Early neurodevelopmental screening: Parent perspectives from the Neonatal Intensive Care Unit

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Infants born preterm are at higher risk of neurodevelopmental problems, including cerebral palsy (CP) compared with infants born at term. Early screening for neurodevelopmental conditions such as CP is crucial to commence early intervention, which can improve motor and cognitive outcomes, and reduce parents stress and anxiety.\(^{1,2}\) The diagnostic category of ‘high-risk of CP’ is now operational\(^{3}\), with evidence suggesting that triangulating brain neuroimaging, General Movements Assessment and Hammersmith Infant Neurological Examination results may reduce the age of diagnosis for CP amongst high-risk infants.\(^{4}\) The possibility of earlier diagnoses of CP is encouraged by families with children with established CP.\(^{5}\) However, clinicians should acknowledge that parent mental health can be at-risk in the Neonatal Intensive Care Unit (NICU) and support should be provided accordingly;\(^{6}\) this extends to early neurodevelopmental screening with a family-centered approach. Dorner et al.’s qualitative study provides insight from interviews with 19 parents within a USA urban Level III and Level IV NICUs about their perceptions and preferences for early neurodevelopmental screening.

Dorner et al. found that parents were mostly accepting of early neurodevelopmental screening, but required the right supports (e.g. emotional preparation, medical expert consultation, social work presence) and information to be able to make an informed decision and cope with the potential state of their child’s neurodevelopmental status. While most parents supported early neurodevelopmental screening for themselves, parents felt that other parents should have the right to refuse screening. Generally, parents felt that potential long term gains from accessing early intervention as a result of early neurodevelopmental screening outweighed initial anxiety and stress during the screening process. Counselling support with respect to existing individual parent/family knowledge and experiences of disability significantly shaped participants expectations and concept of future disability.

This study interviewed a sample of parents who were well-resourced, had high levels of education, were fluent in English, and only one infant in the sample had a major brain injury. While the study’s transferability is limited, the findings provide important insight into the individual needs of parents of...
infants within the NICU who require neurodevelopmental screening. The nature of the questions avoided the specifics involved with the screening process, only identifying it as a hypothetical “non-invasive, non-painful test”. Identifying the specific process of screening to participants may have altered participant responses. Readers are encouraged to consult the interview questions (supplementary files) to gain the context of the responses analysed within Dorner et al.’s study. Parent experiences of early neurodevelopmental screening in different geographical locations, cultural groups, sociodemographic status, infant risk groups, as well as other time points within and beyond the journey through NICU are needed to extend Dorner et al.’s findings.

Dorner et al.’s study highlights the sensitive nature of early neurodevelopmental screening and the depth of information and counselling required to individualise and adequately support and empower parents through the screening process. Finally, the study also emphasises the need to understand parents’ existing knowledge of and experience with disability and acknowledge parents’ day-to-day changes in emotions within the NICU setting.

URL LINK
URL TO THE FULL REVIEW ON THE EBNEO WEBSITE

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