Life after neonatal seizures: Characterizing the longitudinal parent experience.

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Background: Parents of neonates with seizures report persistent symptoms of depression, anxiety, and post-traumatic stress. We aimed to characterize the parent experience of caring for children impacted by neonatal seizures, including longitudinal assessment across childhood.

Methods: This prospective, observational, multicenter study was conducted at Neonatal Seizure Registry (*NSR*) sites in partnership with the *NSR* Parent Advisory Panel. Parents completed surveys at discharge, 12-, 18-, 24-months, 3-, 4-, 5-, 7-, and 8-years. Surveys included demographic information and several open-ended questions targeting parent experience. A conventional content analysis approach was used to analyze qualitative data.

Results: 320 caregivers completed at least one open-ended question, with the majority of respondents at discharge (*n*=142), 12 months (*n*=169), 18 months *(n*=208), and 24 months (n=245). We identified three primary themes: (1) Personal Burden of Care: Parents experienced e*mo*tional distress, financial strain, physical demands, and fears for their child's unknown outcome and potential for seizure recurrence. (2) Managing Day-to-Day Life: Parents described difficulties navigating their parenting role, including managing their child's challenging behaviors, and understanding their child's needs amidst neurodevelopmental impairment. (3) My Joys as a Parent: Parents valued bonding with their child, being a caregiver, and watching their child's personality grow.

Conclusions: Parents of children impacted by neonatal seizures face persistent challenges over time, which are interwoven with the joys of being a parent. Our findings suggest that future interventions should acknowledge and promote parent resiliency and address caregivers' psychosocial needs longitudinally, and provide enhanced support for parents caring for children with medical complexity.