

## **Parents' consent to neonatal decisions about feeding and discharge**

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### **Abstract**

English law requires health care practitioners to obtain parents' consent before all touching of their child. However, nurses tend to leave doctors to request parents' consent to intensive care interventions, and it is generally assumed that before parents can start to care for their baby, they need to have practitioners', mainly nurses', permission. This paper reviews examples of neonatal feeding and discharge decisions that illustrate how consent can be an undeveloped concept in nursing care. Through the sharing of information and medical decision making, the consent process involves implicit or explicit negotiation of anxiety, trust and risk. Decisions about neonatal feeding and discharge can also involve anxiety and risk, and it is suggested that, while avoiding legalistic formalities, more overt sharing of information and decisions about the options could be to the advantage of nurses, babies and parents.

**key words:** decision making, ethics, neonatal nurses, information, law, care

### **Key points**

- 1 Negotiating consent with parents was not a routine part of the nursing care observed in four neonatal units.
- 2 Parents tended to have clearer knowledge and views about matters such as feeding and discharge, than they did about the major medical decisions they were asked to consent to, and many parents wanted to be more involved in making these kinds of care decisions.
- 3 While avoiding legalistic formalities, more overt sharing of information, anxiety, risk and decisions could be to the advantage of nurses, babies and parents.

## INTRODUCTION

There are growing medico-legal pressures on health care practitioners to inform and involve patients or parents, and obtain their consent to all interventions. This paper discusses the part nurses play and could play in neonatal consent processes. The paper briefly reviews policy and practice on consent and on neonatal feeding, then explains the research, presents two case study examples, discusses the relevance of parents' consent to nursing decisions and finally considers the policy implications. The consent literature is mainly about major and medical decisions. Feeding and discharge decisions are reviewed here because they especially clearly relate to nurses and parents, and illustrate how they share information, decision making, responsibility, and practical care of the babies.

### Consent policies and practices

Definitions of consent to medical research (WMA, 2000) also apply to health care treatment and investigations. Consent involves understanding the problem that needs investigation or treatment, the nature and purpose of the intervention, the

risks, benefits, likely effects and any alternative interventions. The person concerned weighs the pros and cons of the proposed intervention and makes a choice, an informed and voluntary (unpressured) decision to give or withhold consent. Valid consent transfers legal responsibility for risks and harms from the practitioner to the patient/parent who consents to undertake them. The consent process also involves an emotional journey from patients'/parents' fear and anxiety, for example about proposed surgery, their hope and trust in the practitioners (Alderson, 1990), and this paper considers the importance of such emotions in consent to nursing care.

The Bristol Inquiry (Kennedy, 2001) and the European Court of Human Rights (ECHR, 2004; Bridgeman, 2005) have confirmed English law, that practitioners need parents' consent before 'any form of touching' of children except during emergencies (Kennedy 2001:440). Shenoy et al. (2003) warn that there will be 'drastic changes to incorporate legal and ethical requirements' in British neonatal intensive care units (NICU).

Despite nurses' constant touching of patients, Aveyard (2005) concludes that consent is an 'undeveloped concept' in nursing care. The UKCC Code (2004) mentions consent solely in relation to nurses passing on patients' information to third parties. Although the Nursing Midwifery Council Code (2002) requires nurses to 'obtain consent before you give any treatment or care' it does not explain what informed consent entails. One of numerous examples of the overlooking of patients'/parents' decisions and consent is a paper on 'Decision making in neonatal nursing: parental participation' (Abdullah, 2004), which is confined to nurses deciding how much to allow parents to participate in their child's care, a reversal of the legal principle of parental consent. Fenwick et al. (2000, 2003) and Lupton and Fenwick (2001) found that nurses relate to mothers primarily as teachers, also that mothers work hard to foster positive and permissive responses in the nurses (Fenwick et al., 2002). Numerous psychological papers assess mothers' stress and anxiety, and implicitly their vulnerable dependence, in ways that do not encourage nurses to treat mothers as responsible partners.

The emphasis in nursing on the ethic of care contrasts with the principle of respect and the ethic of justice that validate consent (Faden and Beauchamp, 1986), and proposes that 'many women – perhaps most women – do not approach moral problems as problems of principle, reasoning, and judgement' (Noddings, 1994:28). In a major work on nursing ethics, Chambliss criticises bioethics principles, 'respect for autonomy, non-maleficence, beneficence and justice', as unhelpfully rights-driven and legalistic, 'geared primarily to physicians. [Bioethics] is written for powerful people [doctors] who make decisions, not the powerless ones [nurses] who carry them out'. Ethical issues in nursing are not 'intellectual puzzles to be solved with the aid of clearly elaborated "principles"...they are a competition of people, who have various goals and methods...real problems in organisational action, constrained by legal, economic, social and personal peculiarities' (Chambliss, 1996:4-5, 118).

This paper considers four questions raised by this literature on ethics and nursing in relation to examples of neonatal decisions about feeding and discharge. Are neonatal nurses as powerless as Chambliss suggests? Might the ethic of care cloak a lack of justice and respect? Can neonatal decisions be made without 'principle, reasoning and judgement'? And how do competing goals and numerous structural constraints affect neonatal nurses' and parents' agency and decision making?

## Neonatal feeding

Research about methods of feeding premature babies emphasises both complexity and also uncertainty about major unanswered research questions. Breast milk produces enzymes, hormones, live cells, and immunoglobulins that constantly adapt to the baby's specific changing needs for nourishment and protection from infection (AAP., 1997). The brains of the premature baby and the term baby at 40 weeks post-conception are very different, partly due to the stress of being in the NICU (Inder, 2000), and possibly also due to: tube feeding ingestion; intolerance of foreign (cows' or soya) proteins; missing the hormonal interactions with the mother, the odours and skin contact of breast feeding that reduce stress and irritability and improve maternal infant interactions (Uauy and Peirano, 1999; Anderson et al., 2003); missing the 'ecology' of breastfeeding, the sensations of sucking, tasting and swallowing, hunger and then satisfaction, the baby being in a sense in charge, and being able to pause and stop; the associated neurochemistry that may affect behaviour, attention and learning with unknown long term effects (Smotherman and Robinson, 1994:64). Bartle (2002) found that about one third of premature babies had feeding intolerance - vomiting, abdominal distension, lethargy, unsettled behaviour or abnormal bowel movements, some were in pain and unwell. The intolerance appeared to be associated with formula feeds or fortifiers added to expressed breast milk (EBM). Fortifiers began to be added in 1980, but have not yet been rigorously compared with unfortified EBM. Although fortifiers are associated with short-term weight gain and head growth, the longer term benefits and risks are not known (McGuire et al., 2004; Kuschel and Harding, 2001). Ziegler (2001:721) warns that the composition of EBM varies so much that the risk of overloading babies with fortifiers may be unacceptable.

The varying breastfeeding success rates between NICUs, and within an NICU when specialist nurses are appointed, suggest that nurses can strongly influence these rates. Good nursing practice to promote breastfeeding includes providing early and continuing information and support for mothers with adequate space and equipment for expressing milk, encouraging skin-to-skin contact between mother and baby and early sucking on the breast before the baby is ready to feed, and avoiding bottle feeds (McGuire et al., 2004). A well-designed study of early enteral EBM feeding policy found that one NICU had a confident team and consistent use of a comprehensive feeding policy; the other was without a policy, leading to inconsistent disputed decisions and staff dissatisfaction (Holm, 2004). The paper also indicates nursing views of parents' participation, in that it identifies senior staff as the sole decision makers, without mentioning parents' views, although mothers might be seen as the main deciders about supplying breast milk and accepting donor milk.

## RESEARCH METHODS AND ANALYSIS

Examples in this paper are drawn from a study of four southern English NICUs 2002-2004. Ethnographic observations of how practitioners and parents share knowledge, decisions and responsibilities were conducted over 18 months (add author ref). With their consent, semi-structured tape-recorded interviews, encouraging detailed narrative accounts of personal views and experiences, were held with 40 senior practitioners, including 18 neonatal nurses. Interviews and informal conversations were also held with the parents (all the mothers, 16 fathers) of a purposive sample of 80 babies, who had confirmed or potential neuro-developmental problems and a range of medical conditions and socio-economic and ethnic backgrounds. Interviews lasted approximately one hour, with a maximum of 150 minutes. The research was

unusual in interviewing parents while they were in the NICU, as well as later at home, and in asking about their reasoning rather than their needs and feelings.

Observation notes and interview transcripts were analysed qualitatively for references to responses to the research questions, and for main themes raised by interviewees in order to develop an empirically grounded descriptive account (Strauss and Corbin, 1998). Transcripts and notes were systematically read and reread for references to themes (reported in a range of papers listed in [authors], 2004). The key theme for this paper is parents' share in decisions about their baby's feeding and discharge. Themes and patterns were noted in relation to each baby's whole neonatal experience, and for illuminating comparisons between different babies and parents, units and practitioners, by shifting between transcripts and observation records. To convey experiences in some detail, this paper concentrates on two cases, although it is informed by general themes observed and discussed with many parents and practitioners.

## FINDINGS

### Two types of information and decisions

In the four NICU, two main kinds of information and decisions affected parents.

1. Neonatologists tended to discuss major interventions and decisions with parents. Nurses supported anxious parents emotionally and helped them to clarify some misunderstandings, but usually recalled doctors if parents needed further information relating to medical decisions.
2. Nurses and junior doctors informed parents in detail about daily routines, mainly in terms of 'this is what we are doing and this is why we are doing it,' but seldom in terms of discussing options or requesting parents' consent.

This paper is mainly about nurses and parents relationships in high dependency and special care when parents tended to be more experienced and practically involved in their baby's care-giving but were less involved, than when in intensive care, in decision making, since consultants' visits and major decisions were less frequent.

### Social context

Parents were immensely grateful for their baby's survival and intensive care. Along the spectrum of types of parents and of nursing practices, many parents felt supported by the feeding and discharge policies, for example, the mother who did not breastfeed her first baby and was delighted after nurses persuaded and helped her to breastfeed her second, and premature, baby. However, Chambliss's points (1996:4-5) that ethics involves competing goals and methods, besides problems of organisation 'constrained by legal, economic, social and personal peculiarities', resonated with frequent dilemmas for nurses trying to promote breastfeeding and to time discharge. For weeks, nurses encouraged and supported mothers' efforts to express and breastfeed, while also aiming not to make them feel anxious and guilty if they failed. Poignantly, some mothers gave up trying just before their baby was ready to breastfeed, or after feeding was established, such as the mother who had to spend days queuing in the council housing office and found the stress too much.

The large, international, frequently changing nursing teams, with their diverse feelings, goals and methods about neonatal feeding, often gave contradictory or ambiguous information about the best type of milk, and timing and pacing of feeds. Rushed nurses might prefer tube to bottle feeding or would rotate the teat vigorously in each baby's mouth to hurry the feeds. Some nurses favoured formula feeds for

increasing weight gain and earlier discharge rates, many discouraged skin-to-skin holding.

Economic pressures include short maternity leave when mothers return to paid work while their baby is in the NICU so that they can take leave later when their baby is at home. Breastfeeding is adversely associated with poverty, and three of the NICU were in inner London where 52% of children live in poverty (Hood 2002). Stress can undermine efforts to breastfeed, and many parents had the extra stresses of being homeless, or asylum seekers, or far from supportive relatives.

Breastfeeding succeeds when mothers can rest, relax, and respond as much as possible to the baby's needs and timing. Yet flexible mothering by day does not fit with timed nursing by night or with other NICU routines, and so can seldom be fully encouraged. Resources could enhance or undermine nursing standards of care. In some but not all units there were curtained alcoves and comfortable armchairs arranged to provide some privacy, enough breast pumps and space in the expressing rooms, water coolers and nearby toilets for mothers to use to encourage them to increase their fluid intake in the hot dry units. One of the four NICU promoted close mother-baby contact by having four, later six, comfortable parents' double bed rooms, and an adjacent transitional ward for mothers to stay. Two others had only two parents' rooms and sometimes mothers slept in hospital corridors. There were exhausting daily journeys, care of other children at home, and little or no help with young visiting siblings. Some, though not all, of the special care areas were calm and supportive where nurses and parents sat in easy chairs, holding the babies for hours. When feeding and discharge progressed smoothly, the parents' views about decision making were seldom observed or discussed, whereas disagreements, like ink in a printer, could show up clearly the boundaries of the parents' part in deciding about care. Two cases of problems will therefore be given, that illustrate how these can arise through structures such as routines and protocols, rather than through individual nurses' agency.

#### Case study 1: Danny

Danny (babies' names have been changed) was born at 28 weeks and 1.04 kg. His young mother thought he might have been premature because she stood all day working as a hairdresser. He had surgery for abdominal problems that were still partly uncertain and unresolved over three months later. During the interview, he leaned against his mother, watching her face and she kept talking gently to him. He had moved a few times between intensive and high dependency care, and was usually in an incubator 'to keep him warm mainly', his mother said, when it was harder for her to keep close contact and to hold him frequently. She was worried that her partner, who had been so involved in her pregnancy, stayed away from the unit because he disliked being watched and instructed by nurses. She was anaemic, and despite painful postnatal problems had been 'sent home' the day after the birth, and had not had time to get medical help for herself. She gave up trying to express breast milk, because she felt too stressed and 'knackered' by long daily bus journeys, and she was assured that Danny would be on donor breast milk. However, Danny was given formula and his vomiting increased: 'you tell them and they don't like listen'. The discharge protocol was that babies must be on 4 hourly feeds before they could go home. (... denotes words omitted.)

Danny's mother: I don't know why, cos a normal baby aint fed every four hours. He does get hungry, but I think he's so used to not having food through

his mouth that he doesn't know that's what he's got to do, cry out for food, because when he's on the tube...every hour it pumps milk through to him...I've seen babies go home with feeding tubes, but I don't know why they won't let him come home on the tube. If you ask them, they say, 'Oh no no no no no.' You think, well why not? They say the reason is that until he's on 4 hourly feeds and demanding it there's nothing they can do.

When Danny managed 4 hourly feeds he seemed to feel bloated and in pain, and had gone back to 2 hourly feeds.

You can't rush him on the bottle...if you force him too much he's only going to keep throwing up... if he's not feeding properly he'll go back on a long line, which I don't want him to do that...If we was at home I would gradually let him feed... you don't sort of know his true pattern until he's home. They [the nurses] all do it differently here...Mmmm I don't know. [Laughs in a resigned way.] Don't knock them or anything, they've done a brilliant job but [pause] it's not their children is it, when it's your own you just want to go home...My health visitor lives round the corner from me, and she's always said she'll come round every day to see if he's all right.

#### Case study 2: Miranda

Miranda was born at 34 weeks by caesarean section, 2.60 Kg, because she had a large tumour for which she had surgery. Her parents, who both had successful careers, felt informed and involved in decisions. 'I'm really impressed with how willing the doctors and the nurses are to discuss...in intensive care.' Later at home, her parents, who had an older daughter, recalled her discharge, which was bound up with feeding decisions.

Miranda's mother: I remember having a few sort of fantasies about sort of snatching her out and putting her under my coat and just walking out...what she needed was to be at home...to be nurtured by us and that she would get better quicker and so I started to question why she was still in the unit...If I just got her home she'd be breastfeeding fine because I'd be with her all the time...you started to realise that you were sort of in a system where you didn't really have... you weren't being given the responsibility to make decisions about your baby and yet you were starting to want to question the ones that were being made, but they were not medical so much as more sort of...nursing...I didn't feel able to really assert my opinion at that point, I became really institutionalised, and also the doctors become more and more disengaged as you get further down the system... and the nurses don't seem to have so much of a dialogue with you, the nurses are more like the workers... you know, it's like you're in a hive or something...they're just doing their system of care, and your baby is in the system, and the dialogue previously has been really with the doctors.

Miranda's father: Yes, but the discharge, it needs to be, the support needs to be tested...not everyone has the same [good] support [at home] as we do.

A nurse had told them that if they tried to take Miranda home the police would be called, but a consultant listened to their views, 'liberated' them, and discharged Miranda on a Friday, against the nurses' view. Babies were not supposed to be sent

home before the weekend, when there are fewer staff on call in case of need. The policy ignores how fathers, relatives and friends are more likely to be available during weekends. Miranda's mother said, that the consultant was 'sort of placing her confidence in us so that we would be responsible parents and be able to cope with her for the weekend'. When Miranda was weighed in the NICU after three days at home, she had gained 90 grams.

Miranda's mother had wanted to see more practical support for breastfeeding and said she was never told about skin-to-skin care, and the unit had only upright chairs that were 'torture' to breast feed on. She felt that in special care there was a lack of comfort and 'of consideration of creating a sort of nurturing, stimulating environment for the babies [it] is still much too clinical and much too sort of industrial' like a 'factory', with people moving through impersonally in transition. There was 'some sort of unwritten code that you weren't supposed to interact with people' including other parents, so that 'everything's all bottled up' and inhibited. 'The nurses have their protocols [and] systems [whereas] things need to be more relaxed and flexible' and responsive, with 'constructive individual care when the babies are no longer ill'. She was especially upset by nurses who left babies to cry, and picked them up only at feeding times, and so dreaded leaving her baby with them. She wanted the special care nurses to be 'switched on emotionally' as the intensive care ones were. When interviewed in the special care room, Miranda's mother said, 'It must be incredibly stressful for the staff, giving bad news, and caring for the babies, and sometimes I haven't come up to the unit because I've been crying and I've been so upset, I didn't want to upset the staff.' She then became too distressed to speak, but wanted to continue, indicating how intensely 'minor' nursing details could matter to parents.

#### Summary of the parents' concerns

Danny's mother wanted to negotiate with the staff about: consistent care ('they all do it differently here'); keeping to agreed decisions, such as about EBM; the type of milk feed; the timing of feeds; slower pacing of feeds; managed transition from tube to bottle feeding; methods to 'wind' Danny (she spoke a lot about that) and relieve his pain; Danny's discharge date; the follow up nursing support at home.

Miranda's parents repeated some points made by Danny's mother and many other parents. They contrasted their 'dialogue' with the consultants, and trust ('placing her confidence in us'), with the nurses seeming like worker bees in a non-negotiable system. Special care nurses have less authority than intensive care ones, but they can still exert great influence over creating an 'industrial' or a calm, warm, nurturing ethos, and also in their feeding and discharge decisions, as shown by considerable contrasts between the special care nurseries we observed.

The three parents mentioned particular supports they had at home, which they believed should influence discharge decisions. They thought that over-rigid NICU systems undermined successful feeding and growth and delayed discharge, through problems that would only be resolved when babies could establish their 'true pattern' and thrive at home.

### DISCUSSION

This paper aims to contribute to debates about parents' consent to neonatal nursing practices by questioning current assumptions in nursing practice, noted or implied in the above literature review and case studies, and summarised in the following comments.

*Nurses are the experts in feeding and discharge decisions, which parents cannot sufficiently understand.* If parents can be involved in highly complex major medical decisions, they are likely to be able to share in routine, minor and nursing decisions about which they may be better informed. Current research knowledge of infant feeding is both so complex and, in many respects, so uncertain, that expertise includes being guided by very close knowledge and observation of the baby, in which parents tend to be most involved.

*Consent procedures are for powerful doctors who make decisions, not powerless nurses who carry them out* (Chambliss, 1996:4-5). Nurses can be powerful, far more so than parents or patients. Their power is shown in the very different kinds of 'industrial' or nurturing ethos they promote in special care, and when they create protocols, which are not simply agreed standards but also, it may sometimes be forgotten, sets of decisions. Protocols are valuable when they conserve high standards, and give nurses authority to defend these against arbitrary variations that might be introduced by new or less informed staff. Protocols can also prevent mistakes and the waste of time and effort over unresolved arguments about best practice. The danger of protocols, however, is that they may be used too rigidly to allow for each baby's changing individual needs, and they may restrict opportunities for parents to share in making decisions about their child.

*Nurses favour the feminist personal ethic of care and not the rights-driven, legalistic ethic of justice. They do not refer to general abstract principles, reasoning, and judgement* (Noddings, 1984). The seemingly compassionate ethic of care can conceal power discrepancies between the person who defines and provides, or withholds, care and the dependant care-recipient, who may have different views about the types of care that are needed. Allmark (2002) concludes that 'there can be no "caring" ethics. What we care about is morally important, the fact that we care *per se* is not.' Would nursing ethics, however caring, be acceptable if it overtly rejected respect and justice?

Examples like the above two case studies, showing how competing goals, methods and numerous structural constraints affect neonatal nurses' and parents' agency, and illustrate the importance of practical and contextual approaches to nursing ethics. How and why do some nurses involve and listen to parents, whereas others do not? A study of nurses' anxiety (Lyth, 1988), which found that each nurse tended to mistrust all the nurses more junior to her, and to be angry about being mistrusted by all the ones more senior to her, illustrates the value of psychoanalytic as well as political understandings of ethics, consent, and anxiety about sharing responsibility. Parents, as untrained and relative strangers, are liable to be mistrusted even more than junior nurses during the anxious timing of discharge, neither too late nor too soon for the baby's safety. Nursing ethics could review how the consent process offers a formula for dealing with this anxiety, without being too formal and legalistic, by explicitly discussing the options, anxieties and risks, and formally agreeing who will take responsibility for the decision. The analysis would move beyond seeing dissenting parents as anxious and stressed, to examine reasons for their disagreements, and potential advantages to nurses, babies and parents when parents take a greater part in decisions about feeding and discharge.

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