An evaluation of the financial and emotional impact of *in utero* transfers upon families: a Scotland-wide audit

The transfer of pregnant women to tertiary obstetric centres for sub-specialist care is likely to cause financial and emotional stress to families. However, the socio-economic and psychological impact of such *in utero* transfers had not been previously evaluated within Scotland. Using a postal questionnaire the feelings and experiences of a group of women who had experienced an *in utero* transfer were explored. The results are presented in this article.

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Key points

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1. The introduction of neonatal networks necessitates centralisation of perinatal care.
2. Pregnant women and their families often require support and guidance in finding accommodation and financial assistance following an IUT.
3. Tertiary referral centres must offer support to women and families displaced by an IUT.

Introduction

The transfer of pregnant women to distant hospital centres is thought to cause financial and emotional stress. For the purposes of this study an *in utero* transfer (IUT) is defined as: "The transfer of the mother to another hospital for maternal care or predicted neonatal care for her newborn(s)".

In contrast an *ex-utero* transfer is where the baby is transferred to another institution after birth. The socio-economic and psychological impact of IUTs on the mother to be and immediate family remains under-explored. Evaluating these factors may assist in a more holistic approach to the future planning and management of IUTs, encompassing the medical, social and financial needs of the infant, mother and immediate family.

To promote clinical expertise tertiary neonatal and obstetric intensive care is provided in a limited number of centres within NHS Scotland. When prematurity or maternal illness necessitates a higher level of clinical care than can be provided locally, best practice is to arrange an IUT to a clinical centre with facilities appropriate to the anticipated clinical need. An IUT can result in the pregnant woman being transferred many miles from home, family and social support mechanisms, at a time when such support may be vital. It may place additional stresses upon families relating to separation, travel and accommodation difficulties. It is common knowledge that difficulties visiting sick infants can influence bonding and child-parent interaction adversely. The effect of separation on partners, siblings and the extended family has not previously been evaluated in a structured manner.

Work originally undertaken by the Clinical Standards Advisory Group (CSAG) in 1993[1] and 1995[2] examined access to and availability of neonatal intensive care, with particular reference to the referral of patients across district boundaries to regional and national centres. Data from a regional survey in Trent region described in the 1993 report stated that:

> "It is accepted that non-referral units should have easy access to intensive care beds in a regional or sub-regional centre and that sub-regional centres should not normally need to transfer their own in-born babies..."

The term 'inappropriate transfer' was used to describe transfers when these criteria were not met.

Subsequent reports[3-5] have consistently cited the following criteria:

- Pregnant women should not travel beyond their nearest referral centre.
- Tertiary centres should not transfer mothers or babies who are booked for care with them.

The second edition of guidance published by the British Association of Perinatal Medicine in 2001[5] reiterated a recommendation from the second CSAG report in 1995 which stated:

> "That, as a quality measure, events when a baby (or mother) is transferred inappropriately, are recorded and a goal of reducing such journeys to 10% of all transfers is set".

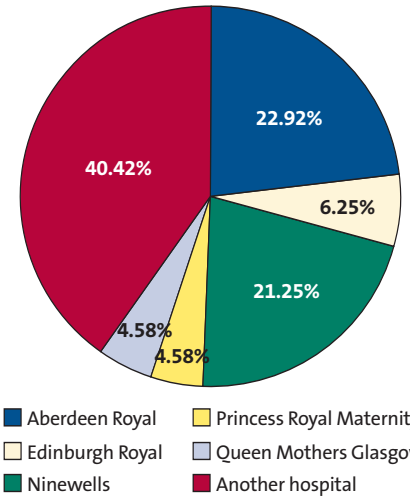

FIGURE 1 Transfer destination.

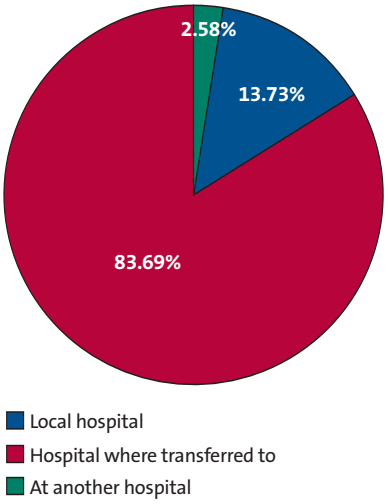

FIGURE 2 Place of birth.

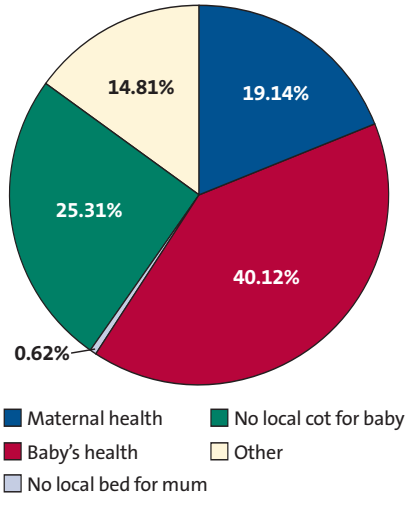

FIGURE 3 Reason for *in utero* transfer.

Evidence from other parts of the UK suggests that most major perinatal centres in the UK are regularly unable to meet demand due to a lack of neonatal cots[3-5].

Aim

The primary aim was to assess the financial, social and emotional consequences experienced by families who had experienced an IUT using a structured questionnaire administered 6-8 months after the event.

Methods

A formatted questionnaire, with subsections relevant to the mother, father and other family members was used to collect data. Most questions utilised a Likert-like scale to categorise subjective data. Questionnaires were posted to women who had experienced an IUT in Scotland between August 2006 and February 2007. Contact was initiated 6-8 months following the IUT, if deemed appropriate by the family General Practitioner (GP), to ensure there was no reason that would render clinical research inappropriate. This time interval was deliberate, aiming to allow sufficient time for reflective responses, as opposed to anxiety that may be expected to predominate immediately following an IUT. Families were contacted regardless of whether the IUT resulted in delivery at a geographically distant hospital or otherwise and irrespective of whether the infant or mother survived to hospital discharge. SPSS v15.0 was utilised for data analysis.

Results

Following consultation with the family GP, of the 559 IUTs which occurred during the study period, 530 (95%) families were sent questionnaires by post. The response rate was 45%. Respondents did not statistically differ from non-respondents with regard to the frequency of premature delivery, maternal outcomes, infant outcomes or whether delivery occurred within 48 hours of the IUT (all $p>0.05$, χ^2-test).

The transfer

The majority of IUTs were by ambulance (74%) with a further 10% air transfers. The destination hospitals are illustrated in **FIGURE 1**. The majority of deliveries occurred at the destination hospital (**FIGURE 2**) with an admission duration <7 days in 80% of cases.

Reason for transfer

Three factors accounted for 85% of IUTs (**FIGURE 3**):

- concerns over fetal health (40.1%)
- a lack of cot availability for baby (25.3%)
- maternal obstetric complications (19.1%)

Eighty-eight per cent of women indicated that they believed that transfer to another hospital was in their best interests for a successful pregnancy outcome.

Effect of transfer on the pregnant woman

Seventy per cent of women were informed in advance that a transfer was likely and 98% of women received an explanation why transfer was indicated. Fifty-five per cent of women felt socially isolated at the destination hospital and 34% felt let down by their local hospital. Twenty per cent reported family difficulties as a consequence of the transfer, primarily with their partner (41%) or with their children (30%).

Effect of transfer on other children and other dependents

Thirty-four per cent of mothers had other children at the time of the IUT. Of these, 65% had one other child, 24% two others, with the remainder having more than two other children. Of those with other children, 20% reported childcare difficulties. Ten per cent of women transferred also had responsibilities for other dependents (elderly relatives, disabled family members).

Effect of transfer on partners

Forty eight per cent of partners travelled to the destination hospital: 62% travelled by private car, 24% by ambulance, with others using alternative transport. Most partners visited the destination hospital on a daily basis (69%), with 90% visiting at least twice-weekly; 39% of families reported travel difficulties.

Effect of transfer on employment

Eighty five per cent of partners were in current employment. Of these, 20% reported difficulties obtaining leave to visit hospital.

Accommodation

Twenty per cent of families stayed in accommodation near the destination hospital. Of these, 34% stayed in hospital rooms, 25% with relatives or friends and 18% in a hotel. Fifteen per cent reported difficulties in finding local accommodation. Fifty-six per cent of all respondents indicated that accommodation near the destination hospital would have been beneficial and eased some of the distress at the time of transfer.

Financial difficulties

Twenty-eight per cent reported financial difficulties related to the IUT. Forty per cent indicated that financial support at this time period would have been welcomed. Financial difficulties correlated with partner employment status ($r=0.3$, $p<0.001$), childcare difficulties ($r=0.17$, $p=0.01$), travel difficulties ($r=0.41$, $p<0.0001$), accommodation problems ($r=0.26$, $p<0.001$) and duration of hospital admission ($r=0.14$, $p=0.03$). Binary logistic regression identified partner employment status [$p<0.001$, $Exp(\beta)=15.7$], childcare difficulties [$p<0.001$, $Exp(\beta)=13.5$], accommodation problems [$p=0.02$, $Exp(\beta)=5.9$] and admission duration [$p=0.04$, $Exp(\beta)=1.1$] as independent predictors of financial problems in descending order of importance.

Duration of time spent at the transfer destination hospital

A longer in-patient admission for the expectant mother at the destination hospital appeared detrimental, being correlated with financial ($r=0.21$, $p=0.001$) and accommodation ($r=0.21$, $p=0.002$) difficulties, as well as with increasing maternal social isolation ($r=0.22$, $p=0.001$).

Comments from mothers and families

The questionnaire allowed free text entries and families used this opportunity to describe their experience of IUT and the effects on their families in their own words. A selection of these comments is displayed in **FIGURE 4**.

"My family had to travel 100 miles to see me"

"...husband spent £800.... parents spent £1300.... other family spent £2100.... I have no idea how much was spent on food/buses/taxis"

"....absolutely appalling that my husband had to make his way back to **** at 3am.... I felt terribly alone, vulnerable and scared.... essential for accommodation.... I am still very emotional about the whole event"

"Hospital accommodation would have been good for me and my family as I was discharged before my baby"

"Hospitals should have rooms for parents to stay, especially when they did not have a choice in the matter of being there in the first place"

"It is a traumatic experience as it is, finding out you are being moved away from familiar surroundings, without having to go through it alone and worrying about my partner when all the time he could have been beside me. It need not have been so traumatic"

FIGURE 4 Comments from mothers and families.

Conclusions

Centralisation of specialised obstetric and neonatal services creates the requirement for an IUT. National guidelines have now been developed to guide clinicians involved in organising IUTs[6]. However, the psychosocial impact of an IUT upon the immediate family is often overlooked and the findings illustrate the need for better support systems, resource planning and perhaps local accommodation for families displaced by an IUT. The present study has also identified factors which should assist in identifying those women and their families for whom additional assistance may be of benefit.

Guidelines exist for designing new neonatal units in the new millennium[8]. These do not take account of the provision of accommodation and additional social requirements to support women and their families when displaced following an IUT.

A significant proportion of women who experience an IUT in Scotland do so due to a lack of local neonatal cots, in contravention to the CSAG clinical standards[1]. Local neonatal cot availability is dependent on two major factors: cot space within the local neonatal ICU to accommodate the infant and an adequate complement of neonatal nursing staff to care for the neonate in the postnatal period. Neonatal nurse staffing levels are often insufficient to cover local cot numbers in NHS Scotland[8]. Careful planning of neonatal staffing and services is required to minimise the adverse socio-economic consequences for pregnant women and their families that are associated with inappropriate IUTs.

References

1. **CSAG**. Neonatal intensive care: access to and availability of specialist services. Clinical Standards Advisory Group. 1993.
2. **CSAG**. Neonatal intensive care: access to and availability of specialist services. Clinical Standards Advisory Group. 1995.
3. **Cusack J, Field D, Manktelow B.** Impact of service changes on neonatal transfer patterns over 10 years. *Arch Dis Child Fetal Neonatal Ed.* 2007;**92**: 181-84.
4. **Gill A.B., Bottomley L., Chatfield S., Wood C.** Perinatal transport: problems in neonatal intensive care capacity. *Arch Dis Child Fetal Neonatal Ed.* 2004; **89**(3):F220-23.
5. **Parmanum J., Field D., Rennie J., Steer P.** National census of availability of neonatal intensive care. British Association for Perinatal Medicine. *BMJ* 2000; **321**(7263): 727-29.
6. **Fenton A, Peebles D, Ahluwalia J.** Management of acute *in utero* transfers: a framework for practice. Report for the British Association of Perinatal Medicine. June 2008. BAPM website.
7. **Laing I., Ducker T., Leaf A., Newmarch P.** Designing a Neonatal Unit. Report for the British Association of Perinatal Medicine. May 2004. BAPM website.
8. **Bliss.** Small babies, short changed? Are we ensuring the best start for babies born too soon in Scotland? The Bliss Baby Report 2007 – Scottish edition. 2007.