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ORIGINAL ARTICLE

Parent concerns for child development following admission to neonatal intensive or special care: From birth to adolescence

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Aim: To describe the presence and nature of parent concerns regarding the development of their children admitted to Australian neonatal units (NNUs), comprising neonatal intensive care or special care.

Methods: In a cross-sectional survey, mothers and fathers provided information regarding concerns for their child's development. The self-administered survey was completed by two separate cohorts; (i) parents of child graduates from Australian NNUs ($n = 381$); (ii) parents of infant's inpatient in two South Australian NNUs ($n = 209$). Data were analysed using thematic analysis and descriptive statistics.

Results: Information was provided for 730 children. Developmental concern was reported for 39% of NNU graduates and 35% of inpatients. Children born very preterm (< 32 weeks' gestation) elicited greater parent concern than those born more mature (Cohort 1: 41% vs 36%; Cohort 2: 49% vs 22%), including in multiple developmental domains (Cohort 1: 17% vs 15%; Cohort 2: 28% vs 4%). Parents with inpatient infants were predominantly concerned about general development-milestones (19.1%) and the potential impact of medical or CNS issues (13.7%). Graduate parents commonly focused on specific domains, such as their child's speech-language (13.7%) and motor (12.9%) development.

Conclusion: Neurodevelopment is a substantial source of concern for mothers and fathers during NNU admission and childhood, particularly for children born very preterm. However, in the first year of life, developmental concerns are poorly defined. This highlights the need for clinical education resources detailing infant developmental expectations and supportive strategies for parents of these high-risk infants.

Key words: child development; father; infant, premature; intensive care, neonatal; parent concerns.

What is already known on this topic

1 Babies admitted to the neonatal unit are at increased risk for adverse long-term neurodevelopmental sequelae.
2 Eliciting and responding to parent concerns is important to the provision of family inclusive, developmentally supportive care.
3 Following hospital discharge, the frequency and type of parent concern for development vary with the child's age.

What this paper adds

1 Parents who experience their child's admission to a neonatal unit (NNU) have substantial concerns for neurodevelopment that extend beyond the risk for cerebral palsy, cognitive impairment, hearing loss or vision impairment.
2 Developmental concerns raised by fathers closely mirror mothers' concerns during NNU admission, with general development-milestones the primary focus.
3 The frequency and nature of parental concerns between birth and adolescence highlight the need to provide additional clinical resources and targeted neurodevelopmental education to support this population.

The incidence of adverse neurodevelopmental sequelae amongst children admitted to neonatal units (NNUs) is high, especially for those born very preterm (<32 weeks' gestation),[1] diagnosed with hypoxic-ischemic encephalopathy,[2] or who require surgery.[3] During their baby's admission to neonatal intensive or special care, parents are counselled regarding risks for long-term neurodevelopmental impairment and understandably worry for their child's health, comfort and future. Indeed, elevated rates of anxiety and depression are well documented among parents during hospitalisation[4] and post-discharge.[5]

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Concerns relating to their child's development may contribute to the psychological distress experienced by parents of children requiring admission to NNU. Eliciting and responding to concerns of parents is important to the delivery of family centred, developmentally supportive care.[6,7] However, for this high-risk population, there remains a significant knowledge gap regarding parental concerns for the neurodevelopment of their child. The aim of this study was to describe the presence and nature of parental concern for the development of their children during NNU admission and in the early childhood years.

Methods

Study design

Cross-sectional data obtained via self-administered parent survey across two separate cohorts: (i) parents of children who had graduated from NNU; and (ii) parents of NNU inpatients.

Cohort 1

Between 11th and 16th May 2015, an invitation and link to complete a voluntary online parent survey were posted to the Facebook page of the Miracle Babies Foundation, a large Australian neonatal consumer organisation for families with infants born preterm or critically ill. Parents who had a surviving child previously admitted to NNU (comprising Neonatal Intensive Care (NICU) or Special Care (SCBU)) as a newborn were eligible to participate. IP addresses were used to determine unique visitors. No incentives were offered for participation.

Cohort 2

Mothers and fathers who were the legal guardian of a newborn inpatient not receiving palliative care in the NNU of the Women's and Children's Hospital (WCH) and Lyell McEwin Hospital (LMH) in South Australia were eligible to participate. Parents needed sufficient English to understand the study documents and survey. Recruitment occurred over 10 months (March–December 2017) at the WCH NICU and SCBU, and over 3 months (October–December 2017) at the LMH providing SCBU only. Parents were approached once their baby was clinically stable.

Measures

The 21-item survey was developed for this research and designed in consultation with mothers ($n = 7$) who had experienced a newborn requiring admission to an Australian NNU. The survey comprised three sections: (i) parenting experience; (ii) parent concerns for the development of their children; and (iii) parent knowledge and preferences for child development education. Section two, parental concerns for their child's development (Appendix S1, Supporting Information), is the focus of this study. For each child, parents completed a dichotomous (yes/no) question; 'Do you have any current concerns for your child's development?' and a free-text response to describe the nature of their concern. For cohort 2, the highest level of parent educational attainment and residential postcode were also collected and hospital medical records were accessed to confirm birth and demographic information. Parents completed the survey on paper or online using Survey Monkey.[8]

Data analysis

An inductive thematic content analysis approach was used to develop, define and agree upon key themes arising from parents' free-text comments regarding developmental concerns. This was performed separately for each cohort. Two authors (Megan L Bater and Michael J Stark) independently coded each parental concern response. When a coding discrepancy occurred, the response was reviewed together with a third author (Peter J Anderson), and consensus reached. There was substantial consistency in developmental domains of concern identified by parents in Cohort 1 (Appendix S2, Supporting Information) and Cohort 2 (Appendix S3, Supporting Information). This resulted in 10 discrete domains (Appendix I). Six related directly to the domain of developmental concern: motor, speech-language, behaviour, sensory, cognition-learning and general development-milestones; four related to concerns for the impact of medical issues: growth-feeding, respiratory, CNS, and other medical.

For every child, parent free-text responses were dichotomised into concern or no concern for each domain. Parents were able to report concern in multiple developmental domains for each child. Where multiple concerns were reported, each was separately coded into the corresponding discrete domain. For example, the response 'Development is very slow compared to my other children. Only just today at 11 months did he hold his bottle for the first time. Still no speech and slow reaction to some things' *(Cohort 1: mother of 26 weeks' gestational age (GA) child)* was allocated to three discrete descriptor domains – general development; motor; and speech/language. Where parents identified concern for two or more children and described concerns in multiple domains but failed to identify which child(ren) each related to, the concern was allocated to the first child only with the remaining siblings coded as Yes to parent-reported concern; domain(s) un-interpretable. All available concerns data were analysed.

The proportion of children for whom parents reported developmental concerns was calculated for each cohort separately. Descriptive statistics were reported as frequencies and percentages, using the child as the index. For each cohort, the Chi-square or Fisher exact test was used to investigate differences in responses between parents whose children were born very preterm compared with later gestations. Statistical significance was set at $P < 0.05$. Data coding and analyses were performed with SPSS version 26.0.[9]

Ethics

The Human Research Ethics Committee at the WCH and the LMH approved this study (HREC/15/WCHN/106). All parents gave consent to participate.

Results

Participants

Cohort 1

Of the 388 parents who participated in the online survey, 5 failed to meet eligibility criteria and 2 had significant missing data.

Table 1 Characteristics of study participants and their children

Parents	Cohort 1 NNU graduates $N = 381$	Cohort 2 NNU inpatients $N = 209$
Mothers	375 (98)	120 (57)
Fathers	6 (2)	89 (43)
First time parent	233 (48)	132 (63)
Repeat NNU exposure	52 (14)	13 (6)
Completed secondary education ≤ year 12†		63 (28)
Attained Bachelor's degree or higher†		93 (45)
SEIFA IRSAD quintile 1 most disadvantaged†		50 (24)
SEIFA IRSAD quintile 5 most advantaged†		21 (10)
Children	$N = 489$	$N = 241$
Gestational age, weeks, median (IQR)	30 (27–33)	32 (29–34)
Very preterm	299 (61.2)	114 (47.3)
Moderate to late preterm	139 (28.4)	92 (38.2)
Term	51 (10.4)	35 (14.5)
Multiple birth	101 (21)	64 (27)
Current age, median (IQR)	2 years (1 month to 4 years)	14 days (8–31 days)

† Data were available for NNU inpatient cohort only. Data presented as *N* (%) unless otherwise stated; Very preterm: Gestational age <32 weeks; Moderate to late preterm: 32 to <37 weeks; Term: ≥37 weeks. IQR, interquartile range; NNU, neonatal unit; SEIFA IRSAD, socio-economic indices for areas index of relative socio-economic advantage and disadvantage.

Table 2 Exemplar quotes from parent free-text comments describing developmental concern

Cohort 1: NNU graduates

- Speech issues, not speaking yet *(mother of 26 weeks' GA toddler, 2 years old)*
- Still attend speech therapy but almost caught up. Barely eats anything – mainly white food *(mother of 26 weeks' GA child, 4 years old)*
- He is almost 12 months and only just starting to roll. He does not move/pivot while on his stomach and cannot crawl or sit up *(mother of 34 weeks' GA infant, 11 months old)*
- No major concern but she is a bit behind with her milestones such as she is not rolling on her own yet. She is being assessed for a helmet for plagiocephaly *(mother of 28 weeks' GA infant, 10 months old)*
- Still struggling with feeding and probably needs an NG again just for night feeds. Also, a little behind physically, but tracking normally *(mother of 25 weeks' GA infant, 8 months old)*
- He has very mild cerebral palsy so he has some fine and gross motor difficulties. He also seems to have some difficulties with concentration and impulsive behaviour *(mother of 25 weeks' GA child, 4 years old)*

Cohort 2: NNU inpatients

- I am unsure how early birth will affect his developmental milestones *(father of 29 weeks' GA baby, day 13)*
- Worried that the 'normal' health issues of premature babies (i.e.: desats, brady's etc.) will impact my boys' development *(mother of 30 weeks' GA twins, day 41)*
- I am worried about her general physical and cognitive development. I have heard a lot of stories and risk factors that come with premmies *(mother of 28 weeks' GA baby, day 20)*
- How prematurity can affect learning outcomes in later life, that is, neurological impairment. Possible effect of oxygen upon eyesight etc. ADHD. Increased risk of SIDS *(father of 26 weeks' GA baby, day 14)*
- Prematurity affecting development, brain bleeds, reflux *(mother of 30 weeks' GA twins, day 56)*
- Vision – ROP surgery. Brain development – bleeds in ventricles. Lung capacity – chronic lung *(father of 25 weeks' GA baby, day 115)*

ADHD, attention-deficit/hyperactivity disorder; GA, gestational age; NG, nasogastric tube; NNU, neonatal unit; ROP, retinopathy of prematurity; SIDS, sudden infant death syndrome.

Therefore, responses from 381 parents (489 children) were included in the analysis.

Cohort 2

Of the 210 parents who consented to participate, 1 did not submit a survey. Therefore, 209 parents with 241 babies (197 (82%) receiving care in SCBU and 44 (18%) in NICU) were included in the analyses. Overall, 590 parents (95 fathers) participated, providing information on developmental concerns for 730 children (Fig. A1).

A large proportion of children in each cohort were born very preterm (cohort 1, 61%; cohort 2, 47%) (Table 1). The proportion of relative socio-economic advantage/disadvantage amongst cohort 2 parents was similar to South Australians' 2016 census data[10]; however, they were more likely to have attained a Bachelor's degree or higher, compared with national census data.[11]

Parent concerns by developmental domain

Exemplar quotes from parent free-text comments describing developmental concern for each cohort are provided in Table 2. A total of 451 concerns were identified for the development of 274 children (cohort 1: 190, 39%; cohort 2: 84, 35%). Amongst children who elicited concern, co-morbidity was high, with concern reported in multiple domains (cohort 1: 79, 42%; cohort 2: 37, 44%).

The focus of parental concern for cohort 1 (Appendix S2, Supporting Information) is often related to specific developmental domains (Table 3), with speech-language (e.g. 'slower at speech than his twin brother') and motor development (e.g. 'not yet walking alone at 18 months') the most prevalent, comprising over 26% of reported concern. Growth-feeding concerns (e.g. 'poor weight gain' or 'food aversion issues') were identified for 6% of children in cohort 1; the same rate as for cohort 2. Among cohort 2, parent concern responses (Appendix S3, Supporting Information) predominantly related to general development-milestones (e.g. 'I am unsure how his early birth will affect his developmental milestones') and potential

Table 3 Parent-reported concerns by developmental domain and gestational age, Cohort 1

	NNU graduate children, $N = 489$	VP (<32 weeks), $N = 299$	MLP & T (≥32 weeks), $N = 190$	*P* value
No concerns	299 (61.1)	177 (59.2)	122 (64.2)	0.3
Single concern for child	102 (20.9)	67 (22.4)	35 (18.4)	0.4
Multiple concerns	79 (16.2)	51 (17.1)	28 (14.7)	0.6
Domain(s) unknown†	9 (1.8)	4 (1.3)	5 (2.6)	
Domain of concern‡				
Motor	63 (12.9)	46 (15.4)	17 (8.9)	0.05
Speech and language	67 (13.7)	37 (12.4)	30 (15.8)	0.3
Behaviour	30 (6.1)	18 (6.0)	12 (6.3)	1.0
Sensory	27 (5.5)	21 (7.0)	6 (3.2)	0.1
Cognition and learning	12 (2.5)	11 (3.7)	1 (0.5)	0.03
General development and milestones	36 (7.4)	25 (8.4)	11 (5.8)	0.4
Growth and feeding	31 (6.3)	19 (6.4)	12 (6.3)	1.0
Respiratory	15 (3.1)	12 (4.0)	3 (1.6)	0.2
Other medical	10 (2.0)	5 (1.7)	5 (2.6)	0.5
Other CNS	10 (2.0)	5 (1.7)	5 (2.6)	0.5
Total concerns elicited§	301	199	102	

† Includes yes to concern but not described by parent or not allocated to a specific child(ren) – excluded from statistical analysis. ‡ See Appendix I and Appendix S2, Supporting Information. § Parents were able to report concern in multiple developmental domains for each child. Data presented as *N* (%). *P* value represents the difference between VP and MLP & T groups. MLP, moderate to late preterm – born between 32 and 36 weeks' gestation; NNU, neonatal unit; T, term – born ≥37 weeks' gestation; VP, very preterm – born <32 weeks' gestation.

Table 4 Parent-reported concerns by developmental domain and gestational age, Cohort 2

	NNU inpatient children, $N = 241$	VP (<32 weeks), $N = 114$	MLP & T (≥32 weeks), $N = 127$	*P* value
No concerns	157 (65.1)	58 (50.9)	99 (78.0)	<0.001
Single concern for child	45 (18.7)	22 (19.3)	23 (18.1)	0.9
Multiple concerns	37 (15.4)	32 (28.1)	5 (3.9)	<0.001
Domain(s) unknown†	2 (0.8)	2 (1.8)	0	
Domain of concern‡				
Motor	13 (5.4)	12 (10.5)	1 (0.8)	0.002
Speech and language	3 (1.2)	3 (2.6)	0	0.1
Behaviour	1 (0.4)	1 (0.9)	0	0.5
Sensory	9 (3.7)	8 (7.0)	1 (0.8)	0.01
Cognition and learning	16 (6.6)	14 (12.3)	2 (1.6)	0.002
General development and milestones	46 (19.1)	34 (29.8)	12 (9.4)	<0.001
Growth and feeding	16 (6.6)	13 (11.4)	3 (2.4)	0.01
Respiratory	13 (5.4)	11 (9.6)	2 (1.6)	0.01
Other medical	21 (8.7)	10 (8.8)	11 (8.7)	1.0
Other CNS	12 (5.0)	11 (9.6)	1 (0.8)	0.004
Total concerns elicited§	150	117	33	

† Includes yes to concern but not described by parent or not allocated to a specific child(ren) – excluded from statistical analysis. ‡ See Appendix I and Appendix S3, Supporting Information. § Parents were able to report concern in multiple developmental domains for each child. Data presented as *N* (%). *P* value represents the difference between VP and MLP&T groups. MLP, moderate to late preterm – born between 32 and 36 weeks' gestation; NNU, neonatal unit; T, term – born ≥37 weeks' gestation; VP, very preterm – born <32 weeks' gestation.

developmental impacts of their baby's diagnosis or medical issues; for example, 'he had bleeds on the brain when he was born due to being resuscitated and we won't know re: his development until he is 2–3 years old' *(mother of a 25 weeks' GA NNU admitted infant, 12 days old)* (Table 4).

Parent concerns for development according to gestational age

Children born very preterm elicited greater parental concern than children born at later gestations (cohort 1: 41% vs 36%; cohort 2:

Table 5 Parent concerns for development according to child's current age, Cohort 1

	Infant <12 months, *N* = 105	Toddler 1–2 years, *N* = 181	Pre-school 3–4 years, *N* = 100	Primary school 5–11 years, *N* = 80	High school 12–15 years, *N* = 23
No concerns	68 (64.8)	108 (59.7)	58 (58.0)	52 (65.0)	13 (56.5)
Single concern for child	19 (18.1)	43 (23.8)	17 (17.0)	17 (21.3)	6 (26.1)
Multiple concerns	16 (15.2)	28 (15.5)	24 (24.0)	9 (13.7)	2 (8.7)
Domain(s) unknown†	2 (1.9)	2 (1.1)	1 (1.0)	2 (2.5)	2 (8.7)
Domain of concern‡					
Motor	15 (14.3)	33 (18.2)	12 (12.0)	3 (3.8)	0 (0)
Speech and language	3 (2.9)	33 (18.2)	23 (23.0)	8 (10.0)	0 (0)
Behaviour	2 (1.9)	3 (1.7)	12 (12.0)	8 (10.0)	5 (21.7)
Sensory	4 (3.6)	12 (6.6)	8 (8.0)	3 (3.8)	0 (0)
Cognition and learning	2 (1.9)	0 (0)	3 (3.0)	4 (5.0)	3 (13.0)
General development and milestones	12 (11.4)	11 (6.1)	8 (8.0)	4 (5.0)	1 (4.3)
Growth and feeding	9 (8.6)	10 (5.5)	9 (9.0)	3 (3.8)	0 (0)
Respiratory	4 (3.8)	6 (3.3)	2 (2.0)	2 (2.5)	1 (4.3)
Other medical	5 (4.8)	1 (0.6)	1 (1.0)	3 (3.8)	0 (0)
Other CNS	2 (1.9)	6 (3.3)	1 (1.0)	1 (1.3)	0 (0)
Total concerns elicited§	58	115	79	39	10

† Includes yes to concern but not described by parent or not allocated to a specific child(ren) – excluded from statistical analysis. ‡ See Appendix I and Appendix S2, Supporting Information. § Parents were able to report concern in multiple developmental domains for each child. Values presented as *N* (%). NNU, neonatal unit.

49% vs 22%), including concerns in multiple developmental domains (cohort 1: 17% vs 15%, p=0.6; cohort 2: 28% vs 4%, p=<0.001) (Tables 3 and 4). There were no significant differences in the presence and nature of parent concern according to gestational age in cohort 1 (Table 3) except for cognition and learning (e.g. '… I worry that later, she may not reach her potential in terms of intelligence because she was born so early'). Cohort 2 parents identified significantly greater concerns over a range of developmental domains for very preterm infants compared with infants born more mature (Table 4), while speech-language and behaviour concerns were reported at comparable frequencies across GA categories.

Parent concerns according to current age of child

Cohort 1 parents reported comparable rates of developmental concern for their children across all age-groups (Table 5). However, the domain of greatest concern differed according to the child's age: motor development for infants (<12 months); motor and speech-language development equally for toddlers (1–2 years); speech-language in pre-school children (3–4 years). Behavioural and cognition-learning concerns both emerged in pre-school, persisted amongst primary school-aged children (5–11 years) and were most frequently reported for adolescents (12–15 years). Infants and pre-school aged children elicited the highest growth and feeding concerns following discharge (both 9%).

Concerns raised by fathers

Information relating to fathers' concerns are reported solely for cohort 2 (Table A1), as fathers comprised just 2% of cohort 1. Fathers reported developmental concern for their infants at a comparable rate to mothers (36% and 34%, respectively) (Table A1). Father identified concerns also closely matched mothers in 7 of the 10 developmental domains. General development-milestones caused fathers the greatest concern, with one explaining that this was due to being 'unaware of milestones that my child should be meeting at this young age – so I am concerned that I don't know what he should and should not be doing' *(father of 24 weeks' GA infant, 63 days old)*.

Discussion

This study makes a valuable contribution to our knowledge of parent concerns for the development of their children admitted to an NNU. Our findings suggest substantial parental concerns for neurodevelopment for children admitted to NICU/SCBU, without particular parental gender bias. Parents with children born very preterm were most likely to express developmental concern. It appears that the nature of parent concern evolves between NNU admission (with a preponderance of general developmental and medical issue concerns) and following discharge; with concerns narrowing to more specific developmental domains with age.

Our findings support the use of cross-sectional surveys to explore parental concerns regarding child development. While this approach has been used by others in post-discharge neonatal follow-up clinics,[7,12–14] our study is unique as the first to include parents whose child is a current NNU inpatient. In line with two previous studies,[13,14] we found parents of both inpatients and graduates expressed concern for just over a third of children. However, other studies report rates of developmental concern that vary from a fifth[12] to just over a half[7] of parents surveyed. This discrepancy may be influenced by many factors. Parent concerns for

developmental risk have been shown to be more prevalent in families experiencing socio-economic adversity,[6,15,16] minority ethnic groups[6,17] and for boys.[15,17] The diverse range and frequency of parent-reported concern between studies may be explained by parents not interpreting 'development' in the same way as health professionals[18] or indeed each other. Some parents may express less concern due to feeling confident that their child will avoid or overcome developmental risk in the same way that they overcame their fragile beginning in NICU[12] and others, who continue to perceive their child as vulnerable to developmental risk, may express more frequent concern.[7]

Differences in our study emerged in the nature of parent-reported concern across age-groups and between cohorts. This finding is consistent with research showing that the presence and nature of parent concern vary with the child's age.[13,15,16,18] Comparators are an important and meaningful tool parents use to appraise the developmental status of their child.[19,20] As a result, the higher proportion of first-time parents in cohort 2 may explain our observation that discrete domains of concern were more commonly specified by cohort 1 parents. It may be that limited parental exposure to information specific to preterm child development works in a similar way, with lack of opportunity for parent comparisons between their infant's abilities and expected developmental milestones leaving parents of preterm infants confused and uncertain. Consistent with the literature,[21] parent comments often indicated limited knowledge of development, confusion about developmental delays[12] and corrected gestational age expectations[13] for their children; for example, 'they're 11 weeks old and still acting like newborns' *(mother of 31 week GA twins at term corrected age)*. Given that 43% of all children born very preterm in our study elicited developmental concern, there is a clear need for further educational resources and early intervention programs for parents to enhance their understanding of age-appropriate development and capacity to support early development following preterm birth and/or admission to NNU.

This study adds to previous research showing preterm birth and NNU admission are associated with high prevalence of parental concern for developmental risk.[17] Surveying parents during NNU admission in addition to post-discharge has captured novel insights through detailed descriptions of developmental concerns for their children. Parent concerns extend beyond the focus of neurodevelopmental outcomes determined by clinicians when counselling families; specifically, risk for cerebral palsy, cognitive impairment, hearing loss or vision impairment.[22] There is potential for this communication gap to adversely impact health professionals' ability to recognise, and therefore address, parental concerns regarding their child's development both during hospitalisation and post-discharge. For example, 'I would've really liked to know about development in premmie babies….the focus was on getting our daughter well enough to go home and was about physical health rather than being inclusive of developmental health' *(mother of 2 years old, born at 34 weeks' GA)*. Our study findings therefore offer valuable insight to guide clinicians' knowledge and sensitivity in interactions with mothers and fathers of children requiring admission to neonatal intensive or special care.

Strengths and limitations

We report parental concerns for child development both in a clinical population and in the community. The results are the first to describe the presence and nature of parent concerns for the development of their children born preterm or critically ill, while still inpatient in NNU. The large number of fathers that provided information regarding developmental concerns for their children in cohort 2 is also a study strength. Mounting evidence highlights the important contribution of fathers to optimal child development,[23] yet research conducted with parents of preterm newborns is often dominated by mothers.[24] It is therefore crucial to include fathers in future research if we are to advance our understanding of their influence on child neurodevelopment in this vulnerable population.

There are some limitations arising from our study. First, NNU graduate parent data were obtained online via a neonatal consumer organisation. We acknowledge this cohort may not be representative and has a potential for bias due to self-selection of participants, with an over-representation of parents with developmental concerns for their child. As such, comparisons between cohort 1 and a wider NNU graduate population may not be possible. The use of convenience sampling to obtain inpatient parent information may also limit generalisability. However, these potential limitations were mitigated in several ways: the large number of parents who contributed information in each cohort; inpatient parent recruitment across two large hospitals, each with different socio-economic risk profiles and infant severity of illness; recruitment occurred at night and weekends to reach working parents not available during office hours. Second, the allocation of qualitative, free-text responses into discrete domains of concern was dependent upon clinician opinion and so could result in different theme classifications if conducted by others. This potential risk to validity was reduced through independent coding and generation of domains of concern by three experienced multi-disciplinary neonatal health-care professionals. Finally, wider generalisability of the findings may not be possible given that the parent survey was available only in English and thus limited participation by parents from non-English speaking backgrounds.

Conclusion

Our results indicate that neurodevelopment is a substantial concern for parents during hospital admission and throughout childhood. Clinicians should consider including general development-milestones, motor, speech-language development and growth-feeding when discussing neurodevelopmental expectations and concerns with parents. Given the frequency of developmental concerns, it is recommended that both mothers and fathers of children born very preterm are the focus of future educational resources and early intervention initiatives to support parent knowledge of child development as inpatients, and post-discharge.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1 Parent survey
Appendix S2: Examples of Cohort 1 parent free-text concern responses (in the words used by parents)
Appendix S3: Examples of Cohort 2 parent free-text concern responses (in the words used by parents)

Appendix: Classification of parent free-text responses into developmental domains of concern (in the words used by parents)

Motor

Fine motor (including handwriting), gross motor, tummy time, neck strength, rolling, sitting, crawl/ing, walk/ing, gait, run/ning, CP, physiotherapy, DDH, dislocated hip, physical development and head preference to right.

Speech and language

Speech issues, expressive/receptive speech, language, talk/ing, saying or speak/ing words, vocal cord, speech therapy and communication.

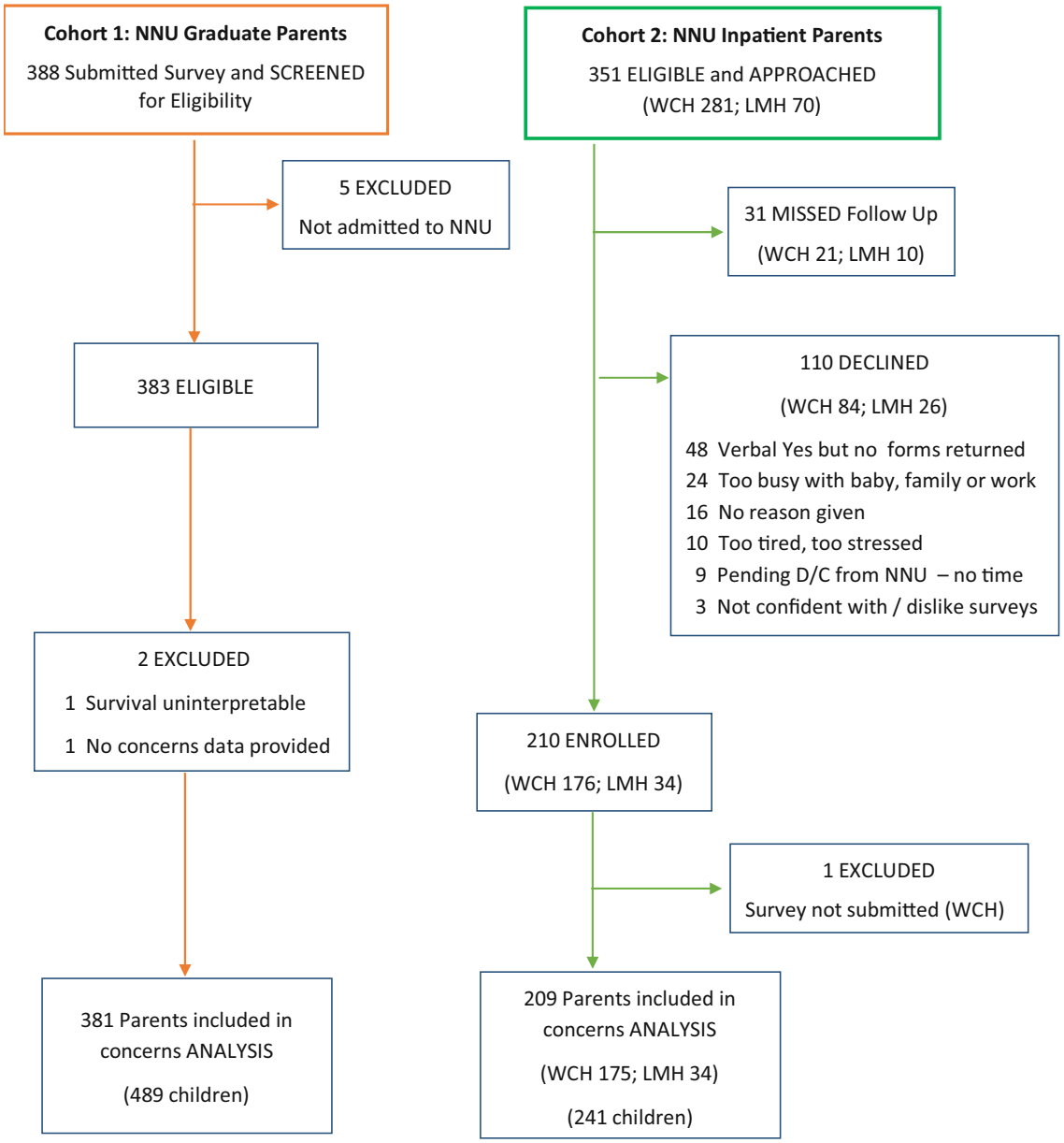

Fig. A1 Participant study flow

Behaviour

Behaviour, difficult character, social, emotional, anxiety, ODD, ASD, ADHD, ADD, autism, Aspergers and bipolar.

Cognition and learning

Cognition, intelligence, learn, attention, lacks concentration, memory, school, mental/neurological/brain/intellectual development and possible learning difficulties.

Sensory

Hear/ing, ears, microtia, glue ear, grommets, deaf, vision, see/ing, eyes, eyesight, ROP, septo-optic dysplasia, optic nerve hyperplasia, nystagmus, blind, sensory, SPD, sensory processing and processing delays.

General development and milestones

Developmental issues, A bit behind on her milestones, Development very slow, Concerns regarding hitting the usual developmental goals, Slower reaching milestones, He has struggled with all aspects of development, Toilet training, Developmentally

Table A1 Summary of concerns for NNU inpatients by parent (Cohort 2)

	Fathers	Mothers
Number of NNU inpatient infants	103	138
No concerns	66 (64.1)	91 (65.9)
Single concern	22 (21.4)	23 (16.7)
Multiple concerns	13 (12.6)	24 (17.4)
Domain(s) un-interpretable†	2 (1.9)	0
Domain of concern‡		
Motor	5 (4.9)	8 (5.8)
Speech and language	2 (1.9)	1 (0.7)
Behaviour	1 (1.0)	0
Sensory	6 (5.8)	3 (2.2)
Cognition and learning	7 (6.8)	9 (6.5)
General development and milestones	15 (14.6)	31 (22.5)
Growth and feeding	6 (5.8)	10 (7.2)
Respiratory	6 (5.8)	7 (5.1)
Other medical	10 (9.7)	11 (8.0)
Other CNS	3 (2.9)	9 (6.5)
Total concerns elicited§	61	89

† Includes concern not described by parent or not allocated to a specific child(ren). ‡ See Appendix I and Appendix S3, Supporting Information. § Parents were able to report concern in multiple developmental domains for each child. Values presented as *N* (%). NNU, neonatal unit.

delayed, Physical developmental delays, Very delayed, Behind her twin sister/brother, Development is very slow compared to my older children, Disabilities, Physiological development, Slow reaction to some things, Taking longer, Concerns over a few things, Not doing what he should be for age, I am worried they might develop slower than normal, Concerns about future development, I worry so much about how he will develop throughout his milestones, Achievement of milestones around all developmental areas, Whether his development at term will be similar as a baby born full term or not re: timing of milestones, Physical /global developmental delay, GDD, PDDNOS, I have concerns about overall long term development, What can I do to support my baby's development when she comes home?, Unsure of what we should be doing to help her development while in the nursery and when we bring her home, Every parent worries about child's development, long-term development is a significant concern, development – long-term effects of preterm birth, we do not really know the consequences until she develops.

Growth and feeding

Growth, size, breast feeding, food, eating/feeding/gagging food aversion, small for age, weight, failure to thrive, FTT, dietician, NGT, PEG, reflux, too big, too small, food intolerance, allergic colitis and low birthweight.

Respiratory

Oxygen, chronic lung disease, BPD, lung problems, breathing issues, desaturation/desats and nasal passage.

Other medical

Cardiac, bradys, heart, ambiguous genitalia, ichthyosis, gastroschisis, SIDS, port stain birthmark, nasal swab, jaundice, health condition, illness, blood tests, examination, antibiotics, steroids, viruses, Noonan Syndrome, Trisomy 21, AVSD, surgery for NEC and wound dehisced, hernia and future health effects.

Other CNS

Epilepsy, head shape, brain/ventricles bleeds, brain damage, lack of oxygen at birth, sedation, meningitis, plagiocephaly and congenital brain malformation.

Abbreviations relating to parent quotes

ADD, attention deficit disorder; ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder; AVSD, atrioventricular septal defect; BPD, bronchopulmonary dysplasia; bradys, bradycardic episodes; CP, cerebral palsy; DDH, developmental dysplasia of the hip; FTT, failure to thrive; GDD, global developmental delay; NEC, necrotising enterocolitis; NGT, nasogastric tube; ODD, oppositional defiant disorder; PDDNOS, pervasive developmental disorder not otherwise specified; PEG, percutaneous endoscopic gastrostomy; ROP, retinopathy of prematurity; SIDS, sudden infant death syndrome; SPD, sensory processing disorder.