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Article type : EBNEO Review

Title of write-up
Early neurodevelopmental screening: Parent perspectives from the Neonatal Intensive Care Unit

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This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/APA.15563](https://doi.org/10.1111/APA.15563)

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27 Manuscript citation

28 Dorner RA, Boss RD, Burton VJ, Raja K, Lemmon ME. Parent preferences for neurodevelopmental
29 screening in the neonatal intensive care unit. *Dev Med Child Neurol* 2020; 62:500-505. PMID 31909496

30 COMMENTARY

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

43

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

53

54 This study interviewed a sample of parents who were well-resourced, had high levels of education, were
55 fluent in English, and only one infant in the sample had a major brain injury. While the study's
56 transferability is limited, the findings provide important insight into the individual needs of parents of

57 infants within the NICU who require neurodevelopmental screening. The nature of the questions
58 avoided the specifics involved with the screening process, only identifying it as a hypothetical “non-
59 invasive, non-painful test”. Identifying the specific process of screening to participants may have altered
60 participant responses. Readers are encouraged to consult the interview questions (supplementary files)
61 to gain the context of the responses analysed within Dorner et al.’s study. Parent experiences of early
62 neurodevelopmental screening in different geographical locations, cultural groups, sociodemographic
63 status, infant risk groups, as well as other time points within and beyond the journey through NICU are
64 needed to extend Dorner et al.’s findings.

65
66 Dorner et al.’s study highlights the sensitive nature of early neurodevelopmental screening and the
67 depth of information and counselling required to individualise and adequately support and empower
68 parents through the screening process. Finally, the study also emphasises the need to understand
69 parents’ existing knowledge of and experience with disability and acknowledge parents’ day-to-day
70 changes in emotions within the NICU setting.

71

72 URL LINK

73 URL TO THE FULL REVIEW ON THE EBNEO WEBSITE

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75 FUNDING

76 Australian National Health and Medical Research Council, Centre for Research Excellence Newborn
77 Medicine (1153176); Career Development Fellowship (1108714 to AJS)

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79 CONFLICT OF INTEREST

80 The authors have no conflicts of interest to declare

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