Transferring babies between units: Issues for parents

This article is based on some material from a research study – *Foretelling Futures: Dilemmas in Neonatal Neurology*, funded by the Wellcome Trust Bioethics Programme (Grant Number 066458). It is a social science research project in four NICUs exploring how practitioners and parents share information and care of the babies. One of the issues arising from the study concerned parents' emotional experiences when their baby was transferred to another NICU or special care unit, which was the case for 31% of babies in the sample. It is suggested that neonatal networks draw up a care plan with contributions from parents and staff about the parents' and babies' psychological as well as medical needs around transfer to another unit.

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Key points

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1. Parents in neonatal units are distressed when their baby is transferred to another hospital.
2. Parents in neonatal units can also be upset when their baby is moved within the unit or the hospital.
3. Careful preparation needs to be made for the transfer, sharing information with the parents about their baby.
4. Neonatal networks need to design a transfer plan incorporating the parents' and babies' emotional needs.

Neonatal units are currently being organised into neonatal networks comprising a range of units providing different levels of care. In a recent report for BLISS[1], it was found that almost three-quarters of neonatal units had to turn babies away at some time in the last six months, as there were not sufficient cots with enough specialist nurses available. The service was overstretched and under-resourced. Nearly all units said they took on more babies than they thought was reasonable for their staff levels. From one in eight babies born prematurely in the UK and Ireland each year, about 17,000 need intensive care[2].

There are many pressures on neonatal units to use the cots provided. Babies are often transferred between units due to shortage of a fully staffed cot[1]. In one article based on work done in 2000, 254 babies were transferred out of a NICU in a 6 month period[3].

The Foretelling Futures research project investigated the views and experiences of staff and parents about sharing information and the care of babies who have uncertain neurodevelopmental futures in four NICUs. The aim of the study was to discover more about fairly new cross-disciplinary developments and the views of neonatal staff and parents, in order to provide coherent research-based information intended to help to raise standards of care and information-sharing in baby units everywhere. Tape recorded, semi-structured interviews took place with 40 senior neonatal staff and with parents of 80 babies who had confirmed or potential neurodevelopmental problems. Parents of 15 babies were interviewed when the child was 4-6 years old. Parents of the remaining 65 babies were interviewed in the NICU and up to six months later at home. The data included detailed studies of babies' responses. There were six multidisciplinary advisory group meetings, and ethnographic observations in four NICUs in the south of England[4].

This article describes one of the issues for parents arising from the study – transferring babies between units postnatally. Twenty babies (31%) in the sample of 65 babies were transferred between units.

Separations and loss

When considering the issue of transferring babies, it is helpful to think about it in terms of a separation and loss, in order to understand its meaning for parents. Parents whose baby is in neonatal intensive care or special care experience many periods of separation and loss. Ian Woodroffe, Neonatal Unit Counsellor, in a lecture at the Rosie Hospital, described the multiple losses parents in neonatal units may have experienced before they come into a neonatal unit[5]. They may have had previous miscarriages, stillbirths, neonatal deaths, and with a premature birth, they have lost a few months of their pregnancy, missing out on the emotional and practical preparation for their baby's arrival.

Having a premature or ill baby in a neonatal unit is a loss of their anticipated positive experience.

Other kinds of separation and loss occur while the baby is in the neonatal unit. The parents may feel they have lost control in the new environment of the neonatal unit; they try to understand and work out what everything means, from the monitors to staff routines, to the medical diagnosis. After some weeks, they become quite knowledgeable about life in the neonatal unit, and feel more secure. Because parents have experienced the traumatic events of a premature birth, or an ill baby, they become extremely sensitive to their surroundings and any changes that take place. They hold steadfastly on to what they know, so any move can cause a great deal of emotional turmoil.

Even a move within the hospital can be upsetting for parents. This might happen when their baby is moved to another part of the room or another room, without notice, a move from intensive care to special care, or being taken to a test in another part of the hospital. If the baby has been moved to another part of the room unexpectedly, parents fear that their baby might have died. More planned changes like being transferred to the paediatric ward or to another hospital can raise anxieties, which may be alleviated by visiting the new place prior to the baby being transferred, but can still be stressful. It is instinctive for parents to be fiercely protective of their baby, and it takes time for them to develop trust in the staff who are looking after their baby. By moving elsewhere, parents are losing the staff who know their baby well, and in whose expertise they have developed a great deal of trust.

One father said:

'These people (the staff) were the parents at that moment in time, I was merely an observer.'

The interviews from this project highlighted the fact that parents can be seen as contributors to knowledge about their baby, not just as learners, and therefore can work together with the staff. Many parents described their baby's personality and behaviour in detail. Although they may not feel like experts in the medical setting of the neonatal unit, their emotional investment in their relationship with their baby, and their observations of their baby, make them experts about their own child.

Parents' feelings about moving the baby within the hospital

When a baby is tranferred from intensive care to special care in the same hospital, although there is relief that the baby is improving, this transfer can still be upsetting. Moving can signify loss and gain:

'It was very traumatic moving from intensive care to special care. It is just that transition. You are so happy until you end up in special care, and you feel out of sorts. Your child isn't getting as much attention any more, all that attention from one nurse. You don't realise you are just so looking forward to getting out of intensive care, and everybody has told you how great special care is, and you just don't feel the nurses in special care are as adequate as the nurses in intensive care.'

Transfer home can be very exciting but the thought of going home, though wished for, can also be alarming:

'I was just watching the doors; because you know they go closer to the door, as they get better they get closer to the front door. It's like nursery F is right next to the end, where the exit is, so I was like watching.'

Actually going home from the unit with the baby can be an anxious time, and is another loss for the parents. They lose the staff who become like a family to them, and often the hospital has been their baby's home for weeks:

'She was…our baby, but not ours. So she was…she felt like the hospital's baby, even after we felt that, because the community support was there. I mean… I've seen other babies in our family where mum and dad decides everything but I have to call the unit to do…to give her a little Gaviscon or, you know just…every little thing, I was so cautious.'

'It was…quite scary when first at home. In the unit, we had to ask permission to do things for Frank, and then at home, it's weird because he's completely ours. In the unit we were his parents, and we didn't need help with the nappies, but we felt we did need it!'

Baby's feelings

Any kind of change in their baby's 'place' is difficult for parents, and it may also be difficult for the babies. Parents in this project discussed their concerns about the way their baby was feeling or was handled by staff. It is often the case that a baby may be handled by a large number of staff. In a study in a Toronto nursery, during a stay of 49 days, a baby was attended by an average of 71 different nurses[6]. Babies are sensitive to the feelings of their parents, and if the parents are stressed and anxious, the babies are likely to sense it[7]. Some parents felt that moving the baby was detrimental to the baby's wellbeing:

'I was like oh right, you know, yeah, then trying to see all the good things about moving, but I wish I'd never ever done it, I wish I'd stuck to me guns and said no. I think from her point of view, she'd have been off oxygen a long time ago, a lot sooner.'

Parents' feelings around transfer of the baby to another unit

Babies are transferred to other units for various reasons: for treatment, due to lack of beds, or to a unit nearer home. Although moving a baby to a unit close to home can be beneficial for the parents in terms of distance and cost, this project highlighted the distress that some parents experienced when their baby was transferred to another unit, and the need for special preparations for this transfer, other than medical. If the baby was transferred to a hospital far from home, it was a great strain on the family for many reasons, one being their removal from their social support system. Some fathers described how torn they felt between being with their partner, or with the baby who was transferred to another hospital. In order to free up cots, in one unit the practice was to transfer babies to another hospital even though they were booked and born at the first hospital. This was emotionally upsetting, and often confusing for parents.

Parents often expressed some anxieties when told their baby was going to be transferred to another unit, sometimes with very short notice:

'They know all the history, it's not going like going back to the local unit, and they're messing it all up, and they might want to carry out more tests. Are they going to be saying different things to what they say here? You know, that she's been cared for twenty-four hours a day, and they've done everything that they can.'

'I'm not sure of the liaison between

here and the local unit. Another reason why I chose to stay here, and not go back to the local unit after last night, is that this is one of the leading teaching hospitals, and although my local unit care for me, I've got no problems with them. I'd rather have follow-up long term, or however long it's going to be, to be carried on here.'

Several parents felt that things were very different between units in all kinds of ways, and they took time to develop trust in the staff in the new unit. Two parents were interviewed together and said:

Father: 'We felt we'd come from a five star hotel, you know, to a B&B'
Mother: 'I think actually those two days were the worst days out of the whole experience, because we felt we were in a new place and...
Father: 'We don't know anybody, and they don't know who we are and…
Mother: 'We felt completely stressed out.
Father: 'and you don't really want to go home, because we thought, what is going to happen? When we come back in the evening, something drastic might have happened, 'cos it seemed as though somebody wasn't paying attention.'

'It was a them and us type of thing, whereas here [in this unit] you're all working towards the aim of getting the baby better, and yes, the baby is your baby and they are looking after him for you, whereas there [in the other unit], I felt that it was their baby really, and they would decide what was being done, with no communication.'

'There was one nurse assigned to his care there, nice to talk to one person about him. The staff are in different uniforms here…wonder if they know what they are doing?'

As previous examples have shown, parents grew to know their baby's likes and dislikes and the kind of handling and treatment they were having. However, some parents felt their observations and knowledge about their baby was not acknowledged in the unit they were transferred to:

'I remember with the…second day she was there or something, and they done a ward round and I was allowed there because she was in a room on her own, and they was asking questions about my baby, and was asking a nurse who had been there…for a couple of hours that morning, who obviously did not know her, so I was answering all the questions, and like the way they looked at me was like…who are you?…Once I'd done that, made that mistake…every time I said something they saw it as me comparing hospitals rather than saying what my baby had liked and was used to….'

Some parents realised they had no choice about their baby being transferred to another unit, and tried to think positively about it:

'I mean in a way, we're trying to feel it was a positive step, in that he was stable enough to be moved, so that he'd reached that rung on the ladder, but I think deep down, we both just sort of thought, ooh we don't want him to go…. somewhere new where we don't know, and will it be as good, and will they be as nice. Because you know, you sort of get used to everybody here, and I mean, we have nothing but praise for here, because for us it's just fantastic, you know.'

These quotations are examples of the kinds of feelings parents have in dealing with the work they need to do in gaining parental control and maintaining contact after separation from their baby. They show the parents' need for security and emotional support, so that they can parent their baby. It is also worth considering how the baby feels about being transferred to another unit, and the baby's responses to different staff and handling, and to parents' anxieties.

Conclusions and recommendations

Neonatal units could benefit from transfer planning that incorporates the parents' and babies' voices about their emotional needs for this transition. It is clear that information needs to be shared, and emotional support provided. Staff might find that learning about the baby from the parents helps to develop a better relationship between staff and parents. This in turn would help parents feel more confident and supported during this transition.

It would be beneficial to design a joint parents and staff care plan that covers feeding, timing and pacing of care, and the baby's preferences for touching, holding, positioning, light and noise (such as the NIDCAP)[8]. Sharing information in this way promotes a positive staff-parent relationship through respecting the parents' knowledge and observations of their baby. The NHS Neonatal Discharge Plan sheet does not provide behavioural information about the baby, such as the baby's likes and dislikes, any comments by the parents about their baby, or any comments on the psychological needs of the mother, father, baby and family.

Staff are under enormous pressures around the logistical issues of transferring babies, and neonatal networks[9] are aware of many of these issues, and are organising their approach to the difficulties they face. It seems that one of the important tasks of neonatal networks is to design the Discharge Plan sheet with the parents' and babies' psychological needs in mind. Also, the problem of staff shortages is ongoing and it is vital that these issues be addressed by hospitals.

Judging from some of the information gathered, parents of babies who are transferred into another unit may need to be treated differently from parents and babies admitted to the neonatal unit directly from the labour ward. Some parents expressed a need to talk to a consultant, which did not always happen if their baby was admitted to the special care unit from another hospital. Parents need to feel included, and valued for their observations of their baby's behaviour in response to his or her care.

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