the overall effectiveness of any provider education efforts. While several studies have been published regarding awareness and knowledge around cCMV of various populations, there are no available studies that have compared pregnancy care provider cCMV knowledge and preventative counseling practices between a state with and without a cCMV health education intervention. To date, infection prevention counseling is the only available mechanism to reduce CMV infections in pregnant women. A published French study (Billette de Villemeur, 2020) found that women responded positively to counseling, resulting in behavioral changes during pregnancy and overall reductions in cCMV infection. cCMV has been noted as a public health emergency but there are no widely accepted policy solutions to help reduce cCMV infections (Cannon, 2005). Utah is the first state to broadly adopt a public health education intervention regarding cCMV. The comparison of Utah and Nevada represents an interesting observational study with implications for implementation across other states.
Furthermore, there are broader policy implications for this work. Utah’s cCMV public health initiative also serves as a case study for other states considering policy solutions to affect provider practices through legislation, not limited to cCMV. Earlier I proposed the use of the DIKW framework to contextualize the dissemination process of moving providers from public health information to knowledge and ultimately to wisdom (Ackoff, 1989). The DIKW pyramid helps visualize and pinpoint where barriers occur in knowledge dissemination, causing a breakdown in the health education process. This study examines these broader implications to inform advocates, policy makers and public health stakeholders.
Chapter 3. Provider Survey Methodology: Reaching a Hard-to-Reach Population

Background

To examine the impact of Utah’s cCMV public health initiative, I decided to focus on the pregnancy care provider population. As one of the key demographics targeted by Utah’s campaign, pregnancy care providers serve an important role in the prevention of cCMV. Pregnancy care providers interact with pregnant women every day in their jobs, providing the opportunity to discuss cCMV preventative measures with their patients.

Medical providers are a highly sought out group for research. Their status as front-line workers place them in a unique position to offer insights into the $4.1 trillion-dollar U.S. healthcare industry (Hartman et al., 2022). However, their demanding schedules and billing structure also make it difficult to recruit them as subjects for research, as they have opportunity costs for survey completion or participation in interviews. The high value of their time creates a decreased effectiveness of using incentives for recruitment (Cook et al., 2016). Additionally, providers typically have office staff who act as gatekeepers making it difficult to speak directly with them (Flanigan et al., 2008). Not unexpectedly, providers on average have a survey response rate 10% lower than the general population (Cummings et al., 2001). This study offers lessons learned from a mixed mode survey campaign across two states as I examine various recruitment techniques and resulting survey response rates.

In this chapter, I explain my survey and interview recruitment approach through a web and mail-based survey. I examine provider response rates to a multimode survey of pregnancy care providers in Utah and Nevada on cCMV knowledge and counseling practices for preventative measures. I provide an overview of lessons learned for conducting survey research with this important but difficult to reach population. All survey research was approved by RAND’s Human Subject Protection Committee.

Survey Participants

For this dissertation survey, the pregnancy care population of interest included OB/GYN attending physicians and residents, Midwives, Family Medicine Physicians, Maternal Fetal Medicine Physicians, Nurse Practitioners and Physician Assistants. Providers were excluded if they practiced in settings that did not provide continuous care like urgent care, cosmetic surgery

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6 The National Health Expenditure Accounts (NHEA) estimated that the U.S. spent $4.1 trillion on health care in 2020, 19.7% of the U.S. Gross Domestic Product. (Hartman et al., 2022)
practices, geriatric specialty care practices, cancer treatment centers, and therapy or rehab centers. Additionally, providers were only included if they were practicing in Utah and Nevada at the time of the survey. Providers licensed but not practicing in these states were excluded.


Table 3.1. Population Sizes

<table>
<thead>
<tr>
<th>Population</th>
<th>Utah</th>
<th>Nevada</th>
</tr>
</thead>
<tbody>
<tr>
<td>OB/GYN Physicians</td>
<td>n=230</td>
<td>n=305</td>
</tr>
<tr>
<td>Family Medicine Physicians</td>
<td>n=880</td>
<td>n=630</td>
</tr>
<tr>
<td>Certified Nurse Midwives</td>
<td>n=90</td>
<td>n=6</td>
</tr>
<tr>
<td>Nurse Practitioners in Women’s Health</td>
<td>n=156</td>
<td>n=119</td>
</tr>
<tr>
<td>Physician Assistants</td>
<td>n=1,410</td>
<td>n=730</td>
</tr>
</tbody>
</table>

7 This number includes those who do not practice in a continuous care setting.
8 This number represents all Physician Assistants in each state and is not specific to women’s health or pregnancy care specifically.

18
Maternal Fetal Medicine Physicians  
n=22  
n=12  
Total  
n=2,788  
N=1,802


Recruitment Strategy

My recruitment strategy evolved over time as I encountered challenges and worked to piece meal a contact list. I began with a web based SurveyMonkey survey that required obtaining provider email addresses. However, provider email addresses are not widely available to the public. To recruit providers for the web survey, I turned to four main resources:

- Contact list collected from a previous web-based survey
- Commercially available contact lists
- Connecting with key individuals to distribute the survey
- Internet searching

For Utah, UDOH provided a previously compiled list of pregnancy care providers (n=247) in the state from an earlier survey. The list included OB/GYNs, MFM physicians, Nurse Practitioners, and Midwives. The list was from 2017 and 94 of the emails had a hard bounce but 74 of the bounces were from a company that no longer existed, making the email addresses inactive, leaving 153 valid email addresses.

Without a previously collected list of contacts for Nevada, I first turned to commercially available lists. Ultimately, I obtained a list from Integrated Medical Database (iMD). iMD receives their contact information from an American Medical Association database, with supplemental sourcing from the state boards and federal agencies such as the Center for Medicare & Medicaid. The list is generally comprised of providers’ personal emails, as this is the preferred email of the physicians for 3rd party communications, and according to iMD, providers tend to be more responsive when using their personal emails than the professional addresses. The list is updated monthly, processed against the USPS National Change of Address database regularly, delivery point validated, and phone verified several times a year. Email permissions were passed in accordance with CAN-SPAM law and best practices for B2B data collection.

In the first batch, iMD provided a total list of 1,636 providers in Nevada including Medical Doctors and Doctors of Osteopathy (n=1,052), Nurse Practitioners (n=481), and Physician Assistants (n=103) that specialize in OB/GYN and family medicine. The list included many contacts that did not meet the inclusion criteria. A total of 468 providers were removed from the contact list because they practiced in a setting that was not a continuous care practice. Another 165 Nevada providers had email addresses that bounced back (e.g., were not delivered). Additionally, the list provided for Utah did not contain family medicine physicians. To address
the gap, I ordered a commercially available list from iMD of 725 family medicine and internal medicine physicians practicing in a primary care setting in Utah.

Another recruitment strategy involved identifying and recruiting key individuals as partners to help distribute the survey and encourage colleagues to participate. The aim of using a known physician’s name to send the invitation was to add peer influence and to increase the odds of physicians’ opening the email and taking the survey. Key individuals included office managers, outreach leaders at medical organizations (e.g., ACOG, Midwife Associations) clinical research managers and medical school staff. I used a combination of the commercial and UDOH provided contact lists as well as searching through medical school directories to identify key individuals and their contact information. I sent personalized emails to each key individual by name requesting their help. I called and/or emailed office managers and asked if they could help distribute the survey to staff in their practice. Two key individuals in OB/GYN departments at medical schools in Utah and Nevada agreed to participate as well as two practice managers for women’s health clinics. The Nevada email was distributed out to 37 individual providers and the Utah email went out to 63 providers.

Lastly, I utilized the internet to fill in any gaps. Since the Nevada list through iMD did not explicitly include midwives (Nurse Practitioners were included that can be practicing as Certified Nurse Midwives), I first collected contact information for this population. Additionally, I mined contact information from the OB/GYN and Certified Nurse Midwife departments at the three medical schools across Utah and Nevada since universities publish professor contact information. Altogether, I gathered an additional 52 contacts in Utah and 22 in Nevada with this approach.

Ultimately, I decided not to offer incentives with my survey. Historically, incentives for providers have not yielded improved response rates (Cook et al., 2016). Additionally, I was limited by my dissertation funding and had to strategically prioritize other costs. Instead of offering incentives, I appealed to the providers’ good will to help a PhD student.

Survey Administration

My survey administration approach was an iterative process, evolving throughout my data collection phase as I learned what did and did not work. What started out as an email only administrated survey, morphed into multimode to increase response rates.

Email

In January 2022, I sent out my first survey request via Outlook to the Nevada providers. The non-personalized email provided a link to the SurveyMonkey survey as well as a request for participation in a phone interview. All recruitment materials can be found in Appendix A.

Because this approach yielded low response rates, I updated my recruitment email to include a more personal request and simplified language, disclosing details about my motivation for the
survey and a picture of my cCMV impacted son Jack. Lastly, key individuals I recruited in Nevada and Utah sent out the survey email to providers in their practice or departments in May and June. One Department Chair for women’s health at a medical school forwarded the recruitment email to their entire department with an introduction noting their personal support. Another key individual at a different medical school sent out the recruitment email to all OB/GYN professors and residents. Finally, two practice managers forwarded the recruitment email to all providers in their practice. Figure 3.1 illustrates an overview of the survey administration timeline.

**Figure 3.1 Survey Administration Process Timeline**

- **Nevada**
  - 1st round: Non-personal recruitment email
  - 2nd round: Personalized recruitment email
  - 3rd round: Email sent by key individual

- **Utah**
  - 1st round: Personalized recruitment email
  - 2nd round: Email sent by key individual
  - 3rd round: Personalized recruitment email

NOTE: All dates were in 2022. The 3rd Nevada and 2nd Utah rounds of survey recruitment were both sent by a key individual within a provider organization.

**Mail**

To help increase the number of responses, I piloted a mail-administered survey to evaluate effectiveness before launching a full-scale mail survey. I selected 13 of the largest women’s health clinics in Nevada from the iMD contact list and mailed out envelopes with recruitment letters, survey questions and metered business reply envelopes to 100 providers. Recruitment letters included a QR code for providers to scan if they preferred to take the web-based survey instead of completing the paper copy. Due to the low number of responses (n=3), I did not launch a full-scale mail administered survey.
Response Rate Results

Of the 1,062 eligible providers contacted in Nevada, 91 providers responded to the survey for an overall response rate of 8.6%. In Utah, out of the 985 eligible providers contacted, 121 providers completed the survey for an overall response rate of 12.3%. The response rates for the various survey modes and recruitment approaches are shown in Table 3.2. Response rates varied across survey mode and recruitment approaches. Emailing providers directly yielded lower response rates than through a key individual and the mail survey had the lowest response rate of all survey modes.

<table>
<thead>
<tr>
<th>Survey Mode</th>
<th>Recruitment Approach</th>
<th>Utah</th>
<th>Nevada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web</td>
<td>Direct Email</td>
<td>10.5% (97/922)</td>
<td>6.8% (70/1025)</td>
</tr>
<tr>
<td>Web</td>
<td>Key Individual Email</td>
<td>38% (24/63)</td>
<td>48.6% (18/37)</td>
</tr>
<tr>
<td>Mail</td>
<td>Direct Mail</td>
<td>Not applicable</td>
<td>3.5% (3/86)</td>
</tr>
<tr>
<td>Combined</td>
<td>Combined</td>
<td>12.3% (121/985)</td>
<td>8.6% (91/1,062)</td>
</tr>
</tbody>
</table>

The response rates by timing of the reminders for the direct email campaigns are graphed for Nevada (Figure 3.2) and Utah (Figure 3.3). For both phases of the Nevada web-survey, the first recruitment email yielded the largest response rates (Figures 3.2). Over time, response rates diminished but spiked with follow up emails for both phases. The Utah survey followed a different pattern and saw an increase in responses for the second email request then diminishing during the first phase of the email survey campaign (Figure 3.3). The third phase however saw the greatest number of responses from the fourth recruitment email (Figure 3.4). For both Figure 3.3 and 3.4, the third phase is not included because this was managed by the key individual, and I did not have insight into the email reminder schedule.

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9 Mail survey was sent to providers who had received an email survey as well, 86 providers were selected from the list of 1,025 Nevada providers.
Figure 3.2. Nevada Direct Email Recruitment Responses Over Time with 3 Email Reminders

NOTE: The third phase is not included because this was managed by the key individual, and I did not have insight into the email reminder schedule.
I examined responses by day of the week across the Utah and Nevada direct email recruitment campaigns (Figure 3.4). Not surprisingly, the lowest number of responses occurred over the weekends. The highest number of total responses were recorded on Mondays.
Discussion

Response rate optimization is critical for survey researchers to ensure adequate population sampling and help improve generalizability of results. With limited resources, it is important to know how to improve overall effectiveness. I deployed a web-based and mail survey for pregnancy care providers in Utah and Nevada across multiple health care systems with various recruitment strategies (personal recruitment approach, endorsed invitation from key individuals, multiple follow-ups) to help bolster response rates. This approach has been used in similar studies to help increase provider response rates with mixed results. Overall, my response rates were lower when compared to other similar studies. I was external to these health care systems creating additional challenges to data collection. A meta-analysis estimated overall healthcare professional response rates at 53% among several survey modes (Cho et al., 2013). However, a study that looked specifically at physician response to a web survey had a much lower overall response rate, 35% (Cunningham et al., 2015). Utilizing key individuals to distribute the email survey yielded the greatest response rates that were comparable to other similar studies (38% for Utah and 48.6% for Nevada).

My mail survey received the lowest total response rate (3.5%). However, the mail survey did not include follow-up outreach with non-responders and only included one round of mailed requests. Studies have shown that telephone call follow-ups to mail surveys helps increase response rates (Armstrong and Ashworth, 2000). I also used First Class mail and metered business letters to return the survey. Other studies have indicated that the use of stamps can be more effective over metered business letters. Another study found that the use of Certified Mail increased response rates by 16.5%. (Flanigan et al., 2008). Due to limited funding, I was not able to use the preferred Certified Mail.
Like other studies, I found a point in each phase of my surveys with diminishing returns to additional recruitment efforts (Cook et al., 2016). For all phases of the email survey request, I decided to stop additional follow-up emails when 1) I noticed many recipients were unsubscribing, reporting me as spam or sending me ‘angry’ emails and/or 2) survey responses were decreasing. One limitation of using Outlook is that recipients could not unsubscribe. Instead, they would send angry emails about receiving the survey request. I also started getting emails from people that they had already taken the survey. These factors weighed in my decision to cut off an email campaign.

There are several potential reasons for my lower response rates. Receiving an email from my Pardee RAND email address helped indicate I was a student, but I was also an unknown entity, and my email could have appeared as spam. Also, several organizations blocked my email before it even had a chance to reach the intended recipient. I kept my survey short (less than 5 minutes) to help reduce survey fatigue and increase response rates, but I had to get past the decision for a provider to click on my SurveyMonkey link.

For the Nevada survey, MailChimp helped me track clicks on the survey link versus opens. My best campaign had an open rate of 27.9% (n=420) with only 5.7% (n=24) clicking on the link. Additionally, I did not provide an incentive, largely due to funding limitations and prior mixed results on the effect on overall response rates (Cook et al., 2016). Finally, the topic of cCMV could have impacted the lower response rates as well. The topic of the survey can deter recipients (Flanigan et al., 2008). Topics that providers consider sensitive or uninteresting are not worthy of the opportunity cost to complete the survey (Flanigan et al., 2008). Surveys with topics relevant to a provider’s practice have been found to obtain higher response rates (Flanigan et al., 2008). My survey included family medicine physicians whose scope of practice is not solely focused on caring for pregnancy, perhaps making them less likely to be interested in the topic. Less than 50% of OB/GYNs have been reported to be knowledgeable of cCMV, possibly making them less interested in the survey (Ross et al., 2008).

All these factors combined could have contributed to the lower response rates. Despite these challenges to survey the pregnancy care provider population because their responses are not substitutable by others, they were the key demographic for my study. Gaining insights into their day-to-day cCMV counseling practices and knowledge could have only been answered by this group. Their unique feedback provides important insight into the differences between these two states and could not have been carried out with a different research method over the same length of time. The next chapter will report on an in-depth analysis of the collected survey data and discuss specific limitations for analyzing the data due to the low response rate.
Pregnancy care providers have a unique role in preventing cCMV. Their interactions with patients at critical time points including pre-conception and at the beginning of their pregnancy make them an important part of the effort to lower CMV transmissions during pregnancy. To better understand provider knowledge of cCMV and characteristics of their counseling practices regarding cCMV prevention for pregnant women, I invited pregnancy care providers in Utah and Nevada to complete a 5-minute survey. This chapter will primarily focus on Research Question 1: What are the cCMV prevention counseling practices and knowledge among pregnancy care providers in Utah and Nevada? There was one survey item also included to address Research Question 2: What are providers’ perceptions of barriers to educating patients about cCMV?

Methods

Participants

As discussed in Chapter 3, overall, response rates were 12.3% for Utah (n=121/985) and 8.5% for Nevada (n=91/1,062). After cleaning the data by removing those who selected “no” for the informed consent, incomplete responses and inclusion criteria, the final responses were lower (n=110 for Utah, n=68 for Nevada). Responses were primarily deleted for being incomplete or indicating they did not provide continuous care to women of childbearing age. Regarding sample size, a final survey sample in Utah of 110 providers resulted in a margin of error of +/- 8.8% with a 95% confidence level. For Nevada, a survey sample of 68 responses yielded a margin of error of +/- 11.5% with a 95% confidence level. This study aimed to balance margin of error and resource limitations and reflects an exploratory look at these populations, like other initial studies. See Chapter 3 for additional details regarding provider survey recruitment and response rates.

Measures

A survey instrument was developed based on a previous online survey of pregnancy care providers fielded by Utah’s Department of Health (UDOH) in 2017/2018 during the intervention. I started with Utah’s survey as it had already been tested on a population of providers. The 37-item UDOH survey contained several questions asking providers knowledge check questions about cCMV prevalence, transmission and sequelae. To help improve response rates, I wanted to keep my survey length under 5-minutes. I chose to trim the knowledge check portion of the survey but keep the counseling practice questions as there are other published studies in the
literature that focus specifically on provider cCMV knowledge and awareness (Ross et al., 2009). My survey was fielded nearly five years after the earlier UDOH version and also after the cCMV public health initiative funding ended in July 2020. Fielding my survey after UDOH stopped distributing materials provided insight into the longevity of the education campaign but also created the potential for recall bias if survey respondents did not accurately remember whether they received cCMV education materials from UDOH. Survey respondents in Utah also might have not been exposed to the cCMV campaign directly if they started practicing in Utah after July 2020. I did include a survey item for participants in Utah that asked about exposure to Utah’s cCMV public health campaign to identify direct exposure among the survey sample. This survey had an advantage over the previously fielded UDOH survey in that it compared responses between providers in Utah and another comparison state.

Prior to implementing my adapted survey, I conducted cognitive interviews (n=3) with health care providers to test out survey questions to ensure clarity and intent. Cognitive interview survey questions can be found in Appendix D. Based on feedback during the cognitive interviews I expanded and modified the questions and answer choices to be more explicit. One key finding from the cognitive interviews was the lack of clarity for the response choices for how frequently providers counsel their patients. The original question/response was:

About how frequently do you educate patients who are pregnant or trying to become pregnant regarding the risks and potential consequences of CMV infection during pregnancy?

a. Every patient  
b. Most patients  
c. Only when time permits  
d. Unsure  
e. I don’t educate patients  
f. Only certain patients (specify)

One interviewee brought up that other providers in a practice might be the one counseling patients, which could lead to a false conclusion that a patient wasn’t receiving CMV counseling. Another interviewee raised that CMV should be included for each option choice for clarity and to update the order of responses to go in decreasing order of a provider’s level of counseling. The response, “only certain patients” remained at the bottom since it had a box to write in an open-ended response. The response options were updated to the following:

a. I educate every patient about CMV  
b. I educate most patients about CMV  
c. I only educate patients when the time permits  
d. I don’t personally educate patients about CMV but someone else in my practice does  
e. My patients do not receive CMV education  
f. Unsure
g. Only certain patients (specify)

The survey focused on sources of cCMV knowledge (1 item), cCMV counseling practices (4 items) and for Utah participants, their experience with UDOH’s materials (2 items). Several questions had options to select all that applies and employed skip logic based on respondents’ answer choices. Appendix B contains the complete provider survey. To recruit for the interview portion of my dissertation, the last survey question was open-ended asking participants to provide their email address if they were interested in a follow up interview. Additionally, there were four questions to capture the demographics of the participants including their professional role, specialty, years practicing and the number of women between the ages of 18 and 44 typically seen per week.

Analysis

I calculated descriptive statistics for all variables. Two-sample t-tests were used to explore differences between responses from Utah and Nevada regarding education and counseling behaviors. Additionally, I performed a two-sample t-test to look at differences between counseling practices for providers in Utah who did and did not receive materials from UDOH. The survey item that asked providers how frequently they counsel patients regarding CMV infection during pregnancy served as the indicator of whether a provider counseled their patient. I calculated Cohen’s $d$ to determine the effect size between populations for survey responses that were statistically significant (p<0.05) to identify practical significance. I also calculated the minimum detectable effect (MDE) size for responses that were not statistically significant to determine if there was sufficient power to detect a statistical difference between populations, or a chance for a Type II error. Additionally, I performed a post-hoc power analysis with an alpha of 0.05 to test the difference between Utah and Nevada provider means regarding cCMV preventative counseling and between providers in Utah who did and did not receive cCMV materials. I performed a content analysis for select open-ended survey responses. Statistical analysis was done using STATA 16.1., College Station, TX: StataCorp LP.

Results

Participant Characteristics

Details of the sample characteristics are provided in Table 4.1. Most survey respondents in both Utah (55.5%) and Nevada (69.1%) were physicians followed by Certified Nurse Midwives in Utah (29.1%) and Nurse Practitioners in Nevada (22.2%). Certified Nurse Midwives are a specialized type of Nurse Practitioner. Physicians in the survey sample had a higher representation than the population for both states Utah (41% physicians) and Nevada (53% physicians). Physician assistants were underrepresented in my sample when compared to both state populations (Utah 1.8% vs. 51%, Nevada 0.0% vs. 40%). However, the percentage of
physician assistants in Utah and Nevada’s populations were calculated from labor statistics that were overrepresented because I could not determine the subgroup of physician assistants who practiced in the areas of women’s health or family/internal medicine. This also posed challenges to determine the total number of pregnancy care providers practicing in both states.

In Utah, OB/GYN was the most common specialty reported by providers who took the survey (46.4%). Family medicine physicians comprise 32% of the pregnancy care provider population in Utah but only 15.5% of the survey sample reported specializing in family medicine. In Nevada, the specialties OB/GYN and family practice were equally represented (44.1%). The population of physicians in Nevada who specialize in family medicine though is lower (35%) (Bureau of Labor Statistics, 2021). The lower representation of family practice in Utah survey respondents could have influenced how the results were interpreted. If family practice providers viewed cCMV preventative counseling as out of scope of their practice, the lower percentage of family practice providers in the Utah sample could have skewed those results to over report cCMV counseling, not reflective of the real population. Whereas the Nevada sample could have under reported cCMV counseling due to the higher percentage of family medicine providers who completed the survey. Maternal Fetal Medicine physicians were overrepresented in both states when compared to the population (Utah 1% vs. 18.2%, Nevada 1% vs. 7.4%). However, the large sample means that I was able to survey 91% of the population of Maternal Fetal Medicine physicians in Utah and 42% of the population in Nevada.

Most providers in both Utah (62.7%) and Nevada (57.4%) saw between 1 and 30 women of childbearing age per week. Some respondents in Utah (31.8%) and Nevada (36.8%) had between 0 and 5 years of experience with an overall average of 13.7 years of experience across both states. Looking deeper at the providers with 5 years or less of experiences, ten providers (Utah n=5 and Nevada n=5) indicated zero years of experience practicing as a pregnancy care provider. All ten indicated a specialty of either family practice or internal medicine. These providers potentially did not consider themselves as a pregnancy care provider (considered it out of scope) and therefore selected zero years of practice. The other potential reason for selecting zero is that they had only been practicing for less than one year at the time of the survey. Four providers in Utah had only one year of experience practicing as a pregnancy care provider at the time of the survey and therefore were not directly exposed to the intervention. While these providers likely did not have direct exposure to the intervention, they exist in Utah’s provider ecosystem that this public health initiative worked to shape. I have included them in this analysis but also performed a secondary analysis without them that can be found in Appendix E.

Table 4.1 Participant Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Utah (n=110)</th>
<th>Nevada (n=68)</th>
</tr>
</thead>
</table>
10 This was very close to the average years of practice among providers in the interviews (13.8 years).
<table>
<thead>
<tr>
<th>Profession</th>
<th>n (%)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midwife</td>
<td>44(40.0)</td>
<td>5(7.4)</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>2(1.8)</td>
<td>15(22.1)</td>
</tr>
<tr>
<td>Physician</td>
<td>61(55.5)</td>
<td>47(69.1)</td>
</tr>
<tr>
<td>Physician Assistant</td>
<td>2(1.8)</td>
<td>1(1.5)</td>
</tr>
<tr>
<td>RN</td>
<td>1(0.9)</td>
<td>0(0.0)</td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Practice</td>
<td>17 (15.5)</td>
<td>30 (44.1)</td>
</tr>
<tr>
<td>Internal Medicine</td>
<td>6 (5.5)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Maternal Newborn Nursing</td>
<td>1 (0.9)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Maternal-Fetal medicine</td>
<td>20 (18.2)</td>
<td>5 (7.4)</td>
</tr>
<tr>
<td>Midwifery</td>
<td>15 (13.6)</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Obstetrician/Gynecologist</td>
<td>51 (46.4)</td>
<td>30 (44.1)</td>
</tr>
<tr>
<td>Patients 18-44 per Week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-10</td>
<td>27 (24.5)</td>
<td>14 (20.6)</td>
</tr>
<tr>
<td>11-20</td>
<td>21 (19.1)</td>
<td>14 (20.6)</td>
</tr>
<tr>
<td>21-30</td>
<td>21 (19.1)</td>
<td>11 (16.2)</td>
</tr>
<tr>
<td>31-40</td>
<td>19 (17.3)</td>
<td>9 (13.2)</td>
</tr>
<tr>
<td>41-50</td>
<td>10 (9.1)</td>
<td>10 (14.7)</td>
</tr>
<tr>
<td>More than 50</td>
<td>12 (10.9)</td>
<td>10 (14.7)</td>
</tr>
<tr>
<td><strong>Time Practicing as Pregnancy</strong></td>
<td><strong>Care Provider (years)</strong></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>35 (31.8)</td>
<td>25 (36.8)</td>
</tr>
<tr>
<td>6-10</td>
<td>20 (18.2)</td>
<td>17 (25.0)</td>
</tr>
<tr>
<td>11-15</td>
<td>11 (10.0)</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td>16-20</td>
<td>14 (12.7)</td>
<td>8 (11.8)</td>
</tr>
<tr>
<td>21-25</td>
<td>8 (7.3)</td>
<td>7 (10.3)</td>
</tr>
<tr>
<td>26-30</td>
<td>9 (8.2)</td>
<td>4 (5.9)</td>
</tr>
<tr>
<td>31-35</td>
<td>5 (4.5)</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td>36-40</td>
<td>6 (5.5)</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>46-51</td>
<td>2 (1.8)</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

I completed a post-hoc power analysis with an alpha of 0.05 for the observed means regarding provider cCMV counseling for Utah and Nevada. I found that given the actual observations of 68 and 110 for Nevada and Utah respectively, only a 57% power was reached. Achieving less than 80% power creates the potential to not detect all true effects in the sample (Type II errors). Within Utah, when I looked at providers who did and did not receive UDOH materials, I achieved a power of 89% with an alpha of 0.05 when comparing the observed mean for cCMV counseling.
cCMV Education Sources

Participant responses to cCMV education sources are shown grouped by state in Table 4.2. I performed two-sample t-testing for each survey question to look for statistically significant differences in responses between the Utah and Nevada survey samples. Respondents in both Utah (83.6%) and Nevada (82.4%) predominantly reported learning about cCMV from formal medical training like medical school or nursing programs. Continuous education was a statistically and practically significant difference between Utah and Nevada providers (p < 0.01, Cohen’s $d = 0.50$) regarding education source. Utah providers were significantly more likely than Nevada providers to report learning about cCMV from continuous education (47.3% vs. 23.5%). UDOH conducted trainings regarding the cCMV newborn hearing targeted screening requirement for midwives as part of Utah’s cCMV legislation that would be considered by survey participants as continuous education. While there was a 10.6% difference on average between providers in Utah who learned about cCMV from other providers when compared to providers in Nevada, the MDE was 19% and therefore was not sufficient powered to detect a statistical difference. Similarly, there was not sufficient power to detect a difference between providers who responded that they were self-taught or do not know much about it (MDE of 16% and 14% respectively).

Table 4.2 Participant Responses to cCMV Education Sources

<table>
<thead>
<tr>
<th></th>
<th>Utah (n=110)</th>
<th>Nevada (n=68)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal medical training</td>
<td>92 (83.6%)</td>
<td>56 (82.4%)</td>
<td>0.82</td>
</tr>
<tr>
<td>Continuous education</td>
<td>52 (47.3%)</td>
<td>16 (23.5%)</td>
<td>**0.001</td>
</tr>
<tr>
<td>Other providers</td>
<td>36 (32.7%)</td>
<td>15 (22.1%)</td>
<td>0.13</td>
</tr>
<tr>
<td>Self-taught</td>
<td>21 (19.1%)</td>
<td>11 (16.2%)</td>
<td>0.63</td>
</tr>
<tr>
<td>Do not know much about it</td>
<td>16 (14.5)</td>
<td>8 (11.8%)</td>
<td>0.60</td>
</tr>
<tr>
<td>Other</td>
<td>5 (4.5%)</td>
<td>2 (2.9%)</td>
<td>0.60</td>
</tr>
</tbody>
</table>

NOTE: *Select all that apply question.

cCMV Counseling Frequency

In both states, some providers indicated that their patients who are pregnant or trying to become pregnant do not receive education regarding cCMV (30.9% in Utah and 47.1% in Nevada). Providers in Nevada were 16% more likely to report that their patients do not receive cCMV education (p < 0.05) when compared to providers in Utah with a medium effect size (Cohen’s $d = 0.34$). Additionally, providers in Utah were significantly more likely to report they educated most patients (13.6%, p < 0.05, Cohen’s $d = 0.31$) and certain patients (20.0%, p < 0.05, Cohen’s $d = 0.31$) than Nevada providers (Figure 4.1). These significant and practical findings suggest a difference between the two population’s cCMV counseling practices (Figure 4.1). The
remaining responses that did not show a statistically significant difference between provider populations were underpowered and had an MDE ranging between 11% and 14%.

**Figure 4.1 How Frequently Providers Counsel Women Who are Pregnant or Trying to Become Pregnant About cCMV**

Survey findings suggest that providers who do counsel patients regarding cCMV in Utah and Nevada were similar in the mode they used to counsel their patients regarding cCMV. For providers whose patients receive some form of cCMV counseling, respondents in both Utah and Nevada mostly indicated that their patients are counseled verbally in person during an appointment (Utah 59.2% and Nevada 61.1%). There were no statistically significant differences noted between Utah and Nevada providers for how they counsel their patients regarding cCMV but the sample was under powered; the MDE ranged from 11% to 28%. The measured differences in this sample between Utah and Nevada were all less than 11% for these responses. A larger sample size is required to ensure the detection of a statistical difference between providers in Utah and Nevada regarding how providers counsel their patients. (Table 4.3).

**Table 4.3 How Providers Counsel their Patients Regarding cCMV**

<table>
<thead>
<tr>
<th>Mode</th>
<th>Utah (n=76)</th>
<th>Nevada (n=36)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbally in person/during appointment</td>
<td>45 (59.2)</td>
<td>22 (61.1)</td>
<td>0.85</td>
</tr>
<tr>
<td>Electronic</td>
<td>4 (5.3)</td>
<td>2 (5.6)</td>
<td>0.95</td>
</tr>
<tr>
<td>Pamphlet/brochure</td>
<td>24 (31.6)</td>
<td>8 (22.2)</td>
<td>0.31</td>
</tr>
</tbody>
</table>
Outside resources & 9 (11.8) & 7 (19.4) & 0.29  
Others in the practice & 5 (6.6) & 6 (16.7) & 0.10  
Do not counsel & 12 (15.8) & 4 (11.1) & 0.51  
Other & 5 (6.6) & 1 (2.8) & 0.41  

NOTE: °Select all that apply question. +First skip logic question, those that selected “My patients do not receive CMV education” for previous question on counseling frequency skipped this question.

**Timing of cCMV Counseling**

The majority of Utah (50.0%) and Nevada (56.3%) respondents indicated they provide cCMV counseling during the first prenatal visit. More providers in Nevada (28.1%) indicated they provide cCMV counseling before a patient becomes pregnant than providers in Utah (18.8%). Nevada providers were significantly more likely to counsel patients at every visit (6.3%, n=2) than Utah providers (0.0%, p <0.05, Cohen’s d = 0.44). However, responses for this answer choice were low. When compared to Nevada, Utah respondents were significantly more likely to select “other” (34.4% for Utah vs. 9.4% for Nevada, p <0.01) with a medium effect size (Cohen’s d = 0.59) (See Table 4.4). There exists the potential that response that were not statistically significant were just underpowered. The MDE for these responses was higher than observed differences between Utah and Nevada providers (between 15 and 27%).

<table>
<thead>
<tr>
<th>Timing of Counseling</th>
<th>Utah (n=64)</th>
<th>Nevada (n=3)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every Visit</td>
<td>0 (0.0)</td>
<td>2 (6.3)</td>
<td>*0.04</td>
</tr>
<tr>
<td>Before she is pregnant</td>
<td>12 (18.8)</td>
<td>9 (28.1)</td>
<td>0.30</td>
</tr>
<tr>
<td>First prenatal visit</td>
<td>32 (50.0)</td>
<td>18 (56.3)</td>
<td>0.57</td>
</tr>
<tr>
<td>20 weeks gestation</td>
<td>1 (1.6)</td>
<td>3 (9.4)</td>
<td>0.07</td>
</tr>
<tr>
<td>When I remember</td>
<td>5 (4.7)</td>
<td>6 (18.8)</td>
<td>0.12</td>
</tr>
<tr>
<td>Do not counsel</td>
<td>3 (4.7)</td>
<td>2 (6.3)</td>
<td>0.75</td>
</tr>
<tr>
<td>Other</td>
<td>22 (34.4)</td>
<td>3 (9.4)</td>
<td>**0.008</td>
</tr>
</tbody>
</table>

NOTE: °Select all that apply question. ++ Second skip logic question, those that selected "My patients do not receive CMV education" for the previous question asking how their patients were being counseled skipped this question. * Statistically significant p<0.05. ** Statistically significant p <0.01.

Due to the large number of “other” responses and the statistical significance, I performed a content analysis on the open-ended answers and identified seven recurring responses (See Table 4.5). Most Utah providers indicated the timing of cCMV counseling depended on patient factors including risk factors or ultrasound findings (n=88) or they counseled during the end of the pregnancy during the 3rd trimester or postpartum (n=7). Some providers who noted they counseled at the end of a patient’s pregnancy called out counseling in response to postpartum cCMV targeted screening for babies who fail the newborn hearing screening.
**Table 4.5 Timing of cCMV Counseling Open Ended Responses**

<table>
<thead>
<tr>
<th>Timing of counseling: Other</th>
<th>Utah (N=22)</th>
<th>Nevada (N=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not counsel personally</td>
<td>33</td>
<td>11</td>
</tr>
<tr>
<td>Dependent on patient factors</td>
<td>88</td>
<td>1</td>
</tr>
<tr>
<td>Patient initiated</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Preconception</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>3rd trimester/postpartum</td>
<td>7</td>
<td>0</td>
</tr>
</tbody>
</table>

**Reasons for Not Providing cCMV Patient Counseling**

In Utah, 33.6% of providers identified “not enough time” as a reason why they don’t counsel patients regarding cCMV (See Figure 4.2). Many of the Nevada respondents (29.4%) indicated that cCMV being “not in the guidelines” was a reason for not counseling patients as well as “not enough time” (25.0%). Utah providers were 14% more likely to not counsel patients regarding CMV because they felt “not informed” when compared to Nevada. (p <0.05, Cohen’s d = 0.32)

While not a statistically significant difference, it is interesting to note that providers in Nevada were 10% more likely than providers in Utah to report they did not counsel because it was not in the guidelines and 8% more likely to not counsel because they did not see the benefit. The lack of statistical significance perhaps comes from being underpowered. There was a MDE of 19%, higher than the observed differences.

**Figure 4.2 Reasons for Not Counseling Patients Regarding cCMV**

* Significant p<0.05
A large percentage of respondents (24.5% for Utah, 16.2% for Nevada) selected the open-ended response of “other” and specified an additional reason for not counseling their patients. I performed a content analysis to identify subthemes within the 33 responses across the two states (See Table 4.6). Some participants in Utah (n=5) and Nevada (n=9) wrote in that they don’t frequently treat pregnant women often as a reason for not counseling. Utah respondents also specified lack of awareness of cCMV (n=5) and that not counseling presented a low risk (n=4).

Table 4.6 Reasons for Not Providing Counseling Open Ended Responses

<table>
<thead>
<tr>
<th>Reason for Not Counseling</th>
<th>Utah</th>
<th>Nevada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls under standard hygiene measures</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Lack of awareness</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Lack of treatment options</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Lack of treatment options, perceptions about unnecessary maternal anxiety and guilt</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Low risk</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Not clinically applicable</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Perceptions about unnecessary maternal anxiety and guilt</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Rarely treat pregnant women</td>
<td>5</td>
<td>9</td>
</tr>
</tbody>
</table>

Comparing Providers within Utah

Most participants (75.5%) in Utah did not remember receiving cCMV materials from UDOH or were unsure. Only 24.5% of providers indicated they did receive UDOH cCMV materials. Within the Utah survey sample, I grouped together providers that did not remember receiving materials and those indicated unsure to further analyze the impact of the intervention on provider counseling practices. Table 4.7 illustrates provider demographics between the two survey populations.

Table 4.7 Survey Participant Characteristics for Providers Who Did and Did Not Receive UDOH cCMV Materials

<table>
<thead>
<tr>
<th>Profession</th>
<th>Number Received UDOH Materials (n=27)</th>
<th>Number Did Not Receive UDOH Materials (n=83)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certified Nurse Midwife</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td>Certified Professional Midwife</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Licensed Midwife</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Physician</td>
<td>7</td>
<td>54</td>
</tr>
</tbody>
</table>
Most providers who indicated they received materials from UDOH were a type of midwife (70.4%) while physicians comprised the majority (65.1%) of providers that did not receive materials. Most providers (50.6%) who did not receive UDOH materials specialized in OB/GYN. For providers that did receive UDOH materials, 40.7% had a specialty of midwifery and 33.3% a specialty of OB/GYN.

To explore the relationship between receiving cCMV materials from UDOH and frequency of provider cCMV counseling, as well as reasons for not providing cCMV counseling to their patients, I performed a two-sample t-test (See Table 4.8).

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Received UDOH Materials (n=27)</th>
<th>Did Not Receive UDOH Materials (n=83)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician Assistant</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>RN</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Specialty</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Practice</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Internal Medicine</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Maternal Newborn Nursing</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Maternal-Fetal medicine</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Midwifery</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Obstetrician/Gynecologist</td>
<td>9</td>
<td>42</td>
</tr>
<tr>
<td><strong>Patients 18-44 per Week</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-10</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>11-20</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>21-30</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>31-40</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>41-50</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>More than 50</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td><strong>Time Practicing (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>6-10</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>11-15</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>16-20</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>21-25</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>26-30</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>31-35</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36-40</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>46-51</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 4.8 Comparing Utah Providers Who Did and Did Not Receive UDOH cCMV Materials
How frequently providers counsel patients

<table>
<thead>
<tr>
<th></th>
<th>My patients do not receive CMV education</th>
<th>Only certain patients</th>
<th>I educate most patients about CMV</th>
<th>Unsure</th>
<th>I only educate patients about CMV when time permits</th>
<th>I educate every patient about CMV</th>
<th>I don’t personally but someone else in my practice does</th>
<th>Incomplete</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3 (11.1)</td>
<td>5 (18.5)</td>
<td>8 (29.6)</td>
<td>1 (3.7)</td>
<td>4 (14.8)</td>
<td>5 (18.5)</td>
<td>1 (3.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td></td>
<td>31 (37.3)</td>
<td>17 (20.5)</td>
<td>7 (8.4)</td>
<td>13 (15.7)</td>
<td>6 (7.2)</td>
<td>4 (4.8)</td>
<td>4 (4.8)</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td></td>
<td><strong>0.01</strong></td>
<td>0.83</td>
<td><strong>0.005</strong></td>
<td>0.11</td>
<td>0.24</td>
<td>*0.02</td>
<td>0.81</td>
<td>0.57</td>
</tr>
</tbody>
</table>

Why providers do not provide CMV counseling

<table>
<thead>
<tr>
<th></th>
<th>Not enough time</th>
<th>Not informed</th>
<th>Not in the guidelines</th>
<th>Do educate</th>
<th>Don’t see benefit</th>
<th>Unsure</th>
<th>Another resource will educate</th>
<th>Someone else educates</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9 (33.3)</td>
<td>5 (18.5)</td>
<td>3 (11.1)</td>
<td>11 (40.7)</td>
<td>1 (3.7)</td>
<td>2 (7.4)</td>
<td>2 (7.4)</td>
<td>1 (3.7)</td>
<td>3 (11.1)</td>
</tr>
<tr>
<td></td>
<td>28 (33.7)</td>
<td>28 (33.7)</td>
<td>19 (22.9)</td>
<td>8 (9.6)</td>
<td>12 (14.5)</td>
<td>6 (7.2)</td>
<td>4 (4.8)</td>
<td>4 (4.8)</td>
<td>19 (22.9)</td>
</tr>
<tr>
<td></td>
<td>0.97</td>
<td>0.14</td>
<td>0.19</td>
<td>***0.000</td>
<td>0.13</td>
<td>0.98</td>
<td>0.61</td>
<td>0.81</td>
<td>0.18</td>
</tr>
</tbody>
</table>

NOTE: * Statistically significant p<0.05. ** Statistically significant p <0.01. *** Statistically significant p <0.001

Providers received cCMV materials from UDOH were significantly more likely to counsel their patients about cCMV (11.1% did not counsel vs. 37.3%, p <0.01, Cohen’s d = 0.58). Additionally, the population that received UDOH cCMV materials were significantly more likely to educate most patients about cCMV (29.6% vs. 8.4%, p <0.01, Cohen’s d = 0.63) and every patient (18.5% vs. 4.8%, p <0.05, Cohen’s d = 0.51). Providers receiving UDOH cCMV materials were significantly more likely to indicate they do educate patients regarding cCMV when asked why they don’t counsel patients (40.7% vs. 9.6%, p <0.001) with a large effect size (Cohen’s d = 0.87). Providers who did not receive UDOH cCMV materials identified “not enough time” (33.7%) and “not informed” (33.7%) as reasons for not providing counseling. Providers who selected “not informed” and did not receive UDOH materials (n=28) had varied years of experience with 32.1% reporting 0-5 years, 42.9% reporting 6-10 years and the remainder spanning 11-30 years and were predominantly comprised of providers specializing in OB/GYN (67.9%). Overall, there was a significant and practical significance between the populations in Utah that did and did not receive UDOH materials.

Utah’s public health initiative ended in July 2020. Examining further the group of 28 Utah survey participants with 0-5 years practicing as a pregnancy care provider who did not receive UDOH materials, five providers (14.9%) indicated zero years of experience. All five of these providers had specializations of family practice or internal medicine. The question asked participants how many years they have been practicing as a pregnancy care provider which could have been misinterpreted by respondents whose practice does not focus on treating pregnant
women like family medicine and internal medicine physicians and don’t see themselves as pregnancy care providers. The remaining 85.7% of providers in the 0–5-year group had between 1 and 5 years of experience as a pregnancy care provider. Ultimately, I decided to include the four Utah providers with 1 year of experience in this analysis. They were exposed to a potentially altered provider practice atmosphere that was shaped by the initiative and were therefore included. None of the significant or practical findings were altered by removing these individuals from this analysis between providers who did and did not receive materials from UDOH. The survey analysis without these providers can be found in Appendix E.

Discussion

This study sought to characterize cCMV knowledge and preventative counseling practices for pregnancy care providers in Utah, a state with a cCMV public health initiative and a comparison state. Most providers in both states reported learning about cCMV from formal medical training in settings like medical and nursing school. However, cCMV as a topic has been noted as being minimally covered in formal medical education (Benou et al., 2021). A 2022 study by Pesch and Muldoon surveyed primary care physicians and newborn hospitalists in Michigan regarding cCMV knowledge and practices. Most (72%) felt that cCMV was not sufficiently addressed in their medical training (Pesch and Muldoon, 2022). For my survey, providers in Utah (n=33) were 13.8% more likely than providers in Nevada to indicate being “not informed” as a reason they do not provide cCMV counseling to their patients, despite the public health initiative (p <0.05, Cohen’s $d = 0.32$). Out of the 33 Utah participants who cited being uninformed, 28 respondents did not remember receiving any cCMV materials from UDOH. Further examining these 28 participants, one provider reported practicing for zero years as a pregnancy care provider with most (67.9%) reporting greater than five years practicing. The provider who indicated they had zero years of experience as a pregnancy care provider specialized in internal medicine. They could have not viewed themselves as a pregnancy care provider and therefore reported never practicing as one (zero years of practice) or they had less than one year of practicing. Additionally, most (67.9%) of this population had an OB/GYN specialty. The remaining five providers who did receive materials but cited being “not informed” were practicing midwives. Two of these providers specified Utah as their source when asked about how they learned about cCMV. All five midwives specified that they received cCMV brochures from UDOH.

Most participants (75.5%) in Utah did not remember receiving cCMV materials from UDOH or were unsure. Additionally, there was not a statistically significant difference between Utah providers who did and did not receive UDOH cCMV materials in reporting feeling “not informed” as a barrier to counseling patients regarding cCMV. These survey findings highlight two challenges to moving from information to knowledge: getting information to providers and knowledge absorption. Information dissemination can be difficult, providers often do not review
education materials they receive in the mail. One study that evaluated a mass mailed educational campaign to increase provider preventative counseling for sexually transmitted diseases found that only two thirds of providers remembered receiving the materials and only one third remembered reviewing the materials in detail (Rabin et al., 1994). Another challenge is ensuring providers absorb information and develop tacit knowledge. One study that implemented a randomized control trial to examine the effects of a mailed continuing education program on improving physician performance for treating hypertension found that information transmitted in the campaign was soon forgotten. Additionally, there was no observed changes in provider performance regarding lowering patient blood pressures (Evans et al., 1986).

In both Utah (33.6%) and Nevada (25.0%), providers cited “lack of time” as a motive for not counseling patients. Despite lack of time, providers in both Utah (59.0%) and Nevada (61.1%) heavily relied on verbal counseling in person during appointments for cCMV prevention instead of other modes outside of the office visit. With constrained time, providers rely on guidelines for clinical decision-making to help reduce cognitive load (Laker et. al, 2018). But, as many providers in Nevada (29.4%) noted in the survey, a reason they do not discuss cCMV preventative measures with their patients is because it is “not in the guidelines”. While the CDC currently recommends educating pregnant women regarding cCMV, the U.S. medical organization ACOG currently does not recommend counseling pregnant women on cCMV preventative measures (CDC, n.d.; ACOG, 2015). ACOG’s guideline on how providers should counsel women about the prevention of contracting CMV states,

“Some have suggested that pregnant women should be instructed on the importance of personal hygiene and safe-handling techniques (e.g., The use of latex or nonlatex gloves and rigorous hand washing after exposure to potentially infected articles, such as diapers, or respiratory secretions), as well as avoidance of sharing utensils with or kissing young children if saliva is present. Such guidelines may be difficult to implement because they often are considered impractical or burdensome. At present, such patient instruction remains unproven as a method to reduce the risk of congenital CMV infection.” (ACOG, 2015)

Despite these noted barriers, my findings suggest providers who received UDOH cCMV materials were significantly more likely to educate their patients regarding cCMV than those who did not receive materials with a medium effect size (p <0.01, Cohen’s d = 0.58). Additionally, when compared to Nevada, Utah providers were significantly more likely to provide cCMV counseling to most or certain patients (p <0.05, Cohen’s d = 0.31). For the survey sample of Utah providers, the majority (55.5%) indicated their patients receive some form of cCMV counseling, after aggregating positive responses to cCMV counseling. When aggregating positive responses, most providers in Utah who received UDOH cCMV materials (85%) indicated their patients receive some form of cCMV counseling whereas only 47% of Utah providers who did not receive materials indicated they counsel patients in some way. Similarly, only 42.6% of Nevada providers indicated their patients receive some form of CMV
counseling. The percentage of providers in Utah who counsel their patients regarding cCMV are higher than reported national averages, with Nevada rates only slightly lower. A 2009 study that surveyed OB/GYNs across the U.S. found that only 44.2% of respondents reported counseling their patients regarding cCMV prevention (Ross et al., 2009).

Timing of cCMV preventative counseling is critical. Risk of medical complications to the baby are greatest during the first trimester (CDC, n.d.). Most providers who do counsel patients in Utah (50.0%) and Nevada (56.3%) talk to their patients about cCMV at the first prenatal visit. Utah providers were significantly more likely to choose “other” for timing (p <0.01, Cohen’s $d = 0.59$). Seven Utah providers (6.4%) specified in the open-ended response that they counseled during either the third trimester or postpartum. These third trimester conversations were most likely driven by Utah’s cCMV targeted screening program that requires all babies that fail the newborn hearing screening to be screened for cCMV. Counseling women about cCMV at the end of their pregnancy misses a key window for CMV transmission in utero. Some providers in the interviews mentioned that they counsel their patients regarding the need for targeted CMV screening during the third trimester so that they are not surprised by the testing in the postpartum phase.

This study had several limitations. Due to feasibility, sample sizes for both states were small and underpowered (<80%) for examining differences in responses between states. The low power of this study creates the potential that responses that were actually statistically significant were not detected. Results may not be generalizable to these provider populations across each state. There is a potential for social desirability bias if providers answered based on what they thought were the desired answers (Latkin et al., 2017). This could have led to an over reporting of providers who counsel their patients in both states. I included Utah providers who reported less than one year of practice and therefore potentially did not have direct exposure to the intervention. Including these providers could have led to an under reporting of cCMV counseling in Utah as it included providers who were potentially not practicing during the active part of the campaign.

Utah’s targeted screening requirements that were also part of the initial legislation could have increased awareness of cCMV among providers, making it challenging to isolate Utah provider’s exposure to cCMV education and awareness as solely part of the public health initiative. This study did not include the perspective of patients. Although other studies have examined OB/GYNs’ provider knowledge, attitudes, and practices, this is the first study to compare two states with and without a cCMV education intervention (Ross et al., 2009). Despite the limitations, the strength of this study comes from addressing a gap in the research literature of the effects of a state-wide cCMV public health initiative on provider cCMV education and counseling practices.
Chapter 5. “It seemed like basically ‘don’t mother’”: Pregnancy Care Provider CMV Counseling Perceptions

While the provider survey examined a high-level view of pregnancy care provider cCMV education and counseling practices in Utah and Nevada, I conducted a set of interviews with this population to further understand provider perceived barriers to conversing with patients regarding preventative cCMV measures. This chapter focuses on Research Question 2: What are providers’ perceptions of barriers to educating patients about cCMV?

Methodology

Participants

I conducted 16 semi-structured phone interviews with pregnancy care providers and a neonatologist practicing in Utah and Nevada between March and September 2022. Respondents were recruited through the pregnancy care provider survey discussed in the previous chapter. The last survey question was open-ended, asking respondents to provide their email address if interested in an interview. Furthermore, I asked each participant to recommend colleagues to contact at the end of each interview (snowball sampling). Providers were eligible for the survey if they were currently providing pregnancy care to women in Utah or Nevada. A neonatologist providing care to cCMV impacted infants, recommended by another interviewee, was included to capture experiences in the Neonatal Intensive Care provider population. Using the survey to recruit for the interviews created the opportunity for selection bias as this sample could be skewed by individuals that had strong opinions regarding cCMV preventative counseling and not representative of the larger provider population. The study protocol was approved by RAND’s Human Subjects Protection Committee. Each provider provided verbal informed consent at the beginning of each interview.

Data Collection

I developed an interview protocol loosely based on the provider survey with in-depth questions to further explore attitudes and barriers to patient counseling. The first six questions focused on provider background including title, specialty, years of practice, time practicing in their current state, number of women of childbearing age seen per week and patient demographics. The core interview questions followed a provider’s cCMV counseling decision

11 Women working in the NICU can be exposed to infants infected with cCMV and are targeted for prevention measures.
logic flow, including their knowledge of cCMV, cCMV counseling practices, and observed patient behavior modification as well as participant experiences with Utah’s Public Health Initiative materials. Table 5.1 highlights a sample of interview protocol questions. The full provider interview protocol can be found in Appendix C.

<table>
<thead>
<tr>
<th>Topics</th>
<th>Sample Questions</th>
</tr>
</thead>
</table>
| cCMV training and education   | What training and education have you received regarding cCMV as a pregnancy care provider?  
|                               | What did this training look like?                                                  
|                               | When did you receive this training?                                               |
| Provider cCMV counseling       | What discussions do you have, if any, about cCMV with your patients?              
|                               | In what circumstances would you choose not to provide education to a patient on CMV? |
|                               | Can you tell me a little bit about why you don’t counsel patients on cCMV?        
|                               | In what cases would you counsel patients regarding CMV?                           
|                               | Have you had any patients contract CMV while pregnant?                            |
| Patient Behavior Modification  | What conditions do you typically counsel for?                                     
|                               | How have you seen patients alter their behaviors in pregnancy?                    
|                               | In your experience, how have patients reacted to cCMV hand hygiene counseling?     |
| Utah Public Health Initiative  | [If located in Utah] What materials, if any, have you received from the Utah Department of Health regarding cCMV?  
|                               | If so, what did you think?                                                        
|                               | Did you learn anything new from the materials?                                    
|                               | Did you pass along any to your patients?                                          
|                               | How did the educational materials influence the ways in which you talk with your patients around the risks of cCMV? |

Provider interviews were recorded and ranged from 16 to 32 minutes with an average of 25 minutes. I transcribed each interview, de-identified any potentially identifying information (e.g., names, specific locations, and practices), and uploaded each transcript to a qualitative analysis software, Dedoose (Version 9.05.54, Sociocultural Research Consultants LLC, Los Angeles, CA).

Data Analysis

I developed a preliminary codebook from the interview protocol. One interview was coded with the initial codebook to test out and refine the codes. The codebook was updated and simplified to reflect themes in the data. All transcripts were then coded, including recoding the first interview in Dedoose. A thematic analysis of the coding was performed to identify recurring themes regarding barriers to clinical prenatal cCMV education (Ryan and Bernard, 2003). Themes are discussed later in this chapter.
After coding, I used a framework matrix to examine provider excerpts for each code (Gale et al., 2013). In the matrix, there was a row for each interviewed provider and columns for each code. Within the code columns, I exported the relevant excerpts for each provider from Dedoose. I then went through the collected excerpts to identify common patterns and emerging themes, documenting them in another column. Creating the matrix in a spreadsheet form in Excel allowed me to condense the information and easily look across the draft themes for each code in pivot tables. I then further refined and condensed my list of themes until I had a list that I thought captured all excerpts for that code, reaching thematic saturation. Next, I used “memoing” to help conceptualize the themes and provide clarity (Birks et al., 2008).

Not all questions were asked of each respondent since some questions were based on earlier responses. In this chapter, I identify themes that emerged both in response to specific questions and those that were spontaneously raised. I used the following frequency rule to describe the number of respondents who discussed a certain theme:

- **few**: less than 10 percent of participants
- **some**: more than 10 percent but less than 40 percent
- **many**: more than 40 percent but less than 75 percent
- **most**: more than 75 percent but less than 95 percent
- **almost all**: all participants or the vast majority (> 95 percent) gave similar answers, and the rest did not comment.

### Results

#### Demographic Characteristics

My sample consisted of 15 pregnancy care providers and one neonatologist (Table 5.2). The majority (56%, n=9) of the interviewees were a type of midwife (e.g., Certified Nurse Midwife, Licensed Midwife, etc.). Twenty-five percent (n=4) were Maternal Fetal Medicine physicians (MFM). There was one respondent each for Internal Medicine, Neonatology and Obstetrics/Gynecology (OB/GYN). Providers had been practicing between 2 and 37 years, with an average of 14 years. On average, providers saw 35 women of childbearing age per week and cared for different patient populations.

<table>
<thead>
<tr>
<th>Interview ID</th>
<th>Type of Practitioner</th>
<th>Time Practicing (Years)</th>
<th>No. of Women of Childbearing Age Seen per Week</th>
<th>Patient Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utah01</td>
<td>CNM</td>
<td>34</td>
<td>50</td>
<td>Cross-section of Utah population</td>
</tr>
<tr>
<td>Utah03</td>
<td>CNM</td>
<td>6</td>
<td>9</td>
<td>Cross-section of Utah population</td>
</tr>
</tbody>
</table>

12 Adapted from: https://www.evalacademy.com/articles/how-to-quantify-qualitative-data
I developed a decision flow model for provider cCMV pregnancy counseling based on theory of planned behavior (Shamblen et al., 2018). Four key domains emerged from the interviews: provider knowledge of cCMV, provider attitudes towards cCMV preventative counseling, provider cCMV pregnancy counseling practices, and perceived patient behavior modification. These key domains and respective sub-domains characterize provider perceptions and practices regarding cCMV pregnancy counseling and observed patient behavior modification. Table 5.3 outlines the four domains and twelve subdomains, with descriptions from the interviews. Below, I describe in detail themes in relation to key domain and sub-domains of cCMV pregnancy counseling.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider knowledge of cCMV</td>
<td>Knowledge proficiency</td>
<td>Pregnancy care provider knowledge of cCMV prevention measures like hand hygiene and avoiding sharing saliva with toddlers</td>
</tr>
<tr>
<td></td>
<td>Method of acquiring knowledge</td>
<td>Formal education and training through medical school or graduate school; experiential training through residency and fellowship; informal learning through research on one’s</td>
</tr>
</tbody>
</table>
own like journal clubs or reading articles; UDOH provided training and materials.

**cCMV experience**
Provider’s firsthand experience with cCMV in their practice with a look at feedback from birth follow up

**Provider beliefs towards cCMV preventative counseling**

<table>
<thead>
<tr>
<th>Belief Area</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness</td>
<td>Providers were not counseling regarding cCMV because they were unaware of prevention measures.</td>
</tr>
<tr>
<td>Perceptions about unrealistic prevention measures</td>
<td>Avoiding toddler saliva was seen as unrealistic for mothers with young children at home.</td>
</tr>
<tr>
<td>Perceptions about unnecessary maternal anxiety and guilt</td>
<td>Providers thought that counseling women regarding cCMV would cause additional anxiety and parental guilt if their child was born with cCMV.</td>
</tr>
<tr>
<td>Lack of treatment options</td>
<td>Lack of FDA approved treatment in pregnancy made providers feel uncomfortable talking to their patients about cCMV.</td>
</tr>
<tr>
<td>Falls under standard hygiene measures</td>
<td>Providers were reluctant to counsel patients specifically about cCMV because prevention fell under standard hygiene measures.</td>
</tr>
</tbody>
</table>

**Provider cCMV pregnancy counseling practices**

<table>
<thead>
<tr>
<th>Practice Area</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling initiation</td>
<td>cCMV counseling in pregnancy was initiated by both providers and patients. Providers initiated when patients had certain risk characteristics (health care worker, daycare worker).</td>
</tr>
<tr>
<td>Provider counseling behaviors</td>
<td>Providers counseled patients on a range of congenital conditions including other TORCH\textsuperscript{13} infections and avoiding raw foods to prevent Listeria. Sometimes providers screen their patients for active cases of cCMV if there are irregular findings on the ultrasound.</td>
</tr>
</tbody>
</table>

**Perceived patient behavior modification**

<table>
<thead>
<tr>
<th>Behavior Modification</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>General behavior modification</td>
<td>Providers perceived that their patients modified their behavior to protect their baby including quitting smoking, changing their diet, and exercising.</td>
</tr>
</tbody>
</table>

\textsuperscript{13} Toxoplasmosis, Rubella, Cytomegalovirus, Herpes (TORCH)
Provider Knowledge of cCMV

In this section, I will discuss the three subdomains that comprise provider knowledge of cCMV: cCMV knowledge proficiency, methods of acquiring knowledge, and cCMV experience. Provider cCMV knowledge collected through formal and informal learning opportunities shape a provider’s counseling practices.

**cCMV Knowledge Proficiency**

While some providers commented that they did not know much about cCMV, all participants indicated that they had previously heard of cCMV. Most providers had some knowledge of cCMV prevention measures. General hygiene like hand washing was most frequently mentioned (n=11) to prevent infection. Many providers discussed the more specific CMV prevention measure of not sharing saliva with your toddlers but only two mentioned the increased risk of exposure for women with children in daycare. Table 5.4 describes the various prevention measures and risk factors participants raised during the interviews.

**Table 5.4. cCMV prevention measures and risk factors raised by participants in interviews**

<table>
<thead>
<tr>
<th>Prevention Measures/Risk Factors</th>
<th>Number of interviewees who spontaneously raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand washing</td>
<td>11</td>
</tr>
<tr>
<td>Don’t share saliva with your toddler</td>
<td>6</td>
</tr>
<tr>
<td>Exposure to children attending daycare</td>
<td>2</td>
</tr>
<tr>
<td>Spreads through urine</td>
<td>2</td>
</tr>
<tr>
<td>Wear a condom</td>
<td>1</td>
</tr>
<tr>
<td>Avoid people who are sick</td>
<td>1</td>
</tr>
<tr>
<td>NICU worker limitations</td>
<td>1</td>
</tr>
</tbody>
</table>

**Methods of Acquiring Knowledge**

All but one of the providers reported they had received some form of training regarding cCMV. Many of the providers reported that their training occurred formally during medical school, graduate school, residency, or fellowship. A couple of providers also utilized informal methods like journal clubs and self-directed reading to further educate themselves about pregnancy care in-general and learned about cCMV in these venues. Providers noted that in their formal training, cCMV was lumped together with other congenital TORCH infections and not focused on cCMV specifically. Congenital CMV training and education occurred largely during residency and fellowship experiences, when their education was more focused on specialty care.
"Because it is so lumped in with all the other congenital infections, I think I did not have an appreciation until I became a resident and then even more as a fellow of the frequency with which people contract CMV during pregnancy and I think specifically it’s, these are the things that can happen if you get a virus while you are pregnant was the approach more so than then any direct CMV knowledge. When I was a resident though, certainly it comes up quite a bit more frequently in terms of people’s concerns over it and that sort of thing." (MFM)

When asked if they had received any cCMV training or materials from the Utah Department of Health, seven providers remembered they had received training while seven had no recollection of any training received\(^\text{14}\). Many providers noted that they are often overwhelmed with this type of information, which could have been received but overlooked. “Honestly, I don’t think so, but it is also possible in the thousands of emails that I get in a week that I have somewhere along the line, but I don’t think so.” (CNM)

A few providers first learned about cCMV at the Utah Department of Health sponsored trainings that focused on education regarding neonatal targeted cCMV screening for babies who fail the newborn hearing screening at birth. Providers remembered learning about cCMV neonatal testing during these trainings but not specific prevention practices. A couple pregnancy providers, in particular, noted they had received the training materials from the Utah Department of Health, but they found the measures to be unrealistic and did not change their counseling practices.

\(cCMV\) Experience

Pregnancy care providers described their personal experience with cCMV cases within their practice. Providers were split between having a positive case of congenitally transmitted CMV in their practice (n=6) and not (n=7). Two providers had women in their practice test positive for CMV but did not transfer the virus to their baby. All (n=3/3) MFM physicians had experience caring for women diagnosed with an active CMV infection in pregnancy, which aligned with their focus on caring for women with prenatal complications. Women suspected or diagnosed with active CMV in pregnancy are likely to be referred to an MFM physician for follow up care and monitoring, increasing their chances of coming across patients with known cCMV.

Midwives had less experience (n=2/8) with cCMV, perhaps because they typically handle uncomplicated births.

Providers’ experiences with cCMV were one of many factors that shaped their decision process of whether or not to counsel patients. As one provider noted, “It is just not something that I have really thought about probably because I haven’t had any babies that have had it.” (LM) Several providers noted lack of follow up as a barrier to knowledge of patients who had babies with confirmed cases of cCMV which can lead to a disconnect between perceptions around cCMV in a provider’s patient population and prevalence. When asked about awareness of

\(^{14}\) Two interviewees were not included because they were not applicable (one in Nevada and one neonatologist).
any positive cases of cCMV in their practice, one provider pointed out, “No and honestly that doesn’t mean that it has never happened; it just means it has never come back to us that information.” (CNM) One provider who cared for pregnant women in a substance abuse clinic could not comment because they did not know if their patients had babies who were positive for cCMV due to lack of follow up in their patient population.

In fact, birth follow up plays a key role in informing pregnancy care providers of a positive case of cCMV in their patient population, increasing the likelihood that they may have cared for families with a child with cCMV. However, in this sample, only one provider said that “I think some of my clients would probably tell me... I see babies through 6 weeks, they usually come back for postpartum visits so if it happened during the first 6 weeks, I would definitely know about it.” (LM).

Utah’s targeted screening program requires cCMV screening for all babies who fail the newborn hearing screening, the leading sequelae. One provider noted the potential lack of follow up for the newborn hearing screening results.

“I wouldn’t necessarily know if they [the baby] failed the hearing tests. Sometimes once we deliver them, the pediatricians are the ones doing those tests and they don’t tell us about the tests because their focus is to tell the parents about the tests.” (MFM)

Additionally, some providers shared that the newborn hearing screening helped increase feedback and identify positive cCMV cases.

“I don’t usually hear too much about it after birth but usually the ones that find out after birth because of the universal newborn hearing screening, most of those did not realize that they had become infected during pregnancy.” (LM)

Provider Beliefs Toward cCMV Counseling

Pregnancy care providers described five main reasons for not specifically counseling patients regarding CMV: 1) lack of awareness 2) perceptions about unrealistic prevention measures, 3) perceptions about unnecessary maternal anxiety and guilt 4) lack of treatment options, 5) prevention practices fall under standard hygiene measures.

Lack of awareness

A common barrier to counseling women regarding cCMV was a general lack of provider awareness. Some providers noted that, “I don’t know much about it” (CPM) but that they would like to learn more. Additionally, a provider who knew about cCMV lacked specific knowledge regarding prevalence, which impacted their decision regarding counseling, “I think the awareness part is important because it is more downplayed, and it is more prevalent than everyone is aware…I think the awareness part is important” (OB/GYN). Another provider who mentioned being uniformed on the topic shared that cCMV counseling was not in their practice protocol, contributing to a lack of awareness.
Perceptions about unrealistic prevention measures: “It seemed like basically ‘don’t mother’”

Among pregnancy care providers who were familiar with cCMV, many considered the recommended prevention measures for cCMV especially not sharing saliva with a toddler as unrealistic and difficult to implement. This was considered particularly challenging for pregnant women who already had a child at home.

“Good luck telling any mother to do that. Honestly, the reality of that is really tricky. It would definitely take a super consciousness; you would have to be very aware because it is just such a normal thing to say are you thirsty? Here, take a drink of my water bottle to your little kids.” (LM).

One provider mentioned that following these preventative measures would go so far as to negatively impact a women’s ability to mother by reducing parental warmth. Avoiding a toddler’s saliva means not kissing on the mouth, sharing food, and utensils, actions that are integral to caring for a child. By following these measures, a mother could come off cold, sterile, and unloving, contradictory to societal expectations around motherhood.

“I did look into this some time ago and it was like don’t share food with your toddler, don’t eat off the same spoon as your child who goes to daycare but it’s like – who is going to do that? That is what mothering is, it’s hands on, it’s full on. I felt like I did read some counseling materials about how to avoid CMV while you are pregnant, and it just seemed very unrealistic. It seemed like basically ‘don’t mother.’ Be sterile with your kid for somebody who already has children and at what benefit?” (CNM)

Toddlers attending daycare are particularly at risk due to the high exposure to the virus among other children (Bale et al., 1999). However, daycare may be the only childcare option for some parents, making it a difficult prevention measure, “People need to go to work, daycare does not stop existing. You can’t not send your child to daycare if that is your only option.” (MFM). Counseling women regarding these measures was perceived as unrealistic and also without sufficient evidence to back up its effectiveness.

Unnecessary maternal anxiety and guilt

Some providers felt that raising the potential for cCMV with their patients would cause unnecessary anxiety. They discussed a lack of control over contracting CMV and limited prevention measures that made it difficult to talk to patients about the virus. Providers did not want to “scare them” (CNM) or inflict undue distress about the risks and side effects of cCMV, especially if prevention measures were perceived as unrealistic. One provider even noted that, “There is harm in counseling about things that are fairly unrealistic to expect for someone who has other children.” (MFM)

Additionally, some providers did not want parents living with the guilt and agonizing over how they could have potentially prevented cCMV. With less straightforward preventative measures compared with other congenital conditions like toxoplasmosis that only requires
avoiding cat litter, cCMV prevention measures were viewed as potentially triggering for anxiety. This notion of not wanting mothers to experience guilt for something that was seen as unpreventable was raised by several providers who felt uncomfortable discussing CMV with their patients.

“Part of me has resistance to that because again it places the responsibility back on parents and there is already so much guilt in the U.S., so much trying to blame parents and pregnant people for everything that could go wrong with a pregnancy that I would hate for a mom to come in, for her infant to be infected with cCMV and her to be like, this is because I kissed my toddler on the mouth.” (MFM)

**Lack of treatment options**

Without an FDA-approved prenatal treatment for cCMV, some providers felt uncomfortable talking to their patients about the virus. Providers noted that the inability to treat cCMV in pregnant women makes it “a conversation that is difficult to have, we feel helpless. I don’t have anything to offer you.” (CNM) When CMV counseling does occur, patients will naturally ask about treatments and providers expressed the limitations of treatment options, “People always want to know, if I do contract it can you cure me of it? And the answer is no, I can’t.” (CNM) The absence of an approved and effective treatment for cCMV serves as a barrier to counseling women regarding their risks and prevention measures.

**Prevention measures fall under standard hygiene counseling**

While some providers did not counsel patients specifically regarding CMV prevention, they felt that these measures would be covered under standard hygiene counseling provided to pregnant women, “Nothing that we wouldn’t be advising people to do anyways. Like hand washing, if you are sick stay home, just nothing special.” (CNM) Providers talked about ways to avoid infection with their patients and the importance of healthy hygiene without calling out CMV specifically. Additionally, a few providers noted that the COVID-19 pandemic has created a greater awareness among the general population for hygiene measures and virus infection prevention that providers saw as encompassing CMV as well.

“I think most of it is just hygiene prevention to prevent the disease. You are pregnant so a lot of it comes down to hygiene, close proximity to those who are sick and hand washing as well. Maybe with COVID things have changed naturally for other reasons. I think it is more of a standard now for everyone in general. I think because we are now all doing it and wearing masks regularly, all those kind of things.” (OB/GYN)

**Provider cCMV Pregnancy Counseling Practices**

Counseling patients regarding cCMV prevention measures was broken down into two subdomains: counseling initiation (who starts the discussion) and provider counseling behaviors (how providers talk to their patients).
Counseling Initiation

Conversations regarding cCMV preventative infection measures were either initiated by the provider or patient during their appointments. Many providers who indicated they talked about cCMV with their patients shared that those conversations were patient driven during prenatal visits. Patients with previous knowledge of cCMV who initiated these discussions tended to work in a high exposure job\textsuperscript{15} (childcare or healthcare). One provider discussed the process around counseling patients:

“If we are having a conversation specifically about CMV, either because they are concerned about it or they read about it, then we start at the beginning and talk about how it is highly prevalent, how most people have been exposed to it, we go through all of it from the beginning. Our limited ability to identify it prenatally but that it caused a large burden of problems in the population and because of that, there are a handful of preventative measures that are recommended, some of which are simple and feel relatively straightforward and some of which don’t. If we are having a dedicated discussion, then I bring those up and mention them. Or if they ask about them specifically.” (MFM)

Providers who initiated a discussion around virus prevention in pregnancy counseled women who had known risk factors based on their professions (NICU nurse, daycare worker, health care worker) and exposure to kids in daycare. Not all of these conversations focused on CMV explicitly but tended to fall under general hygiene counseling. These questions regarding a patient’s profession were not in the protocol but would be discussed if they arose organically.

“As a clinician, I don’t necessarily... [talk about] it, and again, this is making me think of my own clinical practice. What I do tend to do is ask people, what do you do for work? Do you have any other kids at home? So, I ask my patients about their risk factors for it specifically and then that prompts whether I have a conversation about it or not. Do you have a kiddo in daycare? Do you work in a daycare? Do you work in an elementary school? The classic, are you exposed to a whole bunch of kids?” (CNM)

Many providers (7/16) shared that they did not counsel their patients regarding cCMV preventative practices. Providers reported that conversations around cCMV do not come up routinely and were not part of the standard of care in the provider’s practices.

“I would consider counseling patients if they worked in childcare but honestly do not counsel my patients. I also don’t ask patients as a standard what their profession is, so I am not screening every woman for this. I do have a lot of patients with toddlers at home who go to day care and are therefore exposed and at risk. I probably should counsel them too, but I don’t.” (CNM)

\textsuperscript{15} Women working in high exposure jobs were a targeted group of Utah’s public health intervention.
“Just to be honest, it hasn’t been a standard of care where I have worked so I haven’t included it. I thought once we were doing this study on CMV a few years ago, oh cool, that is something I will start doing because it will just be the standard here because I don’t know a lot about it and I haven’t been doing it but then nothing came of it. Nothing as far as I know have come through the pipeline updating our testing or protocol like that. It is one of those things I’m like, oh yeah, I really need to learn about that, but I haven’t.” (CNM)

However, some providers talked to their patients at the end of their pregnancy about cCMV in the context of targeted cCMV testing for infants who fail the newborn hearing screening. Additionally, MFM specialty care providers reported having discussions with patients regarding cCMV after irregular findings showed up on the ultrasound during pregnancy. In these cases, congenital CMV was not addressed by these providers during preconception counseling or early prenatal visits.

One provider who cared for women in a substance abuse clinic reported they always counseled patients regarding CMV. Pamphlets were provided to patients at intake visits that include CMV among other infections like Hepatitis C and HIV. Women at the clinic were screened for CMV as part of their health screening process.

Provider Counseling Behaviors

Many providers discussed several conditions with their patients during pregnancy counseling including Rubella, Herpes, Hepatitis C, Listeria, Mercury, and Toxoplasmosis. Depending on the condition, providers either counseled women on measures to prevent infection or recommended screening and possible treatment. Providers reported that toxoplasmosis, an illness most commonly spread through kitty litter, was frequently brought up with patients. Some providers also counseled patients on avoiding unpasteurized foods to prevent Listeria, not eating raw food like sushi or fish high in Mercury.

Patients were commonly screened for Rubella, Herpes, and Hepatitis C during prenatal screening. Providers perceived these conditions as different from cCMV in that treatment courses of action are available that could be taken if a patient tested positive.

“I think about all the things we screen for in prenatal care and one of the premises...we just added Hepatitis C screening at [Blinded Hospital] maybe 3 years ago and that is now recommend by the CDC and USPSTF but part of the thinking on why we added Hep C screening in pregnancy was that we can treat it. We can actually do something for them. We are not going to just tell you that you have Hep C, we can actually help your baby not get this and there are reasonable, we can’t make it go away, but there are reasonable treatments now for this now where there weren’t 20 years ago.” (CNM)

A few pregnancy care providers cited lack of time as a barrier to pregnancy counseling. With limited time, there is a constraint on providers to cover an expansive checklist with patients and competing demands.
“We have 40 minutes for a new OB appointment and within our chart, we use EPIC [medical record] charting, there is a whole list of things we like to go over at their first visit. There are things like how our practice works and what kind of visit schedule usually happens, and do they have a dentist, and do they wear their seatbelt when they are in the car. What kind of danger signs for when to they would want to call us and what phone number to call? Nutrition and exercise and smoking cessation all those sorts of things. We go through a whole list and talk for a long time about things and make sure we cover everything on the list.” (CNM)

During pregnancy, women can be screened to see if they have an active case of CMV or if amniocentesis can be conducted to confirm a congenital cCMV infection in the baby. Some providers discussed patient cCMV screening but identified lack of treatment options as a barrier to screening for cCMV.

“I don’t [screen] unless, because it is not recommended and also because the results are often difficult to interpret because of the way CMV antibodies don’t always follow the sort of predictable pattern that viral infections normally do with sort of suggesting a recent versus old infection. We don’t have a therapeutic option if we are concerned about infection, so we often end up just torturing ourselves with information that is difficult to interpret, produces a lot of anxiety and with very little actionable options. So, unless someone is symptomatic or if they think they had an exposure of if there are specific ultrasound findings that would prompt and evaluation like that. “(MFM)

Screening can also occur during the preconception phase to identify women who are CMV seronegative, who have never been infected (Leruez-Ville and Ville, 2020). Since women who become infected with CMV for the first time during their pregnancy are more likely to have babies with more severe cCMV sequelae, some non-U.S. countries promote screening women before they get pregnant so that they know their risk levels. One provider discussed barriers to preconception screening.

“‘I mean, I think the bulletin does say keep that in mind, high risk folks and you can consider screening them but again, what are you going to do with that information is the hard part for me. So, are you going to quit your job? I guess for me, the difference would be, I would counsel someone who is a daycare worker they should be washing their hands any ways for all the reasons you should do that. And if they wanted CMV screening, we could do that but it isn’t something I would routinely do.” (MFM)

Perceived Patient Behavior Modification

Two subdomains emerged for perceived patient behavior modification: general behavior modification and specific cCMV behavior modification. Since patients were not interviewed, any behavior modification mentioned was solely from the provider perspective. General behavior modification during pregnancy described observations of women’s openness and willingness to make changes to their lives in response to pregnancy. Additionally, since not all providers
counseled their patients regarding cCMV preventative measures, behavior modification for exercise, smoking and avoiding alcohol during pregnancy can provide insight into perceived general behavior modification.

**General behavior modification**

Overall, most providers shared that their patients were receptive to behavior modification. Pregnancy was seen as a particularly vulnerable time, “‘Yes, pregnancy is a time where patients want to do whatever they can to help protect their baby. They are definitely willing and able to change, I’ve seen it.’” (CNM) Providers witnessed patient’s quit smoking cold turkey, start exercising and change their diet, majorly altering their behavioral health.

“‘Certainty, oh my goodness, absolutely, not just related to CMV, related to all sorts of things. I've seen people who have been smokers for 20 years quit smoking. I've seen quit, cold turkey. It is amazing. I feel like pregnancy is this space and this sort of fits my doctoral project which was on addressing weight gain in pregnancy and addressing obesity. I've seen people completely alter their diets and their exercise routines. People who have never exercised before you tell them this will be helpful for your baby and all of a sudden, they will start exercising. It's this moment of... people will change behaviors that they have never been able to change before for their babies. The motivation is so big. It's this moment of hope that we as clinicians can utilize in a pretty remarkable way’”' (CNM)

**cCMV Behavior Modification**

When asked specifically about CMV behavior modifications, some providers had mixed responses about patient behavior. When counseled about ways to prevent cCMV, some patients went to extensive lengths to protect their baby including quitting their jobs in daycare centers. Others exercised caution with their toddlers and increased handwashing. These measures were viewed by women as feasible, “Occasionally, they will specifically ask why they shouldn’t share utensils with their young kids and then I will explain. Most of the time I think they feel like it is fairly approachable, and they say yeah, ok, that sounds good.” (MFM).

A few providers shared that not everyone was receptive to change. One provider noted that sometimes a patient, “will say, ‘you know what, I’ll take my chances’. Because they are like, that is just too much, I can’t take that on and also have 3 young kids, there is only so much I can do.” (CNM) Also, patients were resistant to acknowledging the virus in the current COVID-19 environment, “Most of them have no idea what it is, they are like, what are you talking about. It seems like a made-up disease. Right now, in Utah, we are struggling with public health stuff in general because of the political part of that.” (IM)

**Discussion**

I used semi-structured interviews of a mix of providers in Utah and Nevada to explore preventative cCMV counseling practices. I developed a conceptual model of key domains and
sub-domains within the provider counseling decision flow. The interviews with providers highlighted multiple barriers to engaging patients regarding cCMV prevention. First, respondents reported that cCMV coverage in their formal training and education was minimal to non-existent. This aligns with a recent systematic review of cCMV knowledge among healthcare providers that highlighted provider lack of education and awareness as a barrier to cCMV preventative counseling (Benou et al., 2021). While many providers were aware of hand washing to prevent cCMV infection, less than half of providers spontaneously identified other measures or risk factors. A 2007 survey by ACOG of Obstetricians/Gynecologists found, “Although 90% of OB/GYNs reported knowing that washing hands reduces the risk for CMV infection during pregnancy, a smaller proportion were aware that not sharing utensils (57%) and avoiding children’s’ saliva (55%) reduces infection risk” (Center for Disease Control, 2008). Additionally, without feedback loops, providers will not be aware of babies in their practice that tested positive for cCMV, further perpetuating an underestimate of cCMV prevalence (Benou et al., 2021).

Furthermore, providers reported that a lack of cCMV treatment options created uncomfortable conversations around CMV prevention counseling, creating an additional barrier. Currently, there are no recommended treatments for cCMV in pregnant women (Rawlinson et al., 2016). While there are other conditions providers felt comfortable discussing and screening for in pregnancy (e.g., genetic conditions without treatment), the uncertainty of transmission and broad range of sequelae pose unique challenges for cCMV pregnancy counseling.

Providers observed pregnant women change their behavior during pregnancy including quitting smoking but cCMV behavior modifications were perceived as unrealistic, potentially causing more harm than benefit. Additionally, providers were not convinced cCMV prevention measures would be effective, sharing a belief that contracting cCMV is out of one’s control. Yet pregnancy is already an anxious time for women and their families, with or without cCMV prevention counseling. A review by Araji et al. from 2020 indicated that 2020% of women have the onset of new general anxiety disorder (GAD) symptoms during pregnancy while the general population reported GAD ranges from 5.1-11.9%.

While the Utah Department of Health training regarding cCMV targeted screening was a source of cCMV knowledge among licensed midwives, they were unaware of cCMV prevention measures to share with their patients. Those who received Utah cCMV materials indicated it did not change their attitudes regarding cCMV counseling in pregnancy. Changing provider practice is difficult and lengthy, following a typical arc of seventeen years from idea to practice (Gupta et al., 2017).

There were several limitations in this analysis. Despite a lengthy recruitment effort, my interview sample was small and only included fifteen interviewees in Utah and one in Nevada, hindering generalizability and the ability to do a comparative analysis between the two states. Perhaps a reason why it was easier to recruit in Utah than in Nevada is that Utah providers were more familiar with cCMV due to the public health initiative in the state. Additionally, only one OB/GYN was interviewed, underrepresenting that population of pregnancy care providers and a
key demographic. If I had more time and funding, I would have kept recruitment open longer and tried other approaches to recruit OB/GYNs to interview. However, I exhausted my available recruitment strategies. With only one Nevada provider interviewee, I cannot draw comparisons between states. There is also the potential for selection bias. Participants who were willing to be interviewed could have been attracted to the study because they were uneducated regarding cCMV and wanted to learn about it or because they were familiar with cCMV and wanted to share their opinions, dominating the themes towards a population that does not counsel on cCMV preventative measures.

Another limitation is that only providers were interviewed regarding patient behavior modification, thus only presenting observations and perceptions around behavior change. A potential for follow on work would be to interview women about behavior modification during pregnancy to gather their perspectives and better understand the feasibility of cCMV preventative measures.

To my knowledge, this is the first attempt to create a conceptual model for cCMV pregnancy counseling practices at the provider level. Despite the limitations, the major strength in this study comes from the in-depth exploration of the reasons involved in a provider’s decision to counsel women regarding cCMV prevention measures, uncovering specific barriers and capturing the complexity of patient counseling. Targeting Utah, a state with a public health initiative to raise awareness and increase education regarding cCMV prevention, provided insight into provider attitudes and practices in a state with broad exposure to a cCMV intervention.
Chapter 6. Discussion and Conclusion

In this study, I explored the impact of the first state public health cCMV education initiative on pregnancy care providers’ knowledge, beliefs, and patient counseling practices through comparison to a similar state without cCMV education and awareness legislation. Without an approved FDA vaccine for the prevention of CMV infection during pregnancy, cCMV prevention solely relies on hygiene counseling for pregnant women or women looking to become pregnant. These findings aim to inform other states considering similar legislation to address congenital conditions that are potentially preventable through patient counseling.

Overall Findings

Overall, this study investigated two main research questions to explore how a state-wide cCMV education and awareness intervention shaped pregnancy care provider cCMV knowledge and counseling practices.

Research Question 1: What are the cCMV prevention counseling practices and knowledge among pregnancy care providers in Utah and Nevada?

Using surveys, I examined differences between pregnancy care providers in Utah and Nevada. Looking at the knowledge layer, providers in both Utah and Nevada predominantly learned about cCMV from formal training. However, Utah providers were 24% more likely to report learning about cCMV from continuous education ($p<0.01$, Cohen’s $d = 0.50$). From the interviews, most providers discussed receiving some form of training regarding cCMV. Training occurred formally but providers noted that cCMV was lumped together with other congenital conditions. Most providers had some knowledge of cCMV prevention measures like general hand hygiene but less than half were aware of specific cCMV measures like not sharing saliva with young children. Providers were split between having a positive case of congenitally transmitted CMV in their practice. All maternal fetal medicine physicians had experience caring for women infected with CMV during pregnancy while midwives reported having less experience with CMV infected patients.

Turning to the wisdom layer, for the survey sample of Utah providers, the majority (55.5%) indicated their patients receive some form of cCMV counseling, after aggregating positive responses to cCMV counseling. When aggregating positive responses, most providers in Utah who received UDOH cCMV materials (85%) indicated their patients receive some form of cCMV counseling whereas only 47% of Utah providers who did not receive materials indicated they counsel patients in some way. Similarly, only 42.6% of Nevada providers indicated their patients receive some form of CMV counseling. The percentage of providers in Utah who
counsel their patients regarding cCMV are higher than reported national averages, with Nevada rates only slightly lower. A 2009 study that surveyed OB/GYNs across the U.S. found that only 44.2% of respondents reported counseling their patients regarding cCMV prevention (Ross et al., 2009). These significant and practical findings suggest a difference between the two population’s cCMV counseling practices.

**Research Question 2: What are providers’ perceptions of barriers to educating patients about cCMV?**

While providers in Utah were more likely to counsel their patients regarding cCMV, a small number cited being uninformed as a reason they do not provide cCMV preventative counseling. Additionally, there was not a significant difference between Utah providers who did and did not receive UDOH cCMV materials in reporting feeling “not informed” as a barrier to counseling patients regarding cCMV in this sample. These findings identify a potential gap and limitation between receiving Utah’s public health materials (information), provider understanding (knowledge), and provider practices (wisdom) regarding CMV prevention counseling and suggest there are potential barriers at play to progress providers up the DIKW pyramid. I used a survey item and semi-structured interviews to explore barriers perceived by pregnancy care providers to cCMV patient counseling and contextualized my findings in the Data, Information, Knowledge, and Wisdom (DIKW) framework. Figure 6.11 illustrates the barriers identified in this study that keep providers from arriving at the final level (wisdom) that results in action.

![Figure 6.11 Data, Information, Knowledge, and Wisdom Pyramid](image-url)
Data to Information

The data layer serves as the foundation of the pyramid. Access to quality and quantity of data can serve as a barrier in progression to the information layer. In this study, providers perceived that a lack of treatment options for cCMV and limited evidence for the effectiveness of cCMV hygiene counseling were factors that disincentivized patient preventive counseling. Ultimately, it appears that a lack of confidence in the data translates to a lack of confidence in the information. There are no FDA approved treatments currently available for women who become infected with CMV during pregnancy. Additionally, there are no available CMV vaccines to prevent cCMV infection (Rawlinson et al., 2016). The uncertainty of CMV transmission to the baby and a wide range of sequelae pose unique challenges for cCMV conversations with patients.

Information to Knowledge

Providers discussed a lack of awareness and knowledge of cCMV as a reason why they don’t counsel their patients. While many providers were aware of hand washing to prevent cCMV infection, less than half of providers spontaneously identified other specific measures or risk factors like avoiding saliva of young children. Providers perceived that cCMV prevention fell under standard discussions around good hand hygiene and did not think it needed to be discussed specifically. As one provider noted, not being aware of the prevalence of cCMV contributes to the decision to not counsel as it is perceived as low risk. Survey respondents indicated their cCMV knowledge came from formal medical training like medical or nursing school. A few providers in Utah (6.4%) specified in the open-ended response of the survey that they counseled their patients during either the third trimester or postpartum missing a key window for CMV transmission prevention in utero. Additionally, some providers in the interviews mentioned that they counsel their patients regarding the need for targeted CMV screening during the third trimester so that their patients are not surprised by the CMV testing that may be required in the postpartum phase if their baby fails newborn hearing screening. Providers who are only talking to their patients about cCMV at the end of pregnancy are missing a key dimension of the initiative’s messaging, representing a gap in knowledge. Lastly, when providers don’t counsel women about cCMV, some indicated it is because it is not in the professional (ACOG) guidelines, a key source for OB/GYN information. These factors act as barriers from moving from the information to knowledge layer.

Knowledge to Wisdom

Provider’s beliefs shaped their practices and transfer from knowledge to wisdom. Providers perceived cCMV preventative measures, especially not sharing saliva with young children as unrealistic. One provider mentioned that following these preventative measures would go so far as to harmfully impact a women’s ability to mother by reducing parental warmth. Some providers felt that raising the potential for cCMV with their patients would cause unnecessary
anxiety. Partly because of the barrier of lack of treatment options for cCMV, talking to women about cCMV without being able to offer treatment was perceived to inflict undue distress. Additionally, some providers did not want parents living with the guilt of thinking they could have potentially prevented cCMV. Providers also highlighted lack of time as a barrier to counseling.

Surveying Providers: Lessons Learned

Through the implementation of a web and mail-based survey I examined the effectiveness of various recruitment strategies. Utilizing a key individual inside an organization to email information about the web-based survey yielded the highest response rates for both states. The first email of each recruitment campaign received the greatest number of responses. Additionally, recruitment reminders sent on Mondays returned the most responses. The piloted mail-based recruitment approach implemented in Nevada yielded the lowest level of response rates.

Policy Implications

From the findings in my study, I’ve identified four key policy implications across the individual layers of the DIKW pyramid.

Data: cCMV Education is Not Enough: Providers Need Evidence and Treatment Options Too

According to diffusion theory, among several attributes, providers consider relative advantage and complexity when deciding to adopt it into their practice (Dearing, 2009). Although a study has shown cCMV preventative counseling in women of childbearing age to be effective at reducing cCMV infections, the comparative value of hygiene measures to prevent CMV infection in pregnancy has limited evaluation (Billette de Villemeur, 2020). Additionally, this study was performed in France and not in a U.S. setting, posing external validity concerns and uncertainty regarding the strength of the evidence. A key barrier to disseminating cCMV preventative practices among pregnancy care providers is limited evidence which documents the effectiveness of hygiene measures to prevent infection during pregnancy, impacting providers’ view of its comparative advantage. Providers in this study were unsure if cCMV hygiene measures that they perceived as unrealistic would have an impact on preventing CMV infection in pregnancy. More research is required to evaluate the effectiveness of hygiene counseling to prevent cCMV to help reduce barriers to counseling.

Additionally, counseling patients about cCMV is complex. Without any available FDA treatments to prevent CMV infection or treat infections during pregnancy, providers felt uncomfortable talking to their patients about cCMV hygiene measures. If providers spoke with patients about CMV infection during pregnancy, they were concerned that the conversation
could turn to treatment options which are not available, thus creating perceived increased maternal anxiety. Options to both prevent and treat CMV infections during pregnancy are needed to reduce barriers to provider counseling and increase effectiveness of cCMV public health education.

**Information: The Role of Guidelines**

Clinical guidelines include recommendations meant to optimize patient care. Introduced in the 1970’s, guidelines are informed by systematic reviews of evidence and a valuation of the benefits and harms of various care options (Guerra-Farfan, et al., 2022). Guidelines help promote consistency of care across physicians and reduce provider cognitive burden (Klein, 2002). Currently, counseling women on ways to prevent CMV infection during pregnancy is recommended by the CDC but initiating counseling discussions with patients is not recommended in ACOG’s guidelines (CDC, n.d.) (ACOG, 2015). This places the decision to counsel at the practice level but none of the interviewees indicated cCMV was on their practice’s protocol of items to cover in patient counseling. The American Academy of Family Physician’s (AAFP) position paper on preconception care outlines various barriers to provider pregnancy counseling including inadequate reimbursement for these services in general (AAFP, n.d.). With limited coverage already for prenatal counseling, cCMV potentially faces a unique challenge for insurance reimbursement due to its absence in professional guidelines.

Survey and interview participants noted lack of time as a barrier to cCMV counseling, struggling to cover standard protocol items with their patients within the 40-minute appointment time slot. With the balance between time constraints and information to cover, guidelines inform scope of practice to help providers decide what to discuss during appointments with patients. A public health education campaign alone to improve provider cCMV counseling behaviors will likely have limitations if it is not also recommended in relevant guidelines. Survey participants in both Utah and Nevada cited professional guidelines as a barrier to counseling patients regarding cCMV. Public health, policy makers and advocacy stakeholders should consider these limitations when considering a public health initiative to increase counseling women of child-bearing age about cCMV preventative measures in pregnancy. If there is a known inconsistency between professional guidelines and an intervention, policy makers should explore other alternative groups to target without that tension. In the case of cCMV, that could look like broadening outreach to pediatricians who also come into contact with mothers of young children and less focus on OB/GYNs.

**Knowledge: Public Health Education is a Potential Policy Solution to Increase Pregnancy Care Provider cCMV Counseling with Limitations**

I found practical and statistically significant results between pregnancy care providers in Utah and Nevada regarding counseling patients about cCMV suggesting Utah’s public health initiative may have shaped provider counseling behavior. Additionally, providers in Utah who
received materials from UDOH were more likely to educate patients about cCMV compared to providers who did not receive. Although there were differences observed in whether providers in these two states counsel their patients about cCMV Utah providers were also more likely to indicate they don’t counsel patients regarding cCMV because they felt uninformed, albeit with a small sample size. There was no statistically significant difference between providers in Utah who did and did not receive UDOH materials in reporting being uninformed as a reason to not counsel their patients about cCMV prevention, suggesting that the public health information initiative alone is not enough to move providers from information to knowledge.

Most providers in Utah (83.6%) and Nevada (82.4%) learned about cCMV from formal medical training. However, cCMV as a topic has been identified as being minimally covered in formal medical education (Benou et al., 2021). A 2022 study by Pesch and Muldoon surveyed primary care physicians and newborn hospitalists in Michigan regarding cCMV knowledge and practices. Most (72%) felt that cCMV was not sufficiently addressed in their medical training (Pesch and Muldoon, 2022). Limited formal medical education on cCMV can drive states to consider other mechanisms to educate providers. But even in a state with a public health intervention, a few providers still felt uninformed about cCMV, suggesting that other paths should be considered in parallel.

A 2003 study examined a public health program in South Carolina that distributed brochures to all health care providers in the state who were expected to see women of child-bearing age to increase provider counseling on taking a multivitamin daily (Cullum, 2003). Noting that practicing providers had increasingly scarce time but an increasing requirement for continuous medical education (CME), the program implementers also provided CME offerings to further disseminate their message. Additionally, they recognized that altering provider counseling required more than just increasing knowledge and created an implementation tool called the Women’s Wellness Rx pad to address the most common cited barrier to counseling women regarding multivitamins: forgetting to bring up because of a lack of time and other issues to cover (Cullum, 2003). When considering other ways to shape provider behavior due to limitations from a sole public health education campaign, lack of time during clinic visits is another factor to be considered that can pose a barrier to implementing knowledge into action. Additional efforts to supplement an education campaign must also be mindful of time requirements on providers to ensure feasibility.

**Wisdom: Engaging Key Individuals**

One approach that has been documented in the literature to increase provider practice adoption is the utilization of opinion leaders (Lomas, 1991; Flodgren et al., 2019). Social Learning Theory postures that individuals seen as credible and trustworthy can help be agents of behavioral change. (Flodgren et al., 2019). Key individuals, also called opinion leaders, have been shown to be effective in altering provider practices and increasing provider adherence to guidelines (Lomas et al., 1991). Opinion leaders are recognized experts in their field and share
information about practice behaviors with their colleagues and follow up about their experiences (Flodgren et al., 2019). A 2003 study that examined three different state programs to increase provider preconception care found that utilizing key individuals to disseminate targeted health messages was critical to increasing patient counselling (Cullum, 2003).

Similarly, in this study, I observed the impact of a key individual on influencing provider survey participation. Survey response rates were highest when recruitment emails were sent by key individuals. Survey participants demonstrated trust when deciding to open the recruitment email and take personal time to respond to a request from the key individual. These are qualities described of opinion leaders which is important for facilitating provider behavior change. To help diffuse cCMV preventative counseling practices, a potential strategy to compliment the roll out of a state-wide public health initiative could be to find key individuals with social influence to disseminate information to their respective provider populations. Knowledge acquisition is likely not enough to change provider counseling behaviors. States looking to adopt cCMV education legislation should consider engaging key individuals to help disseminate information and achieve provider buy-in.

Limitations

This study had several limitations. The cross-sectional design only measured knowledge, beliefs, and counseling practices at one point in time and therefore is not a causal analysis. Data collection for this effort occurred between January and September 2022 but funding for Utah’s public health education initiative ended in July 2020. Although practicing in Utah at the time of the survey, providers included in this study might not have been practicing in Utah when the public health initiative was active. Additionally, looking at the intervention retrospectively might have limited the ability for providers to recall the intervention. However, this allowed for a retrospective look and reflection on provider’s knowledge retention. Because Utah providers included in this study might not have been exposed directly to the intervention, results reported potentially underrepresent the impact of the intervention as I treated all surveyed Utah providers as exposed when comparing to Nevada providers. I already had limited survey responses and did not include knowledge of Utah’s intervention as an inclusion criterion. If I had more time and resources, I could have considered including this as an inclusion criterion to ensure all Utah providers included in the study were exposed to the intervention. I tried to compensate for this by analyzing providers within Utah, comparing those who did and did not remember receiving UDOH materials and the impact on their counseling practices.

Another limitation is the potential for selection bias because individuals who are willing to complete the survey or be interviewed could be willing to do so because they already have more knowledge regarding cCMV. Additionally, there could be a potential for social desirability bias if survey participants responded how they thought they were supposed to respond (Latkin et al., 2017). These biases could have led to an overrepresentation of providers reporting they counsel.
patients regarding cCMV not reflecting the true population in Utah and Nevada. All survey responses were anonymous to try and reduce the potential for social desirability bias.

Low response rates in Utah and Nevada impacted generalizability to the entire population of providers and therefore survey results might not be representative of providers in both states. The limitation of only one interview in Nevada means that I could not compare those findings across both states. Despite these limitations, when comparing the average number of providers reporting they did not counsel patients regarding cCMV between the two states, I got a medium size effect (Cohen’s $d = 0.34$), suggesting practical significance in addition to statistical significance. This study though was underpowered (57%) creating the potential for falsely rejecting a null hypothesis. Responses that were not statistically significant could perhaps actually be significant but were unable to be detected as they fell below the MDE. Patient perspectives were out of scope for this work but may be considered for future work to look at the frequency and characteristics of provider cCMV preventative counseling. When weighing these findings, it’s imperative to note two factors that make Utah unique:

- Utah’s legislation included both an education and newborn targeted screening component. In addition to the education effort, infants born in Utah who fail the newborn hearing screening are screened for congenital CMV at birth (Menlove, et al., 2013).
- Utah has an active cCMV research community. The University of Utah has participated in 6 clinical trials to prevent CMV infection in adults, reduce CMV infection in utero and treat infants born with cCMV (clinical trials.gov, 2023.).

**Follow on Work**

This study examined Utah’s public health initiative from the perspective of pregnancy care providers but did not include women of childbearing age, another target of the intervention. Potential follow-on work could explore cCMV knowledge and awareness among women of childbearing in Utah and Nevada to further examine the impact of the intervention using surveys and semi-structured interviews. Expanding this work to look at the perspective of women would help to understand the reality of pregnancy counseling and the transfer of information, knowledge to wisdom for women of childbearing age.

Additionally, this study did not look at the impact of the targeted screening component of Utah’s cCMV public health initiative. Comparing incidence of cCMV in Utah and Nevada both pre and post Utah’s legislation could further help identify effects of the intervention. Also, more research is needed to evaluate the effectiveness of CMV preventative counseling to reduce prenatal CMV infection in women. Understanding the effectiveness of hygiene education would help to further build up the bottom data layer in the DIKW period. Various education modes should also be explored to help identify optimal counseling practices. To be able to closely examine the impact of education, a U.S. based randomized control trial in multiple settings could be conducted to compare CMV seroconversion in pregnant women who did and did not receive cCMV prevention counseling. Women could be screened for CMV during their
pregnancy and complete surveys to characterize their behavior modification to recommended CMV preventative measures.

Conclusion

In summary, in this mixed methods-study using surveys and interviews, I explored knowledge, counseling practices and barriers to eCMV preventative counseling across two states, with and without a public health education intervention for eCMV. Utah’s legislation was the first funded eCMV state-wide initiatives offering a landmark milestone in the effort to reduce eCMV infections. Based on findings from my study, this approach offers a potential partial solution to increasing patient counseling. Barriers were identified that prevent the flow from data to information to knowledge and lastly to shaping provider actions (wisdom). Further work is needed to reduce systemic barriers in parallel with any potential public health efforts to increase eCMV preventative counseling by pregnancy care providers for women of childbearing age.
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https://www.aafp.org/about/policies/all/preconception-care.html.


“Recommendations to Improve Preconception Health and Health Care --- United States: A Report of the CDC/ATSDR Preconception Care Work Group and the Select Panel on


Schleiss, Mark R., and Don J. Diamond. “Exciting Times for Cytomegalovirus (CMV) Vaccine Development: Navigating the Pathways toward the Goal of Protecting Infants against


Appendix A: Survey Recruitment Details

Figure A1. First Round of Nevada Provider Email Administered Survey

Hi,

My name is Katie Feistel, I’m a Public Policy PhD student at Pardee RAND Graduate School and am currently working on my dissertation related to congenital Cytomegalovirus (CMV). I’m conducting a survey to understand pregnancy care provider knowledge and patient counseling behaviors regarding congenital CMV in Nevada.

If you are able to, I would very much appreciate your help by completing this brief, **5-minute survey** at the link below:
https://www.surveymonkey.com/r/GFC5J5H

Additionally, I’m conducting 30-minute, phone interviews with pregnancy care providers to further understand pregnancy care provider perspectives on congenital CMV. Would you be interested in participating in a 30-minute phone interview? Your participation is completely voluntary. If so, please feel free to contact me at kfeistel@prgs.edu. 
Please let me know if you have any questions, and I appreciate your consideration of this request! Feel free to pass along to any colleagues you think might be interested.

Thank you!

Using Outlook had limitations; I could not view important data analytics like how many people opened the email or clicked on the link. After the first recruitment email to Nevada, I switched over to the MailChimp platform. I was able to import my Excel provider list and create an email template with my recruitment letter. Also, MailChimp allowed for a personalized approach that addressed each email individually to each provider. Switching to MailChimp allowed me better insights into the performance of my recruitment emails like individual email opens and clicks. MailChimp also gives recipients the option to unsubscribe and track email address bounces by type.\(^\text{16}\) I sent out an initial survey recruitment email on January 24\(^{th}\) 2022, and two follow up emails to Nevada providers on January 31\(^{st}\) and February 7\(^{th}\), but I still did not collect many responses (N=28). There was also a large number (n=165) of email addresses that either bounced or participants unsubscribed via MailChimp, ~10% of the contact list for Nevada providers.

\(^{16}\) There are two different types of bounces. Hard bounces occur when the email address is no longer valid. Soft bounces occur when the individual’s email host blocks the email, so it no longer reaches the receiver. MailChimp identifies they type of bounce for email campaigns.
Figure A2. Personalized Recruitment Email

Hi! My name is Katie Feistel, I’m a Public Policy PhD student at Pardee RAND Graduate School and a mom of a child who passed away due to complications from congenital Cytomegalovirus (CMV).

To honor my son, I’m using my dissertation to conduct research on cCMV. I’m conducting a brief, **5-minute survey** to understand pregnancy care provider knowledge and patient counseling behaviors regarding congenital CMV in Nevada. If you are able to, please complete the survey at the link below:  
https://www.surveymonkey.com/r/GFC5J5H

Feel free to pass along to any other pregnancy care providers in Nevada.

Thank you!
Katie

I administered the updated, personal recruitment email for Nevada providers with MailChimp on February 24th with two additional follow up emails on February 27th and March 2nd. The personal approach yielded a higher number of survey responses (n=41). Next, I turned to the Utah provider survey, using MailChimp to send out the first recruitment email February 25th. However, the large number of hard bounces (38%) created a red flag in MailChimp which blocked additional email campaigns for the Utah provider survey. MailChimp includes this feature to protect email recipients from spam email and privacy violations. I switched back to Outlook to administer the follow up recruitment emails, sending follow up emails on February 28th, March 4th, and March 11th and a final reminder on March 18th. I deployed the survey of family medicine physicians in Utah later as I realized I did not have many responses for this
specialty. I sent out the first recruitment email on August 22\textsuperscript{nd}, and reminders on August 25\textsuperscript{th}, August 31\textsuperscript{st}, and September 6\textsuperscript{th}. 
1. What best describes your professional title?
   a. Physician
   b. Physician’s Assistant
   c. Nurse Practitioner
   d. Certified Nurse Midwife
   e. Other (specify)

2. What is your specialty?
   a. OB/GYN
   b. Family Practice
   c. Maternal-Fetal medicine
   d. Internal Medicine
   e. Other (specify)

3. How many years have you been practicing as a pregnancy care provider?
   a. Sliding scale between 0 and 50

4. How many women of between the ages of 18 and 44 do you typically treat per week?
   a. 1-10
   b. 11-20
   c. 21-30
   d. 31-40
   e. 41-50
   f. More than 50

5. How did you learn about congenital Cytomegalovirus? (Select all that apply)
   a. Formal medical training
   b. Learned from other providers
   c. Continuous education
   d. Self-taught
   e. I don’t know much about it
   f. Never heard of it
   g. Other (specify)

6. How frequently do you educate patients who are pregnant or trying to become pregnant regarding the risks and potential consequences of CMV infection during pregnancy?
   a. I educate every patient about CMV
   b. I educate most patients about CMV
   c. I only educate patients about CMV when the time permits
   d. I don’t personally educate patients about CMV but someone else in my practice does
   e. My patients do not receive CMV education
   f. Unsure
7. **How** do you educate patients who are pregnant or trying to become pregnant regarding the transmission of CMV infection? (Check all that apply then press okay)
   a. Verbally in person/during appointment
   b. Through an electronic message
   c. With pamphlet/brochure
   d. Provide outside resources (website, etc.)
   e. I don’t personally educate patients about CMV but someone else in my practice does
   f. My patients do not receive CMV education
   g. Other

8. **When** do you educate patients who are pregnant or trying to become pregnant regarding the transmission of CMV infection? (Select all that apply)
   a. At every visit
   b. Before she is pregnant
   c. At the first pre-natal visit
   d. At 20 weeks gestation
   e. Only when I remember
   f. My patients do not receive CMV education
   g. Other (specify)

9. When you don’t educate, what factors impact your decision to **not** educate patients who are pregnant or trying to become pregnant regarding the risks and potential consequences of CMV infection during pregnancy? (Select all that apply)
   a. Do not see the benefit
   b. Someone else in my practice is responsible for patient education
   c. Do not have enough time
   d. Not in professional guidelines
   e. Do not feel informed enough on the topic
   f. Feel individual will get the information from another resource
   g. I do educate them
   h. Unsure
   i. Other (specify)

10. [Only question for Utah] Have you ever received any materials related to CMV from the Utah Department of Health?
    a. Yes
    b. No
    c. Don’t know

11. [If yes to previous question] What materials that you received from the Utah Department of Health did you find most beneficial?

83
a. open ended response
Appendix C: Interview Protocol for Pregnancy Care Providers

Background

1. Confirm Title/Position

2. What is your specialty?

3. How long have you been practicing (post-training e.g., residency)?

4. When did you start practicing in [STATE]?

5. How many women of childbearing age do you see on average per week?

6. What are the demographics of your patients?

CVM Practices

7. What training and education have you received regarding CVM as a pregnancy care provider?
   a. Probes: what did this training look like, when did you receive this training, were you a resident, attending, fellow, etc. What does ACOG recommend?

8. What discussions do you have, if any, about CVM with your patients?

9. [If yes] In what circumstances would you choose not to provide education to a patient on CVM?

10. [If no] What are some reasons that you don’t counsel patients on CVM?
a. Probes: What conditions do you typically counsel for? Have you had any patients contract CMV while pregnant?
b. Probe: lack of time in patient visit, consider not important. Do not want to scare patients, etc.

11. How have you seen patients alter their behaviors in pregnancy?

12. In your experience, how have patients reacted to cCMV hand hygiene counseling?

13. What do you think are effective measures for patients to help reduce their risk of cCMV infection?

14. [If located in Utah] What materials, if any, have you received from the Utah Department of Health regarding cCMV? If so, what did you think?

   a. Probe: Did interviewee learn anything new from the materials? Did they pass along any to their patients?

15. [If yes] How did the educational materials influence the ways in which you talk with your patients around the risks of cCMV?
Appendix D: Cognitive Interview Pregnancy Care Provider Survey

2. What best describes your professional title?
   a. Physician
   b. Physician’s Assistant
   c. Nurse Practitioner
   d. Certified Nurse Midwife
   e. Other (specify)

PROBE: Do the response options make sense? Are there response options that you think may be missing?

3. What is your specialty?
   a. OB/GYN
   b. Family Practice
   c. Maternal-Fetal medicine
   d. Internal Medicine
   e. Family Practice
   f. Other (specify)

PROBE: Do the response options make sense? Are there response options that you think may be missing?

4. How many years have you been post-training?
   a. Sliding scale between 0 and 50

PROBE: What is confusing about this question if anything?

5. How many women of between the ages of 18 and 44 do you typically treat per week?
   a. 1-10
   b. 11-20
   c. 21-30
   d. 31-40
   e. 41-50
   f. More than 50

PROBE: How would you respond to this question? Can you walk me through your thought process?

6. How did you learn about congenital CMV?
   a. Medical School
   b. Learned from other providers
   c. Continuous education
   d. Self-taught
   e. I don’t know much about it
   f. Other (specify)
PROBE: Do the response options make sense? Are there response options that you think may be missing?

7. About **how frequently** do you educate patients who are pregnant or trying to become pregnant regarding the risks and potential consequences of CMV infection during pregnancy?
   a. Every patient
   b. Most patients
   c. Only when time permits
   d. Unsure
   e. I don’t educate patients
   f. Only certain patients (specify)

PROBE: How would you go about responding to this question? Can you walk me through your thought process?

8. **How** do you educate patients who are pregnant or trying to become pregnant regarding the transmission of CMV infection? (Check all that apply then press okay)
   a. In person/during appointment
   b. Through an electronic message
   c. With pamphlet/brochure
   d. Provide outside resources (website, etc.)
   e. I don’t educate
   f. Other

PROBE: Do the response options make sense? Are there response options that you think may be missing?

9. **When** do you educate patients?
   a. At the first pre-natal visit
   b. Before she is pregnant
   c. At 20 weeks gestation
   d. At every visit
   e. Only when I remember
   f. I don’t educate them
   g. Other (specify)

PROBE: What additional information or instructions may you need to respond to this question?

10. When you don’t educate, what factors impact your decision to not educate patients who are pregnant or trying to become pregnant regarding the risks and potential consequences of CMV infection during pregnancy?
    a. Do not see the benefit
    b. Do not have enough time
    c. Not in professional guidelines
d. Do not feel informed enough on the topic
e. Feel individual will get the information from another resource
f. Unsure
g. I do educate them
h. Other (specify)

PROBE: How would you go about responding to this question? Can you walk me through your thought process?

11. [Only question for Utah] Have you ever received any materials related to CMV from the Utah Department of Health?
   a. Yes
   b. No
   c. Don’t know

11. [If yes to previous question] What materials did you find most beneficial?
   a. open ended response
Appendix E. Survey Analysis without Providers with Less than One Year of Practice in Utah

I also performed a statistical analysis of the survey data without the four Utah providers who indicated they had one-year of practice. The only findings impacted by removing this group was that there was no longer a statistically significant difference between the Utah providers who reported being “uninformed” as a reason they do not counsel patients regarding cCMV prevention versus providers in Nevada (from p=0.04 to p=0.09) and Utah providers were not statistically more likely to report counseling most patients about cCMV than providers in Nevada (from 0.048 to 0.06).

Table D.1 Participant Responses to cCMV Education Sources*

<table>
<thead>
<tr>
<th></th>
<th>Utah (n=106)</th>
<th>Nevada (n=68)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal medical training</td>
<td>84.0</td>
<td>82.4</td>
<td>0.78</td>
</tr>
<tr>
<td>Continuous education</td>
<td>47.2</td>
<td>23.5</td>
<td>**0.001</td>
</tr>
<tr>
<td>Other providers</td>
<td>33.0</td>
<td>22.1</td>
<td>0.12</td>
</tr>
<tr>
<td>Self-taught</td>
<td>19.8</td>
<td>16.2</td>
<td>0.55</td>
</tr>
<tr>
<td>Do not know much about it</td>
<td>14.1</td>
<td>11.8</td>
<td>0.65</td>
</tr>
<tr>
<td>Other</td>
<td>3.8</td>
<td>2.9</td>
<td>0.77</td>
</tr>
</tbody>
</table>

NOTE: *Select all that apply question. ** Statistically significant p <0.01.

Table D.2 Frequency Providers Counsel their patients Regarding cCMV

<table>
<thead>
<tr>
<th></th>
<th>Utah (n=106)</th>
<th>Nevada (n=68)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>My patients do not receive CMV education</td>
<td>30.2</td>
<td>47.1</td>
<td>*0.02</td>
</tr>
<tr>
<td>Only certain patients</td>
<td>20.8</td>
<td>8.8</td>
<td>*0.04</td>
</tr>
<tr>
<td>I educate most patients about CMV</td>
<td>13.2</td>
<td>4.4</td>
<td>0.06</td>
</tr>
<tr>
<td>Unsure</td>
<td>12.2</td>
<td>10.3</td>
<td>0.69</td>
</tr>
<tr>
<td>I only educate patients about CMV when time permits</td>
<td>9.4</td>
<td>7.4</td>
<td>0.64</td>
</tr>
<tr>
<td>I educate every patient about CMV</td>
<td>8.5</td>
<td>5.9</td>
<td>0.53</td>
</tr>
<tr>
<td>I don't personally but someone else in my practice does</td>
<td>4.7</td>
<td>10.3</td>
<td>0.16</td>
</tr>
</tbody>
</table>

NOTE: * Statistically significant p<0.05

Table D.3 How Providers Counsel their patients Regarding cCMV**+

<table>
<thead>
<tr>
<th></th>
<th>Utah (n=74)</th>
<th>Nevada (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Method of Counseling</td>
<td>Utah (%)</td>
<td>Nevada (%)</td>
</tr>
<tr>
<td>----------------------</td>
<td>----------</td>
<td>------------</td>
</tr>
<tr>
<td>Verbal in person/during appointment</td>
<td>59.5</td>
<td>61.1</td>
</tr>
<tr>
<td>Electronic</td>
<td>5.4</td>
<td>5.6</td>
</tr>
<tr>
<td>Pamphlet/brochure</td>
<td>31.1</td>
<td>22.2</td>
</tr>
<tr>
<td>Outside resources</td>
<td>12.2</td>
<td>19.4</td>
</tr>
<tr>
<td>Others in the practice</td>
<td>6.8</td>
<td>16.7</td>
</tr>
<tr>
<td>Do not counsel</td>
<td>16.2</td>
<td>11.1</td>
</tr>
<tr>
<td>Other</td>
<td>6.8</td>
<td>2.8</td>
</tr>
</tbody>
</table>

NOTE: *Select all that apply question. +First skip logic question, those that selected “My patients do not receive CMV education” for previous question on counseling frequency skipped this question.

Table D.4 Timing of cCMV Counseling **

<table>
<thead>
<tr>
<th>Timing</th>
<th>Utah (n=62)</th>
<th>Nevada (n=32)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every Visit</td>
<td>0.0</td>
<td>6.3</td>
<td>*0.04</td>
</tr>
<tr>
<td>Before she is pregnant</td>
<td>17.7</td>
<td>28.1</td>
<td>0.25</td>
</tr>
<tr>
<td>First pre-natal visit</td>
<td>0.50</td>
<td>56.3</td>
<td>0.57</td>
</tr>
<tr>
<td>20 weeks gestation</td>
<td>1.6</td>
<td>9.4</td>
<td>0.08</td>
</tr>
<tr>
<td>When I remember</td>
<td>8.1</td>
<td>18.8</td>
<td>0.13</td>
</tr>
<tr>
<td>Do not counsel</td>
<td>3.2</td>
<td>6.3</td>
<td>0.50</td>
</tr>
<tr>
<td>Other</td>
<td>37.1</td>
<td>(9.4)</td>
<td>**0.004</td>
</tr>
</tbody>
</table>

NOTE: *Select all that apply question. ++ Second skip logic question, those that selected “My patients do not receive CMV education” for the previous question asking how their patients were being counseled skipped this question. * Statistically significant p<0.05.** Statistically significant p <0.01.

Table D.5 Reasons for not providing cCMV Counseling *

<table>
<thead>
<tr>
<th>Reason</th>
<th>Utah (n=106)</th>
<th>Nevada (n=68)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not enough time</td>
<td>34.0</td>
<td>25.0</td>
<td>0.21</td>
</tr>
<tr>
<td>Not informed</td>
<td>27.4</td>
<td>16.1</td>
<td>0.09</td>
</tr>
<tr>
<td>Not in the guidelines</td>
<td>20.8</td>
<td>29.4</td>
<td>0.20</td>
</tr>
<tr>
<td>Do educate</td>
<td>17.9</td>
<td>10.3</td>
<td>0.17</td>
</tr>
<tr>
<td>Don't see benefit</td>
<td>18.0</td>
<td>10.2</td>
<td>0.17</td>
</tr>
<tr>
<td>Unsure</td>
<td>7.5</td>
<td>7.4</td>
<td>0.96</td>
</tr>
<tr>
<td>Another resource will educate</td>
<td>6.6</td>
<td>4.4</td>
<td>0.55</td>
</tr>
<tr>
<td>Someone else educates</td>
<td>4.7</td>
<td>10.3</td>
<td>0.16</td>
</tr>
<tr>
<td>Other</td>
<td>19.8</td>
<td>16.2</td>
<td>0.55</td>
</tr>
</tbody>
</table>

NOTE: *Select all that apply question .
**Table D.6 Comparing Utah Providers Who Did and Did Not Receive UDOH cCMV Materials**

<table>
<thead>
<tr>
<th>How frequently providers counsel patients</th>
<th>Received UDOH Materials (n=27)</th>
<th>Did Not Receive UDOH Materials (n=83)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>My patients do not receive CMV education</td>
<td>11.5</td>
<td>36.2</td>
<td>*0.02</td>
</tr>
<tr>
<td>Only certain patients</td>
<td>19.2</td>
<td>21.3</td>
<td>0.83</td>
</tr>
<tr>
<td>I educate most patients about CMV</td>
<td>26.9</td>
<td>8.8</td>
<td>*0.02</td>
</tr>
<tr>
<td>Unsure</td>
<td>3.8</td>
<td>15.0</td>
<td>0.13</td>
</tr>
<tr>
<td>I only educate patients about CMV when time permits</td>
<td>15.4</td>
<td>7.5</td>
<td>0.24</td>
</tr>
<tr>
<td>I educate every patient about CMV</td>
<td>19.2</td>
<td>5.0</td>
<td>*0.02</td>
</tr>
<tr>
<td>I don’t personally but someone else in my practice does</td>
<td>3.8</td>
<td>5.0</td>
<td>0.81</td>
</tr>
</tbody>
</table>

**Why providers do not provide CMV counseling**

<table>
<thead>
<tr>
<th>Why providers do not provide CMV counseling</th>
<th>Received UDOH Materials (n=27)</th>
<th>Did Not Receive UDOH Materials (n=83)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not enough time</td>
<td>34.6</td>
<td>33.8</td>
<td>0.94</td>
</tr>
<tr>
<td>Not informed</td>
<td>15.4</td>
<td>31.2</td>
<td>0.12</td>
</tr>
<tr>
<td>Not in the guidelines</td>
<td>11.5</td>
<td>23.8</td>
<td>0.19</td>
</tr>
<tr>
<td>Do educate</td>
<td>42.3</td>
<td>10.0</td>
<td>***0.0001</td>
</tr>
<tr>
<td>Don’t see benefit</td>
<td>3.8</td>
<td>15.0</td>
<td>0.13</td>
</tr>
<tr>
<td>Unsure</td>
<td>7.7</td>
<td>7.5</td>
<td>0.97</td>
</tr>
<tr>
<td>Another resource will educate</td>
<td>3.8</td>
<td>7.5</td>
<td>0.52</td>
</tr>
<tr>
<td>Someone else educates</td>
<td>3.8</td>
<td>5.0</td>
<td>0.81</td>
</tr>
<tr>
<td>Other</td>
<td>11.5</td>
<td>22.5</td>
<td>0.23</td>
</tr>
</tbody>
</table>

**NOTE:** * Statistically significant p<0.05. ** Statistically significant p <0.01., *** Statistically significant p <0.001