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# **Parental Participation in NICU-Based Occupational Therapy, Physiotherapy, and Speech and Language Therapy: A Qualitative Study**

## **Abstract**

### **Background**

Parent involvement in neonatal care is beneficial to families and infant outcomes. Few studies have explored parental experiences of neonatal therapy participation.

### **Purpose**

This study had two purposes: 1) to explore parental attitudes and beliefs about participating in neonatal therapies, and 2) to identify barriers and facilitators to parental involvement and suggest ways to optimise neonatal therapy services.

### **Methods**

The study design and data analysis were informed by constructivist grounded theory methods. Semi-structured telephone interviews were conducted with nine mothers of children who had received neonatal therapy.

### **Findings**

After an early period of fear and powerlessness, a transition point occurred where the survival of their infant became more certain and parents were able to consider the future. At this point, participation in therapies was perceived to be more relevant.

Therapy participation was experienced as a means of re-gaining autonomy and control in a context of trauma, but parents encountered barriers related to accessing therapists and external demands on their time.

### **Implications for Practice**

Parental participation is best facilitated by frequent and flexible access to neonatal therapists and staffing levels should reflect this. On commencing therapy, parents should be given therapists' contact details to maximise opportunities for face-to-face encounters.

### **Implications for Research**

Future research is needed to explore parental readiness to participate in therapies in the NICU. Research exploring the impact of parental involvement in therapies over a longer time-frame would be beneficial. Finally, there is a need to determine efficacy and effectiveness of parent-delivered neonatal therapies.

### **Keywords**

Neonatal intensive care unit, neonatal therapies, parents, participation, family centred care, family integrated care, qualitative research, interviews, grounded theory

## Background and Significance

Historically, infants admitted to neonatal intensive care units (NICUs) were cared for by specialist doctors and nurses, while parent and child were almost completely separated<sup>1</sup>. Parental presence and participation in the neonatal setting is now recognised as an important component of high quality care<sup>2</sup>. With supervision and support from the neonatal team, family integrated care provides parents with the skills to be the primary caregivers for their child<sup>2</sup>. Family integrated care has been shown to reduce time to full enteral feeding, improve weight gain, reduce time to full oral feeding, improve breastfeeding rates, reduce length of stay, and reduce parental stress and anxiety<sup>3-5</sup>. In addition to medical and nursing care, infants in the NICU ideally have access to specialist occupational therapists, physiotherapists and speech and language therapists<sup>6,7</sup>. As well as working alongside the nursing and medical teams to support developmental and family integrated care, neonatal therapists treat complex conditions, including neurological impairment, reduced lung function, and swallowing disorders<sup>8-10</sup>. If applying the family integrated care principles to therapies, it follows that parents should be trained and supported to deliver therapy programmes in the NICU and at home after discharge. However, therapy interventions are often complex, going beyond typical parenting and nursing activities<sup>8-10</sup>. While there is some evidence that parent-delivered neonatal therapy may benefit infant outcomes<sup>11</sup>, the impact on parents is an under-researched area.

## Literature Review

Although most research is limited to experiences of specific interventions rather than neonatal therapies as a whole, it tends to report positive parental views about their participation in neonatal therapies. In several studies, parents expressed initial fears and

worries they may accidentally harm their fragile infant; however participation in these interventions was found to facilitate parents taking ownership of, learning about, and bonding with their baby<sup>12-15</sup>. Study have found that after an initial phase of feeling helpless and dependent on the nurses, participation in the studied interventions helped parents feel confident, empowered, competent, and more in control<sup>13,14</sup>. Participation in these interventions facilitated parents seeing themselves in a parenting role and viewing their baby as an active individual rather than passive and fragile<sup>13,14</sup>. In a study of mothers' experiences of early intervention, including therapies on the neonatal unit, neonatal admission was found to require a significant adjustment period for parents<sup>16</sup>. Being introduced to neonatal therapies during this time was often positive, though some parents did not yet understand the need for interventions that were focused on the future rather than their child's immediate medical needs. Several studies identified **that** while parents wanted to participate in therapies, competing demands for their time and insufficient time with the therapist led to reduced participation and education opportunities<sup>13,15,16</sup>. For some parents, being unable to spend sufficient time with the therapist had a negative impact on their confidence<sup>15</sup>.

Three of the above studies reflect parent experiences of specific interventions<sup>12-14</sup>, two of which were under research, not clinical, conditions<sup>12,14</sup>. One paper explored therapies beyond a single intervention and was limited to three mothers' experiences of feeding interventions<sup>15</sup>. Parent views and experiences of delivering a wide range of complex therapy interventions in the NICU remains an under-researched area. This study aims to explore parent attitudes and beliefs about therapies on the NICU, including barriers and facilitators to their involvement, and to identify strategies to optimise therapy services.

## Methods

### Design

This qualitative research was guided by Charmaz's constructivist grounded theory approach<sup>17</sup> and contributions from a parent consultation group. The study was carried out as a component of a master's degree by a student researcher who is also a therapist based in the NICU under study.

### Sample

To obtain the views of families with most to gain from service optimisation, a purposive sampling strategy was used that targeted parents of children with long-term therapy needs. Although purposive sampling can be problematic for grounded theory<sup>18,19</sup>, practicalities prevented further exploration of categories by theoretically sampling for comparative experiences. All participants were parents whose child had been admitted to the same 28-cot NICU in north west England, incorporating intensive care, high dependency, and special care. The NICU's therapy team is comprised of one occupational therapist, one physiotherapist, and one speech and language therapist. No in-house social work or psychology services are available. Some infants, such as those with a neurological impairment, are routinely seen by the therapy team as soon as they are medically stable. Others are referred for therapies by the medical or nursing team if there is a concern about the infant's development. Therapy services are typically available 1-2 days per week and complement the developmental care and family integrated care practices that routinely take place on the NICU. On discharge, high risk infants, such as those born before 30 weeks, are transferred to community therapies for ongoing care. All interviews occurred post-discharge, and all participant's children were

under 2 years corrected age and had received therapies while on the NICU. Parents were excluded if aged under 18 years or if not able to speak and understand English sufficiently for informed consent and interviews. Parents accessing a neonatal follow up feeding clinic were approached by a clinician not involved in the research. Twenty-two eligible parents agreed to receive study information and of these, nine parents participated in the interviews. Recruitment continued until theoretical saturation<sup>17</sup>.

### **Data collection**

Nine telephone interviews were conducted using a flexible topic guide supplemented with additional topics generated via the analysis of preceding interviews (see Tables 1 and 2). Topics included the circumstances of neonatal admission, parent views of their child's therapy needs, facilitators and barriers to therapy involvement, and suggestions for reducing these barriers. Interviews were held between October 2017 and May 2019 and were audio-recorded and transcribed verbatim by the researcher. Identifying information was removed and participants were allocated a random numerical identification code. Following the interview, participants were given the opportunity to verify their transcript. Three parents accepted this opportunity and were happy that it represented their interview. No participants withdrew their data.

### **Analysis**

Data analysis commenced with verbatim transcription following each interview and used a constant comparative approach<sup>17</sup>. Following line-by-line coding, conceptual focused codes were identified that occurred frequently or held particular analytic significance, then combined, clarified and refined<sup>17</sup>. Fourteen additional topics were

identified during the first five interviews (see Table 2). Theoretical saturation was achieved by the sixth participant's interview, from which point no additional topics were raised by participants or the interviewer. Operational and theoretical memo writing was used throughout the study to document research processes, explore areas of analytic significance, identify gaps in data, and develop and refine codes and categories<sup>17,20</sup>. As a member of the clinical team, the researcher was directly involved in the care of several of the participant families. Therefore, reflexive memo-writing was undertaken throughout the study to acknowledge and explore the influence of this relationship on the research and explore other ideas and thoughts relevant to potential preconceptions and biases<sup>17</sup>. Cases that contrasted with the most commonly reported experiences and views were identified and used to consider alternative explanations for the patterns seen in the data<sup>17</sup>. Due to regulations, analysis was carried out by the first author only.

## **Ethics**

The study design and procedures were approved by Yorkshire & The Humber – Leeds East Research Ethics Committee (approval number 17/YH/0260). Due to the sensitive subject matter, the researcher stressed that interviews could be stopped at any point and support resources were routinely provided.

## **Results**

All participants were mothers who had been involved in their child's therapy during NICU admission (see Table 3). Admissions ranged from 3 to 18 weeks (mean = 11.11, SD = 5.78) and were due to prematurity (55%), genetic conditions (22%), congenital heart defects (11%), and brain injury (11%). During the transcript verification process,



one participant showed the transcript to her baby's father and confirmed he had no further insights to add. The core category that emerged from the data was neonatal therapies as a means of regaining parental autonomy in a context of trauma. Two stages of parenting on the NICU were described. Following a triggering traumatic event and NICU admission, stage 1 of the parental journey involved a loss of autonomy and control. A transition period then occurred, during which neonatal therapies became relevant to parents. This transition led to stage 2, where parents re-gained autonomy and felt more control over their baby's outcomes and future. These phases ended when parents were home with their baby.

#### Triggering event

The triggering event commenced when an incident occurred in pregnancy or soon after birth and there was a realisation that the future health and survival of the baby was in jeopardy. For some parents, the events leading to admission to the neonatal unit developed gradually. For others, a sudden event occurred whereby it was immediately clear that the baby was unwell and in danger. Two parents had previous experience of baby loss or high-risk pregnancy and experienced pregnancy as an anxious time. For most, however, the baby's illness was entirely unexpected. Regardless of how the triggering event developed, parents found themselves with an uncertain future and an unravelling picture; a situation in which they could do little but wait.

"I literally had the most perfect pregnancy. I even had the combined screening ... so it was quite a shock" (Participant 4)

### Stage one of the journey: Loss of autonomy and control

While some parents received prompt reassurance that their baby was not in life-threatening danger, for many parents the triggering event led to a phase of helpless waiting and having to cope with an unfolding picture of an uncertain future and a need to rely on medical experts for their child's survival and much of their care. This phase represented a time when parents were focused on survival. Although parents felt positive regarding the medical and nursing care their child received, their autonomy was reduced, and parents felt helpless in an unfamiliar landscape of high-tech medicine.

"It's a situation where you're ... just not in any control at all, you have to totally rely on doctors and nurses and specialists ... you have, you know, no real control over how your baby is ... going to progress, other than just being there and comforting them as much as possible." (Participant 6)

Parents found several ways to cope with this situation, including focusing on the positives and facing the problems immediately at hand.

"I just wanted to face what was the most primary need of [my baby], and deal with that ... you just have to deal with what's in front of you." (Participant 5)

Therapies that focused on future development were not yet a priority for families in this phase. For many parents, the prospect of meeting more staff and being given information about a future that was not yet certain was considered to be unhelpful and an additional stress during an already traumatic time.

“In the early days I didn’t even think about feeding or muscles or sort of anything to do with anything like that. I was just thinking is she going to be alright? ... [Someone talking about the future] would have been more overwhelming that the situation already was.” (Participant 2)

Transition point: “Something to look forward to”

The transition period began when survival became more certain and the family re-focused their attention on the future. This marked the time at which parents both valued and found relevance in developmental therapies. This point sometimes raised worries about disabilities and how families would cope but also came with excitement about upcoming milestones and the prospect of taking their baby home. At this time, parents valued meeting their child’s therapists and becoming involved in therapies.

“I was excited. This is like getting closer to [baby] going home.” (Participant 8)

Stage two of the journey: Re-gaining autonomy and control

Despite ongoing uncertainties and fears, parents experienced participating in neonatal therapies as a means of re-gaining autonomy and control. At this time, neonatal therapies facilitated parental participation in typical parenting occupations, such as feeding and assisting their child to achieve developmental milestones. Parents valued their involvement in these therapies and experienced therapies as a means by which they could regain some control over their child’s destiny and learn about how to help their child develop and progress towards home.

“Feeling like I had a little bit of control over making sure how we felt ... was heard and incorporated into her care, was like huge. You know, in that time where you’re just, you’re a bit lost, the more you know ... the more you feel like you can help her, and the quicker ... you can help her get better.” (Participant 6)

Parents also found the specialist knowledge they gained from therapists empowering and a means by which they could advocate for their baby.

“They listen more to a fellow colleague, don’t they? ... [The therapist] was able to back me up.” (Participant 1)

In contrast to experiences of participating in medical care, parents viewed therapies as an approachable way of participating in neonatal activities and a natural part of parenting. Parents particularly valued therapists being available to support them in developing their confidence. While most parents described feeling comfortable undertaking therapeutic activities, some parents were initially concerned they may hurt their baby. This was overcome with support from the therapists and practice.

“I felt a bit more positive because it wasn’t medical ... It wasn’t any more added pressure to it because obviously playing with a toy, it’s just something you’ll do with a baby anyway.” (Participant 7)

Parents invariably wanted to be involved in therapies but frequently encountered a barrier: accessing the therapist. While parents had varying views on their own child’s

therapy needs, all parents felt therapy needed to be provided flexibly in order to accommodate their own schedules and the changing needs of their child.

“It would be nice if ... they would ... have that, that one-to-one ... with the parents, and just say, “this is what’s happened, and this is what you can do to help”, not just the nurses coming over to you and telling you.” (Participant 3)

Parents appreciated that therapists faced competing demands for their time; however, having to wait to access therapists or having insufficient access to therapy time was a source of confusion, frustration, anxiety, reduced parental confidence, and some parents viewed this as leading to delays in their child’s development.

“I think [not being able to access the therapist] may have ... affected my confidence ... so for me it was like, well how do I do this? Like, do I do it this way, or that way? ... the nurses only know what’s wrote down” (Participant 7)

For some families, the therapy process was delayed until their baby was home and work with the community therapy teams began.

“[Community therapists] showed me ways of trying to help him ... If the [neonatal therapists] would have told me that from the beginning ... he might be more developed now.” (Participant 8)

Home with baby: “A sense of satisfaction”

When home with their baby, parents were able to reflect on the impact of therapies on their child's development and their own role in this process. Parents gained confidence from having participated in neonatal therapies and took satisfaction from having positively influenced their child's recovery and development.

“Coming home [having participated in neonatal therapies] just made me feel so much more confident with him, knowing that actually I can follow him, knowing what signs to look for.” (Participant 9)

“Looking at him and the fact that he's come such a long way, it just gives me that sense of satisfaction.” (Participant 4)

#### Facilitating parental involvement in therapy on the NICU

Suggestions for facilitating parental involvement in therapies included parents being able to directly access the therapy team, having an appointment-based system, and having ‘on call’ access as needed.

“Direct contact that would be very helpful ... if you're oh, we're not sure what this plan is the nurses have told me about, we could ring you and say could you just go through what, what we're doing sort of thing.” (Participant 2)

### **Discussion**

This study aimed to explore parental attitudes and beliefs about therapies in the NICU and identify barriers and facilitators to parental therapy participation. In this sample,

parents experienced different phases of parenting on the neonatal unit, with therapies becoming increasingly relevant to parents in the latter phase, when survival became more certain. Participation in neonatal therapies was experienced as a means of regaining control and autonomy as a parent in a context of trauma and as a facilitator for parents to advocate for their baby and carry out usual parenting activities. Although parents both wanted and needed to participate in therapies, they faced barriers in accessing therapists due to therapist availability and demands on the parents outside the hospital.

These findings are generally consistent with previous studies of parent experiences of participating in therapy interventions in the NICU and expand on these intervention-specific findings to inform neonatal therapy services more broadly. Previous literature not only describes some initial hesitance and fear at the prospect of participation in neonatal therapies, but also indicates that participation is ultimately a facilitator for parents to learn about, bond with, and take ownership of their baby<sup>12–16</sup>. Gibbs et al.<sup>16</sup> identified neonatal admission as a time of significant adjustment, while Nelson and Bedford<sup>13</sup> and Øberg et al.<sup>14</sup> reported parents transitioning from one phase to another; starting with feelings of helplessness and reliance on the nursing staff and transitioning into their parental role via participation in therapy. As reported by parents in the present study, other research has identified parental participation in therapies to be limited by demands on the parents' time outside the hospital, such as family responsibilities<sup>13,15</sup>. Similarly, other studies have reported barriers related to the therapist's schedule and similar consequences for parents as reported in the present study, such as reduced confidence when carrying out therapeutic activities<sup>15,16</sup>.

Parents in the current study anticipated that they would have been reluctant to engage in the neonatal therapy process prior to their baby being medically stable due to fears of bonding with a baby who may die and because survival was the priority at the time. This was particularly the case for parents of preterm infants who were facing a long wait for their baby to mature. For these parents, it was the baby's survival prospects that led to the transition from fear and helplessness to facing and engaging with their baby's future development. Nelson et al.<sup>13</sup> also reported that parents had to overcome these early fears prior to engaging in therapies, and Gibbs et al.<sup>16</sup> found some parents to be focused on the here-and-now during the neonatal stage with appreciation for future-focused therapies developing after discharge home. In contrast, Oberg et al.<sup>14</sup> found the transition point was triggered by therapy commencement rather than the baby's medical progression. Undertaking therapeutic activities was a process through which parents moved from feeling powerless to help their fragile infant to being an empowered parent. Through this transition, their view of their child changed and they now saw them as less fragile and more 'real'<sup>14</sup>. It is possible that while parents in the present study expressed a preference for delaying therapies until their child was medically stable, early therapy education and interventions could be initiated in a manner sensitive to parents' fears and priorities while also supporting parents to gain appreciation of their child's strengths and become empowered in their parenting role earlier in their neonatal journey.

This study has several strengths and limitations. Participants were already familiar with, or were given time to informally get to know, the researcher. Thorough consideration of beliefs and potential biases that could affect the study was undertaken to minimise the



impact of these factors on data collection and interpretation<sup>17</sup>. Negative case analysis was used, and transcript verification was offered to all participants. A coding system was used based on early data and was repeatedly revised and tested. Finally, researcher bias was considered via reflexive memo-writing. Due to regulatory restrictions that confined the sample to one hospital site, the study was not able to make full use of theoretical sampling as defined by Charmaz<sup>17</sup>. The sample was restricted to mothers, all of whom had experience of the same neonatal unit. Nevertheless, the use of an iterative data collection approach and the emergence of recurrent codes and themes provide some confidence that saturation of the key categories was achieved by the sixth interview.

#### Implications for practice

When parents are not empowered to participate in therapies, their confidence in carrying out parenting activities suffers. They are denied the opportunity to learn about their baby, to develop parental confidence, and to contribute to their child's development and recovery. **A strong therapist-nurse collaborative relationship is essential for supporting parental participation in therapies on the NICU, with backing from the wider team and organisation to ensure therapy staffing is sufficient to provide regular, frequent, and flexible therapy services.** Suggestions for optimising NICU-based therapy services to meet the needs of parents are outlined in **Table 4.**

#### Implications for research

Further research into the parent neonatal journey and influences on readiness to participate in therapies would be beneficial. Children admitted to a NICU may have long-term, complex health needs and require ongoing therapeutic interventions. It is not

known how parents view their participation in these activities over a longer, and possibly indeterminate period. Finally, research on the efficacy and effectiveness of parent-delivered neonatal therapies would be beneficial to support clinical practice.

### **Conclusion**

Parental views about participating in therapy activities are influenced by timing and their stage in the journey from neonatal admission to home. The timing of therapy initiation in the neonatal intensive care setting must recognise that parents are operating in a context of trauma and may not have yet reached the transition point whereby therapies and future development are a priority for the family. When parents have transitioned from a phase of helplessness and uncertainty and are better able to see a future for their child, participation in neonatal therapies can help parents to re-gain control and autonomy in this context of trauma. Neonatal therapy services should endeavour to actively welcome and facilitate parental participation in therapies, and staffing calculations should accommodate the need for neonatal therapists to be available frequently and flexibly in order to meet the needs of parents and their children.

### **Conflicts of Interest: None.**

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### Figure and Table Legends

Table 1: Topic guide

Table 2: Additional topics stemming from interview data

Table 3: Participant characteristics

Table 4: Key points for NICU therapy service delivery