Awareness and Knowledge of Cerebral/ Cortical Visual Impairment (CVI) Among NICU Providers: A Single-Center Survey

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Background

- **Cerebral/cortical visual impairment (CVI)** is the leading cause of childhood blindness in developed countries, and its diagnosis is increasing worldwide.
- Risk factors of CVI in the neonatal period include hypoxic-ischemic encephalopathy, periventricular leukomalacia, stroke, Infection, and seizures[1,2].
- Although these risk factors are commonly diagnosed in the NICU counseling families of infants in the NICU regarding monitoring for CVI is not yet standard practice.

Methods

- We developed a detailed REDCap survey of 24 questions using guidance from national organizations, including the American Academy of Pediatrics, the American Academy of Ophthalmology, and the Perkins School for the Blind **(Box 1).**
- The survey link was distributed to neonatal physicians, registered nurses, respiratory therapists, speech-language pathologists, occupational therapists, and physical therapists.
- The survey included:
  - **Seventeen questions** directed to all providers that evaluated awareness, knowledge, and interest in further education or guidelines.
  - **Seven questions** targeted to physicians that explored current practices for identifying and following at-risk infants, referral patterns, and perspectives on integrating standardized CVI risk guidelines into clinical care.
  - **Two vignettes** representing infants with high risk for CVI.

Results

- The survey was emailed to 272 providers.
  - **62** total respondents **(61% nurses and 23% physicians).**
  - **66%** of respondents affirmed that they knew the definition of CVI.
  - **95%** said they did not discuss CVI with families. **(Fig 1)**
- **Among physicians:**
  - **57%** described not knowing when to suspect an infant is at risk of CVI.
  - **100%** indicated the need for guidance on how to navigate conversations about CVI. **(Fig 2)**

Discussion and Conclusions

- Our findings indicate that **CVI remains insufficiently understood by NICU providers**. This highlights a clear need for enhanced provider education and guidance regarding CVI and how to effectively counsel families.
- Using this information, our team **developed a CVI clinical practice guideline** for use in the NICU containing materials for staff and parent education, as well as a streamlined process for referring infants identified as having an increased risk of CVI. **(Figs 4&5)**

References

1. Chang, M. Y., & Merabet, L. B. (2024). Special Commentary: Cerebral/Cortical Visual Impairment Working Definition: A Report from the National Institutes of Health CVI Workshop. Ophthalmology, 131(12), 1359–1365. https://doi.org/10.1016/j.ophtha.2024.09.017
2. Lehman SS, Yin L, Chang MY. Diagnosis and care of children with cerebral/cortical visual impairment: clinical report. Pediatrics. 2024;154(6):e2024068465. https://doi.org/10.1542/peds.2024-068465

Figure 1. Examples of survey responses from the whole cohort (n= 62)

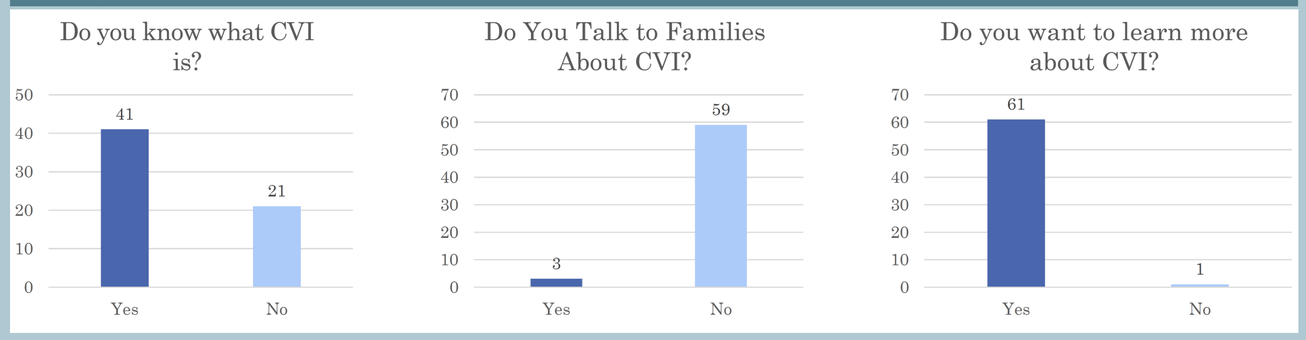


Figure 2. Examples of survey responses from physician cohort (n=14)

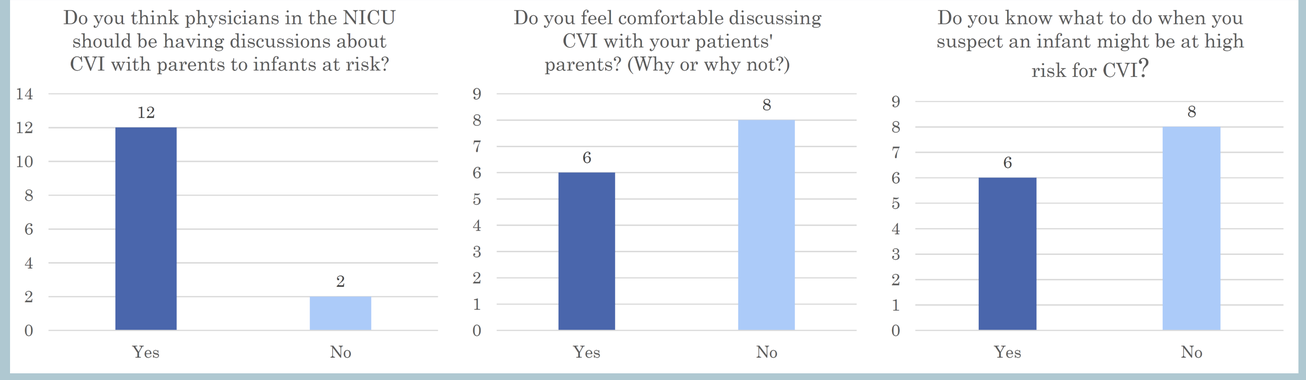
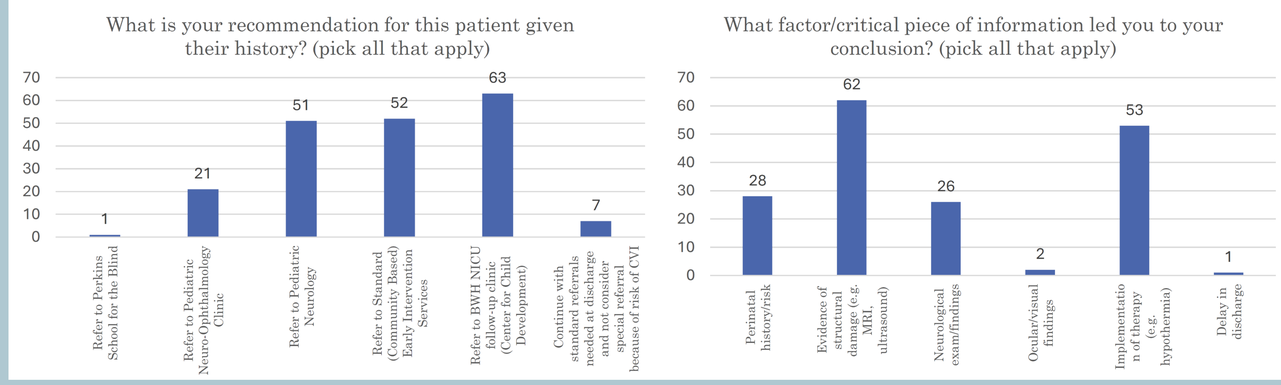


Figure 3. Example of case study responses from whole cohort (n=62)

Case Study 1:
There is a term infant with HIE who received therapeutic hypothermia for moderate encephalopathy. MRI showed very small areas of brain injury. The baby was discharged at day 6 with normal neurological examination.



Box 1. Summary of Survey Questions

Questions for All Providers (n = 17)

1. Do you know what CVI is?
2. Do you talk to families about CVI?
3. Do you want to learn more about CVI?
4. Do you think there should be a guideline to help determine what a patient's risk for CVI is and instruct on how physicians should proceed based on that risk?
5. What are some common risk factors of CVI? (pick all that apply)
6. Where did you learn what you know about CVI currently?
7. Do you feel comfortable discussing CVI with your patients' parents?
8. Do you think there is enough education available for healthcare providers on CVI?
9. How often do you encounter patients who may be at risk for CVI?
10. Do you include CVI as part of your discussions during discharge or follow-up planning?
11. How confident do you feel identifying infants at risk for CVI?
12. Have you ever referred a patient for evaluation of CVI?
13. What challenges do you face in discussing or identifying CVI?
14. Do you think additional training would help improve your ability to discuss CVI with families?
15. Have you participated in any institutional or continuing education on CVI?
16. Do you believe CVI is adequately represented in current neonatal or pediatric curricula?
17. Do you believe early identification of CVI can improve outcomes for affected infants?

Questions for Physicians Only (n = 7)

18. Do you currently screen for CVI or visual impairment in your clinical practice?
19. What criteria or findings prompt you to consider a referral for CVI evaluation?
20. How do you typically counsel families about the risk of CVI following brain injury?
21. What specialists do you usually involve in the evaluation or management of suspected CVI?
22. How often do you refer patients at risk for CVI to ophthalmology, neurology, or developmental follow-up?
23. What barriers do you face when trying to implement CVI risk assessment in your practice?
24. Do you think standardized CVI risk guidelines would be helpful in improving patient care?

Figure 4. MGB CVI Clinical Practice Guideline

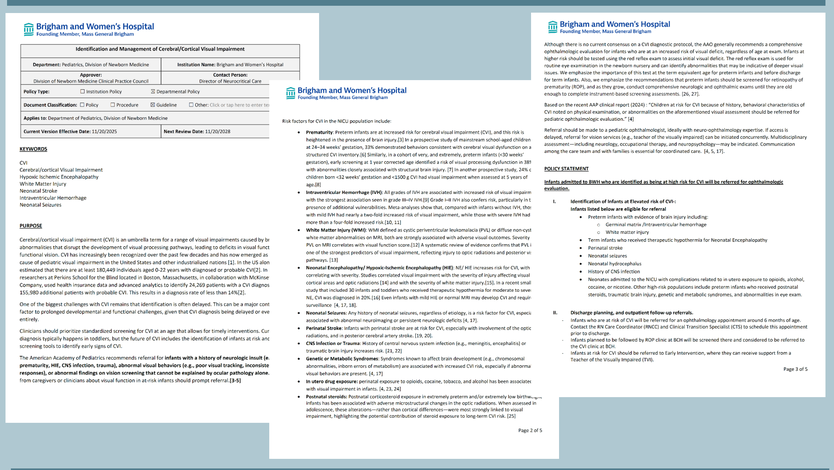
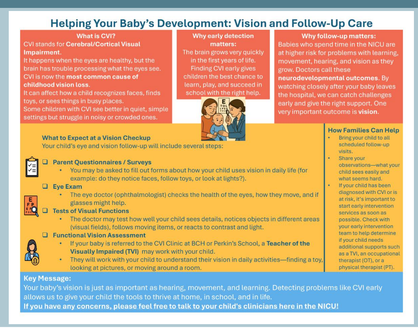


Figure 5. MGB CVI Parent Education Sheet



Please reach out to Dr. Mohamed El-Dib at mel-dib@bwh.harvard.edu if you have any further questions.