Eliciting parental views regarding early discharge to home care for premature infants

Preterm infants are preverbal and cannot suggest improvements in healthcare provision and must rely on parents to be their 'voice'. This article describes how seeking parents' views in a local unit in the South West England led to changes in service provision.

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Key points

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1. Patients/users should be involved with improvements in healthcare services.
2. Patient Advice and Liaison Service (PALS) and Patient and Public Involvement (PPI) forums facilitate user involvement.
3. A collaborative practice development project was commenced as a result of canvassing parental views.
4. Local parents positively support an early discharge to home care.

A major element of the NHS Plan[1] is that patients/users are involved with improvements in healthcare services. This article describes how the results of local parent's views through the Patient Advice and Liaison Service (PALS) forum led to a collaborative practice development project between neonatal staff at an acute hospital in the south west of England and the Practice Development Centre of a local university. Obtaining parental views in the first instance presented an opportunity to engage parents positively in service improvement[2] and opened a possibility for the neonatal unit to do things differently. This would entail designing future service needs which would be delivered holistically around an infant's requirements rather than just focusing on illness or problems[3].

Background to PALS

PALS, a service developed in most NHS healthcare providers in England[4] aims to provide a means through which user voices will lead to changes in service provision and organisational culture[5]. In 2003 local patient and public involvement (PPI) forums[5] were developed, with the purpose of ensuring that public services became more receptive to patients and carers[6]. Despite some criticisms of PPI being separated from mechanisms to improve services and health outcomes[6], the system does offer an opportunity and a mechanism to involve unrepresented individuals, in this case the parents of premature infants[7].

Parents themselves find it problematic to be advocates for their infant in the hospital environment and although this issue is much highlighted in the literature, actual complaints from parents about neonatal care appears less than within other healthcare areas[8]. Research by Gavey (2007) into parental perceptions of neonatal care discusses how parents were appreciative of the care their infants received but were unwilling to criticise healthcare provision. Premature infants are reliant on their parents to be their advocate in relation to services and healthcare provision[9], and it is imperative that their needs are taken into consideration when setting and assessing standards of care[10]. Healthcare professionals and service providers have a duty of care to hear and respect premature babies' voices through their parents[10].

Parents' experiences of their infants' journey through neonatal care facilitated through the PPI forum, provides an opportunity to discuss issues, both positively and negatively. Furthermore it enables healthcare professionals to view an experience that may be unknown[2], as well as ensuring that organisations change as a response to patient experiences[11]. However, engaging users just for their views is not sufficient; PPI needs to be seen as a real opportunity to provide meaningful engagement for improvement of services[2]. In the author's local area the views of parents about the potential for early discharge for their premature baby was largely unknown, therefore it was considered important in the first instance to identify their opinions so as to base future service provision on these as far as possible.

Literature review around early discharge

A literature review was carried out prior to seeking the views of local parents, which established that it is possible to discharge premature infants early, providing they are physiologically stable with targeted community follow-up to prevent re-hospitalisation[12-14]. Included within an early discharge criteria should be the family's willingness to take their preterm infants home earlier[12,15] and their readiness to provide capable care in the home[16].

Implementation of developmental care, infant massage, kangaroo mother care and the endorsement of breast milk with appropriate nutritional supplementation have been shown to improve infant outcomes which in turn contributes to shorter hospital stays[13]. However length of stay in hospital is also dependent on each individual service provider's organisation of neonatal care and the provision of home care support[17].

In California it has been established that moderately preterm infants cared for in neonatal units were discharged earlier than their equivalents in the UK, although a unit based in Cambridge (UK) describes their age of infant discharge as being similar to the Californian cohort[18,19]. What appears to be a strong factor in facilitating an earlier and safe discharge of infants to home care is the provision of a community neonatal service[13,19].

In the UK it has been highlighted that there appears to be no reliable description of what constitutes a community neonatal service and provision of this service is at best inconsistent, although families have access to primary healthcare services[20,21]. It is commonly known that parents are often unaware of what support is available in the community and how to access it[22]. In the preterm population specialised support from neonatal nurses is essential[14,21] since an earlier transition to home care has long-term benefits for the whole family[13].

Merritt et al (2003) describe how drawn-out hospitalisation stays have demonstrated poor parent-infant interactions, failure to thrive, child abuse/abandonment and parents who grieve for the loss of a 'normal term' infant. Although neonatal units are able to care for premature infants with extensive technology and highly skilled staff [13], many infants are often only moderately preterm and healthy, and may simply require the availability, but not make use of intensive therapy[23]. Parents who commence parenthood within highly technical environments which result in prolonged hospital stays for their infant, experience major disruption to their family routines and parenting abilities following discharge[24]. Therefore infants wherever possible, should be cared for within their family unit[25]. Neonatal care that empowers full parental involvement and participation in their infants' ongoing care, thorough preparation for discharge and home support following discharge, appears to set the scene for an early discharge from the NICU[13].

The PPI project

Having established a sound evidence base for early discharge home the next step was to obtain the views of local parents. It was deemed important to elicit parental perspectives first, to ensure that they felt fully involved and that this was indeed what they wanted. Thus an application seeking the views of parents was submitted to the local PALS department. It was anticipated that this would create an opportunity for local parents to represent their premature infants and have a say in options about future service needs[2], and an opportunity for neonatal staff and PALS to collaborate[9].

Meetings with parents usually commenced with a question asking parents to describe how they were finding parenthood following discharge from the local neonatal unit. This was to help put the parents at ease, and during the sessions various aspects of their stories were explored by the author. Parents were already aware from an information pack provided prior to meeting up that their views were being sought on an early discharge and if the service were available to them would they have been interested in going home early? Thus these PPI sessions provided a potential mechanism for change as seen from a parental perspective[26], but only if parents felt that local provision of neonatal care was 'wanting' in some areas. Their stories were tape recordered so the author could check her notes for accuracy and the transcribed narratives were sent back to each family for comments and to confirm accuracy of reporting.

Outcomes from the PPI sessions

Generalisation of findings from the parents' stories to the whole population of parents of premature babies across the UK was not the purpose of the PPI project; however the overwhelming response of these parents was in favour of an early discharge to home care. The author when transcribing the stories began to be aware that a number of themes were common to all the parents and these centred around:

- Parents' views on early discharge
- Mothering in NICU
- Length of stay

In the following sections their comments are used to illustrate and describe why they felt an early discharge to homecare would be beneficial.

Parents views on early discharge

Parents would have liked to have taken their baby home sooner if this had been possible.

> "I have to say I couldn't wait to bring my babies home" – Val*
>
> *(*names changed to protect identity)*
>
> "My babies did not fit into the criteria for going home early due to one of the twins still being dependent on oxygen. However if I had had an opportunity to take them home earlier I would have jumped at it" – Meridy*
>
> "We kept on saying to the staff on neonatal unit that it was only Gray's feeding that was stopping him from going home, everything else was fine apart from his jaundice which kept on fluctuating a bit. We kept asking surely we could take him home as he was well?" – Rose and Peter*

The above three extracts strongly support the parents' desire to have their infant home earlier than the 'traditional' time as specified and dictated by some neonatal units. This need to have their premature infant home was further compounded by the practical stresses of having an infant being unnecessarily (in their minds) resident in the neonatal unit, since having to travel in and out of hospital several times per day was wearisome. Val explained how her twins were hospitalised for three weeks and for two of those weeks there were no major problems, as during this time her babies just needed to establish feeding. Constantly travelling into hospital each day was stressful and tiring. This is intensified by the competing demands of family life[27].

Hospital stays for well or moderately premature infants that are prolonged interrupt family routines and delay family adjustment[13] as the following excerpts demonstrate.

> "We did not stay all day as we needed to go home in-between coming into

> hospital as we still had the ongoing responsibilities of keeping the family home maintained i.e. shopping washing etc. It felt like we were only at home to eat and sleep. We did not want to leave our baby whilst he was in hospital but felt we had to go home" – Rose and Peter

> "During the eight weeks of our baby's stay in hospital my husband and I did find it difficult travelling back and forth, because we were mindful of our other child who was only six years of age at the time and we tried to maintain a sense of normality for his sake" – Beryl*

Some parents revealed feeling guilty at not going back to hospital because chores at home tired them out, thus reducing time which could have been spent with their baby.

> "You go in every day but you still feel guilty that someone else is taking care of your babies for you even though it's not your fault" – Val

Mothering in NICU

The journey to becoming a mother begins during pregnancy and women embarking on motherhood face many challenges. These range from a change of role from being a non-parent with responsibilities to oneself (and perhaps a partner)[28], to a transition to caring for a new infant and acquiring mothering skills[29]. However, mothers whose infant is born prematurely are often mentally and physically unprepared for motherhood[29], and in many instances admission into a neonatal unit is unexpected with minimal time to adjust[28]. These issues are further complicated by having to establish mothering in an unfamiliar and intimidating environment of the neonatal intensive care unit (NICU)[30,31].

> "I felt at times that I had to ask permission to change my baby's nappy or check that it required changing although I understood that it was to protect Gray from too much 'messing about'. I did not feel that myself or my husband could open the incubator and take Gray out. We had to wait for a nurse to say "oh, you going to have a cuddle?" – Rose and Peter

Neonatal literature further reveals that parents' participation is often limited by healthcare professionals deciding on how much contact parents can have with their premature infant[28,32].

> "In terms of being in control – I think it was more that mostly we weren't said "no" to when we asked to do things, but some members of staff would suggest things to us or say we didn't need to ask, whereas others would only offer when we expressly asked"– Meridy

The following extract obtained from Beryl shows how premature birth and admission to a neonatal unit can have the effect of dehumanising an infants' birth and distancing Beryl from her role as a mother[33].

> "When I was taken up to the neonatal unit following an emergency caesarean section for raised blood pressure to visit my daughter for the first time, I felt very emotional and terrified as I had not seen a baby that small before…. My first impression of her was as 'a tiny red thing' – Beryl

Describing one's infant daughter as 'a thing' speaks for itself. Parents and especially mothers who have experienced a preterm birth have to cope with major changes in their expectations (perceived nice cuddly term baby: in reality a 'thing') and way of life (infant in hospital with a prolonged stay), different from what was anticipated as 'normal' parenting[22]. Infants as objects with mothers feeling isolated and not attached to their newborn premature child have been discussed in an insightful article[28].

The basis of motherhood not only centres on the ability of a mother to create strong nurturing bonds with her infant but also securing her child's future survival by either breast or bottle feeding[28]. Breastfeeding a premature infant remains challenging and studies depicting breastfeeding intentions when the infant is born prematurely suggest lower rates of initiation than those infants born at term[34]. The World Health Organisation (WHO), UNICEF, and DH (including vast published resources) recommend breastfeeding premature and term infants from birth until at least six months of age, and although it is generally accepted that 'breast is best', circumstances within neonatal units make breastfeeding more problematic for mothers of premature infants[35].

> "At around 34 weeks my babies were at the stage of feeding and growing although one of the twins was still dependent on oxygen. I was breastfeeding and I felt particularly sensitive around the issue of 'topping up' and it upset me when my babies were topped up with formula milk through tube feeds. It made me feel inadequate and a failure for not being able to provide enough milk for my babies. This added to the feelings of guilt that I was already experiencing" – Meridy

The importance of the mother-infant relationship to their infants' long term developmental outcome has been described by Davis, Mohay and Edwards (2003) in their paper looking at historical involvement of mothers in caring for their premature infants. The article provides neonatal staff with an insight into how far parent and infant care has evolved over the years and suggests this knowledge can be used to plan for future neonatal service provision[36]. The difficulties mothers have in establishing a feeling of motherhood towards their hospitalised premature infant is not in doubt[30,31,37], and advocating an early discharge to supported home care can help alleviate some of the issues already discussed.

Length of stay

Once parents are aware that their infant is going to survive, they increasingly start to focus on length of stay and a possible date of discharge[23]. It is probably the period where preterm infants are physiologically stable but still require extra care such as naso-gastric tube (NGT) feeding that parents find most frustrating as this transition between methods of feeding can range from one to several weeks[38]. Although the literature counsels healthcare professionals to support parents to be patient during this period of transition[38] the following quotes highlight the frustrations of waiting.

> "The phase that premature babies go through when they are catching up (feeding and growing) is frustrating for us as parents because we are just waiting for our baby to catch up and it can be a very slow and long slog"– Meridy

> "When I was told I couldn't bring them home until term I was mortified because that was two months down the road and no way did I want to wait that long" – Val

The last few days/weeks of hospitalisation for many well premature infants are typically of low acuity in terms of care delivered by healthcare professionals, and may be provided in the infant's home where parents are in their natural environment[23,38]. Planning for discharge needs to start early on by involving parents in all aspects of their infant's care needs[14,15], so that when the infant is finally ready to be discharged parents are more than capable of providing care at home. Many neonatal units have embraced parental participation and promote family-centred care as a philosophy[32] and this is supported by most of the mothers in their stories.

> "My husband and I were fully involved in the care of our babies and felt able to question and challenge decisions" – Meridy

> "The care and support from the neonatal staff was fantastic, and without this support I would not have known what I was doing or how to care for my babies" – Val

> "During our baby's stay in the neonatal unit both myself and Peter were fully involved in our son's care and did most of the caring such as nappy changing and NGT feeds" – Rose and Peter

Although planning for discharge should commence on admission of an infant, a seamless process is not always evident where parents and healthcare professionals work together towards a shared objective: to secure discharge[39]. The following extract highlights conflicting messages for one family.

> "One member of staff indicated Christmas and another New Year for the discharge of Gray. We knew that it was only the feeding that was delaying his discharge and so we kept on asking if we could take him home tube feeding. We did not always feel involved in decisions about Gray's discharge despite us asking repeatedly if we could take him home. Just as we had resigned ourselves to being in hospital over Christmas we were suddenly told on the Monday (a week before Christmas) that *I could* room in that night with a view to going home either on Tuesday or Wednesday at the latest. This was very frustrating as now all of a sudden he's now allowed home!" – Rose and Peter

Identifying sources of potential delay in discharge for well premature infants present an opportunity to improve discharge practices and emphasises the need within neonatal units to initiate and provide a seamless discharge planning process[13].

Discussion

The information obtained from the PALS/PPI project did indeed clarify that parents in the author's local area supported the notion of an early discharge to home care with community support, which reflects the findings of the literature. As a result the project team initiated a pilot programme of early discharge based on parents' needs – a report of which will be published later.

Furthermore parents who were initially contacted were keen to participate and the following quotes obtained from email correspondence prior to meeting up confirm this.

> "I think that it would be a fantastic idea to start this sort of project. It would firstly relieve the special care room for more intensive care babies and also give the parents the opportunity to care for their babies sooner than expected with help, which to me sounds like a good plan" – Val

> "I would be happy to participate in an interview…. I hope my views and experiences can be useful for your project" – Meridy

This is seen as positive in view of an earlier statement which highlighted the reluctance of parents to criticise neonatal care. Val became one of the members on the project planning team and offered to be a support for any parent participating in the early discharge programme.

Conclusion

This article has aimed to highlight that user involvement in the evaluation of neonatal care provision in the author's local area via the PALS/PPI forum provided an ideal opportunity for service providers to receive constructive feedback about the care they offer[26], and to reconfigure services as a result of that feedback[2]. In this case an early discharge to home care seemed important to local parents. The immediate message is that neonatal care provision must promote the health and welfare of premature infants and that includes enhancing family relationships which infants wholly depend on[10]. Working collaboratively with parents around implementation of an 'intervention' such as early discharge with community support, contributes not only to the provision of clinical care and the development of services but also facilitates the return of infants to their rightful place – the family home[9,40].

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