Parental costs of neonatal visiting

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Abstract

Interviews with 93 mothers of 109 low birthweight infants admitted to a regional neonatal intensive care unit showed that, although 82 (88%) mothers visited on a daily basis, some families faced considerable travelling difficulties. Five families travelled more than 100 miles and three families had twin siblings in different neonatal units. Analysis of the travelling and associated expenditure strongly indicates that the parents in most need received little or no help from the statutory authorities and only 26 (28%) families received financial help from any source. There emerges a strong case for offering appropriate financial help to parents on low incomes to facilitate visiting and increase family contact.

(*Arch Dis Child* 1993; 68: 597-599)

Parents of infants in neonatal intensive care units (NICUs) need the opportunity to develop caring relationships with their sick infants.¹ An inability to visit can result in bonding failure and subsequent difficulties in parent/child interaction, occasionally leading to neglect and abuse.² Hospital visits can impose financial stresses on parents already under emotional strain.³

As part of a larger study of parental perceptions of neonatal intensive care, mothers described the problems in travelling to the unit and the financial and logistical costs of visiting their sick child over a prolonged period.

Subjects and methods

The study group consisted of 93 mothers of 109 infants weighing less than 2500 g at birth and staying on the unit for 10 days or more before discharge home or transfer to their local special care baby unit (SCBU). After an initial explanatory discussion and written consent, mothers were interviewed in private by the same interviewer (AM) in the week before the infant's discharge or transfer (61 or 66%), or at home in the week of the infant's discharge (32 or 43.4%). All 106 mothers of infants matching the criteria for inclusion were approached, but 13 (12.3%) declined to take part in the study. A semistructured interview was used to elicit information on the following topics which might have a bearing on parental visiting practice: travel; family structure; and socio-economic status.

All parents were interviewed by one of two dedicated social workers and given information (DSS leaflet NI146) on available statutory and voluntary help.

The data were analysed using the statistical

package for social sciences (SPSS-X) on the Manchester University Amdahl computer.

Results

The 109 infants were born at gestational ages ranging from 22 to 37 (median 31) weeks, with birth weights ranging from 495 to 2660 g (median 1458 g). There were 22 outborn infants (20%), of whom 20 (18.3%) returned to the referring hospitals when they no longer needed intensive care. Three infants (3%) had a sibling twin in a different unit and a further three infants (3%) were transferred to a specialist hospital for tracheostomy care. The length of stay on the NICU varied from 10 to 176 (median 36) days.

In total 61 (56%) infants were ventilated for 1-77 (median 16) days. Multiple gestations accounted for 16 (15%) infants of whom five (31%) died on the NICU (four were sibling twins and one a sibling triplet). Two singleton infants died after transfer back to the SCBU. Of the study group, seven (6%) infants died in neonatal units; none died in the first year of life after discharge home.

VISITING PATTERNS

Of the 93 mothers interviewed, 82 (88%) managed to visit their infants on the unit on a daily basis. For 37 (45%) of these there was at least one occasion on which they had wished to visit the unit but had been unable to travel. Most mothers (86%) spent over one hour on the unit at each visit. Those who remained for a shorter period experienced problems with personal health (three women), support for other children at home (four women), and financial constraints related to transport (four women).

METHOD OF TRAVEL TO UNIT

For seven mothers (8%) who walked to the unit and five (5%) who obtained lifts from families and friends, no costs were incurred; public transport was used by 21 (23%). The six (7%) families who used taxis found them quicker, more direct, and cheaper than two bus fares for both parents and siblings. For 54 (58%) families using their own vehicles costs were calculated on the Automobile Association technical services breakdown of the running costs of a 1.0 l car on the cheapest petrol. At the midpoint of the study in April 1990 this was £0.39 per mile.⁴

DISTANCES TRAVELLED TO UNIT

For 59 (63%) mothers travel to the NICU was less than 11 miles round trip for each journey,

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Accepted 28 December 1992

Table 1 Individual costs for families who travelled 50 miles or more round trip to the neonatal intensive care unit (NICU)

Distance of trip (miles)	Cost of one trip (£)	No of visits	Time in NICU (days)	Total travel costs (£)	Source of help
240	94	5	19	470	Family help
214	83	8	46	644	No help (sibling twin in local SCBU)*
190	74	20	35	1480	No help
108	42	22	22	926	Family/friends
52	20	20	64	400	Family/friends/DSS*
50	19	15	15	295	No help
466	182	Mother admitted to ward	90	6000	Father's travel costs and loss of income; family help
60	12	19	47	228	DSS/NICU social worker; NICU fund

*SCBU=special care baby unit; DSS=Department of Social Security.

Table 2 Costs of travel for families with low income

Cost	Unsupported mothers	Unemployed fathers	Social class IV	Social class V
Minimum (£)	0	0	27	14
Maximum (£)	470	374	425	780
Median (£)	108	30	97	113

but 24 (26%) faced a journey of between 21 and 30 miles; two (2%) travelled up to 40 miles and three (3%) up to 60 miles. Five (5%) families lived more than 100 miles from the unit and undertook a car journey of more than 90 minutes in each direction.

COSTS OF TRAVEL TO UNIT

The figure shows the calculated total cost of visiting the NICU. Table 1 details the costs for individual families who travelled 50 miles or more round trip to the NICU. Table 2 shows the costs of travel for families with a low income and table 3 the sources of help for these families.

Table 3 Help with travel costs for families with low income

Type of help	Unsupported mothers	Unemployed fathers	Social class IV	Social class V	Total
No help	4	6	6	3	19
Family only	2	0	1	1	4
Family/friends	1	0	0	0	1
Social worker (NICU)*	0	1	2	1	4
DSS*	0	1	0	0	1
Family/DSS/social services	1	0	0	1	2
Family and NICU social worker	0	0	1	0	1
Total	8	8	10	6	32

*NICU=neonatal intensive care unit; DSS=Department of Social Security.

Total travelling costs for families visiting infants in neonatal intensive care units.

Data analysis suggests that many parents in pressing need were unlikely to receive financial assistance from any source (table 3). Only 26 (28%) families received help with travelling expenses. Of the 32 (34%) low income families – that is, one parent families or families where the father was unemployed, and those in social classes IV and V,⁵ only 13 (41%) received help (see table 3).

ADDITIONAL COSTS

Additional costs related to babysitting, child care, and arrangements for siblings were not included in the travelling costs. Neither were the costs of visiting siblings in another unit, so these figures are the minimum additional expenditure. For seven (8%) families difficulty in arranging child care inhibited visiting. Mothers who had other children under secondary school age arranged their visits to the unit around childminding and collecting children from school. In this group of 45 (48%) mothers 23 (51%) had one dependent child, 13 (29%) had two, five (11%) had three, and four (9%) had four dependent children. Only one of 45 was an unsupported mother.

Discussion

Smith and Baum, looking at visiting in six neonatal units in an attempt to measure costs for families, described the additional financial and social stress imposed on parents by the costs of visiting.³ They were surprised by the small number of families who received financial aid and, 10 years later, little appears to have changed. Most parents received little or no financial help for neonatal unit visits even though, without conspicuous evidence of hardship, the cost of travel for a third of all parents was more than £200. Only a quarter of those in greatest need of financial help received assistance from statutory organisations, although premature births are usually unexpected and parents are unlikely to have budgeted for the extra expense involved in neonatal visiting.

SOURCES OF FINANCIAL HELP

Sources of financial assistance for parents are limited. If help cannot be obtained from the Department of Social Security, application can be made to hospital endowment funds, social services departments, various national charities, and councils for voluntary services.

Income support

Income support is available to those who are unemployed or employed for less than 24 hours a week and have capital of less than £8000. Under the provisions of the social fund such recipients are eligible for community care grants and loans and for reimbursement of travelling expenses. Social workers have reported that the social fund claim form SF300 is too long and is confusing for claimants to complete (P Dalaya, Assessing the need for a travel grant scheme for families with a baby in

special care. Unpublished report available from BLISS-LINK, 17 Emerald Street, London WC1N 3QL). There is a long waiting period while the form is assessed and parents may run into debt while waiting. Parents are often not fully reimbursed.

Problems arise because the social fund is discretionary and the Department of Social Security may choose to pay for only one parent to visit and for only one trip each day, even when mothers wish to breast feed. Travel must be by the cheapest route, which may not be the most direct, using second class fares on public transport, but petrol costs may be reimbursed if public transport is unavailable. In practice mothers receiving income support who successfully applied for community care grants from the Department of Social Security (table 3) regularly waited up to two weeks for their allowance, even though their need might have been immediate.

Family credit

Family credit is available for working parents on a low income. Their income is topped up to a level related to family size and commitments. These families, and those in receipt of unemployment benefit or invalidity benefit, are ineligible for help with travelling expenses.

Endowments and charitable trusts

An inadequate local fund is available to provide financial assistance to families in immediate need. Grants are made at the discretion of the social worker or the senior NICU nursing sister.

Staff on intensive care units are increasingly aware of the travelling difficulties facing many parents and of the need for support during this time. In the face of the under provision of neonatal intensive care cots, the shortfall of trained nurses in many districts, and the unlikely short term resolution of these problems, parents will continue to face long journeys to regional NICUs at their own expense. For parents on low incomes the costs of travelling, even to the local unit, can be particularly burdensome and cause financial hardship that outlasts the child's return home.

RECOMMENDATIONS

There clearly exists a need for greater availability of neonatal intensive care to avoid cross regional travel and the extra stress this imposes on parents. If the financial and organisational arguments against the local provision of neonatal intensive care cannot be overcome, there is a strong case for offering realistic financial help to parents on low incomes to facilitate visiting and increase family contact.

This work was supported by the fundraising society of the special care baby unit of Hope Hospital. Thanks are also due to the staff of the NICU and to all the families who cooperated in the study.

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