Background

- Neonatal outcomes research assesses a multitude of physical and psychological factors affecting preterm infants and their families. Prognosis is often defined through initial outcomes at 18 months corrected age.
- Little is known about how parents view their children, and whether their perceptions mirror those of healthcare professionals.

Objectives

- To explore parental perspectives regarding their premature child at 18 months corrected age.
- To investigate whether reported answers correlate with level of impairment determined through standardized follow-up measures.

Methods

- Design: retrospective mixed-methods analysis of a prospective observational study cohort.
- Population: All surviving infants born <29 weeks of GA in 2009-2012 who underwent neurodevelopmental assessment at 18-months CA (neuromuscular assessment and Bayley-III scales).
- Setting: Level 3 NICU and follow-up center in a University Hospital.
- Outcome: Parents were asked two open-ended questions: “What concerns you most about your child?” and “Please describe the best things about your child.”
- Statistical analysis: Thematic analysis and coding of parental answers by 3 independent investigators. Chi-square analysis was performed to identify similarities and differences of invoked themes among parents.

Results

Participants: At 18 months CA, 190 of 323 eligible children had both neurodevelopmental data and parental responses (59%). 93 (49%) had no disability, 82 (43%) had mild-mod disability. 15 (8%) had severe disability.

Positive themes

1. Positive personality (61%), either social (19%), easygoing (19%) or curious (18%): “He is determined to do things by himself”;
2. Happiness (40%); “He smiles and is happy, loves hugs”;
3. Development (40%), especially making progress (21%): “She is learning very fast”;
4. Physical health (11%): “He has a good appetite”.

Concerns

1. Neurodevelopment (56%), most particularly language (25%) and behavior (20%): “He is not talking much, always throws his toys”;
2. Physical health concerns (24%) including nutrition and growth (17%): “He is small”; “Feeding her is so hard”;
3. 16% of parents specifically stated they had no concerns;
4. Concerns about the future (5%).

Concerns vs neurodevelopmental impairment

- Developmental
- Health concerns
- None (explicit)
- Future

Discussion

- Positive themes were invoked with a similar frequency by parents, regardless of neurodevelopmental impairment category.
- This echoes prior research regarding positive aspects of parenting a child with a disability.
- Caregivers expressed feeling encouraged by their child’s progress and physical health, even in the face of disability.
- Concerns were also invoked rather similarly across NDI categories.
- Only parents whose children had mild-moderate NDI were more likely to report worrying about development, compared to others (p < 0.05).
- Limitation: ND outcomes could be over-represented in parental answers as this is the main purpose of Neonatal Follow-Up Clinics.
- Strength: First study to examine parental perspective regarding ND outcomes at 18 months following preterm birth.

Conclusions

- Neurodevelopmental outcomes are a significant concern for parents, specifically language and behavior.
- Independent of child’s NDI, parents overwhelmingly report similar positive aspects.
- Outcome research should incorporate parental perspectives, enabling physicians to provide balanced information to parents of all preterm infants.

References