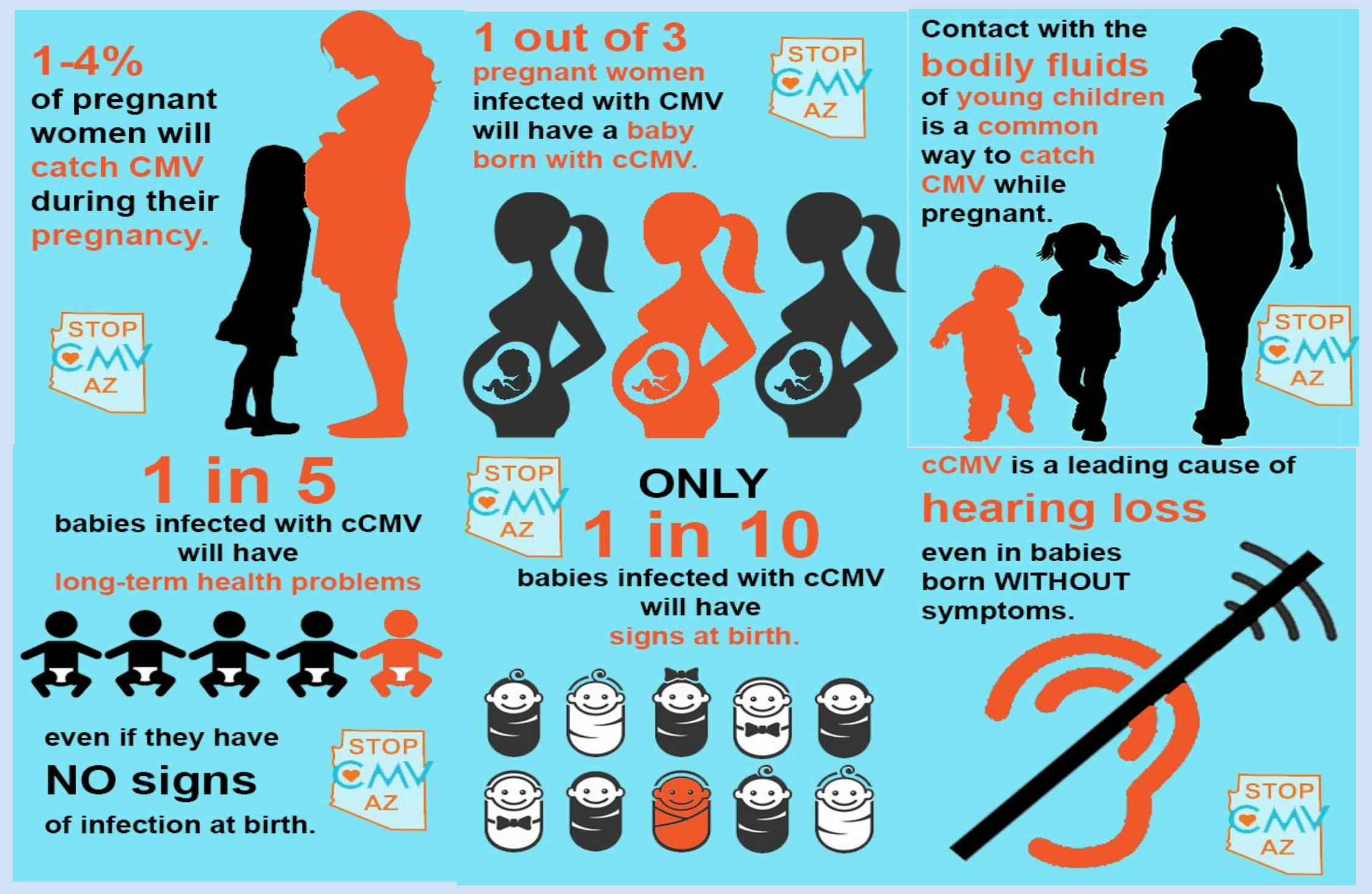
Describing the gap in patient-provider knowledge regarding congenital cytomegalovirus (cCMV) transmission

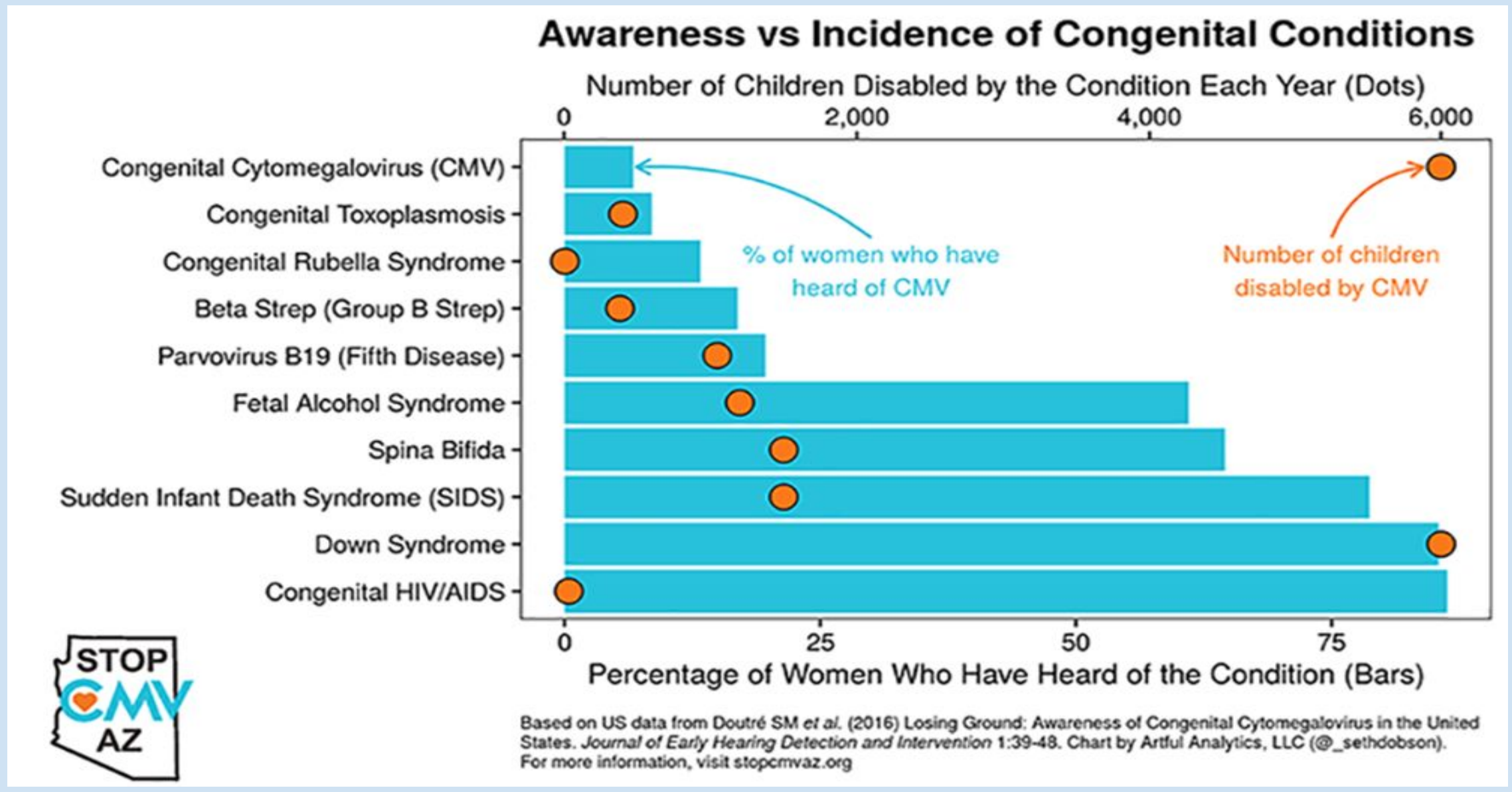
Kinza Naeem[1], Tanisha Trivedi[1], Kathleen Muldoon[1,2]

[1]Arizona College of Osteopathic Medicine, Midwestern University, [2]Department of Anatomy, College of Graduate Studies, Midwestern University

INTRODUCTION

- Congenital CMV (cCMV) is a leading cause of neurodevelopmental disability and the most common non-genetic cause of sensorineural hearing loss. While most adults with a CMV infection are asymptomatic, infection in utero can lead to lifelong disabilities, including microcephaly, vision loss, cerebral palsy, seizure disorders, and cognitive impairment (Tastad, 2019).
- CMV infections are transmitted through direct contact with infectious bodily fluids such as saliva, breastmilk, blood, and urine. Transmission can also occur through a non-primary infection, from reactivation of a previous infection, or exposure to a different strain of the virus (Pass & Arav-Boger, 2018).
- Despite the potential for prevention through simple hygiene measures, such as frequent handwashing and not sharing utensils, public awareness of CMV remains low (Jeon, 2006).
- Many newborn hospitalists and primary care physicians have limited knowledge of cCMV and feel less confident in managing affected infants (Pesch & Muldoon, 2022).





Based on US data from Doutré SM *et al.* (2016) Losing Ground: Awareness of Congenital Cytomegalovirus in the United States. *Journal of Early Hearing Detection and Intervention* 1:39-48. Chart by Artful Analytics, LLC (@_sethdobson). For more information, visit stopcmvaz.org

HYPOTHESIS

We hypothesized significant differences in baseline understanding between these groups.

OBJECTIVES

1. Quantify the perception gap regarding health risk knowledge of congenital cytomegalovirus (cCMV) between families with affected children and the healthcare providers who serve them, with a specific focus on virus transmission.
2. Leverage our findings to identify key areas for targeted educational interventions.

METHODS

We recruited families affected by cCMV and health care providers in Arizona via e-mails and social media posts in Fall 2020-2021. Participants completed an online, anonymous 24-question survey using Survey Monkey. We compared responses between groups regarding routes of transmission. 28 responses from health care providers and 1477 families were used for the analysis.

RESULTS

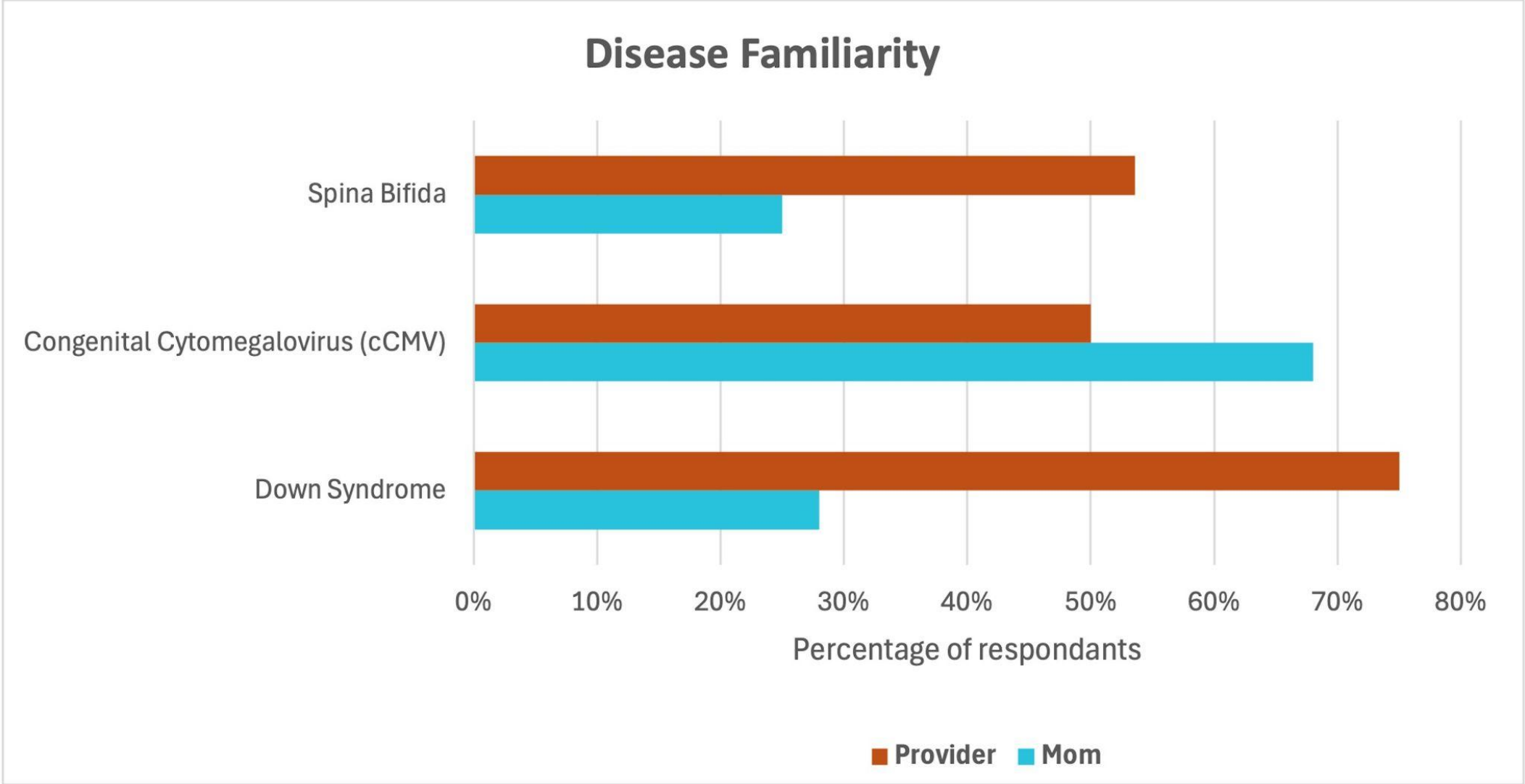


Figure 1. Awareness (measured as self-reported familiarity) of congenital disorders amongst families who have been affected by cCMV and health care providers

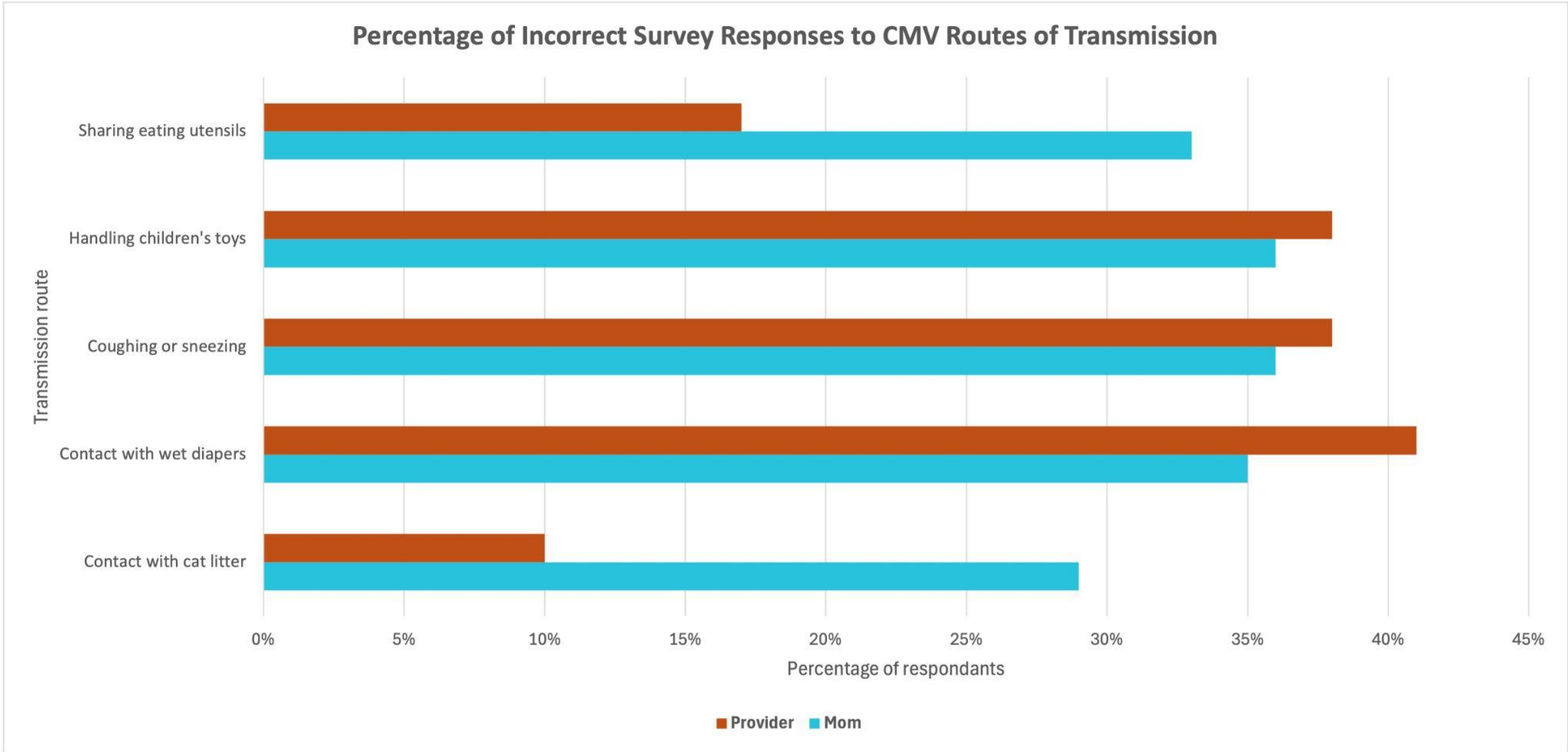


Figure 2. Percentage of incorrect survey responses to whether an action can cause transmission of CMV

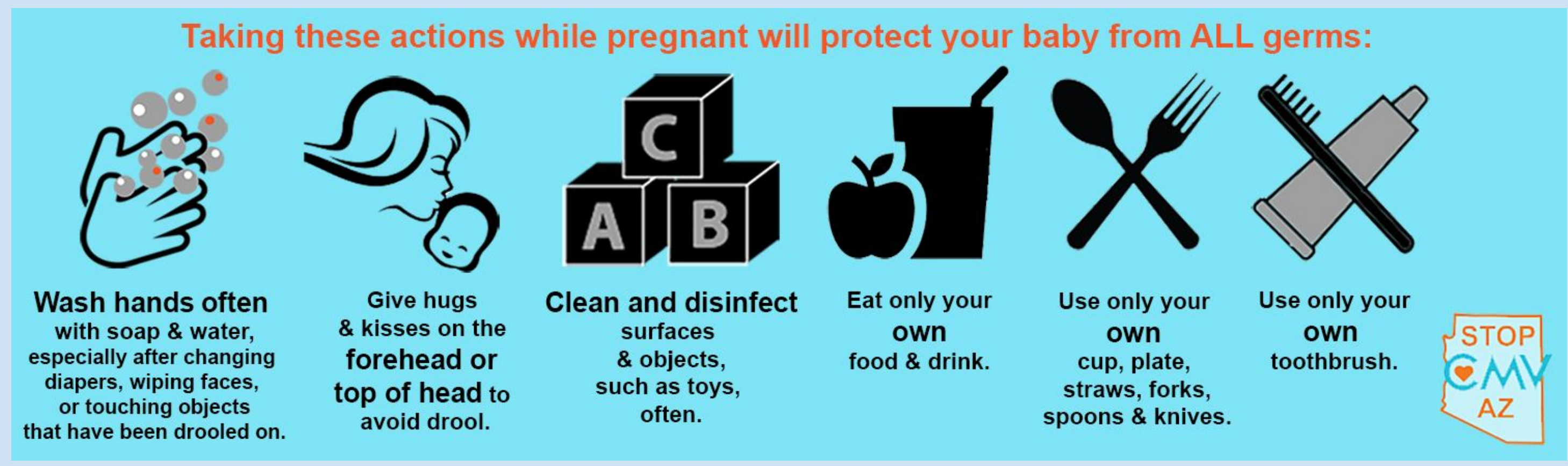
Family responses to survey regarding CMV routes of transmission		
Route of Transmission	*Answer*	
	Yes	No
Contact with cat litter	29%	45%
Contact with wet diapers	37%	35%
Coughing or sneezing	37%	36%
Handling children's toys	37%	36%
Sharing eating utensils	38%	33%

ORANGE=Incorrect
BLUE=Correct

Health care provider responses to survey regarding CMV routes of transmission		
Route of Transmission	*Answer*	
	Yes	No
Contact with cat litter	10%	76%
Contact with wet diapers	48%	41%
Coughing or sneezing	48%	38%
Handling children's toys	48%	38%
Sharing eating utensils	69%	17%

Table 1. Responses of families who have been affected by cCMV to "By which of the following ways can people contract or spread cytomegalovirus (CMV) infection?"

Table 2. Responses of health care providers to "By which of the following ways can people contract or spread cytomegalovirus (CMV) infection?"



CONCLUSIONS

The findings of this study highlight both lower demonstrated health risk knowledge than appropriate to prevent CMV transmission, as well as a knowledge gap between physicians and patients regarding CMV health risk knowledge. This disparity is concerning, as effective healthcare delivery relies heavily on shared decision-making and informed patient participation.

Our study underscores the need for targeted educational interventions to bridge this gap. Addressing these challenges will require a multi-faceted approach, including the development of standardized educational materials, integration of patient education into routine care, and leveraging digital platforms to disseminate information.

OUTCOMES

The anticipated outcome of this study is to inform and drive systemic improvements in cCMV screening, treatment, and family support services.

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