Parents’ Knowledge and Attitudes About CMV Screening in Utah

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• NIH U01 PI CMV multi-institutional study (Park)
• NIDCD R01 co-I Cochlear Implantation (Park)
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Utah Legislative Efforts:
Utah CMV Public Health Initiative (July 2013):

- DOH create education program about birth defects associated with and ways to prevent cCMV
- Annual budget $30,000
- Targets women of childbearing ages, child care and health care providers
- Infants fail NBHS be tested for CMV within first 3 weeks of life
Utah CMV Public Health Initiative (July 2013):

- 21-day period – differentiate cCMV from postnatally acquired CMV
- Rule (R398-4) – eligibility criteria for CMV screening
- Fail both inpatient and return outpatient screening or
- Fail first hearing screening if occurs after age 14 days
Utah CMV Public Health Initiative (July 2013):

• Testing designed to identify cCMV infants with hearing impairment

• Special populations (e.g. NICU), testing for cCMV left discretion of medical provider
What do parents know and how do they feel about CMV screening?

• One objection to CMV screening is parent anxiety

• Also interested in what parents know about CMV for prevention
Attitudes towards CMV Screening

• 2009 national survey (HealthStyles, N = 1589 parents of child younger than 19 years)
  – 84% would want to have newborn tested even if not performed routinely
  – 87% would want newborn tested if they had to pay $20
  – 84% would want to know “if my child has CMV even if he or she never develops problems”
  – 47% “would worry that CMV test would lead to unneeded doctor visits and expenses”
  – -32% “think CMV problems are too rare to think about”

Attitudes towards CMV Screening

3 clusters of parent respondents:
- strongly in favor (31%)
- moderately in favor (49%)
- weakly opposed (20%)

Utah Survey

- $N = 356$ parents in ENT clinic (53% male children, $M$ age = 27 months, range 2 weeks to 18 years; 65% 24 months or younger)
Attitudes about CMV Screening

“Would want to have my baby tested even if my doctor/hospital didn't do it routinely”

- Agree or Strongly Agree: 50%
- Disagree or Strongly Disagree: 39%
- Neutral: 11%

“Would want to know if my child has CMV even if he or she never develops problems”

- Agree or Strongly Agree: 71%
- Disagree or Strongly Disagree: 20%
- Neutral: 9%
Attitudes about CMV Screening

"Would be willing to pay $20 to have my baby tested for CMV"

- Strongly Agree or Agree: 70%
- Agree: 22%
- Neutral: 8%

"Would be more worried about the stigma associated with a CMV diagnosis than about the health effects of CMV"

- Strongly Disagree or Disagree: 62%
- Disagree: 30%
- Neutral: 8%
Attitudes about CMV Screening

"would worry that the CMV test would lead to unneeded doctor visits and expenses"

- 55% Strongly Disagree or Disagree
- 31% Neutral
- 14% Strongly Agree or Agree
Parents’ Knowledge of CMV Law

Most parents were unfamiliar with the law

- Required by law in Utah if failed newborn hearing screen
- Required by law of all newborns

[Bar chart showing the percentage of parents who knew the law correctly, incorrectly, or were not sure.]
Parents’ Knowledge of CMV

CMV is not very contagious
Parents not familiar with CMV
CMV is a common virus that can infect almost anyone
Parents’ Knowledge of CMV

spread through contact with body fluids

- Correctly
- Incorrectly
- Not Sure
Is the Lack of cCMV Awareness in Utah Because we are not screening?

• What have been the results from the Utah mandate?

• Sociodemographic or health care characteristics related to compliance for CMV screening and diagnostic hearing evaluation
Methods:

- Data from Utah DOH early Hearing Detection and Intervention (EDHI) Tracking and Data Management System (HiTrack)
- Utah Vital Records database for births
- Evaluated period 24 before and after law
Methods:

• Descriptive stats on sociodemographic characteristics related to CMV screening and 3 month diagnostic audiologic milestone

• Multivariate logistic regression analyses assessed characteristics linked to CMV screening by 3 weeks of age and audiologic evaluation by 3 months of age
Summary of CMV Screening Outcomes:

- 234/509 (46%) underwent CMV screening within 21 days of age
- 14/234 (6%) tested within 21 days CMV +
  - 6/14 (43%) – hearing loss
- 7/80 (8.8%) tested after 21 days CMV +
  - 1/7 DBS +
  - 3/7 (42.9%) – hearing loss
Impact HT-CMV Testing on Diagnostic Hearing Testing:

• Timely diagnostic hearing evaluation 56% (2 years prior) and 77% (2 years after law)!
• After the law, 86.6% diagnostic hearing evaluation among CMV screened vs 61.5% diagnostic hearing testing among non-CMV screened group
• HT-CMV benefits not just CMV infected but ALL children who fail their newborn hearing screen

Awareness Results Similar Elsewhere:

• National Survey 4184 participants (2181 women; 2003 males)
• 2010 Health Styles Survey
• 7% males; 13% women heard of CMV
• Many women practiced high risk behavior at least weekly w youngest child:
  Kissing lips (69%), sharing utensils (42%), sharing food (62%) and not washing hands after handling child’s toys (74%)

Cannon M et al. Preventive Medicine, 2012
Awareness Results Better in Italy:

- Computer-assisted web questionnaire (Milan University, Italy)
- N=10,190 respondents
- 52.5% heard of CMV
- 31.8% know congenital infection
- < 50% know symptoms from CMV
- Hygienic measures known 55-75%

Binda et al. *BMC Infect Dis* 2016
Mothers’ attitudes towards prevention behaviors

• Women amenable to hand washing and not putting pacifier in mouth

Women less positive about:
• not food sharing
• not kissing child on lips

Where to go from here?

• Excellent results from HT-CMV- providers
• Need to improve campaign on awareness to the public
• Prevention for now may be the key
Hygiene and its impact on primary CMV infection:

• Prospective study
• Pregnant patients informed of CMV and measures for prevention
• N=5312 seronegative initially
• 16 developed primary infection→ 3 newborns infected, one sCMV
• Rate lower than historical uneducated patients

Role Prevention:

• Protective measures relied on frequent hand washing, especially after exposure to a child’s saliva or urine (e.g., diaper changes, handling dirty laundry, touching the child’s toys, etc)
• Avoid intimate contact with young children (e.g., kissing on the mouth, sleeping together, sharing washcloths, utensils, food or drink, etc.)
• Counseling provided by obstetricians or midwives at the first general visit, and lasted about 5–10 min.
Role Prevention:

- RACE-FIT: Reducing Acquisition of CMV through Education
- Phase 1 – educational film
- Phase 2- randomized trial CMV seronegative pregnant women a) rx as usual b) educational intervention
- Jan. 2017-Sept 2019
- Outcomes: incidence CMV newborns, parental adherence, knowledge, acceptability, anxiety
Conclusion:

- Favorable attitudes towards CMV screening
- Despite successful Utah mandate- low awareness among families
- Efforts should be directed at prevention in ALL pregnant moms
- Prevention measures should improve awareness