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Parents' experiences of neonatal care in England

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Cover Page Footnote

We would like to thank NHS England for part-funding the neonatal survey and for encouraging neonatal units to participate. Also thank you to Tamara van Doorn and Cara Witwicki for assisting with the survey fieldwork. Finally, we would like to acknowledge the parents for taking the time to give their views by completing a questionnaire.

Parents' experiences of neonatal care in England

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Abstract

With the greater need for specialist neonatal care in England over the last decade, increased attention has been given to developing and implementing quality measures to ensure that babies and their families receive the highest quality care. Patient experience is recognised as a key measure of quality, therefore it is essential to assess parents' experiences of neonatal services to understand how these can be improved. In this paper we detail findings from the second large scale survey of parents' experiences of neonatal care carried out in England in 2014, focusing on results that highlight aspects of family-centred care: information sharing; communication; support; and involvement. The results reveal great variations between individual units, as well as highlight key areas in which units could improve to provide family-centred care. This includes parents being able to speak to their doctor more, as well as receiving important information to understand their baby's condition, and about support services available. Positively, many parents felt they were able to visit their baby as much as they wanted and were involved in their day-to-day care, which are fundamental to parents forming a bond with their baby. The survey is a rich data source that provides neonatal units in England with results that allow them to focus improvement efforts on what matters most to those using their services. It also enables neonatal units to evaluate how they are performing on key standards of care, supporting them in striving for clinical best practice.

Keywords

Patient experience, health care, neonatal care, communication, family-centred care, surveys, quality of care, National Health Service

Introduction

With the greater need for specialist neonatal care in England over the last decade, increased attention has been given to developing and implementing quality measures to ensure that babies and their families receive the highest quality care. In 2009, a Neonatal Taskforce was established in response to the National Audit Office report (*Caring for Vulnerable Babies: The reorganisation of neonatal care in England*),¹ which highlighted some concerns in the consistency of delivering neonatal care across the country. The taskforce, which consisted of members from the National Health Service (NHS) and Bliss (the special care baby charity), and supported by the Department of Health, created a set of measures to ensure the delivery of high quality care in their *Toolkit for High-Quality Neonatal Services (toolkit)*.² The *toolkit* which outlines markers of good practice, as well as the *Bliss Baby Charter Standards*³ which complements the *toolkit*, emphasise the need for neonatal care to adopt a philosophy of family-centred care, which "puts the physical, psychological and social needs of both the baby and their family at the heart of all care given".² Further, principle 4 of the *Bliss Baby Charter Standard* states that "developing a culture of continuous improvement that involves and is informed by parents, maintains high

quality care for babies and their families and encourages units to continually raise the bar in provision of family-centred care".³ It is crucial therefore to assess parents' experiences of neonatal services to understand how the quality can continually be improved.

Patient experience is widely recognised as one of the central elements of quality in the NHS in England. In the *NHS Five Year Forward View*⁴ the government outlined that patients' experiences of NHS care is still one of the central components of healthcare quality, along with patient safety and clinical effectiveness. Quality of care includes the compassion, dignity and respect with which patients and their families are treated. It can only be improved by analysing and understanding patients' satisfaction with, and experiences of their care and treatment.

In this paper we detail findings from a large scale survey of parents' experiences of neonatal care carried out in England in 2014. The primary purpose of the survey was to help neonatal units better understand the experiences of the parents who use their services, providing them with evidence to help make improvements to the care they provide.

Methods

Questionnaire

Initially developed in 2010, the questionnaire was used in the first national survey of parents' experiences of neonatal care in England. The questionnaire was developed by Picker Institute Europe in consultation with Bliss and representatives from neonatal networks in England. To inform questionnaire development, a review of policy and quality standards on neonatal care (such as those produced by the National Institute for Health and Care Excellence in 2010⁵; the NHS & Department of Health in 2009²; and the Royal College of Nursing in 2011⁶), findings from recent research studies (such as the POPPY project⁷), and the content of existing questionnaires examining parent satisfaction with and experiences of neonatal care was conducted.

In addition to this, four focus groups were carried out with parents who had recently experienced neonatal care to establish the issues which were of most importance to them. Following these activities, a draft questionnaire was developed and fifteen cognitive interviews were conducted with parents to test the relevance and validity of the questionnaire. In doing this we considered the cognitive process of responding in terms of the model described by Tourangeau.⁸ Revisions were made to the questionnaire during this testing phase, and further amendments were made following consultation with Bliss and the network representatives.

In 2014, the performance and relevance of the items seen in the 2010 survey were evaluated. This included examining missing response data from the 2010 survey and undertaking a consultation exercise with neonatal network leads to ensure that items were consistent with current service provision. The amended questionnaire was again cognitively tested with twelve parents before being finalised for use.

Data collection

The paper-based self-completion questionnaire was mailed out to 15,944 parents from 88 neonatal units in England. Fieldwork was carried out between May and December 2014 and was conducted in two waves in order to obtain a sufficiently sized sample to allow results to be presented at neonatal unit-level.

Parents aged 16 and over were eligible for the survey if their baby had received neonatal care for 24 hours or longer and had been discharged home during the specified sampling period. For each unit, up to 100 parents were sampled per wave.

Parents were sent a questionnaire, a covering letter, a multiple language sheet offering help with the survey, and a freepost envelope. Those wishing to complete the survey

filled it in and returned it in the freepost envelope. Non-responders were sent a reminder letter after 2-3 weeks, and another questionnaire and final reminder letter after a further 2-3 weeks. All documents were compiled in accordance with the *Tailored Design Method* to increase interest in the survey and maximise response rates.⁹

A Freephone helpline for patients who had any queries or concerns about the survey was provided. This included links to LanguageLine with immediate access to interpreters in over 100 languages. Parents wishing to opt-out of the survey could do so by returning the questionnaire blank, or by calling the Freephone helpline.

Following the survey fieldwork, all participating neonatal units received a detailed report of their individual unit's results and were invited to attend one of two regional action planning workshops hosted by the Picker Institute and Bliss. The workshops provided protected time for staff to work through and understand their own results, identify and prioritise areas for improvement, as well as share experiences and network with others.

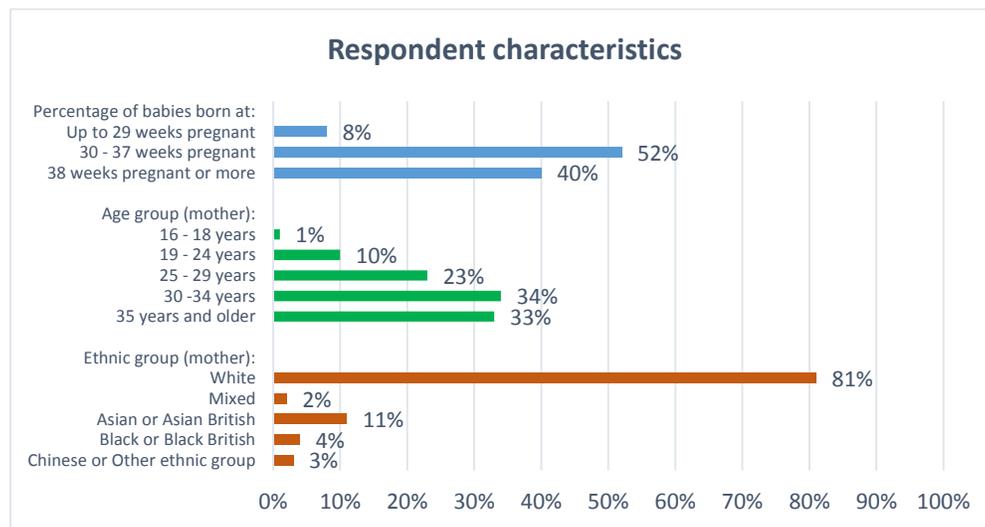
Data analysis

Data was cleaned and analysed using the statistical package SPSS Statistics 22. For questions measuring performance, the individual responses given by respondents were converted into scores on a scale of 0 to 100 with a score of 100 representing the best possible response and a score of 0 representing the least favourable response. Therefore, the higher the score the better the performance. The overall unit score for each question was calculated as an average of the individual scores. Scoring data in this way allowed all the different response options to be taken into account when evaluating performance rather than just looking at the best or worst possible answer.

The data was 'standardised' by the age of respondents and by the gestational age of their baby at birth (i.e. 37 weeks or less and 38 weeks or more). This was to ensure that no unit appeared better or worse than another because of its respondent profile, allowing a more accurate comparison of results.

All participating neonatal units received a detailed report of their results showing how they compare to (i) other units of the same type (Special Care Baby Units, Local Neonatal Units, or Neonatal Intensive Care Units), (ii) units in the same network (all units in the same geographical area for example London), and (iii) the national average results (i.e. all participating units).

Figure 1. Respondent Characteristics



Results

Response

Overall, responses were received from 6,000 parents, and after taking into account undelivered questionnaires and those parents ineligible for inclusion, a response rate of 37.6% was achieved. The highest response rate achieved by a participating neonatal unit was 59% and the lowest response rate was 9%. Respondent characteristics can be seen in Figure 1. A total of 73 calls were received across all participating units to the Freephone helpline, which included only one LanguageLine request.

Overall Results

This section provides the results of all neonatal units who participated in the Neonatal Survey 2014. The tables present the overall scores for questions asked to parents in the survey according to four key themes that are core to family-centred care, namely: Information, Communication, Support, and Involvement. The overall unit score for each question was calculated as an average of the individual scores. The higher the score the better the performance. Please refer to "data analysis" section for more detail about the scoring format.

Information

Parents were asked about their experience of receiving important information about the neonatal unit, such as the facilities available to them and practices and procedures for infection control. Parents were also asked about receiving written information about their baby's condition and treatment, as well as information about support services that were available to them. Table 1 outlines the scores for these questions.

Communication

The survey included key questions about parents' experiences of communication with and between staff, as well as the quality of communication and support parents received. Table 2 highlights those questions vital to building rapport between staff and parents including if staff introduced themselves to parents and whether parents knew who was responsible for their baby's care on the unit. Further, parents were asked to provide feedback about communicating with staff about their baby's care and treatment, including whether they were able to speak to a doctor, and if they received answers to their questions in a way they could understand. Further, parents were asked whether they felt staff shared information about their baby, and if they received conflicting information about their baby's care or condition.

Support

Table 3 presents the scores for those questions that focus on staff sensitivity and the availability of staff to provide support to parents if they were concerned.

Involvement

Table 4 presents the scores for questions that explored how involved parents felt they were in the care of their baby as well as in discussions about their baby's condition or treatment.

Variations in results across neonatal units

Findings from previous research, including the POPPY project and the 2010 Picker neonatal survey has shown that "parents' experiences of neonatal care, and the extent to which services are 'family-centred', can vary enormously between units".^{7,10} The 2014 Picker survey results also highlighted large variations in scores across neonatal units. Those questions showing the greatest variation across neonatal units in parents' experiences relevant to this

Table 1. Receiving information/being introduced to the neonatal unit

Question	Mean score out of 100
Were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents)?	76
Were infection control practices explained to you, such as hand washing and procedures for visitors?	85
Were you given enough written information to help you understand your baby's condition and treatment?	53
Did staff give you any information about parent support groups, such as Bliss or other local groups?	53

Table 2. Communication

Question	Mean score out of 100
When you visited the unit, did the staff caring for your baby introduce themselves to you?	79
Were you told which nurse was responsible for your baby's care each day s/he was in the neonatal unit?	90
Were you able to speak to a doctor about your baby as much as you wanted?	66
In your opinion, was important information about your baby passed on from one member of staff to another?	84
Did staff give you conflicting information about your baby's condition or care?	67
If you asked questions about your baby's condition and treatment, did you get answers you could understand?	88
Overall, did you have confidence and trust in the staff caring for your baby?	92

Table 3. Emotional support from staff

Question	Mean score out of 100
Were you able to talk to staff on the unit about your worries and concerns?	88
Were the nurses on the unit sensitive to your emotions and feelings?	85
Were the doctors on the unit sensitive to your emotions and feelings?	83
Overall, did staff help you feel confident in caring for your baby?	89
Were you offered emotional support or counselling services from neonatal unit staff?	57

paper are displayed in Table 5. Questions where the range in the overall unit scores was greater than 50 and are key to family-centred care are presented. This demonstrates that for many of the themes covered by the questionnaire, performance is incredibly varied across neonatal units. For example for the question, 'Were infection control practices explained to you, such as hand washing and procedures for visitors?', the best performing neonatal unit on this question achieved a score of 98 out of 100, whereas the worst performing neonatal unit on this question only achieved a score of 42.

Table 5 indicates where there is greatest room for improvement for neonatal units scoring low at these questions. These questions present a challenge for low scoring neonatal units, as there is a larger gap in scores to overturn to become one of the best performing neonatal units on these questions, compared to those with a smaller range.

The scores with the smallest variation, where the range is 20 or lower, are displayed in Table 6. These are the areas where neonatal units showed similar performance.

Table 4. Involvement in care

Question	Mean score out of 100
Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding?	89
Did you have as much skin-to-skin contact with your baby as you wanted?	72
Did the neonatal staff include you in discussions about your baby's care and treatment?	78
Were you told about any changes in your baby's condition or care?	89
When a ward round was taking place, were you allowed to be present when your baby was being discussed?	80
Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	74
Were you able to visit your baby on the unit as much as you wanted to?	95

Table 5. Questions where the range in the overall unit scores (i.e. the gap between the lowest and highest score) was greater than 50

Question	Minimum unit score	Maximum unit score	Range across units
Did staff refer to your baby by his/her first name?	33	100	67
When a ward round was taking place, were you allowed to be present when your baby was being discussed?	38	99	61
Were you offered emotional support or counselling services from neonatal unit staff?	33	92	59
Were infection control practices explained to you, such as hand washing and procedures for visitors?	42	98	56
Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times?	41	95	55
Did staff give you any information about parent support groups, such as Bliss or other local groups?	34	87	53

Table 6. Questions where the range in the overall unit scores was 20 or lower

Question	Minimum unit score	Maximum unit score	Range across units
Were you told about any changes in your baby's condition or care?	77	96	19
Did you feel prepared for your baby's discharge from neonatal care?	76	96	20
How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or treatment?	78	97	20

Discussion

Neonatal staff have an especially great responsibility not only in caring for vulnerable babies, but also assisting parents who may be particularly concerned and emotional during a time of uncertainty. Family-centred care (FCC) is considered a standard by many in paediatric healthcare,¹¹

and “ultimately...may enhance attachment between a baby and the family result[ing] in improved long-term outcomes for both”.² Wigert, Dellenmark and Bry¹² note that employing FCC in neonatal settings has shown to improve collaboration between parents and staff, alleviate stress and insecurity on the part of parents, and improve satisfaction of communication with doctors. Good quality communication between parents and staff then includes

providing parents with important information about their baby's condition and care; providing support and comfort to concerned or emotional parents; as well as "educat[ing] and guid[ing] parents so that they can actively participate in caring for their child and become true "partners" with the medical team in the decision-making process".¹³ This paper focused on those results from the survey that highlight aspects of family-centred care including information sharing, communication, support from neonatal staff, and parents' involvement in care.

Information

Although there is no consensus on particular actions and practices of family-centred care, one of the cornerstone principles for successful implementation of FCC includes information sharing.¹¹ Following this, principle 3.2 of the *Toolkit for high-quality neonatal services (toolkit)* highlights that all parents should be "introduced to facilities, routines, staff, and equipment on admission to a neonatal unit".² This is particularly important to assist parents to feel at ease in an unfamiliar environment "filled with hi-tech equipment and busy medical staff".¹³

On the whole, units scored well on introducing parents to facilities such as rules and procedures (score of 76 out of 100). Further, units received an overall score 85 out of 100 on explaining infection control practices, such as hand washing and procedures for visitors. However, there was large variation among units on this question, with the lowest scoring unit receiving a worryingly low score of 42, compared to 98 for the highest performing unit. It is not only important that parents know these procedures to ensure infection control practices are implemented, but it also puts parents at ease that the greatest care is being taken around their baby.

Very ill babies who have received care on a neonatal unit will most likely require additional support long after they are discharged from the neonatal unit. Information regarding support groups and who to contact in hospital for queries or advice should be accessible to parents such as highlighted in principle 3.8 of the *toolkit*.² Further, providing parents with written information about their baby's condition and treatment that they can refer to at their convenience is important. As highlighted in Table 1, there is room for improvement overall for units to provide parents with information about additional services and support, as well as written information about their baby's condition and treatment. Those parents who wanted or needed the latter only gave units a score of 53 out of 100. Similarly a number of parents were not given any information about parent support groups, such as Bliss or other local groups (score of 53). It was highlighted at the action planning workshops that units should be proactive in collaborating with local organisations or charities to provide assistance to parents and their baby during their stay on the unit as well as after discharge.

Communication

Good communication between staff and parents is vital for ensuring family-centred care. An important part of building rapport includes parents feeling that they and their infant are treated as individuals and with dignity. Orzalesi and Aite¹³ outline basic requirements for good communication to be achieved in a busy and somewhat confusing environment which includes staff members introducing themselves and their role defined. Knowing who is responsible for their baby's care is valuable in making parents feel in control during an uncertain time. Parents were positive about staff caring for their baby introducing themselves (79 out of 100), as well as knowing which nurse was responsible for their baby's care (score of 90).

Research has shown that to gain parents' trust and confidence in staff they need to know that staff, and in particular doctors, are providing them with honest and accurate information regarding their child's condition or diagnosis.^{13,14} It is also important for parents to have access to staff members to answer questions or give explanations, especially in an environment where conditions change frequently and abruptly, and to reduce the risk of misunderstanding seemingly conflicting information. Despite parents reporting they received clear answers to questions about their baby's condition or treatment (score of 88 out of 100), they felt they were not able to talk to a doctor about their baby as much as they wanted (score of 66). Further, although a large proportion of parents felt that important information was shared between staff members (score of 84), a number of parents reported receiving conflicting information about their baby's condition or care (score of 67). The nature of a neonatal unit, particularly neonatal intensive care units (NICUs), is to care for critically ill babies whose condition is vulnerable and may fluctuate. Therefore it is crucial for staff to be in constant communication with parents to update them on developments. At the very least staff should caution parents that changes may occur and quick decisions will need to be made so as to manage expectations and relieve some of the shock when conditions change. Open and honest communication between parents and staff is central to maintaining that relationship vital to successful FCC.¹⁴

Support

Beyond receiving factual information and understanding the technical aspects of care, studies have shown that effective and caring communication between staff and parents is crucial to assist parents to manage the uncertainty about their child's health.¹²⁻¹⁴ Parents are dependent on staff to help them cope with the overall experience,¹⁴ and quality communication includes clear and frequent information sharing, as well as providing parents with opportunities to discuss their experiences and receive emotional support from staff. Standard 2.3 of the *Bliss Baby Charter* states that the "psychological and social

aspects of care for the whole family (including siblings) are recognised and included throughout the baby's care pathway",³ and it is one of the markers of good practice outlined in the *toolkit*.²

Positively, results from the survey indicate that parents were able to talk to staff about their worries and concerns if they had any (score of 88 out of 100), and felt that both nurses (score of 85) and doctors (score of 83) were sensitive to their emotions and feelings. However, as seen in table 5, there was large variation between units on whether parents were offered emotional support or counselling services by neonatal staff, and overall units only received a score of 57 out of 100 from parents who would have liked this.

Involvement in Care

Both the Department of Health's *toolkit*,² and the NICE quality standards for neonatal care⁵ identify the importance of parents being involved in decision-making about the care and treatment of their baby. Principle 3.5 of the *toolkit* states that parents should be "encouraged and supported to participate in their baby's care at the earliest opportunity, including: regular skin-to-skin care; feeding; and day-to-day care, such as nappy changing".² This is supported by the NICE quality standards which highlights in statement 5 that "parents of babies receiving specialist neonatal care [should be] encouraged and supported to be involved in planning and providing for their baby".⁵

Results from the survey show positively that, overall parents were involved as much as they wanted in their baby's day-to-day care (score of 89 out of 100), and most parents were able to visit their baby on the unit as much as they wanted (score of 95). That said, even though units received an overall score of 74 out of 100, staff could do more to arrange the baby's care to fit in with parents' usual visiting times, with large variation between units (the lowest unit scored 41 and the highest 99). Further, staff could provide more opportunities for parents to have skin-to-skin contact with their baby (score of 72) as this is particularly important for parents to form a bond with their baby.

Although a large number of parents felt that they were told about changes in their baby's condition or care (score of 89), and were somewhat involved in discussions about their baby's care and treatment (score of 78), there was a large variation between units in the extent parents were allowed to be present during ward rounds when their baby was being discussed (difference in score of 55). Discussions held at the regional workshops revealed staff concerns with needing to balance allowing parents to be present when their baby is discussed yet maintaining confidentiality during ward rounds. Positively, parents felt that staff helped them feel confident in caring for their

baby (score of 89), and had confidence and trust in the staff caring for their baby (score of 92).

Conclusion

The results presented in this paper are from the second survey of parents' experiences of neonatal care in England conducted by Picker Institute Europe with support from Bliss and NHS England. The increased need for specialist neonatal care in England over the last decade, has seen much needed attention given to developing and implementing quality measures to ensure that babies and their families receive the highest quality care. Understanding and using parents' experience is central to measuring quality care, in particular the successful implementation of family-centred care.

Family-centred care is based on creating partnerships and collaboration between healthcare providers and families or parents, and requires open and sensitive communication, particularly in times of distress and uncertainty. It also requires staff to support parents to be involved in decisions about their baby's treatment, as well as their day-to-day care. The results reveal that parents' experiences of neonatal care, and the extent to which services are "family-centred" vary substantially on key areas between individual units. Results also highlight those areas in which units could improve to ensure family-centred care, particularly in providing parents with important written information to help understand their baby's condition and treatment. As well as about services and support available to them such as access to support groups like Bliss. Further, the results revealed that parents would like to be able to speak to their doctor more, and many reported receiving conflicting information from staff. That said, many parents felt they were able to visit their baby as much as they wanted to, and were involved in the day-to-day care of their baby. This is fundamental for parents to form a bond with their baby and to feel in control in an uncertain environment. Overall, parents reported great confidence and trust in the staff caring for their baby.

The survey has shown itself to be a rich data source that provides neonatal units in England with results that allow them to focus specific improvement efforts on what matters most to those using their services. It also enables neonatal units to evaluate how they are performing on key standards of care, supporting them in striving for clinical best practice. The survey also provides valuable evidence for voluntary sector organisations (such as Bliss), regulators, and national bodies such as the National Institute for Health and Care Excellence (NICE) and NHS England on the current standard of neonatal care in England. Findings from research such as this can and should influence the organisation of neonatal care on both a local and national level. What this looks like will be

determined by the specific units or organisations reviewing the evidence provided.

Limitations

The response rate of 38% is lower than would be expected of a survey of this kind (for example, the response rate for the 2013 national survey of women's experiences of maternity services in England was 46%), therefore reported experience is missing for over 60% of those invited to participate. Further analysis of responder and non-responder characteristics will be carried out to help understand how different groups are interacting with the survey.

Sample sizes were small at individual neonatal unit-level, and whilst this was not unexpected due to the nature of the service and care provided, it did have an influence on unit-level reports especially where response rates were low. Results were not shown for questions answered by fewer than 20 people, and this meant that for units with a small sample size and a low response rate there was a strong likelihood that results would have to be suppressed from their reports.

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