Cytomegalovirus lies dormant in most US adults, but few have heard of it

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"Why didn't anyone tell me about this virus?" is a frequent response I hear from parents upon learning their newborn is infected with cytomegalovirus, or CMV. Although more than half of the U.S.

population will be infected with CMV by the age of 40 and the disease is common worldwide, few people have ever heard of it.

CMV belongs to the same virus family as cold sores and chickenpox and, like those viruses, lives in the body for life. Most children and adults experience very mild or even no symptoms with their initial infection. A healthy immune system is typically able to keep CMV under control so people don't become sick or even know the virus is living in their body.

So if most people are unlikely to get sick from CMV at any age, then why is the virus so important to understand? As an infectious disease and immunology specialist, I have focused on this question for most of my two-decade career. One major reason is that CMV—unlike the other viruses in its family—can pass from mother to fetus during pregnancy.

Congenital CMV, or cCMV, is the most common infection before birth and the leading infectious cause of birth defects. About one in every 200 infants—typically 20,000 to 30,000 infants in the U.S.—are born with cCMV per year, and nearly 20% of them have permanent neurodevelopmental disabilities such as hearing loss or cerebral palsy. Every year, more children are affected by cCMV than several familiar childhood conditions like Down syndrome and fetal alcohol syndrome. Compared to later stages of pregnancy, CMV infection in the first trimester carries the highest risk of stillbirth or severe effects when the immune system and organs like the brain are developing.

Rates of cCMV differ significantly by race, ethnicity and other demographic factors, with Black and multiracial infants twice as likely to have cCMV compared to other groups. Black and Native American infants also have a higher risk of death from cCMV compared to white infants.

Looking for CMV during pregnancy

Screening for rubella, HIV and syphilis is routine for early prenatal care in the U.S. Counseling to avoid kitty litter to prevent toxoplasmosis is also common. If CMV can infect a fetus and cause birth defects, then why aren't pregnant people tested and treated for this virus too?

Prenatal CMV screening is not standard of care due to several limitations of the current testing approach. Some available tests can be difficult for health care providers to interpret. Testing provides information about whether the parent has CMV, but it does not sufficiently predict the risk of fetal transmission or severe symptoms.

Prenatal screening for a healthy person with a normal pregnancy does not usually offer useful information. That's because anyone can have a baby with cCMV regardless of whether they tested positive or negative for it before or earlier in pregnancy. CMV testing may be useful for pregnant people who are experiencing acute illness, such as prolonged fever and fatigue, or who have an abnormal fetal ultrasound.

Even if more accurate tests were available, there are currently no medical interventions approved by the Food and Drug Administration to reduce the risk of fetal CMV infection. Biweekly antibodies against CMV seem to reduce fetal transmission when given around conception or during the first trimester, but CMV is rarely diagnosed that early in pregnancy.

Researchers are currently evaluating the drug valacyclovir as a potential treatment to prevent fetal transmission. Valacyclovir is commonly used to prevent or treat genital herpes during pregnancy. Findings from a recent clinical trial in Israel suggest that valacyclovir may reduce the risk of CMV transmission to the fetus.

In general, valacyclovir does not work as well as other CMV drugs that people cannot take during pregnancy. As a result, a much higher dose is

required to reduce the risk of fetal CMV infection, which may cause significant side effects for pregnant people.

Although the use of valacyclovir to prevent cCMV is not standard in the U.S., and research on its effectiveness remains limited, the drug is used for this purpose in some areas of the world.

Screening newborns for CMV

Like pregnant people, babies are screened for many potentially serious conditions. An accurate CMV test for newborns is available, and many studies support the benefit of early CMV diagnosis. So why isn't there universal CMV screening for infants?

While some birth centers provide early CMV testing, most U.S. states do not mandate newborn CMV screening. My team and I surveyed 33 hospitals in Massachusetts from late 2020 to early 2021 and found that less than half are consistently screening infants for cCMV infection. Of those, only a few have a written testing protocol. Only two hospitals performed cCMV screening on all infants admitted to the newborn nursery.

Standardizing public health education and CMV screening guidelines could help reduce the incidence and burden of cCMV disease on children and their families. In July 2013, Utah became the first state to pass legislation mandating a CMV public education program and testing for infants who do not pass the newborn hearing screen. In February 2022, Minnesota became the first—and remains the only—state to require CMV screening of all newborns, although Massachusetts and Indiana have pending universal screening bills. So far, 17 states have enacted laws requiring cCMV education or targeted screening of newborns who meet certain criteria, and many others are considering similar options.

On the other hand, designing, funding and implementing a new infant screening program is complex and time-consuming, and may potentially divert resources from other equally important health initiatives. Most newborns with cCMV appear physically normal at birth and develop normally over their lifetime, leading some to question the benefits of CMV screening for those children.

However, infants may have abnormalities that are not visible at birth, and there isn't a reliable way to predict whether they will have progressive health problems. Without screening all newborns for CMV, those who appear normal at birth will not be fully evaluated, considered for treatment or monitored for effects that develop later, such as hearing loss.

Spreading CMV awareness, not infection

Decreasing the incidence of cCMV infection is unlikely without increasing awareness. Most people have not heard of CMV or are unwaware of what they can do to reduce their chances of getting CMV during pregnancy.

Many adults are repeatedly exposed to one of the major risk factors for CMV infection: a young child who regularly attends large-group child care. Infections like CMV spread easily among children in settings where group play, meals and diaper changes become daily opportunities for transmission. Children can appear quite healthy but carry CMV in their saliva and urine for weeks or even months after infection. When an unsuspecting pregnant caretaker comes into contact with those body fluids, they can become infected as well.

For people who are pregnant, simple behavior changes such as kissing a child on the head instead of the lips, not sharing food or utensils, and frequent handwashing can significantly reduce the risk of getting CMV.

Educating the public, policymakers and health care providers will improve the diagnosis, prevention and treatment of cCMV, so no parent suffers the thought "If I had only known…"

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