

PARENTS' REACTIONS TO HYPOTHETICAL CCMV RESULTS ON NEWBORN SCREENING

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Introduction

Congenital cytomegalovirus (cCMV) is the most common congenital viral infection in the US. cCMV is associated with hearing loss, developmental delays, and other health concerns in 15-20% of infected children.^{1,2} The presentation of cCMV is highly variable and symptoms can manifest up to 4 years following birth. Due to the frequency of cCMV and evidence that early detection of symptoms may result in better outcomes for affected children, cCMV is being considered for universal newborn screening programs worldwide. At this time, screening is unable to predict if, when, or which symptoms will present, only detecting the presence of the virus.

Much research has been performed on developing effective screening methods and ways to implement screening for cCMV, but there is a lack of understanding of how this screening will affect the parents of cCMV-positive children. This research gap has been identified as one primary obstacle to the adoption of universal newborn screening.³ In our study we aimed to identify whether there are significant differences in parental stress, worry, or decisional regret between parents who receive either a hypothetical positive or negative cCMV newborn screening result.

Method

Participants

Participants were recruited through Amazon Mechanical Turk (MTurk). Participants were required to have one or more children, be at least 18 years old, and currently live in the United States. In total, 119 individuals completed the survey and were included in data analysis. Relevant demographic information includes:

- Average Age: 41 years old (range 23-69)
- Average Number of children: 2 (range 1-6)
- Relationship to child: 55.7% biological mothers, 42.6% biological fathers, 1.7% adoptive parents
- Race/Ethnicity: 69% White, non-Hispanic
- Education: 74% with 4-year degree or greater
- 16.8% of parents currently have a child with cCMV

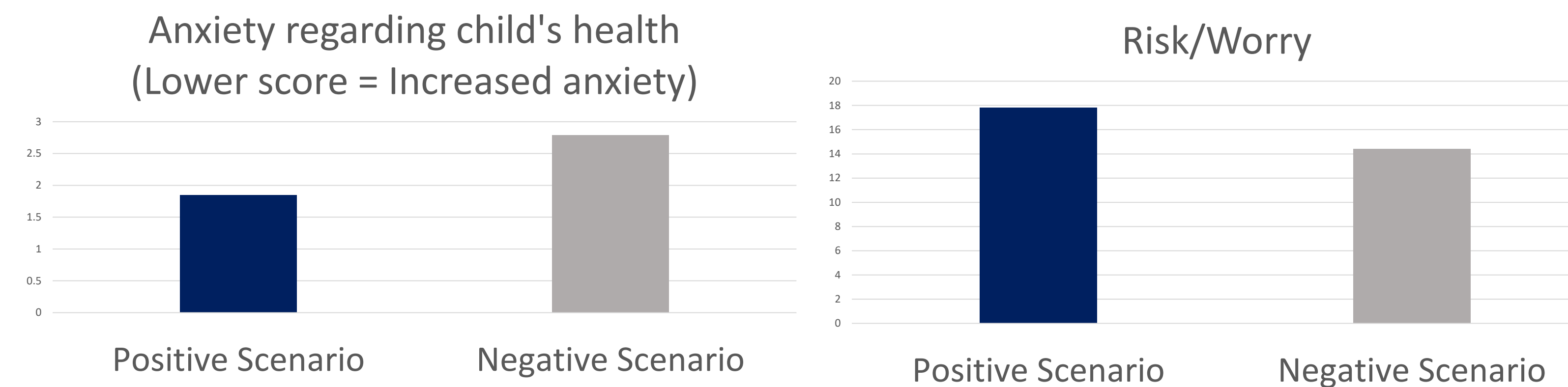
Instruments

A 69-item survey was developed and completed by participants. Participants were first asked a series of questions regarding their demographics and their child's current cCMV and overall health status. Participants were then given a hypothetical positive or negative cCMV newborn screening result and asked to answer a series of questions based on their hypothetical situation. These questions involved parents' risk perception and worry for their child to develop hearing loss, the Parental Stress Scale (PSS)⁶ and the Decisional Regret (DR)⁷ scale. The last section of the survey included two open-ended questions asking about participants' personal views on universal cCMV screening.

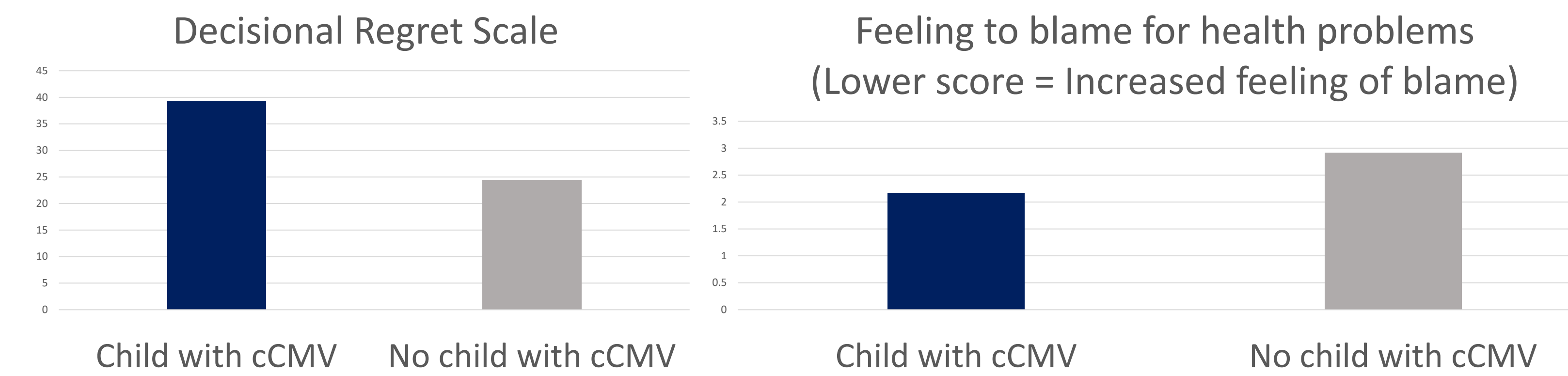
Procedure

After consenting to be a part of the research study, each participant completed the entire survey. The survey was designed to take approximately 15 minutes to complete. Participants were compensated \$1.50 to complete the survey.

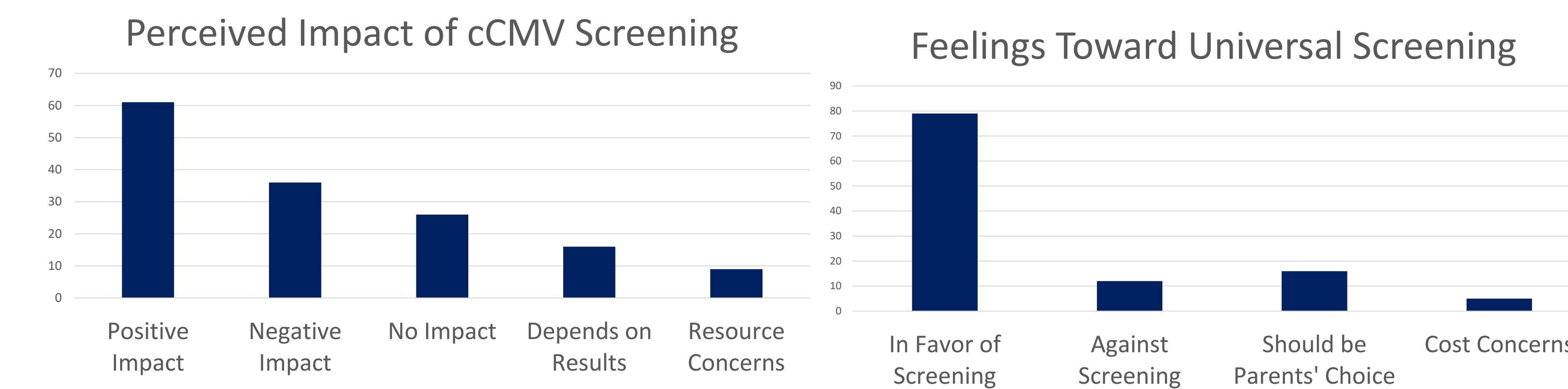
Results



Multivariate analysis of variance (MANOVA) was used to analyze the effects of participant scenario placement (either a hypothetical positive or negative cCMV newborn screen test on their child), and participant demographics. Participants given a hypothetical positive cCMV result reported increased anxiety regarding their child's health ($p < .001$; $\eta_p^2 = .20$). Participants also reported increased risk perception and worry regarding their child's health status ($p < .001$; $\eta_p^2 = .09$).



When demographic variables were analyzed independently, having a child with cCMV was found to have a significant effect. Participants who currently have a child with cCMV reported increased feelings of decisional regret regarding testing ($p = .006$; $\eta_p^2 = .07$), and feelings of blame for their child's health problems ($p = .005$; $\eta_p^2 = .08$), regardless of which hypothetical situation they viewed.



When participants were asked how they felt cCMV screening would affect their family, the largest category of response was that screening would have a positive impact ($n=61$). Most participants believed that screening allows parents to be more prepared to care for their child. Similarly, the majority of participants felt in favor of universal screening for cCMV ($n=79$). This response is similar to prior research that demonstrates a high level of interest in screening programs for cCMV in the general public.⁴

Discussion

Findings

The differences between positive and negative scenarios are similar to prior research on parents of healthy children who received false positive newborn screening results, which showed increased parental stress and hospitalizations of their children in these cases.⁵ There were no differences in parental stress, decisional regret, or the remaining cCMV impact questions between parents in the positive and negative scenario. This suggests that while parents may worry about health risks associated with cCMV, it does not impact how capable they feel to raise their child.

The differences observed between parents who currently have a child with cCMV and those who do not may indicate that cCMV has a greater impact on these psychosocial aspects than one might expect. Because cCMV is an infection initially contracted by the gestational parent, parents might feel like they did something wrong during pregnancy to result in this diagnosis and subsequent health problems. Education on the high frequency and lack of signs of cCMV infection following a positive screen may help to minimize feelings of blame in parents.

The responses to the open-ended questions demonstrate a general positive reaction towards universal cCMV screening. The majority of responses in both questions indicated screening was a good idea and would lead to positive impacts on families of affected children. The reservations around screening involved increased stress and worry in families or logistic concerns following testing such as increased doctor's appointments and costs associated with testing. These concerns emphasize the need for clear communication about cCMV, its risks, and appropriate follow up needs following a positive screen.

Limitations

- One limitation of this study is that the survey was conducted on participants who were given a hypothetical scenario, rather than parents who have recently had cCMV testing on their child. Because of this, it may be difficult to generalize these findings for true newborn screening results.
- Our study only assessed parent's reactions immediately following the test result being delivered. Because health concerns associated with cCMV may not arise for up to 4 years following birth, it is unknown if the reactions identified in our survey are short-term concerns or will last over time.

Recommendations

Future research efforts would ideally involve new parents who have recently undergone cCMV screening for their child, as this would give a more accurate representation of the screening experience. Researchers may want to focus on emotions identified through this study in the future, namely increased parental worry, stress, and feelings of blame. As the parent experience is better understood in the future, research identifying ways to mitigate adverse psychosocial effects may be conducted to improve the process of diagnosis and managing follow up.

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