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Losing Ground: Awareness of Congenital Cytomegalovirus in the United States

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Abstract

One in 150 infants is born with cytomegalovirus (CMV) and one in 750 will have lifelong disabilities due to CMV. Even though congenital CMV is the leading viral cause of congenital disabilities and the leading non-genetic cause of childhood hearing loss, most adults have never heard of it. Data from the 2015 and 2016 HealthStyles™ surveys were analyzed and compared to data from similar studies and show an awareness rate of 7% for U.S. adults (5% for men and 9% for women), a statistically significant decrease from 2005 and 2010 HealthStyles™ surveys. Predictors of awareness include gender and education level. The presence of a child ages 0–5 in the household does not increase the chance that an adult in the household is aware of CMV. CMV is a large public health burden and further research needs to be focused on awareness and prevention of the negative sequela associated with congenital CMV.

Acronyms: CDC = Centers for Disease Control and Prevention, CMV = Cytomegalovirus, IOM = Institutes of Medicine (now known as National Academies of Sciences, Engineering, and Medicine), STD = Sexually Transmitted Disease

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Introduction

Cytomegalovirus (CMV) is a member of the herpes family of viruses, spread through bodily fluids including saliva, blood, genital secretions, urine, and breast milk. Ninety percent of the U.S. population has had CMV by the time they are 80 years old and most do not experience any symptoms (Fowler & Boppana, 2006; Staras, Dollard, & Radford, 2006).

Nonetheless, CMV has a very heavy disability burden when acquired congenitally. It is the leading cause of non-genetic hearing loss (Fowler & Boppana, 2006) with 15–20% of bilateral moderate to profound sensorineural hearing loss caused by CMV (Grosse, Ross, & Dollard, 2008). Congenital CMV also causes mental retardation, cerebral palsy, and many other disabilities (Dollard, Grosse, & Ross, 2007). Approximately 0.7% of infants are estimated to be born with congenital CMV in the United States, leading to 30,000 annual cases. About 90% of these babies are referred to as asymptomatic because there are no clinically apparent symptoms of the infection, and 10% are referred to as symptomatic because there are obvious clinical abnormalities (Boppana, Ross, & Fowler, 2013). Approximately 6,000, or one in five of those newborns with congenital infection will go on to develop permanent disabilities such as microcephaly, hearing loss, vision loss, cerebral palsy, seizure disorders, or cognitive impairment (Cannon, 2009).

According to the Institute of Medicine (IOM, 2000), the cost of medical and educational care for children with disabilities known to be due to congenital CMV in the United States is $1.9 billion per year. Given such high costs associated with congenital CMV, the IOM identified the development of a vaccine to prevent congenital CMV as a top priority. However, a vaccine appears to be years, if not decades away (Adler & Nigro, 2013).

There is no FDA-approved treatment for congenital CMV, but recent research by Kimberlin et al. (2015) on the use of Valganciclovir to treat symptomatic congenital CMV infections is promising. Even if an approved treatment or a vaccine can be developed and becomes widely available, the best alternative for reducing the incidence of congenital CMV at the present time appears to be more widespread use of basic hygiene practices among pregnant women to avoid transmission via saliva or urine from young children (Adler & Nigro, 2013; Pass & Anderson, 2014; Swanson & Schleiss, 2013). The first step in improving hygiene practices that will likely lead to reducing the incidence of congenital CMV, is ensuring that the general public, especially men and women of childbearing age, knows about the existence and consequences of CMV.

This paper presents previously unpublished findings from the 2015 and 2016 HealthStyles™ surveys about the awareness of CMV among adults in the United States. It uses the results of analyses to identify further research needs and guidance for policymakers and public health programs on where to focus efforts to increase awareness of congenital CMV.

CMV Transmission

Pregnant women are most likely to contract CMV from young children and intimate partners (Fowler & Pass, 2006). CMV is transmitted from young children to pregnant women through urine or saliva during diaper changes, sharing of eating utensils, or exchanging saliva when kissing. CMV can also be sexually transmitted.

Johnson, Anderson, and Pass (2012) documented a number of factors associated with acquisition of CMV infections, often referred to in the literature as seroconversion. Seroconversion is when a person transitions from seronegative (has never had a CMV infection) to seropositive or seroconverted (has had a CMV infection). Low income pregnant women have almost three times the incidence (6.8%) of CMV infection compared to middle income pregnant women (2.5%). Thirty-seven percent of women in sexually transmitted disease (STD) clinics and 7.9–10% of daycare workers contract CMV infections each year. At the highest risk for CMV infection are parents of children who have recently had an active CMV infection and have CMV in their saliva, urine, and other bodily fluids that could be passed to another person (often referred to as shedding the virus).

CMV Prevention

Stowell, et al. (2014) found that while the CMV virus can live for up to 15 minutes on hard plastic and up to 5 minutes on crackers, no viable virus was recovered after washing hands with soap, sanitizer, or even just with water. The Centers for Disease Control and Prevention (CDC) recommend that an effective way of reducing exposure to and the incidence of CMV infection is by "regular hand washing, particularly after changing diapers." (CDC, n.d.). Research studies have demonstrated that this and other preventative steps are effective. For example, Adler and Nigro (2013) found that only 3% (one of 37) of CMV-seronegative pregnant women with an infected young child who were educated about using simple hygiene practices in their daily routines seroconverted to CMV during pregnancy, while 42% (65 of 154 women) of pregnant women who were not educated seroconverted.

Other studies support the implementation of preventative hygienic precautions. Revello et al. (2015) found that only 1.2% of women who were given hygiene information and prospectively tested until delivery acquired a CMV infection, compared to 7.6% in a comparison group that were neither tested nor informed about CMV during pregnancy. Importantly, 93% of these women felt hygiene recommendations were worth suggesting to all pregnant women at risk for infection. In an earlier study, Vauloup-Fellous et al. (2009) found, for 2,595 seronegative women, that the incidence of maternal CMV conversion was reduced from 0.035% per woman-week to 0.008% per woman-week (P = .0005) following an educational intervention. Women were less than 25% as likely to acquire a CMV infection when the woman and her partner were given detailed information on preventative hygienic measures verbally and in writing.

Previous Assessments of CMV Awareness

The public health impact of congenital CMV infection is substantial and under-recognized. (Swanson & Schleiss, 2013). While congenital CMV is one of the most common causes of congenitally acquired childhood disabilities and is preventable, most women of childbearing age have never heard of it (Cannon, 2009; Jeon et al., 2006; Ross, Victor, Sumartojo, & Cannon, 2008).

Three surveys of public CMV awareness in the United States have been conducted in the past decade. Jeon et al. (2006) surveyed 643 women at seven geographic locations (Atlanta, GA; Birmingham, AL; Cleveland, OH; Provo, UT; Richmond, VA; Chicago, IL; and Houston, TX) and found that only 142, or 22%, of women surveyed had heard of congenital CMV. Women's awareness statistically significantly increased with higher levels of education, older age, and previous employment in a healthcare profession. When multiple regression analyses were used to adjust for other covariates, age no longer predicted awareness, but higher levels of education (high-school diploma or less, OR = 1.0; some college, OR = 1.5; bachelor's degree or more, OR = 2.1; $p = .03$) and employment in a healthcare profession (no, OR = 1.0; yes, OR = 6.8, $p < .0001$) remained statistically significantly related. The study found no statistically significant differences by income, race and ethnicity, or between women who had been pregnant and who had never been pregnant. The study also found that employment in a daycare setting did not impact awareness (no, 21%, OR = 1.0; yes, 27%, OR = 1.4; $p = .18$).

Jeon et al. (2006) also found that most women, even those who had heard of CMV, could not identify modes of CMV transmission or prevention and 23% (83 of 137) incorrectly stated that CMV could be prevented by avoiding cat litter. One strength of the study was that it compared awareness about CMV with awareness about other birth defects and childhood illnesses and first reported the disparity between awareness and incidence rates of various childhood conditions. Jeon et al. (2006) noted that 53% of respondents were aware of congenital rubella syndrome, which had been eradicated in the United States, compared to 22% who were aware of CMV. Comparing CMV awareness with other diseases and conditions provides context for the results and makes them more relevant for decision- and policymakers.

A limitation of Jeon et al.'s (2006) study was that participants were recruited from pediatric outpatient clinic waiting rooms (4 sites), an obstetrics/gynecology clinic, a university's student center, and medical students and support staff in a hospital. The fact that the survey was a convenience sample administered in mainly healthcare settings means that it may not be representative of all women in the United States (for example, women with knowledge about CMV were likely oversampled given that the survey was conducted in health care settings).

Awareness of congenital CMV was also queried in the 2005 and 2010 HealthStyles™ survey, a subset of a consumer mail survey of U.S. adults over 18 years of age commonly used by the CDC for public health planning (Ross et al., 2008). HealthStyles™ surveys oversample certain demographic groups to enable more precise estimates about responses from people in those groups, but then the data are weighted to create a nationally representative sample with respect to age, sex, race/ethnicity, income, and household size. In the 2005 HealthStyles™ survey, 2,656 females and 2,163 males responded to four CMV-related questions, but the analyses reported by Ross et al. (2008) only focused on women because they are at risk for transmitting CMV to an unborn child. The potential role of a sexual partner in spreading CMV to a pregnant woman was not considered. Four questions asked whether participants had heard of CMV, where they learned about CMV, knowledge about the effects of CMV, and whether they would willingly adopt measures to prevent CMV while pregnant. The survey also collected demographic variables including sex, age, income, race and ethnicity, level of education, and household size.

Ross et al. (2008) reported that 14% of women had heard of CMV, and consistent with Jeon et al. (2006), knowledge increased with level of education (did not graduate high school, 10%, OR = 1.0; graduated high school, 6%, OR = 0.6; attended college, 13%, OR = 1.4; graduated college, 22%, OR = 2.6; 5–8 years of graduate school, 23%, OR = 2.7; $p < 0.001$). Knowledge also increased with household income, but not when other covariates were controlled using multiple regression analyses.

Ross et al. (2008) also found that the preventative hygiene measures previously recommended by the CDC were judged to be easy to adopt by a large majority of participants, regardless of whether participants had heard of CMV. For example, 90% reported that washing hands would be very easy to adopt and 65% reported that it would be easy to adopt the recommendation to not share eating utensils with a young child. Fewer participants, 48%, reported that not kissing a young child on the mouth would be very easy, but 20% reported it would be somewhat easy.

The 2010 HealthStyles™ survey, with a sample of 2,181 women and 2,003 men, showed 13% of women and 7% of men had heard of CMV (Cannon et al., 2012). As with the 2005 survey, Cannon et al. (2012) only reported analysis results for women. Congenital CMV awareness varied by age, race/ethnicity, educational attainment, geographic region, and household income, with the strongest association between CMV awareness and the educational level of the respondent, even though awareness among women with post-graduate education was only 21%. Because only linear trend data were reported, odds ratios cannot be compared to previous surveys. The 2010 survey did not repeat questions related to the ease of implementing the CDC's recommended precautions, but added questions regarding the number of times women with children under age 19 engaged in risk and preventative behaviors while their youngest child was still in diapers. The study found that both risk and preventative behaviors are common (e.g., 69% of women reported kissing young children on the lips, 42% reported sharing utensils with young children, 95% reported washing hands after diaper changing, and 65% reported washing hands after wiping a child's nose).

Recently, Thackeray and Magnusson (2016) assessed childcare provider awareness of CMV and other infectious diseases by asking a random sample of licensed family and residential childcare providers in Utah to complete a 29-item questionnaire on awareness of CMV and other infectious diseases. The study focused on awareness as well as knowledge of how to prevent diseases in childcare settings. Thackeray and Magnusson found that 18.5% of 306 respondent childcare providers had heard of CMV. For comparison, 99.4% were aware of influenza, 67.2% of giardia, 24.9% of toxoplasmosis, and 23.2% of enterovirus. Because childcare providers are at higher risk for CMV infections and may be serving infants and young children with asymptomatic CMV infections, it is particularly important that they are aware of CMV (Thackeray & Magnusson, 2015). While targeted information has been provided to licensed childcare providers in Utah (Utah Department of Health, n.d.), public awareness efforts should reach both licensed and unlicensed childcare providers everywhere.

Finally, a 2014 survey of congenital CMV knowledge among medical students (Baer, McBride, Caviness & Demmler-Harrison, 2014) found that 34% of first year medical students and 100% of second through fourth year medical students at Baylor University, were somewhat or very familiar with CMV. Self-reported awareness by these students who were enrolled at a university with a history of significant research conducted on congenital CMV, was confirmed based on second through fourth year students' knowledge of modes of CMV transmission and signs and symptoms of CMV. Similar studies have not been conducted at other institutions where CMV research is not a priority. Consistent with results from the 2005 HealthStyles™ survey of CMV awareness completed by the CDC showing correlation with employment in a medical field, students' awareness in this study was strongly correlated with level of medical education ($p <.0001$).

In summary, CMV awareness among the general population is low and appears to be declining over time. While there are some predictors of CMV awareness, even those factors only raise CMV awareness levels among the general population slightly. This article uses data from more recent HealthStyles™ surveys to evaluate whether CMV awareness rates are declining and discusses potential research and public health policy mechanisms that could be used to increase awareness about CMV.

CMV Awareness Programs
Recently, there have been a number of public health efforts to increase awareness about CMV. In 2013, the Utah Legislature unanimously passed the first CMV public health initiative law (McVicar, 2014). Utah's law mandates that the Utah Department of Health implement a public health education campaign to inform women who are pregnant or might become pregnant about CMV, the risks associated with CMV, and the recommended prevention measures. The law also mandates an education campaign for medical and child-care professionals. The charge for implementation was given to the Early Hearing Detection and Intervention (EHDI) program within the state's Department of Health.

Utah's law was the first of its kind and appears to have spurred action in several other states. As of 2015, five states had enacted CMV laws (Doutre, 2015). Based on enactment of these laws, multiple programs have been initiated by state Departments of Health to educate women about CMV. In addition to legislatively-mandated public awareness programs, other EHDI programs are leading efforts to raise awareness of CMV (Mirizzi et al, 2015).

A number of non-profit organizations are also working to raise awareness of CMV. The National CMV Foundation (2015) was founded when four non-profit CMV organizations joined forces with an aim to "empower women, parents, families, and local community networks through grassroots engagement to facilitate conversations about CMV and to champion the cause against congenital CMV" (http://www.nationalcmv.org).

As public health programs and non-profit organizations work to increase awareness about CMV, it is important to document how people's awareness of CMV is changing. Such efforts will help focus educational efforts, identify factors that influence likelihood of CMV awareness, evaluate effectiveness of approaches to increasing CMV awareness, and determine areas of need and opportunity for the greatest impact. This article combines results from the previously-reported 2005 and 2010 HealthStyles™ survey data (Ross et al., 2008; Cannon et al., 2012) with previously unreported analyses from the 2015 and 2016 HealthStyles™ survey data to examine whether public awareness about CMV is increasing, decreasing, or staying the same.

Methodology

Data Set
The National CMV Foundation contracted with Porter Novelli to include the same awareness question about CMV in the 2015 and 2016 Summer HealthStyles™ surveys that had been asked in the 2005 and 2010 versions of the survey. *Have you heard of the following: congenital rubella syndrome, beta strep (Group B strep), HIV/AIDS, congenital cytomegalovirus (CMV), Down syndrome, sudden infant death syndrome (SIDS), fetal alcohol syndrome, autism, spina bifida, congenital toxoplasmosis, and parvovirus B19?* The resulting data were provided to Utah State University for analysis. Both data sets were collected by Porter Novelli Public Services via GfK's KnowledgePanel® (a national, probability-based panel that is representative of the entire U.S. population). GfK's KnowledgePanel® consists of 55,000 panel members who are randomly recruited from a sample frame of residential addresses "including households that: have unlisted telephone numbers, do not have landline telephones, are cell phone only, do not have current internet access, and do not have devices to access the internet" (GfK, 2013). GfK provides household without phone and or internet with a laptop computer and internet access. The panel of 55,000 is continuously replenished and respondents for individual surveys are selected from the larger panel to ensure a representative sample.

The summer 2015 HealthStyles™ survey was conducted from June 11 to June 29, 2015 with 4,127 adults completing the survey (a response rate of 67%). All respondents received compensation for completing the survey in the form of cash-equivalent reward points worth approximately $10. Respondents with incomplete responses (who did not answer at least half of the questions, $n = 7$) and speeders (who completed the survey in 7 minutes or less, $n = 33$) were removed from the data.

The summer 2016 survey was conducted from June 24 to July 11, 2016 using the same procedures and had a response rate of 68% with 4,203 of 6,166 adults completing the survey. Participants received the same compensation as that provided in 2015. Incomplete ($n = 10$) and speeder ($n = 39$) responses were removed from the data set.

Participants responded to a question asking if they had heard of the following conditions: congenital rubella syndrome, beta strep (Group B strep), HIV/AIDS, congenital cytomegalovirus (CMV), Down syndrome, sudden infant death syndrome (SIDS), fetal alcohol syndrome, autism, spina bifida, congenital toxoplasmosis, and parvovirus B19. The question asked for each condition was "Have you heard of [condition]?". Response choices were *Yes*, *No*, or the participant could refuse to answer the question. Respondents' awareness of CMV compared to awareness of other conditions provides context to policy and decision makers and allows for analysis of awareness compared to disease burden, making a case for the potential impact of CMV awareness initiatives.

Data were also available about each respondent's race/ethnicity, gender, zip code, whether the respondent currently had children under age 18, ages of the respondent's three youngest children, age, education (highest degree received and categorical), household size, household income, marital status, metro status (metro or non-metro), census region, employment status, housing status (own, rent, or occupied without payment of rent), and state of residence. Weights were provided so that survey responses could be matched to U.S. Current Population

Survey proportions using 9 factors: gender, age, household income, race/ethnicity, household size, education, census region, metro status, and prior internet access.

Data Analysis

An analysis of descriptive statistics was conducted for all study variables for both the 2015 and 2016 HealthStyles™ data using the R statistical software program. Rates of awareness for CMV were computed using data weighted for representativeness and stratified by demographic characteristics. In addition, CMV awareness rates were compared to awareness rates for other conditions queried in the survey.

A total of five logistic regression models were used to assess both the trend and characteristics related to CMV awareness. One model tests the trend across time, using the year as the independent variable. Two logistic regression models per year were used to determine the association of demographic conditions with CMV awareness, where CMV awareness was the binary outcome for both models. The first model examined basic demographic predictor variables: age, race, gender, education, and household income. The second model added two additional predictor variables to the model to examine parenthood and age of children: household presence of children under ages 0–1 and household presence of children ages 2–5. These variables were chosen based on the relativity of CMV awareness to families experiencing pregnancy and the increased risk of acquiring CMV from a young child.

Results

The 2015 and 2016 HealthStyles™ CMV awareness rates are 6.79% and 6.70% in the overall U.S. population when weighted for representativeness. Awareness rates for all levels of the various demographic characteristics are similarly low as shown in Table 1. Females have a higher rate of awareness than males (9.08% and 9.17% in 2015 and 2016 compared to 5.72% and 4.92%), but the number of females reporting awareness of congenital CMV has decreased from 14% and 13% in 2005 and 2010. Figure 1 is a summary of HealthStyles™ survey data from 2005, 2010, 2015 and 2016, showing a decrease over 11 years for women from 14% to 9% and for men a decrease from 2010 to 2016 from 7% to 5%. Data from the 2005 survey were not reported for men.

Table 1. U.S. Congenital Cytomegalovirus Awareness By Demographic Characteristics, 2015 and 2016

	2015 (*N* = 4121)	2016 (*N* = 4197)
	% (*n*)	% (*n*)
Overall Awareness (weighted)	6.79% (310)	6.70% (300)
Gender		
Male	5.72% (109)	4.92% (98)
Female	9.08% (201)	9.17% (202)
Race		
White	7.41% (256)	7.11% (250)
Black/African-American	7.67% (32)	7.69% (34)
Hispanic	2.92% (13)	5.13% (24)
American Indian or Alaska Native	12.12% (4)	0.00% (0)
Asian	10.81% (12)	6.14% (7)
Hawaiin/Pacific Islander	0.00 % (0)	0.00% (0)
2+ Races	5.89% (6)	9.00% (9)
Currently have children under Age 18?		
Yes	10.23% (134)	9.77% (136)
No	6.25% (175)	5.86% (164)
Age		
18–29	7.52% (41)	7.49% (494)
30–44	8.88% (82)	8.75% (86)
45–59	8.08% (111)	8.25% (111)
60+	5.94% (76)	4.80% (66)
Education		
Less than High School	3.77% (11)	3.62% (10)
High School	3.82% (47)	5.06% (63)
Some College	8.45% (106)	6.37% (81)
Bachelor's Degree or Higher	10.86% (146)	10.40% (146)
Professional or Doctorate Degree	20.16% (26)	20.41% (30)
Marital Status		
Married	8.13% (188)	7.29% (179)
Divorced	7.68% (34)	7.46% (37)
Never Married	6.17% (52)	7.20% (58)
Living with Partner	7.09% (19)	6.02% (10)
Metro Status		
Metro	7.73% (267)	7.39% (265)
Non-Metro	6.44% (43)	5.71% (35)

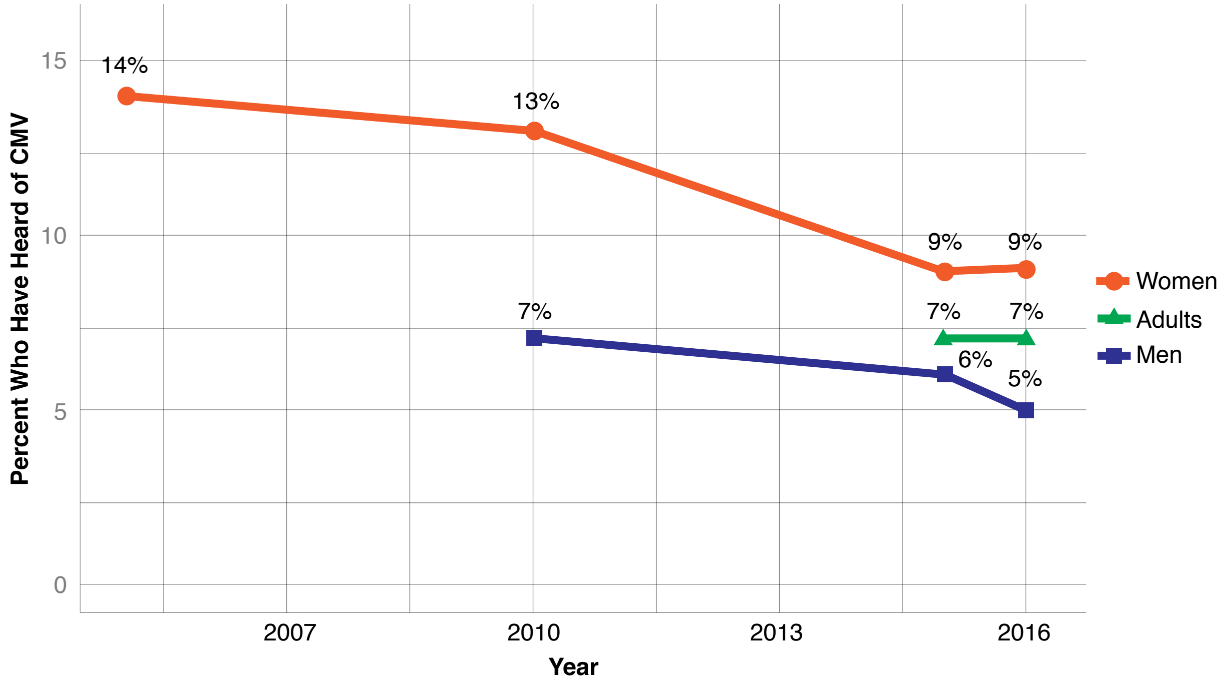

Figure 1. Percentage of participants in the 2005–2016 HealthStyles™ surveys who reported they had heard of congenital CMV: for all adults and by gender.

A logistic regression analysis of awareness rates across years from 2005 – 2016 shows that the decrease in awareness among U.S. women is statistically significant (OR = 0.94, 95% CI = [0.93, 0.95], p < .0001). The lack of a combined rate reported in previous analyses does not allow for exploration of the statistical significance of the decline of overall awareness.

CMV awareness was compared to awareness of other congenital conditions associated with negative developmental outcomes, up to and including death. Respondents are least aware of CMV compared to the 10 other conditions. Table 2 presents 2015 and 2016 awareness rates of the 10 comparable conditions to congenital CMV and the estimated annual frequency, in number of congenital or infant cases that result in long-term disabilities for each condition. Figure 2 shows the disparity between awareness using 2016 results and frequency of the 11 surveyed conditions. Although other diseases with low awareness have relatively low occurrences, the difference between CMV's relatively high occurrence and its low awareness is contrasted with Down syndrome, which has a similar occurrence rate (6,000 babies born with Down syndrome each year) but 85% to 89% report awareness of Down syndrome compared to 7% awareness for CMV.

Table 3 presents the results of each multivariate logistic regression model, reported as adjusted odds ratios (i.e., each odds ratio has been statistically adjusted for all other variables in the model), and their confidence intervals. In the first model, which included basic demographic predictor variables (age, race, gender, education, and household income), both gender and education level are statistically significant predictors of CMV awareness. In that model, women had an odds of awareness of one and a half to two times greater than men (2015: AOR = 1.56, 95% CI = [1.22, 2.00], $p < .001$; 2016: AOR = 1.94, 95% CI = [1.52, 2.51], $p < .001$) and Hispanic adults (men and women) were less than half as likely to be aware of CMV as white adults (2015: AOR = 0.37, 95% CI = [0.19, 0.67], $p < .001$). Education also was statistically significantly associated with awareness about CMV. For each increase in unit of education, the odds of awareness increased by 1.5 times (2015: AOR = 1.50, 95% CI = [1.29, 1.74], $p < .001$; 2016: AOR = 1.43, 95% CI = [1.23, 1.66], $p < .001$).

The second model included the presence of children ages 0–1 or ages 2–5 in the household, which was used as an indicator of whether the household had recently experienced a pregnancy. Adding these factors did not change the relationships seen in Model 1 for either year. Further, the additional variables (the presence of household members ages 0–1 or ages 2–5) does not statistically significantly predict CMV awareness.

Table 2. Percentage of U.S. Adult Awareness of Childhood Conditions Comparable to Congenital Cytomegalovirus

Condition	2015 Awareness	2016 Awareness	Approximate Annual U.S. Frequency[a]
Congenital Cytomegalovirus (CMV)	6.79%	6.70%	6,000[b]
Congenital Toxoplasmosis	8.27%	8.53%	400[c]
Congenital Rubella Syndrome	16.80%	13.27%	< 3[d]
Beta Strep (Group B Strep)	17.87%	16.91%	380[e]
Parvovirus B19 (Fifth Disease)	22.52%	19.63%	1045[f]
Fetal Alcohol Syndrome	65.56%	61.04%	1200[g]
Spina Bifida	69.42%	64.54%	1500[h]
Sudden Infant Death Syndrome (SIDS)	83.96%	78.70%	1500[i]
Autism	88.59%	84.28%	60,000[j]
Down Syndrome	89.57%	85.44%	6,000[k]
HIV/AIDS	91.13%	86.33%	30[l]

Note. Awareness data taken from the 2015 and 2016 HealthStyles™ surveys.
[a] Approximate frequency of infants affected with long-term disabilities, including death, by each condition. [b] Cannon, M. J. (2009). Congenital cytomegalovirus (CMV) epidemiology and awareness. *Journal of Clinical Virology, 46*(Supp. 4), S6–S10. doi: 10.1016/j.cv.2009.09.002. [c] Guerina, N. G., Hsu, H. W., Meissner, H. C., Maguire, J. H., Lynfield, R., Stechenberg, B., . . ., The New England Regional Toxoplasma Working Group. (1994, June). Neonatal serologic screening and early treatment for congenital toxoplasma gondii infection. *The New Journal of Medicine, 330*(26), 1858–1863. [d] https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6212a3.htm#fig [e] Giorgio, E., De Oronzo, M. A., Iozza, I., Di Natale, A., Cianci, S., Garofalo, G., . . . Politi, S. (2010). Parvovirus B19 during pregnancy: A review. *Journal of Prenatal Medicine, 4*(4), 63–66. [f] http://www.cdc.gov/abcs/reports-findings/survreports/gbs10.html [g] May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., . . . Hoyme, H. E. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics, 134*, 855–866. [h] http://www.cdc.gov/ncbddd/spinabifida/data.html [i] http://www.cdc.gov/sids/data.htm [j] http://www.cdc.gov/ncbddd/autism/data.html [k] http://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html [l] HIV diagnosis at < 1 year, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6253a1.htm

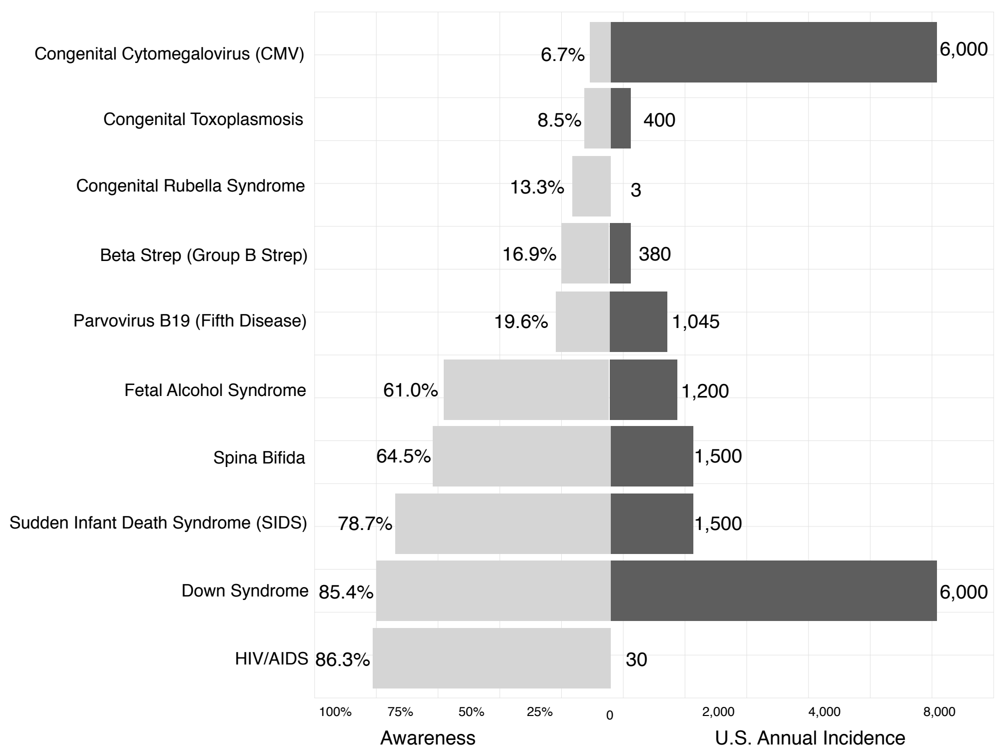

Figure 2. U.S. adult awareness of childhood conditions from the 2016 HealthStyles™ surveys with approximate annual U.S. incidence of disability due to each condition.

Table 3. Results of Logistic Regression Analyses Identifying Factors That Do and Do Not Predict CMV Awareness (2015 and 2016)

Odds Ratio (95% CI)	2015 Model 1[a]	Model 2[b]	2016 Model 1[a]	Model 2[b]
Gender	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Male	1.56 (1.22, 2.00)*	1.56 (1.22, 2.00)*	1.94 (1.52, 2.51)*	1.94 (1.52, 2.51)*
Female				
Education	1.50 (1.29, 1.74)*	1.50 (1.30, 1.74)*	1.43 (1.23, 1.66)*	1.43 (1.23, 1.66)*
Ethnicity				
White				
Non-Hispanic	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Hispanic	0.37 (0.19, 0.67)*	0.37 (0.19, 0.67)*	0.64 (0.40, 1.04)	0.66 (0.40, 1.03)
Precence of Household Members age 0-1		0.89 (0.37, 1.82)		1.18 (0.67, 1.98)
Prescence of Household Members age 2-5		1.02 (0.69, 1.46)		1.09 (0.78, 1.48)

[a] Model includes independent variables: age (four categories), gender, education level (less than high school, high school, some college, bachelor's degree or higher), household income, race, and ethnicity.
[b] Model includes independent variables: age (four categories), gender, education level (less than high school, high school, some college, bachelor's degree or higher), household income, race, ethnicity, presence of household members ages 0–1, and presence of household members ages 2–5.
* (p < .001)

Table 3 presents the results of each multivariate logistic regression model, reported as adjusted odds ratios (i.e., each odds ratio has been statistically adjusted for all other variables in the model), and their confidence intervals. In the first model, which included basic demographic predictor variables (age, race, gender, education, and household income), both gender and education level are statistically significant predictors of CMV awareness. In that model, women had an odds of awareness of one and a half to two times greater than men (2015: AOR = 1.56, 95% CI = [1.22, 2.00], $p < .001$; 2016: AOR = 1.94, 95% CI = [1.52, 2.51], $p < .001$) and Hispanic adults (men and women) were less than half as likely to be aware of CMV as white adults (2015: AOR = 0.37, 95% CI = [0.19, 0.67], $p < .001$). Education also was statistically significantly associated with awareness about CMV. For each increase in unit of education, the odds of awareness increased by 1.5 times (2015: AOR = 1.50, 95% CI = [1.29, 1.74], $p < .001$; 2016: AOR = 1.43, 95% CI = [1.23, 1.66], $p < .001$).

The second model included the presence of children ages 0–1 or ages 2–5 in the household, which was used as an indicator of whether the household had recently experienced a pregnancy. Adding these factors did not change the relationships seen in Model 1 for either year. Further, the additional variables (the presence of household members ages 0–1 or ages 2–5) does not statistically significantly predict CMV awareness.

Discussion

Awareness of congenital CMV decreased by nearly 50% from 2010 to 2015 and 2016 despite the large disease burden and high frequency of infections. The 2015 and 2016 HealthStyles™ survey data showed lower awareness rates despite increased attention to congenital CMV in the public health and policy arenas. It is noteworthy that CMV awareness is even lower than congenital rubella syndrome, which has been eradicated, and lower than other less common conditions. Most of the documented efforts by public health entities to increase CMV awareness (e.g., Doutre, 2015; Mirizzi et al., 2015) have taken place since 2013 so it may be too early to see the impact of those activities, but the fact that CMV awareness appears to be declining is a serious concern.

Consistent with previous research, analyses of the HealthStyles™ survey data across multiple years showed that women are more likely to be aware of CMV than men. This difference is expected as congenital CMV is most relevant to pregnant women but the odds ratios of 1.56 (2015) and 1.94 (2016) are lower than desirable in order to promote prevention of transmission from mother to fetus during pregnancy. These data suggest that women's doctors may not be counseling them on CMV despite its prevalence and the associated disability burden.

The significance of the differences by demographic factor are further explored in the logistic regression models. In addition to CMV awareness being higher among women in 2015 and 2016 than for men, CMV also varied by race/ethnicity. Adult respondents reporting Hispanic ethnicity reported lower CMV awareness (2.92% in 2015 and 5.13% in 2016) than adults in general and adults reporting any other race or ethnicity category. If an adult currently has children under age 18 he or she is more likely to be aware of CMV, but awareness in this group remains low (10.23% in 2015 and 9.77% in 2016).

CMV awareness increases with increasing levels of education as reported in previous studies. The correlation of awareness with education level is concerning. Women with low socioeconomic status have almost three times the incidence of CMV infection compared to middle income pregnant women (Johnson et al., 2012) and it appears that awareness of CMV is often associated with higher education levels that may not be accessible to women of lower socioeconomic status. But, even in the most aware group (those with a professional or doctorate degree, $n = 131$), only 20% of the respondents to the 2015 and 2016 HealthStyles™ surveys had heard of CMV. Public awareness and education initiatives are needed at all levels.

At the highest risk for CMV infection are parents of children who have recently had an active infection and are shedding the virus in bodily fluids (Johnson et al., 2012). The surrogate measures to this variable are the measures of adults who report the presence of children ages 0–1 or the presence of children ages 2–5 in their household. The presence of children of these ages in the household were not statistically significantly related to CMV awareness. A large majority of respondents, 89.5%, did not report having any children ages 0–1.

Conclusions

Analyses of the 2015 and 2016 HealthStyles™ survey data shows that awareness of CMV is decreasing among adults in the United States. Because of the high burden of disease associated with congenital CMV, it is alarming that the virus is relatively unknown. There is good evidence that preventative hygienic measures taken by women and their partners can reduce the risk of CMV infection and thus the risk of transmitting CMV to a fetus (Adler and Nigro, 2013; Revello et al., 2015; Vauloup-Fellous et al., 2009). A logical precursor to the wider implementation of preventative hygienic measures is increased awareness of CMV. Therefore, the decreasing trend in CMV awareness documented by the HealthStyles™ survey data from 2005 to 2016 is of great concern.

CMV awareness is low for all subsets of the U.S. population, but it is especially low for Hispanic adults. Even though awareness is higher for women and those with higher education levels, awareness in those groups remains alarmingly low considering CMV's disease burden and incidence rate. Furthermore, because CMV can be transmitted through sexual relations, it is important for men to be aware of what CMV is and how to prevent it.

The fact that CMV awareness is so low and is decreasing will hopefully help public health policymakers and program officials prioritize and focus their efforts to increase CMV awareness and prevention efforts. The data from the HealthStyles™ surveys also provide baseline data for beginning to evaluate CMV public health programs and specific initiatives, whether mandated by legislation or prioritized by stakeholders. Continued resources must be dedicated to increase awareness and prevention of this harmful virus.

Limitations

The greatest limitation of this study is the narrow definition of CMV awareness. Survey respondents responded to one yes/no question: "Have you ever heard of congenital cytomegalovirus (CMV)?" Ideally, additional questions would be asked to validate respondents' awareness of CMV, such as how CMV is acquired, what the symptoms of CMV are, what measures may be taken to prevent CMV, or if there is a CMV vaccine available. Reponses to these questions would allow policy makers and public health officials to better target their efforts to increase CMV awareness and prevention initiatives.

Another limitation of this study was the inability to evaluate CMV awareness by state and set a baseline for CMV awareness for states working to increase CMV awareness. Although state data were provided for each participant, sample sizes from most states were too small to establish awareness rates by state. These data would be useful in planning for CMV awareness programs.

Implications for Further Research

Although the data collected through the HealthStyles™ survey are useful in establishing the need for CMV awareness campaigns and education, further research is needed in many areas related to CMV awareness. First, no reported research has been conducted on the efficacy of different methods of raising public awareness and whether raising awareness of CMV leads to behavior changes in pregnant women.

Research has established the reasonableness and efficacy of recommended hygienic measures for reducing risk of acquiring a CMV infection during pregnancy (Adler and Nigro, 2013; Revello et al., 2015; Vauloup-Fellous et al., 2009). However, further research is needed on how to best educate women about hygienic practices and when is most appropriate. For example, it would be useful to know if high school health education programs can effectively reach women who are just reaching child-bearing age. The correlation between education level and CMV awareness suggests a need for further research to study public health programs including those for high school students and other young adults. It would be useful to examine high school and undergraduate health education curriculum to determine whether information about CMV is currently included. In addition, further research should be conducted to determine whether health care providers are informing women planning to become pregnant and their sexual partners of CMV.

Implications for Policy and Public Health Programs

As state EHDI programs, other state agencies, and non-profit organizations embark on public awareness programs, consideration should be given to the fact that CMV awareness seems to be declining. There is a great need for general awareness and all populations are in need of education about congenital CMV including low socioeconomic and Hispanic populations. Consideration should be given to educating young adults at the beginning of their childbearing age. Programs should also ensure that educational materials are available to adults of all races and ethnicities, especially those with Hispanic ethnicity.

Although women are more likely than men to know about congenital CMV, it should be the goal of public education campaigns to raise awareness of both men and women. Because CMV can be spread through sexual activity (Fowler & Boppana, 2006; Staras et al., 2006), men should also be aware of and exercise hygienic precautions during a partner's pregnancy to reduce the risk of obtaining a CMV infection.

CMV awareness rates are alarmingly low and there is a significant need for CMV education programs. As more states and other organizations pursue CMV awareness programs, further work will be needed to establish measures of the effectiveness of the public health and policy actions related to CMV. More detailed data, with larger sample sizes on a local scale, are needed to evaluate efforts of state stakeholders and non-profit organizations in developing policy and public information programs for CMV.

References

Adler, S. P., & Nigro, G. (2013). Prevention of maternal-fetal transmission of cytomegalovirus. *Clinical Infectious Diseases*, 57(Supp. 4), S189–S192. doi: 10.1093/cid/cit585

Baer, H. R., McBride, H. E., Caviness, A. C., & Demmler-Harrison, G. J. (2014). Survey of congenital cytomegalovirus (cCMV) knowledge among medical students. *Journal of Clinical Virology*, 60(3), 222–242. doi: 10.1016/j.jcv.2014.03.023

Boppana, S. B., Ross, S. A., & Fowler, K. B. (2013). Congenital cytomegalovirus infection: Clinical outcome. *Clinical Infectious Diseases*, 57(Supp. 4), S178–S181. doi: 10.1093/cid/cit629

Cannon, M. J. (2009). Congenital cytomegalovirus (CMV) epidemiology and awareness. *Journal of Clinical Virology*, 46(Supp. 4), S6–S10. doi: 10.1016/j.cv.2009.09.002

Cannon, M. J., Westbrook, K., Levis, D., Schleiss, M, Thackeray, R., & Pass, R. (2012). Awareness of and behaviors related to child-to-mother transmission of cytomegalovirus. Preventative Medicine, 54(5), 351–357. doi: 10.106/j.ypmed.2012.03.009

Centers for Disease Control. (n.d.). Preventing Congenital CMV Infection. Retrieved from http://www.cdc.gov/cmv/prevention.html

Dollard, S. C., Grosse, S. D., & Ross, D. S. (2007). New estimates of the prevalence of neurological and sensory sequelae and mortality associated with congenital cytomegalovirus infection. *Review of Medical Virology, 17*(5), 355–363.

Doutre, S. M. (2015). Reducing congenital cytomegalovirus infection through policy and legislation in the United States. *Microbiology Australia, 4,* 162–164.

Fowler, K. B., & Boppana, S. B. (2006). Congenital cytomegalovirus (CMV) infection and hearing deficit. *Journal of Clinical Virology, 35*(2), 226–231.

Fowler K. B., & Pass, R. F. (2006). Risk factor for congenital cytomegalovirus infection in the offspring of young women: Exposure to young children and recent onset of sexual activity. *Pediatrics, 118*, e286–e292.

GfK (2013). KnowledgePanel® Design Summary. Retrieved from http://www.knowledgenetworks.com/knpanel/docs/knowledgepanel(R)-design-summary-description.pdf

Goderis, J., De Leenheer, E., Smets, K., Van Hoecke, H., Keymeulen, A. & Dhooge, I. (2014). Hearing loss and congenital CMV infection: A systematic review. *Pediatrics, 134*(5), 972–982. doi: 10.1542/peds.2014-1173

Grosse, S. D., Ross, D. S., & Dollard, S. C. (2007). Congenital cytomegalovirus infection as a cause of permanent bilateral hearing loss: A quantitative assessment. *Journal of Clinical Virology, 41*(2), 57–62. doi: 10.1016/j.jcv.2007.09.004

Institute of Medicine. (2000). *Vaccines for the 21st Century: A Tool for Decision Making.* Washington, DC: National Academies Press.

Jeon, J., Victor, M., Adler, S., Arwady, A., Demmler, G., Fowler, K., … Cannon, M. J. (2006). Knowledge and awareness of congenital cytomegalovirus among women. *Infectious Diseases in Obstetrics and Gynecology, 2006*, 1–7.

Johnson, J., Anderson, B., & Pass, R. F. (2012). Prevention of maternal and congenital cytomegalovirus infection. *Journal of Clinical Obstetrics and Gynecology, 55*(2), 521–530. doi: 10.1097/GRF.0b013e3182510b7b

Kimberlin, D., Jester, P., Sanchez, P. J., Ahmed, A., Arav-Boger, R., Michaels, M. G., . . . Whitley, R. J. (2015). Valganciclovir for symptomatic congenital cytomegalovirus disease. *New England Journal of Medicine, 372*, 933–943. doi: 10.1056/NEJMoa1404599

McVicar, S. B. (2014). UCA 26-10-10 (HB 81 Utah Legislative Session 2013) Cytomegalovirus public health initiative & testing update, *Utah Department of Health*. Retrieved from http://le.utah.gov/interim/2014/pdf/00004466.pdf

Mirizzi, A., Behringer, D., Coverstone, K., McVicar, S. B., Ward, A., & Doutre, S. (2015, March). *The state of congenital CMV education and testing initiatives across the United States.* Panel discussion presented at the National Early Hearing Detection and Intervention Meeting, San Diego, CA.

National CMV Foundation. (2015). Cytomegalovirus (CMV) non-profit organizations join forces: Vision to eliminate congenital CMV in the United States by 2045. [Press Release]. Retrieved from https://www.nationalcmv.org/NCMVF/media/ncmvf/hero/Joint-Press-Release_120115.pdf

Pass, R. F., & Anderson, B. (2014). Mother-to-child transmission of cytomegalovirus and prevention of congenital infection. *Journal of the Pediatric Infectious Disease Society, 3*(Supp. 1), S2–S6.

Revello, M. G., Tibaldi, C., Masuelli, G., Frisina, V., Sacchi, A., Furione, M., . . .the CCPE Study Group. (2015). Prevention of primary cytomegalovirus infection in pregnancy. *EBioMedicine, 2*(9), 1205–1210.

Ross, D. S., Victor, M., Sumartojo, E., & Cannon, M. J. (2008). Women's knowledge of congenital cytomegalovirus: Results from the 2005 HealthStylesTM survey. *Journal of Women's Health, 17,* 849-858. doi: 10.1089/jwh.2007.0523

Staras, S. A., Dollard, S. C., & Radford, K. W. (2006). Seroprevalence of cytomegalovirus infection in the United States, 1988–1994. *Clinical Infectious Diseases, 43*(9), 1143–1151.

Stowell, J. D., Forlin-Passoni, D., Radford, K., Bate, S. L., Dollard, S. C., Bialek, S. R., Cannon, M. J., & Schmid, D. S. (2014). Cytomegalovirus survival and transferability and the effectiveness of common hand-washing agents against cytomegalovirus on live human hands. *Applied Environmental Microbiology, 80*(2), 455–461. doi: 10.1128/AEM.03262-13

Swanson, E. C., & Schleiss, M. R. (2013). Congenital cytomegalovirus infection: New prospects for prevention and therapy. *Pediatric Clinics of North America, 60,* 335–349. doi: 10.1016/j.pcl.2012.12.008

Thackeray, R., & Magnusson, B. M. (2016). Women's attitudes toward practicing cytomegalovirus prevention behaviors. *Preventive Medicine Reports, 24*, 517–524.

Utah Department of Health. (n.d.). Cytomegalovirus (CMV) Public Health Initiative. Retrieved from health.utah.gov/cmv

Vauloup-Fellous, C., Picone, O., Cordier, A. G., Parent-du-Châtelet, I., Senat, M. V., Frydman, R., & Grangeot-Keros, L. (2009). Does hygiene counseling have an impact on the rate of CMV primary infection during pregnancy? Results of a 3-year prospective study in a French hospital. *Journal of Clinical Virology, 46*, S49–S53.