ORIGINAL ARTICLE

Impact of community neonatal services: a multicentre survey

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Objectives: To explore the impact of a community neonatal service on high risk infant survivors in the first year of life.
Design: Retrospective multicentre survey. Postal questionnaires were sent to selected parents.
Setting: Thirty two neonatal units in England and Wales.
Patients: Inclusion criteria: infants over 12 months of age with birth weight ⩽1500 g, or who received level I intensive care for at least 48 hours. Exclusion criteria: multiple births, infants who had died or had severe congenital abnormalities. A total of 3367 eligible infants were selected, and their parents were sent a questionnaire; 65% responded.
Main outcome measures: Length of stay on the neonatal unit from birth to initial discharge. Readmission to hospital during the first year of life.
Results: The median length of stay in units with a community neonatal service was 35 days compared with 37 days in units without. When adjusted for infant and parent characteristics, the median length of stay was reduced by 12.6% where a community neonatal service was provided (95% confidence interval 5.3% to 19.3%). The readmission rates were 44.6% in units with a community neonatal service and 43.5% in units without. There was no significant reduction in the adjusted odds of readmission.
Conclusions: The retrospective nature of this study means that these findings cannot be definitely attributed to the presence of a community neonatal service. However, the results suggest that community neonatal services may reduce the length of stay without any subsequent increase in readmission.

The incidence of very low birth weight (< 1500 g) is increasing in industrialised nations. In England and Wales, it increased from 0.8% in 1983 to 1.2% in 1998.[1] These infants and their families receive highly skilled care and support while undergoing intensive care in neonatal units (NNUs), but often this support is discontinued after discharge into the community. The burden of care is then transferred to the parents and members of the generic primary healthcare team, who may have minimal specialist training in the management of these high risk infants.

Controlled studies have examined the effectiveness of early discharge and home support programmes for low birthweight or preterm infants.[2–8] They have found that reductions in average length of stay (LOS) can be achieved with no apparent increase in readmissions. However, these studies have been criticised for being single centred and of small sample size.[9] Discharge planning for high risk neonates including home support has been recommended,[10] and in the United Kingdom community neonatal services (CNSs) have been introduced,[11] but there has been little controlled research into their impact on LOS of infants in the NNU or on hospital readmission rates within the first year of life.

We carried out a study to explore the impact of specialist CNSs on the following:

(1) length of stay in hospital from birth to initial discharge among high risk infant survivors;

(2) number of hospital readmissions required by these infants in the first year of life;

(3) support and quality of care provided to the family in the first year of life after discharge from the NNU;

(4) overall costs of treatment in the first year of life.

This report focuses on the results of objectives 1 and 2 in relation to LOS on the NNU and readmission in the first year of life. The results of the parental reports (objective 3) have been published elsewhere.[12] Insufficient data were available on costs to carry out an adequate economic analysis (objective 4).

METHODS

Selection of NNUs

Figure 1 shows the sampling procedure. NNUs were selected on the basis of information from a national survey of all 217 neonatal services in England and Wales.[13] A total of 166 units (76%) responded and 120 (55%) were willing to participate in future research. The survey showed that there was no consistent definition of what constituted a CNS. Therefore, for the purpose of this study, the research team designated a NNU as having a CNS if they had provided the following for a minimum of three years:

- home visits offering nursing care and specialist advice for a minimum of five days a week for the first four weeks after discharge from the NNU;
- advice to families, as required, until the infant was at least 12 months old;
- named nurse(s) providing a link between primary and secondary healthcare services.

Units that partially fulfilled these criteria or had introduced these services within the last three years were classified as having a partial CNS and were not considered for inclusion (n = 30). From the remaining 90 units (35 with CNS), a potential sample of 24 pairs of units with and without a CNS was identified.

The pairing was carried out on the basis of delivery rate, number of intensive care cots, and socioeconomic and geographical characteristics of the catchment areas. Pairs of

Abbreviations: NNU, neonatal unit; LOS, length of hospital stay; CNS, community neonatal service

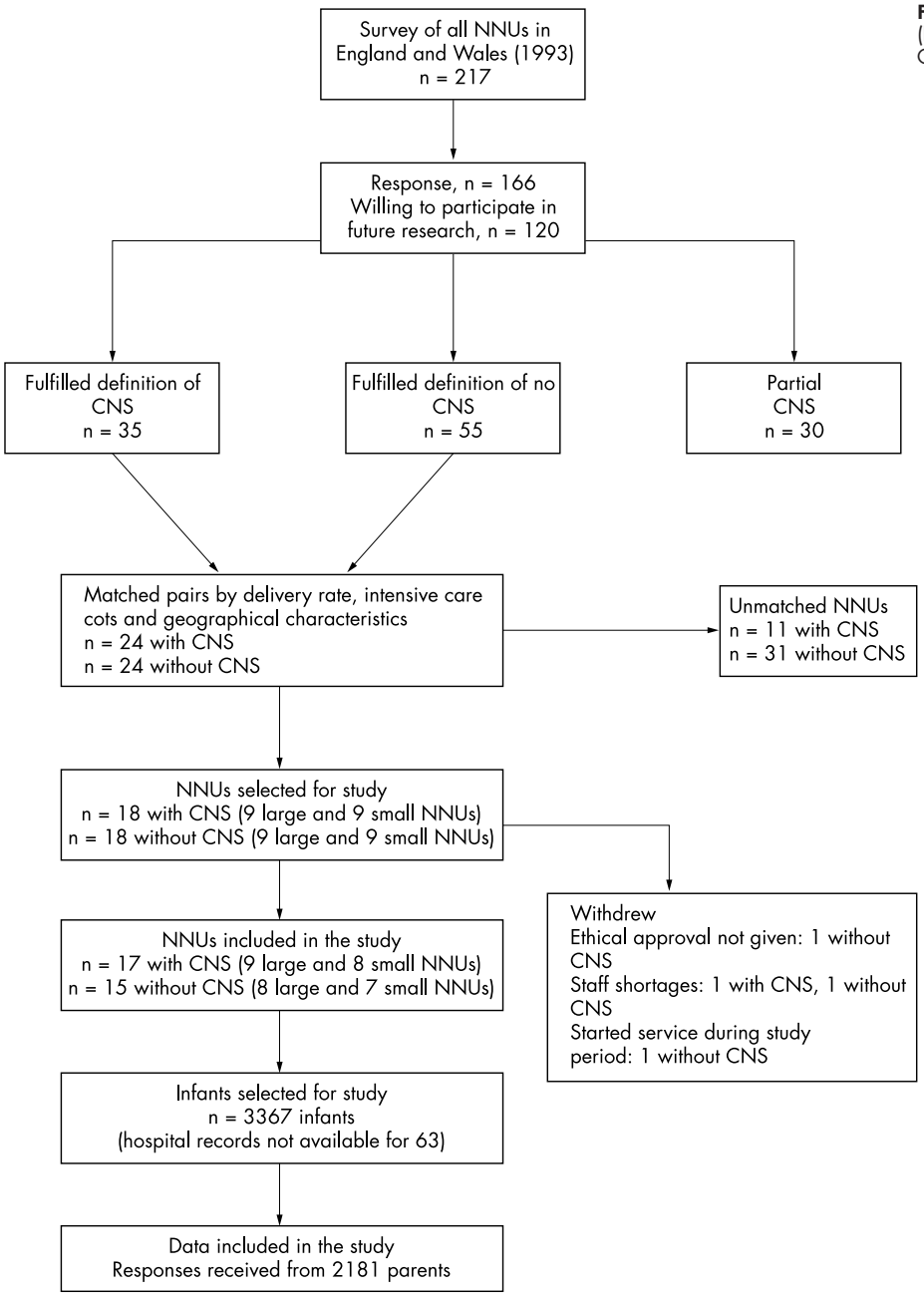

Figure 1 Selection of neonatal units (NNUs) and infants. CNS, Community neonatal service.

NNUs were selected for inclusion in the study, which covered most regions in England and Wales.

Ethical approval was sought from local research ethics committees. The final number of participating NNUs was reduced from 36 to 32 units (17 with CNS; 15 without CNS). One ethics committee refused permission for the research to be undertaken in their area. Three units were later removed, two because of staffing crises. One unit started a CNS during the study period and no longer fulfilled the study criteria.

Selection of infants

Infants were eligible for inclusion if they had been born at least 12 months previously and had a birth weight below or equal to 1500 g or had received level I intensive care for at least 48 hours. Multiple births, infants who had died, and those with severe congenital abnormalities were excluded. Consecutive infants were selected from each NNU's admissions register, working backwards in time from the most recent eligible birth. Hospital records were unavailable for 63 infants.

Outcome measures

The primary outcome measures reported here are LOS from birth to initial discharge and readmission to hospital during the first year of life (any readmission versus no readmission).

An introductory letter explaining the study (online at www.archdischild.com), an information sheet, and a questionnaire (online at www.archdischild.com) were sent to parents inviting them to participate in the research. As no previous studies had been undertaken in the United Kingdom to examine specialist CNSs, it was necessary to design an instrument suitable for completion by parents. The instrument was designed and tested for reliability in an earlier study.[14] The format allowed the parents to reflect systematically through this episode in their lives, starting with details about the neonatal intensive care unit and finally answering questions about their own perceptions. The introductory letter was signed by the nurse manager of the NNU to reassure the parents that permission for the research had been obtained. Parents were told that they could contact the nurse manager if

Table 1 Infant and parent characteristics

	NNU with a CNS	NNU without a CNS
Number	1104	1077
Birth weight (g)	1680 (0.84)	1710 (0.77)
Discharge weight (g)	2370 (0.64)	2400 (0.58)
Gestation (weeks)		
⩽25	45 (4)	26 (2)
26–29	283 (27)	282 (26)
30–32	354 (33)	353 (33)
33–36	235 (22)	278 (26)
⩾37	149 (14)	144 (13)
Male	572 (52)	595 (55)
Mother employed	482 (46)	466 (45)
Husband/partner employed		
Yes	834 (82)	827 (81)
No	94 (9)	109 (11)
N/A	94 (9)	87 (8)
Age mother finished education		
<16 years	72 (7)	52 (5)
16–17 years	605 (61)	581 (58)
18–20 yreas	214 (22)	250 (25)
21 years or more	99 (10)	113 (11)
Accommodation		
Owner occupied	718 (71)	718 (72)
Council/housing ass	240 (24)	231 (23)
Private rented	55 (4)	55 (4)
Other	14 (1)	29 (1)

Data are number (%) except for birth weight and discharge weight which are mean (SD).
NNU, Neonatal unit; CNS, community neonatal service.

they had any questions about the research or any difficulty with the questionnaire.

Agreement between the parents' responses and the hospital records was ascertained by comparing the LOS and number of readmissions for a 15% sample of the infants selected.

Statistical methods

We used generalised linear models to obtain covariate adjusted estimates of the CNS intervention effect—that is, the average difference between the outcomes of an infant on a unit with a CNS compared with a similar infant on a unit without a CNS. As outcomes from patients of the same NNU might be correlated, we used generalised estimating equations (GEE)[15] for fitting the models in SAS (Cary, North Carolina, USA). Unit size, infant characteristics (sex, gestational age, birth weight), and parental characteristics (employment of mother and father, age when mother finished full time education, and accommodation) were included as covariates, with categories as shown in table 1. Specifically, we used a linear model for the logarithm transformed end point LOS (analogous to multiple linear regression). The logarithmic transformation of LOS was used to establish a normal distribution. A logit link was applied to the binary end point readmission within the first year (analogous to logistic regression). Cases with missing information on the end point or any covariates were excluded from these analyses.

Sample size

Statistical power of this study was estimated as described by Donner.[16] The magnitude of within unit correlations for the outcomes proposed here were not known, but experience from other health research suggested that they will lie between 0 and 0.15.[17] The study was powered to detect a difference of 20% in LOS (based on previous data showing a mean of 1.64 and SD of 0.26 in log LOS in similar infants[18]) and a difference of 15% *v* 25% in readmission (based on an earlier study[19 20] and an unpublished audit[21]). A target sample size of 18 large and 18 small units, with 120 and 60 infants per unit was selected. This was inflated to 140 and 70 infants respectively to allow for non-response, giving a total sample size of 3780 infants. The within unit correlation was assumed to be 0.05, with a significance level of 0.05. This gives 91.4% power for LOS, and 82.9% power for readmissions.

RESULTS

A total of 3367 questionnaires were sent to parents of eligible infants, all of whom were born within one to three years previously, with 38% being born more than two years previously. Responses were obtained from 2181 parents (overall response rate 65%; range across NNUs 30–88%). Allowing for missing data, a final sample size of 1861 (55%) for LOS and 1853 (55%) for readmission was attained for covariate adjusted analysis. The highest response rate in an area with a CNS was 86% (88% without a CNS); both of these units were in industrialised urban areas. The lowest response rate was 39% where a CNS was provided (30% without a CNS), one unit being in an area of severe deprivation and the other in an inner city area.

Table 1 shows the characteristics of the parents and infants.

Agreement between parent's responses and hospital records

Five hundred hospital records were requested, and a total of 451 were received. These included 223 respondents, and 228 non-respondents. Reported LOS was within one day of the hospital record for 90% (201/223) of responses. Some 94% (210/223) of responses agreed with the hospital records on readmission. For non-respondents, the hospital records showed a median LOS of 31 days (29 with CNS, 32 without CNS), and 44% (101/228) had a recorded readmission. On the outcomes studied there is very little difference between non-respondents and respondents. However, only a limited amount of information was available for non-respondents.

LOS

Figure 2A shows the LOS within each unit. Units with a CNS had a median of 35 days (mean 43) LOS, whereas those without had a median LOS of 37 days (mean 47). The distribution of LOS was positively skewed: although most infants stayed for less than 40 days, some remained in NNUs for up to nine months. When adjusted for infant and parent characteristics, the average LOS was reduced by 12.6% when a CNS was provided (95% confidence interval 5.3% to 19.3%, $p = 0.001$). Infants who had a prolonged stay (⩾ 90 days) on the NNU accounted for 10% of the sample.

Readmissions in the first year of life

The readmission rates were 44.6% where a CNS was provided and 43.5% where no CNS was provided. Figure 2B shows the rates by NNU. Readmission rates across all the units ranged from 32% to 61%. When adjusted for infant and parent characteristics, there was a non-significant reduction in the odds of readmission of 1.6% when a CNS was provided, but this result is very imprecise (95% confidence interval –20.5% to +21.8%, $p = 0.88$).

Most infants (84%) were readmitted three times or less. The main reason for all readmissions was chest conditions (range across NNUs 46–53%), followed by surgical conditions (range across NNUs 10–21%), and then feeding problems (range across NNUs 8–11%). Three quarters of infants discharged home dependent on oxygen were readmitted. More than three quarters of infants discharged home requiring tube feeds were readmitted in their first year of life, and two thirds were readmitted more than once.

DISCUSSION

Two thirds of parents responded to the questionnaire, which could be considered a good response rate for a postal survey, particularly considering the length of time between discharge of the infants and the survey. Although a third failed to return

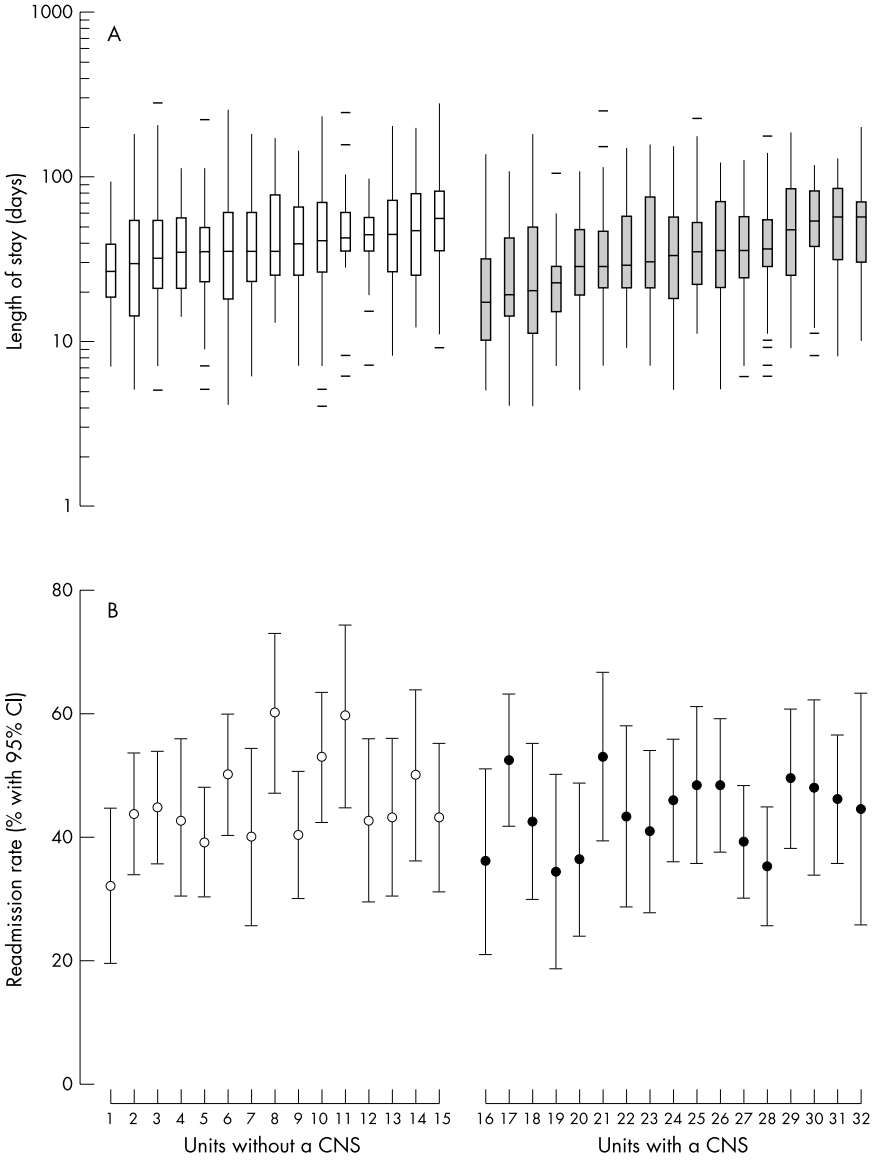

Figure 2 (A) Length of stay (from birth to initial discharge) and (B) readmission rate (proportion of infants admitted at least once in the first year of life) for neonatal units with or without a community neonatal service (CNS). Length of stay is shown using box plots with outlying observations indicated by horizontal marks. Readmission rates are given as percentages with 95% confidence intervals.

the questionnaire, the random sample of non-respondents showed little difference in the primary outcomes between these and the responders.

Controlled studies, including randomised controlled trials,[2 3 6] have indicated that high risk infants could be discharged home earlier by implementing specialist community services. However, these studies were limited to single unit providers, of small sample size, used different methods of data collection, and may not be representative of services generally. Most were undertaken outside the United Kingdom where the systems of community health care are different. Raddish and Merritt[9] identified several methodological limitations in a review of studies of early discharge home of premature infants. The present study goes some way to addressing some of these issues. The sample size was large (2181 infants), and the study was multicentred (32 NNUs) and covered a wide geographical area. The sample selection included most high risk infants, such as very low birthweight infants, as well as infants who required intensive care for more than 48 hours after birth. The main limitation is that it was retrospective, relying on the accuracy of hospital records and parental recall. However, good agreement was shown in this study between hospital records and parental recall.[13]

The LOS reported in this study was typical of those seen in previous controlled studies. Most studies reported mean LOS to discharge; these ranged from 23 to 47 days in the intervention group and 31 to 58 in the control groups.[2 5 6 8] If LOS data are to be used to make projections about cost savings, the arithmetic mean is the most informative summary,[22] although the median may be more useful for other purposes such as informing parents of the typical length of stay. We found that mean LOS was reduced by about four days in units where a CNS was provided. This reduction in LOS is at the lower end of the scale compared with other studies, which showed reductions in LOS of 2–19 days.[2–6 8] However, these studies usually focused on achievement of earlier discharge as a key aim of the intervention. Large variation in the LOS was seen between units in this study, and it appears that some units with a CNS may have aimed for and achieved earlier discharge, whereas others either did not focus on this or did not achieve reductions. The proportion of infants with prolonged stay on the NNU is similar to a national survey (1988–1990) in the United Kingdom.[23]

Only a few studies report the number of readmissions associated with early discharge programmes.[2 3 8] The readmission rates ranged from 15% to 30% at 12–18 months after birth, and were very similar in the intervention and control groups. We found that 45% of infants were readmitted in the first year of life, which is similar to those found in studies specifically

investigating readmission rates in high risk infants.[19 24–26] Neither previous studies nor this one provide sufficient evidence to rule out an important difference in readmission rates. The confidence interval found in this study indicates that the difference in readmission rate between units with and without a CNS could be as large as 20% in either direction. Further research is needed on this aspect because earlier discharge could be at the cost of increased risk of readmission. However, no association was seen in this study between shorter LOS and higher readmission rate across units.

We hoped to assess the costs of treatment within the first year of life. However, this was a retrospective study, and sufficiently detailed costs could not be obtained for an adequate economic analysis. Two randomised controlled trials[2 3] have shown substantial cost savings from early discharge and community based intervention programmes. Evaluation of the long term costs of care for high risk infants is complex.[1]

Conclusion

The validity of these findings may be limited by the retrospective data collection, with a long period of time elapsing before the questionnaire was distributed. However, the recall of most of the respondents was accurate. This research involved a large number of NNUs in England and Wales, and the findings are consistent with earlier studies that have suggested that LOS on the NNU can be reduced by providing a CNS. Although the findings of this study cannot be definitely attributed to the presence of a CNS, the results do suggest that such a service may be beneficial. Any future studies should use prospective data collection and contain a full economic analysis. The impact of CNSs on primary healthcare provision should also be considered.

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