

Factors associated with information satisfaction among parents of sick neonates in the neonatal unit

It is vital that parents of sick babies on the neonatal unit receive effective communication from the health professionals caring for their baby and that they are included in decision making regarding proposed treatment. However in this very stressful environment parents may not always understand or retain the information given to them. This article reviews the literature concerning parents' satisfaction with information received on the neonatal unit and identifies the factors important in effective communication.

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Key points

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1. Parents value the nurturing and sharing aspects of communication.
2. Provision of accurate and timely information is important to parents on the neonatal unit.
3. Updating staff on the tenets of family-centred care may improve the quality of neonatal information provision.
4. More studies need to be carried out on how to improve confidentiality when providing information to parents of sick babies.
5. Fathers who are absent when important information is provided about their sick baby may benefit from audio recorded information.

Effective communication is paramount between parents of sick neonates and the direct care providers. Parents need to participate in decision making regarding their baby's well being. They value open and honest communication¹. Mothers and fathers value different modes of communication². Recording communication between parents of sick babies and the consultant can be useful to parents as it may help them to recall the information they received during the initial stressful period in the neonatal unit³. It is therefore important to analyse what parents benefit the most about the information they receive and examine their preferred method of communication. This literature review will critically review parents' satisfaction with the information they receive on the neonatal unit and make recommendations for the future.

Search strategy

In November, 2011, a comprehensive search for all peer-reviewed primary research articles, on parents' satisfaction with information received about their sick babies on the neonatal unit was undertaken. Using EBSCO and OVID hosts, a search for qualitative and quantitative primary research studies in English was undertaken using the search 'information and parents and neonatal and unit and satisfaction'. The search produced 24 primary research articles, 17 articles met the inclusion criterion with the aforementioned search words. Data from the most relevant articles are summarised in this article (FIGURE 1).

Literature review

Parents' perception of health professionals' communication

In 2007 Jones et al² investigated parents' perception of how health professionals communicated in a semi-structured interview of 20 mothers and 17 fathers whose babies were one-week old in the neonatal unit. They found that parents felt that nurses communicated better than doctors. Nurses were more effective when they were able to change their behaviour or conversation to meet the needs of parents. Parents reported caring attitude and information sharing as an essential part of communication. Two-way information between parents and health professionals was useful, whereas conflicting information was not. Fathers identified indirect or inadequate explanation as poor communication. Fathers felt the emotional aspect of communication was unnecessary.

Ammentorp et al⁴ in a Danish survey in 2007 identified a lack of clarity in the information provided to parents. Utilising an electronic questionnaire, they investigated reasons why parents in a paediatric unit were less satisfied with the care provided. Out of 780 parents who participated, 88% felt they had experienced kindness; 72% felt taken care of; 65% of parents felt they were well-informed. The majority of the parents were satisfied with information provided about transfer and information given by doctors. However, 66% of parents were less satisfied with the amount of time the nurses spent with

Author	Date	Study design and sample size	Focus of study
Jones L., Woodhouse D., Rowe J. ² .	2007	A semi structured interview of 20 mothers and 13 fathers.	Parents' perception of nurse patient-communication: a study in the NICU environment
Koh G., Budge D., Butow P., et al ³ .	2008	A quasi-randomised controlled trial of audio-taped conversations that 102 mothers had with their consultants. For comparison 98 mothers in the control group were not provided with audiotape.	The value of audio recordings of consultations with doctors for parents of critically sick babies.
Ammentorp J., Rasmussen A.M., Norgaard B., et al ⁴ .	2007	A survey of 780 parents.	Measuring parent satisfaction as a basis for quality improvement.
Redshaw M.E., Hamilton K.E. ⁵ .	2010	A survey of all neonatal units in UK. 153 (75%) responded.	Facilities, information and support for parents: family-centred care.
Willis K., Nath P., Thurlow C. James M. ⁶ .	2011	A 12-point postal questionnaire survey of 134 parents of babies admitted to the neonatal unit from August-October 2009.	Parental perception of staff-parent communication in the neonatal unit.
Bramwell R., Weindling M. ⁷ .	2005	A survey of communication and ward round policies across neonatal units in the UK; 34 of the 37 centres responded.	Families' views on ward and communication rounds in neonatal units.
Kowalski W.J., Leef K.H., Mackley A., et al ⁸ .	2006	A 19-item questionnaire survey of 101 parents of infants 32 weeks or less.	The sources of information, communication, expectations and what parents value the most.
Penticuff T., Arheart K. ⁹ .	2005	A tri-ethnic sample of mothers of 154 very-low birthweight infants; 77 parents in control group and 77 in the intervention group.	The effect of collaborating with parents when making medical decisions. Providing comprehensive information on parents' satisfaction with neonatal intensive care.

FIGURE 1 Articles reviewed for this study.

them. Parents were unhappy about having to wait for a long time before being able to get in touch with staff. In addition, 80% were less satisfied with information received concerning delays prior to transfer. They would have liked to know the length of time they would need to wait before transfer to another unit. Fifty-seven per cent were unhappy about the plan for admission. Nonetheless, dissatisfied parents still rated doctors and nurses exceptionally well on having had good communication with parents and having proper knowledge of their child's condition.

A 2010 survey by Redshaw and Hamilton⁵ of family-centred care (FCC) policy across all neonatal units in the UK reported variation in facilities, information given, and support for parents and emphasised the need for uniformity in FCC provision. The majority of units had written information available concerning equipment (72%), ventilation (64%) and breastfeeding (91%). Parents had free access to notes in 20% of units; 14% of the units excluded parents from ward rounds. Twenty-seven per cent of units had a policy of keeping in contact with parents. Half

(47%) of units did not have the services of a social worker, psychologist, counsellor or psychiatrist and only 15% had a unit-based family care nurse.

In 2011 Willis et al⁶ sent out a 12 point questionnaire by post to the 134 parents of babies admitted to the neonatal unit from August-October 2009. Of the 74 (55%) responses, 50 (68%) were from mothers and 22 (30%) were from both parents. The babies' gestational ages ranged from 28 to 43 weeks (median 39.5 weeks). Birthweights ranged from 592 to 5020g (median 3165g). Fifty-nine (80%) of the parents had communication with medical staff within 24 hours of admission. Sixty-seven (91%) of the parents had regular information updates during their baby's stay; 40 (60%) were regularly updated by the nurses and 15 (22%) by both nursing and medical staff. A total of 68 (92%) parents were happy with the time spent with them, ease of understanding and sensitivity of conveyance of the information; 66 (89%) reported overall satisfaction with the communication; but six (8%) were dissatisfied.

Confidentiality and communication during ward rounds

A structured interview of 86 parents with babies in NICU by Bramwell and Weindling in 2005⁷ suggested that parents were often unclear about the purpose or schedule of ward rounds. Of the 73% of parents who visited during ward rounds, only 15% had come in specifically to talk to doctors. Some parents felt the ward round was a reliable source of information and 86% of parents felt it would be beneficial to hear what doctors had to say, but a few (7%) did not find their experiences enjoyable. Some parents wanted doctors to talk to them about their child's progress and wanted to be more involved, while others found ward rounds intimidating.

In the same study, ward round practices of neonatal units across 37 areas in the UK were surveyed. Thirty four of the 37 centres responded. Eighteen neonatal units had one ward round a day; thirteen units had two rounds daily and three units had three rounds daily. Eight of the 34 neonatal units allowed all parents to be present during ward rounds. Eight did not allow

parents to be present, eighteen allowed only the parents of the child to be discussed to be present during ward round.

In their 2006 study Kowalski et al⁸ examined useful ways of communicating information to parents using a 19-item questionnaire given to the parents of infants 32 weeks or younger prior to discharge from the NICU. They concluded that 96% of parents (97 of 101) felt that doctors provided the required information. Sixty-four per cent of the parents reported being given information during the ward rounds. Twenty five per cent of parents were given information during prenatal consultation; 31% received information immediately after delivery; 47% were spoken to at a separate time from ward round and 12% reported being spoken to before discharge. The majority (67%) said ward round was a better time for providing information as opposed to during prenatal consult (36%) or before discharge (50%). Fifty-nine per cent of parents would prefer a different time from ward round to discuss their baby's progress. The majority of the parents reported that some problems were not fully explained to them⁸. Overall, 91% still felt that doctors did an excellent job and felt reassured by doctors when worried. Nurses spent the most time with parents, explained their child's condition to them and were their principal source of information (56/75, $p<0.01$). Nevertheless, parents still expected the doctor to discuss any changes to their baby's condition.

Irrespective of information obtained from health professionals, 64% of parents spent at least one hour per week reading books on their child's condition and 8% of parents obtained information from the internet, despite finding internet information frightening⁸.

Audiotape conversations with neonatologists

A quasi-randomised controlled trial by Koh et al³ evaluated the effectiveness of audio taped conversations that 102 mothers had with their consultants. For comparison 98 mothers in the control group were not provided with audiotape discussion with their consultant. The majority of the mothers in the audiotape group (91%) had listened to the tape once by day 10, twice by four months and three times by 12 months.

At four months, mothers in the audiotape group were 75% more likely to

remember all the information about treatment than mothers in the control group. Six mothers in the control group could not remember their conversations at all. Overall, there were no significant differences between the groups in their satisfaction with conversations at day 10. There was no difference in the level of postnatal depression and anxiety scores among mothers given audiotapes either at day 10 or at four and twelve months later, compared with those not given audio tapes.

Audiotape recording enhanced recall of information, not mothers' well being or satisfaction with the conversations. However, parents whose babies had poor outcomes and received the audiotape were more satisfied with the information provided. This result suggests that both the content of information provided as well as how health professionals disseminate information are paramount. Research is required to assess the communication style that will best meet the needs of each set of parents.

Social perspectives of communication

In 2005 Penticuff⁹ tested the effect of work collaboration between doctors, nurses and parents in a tri-ethnic sample of 154 very low birthweight infants. There were 77 parents in the control group and, 77 parents in the intervention group. In the control phase which lasted two years, professionals carried out routine communication and interaction with the control group parents. Control group parents completed all the survey instruments either in the NICU, in the hospital or at home.

In year three following completion of data collection for the control group, the study entered a professionals' training phase. Neonatal nurses were given instructions on how to help parents use the Infant Progress Chart (IPC), and neonatologists and neonatal nurse practitioners were familiarised with the Care Planning Meeting agenda. Intervention parents received IPC training and used the IPC when visiting their infants in the NICU. They also participated in these Care Planning Meetings and completed all survey instruments immediately following each meeting.

Compared with the control group, the parents in the intervention group had fewer unrealistic concerns ($p<0.018$); they had less uncertainty about their infant's medical condition ($p<0.003$); and had less

decision conflict ($p=0.001$). They were more satisfied with the medical process ($p<0.012$) and the inputs they had to decisions. They also reported more shared decision making with professionals ($p<0.010$). There were no statistically significant differences in satisfaction with infant care, satisfaction with decisions made about infant's treatment or satisfaction with the relationship with doctors and nurses.

Mothers receiving income support were more satisfied with their decision input than mothers who were not eligible. Poor mothers in both groups were significantly unsure of their infant's medical condition. Ethnic minority mothers in both groups were less satisfied with their care than were Caucasian mothers. The intervention was particularly helpful in providing understanding and collaboration with mothers who had a low income, were young, and from an ethnic minority. The study highlights social class, economic and educational issues as significant factors among mothers of sick babies.

Discussion

Clearly, parents value timely, honest and accurate information. Therefore, health professionals must provide clear, straightforward information including appropriate social support¹⁰. Parents also need to participate in the decision-making process. This can only be enhanced by evaluation of FCC policies and regular staff training¹¹.

A robust system is likely to address the information issues and enhance parents' experience¹².

Mothers value relationship building during communication. Fathers tend to require honest, clear, accurate information. Information preferences for each gender or personality must be considered when planning how information should be provided to parents. Conner and Nelson¹² reported communication as the most reported domain of satisfaction within paediatric healthcare services.

Parents identified several dimensions of communication, such as open and honest dialogue, sharing of factual information, providing complete information, and preparing parents for uncertainty. Medical information must be communicated in a meaningful way that is interpretable by the parents, irrespective of the informer. Effective communication may positively affect parents' perception and satisfaction

with care. Healthcare professionals must be trained to communicate care needs and share medical information with empathy and clarity¹². Parents value clear communication and regular updates. Parents identified nurses as the key source of information⁶.

Parents are not always able to recall information during stressful periods on the NICU. Recording information on audiotape is a practical means of providing parents with supplementary verbal information and it helps them recall information especially if they have difficulty interpreting medical terminology, technology and interventions³.

Some parents perceive ward rounds as the best time and place to address communication issues, others value arranging separate meeting times to discuss their child's health. Maintaining confidentiality must be considered during ward rounds. Studies must address how confidentiality could be maintained.

Neonatal units must have standardised communication systems and policies and address the physical, interpersonal and communication needs of families in a timely and structured approach⁵.

Logistic regression tests were performed in a survey of 210 parents with babies admitted to the neonatal unit at Homerton Foundation Trust. They showed that parents were 33 times more likely to be satisfied with the information received if their questions were answered ($p < 0.0001$) and 13 times more likely to be satisfied if they found it easy to discuss concerns with staff ($p < 0.004$). Those parents seen within 24 hours were 10 times more likely to be satisfied with information received ($p < 0.021$)¹³.

Conclusion and recommendations

Maintaining confidentiality when communicating information to parents is imperative. Research is needed to evaluate how best to disseminate information to parents and how soon information should be provided. Parents do not tend to recall information given to them in the early stages of admission. Recording parents' conversations with consultants or designing a portfolio that can be updated daily by both parents and health professionals has been suggested by parents themselves as a useful tool^{3,4}.

Most fathers are not able to be present on the neonatal unit during the day time for work reasons and so attention has

focused on mothers, both within clinical practice and the literature. The role and involvement of fathers in the decision making needs to be explored. Fathers may also benefit from audio recording and replaying of information they missed. The mothers of babies with poor outcomes who received the tapes were significantly more satisfied with the conversation than similar mothers in the control group³.

Parents are happy with either the nurse or doctor communicating with them. A pleasant, attentive, caring attitude and the desire to work in partnership with parents are important attributes when communicating information to parents. The environment needs to be conducive for supporting the needs of families in such stressful periods.

Finally, neonatal units must invest in education and update of health professional's communication skills. Information delivered to parents must be consciously evaluated. It may be useful to document parents' response to information provided to them in medical and nursing notes. Research needs to be ongoing; parents and staff must be part of this process.

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