

*Brief Communication*

## Preterm birth a long distance from home and its significant social and financial stress

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### Abstract

The present paper reports a retrospective cohort of preterm infants admitted to our hospital who delivered outside the normal geographical catchment area of the mother's local level three neonatal nursery. Nineteen mothers had 21 preterm infants (23.1–34.9 weeks, 500–2330 g born) where 14 infants required ventilation (median 57 h, range 3–428). Eighteen survivors had a median length of stay of 41 days (range 3–91). Twelve of 19 mothers were interviewed: all described isolation, loneliness, poor social support and significant financial hardship related to getting their infants back to a local hospital or home. To avoid these problems, we recommend confining travel to within a short distance from home or local maternity unit after 22 weeks.

**Key words:** family relations, premature infant, premature labor, psychological stress, travel.

### Introduction

There is considerable stress associated with the admission of a sick newborn infant to an intensive care nursery.<sup>1–4</sup> Mothers who deliver preterm infants require a great deal of support from their spouse, family and friends.<sup>3–5</sup> Mothers of very low birthweight infants (<1500 g) have particularly high levels of psychosocial distress if their infant requires prolonged respiratory support.<sup>6</sup> The problems associated with admission of a sick newborn infant a long way from home, and the need for repatriation of that infant once well enough to travel, have not been well documented. Smit reported a case series of babies born outside The Netherlands requiring repatriation: parents experienced a lack of support and social contact from family and friends, and substantial financial expenses from the extended stay abroad and eventual repatriation.<sup>7</sup> The extent of the problem of preterm delivery away from the mother's usual place of residence and outside the normal geographical catchment area of her local level three neonatal nursery is unknown. The aim of the present paper was to determine the extent of this problem by determining the proportion of preterm infants admitted to the level three neonatal unit at the Royal Women's Hospital (RWH) in Brisbane under these circumstances. The other aim was to determine the circumstances of delivery of these preterm infants, and to determine the emotional, social, psychological and financial burden on the families.

### Materials and methods

Infants admitted to our nursery from 1 January 1996 to 31 October 2000 with a home postcode outside Queensland were identified from the neonatal database: those from outside our usual catchment area (Queensland and Northern New South Wales) were included in the present study. Infants were excluded where confinement was planned in Brisbane.

We recorded data from the chart of each infant on maternal demographic and obstetric details, *in utero* transfer or retrieval needs, birthweight, gestational age (GA), length of nursery stay, and infant problems. We noted any risk factors for preterm delivery (i.e. multiple pregnancy; chronic maternal illness; drug dependency; treatment for infertility; maternal age <18 or >35 years; past history of therapeutic termination, miscarriage, stillbirth, preterm birth, or cervical incompetence). We noted the circumstances of the mother's travel in our catchment area. The number of out of town infants as a proportion of admissions was determined as a surrogate measure of the incidence of this occurrence (Table 1).

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**Table 1** Number of infants admitted who were born away from the mother's usual place of residence, and outside the normal geographical catchment area of her local level three neonatal nursery, as a proportion of admissions

Gestation group	<i>n</i>	<i>n</i> admissions	%
<24 weeks	2	24	8.3
<28 weeks	7	362	1.9
<32 weeks	15	1059	1.4
<34 weeks	20	1665	1.2
<37 weeks	21	2852	0.7
All	23	5248	0.4

We wrote to the parents of surviving infants asking for permission for an investigator to contact them by telephone. If the parent/s agreed they were contacted by a follow-up telephone call. Questions asked can be seen in Table 2. The study was approved by the RWH Research Ethics Committee.

## Results

The number of unplanned deliveries away from home as a proportion of admissions at various GA are shown in Table 1.

Nineteen mothers had 21 preterm infants: 14 mothers were travelling on holidays and five were visiting relatives or attending weddings. Nine (47%) of the pregnancies were considered to be at high risk of preterm delivery. Seventeen went into preterm labour for various reasons and two required urgent Caesarean section for antepartum haemorrhage.

Of the 21 preterm infants the median GA was 30.2 weeks (23.1–34.9 weeks); the median birthweight was 1230 g (500–2330 g). Twelve of the 21 infants (57%) were transferred *in utero* from another hospital, and six (29%) infants required retrieval, after delivery, from outside Brisbane. Of the 21 preterm infants, 14 required ventilation for a median (range) of 57 h (3–428).

Three infants died prior to discharge; the remaining 18 had a median (range) length of stay in our hospital of 41 days (3–91). Ten were then transferred to hospitals nearer home and eight were discharged home.

Twelve out of 19 mothers (63%) agreed to be interviewed by phone and the results are summarised in Table 2. All parents interviewed described experiencing a variety of emotions: feelings of isolation, loneliness and separation were frequently described. Concerns for the partner and his ability to cope with the separation were also reported. Statements included:

'I felt guilty that I was there and [he] wasn't. I would ring him and tell him how beautiful she looked and I could tell he was disappointed.'

'My husband was not present at the birth so he had a poor appreciation of the stress and trauma I went through. We were close to separation.'

'It was very emotional being away from home, the uncertainty of having a premature baby as well as the stress on my husband.'

All parents interviewed noted the financial burden of having their baby away from home. Statements included:

'Financially it was a great strain.'

'We had to take out a \$20 000 loan due to financial difficulties.'

'There was my loss of income ... as well as my husband's.'

Ninety percent of parents reported that they 'really missed the support of friends and family'.

## Discussion

Approximately 1% of preterm infants admitted to our neonatal unit are there because their mothers were travelling in Queensland or Northern New South Wales, well away from their home and regional tertiary neonatal unit. The majority of mothers required long-term accommodation in Brisbane at not insignificant cost, with little local family support. The problems encountered by preterm infants and their families, because of delivery while travelling, are significant.

In Australia and New Zealand there are approximately 3200 admissions of infants <32 weeks GA per year.<sup>8,9</sup> If the number of infants admitted to our neonatal unit from outside our usual geographical catchment area is consistent across Australia and New Zealand, this would equate to approximately 43 infants <32 weeks GA admitted to neonatal units under similar circumstances every year.

The social and psychological stress associated with having a child admitted to an intensive care nursery is well documented. Hickey and Rykerson listed the most frequently reported parental stressors and needs as: fears about outcomes, concerns about procedures/treatments, hospital expenses, feelings of guilt and anger, and concerns for family functioning.<sup>1</sup> Miles *et al.* found that the highest source of support for parents was the other parent.<sup>2</sup> Parents experience considerable stress and require sympathetic understanding and support.<sup>3,6</sup> Lindsay *et al.* have identified that parents of preterm babies feel a sense of social isolation and a critical need for human support.<sup>4</sup> Shields-Poe and Pinelli found that the most helpful support to mothers are their spouses; family and friends are also very important.<sup>5</sup> This information is consistent with our findings. We have shown that having a baby a long way from home causes loneliness and isolation, complicated by the distinct lack of family support. While the sources of stress reported by mothers in the present study are consistent with those reported by others, they cannot escape being compounded by the greater degree of social isolation experienced with admission of an infant to a tertiary neonatal unit a long way from home. Having a sick infant closer to home will help to decrease the feelings of loneliness and isolation and allow for optimal family support.

Financial hardship was experienced by many of the study families. In Australia, financial support is available for those who need to travel a long distance from home for medical care from schemes such as the Isolated Patient's Travel and Accommodation Assistance Scheme (IPTAAS). However, this support *is not available to those who travel*

**Table 2** Phone interview questions and response summary

Question	<i>n</i>
Why were you travelling when baby was born?	
Holidays	7
Visiting	4
Wedding	1
What was the method of travel to Queensland?	
Car	5
Air	7
Was your partner travelling with you?	
Yes	9
Where was your partner when baby was born?	
Present at birth	7
At home	2
In transit	3
Initial planned length of travel/stay? (median)	10 days (IQR 4–14 days)*
Eventual length stay in QLD? (median)	70 days (IQR 46–90 days)*
Where did you stay while baby was in hospital?	
Ronald McDonald House	4
Ronald McDonald House + other	2
Friends	1
Relatives	5
How much did the accommodation cost?	
\$500–\$1000	6
\$1000–\$1500	1
\$1500–\$2000	2
\$2000–\$2500	2
\$20 000 loan	1
Did you receive financial support? How much?	
Yes	4 (all partial)
No	8
What was the source of funding?	
Patient Transport Assistance Scheme	2
Private Health Fund	1
South Australian Health Commission	1
Nil	8
Were you ever diagnosed with postnatal depression following the pregnancy?	
Yes	2
If you could have your time over again would you prefer to have your baby nearer to home?	
Yes	12
If you have or were to become pregnant again would you travel?	
Yes	2
No	10
At what stage do you think travel would be OK or not OK?	
Never OK to travel during pregnancy	6
Would you advise other pregnant mothers to travel during pregnancy?	
Yes (depending on the individual situation)	5
No	7
Did your obstetrician give you advice on travel during your pregnancy?	
Yes	4
No	8
What did he/she advise you?	
All four that received advice were told travel would be OK	
Did you agree with the advice?	
All four that were given advice disagree with the advice given	

Table 2 *Continued*

Question	<i>n</i>
What problems did having a baby away from home cause?	
Financial difficulties	9
Loneliness and isolation	8
Family support issues	8
Relationship difficulties	6
Friends	3
Children	4
Accommodation	2
Pet care	2
How did you get to discharge hospital or home?	
Royal Flying Doctor Service	3
Commercial flight	6
Road	3
How much did this [repatriation] cost?	
Nil	3
\$300–\$1000	9

\*Mann-Whitney *U*-test,  $P = 0.0001$ . IQR, interquartile range.

*voluntarily* and then need medical assistance. When the period of stay for that medical care is prolonged, as it often is in cases of significant prematurity, the financial burden for accommodation, and later repatriation, can be substantial; thus, compounding the emotional strain of these events for many families. Families of infants from our own catchment area do not have to pay accommodation and repatriation costs.

The risk of preterm delivery is 5–12%.<sup>10,11</sup> The risk of delivering <32 weeks' gestation is approximately 1%.<sup>10–14</sup> The risk of preterm birth is markedly increased for multiple pregnancies, chronic maternal illness, smoking and drug dependency, treatment for infertility and maternal age <18 or >35 years. The risk is increased if there is a past history of therapeutic termination, miscarriage, stillbirth, preterm birth, or cervical incompetence.<sup>10–14</sup> In the present cohort almost half had risk factors that would increase the likelihood of preterm birth.

An understanding of the consequences of preterm delivery while travelling is crucial when advising mothers who plan to travel during pregnancy after 22 weeks' gestation. The data we have provided, coupled with the epidemiological data on the risk of preterm delivery and factors that increase this risk, can assist those advising mothers during pregnancy. The present study highlights the need to raise awareness among mothers, obstetricians and general practitioners of the possible consequences of travelling during pregnancy. We do not suggest that it is the travelling that increases the risk of preterm delivery. As far as we are aware there are no data available to suggest this. We have, however, documented some of the difficulties that arise should preterm delivery occur while travelling. If families wish to avoid those difficulties then we would recommend confining travel to within a short distance (less than 1 h drive) from home or local maternity unit after 22 weeks.

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