Journal of Paediatrics and Child Health

doi:10.1111/jpc.16170

ORIGINAL ARTICLE

Impact of current Australian paid parental leave on families of preterm and sick infants

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Aim: Parents of preterm or sick infants are at increased risk of mental health problems. The financial stress associated with an infant's prolonged hospital stay can have an additional negative effect on families' wellbeing and child development. This study explores parent use of Australian paid parental leave (PPL) and the financial impact of having an infant requiring neonatal care.

Methods: Retrospective, cross-sectional, online survey study conducted from November 2020 to February 2021. Participants were parents of babies born from 1 January 2013, admitted to a neonatal intensive care unit or special care nursery in Australia. The survey explored use of Australian Government and private sector PPL, and financial stress. Parent-reported anxiety and depression were measured using the EuroQol Group 5D-5L Anxiety and Stress Subscale.

Results: Two hundred and thirty-one parents responded of which 93% had a preterm infant. Seventy-three percent of infants were hospitalised for more than 1 month, and 34% were readmitted to hospital within the first year following discharge home. Eighty-three percent of parents reported moderate, severe or extreme levels of anxiety or depression. Seventy-six percent reported that having a child in hospital had a moderate-very large financial impact on their family. Parents identified main costs to be travel, food, inability to work and direct medical costs.

Conclusions: Having an infant born preterm or sick has significant emotional and financial implications for families. The current Australian Government PPL scheme does not adequately support parents of preterm or sick infants, and a change is urgently needed to improve outcomes for this vulnerable population.

Key words: Federal Government; neonatal intensive care; newborn infant; parental leave; policy analysis; premature birth.

What is already known on this topic

1 Preterm or sick infants can require prolonged hospitalisation and their caregivers can experience significant emotional distress.
2 Infants admitted to a neonatal unit are at increased risk of developmental difficulties and ongoing health complications across early childhood.
3 The current Australian paid parental leave scheme does not provide any extra parental leave payments to caregivers of infants requiring prolonged hospitalisation.

What this paper adds

1 Caregivers who have an infant admitted to a neonatal unit for an extended period use a range of leave before and after their infant's birth – leave that parents of healthy infants would not typically use until discharged home.
2 In addition to emotional distress, families of infants admitted to a neonatal unit for an extended period can experience significant financial stress, both of which can continue during their child's first year of life.
3 Additional paid parental leave is needed for parents whose infants require prolonged hospitalisation after birth.

It is widely acknowledged that what happens to children in the first 1000 days after birth shapes the way their brains, bodies and emotions develop throughout life.[1] The time infants and parents/caregivers spend together early in life provides opportunities to establish securely attached relationships and is critical for optimal child development and bonding. Infants who are born preterm and/or sick and admitted to a neonatal intensive care unit (NICU) or special care nursery (SCN) have disrupted bonding in the early neonatal period due to extended time spent in hospital and the nature of hospital care.

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Conflict of interest: None declared.

Accepted for publication 10 July 2022.

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The current Australian Government paid parental leave (PPL) scheme helps promote child development through enabling parents to spend time with their infants during a critical period of development rather than go to work. The scheme allows eligible primary caregivers of newborn or adopted children up to 18 weeks of PPL at the national minimum wage.[2] An eligible secondary caregiver can access 2 weeks of PPL under the Dad and Partner Pay (DaPP) scheme,[2] and some parents also have access to industry PPL. However, in Australia, 18.2% of liveborn infants do not go home following the early days post-birth, and instead require urgent hospitalisation and critical care in a NICU or SCN.[3] Infants born preterm (<37 weeks' gestation), those with respiratory distress, encephalopathy, congenital abnormalities, or conditions requiring surgery, can remain in hospital for several weeks or months, with approximately 6% staying two or more weeks.[3,4] Therefore, parents may be separated from their infant for extended periods, and may also be caring for other children, making it an extremely stressful and challenging time. Additionally, financial stress associated with an infant's prolonged hospitalisation and ongoing medical needs post-discharge can place significant strain on families.[5,6] For many, when their infant is ready to be discharged home, they have often exhausted most, if not all, of their leave entitlements. This limits their ability to spend time at home during a critical period of their child's development.

Preterm birth and neonatal conditions can have lifelong implications for the health and wellbeing of children and families. Preterm birth increases the chance of impairments in neurosensory, physical, social–emotional and academic functioning,[7,8] with around one in two infants born extremely preterm (<28 weeks' gestation) experiencing a developmental impairment in early childhood.[9] Hospital readmissions across the first year of life are common for children born preterm, and families often isolate to an extent to avoid illness in early childhood. Preterm birth can have an ongoing negative influence on parent mental health, family functioning[10] and the parent–infant attachment relationship.[11] Parents of infants admitted to NICU/SCN are at increased risk of mental health concerns such as anxiety, depression and post-traumatic stress, which are associated with poorer child development.[12] The emotional impacts of having an infant admitted to NICU/SCN can be felt by parents both during their infant's hospital stay and for many years after bringing them home.[5]

Financial support for families during their infant's early life can influence future health and development outcomes.[13,14] Currently, caregivers with an infant admitted to NICU/SCN for

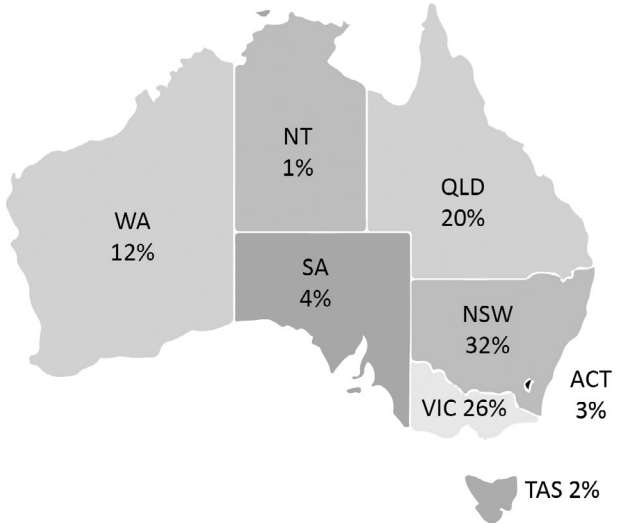

Fig. 1 Participant location.

Table 1 Participant characteristics

Parent demographics ($n = 231$)		
Female	225/231 (97.4)	
Male	6/231 (2.6)	
Birth mother	224/225 (99.6)	
Other children at home	70 (30.3)	
Primary carer	196/231 (84.9)	
Secondary carer	6/231 (2.6)	
Shared carer	29/231 (12.5)	
Index of Relative Socio-economic Disadvantage† – lowest to highest quintiles	33 (14.4), 36 (15.7), 52 (22.7), 57 (24.9), 51 (22.3)	
Employment‡	**Person completing survey ($n = 231$)**	**Partner ($n = 224$)**
Full-time employment	164 (71.0)	204 (91.1)
Part-time employment	67 (29.0)	9 (4.0)
Unemployed	—	8 (3.6)
Not sure	—	3 (1.3)
Short-term contract (<6 months)	1 (0.4)	1/213 (0.5)
Long-term contract (>6 months)	22 (9.5)	13/213 (6.1)
Permanent employment	191 (82.7)	177/213 (83.1)
Casual employment	10 (4.3)	6/213 (2.8)
Self-employed	7 (3.0)	16/213 (7.5)
Infant demographics		
<28 weeks' gestational age	69 (29.9)	
28–36 weeks' gestational age	147 (63.6)	
>37 weeks' gestational age	15 (6.5)	
Twins	27 (11.7)	
Received neonatal intensive care	57 (24.7)	
Received special care	35 (15.2)	
Both neonatal intensive care and special care	139 (60.1)	
	Baby 1	**Baby 2 (twin)**
Readmitted to hospital	78/231 (33.8)	9/23 (39.1)
Readmitted >once	35/231 (15.1)	3/23 (13.0)

† Higher scores indicate areas with lower relative disadvantage.
‡ Year before birth. *n* (%) unless specified.

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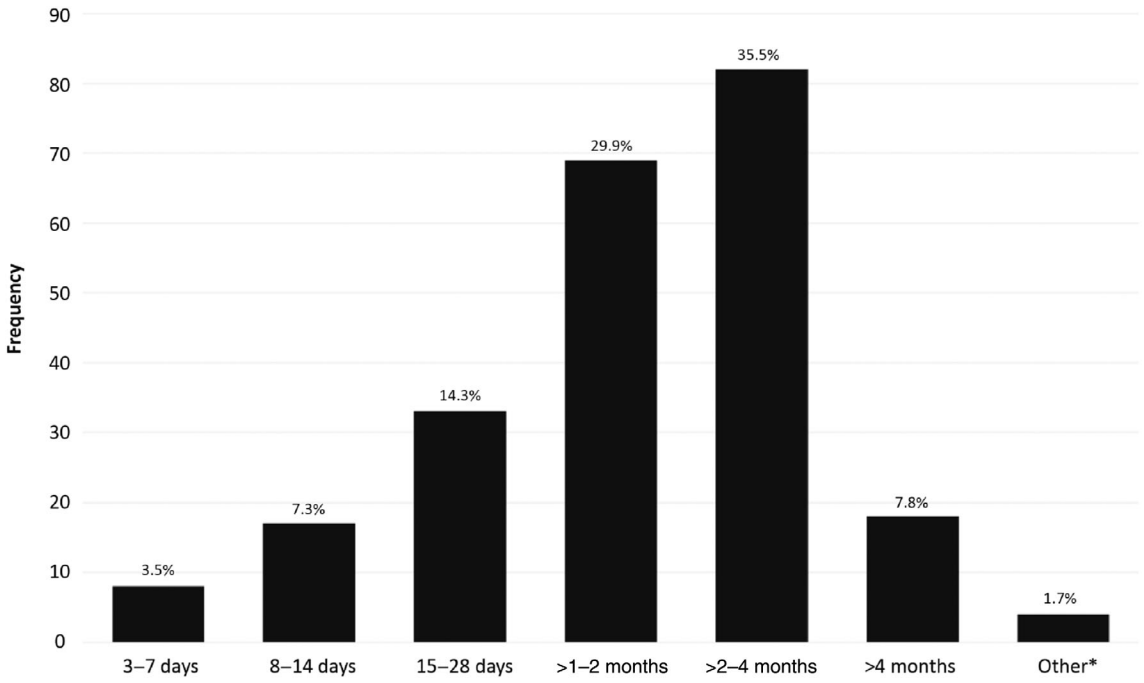

Fig. 2 Infant length of hospital stay ($n = 231$). *Three infants were still in hospital at the time of survey completion and reason for 'other' length of stay not specified for $n = 1$.

extended periods are not entitled to extra parental leave payments under the Australian Government PPL scheme. Consumers, advocate groups, health professionals and economists have recently come together to call for Australian Government reform of the PPL and DaPP policy, to support parents and infants with a prolonged NICU/SCN admission.[4] There is a need to explore parental perspectives of the financial consequences of preterm birth and infant hospitalisation, given the potential negative effect on families' wellbeing and child development.

The aim of this study is to explore parent use of Australian Government and industry PPL schemes, and the financial impact of having an infant requiring an extended stay in a NICU/SCN directly after birth.

Methods

Design and participants

This study was a retrospective cross-sectional, online survey. Eligible participants were parents with infants born on or after 1 January 2013 and admitted to a NICU/SCN in Australia. Eligibility criteria aligned with commencement of the DaPP scheme in 2013 to ensure the cohort included both the PPL and DaPP schemes. Participants were required to be 18 years or older, able to read and write in English and have been in paid employment (full-time, part-time or casual) the year prior to the birth. Individuals involved in survey development were excluded from participating.

Participants were recruited over 13 weeks from November 2020 to February 2021 through social media (Facebook, Twitter, Instagram, LinkedIn), websites for the Murdoch Children's Research Institute, Miracle Babies Foundation and the Centre for Research Excellence in Newborn Medicine at Murdoch Children's Research Institute. Recruitment material linked to the survey, which was hosted on a secure REDCap database. In a secondary snowballing recruitment approach, members from the Centre for Research Excellence in Newborn Medicine's Consumer Advisory Group were emailed the survey link to participate and share. Participants confirmed by way of a tick box that they met the eligibility criteria stated above. Consent was implied by participants entering information and completing the survey.

Survey development and administration

The survey was developed by the authors using an online REDCap database and was self-administered, taking approximately 20 min to complete (see Supporting Information for the survey). Survey questions were dichotomous or categorical. Participants were asked a range of demographic questions including age, gender, primary carer status, single parent status, geographical location and employment status. Child demographics were collected including estimated length of hospital stay, multiple birth status (twins/triplets), main type of hospital stay (NICU/SCN), gestational period and reason for hospital admission.

The survey questions explored uptake of Australian Government and industry-funded PPL, and other leave types prior to birth, during initial hospitalisation and in the first year of life. The EuroQol Group 5D-5L Anxiety and Stress Subscale[15] was used to measure parent perceived health status (anxiety or

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depression) during hospitalisation and over the following year post-hospitalisation, using a 5-point Likert scale. Financial impact was measured using a 5-point Likert scale ('no impact' to 'a very large impact') pre, during and after hospitalisation.

The timing and reasons for return to work, use of childcare and financial stress during and after hospitalisation were also explored.

Analysis

Data were analysed using Stata version 16 (Stata Corp, College Station, TX, USA). Descriptive statistics were used to summarise survey demographics and outcomes. Proportions were used for categorical data and means and standard deviations for continuous data. The Index of Relative Socio-economic Disadvantage, based on postcode area, was reported as quintiles, using Socio-economic Indexes for Areas, Australia, data.[16] For ease of interpretation, uptake of leave types pre, during and after hospitalisation, and financial impact, were graphically presented. Responses on the financial impact of hospitalisation were dichotomised as 'none/little' and 'moderate/large/very large'. For the EuroQol Group 5D-5L Anxiety and Stress Subscales, responses scored as 1 or 2 (not anxious or depressed or slightly anxious or depressed) were dichotomised as 'none/slightly' and scores of 3–5 (moderate, severely, or extremely anxious or depressed) were categorised as 'moderate-extremely' anxious or depressed.

Ethics

This study was approved by the Royal Children's Hospital Human Research Ethics Committee. Partially completed surveys were included in the analysis unless participants expressly withdrew their consent.

Results

Participants

Two hundred and thirty-one respondents completed the survey in Australia, with the highest proportions of participants from New South Wales (n = 74, 32%) and Victoria (n = 59, 26%) (Fig. 1). The distribution of respondents across Socio-economic Indexes for Areas codes on the Index of Relative Socio-economic Disadvantage was similar (Table 1). Ninety-seven percent (225/231) of respondents were female (birth mother n = 224) and six were male. The majority of respondents identified as the primary carer (n = 196) and 30% (n = 70) had at least one other child at home. More than half of respondents (57%, n = 127/224) stopped work early prior to the birth due to pregnancy-related illness or complications. The employment characteristics of the participants are detailed in Table 1.

Infant characteristics

The majority of respondents had a preterm infant, with 30% born <28 weeks' gestation (Table 1). Following birth, 73% of infants stayed in hospital for more than 1 month (Fig. 2), with 35% (82/231) and 8% (18/231) staying in hospital for between 2–4 months and >4 months, respectively. Just over a third of infants (78/231, 34%) were readmitted to hospital within the first year following discharge home, and of these 45% (35/78) were readmitted more than once.

Mental health

On the EuroQol Group 5D-5L Anxiety and Stress Subscales, the majority of respondents (171/206, 83%) reported feeling moderate/severely/extremely anxious or depressed whilst their infant was an inpatient (Table 2). Fewer respondents (128/190, 67%), though still the majority, reported feeling moderate/severely/extremely anxious or depressed during the first year once their infant was discharged home.

Type of leave and return to work

Parents used a range of leave before and after the birth (see Fig. 3). Ninety-three percent of respondents received government PPL/DaPP. Whilst their child was in hospital, 43% of respondents accessed their PPL or DaPP, and 21% took unpaid leave.

Table 2 Financial and mental health impact of hospitalisation

Financial stress and impact of hospitalisation (yes)	
Financial stress pre-birth	91/126 (72.2)
Financial stress whilst baby in hospital	149/207 (72.0)
Financial stress during first year	154/210 (73.3)
Financial impact whilst baby inpatient† (n = 207)	157 (75.8)
Financial impact in first year† (n = 197)	147 (74.6)
Moderate-very large impact of costs whilst inpatient† (n = 219)	
Travel	177 (80.8)
Extra childcare for other children	29 (13.2)
Accommodation	32 (14.6)
Food	165 (75.3)
Unexpected loss of income	141 (64.4)
Carer health-care costs	65 (29.7)
Moderate-very large impact of costs in first year† (n = 210)	
Direct hospital or medical costs	98 (46.7)
Travel (e.g. parking, hospital parking)	135 (64.3)
Medications	89 (42.4)
Equipment	26 (12.4)
Income loss from not being able to work	120 (57.1)
Carer health-care costs (e.g. psychology)	69 (32.9)
Mental health impact of hospitalisation‡	
Felt anxious or depressed whilst baby IP	Mod/sev/extremely = 171/206 (83.0)
Felt anxious or depressed in first year	Mod/sev/extremely = 128/190 (67.4)

† Moderate-very large impact vs. none-little impact. ‡ Moderate-extremely anxious or depressed vs. none/slightly. n (%) unless specified.

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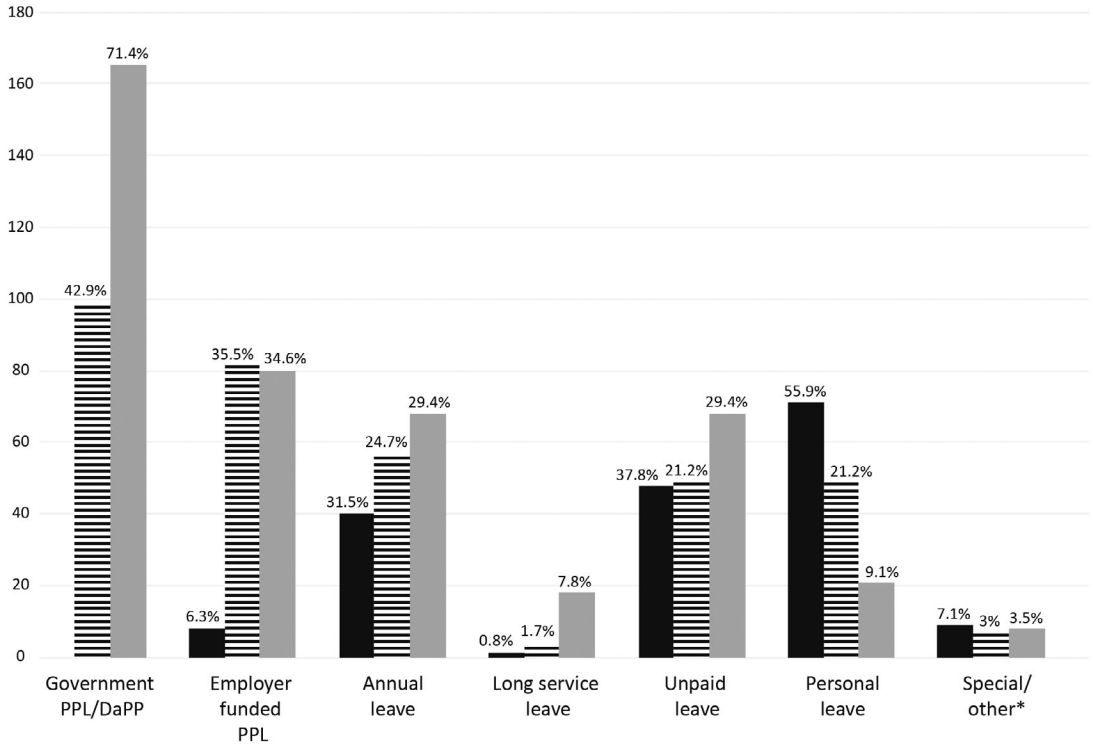

Fig. 3 Type of leave whilst unable to work, during infant's hospital stay and first year after leaving hospital. *Participants who were 'unsure' or received 'other' leave types are represented as one category. (■), Type of leave while unable to work (prior to birth) $n = 127$; (≡), type of leave while baby in hospital ($n = 231$); (■), type of leave in first year after baby left hospital ($n = 231$). DaPP, Dad and Partner Pay; PPL, paid parental leave.

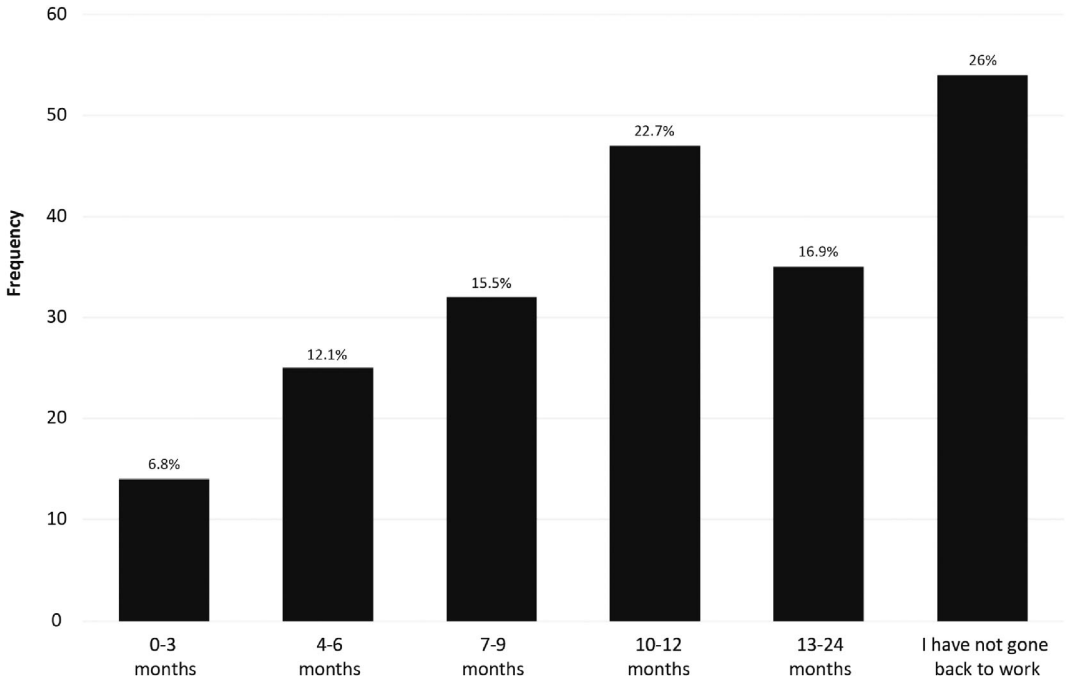

Fig. 4 Length of time before returning to work ($n = 207$).

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Seventy-one percent used government PPL/DaPP after their infant left hospital, and 29% took unpaid leave.

Ninety-six percent of respondents used all of their Australian Government PPL prior to returning to work. Nineteen percent of respondents returned to work within 6 months of birth and 26% had not returned to work at the time of completing the survey (Fig. 4). Forty-five percent (84/188) of parents could not access childcare because of their child's health issues, and 28% (15/54) were unable to return to work due to their child's medical needs.

Financial impact

The majority of parents reported financial stress whilst their infant was in hospital (72%, 149/207) and during their child's first year of life (73%, 154/210). Seventy-six percent (157/207) reported that having a child in hospital had a moderate-very large financial impact on their family, and a similar proportion (75%, 147/197) reported a moderate-very large financial impact in the first year of life (Table 2). The main costs identified with a moderate-very large financial impact were travel, food, loss of income (including not being able to work) and direct medical costs (e.g. medications) in the first year of life (Fig. 5).

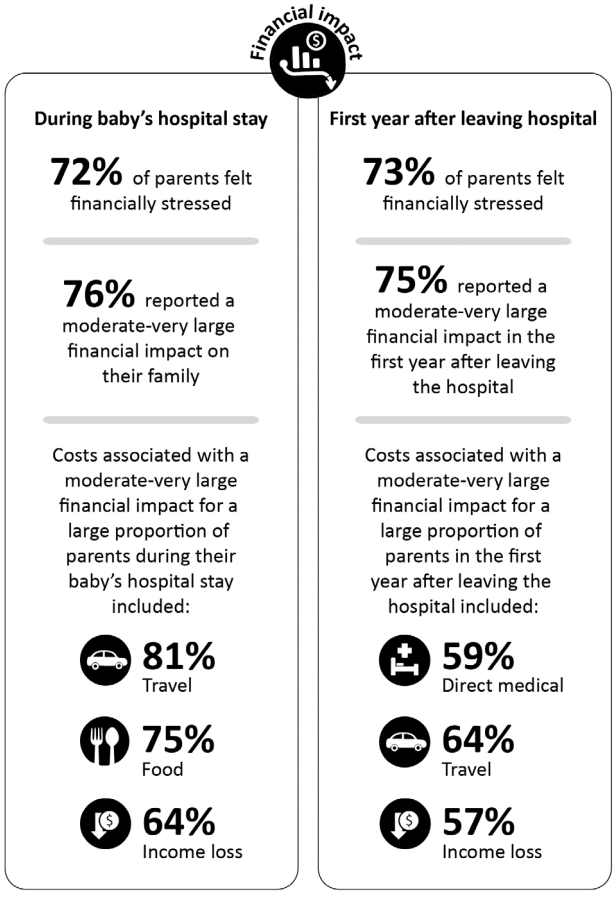

Fig. 5 Financial impact of hospitalisation.

Discussion

Having an infant born preterm and/or sick is a stressful and challenging time for families.

The current study used a nationwide sample to explore parent use of Australian Government and industry PPL schemes, and the financial impact of an infant's extended stay in a NICU/SCN directly after birth. We also explored the emotional burden for families of an infant's extended hospitalisation. In the current study, the majority of infants were born preterm (93%), and more than half (65%) required hospitalisation for a period of 1–4 months, and 15% had multiple readmissions in the first year. Prolonged separation during hospitalisation can alter the parent–infant relationship and opportunities for social, motor, cognitive and language interactions may be limited, further compromising child development.[17,18]

The current study's findings support the existing literature on the emotional impact and mental health challenges for parents of preterm infants.[5,19] Eighty-three percent of parents reported moderate-extreme levels of anxiety or depression whilst their infant was in hospital. Alarmingly, this level of emotional distress continued over their child's first year of life for many parents (67%). The known association between parental mental health and child development, as well as the increased risk of developmental impairments in the preterm population, highlights the urgent need for increased support of these parents.

Alongside the mental health challenges, nearly three quarters of parents reported financial stress, both during their infant's hospital stay and across their child's first year of life. Financial distress and medical financial burden are common in families of hospitalised children, regardless of family income bracket.[20] In an Australian study of families of babies admitted to a NICU for two or more weeks, the median cost per week was approximately one quarter of the average gross weekly income, with major costs related to lost income, food and transport expenses.[21]

Very few NICU/SCNs have the capacity for parents to stay with their infants overnight. For families looking after other children at home and travelling daily to the hospital, parking and hospital food can be significant expenses, as demonstrated by the current study. The ongoing health implications associated with preterm birth and its financial impact on families were also emphasised; 59% of parents reported that medical care costs had a moderate-very large financial impact, and 34% of infants were readmitted to hospital during their first year. Further, 45% of parents were unable to use childcare due to their child's health issues, and income loss during this time had a moderate-very large financial impact for many parents (57%).

Another key finding was that parents used a range of leave, even prior to their child's birth. More than half (57%) of respondents needed to stop work early before the birth, due to pregnancy-related complications, and 38% of these took unpaid leave during this period. Parents also used a range of leave which parents of healthy term born infants would not have used until their baby was home, such as Australian Government PPL/DaPP. Under the current Australian Government schemes, parents of babies born preterm and/or sick receive no additional leave allowance, despite additional weeks and months in hospital. Data from the Organisation for Economic Co-operation and Development demonstrates that parental leave policies vary widely between

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countries with regards to length of leave (0–52 weeks) and percentage paid. Countries around the world have begun to acknowledge the financial strain for families whose babies require hospitalisation and are adjusting their leave payments accordingly.[22,23]

The survey was cross-sectional and included parents of preterm infants born across all gestational age groups and from all states in Australia. Further, by including eligible participants from 1 January 2013 we captured experiences following the introduction of the DaPP scheme. We acknowledge some limitations; the study had a small sample size, considering the survey timeframe. It is not possible to analyse how representative this is of the larger group of preterm births/sick children requiring ICU admission and the results therefore need to be interpreted in this context. The survey used existing networks as well as social media, and therefore the respondents may have been more likely to be similar. Further, the majority of respondents identified as the birth mother. Thus, the findings of this study may not reflect the experiences of fathers and partners. Additionally, parents who experienced difficulties may have been more likely to self-select to complete the survey. Participants may also have recall bias as it was a retrospective survey, influencing the accuracy of recall. The current study focused on parental experience following extended hospitalisation for their infant and did not include analysis of socio-economic status of the participants.

Conclusions

A nationwide change to the Australian Government PPL scheme to accommodate parents of preterm and/or sick infants is needed given that many parents will use their PPL prior to their infant being discharged home and the additional financial and emotional stress following prolonged hospitalisation. We recommend a review of the government and industry PPL schemes and suggest 1 week of extra parental leave pay for primary caregivers for every week an infant is in hospital beyond 2 weeks, with a maximum of 14 weeks extra pay. In addition, we recommend 2 weeks of extra DaPP for fathers and partners.[4]

By extending both PPL and DaPP, parents will be able to spend more time with their infant whilst hospitalised and experience lower levels of financial stress. Evidence from studies focused on parental engagement in neonatal care have shown clear health benefits for infants, including reduced length of hospital stay.[24–26] However, inadequate provision of government PPL and DaPP may impede the capacity and availability of parents to engage in these evidence-based health-care approaches. Providing additional government financial support to parents can assist in mitigating the financial and emotional cost of having a preterm and/or sick infant and may ultimately improve both parent and infant health outcomes.

Acknowledgements

This work was supported by the Australian National Health and Medical Research Council Centre of Research Excellence in Newborn Medicine (GNT 1153176), Career Development Fellowships (1108714 to AJS; GNT1141354 to JC), the Melbourne Disability Institute and the Victorian Government's Operational Infrastructure Support Program. The funder did not participate in the work. Open access publishing facilitated by The University of Melbourne, as part of the Wiley - The University of Melbourne agreement via the Council of Australian University Librarians.

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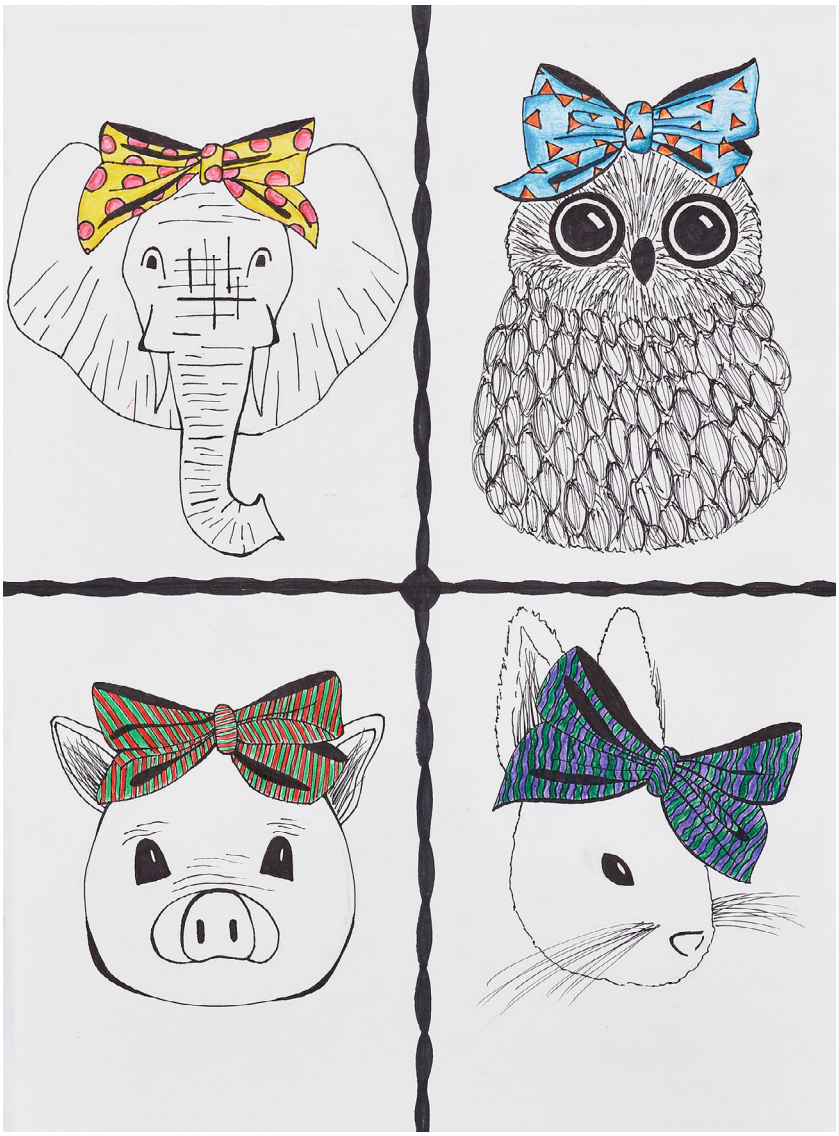
Supporting Information

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

Appendix S1 Supporting Information.



Animals in bows by Irene Meli (aged 12) from "A Pop of Colour" art competition, Youth Arts, Children's Hospital at Westmead

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