Parental experience of interaction with health care professionals during their infant's stay in the neonatal intensive care unit

Katie Gallagher[1*], Chloe Shaw[1], Narendra Aladangady[2], Neil Marlow[1]

1: UCL Elizabeth Garrett Anderson Institute for Women's Health, University College London, London, United Kingdom

2: Neonatal Unit, Homerton University Hospital NHS Foundation Trust, Homerton Row, London and Queen Mary's University of London, London,

[*]Corresponding author:
Katie Gallagher
Honorary Senior Research Associate
UCL Elizabeth Garrett Anderson Institute for Women's Health
University College London
74 Huntley Street
London WC1E 6AU
United Kingdom

Email: Katie.gallagher@ucl.ac.uk

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Abstract

Objective: to explore the experiences of parents of infants admitted to the neonatal intensive care unit towards interaction with health care professionals during their infants critical care.

Design: Semi structured interviews were conducted with parents of critically **ill** infants admitted to neonatal intensive care and prospectively enrolled in a study of communication in critical care decision making. Interviews were transcribed verbatim and uploaded into NVivo V10 to manage and facilitate data analysis. Thematic analysis identified themes representing the data.

Results: Nineteen interviews conducted with 14 families identified 4 themes: (1) initial impact of admission affecting transition into the neonatal unit (2) impact of consistency of care, care givers and information giving (3) impact of communication in facilitating or hindering parental autonomy, trust, parental expectations, and interactions (4) parental perception of respect and humane touches on the neonatal unit.

Conclusion: Factors including the context of infant admission, inter-professional consistency, humane touches of staff and the transition into the culture of the neonatal unit are important issues for parents. These issues warrant further investigation to facilitate individualised family needs, attachment between parents and their baby, and the professional team.

186 words

OBJECTIVE

The admission of a critically ill baby to the neonatal unit often represents a deeply traumatic time for parents.[1,2] Symptoms of stress, anxiety and post-traumatic stress have been reported both during admission and after discharge of the baby[3-6], suggesting that even a brief stay on the neonatal unit can have a long lasting impact on the family and highlighting the importance of family support. Careful communication and engagement during the critical care given to their baby allows parents to cope more effectively with the emotional stress, but remains an area that is often criticised by parents who have understandable deep anxiety caused by their baby's admission to a neonatal unit.[2,6-9]

Many of the studies that have explored parental experiences of the neonatal unit, and of medical communication in this environment, are retrospective[8-13] and miss the opportunity of gathering information at the time about parental experiences of engagement in the care of their baby and the clinical course, particularly around critical care decision making. As shown by Wraight et al,[14] however, gathering data from parents in real time on the neonatal unit is important as it allows us better to understand how parents navigate through a range of decisions, the provision of complex information, and how they view their baby's condition. These processes are integral to parental engagement and any ultimate critical care decisions which parents make for their infant.[14]

This study explored the experiences of parents towards interaction with health care professionals during their infants admission to the neonatal intensive care unit. The study formed part of a wider programme of research into communication between parents and health care professionals during critical care decision making.

DESIGN

The wider study and the interviews were introduced to eligible parents of critically ill infants by the attending neonatologist either at or shortly after the infants admission. Wider participation involved the recording of conversations between parents and their consultant neonatologist, therefore any neonatologist participating in the study could identify eligible parents. If parents were interested in

sharing their experiences through an interview, a member of the research team followed up with the parents usually within 48hrs, discussed participation in more detail, obtained signed informed consent, and arranged interviews. Thirty one families were recruited to the overall study from a single tertiary neonatal intensive care unit in England from July 2013 to April 2014. Of the 31 families, 14 volunteered to be interviewed, 5 families were lost to follow up, and participation was declined by 9 families for a range of reasons including: the death of the baby and/or feeling too overwhelmed (5) a further pregnancy and the family not wishing to revisit the experience at this point (2) and no reason (2). Three families did not get admitted to the neonatal unit due to either the death of the mother or the baby prior to admission.

Qualitative interviews

Families were invited by the research team to share their experiences at the start of their babies stay and again at discharge to allow families the opportunity to discuss all aspects of communication during their infants stay. The semi-structured interview schedule was developed through identifying relevant areas in the literature followed by expert content review by two study supervisory groups, one comprising parents (all non-health professionals) and the other a multidisciplinary research advisory group. Interviews were conducted by a female postdoctoral researcher with training in interview techniques and a background in conversation analysis. Interviews took place in a quiet room on the neonatal unit away from the main ward area (n=15), or at the parents home (n=4). Both the timing and location of the interviews were scheduled at the parents discretion. Each lasted around an hour and was audio recorded. All parents were offered a copy of the interview on an MP3 player to keep; of the 14 families 11 accepted this offer, 2 declined and one was lost to follow-up. Interviews were transcribed verbatim and uploaded into NVivo V10 for data management and analysis.

Data Analysis

Data were analysed using thematic analysis[15] where themes within the data were identified which provide a detailed understanding of the perspective of the participants towards the phenomenon in

question. Data were systematically coded in specific detail and then grouped together into broader themes which reflect the content of specific areas of discussion. Themes were revisited to ensure that data saturation had been reached and no new themes were emerging. Two researchers (KG & CS) independently coded the interviews and identified themes, prior to reviewing the data as a whole together to increase the validity of the analysis and reduce any potential for lone researcher bias.

Ethical approval

The study was approved by the North East London Research Ethics Committee (Ref. 12/lo/1949) and Research and Development Department of the participating NHS Trust (PA1301).

RESULTS

Fourteen families participated in the interviews, totalling 18 participants (12 mothers and 6 fathers). Five families chose to have a second interview due to the length of stay of their infant in the neonatal unit, resulting in a total of 19 interviews. Parents were from a broad range of backgrounds and their infants had a range of conditions characterised by the need for critical care (Table 1).

Parent details (n=18)	
Ethnicity	
Portuguese	1
Pakistani	4
White British	8
White other	2
Black African	2
Bengali	1
Marital status	
Married	8
Cohabiting	2
Single	1

Separated	1
Not recorded	2
Infant Details (n=16)	
Sex	
Boy	10
Girl	6
Gestation	
23 weeks	2
24 weeks	2
25 weeks	4
27 weeks	1
28 weeks	1
30 weeks	1
31 weeks	1
34 weeks	2
37 weeks	1
41 weeks	1
Primary Diagnosis	
Extreme prematurity	9
IUGR (28/40 & 31/40)	2
Volvulus	1
Sepsis	1
Pseudohypoaldosteronism	1
Meconium aspiration	1
Low birth weight (37/40)	1

Table 1: Parent participant demographics and infant details

Four of the families had twins. For 2 of these families, one twin had died in a different neonatal unit to that of the study unit. For two families both twins were present in the study neonatal unit and

participating in the study. Five families chose to have a second interview due to the length of stay of their infant. In total, 5 interviews were with both parents present, 11 with mothers only and 3 with fathers only. Thematic analysis of the transcripts identified 15 themes, which could be grouped into 4 organisational themes: (1) initial impact of admission affecting transition into the neonatal unit (2) impact of consistency of care, care givers and information giving (3) impact of communication in facilitating or hindering parental autonomy, trust, parental expectations and interactions and (4) parental perception of respect and humane touches of staff. Each theme and the corresponding representative verbatim quotes can be found in tables 2, 3, 4 and 5.

The first theme, "initial stressors", comprised 4 basic themes which represented the data: (1) sudden and/or expected delivery of the baby (2) postpartum issues (3) the wider family context (4) and neonatal unit orientation (table 2). Families (F) discussed their infant's admission as a response to the sudden and often unexpected delivery of their baby and their wider family dynamics. Mothers discussed how they struggled to cope with their baby's admission when they themselves were still physically recovering from giving birth, and the difficulties they faced adjusting to the neonatal unit environment.

Organisational Theme: *basic themes*	Quotes
Initial Stressors: *sudden and/or unexpected delivery*	F6 "she looked down there and she's like, you're six centimetres, and her face…and I could hear her run, and then all of a sudden…that's when it started, everybody come in, people scanning me, people checking me, people talking to me, telling me right, this is what's happening, we want to get you to (hospital), but you're too far gone, you're going to have to deliver here, you're delivering tonight, you're delivering now" F6 "I just laid there… I just laid there after giving birth to two babies, there was no babies, in the room"
Postpartum issues	F9 "I got transferred in the afternoon, but I was really sore, I had a drain, I had a bag with my urine in it…and when I saw him, and he was so bruised, I couldn't even look at him without crying, so I think I just slept off the morphine for the rest of the day"

Family	F7 “when I came home from here, our eldest…she burst into tears didn’t she and said ‘it’s nice to have you home but it’s weird that you’ve had two babies and they’re not here, like [sic] where are they?’”
Orientation	F14 “It was a bit confusing when we first went in, cause we didn’t quite know, what we were supposed to do, and actually we bought all stuff for (name), nappies, cotton wool and all her clothes, and blankets and stuff like that…you just figure it out”

Table 2: organisational and basic theme 1:Initial stressors: factors which parents faced at the start of their neonatal journey

The second theme, “consistency”, comprised 3 basic themes: (1) inconsistent primary carer (2) information giving and (3) standards (table 3). Families discussed aspects of consistency during their infant’s admission and the resulting implications for their baby and themselves. They discussed the impact of inconsistent primary carers on both themselves and their infant, and their perceptions of information sharing between a large interdisciplinary team, and perceived differences in standards of care between professionals.

Consistency: *inconsistent primary carer*	F17 “the challenge that we’ve had is…there is no primary carer so there’s no one that knows whether her progress is going up or down from day to day, or from week to week, yes I’m her primary carer but I know nothing about medicine” F3: “I don’t feel comfortable seeing a new nurse every day with my baby, I want somebody I know, I’m familiar with, I know she’s doing her job well and I know she’ll take care of my baby…every day seeing somebody new, I have to sit with them, trying to find out if they’re ok…and not careless…because obviously I get scared”
Information giving	F3: “that day when the doctor told us about the bleed in the brain, he should have been a bit more specific…that day was really traumatic for us, we were crying our eyes out, because obviously we don’t want anything happening to our baby, and then at night, we came back again, and there’s another doctor, and the other doctor told us no no, it’s not a bleed, it’s a tiny bruise, and it doesn’t need anything”

Standards	F10 “she was coming to insert the (second) cannula…I said you need to explain to me (why a second cannula is required)…she said this is the way it is and I said well yesterday you guys gave (drug) and (drug) through the same cannula, if that was ok yesterday, why isn’t it ok today? If it’s not ok, why the hell did you give it yesterday?...the doctor came back and explained actually you’re right, you don’t need to give it in a separate cannula”

Table 3:Organisational and basic theme 2: Consistency: how consistency of carers, information and standards during their neonatal stay impacted parents

The third theme, “communication”, comprised 4 basic themes: (1) parental autonomy (2) trust (3) managing expectations (4) insensitive communication (table 4). Communication between families and professionals impacted the parental experience significantly; from building relationships and trust allowing parents to cope more effectively through to the distressing effect of insensitive communication. Parents highlighted the importance of clarity in information giving, to allow them to appropriately manage their own expectations of their baby’s progress and to facilitate their participation in discussions about treatment planning.

Communication: *parental autonomy*	F3 “at the end of the day, I’m his mother and I’m supposed to be looking after him, so I need to know that everything that’s happening with him is correct and I need to keep an eye on everything…at the end of the day, if anything goes wrong, I’m the one who is going to lose everything” F17: “it’s a balance between information, being honest but acknowledging I’m still a parent and you’re talking about my child, and yes, your medical opinion is what counts, but my opinion counts too, and we’re in partnership” F20: “what their thought process is, that sort of reassures me. That reassures me, if I can work out the rationale, I’m happy with that, that’s the thing that’s quite reassuring to me”
Trust	F2 “as far as I’m concerned, they updated us on her condition, the situation…because I’m not a doctor, I’m not expecting to treat my daughter, so I just leave in their hands, for all decisions…and I’m happy with that” F5 “they’re looking after the most precious thing in my life, and I’m really trusting them, to look after him”

Managing expectations	F23 “we didn’t realise at the time, I think with what (doctor) was saying, was really describing the plan for the next 7 days, but we didn’t realise, I think with the benefit of hindsight it would have been helpful to say, this is what’s gonna be happening over the course of the next 7 days” F27 “they will reassure you, like I said they can’t guarantee you what’s going to happen in the future, but they could tell you what’s happening on that day and what happen in a few days along the line” F20: “the more comfortable we've got with knowing the staff, it's easier now to actually just go over and ask, what's going on…every single day that we come in we take the opportunity to just grab one of the regs after the ward round and just, they're very happy to just give us an update, and actually when it comes to talking to the consultant, there's no nasty surprises, you're all up to date”
Insensitive communication	F23 “they were talking about needing to do a blood transfusion and the question you asked was ‘oh do you have enough blood…which the nurse then immediately laughed hysterically ‘of course we’ve got enough blood, we’re a hospital’ which I understand that…I said ‘d’ya want any of mine’…obviously they’re doing this job every single day but sometimes It’s just nice to think a little more about how that came across…why have you just laughed at us and we’re asking the question”

Table 4: Organisational and basic theme 3: Communication: how different aspects of communication impacted upon the experiences of parents

The fourth theme, “respect”, comprised 4 basic themes: (1) parental empathy (2) professionalism (3) multidimensional and (4) humane touches of staff (table 5). The concept of respect united parents: parents wanted professionals to get to know and respect their baby as an individual, and to respect their parental role and family situation. They discussed the importance of professionals having respect for their role and views, and of seeing multidimensional respect between both professionals themselves and with other families. Finally, participants discussed elements of humane touches by individuals caring for their baby which made them feel respected as parents.

Respect: *parental empathy*	F23 "I thought I'll practice what we'd been shown (by the occupational therapist, how to hold her baby), the nurse hadn't said anything about not touching or anything like that, so washed my hands and then went to do what been practicing, bearing in mind the OT had told the nurse that we'd been shown how to do it properly, and then the nurse just shouted out 'no mum! Don't touch her!' And it was just like 'okay'…she could have come up to me and just said 'look mum…don't do it at the moment we need to keep an eye on her temperature, rather than shouting in front of everybody…you're very sensitive you don't wanna [sic] hurt her…but you want to be part of the team" F14 "I made a request she only be given (brand formula) at night when I wasn't there, because I noticed that when she was on (formula) she wouldn't breast feed, she'd be too sleepy from the formula…my request was looked after so that was good…cause you know she's under the hospital care, so they know what's best for her, but it was nice to be acknowledged that, yeah, you are the mother"
Professionalism	F3 "I could see that his diaper was dirty, and she (nurse), I don't know if she saw it or didn't see it, but it's hard to miss…I thought maybe she has a routine, maybe she'll check it after she checks the gases…I went to express, and after an hour I come back, and the diapers still dirty. I asked her, are you going to change his diaper, and she said no when I come back from my break…now obviously they take a break for one hour, I'm a mother, I cannot see my baby lying in filth"
Multidimensional	F27 "when the doctor spoke to me (about baby doing well) and then went to the other (parent and said)…your baby's really really ill…you're boosting me up but you're knocking her confidence down…I did reassure the other parent and say…we'll all hold each others hand and pull each other up when it's like this…your child is gonna [sic] fight it" F17 "we spent forty five minutes an hour with (consultant) agreeing what the plans going to be, and the following week, the first thing that was done, the first consultant was on board threw the plan out the window"
Humane touches	F6 "one of the nurses left a note on the incubator for, it said to mum and dad, and it was just a little update, saying I've been really good, and just saying what had happened that day, and it's nice that some of the nurses can take that time out, and make that personal touch"

Table 5: Organisational and basic theme 4: Respect: how the perceived concept of respect on the neonatal unit impacted parents

DISCUSSION

The aim of this study was to explore parental experiences of interaction with health care professionals during the care of their critically ill infant admitted to the neonatal intensive care unit. Thematic analysis of 19 semi structured interviews identified 4 themes which highlight the importance of the context of infant admission, inter-professional consistency, individual clinical style and culture as perceived by the parents as determinants of parental support and engagement. Our study is one of only a few which provide an insight into the experiences of parents during the critical care of their infant in real time, and our results from a diverse sample of parents provide a crucial understanding of how parents assimilate information and navigate the hospitalisation of their critically ill newborn.

The study is limited in that it only provides the perspective of 14 families in one neonatal unit, and as the overall inclusion criteria for the programme of research identified infants who were extremely sick, our results may not be reflective of all parents in the neonatal unit. Parents may also have been reluctant to criticise the professionals caring for their baby as the interviews were conducted whilst their babies were receiving treatment.

Our findings that respect, consistency of infant carer and communication impact upon parents' ability to adapt to the neonatal environment, reflect previous studies which identified similar themes of parents wanting their role respected and encouraged[7,10] clear and consistent information and the impact of interpersonal relationships with staff.[9,10] When exploring information needs, parents report a desire for consistent, accurate and honest information in order to feel engaged in their baby's treatment, with poor communication leading to feelings of isolation and exclusion from the parental role.[2,7,9] This is reflected by parents in our study who discussed how they felt more able to cope with difficult information when they understood the rationale behind recommendations. Parents also discussed the security they felt in relationships with regular care givers, as they felt more comfortable asking questions to gain the information they needed to manage their own expectations of their baby's progress, and thus be able to contribute to joint discussions about treatment and involvement in care. When parents felt this engagement was not respected through conflict with another professional, either direct or indirect, they discussed their frustration and unhappiness with their

baby's care team. Our findings from the 5 families who were interviewed twice suggest this does not change over time; parents at both time points reinforced their need for clear and consistent information using different clinical scenarios to discuss their needs. These findings reflect those of Russell et al[6] and the UK Poppy study[16] who found that parents experienced dissatisfaction and anxiety if they received conflicting information or if they felt that they had gone against the advice of another professional. Our findings provide an important insight into these engagement issues by suggesting that improved communication is required between professionals themselves, regarding treatment plans and previous discussions with parents, in order to help parents feel more comfortable and confident with their baby's carers.

Parents identified inconsistent care givers and resulting variation in communication styles resulted through being part of a large interdisciplinary team. Few studies have explored associations between care teams and family outcomes however those that have identify positive correlations between smaller and more consistent teams with improved short term outcomes for both infants and parents; a retrospective analysis of electronic health records in an American NICU between 2002 and 2010 found families who experienced increased continuity of care expressed higher levels of satisfaction with nursing care, regardless of birth weight, length of stay and team size.[17] The importance of team structure was further highlighted in a similar study by Miedaner et al who found positive correlations between team continuity, a higher rate of non-invasive respiratory support and parents' perceptions of how well they knew their baby's nurse.[18] Parents in this study echo these findings through concerns that inconsistent care givers results in professionals who do not know their baby well enough to assess their overall day to day progression, making it difficult for parents to build and maintain trusting relationships with the care giver. Staff scheduling and the potential for named care teams is thus an area which requires further exploration to determine the impact upon outcomes, particularly as neonatal units continue to expand in capacity. Regular care givers may arguably facilitate easier knowledge transfer between staff during handover, allowing parents to feel more confident that information is not 'lost' in large complex teams.

Our findings highlight challenges faced by parents in reconciling the often sudden and unexpected birth of their infant with the simultaneous learning of a new medical language, whilst trying to bond with their baby in an unknown environment; a finding consistent with similar research.[9,19] What our findings further suggest is that this complex process of navigating parental roles and responsibilities through behaviours, processes, communication and information may be reflective of a cultural adaptation to the neonatal unit,[20] where parents are socialised into the neonatal community and its established norms and values, behaviours and attitudes. For parents the culture may be strikingly different to anything they have experienced but for the neonatal team, working in this environment on a daily basis, it may operate at a subconscious level.[21] Differences in perspectives and the resulting misalignment of expectations may explain areas of care where parents report dissatisfaction including lack of clarity on their parental role, lack of opportunity to forge and maintain trusting relationships with consistent care givers, lack of opportunity to ask questions and gather information, and lack of consistency in professional advice.[7,9,10] It may also underpin why parents report the humane touches of staff and their own engagement in their baby's care as important: these concepts allow parents to assimilate information and feel involved in their baby's care planning. A recent pilot study compared the impact of "parent-integrated care" in a single unit in Canada where parents assumed primary responsibility for cares such as nappy changes, bathing and feeding, alongside some traditional nursing roles such as recording observations in the neonatal unit, with professional led care.[22] Initial positive findings highlighted short term outcomes such as improved rates of breastfeeding at discharge and increased weight gain in infants.[22] Long term, however, this promotion of the parental role may result in a cultural shift which ultimately changes the nature of communication and care in the neonatal unit, as parents are instantly empowered to assume a level of autonomy through responsibility for their infant.

The interpersonal relationships which parents discussed as being so vital in all aspects of their baby's hospitalisation are echoed by parents in previous studies, where elements such as small talk with staff, and being made to feel like an individual, helped them to cope more effectively.[9,10,23] Individual

clinician style and inter-professional consistency were also highlighted by parents as critically important issues that determine whether parents feel supportively engaged during neonatal critical care. Our study explores the impact of these relationships in real time, highlighting the importance of not only the relationships between parents and professionals but between professionals themselves in the care of the families. Of particular interest was the impact of interactions for families who were interviewed twice. All five families remembered any positive interactions or moments with staff discussed during interview 1, and discussed these further in interview 2. Three of the 5 families however had also perceived a particularly negative experience during their stay and discussed this in detail during interview 1 and 2 and the resulting impact it had upon them. These interactions clearly have a vital and long lasting role in how parents build relationships with the professional team, potentially impacting upon how professionals are able to identify individual family needs and facilitate bonding between the parents and their baby. Further research is required to determine what impact this has on the families stay in the neonatal unit and beyond.

Conclusion

Our findings suggest a range of areas which parents have highlighted as important to their experiences with health care professionals on the neonatal unit, including individual clinician style, inter-professional consistency, and the impact of interpersonal relationships. Such factors may be reflective of a particular neonatal unit culture which has yet to be formally recognised. This requires further exploration to determine any impact this may have, and to help identify how parental support can be improved in order to facilitate an easier transition for families into the neonatal environment.

What is already known on this topic:

- The admission of a critically ill baby to the neonatal unit is traumatic for parents
- Engagement and communication with health care professionals is crucial in supporting parents
- Many studies are retrospective missing the opportunity to understand parental experience during real time critical care

What this study adds:

- An insight into the experiences of parents during the critical care of their infant in real time
- Parents still identify areas where better practice is required to facilitate engagement during the critical care of their infant
- The context of infant admission, inter-professional consistency and culture are important issues for parents which warrant further investigation

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