Community-based healthcare costs for children born low birthweight, preterm and/or small for gestational age: data from the longitudinal study of Australian children

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Abstract

Aim: Children born low birth weight, preterm and/or small for gestational age sustain substantially increased costs for hospital-based health care and additional educational support in the first few years of life. This is the first study internationally to investigate costs beyond hospital care, to community-based health care and prescription medicines across early and middle childhood with actual cost data, and to examine these costs according to the severity of perinatal risk.

Method: In the prospective Longitudinal Study of Australian Children, we followed two cohorts of children from 0-5 years. (no increased perinatal risk, n=3,973; mild risk, n=442; and moderate-to-high risk, n=297), and from age 4-9 years (no increased perinatal risk, n=3,629; mild risk, n=465; and moderate-to-high risk, n=361). Children were defined as mild risk if born 32-36 weeks, with birth weight 1500-2499 g, and/or small for gestational age (SGA, <5-9th percentile), and moderate-to-high risk if born <32 weeks, birth weight <1500 g and/or extremely SGA (<5th percentile). Federal government expenditure (2011 $AUD) on health care attendances and prescription medication from birth to nine years were calculated via data linkage to the Australian Medicare records.

Results: Mean costs per child were $362 higher (95% CI $156; 568) from 0-5 years and $306 higher (95% CI $137; 475) from 4-9 years, for children with any compared with no increased perinatal risk (p<0.001). At the population level, an additional $32M was spent per year for children 0-9 years with any relative to no increased perinatal risk.

Conclusions: Perinatal risk is a major public health issue conferring considerable additional expense to community-based health care, most marked in the first year of life but persisting up to at least ten years. Even without additionally considering burden, these findings add to the urgency of identifying effective mechanisms to reduce perinatal risk across its full spectrum.
The long-term outcomes for children who are born preterm, low birth weight or small for gestational age are a growing public health concern. Rates of these perinatal risks in the developed world are increasing (Doyle et al. 1999, Badgery-Parker et al. 2012) and associated with elevated health and developmental difficulties in the neonatal period and infancy, as well as long-term cognitive, physical and mental health problems (Anderson and Doyle 2008, Gray et al. 2004, Wood et al. 2005). The increased expenditure associated with perinatal risk for early childhood hospital-based health care is well established and described in the literature. However, costs associated with non hospital-based health care remain largely unknown. The current study is the first internationally to use representative Australian cost data to investigate longitudinally the community-based health care costs from infancy up to age 10, for children with mild and moderate-to-severe perinatal risk.

Studies examining the costs associated with perinatal risk have shown very high expenditure for neonatal intensive care and/or other hospitalizations in the first year of life (Doyle 2004, Russell et al. 2007). Research has also demonstrated that increased costs for hospital admissions persist across the first five years (Petrou et al. 2003, Korvenranta et al. 2010b), and high costs are associated with increased use of special education programs (Chaikind and Corman 1991). However, to our knowledge, only two studies have examined non-hospital based costs beyond the first years of life. A Finnish study found that very preterm birth was associated with considerable costs associated with social welfare services and therapies at five years (Korvenranta et al. 2010a), although they estimated costs for one year only and in reference to a high-risk group. A UK study (Mangham et al. 2009) found that decreasing gestational age was associated with inflated public sector costs for the first 18 years of life. While novel and drawing on a large dataset, these cost estimates were generated using a decision-analytic model, rather than from direct measures of actual services used and costs incurred.

Given the limitations of these two studies, the costs of health care beyond the hospital setting and beyond infancy remain unclear. Further, while early life costs are substantially increased for very high-risk groups, these children represent only a small proportion of all children born preterm, low birth weight, or small for gestational age. Research is required to investigate whether increased costs
are also present for children with less severe perinatal risk. The current study addresses these limitations by examining costs for community-based health care across the first ten years of life in two large, nationally-representative Australian cohorts. The study aims were to compare children born with no increased perinatal risk to those with mild and moderate-to-high risk, across federal government mean costs from children’s first year of life and up to age 10, for (1) community-based health care (Medicare Benefits Scheme), (2) prescription medication (Pharmaceutical Benefits Scheme), and (3) total Medicare combined costs; and to estimate the resultant population-level costs. The final aim (4) was to determine whether combined costs vary by year of life, for each of the three perinatal risk groups.
Study design

The Longitudinal Study of Australian Children is a nationally-representative prospective cohort study of children’s growth and development. Children were selected from the Australian Medicare scheme database using a two-stage cluster sampling design (Soloff et al. 2005, Gray and Sanson 2005). Of the contactable families selected, 5,107 infants (64% initial response rate) participated in the Birth (B) cohort and 4,983 4-5 year old children (59% response rate) in the Kindergarten (K) cohort, each commencing in 2004. Children from both cohorts were included in the current study if they had successful Medicare data linkage (B cohort 93%; K cohort 92%) and had complete birth weight and gestational age data (collected at Wave 1). Final sample sizes were N=4,712 for the B cohort, and N=4,455 for the K cohort.

Measures

Definition of perinatal risk: Data for birth weight and gestational age were collected via primary carer-report at the face-to-face interview, at Wave 1. In Australia, gestational age is generally calculated from the first day of the last menstrual period or estimated by prenatal and/or postnatal assessment (Roberts and Lancaster 1999). Children were classified into one of three groups. The ‘mild perinatal risk’ group included children born 32-36 weeks, with birth weight 1500-2499 g, and/or born small for gestational age (SGA, 5-9th percentile for weight by gestational age and gender, using Australian national birth weight percentiles 1991-1994 (Roberts and Lancaster 1999). The ‘moderate-to-high perinatal risk’ group were born very preterm (<32 weeks), very low birth weight (<1500 grams), and/or extremely SGA (<5th percentile). In the B cohort, this definition identified 3,973 children with no perinatal increased risk, 442 with mild risk, and 297 with moderate-to-high; and 3,629 children with no increased risk, 465 with mild risk, and 361 with moderate-to-high risk in the K cohort.
Outcome measure (health care costs): Data from the national Medicare Benefit Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS), together comprising the Australian Medicare subsidized health care scheme, were used to estimate the costs to the Australian federal government for prescription medication and health care attendances outside the hospital setting (Commonwealth Department of Health and Aged Care 2000, Willis and Reynolds 2008). Primary health care in Australia is funded through a combination of local and federal government (68.7%), private health insurance (7.6%) and individual out-of-pocket expenses (Australian Institute of Health and Welfare 2010). Through the MBS, the Federal government subsidizes mainly non-hospital based medical practitioners for providing care up to a pre-determined cost, with any ‘gap’ costs paid by the patient. Most services covered by MBS are visits to health professionals, although it also includes non-hospital diagnostic and pathology services (Commonwealth Department of Health and Aged Care 2000, Willis and Reynolds 2008). The costs of prescription medications are subsidized by the PBS, in which a pre-determined list of medications are subsidized up to approximately 83% of the cost with the remainder paid by the patient (Willis and Reynolds 2008).

With permission from the primary carer, health care costs were obtained by linkage with Medicare Australia data. Costs were inflated to 2011 Australian dollars ($1.00 AUD = $1.02 USD, as at 5th September 2012) using the consumer price index figures provided by the Australian Bureau of Statistics (www.abs.gov.au). Costs for each child were estimated over a six year period; from birth and up to the child's sixth birthday for the B cohort, and from the child's fourth to tenth birthday for the K cohort.

Characteristics of the child and the family: The child's primary caregiver provided a range of information at Wave 1. Parents were asked whether the child was an Indigenous Australian, whether their child had any special health care needs, i.e., any medical or behavioral condition(s) of at least 12 months duration requiring additional care (Bethell et al. 2002), and were asked to rate their child’s global health for one item on a 5-point likert scale, ranging from excellent to poor (Landgraf et al. 1996). Child corrected age (weeks) was calculated using chronological age and weeks of gestation.
The primary caregiver also reported on the family environment (maternal smoking during pregnancy, mother’s primary language at home, single parent status, and parent education). Geographic remoteness was classified using the Accessibility/Remoteness Index of Australia (Department of Health and Aged Care (DoHAC) 2001). Socioeconomic position (SEP) was calculated using a composite variable, ranking each family’s relative socioeconomic position based on parental income, education and occupational prestige (Blakemore and Strazdins 2009).

Analyses

Analyses were conducted in Stata version 12.0 using the survey methods procedure to weight the analyses to account for the unequal probability of participant selection into the sample, non-response and sample attrition; and the multi-stage, clustered sampling design (StataCorp 2009, Soloff et al. 2006). Outliers were defined as cases with costs over $10,000 for MBS data and over $8,000 for PBS data in any single year, and were excluded from all analyses (n=7). Summary statistics were estimated for each cost category (MBS, PBS and combined) for each perinatal risk group. General linear model regression analyses were used to estimate means and 95% confidence intervals for between-group differences. Yearly population cost estimates were calculated using population size estimates from Australian 2006 population statistics for children (Australian Bureau of Statistics 2010). Individual group means and standard errors were estimated for total Medicare costs (PBS and MBS), to illustrate differences by year of life, for each cohort. We present both unadjusted mean differences and those adjusting for child gender, Indigenous status, geographic remoteness, socioeconomic position, single parent status, language spoken at home and mothers’ and fathers’ education.

For all participants, mean MBS and PBS costs were substantially higher than median costs, reflecting a positive skew typical for cost data. The primary analysis was based on mean costs and differences as these are regarded as the more representative of expected costs at a population level, and the use of standard linear regression techniques to estimate these parameters is supported in large
public health datasets (Lumley T et al. 2002). Ideally the bootstrap method would be used to ensure robustness of the standard error calculations for skewed data. This method could not be implemented in conjunction with the survey methods (weighting and first-order Taylor linearization) in place to account for the complex survey design. A comparison of means with and without bootstrapping using the data without the survey design revealed very small differences ($1-5 maximum difference in 95% confidence interval bounds for total Medicare mean costs per child).

Sensitivity analyses were run to test the effect of excluding from the no increased PR group those full-term, normal birth weight children who had been hospitalized for seven or more days or ventilated at birth (B cohort only).

**Results**

**Sample characteristics by perinatal risk**

Sample characteristics by perinatal risk are shown in Table 1. While children in the moderate-to-high and mild perinatal risk groups had similar mean gestational ages, there was a gradient across the three groups for birth weight and weight for gestational age, with the lowest weights in the moderate-to-high risk group. Gender distributions were similar across perinatal risk groups in both cohorts. Indigenous Australian children were over-represented in both the mild and moderate-to-high risk groups. A gradient effect was evident across both cohorts in terms of physical health (special health care needs and global health) and the social environment (maternal smoking during pregnancy; socioeconomic position; single parent status; language other than English at home; and maternal education), with poorer health and social disadvantage increasing with perinatal risk. No associations between geographic remoteness and perinatal risk were evident.

**Perinatal group comparisons of health care costs**

PBS, MBS and total Medicare costs are shown in Table 2. The mild and moderate-to-high perinatal risk groups had higher costs than the no increased perinatal risk group for health care
attendances (MBS) and prescription medication (PBS). MBS and PBS costs were higher for younger children (0-5 years) than older children (4-9 years). Table 3 shows the mean differences per child (relative to the no increased perinatal risk group) in total Medicare costs for those of mild and moderate-to-high perinatal risk. Unadjusted mean differences were consistently higher for the two perinatal risk groups across childhood. Cost differences for the mild perinatal risk group were greater for younger (0-5 years) compared to older children (4-9 years). However, there was no clear cost gradient by perinatal risk severity; unadjusted mean cost differences between the mild and moderate-to-high risk groups were not significant for either cohort (p>0.05). Using unadjusted mean differences, the population-level costs for mild and moderate-to-high perinatal risk were estimated as an additional $32M per year on health care costs for children with mild or moderate-to-high perinatal risk, from 0-9 years. Adjustment for child and family social characteristics resulted in substantively increased mean differences in the early years (0-5 years), and much less pronounced differences for older children (4-9 years). Finally, results from the sensitivity analyses are presented as a footnote to Table 3, and indicate that mean cost differences between the perinatal groups were substantially increased when excluding these sick children (n=423).

Health care costs by year of age and perinatal group

Estimates for total unadjusted Medicare costs by age are shown in Figure 1. Costs associated with perinatal risk were consistently elevated relative to the no increased perinatal risk group at every year from age 0-9. However, some differences were evident between the cohorts. In the first six years, the direction of differences between the mild and moderate-to-high perinatal risk groups was unclear, with the mild risk group showing higher costs in the first two years of life, and no differences in these costs by the third and fourth years. In contrast there was a consistent severity gradient from 4-9 years, whereby the mild risk group had higher costs compared to the no increased perinatal risk group, and the moderate-to-high risk group generally showed the highest associated costs overall.
Discussion

This is the first study to examine non-hospital based health care costs associated with perinatal risk beyond infancy. We found that higher community-based health care costs were observed for children born with mild and moderate-to-high perinatal risk from birth up to ten years of age, for both health care attendances and prescription medications. Total Medicare costs in the early years (age 0-5 years) were considerably higher compared with later childhood (age 4-9). There was no clear gradient of costs according to severity of perinatal risk. At the population-level, we estimated that the Australian government spent an additional $32M AUD per year on Medicare-subsidised community health care for all children with perinatal risk from 0-9 years of age.

A key strength of our study was the nationally representative nature of our data. Our study is the first internationally to demonstrate with actual cost data both the persistence of increased health care costs across early and middle childhood, and the effects of mild as well as moderate-to-severe perinatal risk on population-level health care costs. Previous research has focussed on costs associated with high-risk cases, leading to intervention programs and clinical/community services being targeted to these children only; whereas our data were representative of the broader childhood population of Australia. Most important in terms of policy, our research highlights substantially increased costs to government associated with the health care of children with mild perinatal risk.

The Medicare costs reported here represent only one aspect of the monetary cost associated with perinatal risk. This study was restricted to health care funded within the Medicare schemes, and thus our estimates do not include costs of hospital-based care, which account for a large component of initial health care costs for children born with perinatal risk, particularly those with moderate or high risk. Other government costs also include those associated with special education (Chaikind and Corman 1991) and additional educational supports. Wider societal costs include family out-of-pocket expenses for medical care and treatments, and costs associated with parent time and loss of work productivity. While our findings do not represent the full costs of prematurity, they do provide a
unique and previously neglected representation of the wider costs associated with perinatal risk. Previous research has focused almost solely on hospital-based costs, which are primarily relevant to children with high perinatal risk, and do not capture the costs of universal care; i.e., primary medical care provided in community-based settings, which may be more relevant to children with mild and moderate risk.

It is important to note that while the Medicare costs did not differ substantially between mild and moderate-to-high risk groups, overall health care costs that include hospital services may differ significantly, especially in the first few years of life. Children with moderate-to-high perinatal risk tend to have more medical complications and longer periods of hospitalization than children with mild perinatal risk (Doyle 2004, Russell et al. 2007, Engle et al. 2007). Such differences in hospital costs may also affect the costs reported here if lengthy hospitalization reduces the use of community-based health care in the moderate-to-high risk group. Given these considerations, our findings are important in showing that the health care cost differences between children with and without perinatal risk extend beyond purely hospital settings in the infancy years, reflecting differential use of the universal health care sector sustained throughout early and middle childhood.

The families of children with perinatal risk in the current study had higher rates of socio-economic disadvantage, and the moderate-to-high risk group had the highest rates of disadvantage overall. Thus, it is possible that the cost differences between the perinatal groups are an underestimate of the true cost of perinatal risk, due to the tendency for disadvantaged families to be slightly under-represented in the LSAC cohorts and for these families to under-utilise community-based health care and to use hospital-based emergency care as an alternative. This was evidenced by the substantial increase in costs for the younger children with perinatal risk (0-5 years) when analyses were adjusted for social vulnerability. The difference between unadjusted and adjusted cost differences may reflect different socio-demographic patterns in community versus hospital based care (Raphael et al. 2009, Fergusson et al. 1984). It is therefore likely that cost differences presented in this paper are conservative estimates.
Conclusion

This was the first study internationally to investigate community-based health care and prescription medicine costs according to the severity of perinatal risk across early and middle childhood with actual cost data. Our study shows substantial and persistent increases in community-based health care costs to government from infancy up to age 10 years, for both mild and moderate-to-high perinatal risk groups. These findings show that perinatal risk represents a major public health issue. In this light, there needs to be greater research emphasis on methodologies for prevention/reduction of both mild and high levels of perinatal risk, and most importantly, in targeting known modifiable prenatal risk factors for the prevention of negative outcomes in children who are born preterm, low birth weight and/or small for gestational age.
Key Messages

Relatively little is known about the true long-term costs associated with children born preterm, low birth weight or small for gestational age. Existing studies are heavily focused on hospital costs and neonatal care while longer-term studies rely on model-based estimates. This study is the first internationally to provide detailed cost data for community-based health care from a population-based longitudinal study. Results show the additional costs of perinatal risk are highest in the first year of life but persist up to at least 10 years of age for those with both mild and moderate-to-high perinatal risk.

References


Statacorp (2009) Stata Statistical Software. TX: StataCorp LP, College Station.


### Table 1: Sample characteristics at Wave 1 by perinatal risk groups.

<table>
<thead>
<tr>
<th></th>
<th>B cohort (0-1 years)</th>
<th>K cohort (4-5 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mod-high PR</td>
<td>Mild PR</td>
</tr>
<tr>
<td><strong>Unweighted sample size</strong></td>
<td>n = 297</td>
<td>n = 442</td>
</tr>
<tr>
<td>Gestational age (weeks), mean (sd)</td>
<td>37.18 (4.46)</td>
<td>36.81 (2.56)</td>
</tr>
<tr>
<td>Birth weight (grams), mean (sd)</td>
<td>2,227 (812)</td>
<td>2,689 (410)</td>
</tr>
<tr>
<td>Birth weight &lt;10th percentile for gestational age, %</td>
<td>82.8</td>
<td>47.0</td>
</tr>
<tr>
<td>Corrected age at baseline in months, mean (sd)</td>
<td>8.88 (2.71)</td>
<td>8.90 (2.64)</td>
</tr>
<tr>
<td>Male, %</td>
<td>50.0</td>
<td>52.6</td>
</tr>
<tr>
<td>Indigenous, %</td>
<td>10.4</td>
<td>7.0</td>
</tr>
<tr>
<td>Special health care needs, %</td>
<td>11.7</td>
<td>8.6</td>
</tr>
<tr>
<td>Child global health poor/fair, %</td>
<td>6.0</td>
<td>4.2</td>
</tr>
<tr>
<td>Mother smoking during pregnancy, %</td>
<td>28.7</td>
<td>26.8</td>
</tr>
<tr>
<td>Least advantaged SEP quartile a, %</td>
<td>35.1</td>
<td>31.1</td>
</tr>
<tr>
<td>Most advantaged SEP quartile a, %</td>
<td>15.0</td>
<td>21.2</td>
</tr>
<tr>
<td>Single parent family, %</td>
<td>17.4</td>
<td>15.5</td>
</tr>
<tr>
<td>Speak language other than English, %</td>
<td>23.0</td>
<td>18.5</td>
</tr>
<tr>
<td>Mother did not complete Year 12, %</td>
<td>50.0</td>
<td>46.3</td>
</tr>
<tr>
<td>Remote/very remote location, %</td>
<td>3.5</td>
<td>5.0</td>
</tr>
</tbody>
</table>

**Note:** p-values are from chi-square or regression analyses.

*SEP = Socioeconomic position; comparison to middle 50% for SEP.
<table>
<thead>
<tr>
<th></th>
<th>B cohort (0-5 years)</th>
<th>K cohort (4-9 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mod-high PR</td>
<td>Mild PR</td>
</tr>
<tr>
<td><em>Weighted percentages</em></td>
<td>6.7%</td>
<td>9.7%</td>
</tr>
<tr>
<td><strong>MBS ($)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>82; 15,415</td>
<td>32; 16,724</td>
</tr>
<tr>
<td>Mean cost (95% CI)</td>
<td>2,242 (1,998; 2,487)</td>
<td>2,284 (2,089; 2,479)</td>
</tr>
<tr>
<td><strong>PBS ($)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0; 21,387</td>
<td>0; 20,873</td>
</tr>
<tr>
<td>Mean cost (95% CI)</td>
<td>162 (50; 275)</td>
<td>197 (98; 297)</td>
</tr>
<tr>
<td><strong>Total Medicare ($)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>82; 35,248</td>
<td>32; 37,597</td>
</tr>
<tr>
<td>Mean cost (95% CI)</td>
<td>2,405 (2,105; 2,704)</td>
<td>2,481 (2,221; 2,741)</td>
</tr>
</tbody>
</table>

*a* Costs over six years, in 2011 $AUD, rounded to the nearest dollar. Note that outliers were excluded for high costs within a single year, whereas this table represents costs over 6 years.

*b* Weighted percentages with outliers excluded.

*c* B cohort: Total Medicare recalculated with outliers included: Not at increased PR: mean cost per child (2,116, 95% CI = 2,036; 2,197). Mild PR: mean cost per child (2,481, 95% CI = 2,221; 2,741). Moderate-to-high PR: mean cost per child (2,658, 95% CI = 2,220; 3,117).

*d* K cohort: Total Medicare recalculated with outliers included: Not at increased PR: mean cost per child (1,340, 95% CI = 1,283; 1,397). Mild PR: mean cost per child: (1,634, 95% CI = 1,392; 1,876). Moderate-to-high PR: mean cost per child (1,725, 95% CI = 1,424; 2,026).
Table 3: Adjusted and unadjusted mean cost differences and population cost estimates \(^a\), over 6 years (0-5 and 4-9), by perinatal risk groups.

<table>
<thead>
<tr>
<th></th>
<th>Unadjusted cost differences</th>
<th>Adjusted cost estimates (^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean difference ((95% \text{ CI}) \text{ ($)})</td>
<td>(p) ((95% \text{ CI}))</td>
</tr>
<tr>
<td>Mod-high PR versus not at increased PR</td>
<td>317 (12; 621) 0.04 1.15 (1.01; 1.31)</td>
<td>5 886 (222, 11 531)</td>
</tr>
<tr>
<td>Mild PR versus not at increased PR</td>
<td>393 (126; 661) &lt;0.01 1.19 (1.07; 1.33)</td>
<td>10 933 (3 505, 18 389)</td>
</tr>
<tr>
<td>Any PR versus not at increased PR</td>
<td>362 (156; 568) &lt;0.01 1.17 (1.08, 1.28)</td>
<td>16 792 (7 237, 26 348) (^d)</td>
</tr>
</tbody>
</table>

B cohort, from birth up to age 6

K cohort, from age 4 up to age 10

| Mod-high PR versus not at increased PR | 406 (103; 709) <0.01 1.31 (1.10; 1.56) | 8 924 (2 264, 15 585) | 458 (71; 845) |
| Mild PR versus not at increased PR | 225 (52; 399) 0.01 1.17 (1.04; 1.31) | 6 410 (1 481, 11 368) | 206 (19; 394) |
| Any PR versus not at increased PR | 306 (137; 475) <0.001 1.23 (1.11, 1.40) | 15 444 (6 915, 23 974) | 318 (117; 519) |

\(^a\) In 2011 \$AUD, rounded to nearest dollar, with outliers excluded.

\(^b\) Models adjust for child gender, Indigenous status, geographic remoteness, socio-economic position, single parent status, language spoken at home, and mothers’ and fathers’ education.

\(^c\) Estimated whole population cost per year (calculated as: unadjusted mean differences multiplied by population size), in thousands and rounded to nearest thousand.

\(^d\) Population cost for any perinatal risk for B cohort only: re-estimated with full term, normal birth weight children for whom ventilator used or hospitalized at birth for 7 or more days excluded from the not at increased risk group: 18 462 (11 643, 25 281).
Figure 1: Bar graph showing total unadjusted Medicare costs per year (in 2011 $AUD), across six age brackets for cohorts B and K. Note: Error bars represent standard error.