

'A hard-won capability': the experiences of parents managing their babies' medicines after discharge from a neonatal unit.

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Abstract

Parents of babies who required neonatal care are responsible for managing their medicines after they are discharged home. There is wide variation in the information and amount of preparation given to parents prior to assuming this challenging task. The aim of the Parent co-Designed Drug Information for parents and Guardians Taking Neonates home (PADDINGToN) study was to explore parents' experiences of managing their babies' medicines post discharge from a neonatal unit and to use this information to develop suitable resources for future families.

A qualitative participatory interpretative approach using a mixture of remote and face-to-face small group interviews or one-to-one interviews was used. Parents were recruited using social media advertisements and convenience sampling from five study sites (four neonatal units in England and one in Ireland). Parents from other neonatal units were invited to take part through social media advertisement. The interviews were audio-recorded and inductive reflexive thematic analysis was used to analyse the data.

Seventeen parents (14 mothers, 3 fathers) participated. One over-arching theme, 'A hard won capability', and four major interpretive themes were generated from the analysis of the data: Being in NICU and the prospect of going home: emotional and practical challenges; Living the reality of being at home: the uncertainty associated with giving medicines; Being at home: battling the system and a lack of support/knowledge; and Suggesting ways forward: parents' lived insights into improving information and resources.

Despite the challenges they faced, parents developed strategies for safely and reliably managing medicines administration and they assimilated knowledge, built their confidence and achieved a capability in medicines administration. Their experiences have been used to build a suite of medicines administration resources to support future parents.

Keywords

neonate, medicines administration, parent, neonatal unit, home

Contribution to the field

Parents of babies who required neonatal care are responsible for managing their medicines after they are discharged home. There is wide variation in the information and amount of preparation given to parents prior to assuming this challenging task. The aim of the Parent co-Designed Drug Information for parents and Guardians Taking Neonates home (PADDINGToN) study was to explore parents' experiences of managing their babies' medicines following discharge from a neonatal unit and to use this information to develop suitable resources for future families. To our knowledge, this is the first study which has used a co-design methodology to develop medicines resources for parents taking babies home for the first time. A qualitative participatory interpretative approach using a mixture of remote and face-to-face small group interviews or one-to-one interviews was used. Parents were recruited using social media advertisements and convenience sampling from five study sites (four neonatal units in England and one in Ireland). Parents from other neonatal units were invited to take part through social media advertisement. The experiences described by parents in this paper have been used to build a suite of medicines administration resources to support future parents.

Introduction

Over 90,000 babies are cared for in neonatal units in the UK and Ireland annually (1). This means that approximately 1 in 7 babies will require neonatal care because they are born too early, have too low a birth weight or have a medical condition that needs specialist treatment (2). This specialist treatment often involves complex medication regimens and is associated with the risk of medication errors. The medication-use process within the Neonatal Intensive Care Unit (NICU) is complex including the use of off-label and licensed medications (3, 4). As medication administration has the potential for considerable consequences if errors occur (5), this has been described as being particularly worrisome (5, 6). Medication error rates in NICU are reported as ranging from 4 to 35.1 per 1000 patient-days (7).

At discharge home, 28% of babies born prematurely are prescribed more than three medicines with the median number of medicines per patient at discharge being 2.5 (range 2 to 7) (8). Family Integrated Care (FICare) encourages parents to give medicines in hospital, thus preparing them for discharge home. However, even in NICUs with established FICare programmes, there is variability in approach. As the establishment of FICare programs is not widespread practice, most medicines are still given by nurses (9, 10,11). Murray et al. explored the views of parents and healthcare professionals (HCPs) around parent-led administration in the NICU. HCPs acknowledged the need for parents to take an active role but had some concerns about practicalities and accountability of parents administering doses on NICU. The study identified the need for clear guidance to facilitate parent participation whilst ensuring patient safety (9). Morris et al. reported similar findings with nursing staff wanting clear documentation to ensure accountability for who was responsible for administering medicines and the need for a communication process with parents around any prescription changes (8). Once at home, the responsibility for medicines administration falls on parents (1) and findings show that the frequency that parents administer medicines at home is increasing (12). There are many factors contributing to this trend including improving survival from serious health problems, the increasing use of medicines to treat health problems, and the desire to move the delivery of care closer to home. A systematic review of carers for all ages has estimated the median rate of medication errors and unintentional medication discrepancies for adults following discharge was 53% (13). The frequency of paediatric medication errors by parents or carers at home varies from 30-80% with risks depending on caregiver characteristics and whether the prescription contains ≥ 3 drugs (14). In cases where a parent was responsible for the administration of medicines to infants born prematurely, the overall administration error rate was 66.3%, with the most common error (54%) being the measurement of a dose which differed from the prescription (54%) (15).

Research has shown about a quarter of all families who start a new medicine experience a problem when administering their medicine within the first month (16). This is perhaps unsurprising as there is variation in both the information supplied prior to discharge and the support given to parents in the administration of medications. There is a deficit in studies focusing on the support and preparation needed by parents of premature babies so they can effectively, safely, and confidently undertake medicines management at home.

This paper reports on findings from focus groups with parents that were part of a larger mixed-methods study Parent co-Designed Drug Information for parents and Guardians Taking Neonates

home (PADDINGToN) that focused on co-designing drug information for parents taking neonates home from neonatal units.

The broad aim of this sub-study was to explore parents' experiences of medicines management of their baby post discharge from neonatal units. The particular focus was the information and preparation they received about medicines prior to discharge and whether there were any gaps in the information or preparation provided. How they addressed such challenges and their suggestions for improving practice were also explored.

Methods

This study used a qualitative participatory interpretative approach using face-to-face and remote small group or one-to-one interviews. It was conducted in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (17). A participatory approach was core to the study. Parent participation was evident through the engagement with two very active parent representatives on the study management group. These parents provided sustained and invaluable insight and guidance to the design of the overall study. They contributed to structure, content and wording of the questionnaires, interviews, focus groups and information sheets and were directly involved in the co-design workshops which formed the final stage of the study (not reported in this paper). These co-design workshops involved a larger group of parents and developed the medicines information resources. A group of 22 HCPs and a new group of parents (n=26) who were not involved in the initial co-design reviewed the resources to refine factors such as content, layout and appearance of the resources.

Ethics approval was gained via London - Bloomsbury Research Ethics Committee (IRAS ID: 21/LO/0351) and the Rotunda Hospital Ethics Committee (REC-2021-O13).

Recruitment and consent

Parents were identified via social media advertisements and the five participating study sites; three in the north-west of England, one in the north of England and one in Ireland. Inclusion criteria were parents (aged ≥ 16 years) of babies receiving care or discharged within the last 5 years from a neonatal unit who will/did require medication to be continued after discharge from hospital. Exclusion criteria included parents/carers who do not speak English. Researchers confirmed appropriateness and eligibility with clinical teams prior to approaching potential participants. For parents of babies recruited via the study sites, researchers did not approach parents whose baby was considered unlikely to survive. Convenience sampling was used with the intention of recruiting up to 25 participants who met the eligibility criteria. The window for recruitment was 4 months and this, along with COVID-19 pandemic restrictions, meant that the planned target of 25 participants was not achieved. However, the data were sufficiently rich to ensure the team were confident of the quality, breadth and depth of the dataset. Written informed consent or e-consent for participation was taken by (RD, JC and AG) and was undertaken either face-to-face, or remotely by telephone or via a secure video platform (Zoom or Teams).

Small group and one-to-one semi-structured interview methods

Initially, the research plan had been to undertake focus groups as they are an ideal method of both generating concentrated data on a topic through interaction between the participants and researcher to explore the differences and similarities between their experiences and contexts (19,

20). However, the constraints imposed by the COVID-19 pandemic meant that it proved impossible for sufficient participants (around 5-8 parents) to be available to attend a remote (Zoom or Teams) or in-person group at the same time. Therefore, the method had to shift, and parents were invited to participate in remote or in-person small group or individual interviews. Some of the principles of focus groups remained place (e.g., two researchers were involved in each interview; one taking the lead for asking questions and the other taking notes, providing additional support and being alert to identifying any potential participant distress) (21,22). The emphasis in the interviews was on encouraging interaction, sharing experiences and ideas and active listening.

The interviews were semi-structured. Short personal introductions by participants and researchers were followed by discussion of the topic areas identified from the PADDINGToN e-survey to parents and HCPs. The small group and individual interviews were undertaken between December 2021 and March 2022 by RD, CB, LB, AG, and JC. The interviews were composed of five main sections: Section 1 welcome, explanation and then an opportunity for each parent to tell an outline story of their experience; Sections 2-4 focused on information about medicines (what information, when it had been given and who gave the information); and Section 5 focused on recapping what had been discussed, checking-in to ensure parents were not upset and reminding parents about what to do if they were upset (see Supplementary File X: Overview of interview structure).

Two researchers (LB, JC) have previous experience of undertaking qualitative interviews and 3 (RD, AG, FO'B) had minimal experience. However, in preparation for undertaking the interviews, a qualitative researcher (BC) with extensive experience of undertaking small group and one-to-one interviews provided guidance and support via remote preparation and feedback sessions.

The interviews were digitally audio-recorded and field notes were made to support the analysis of the data. The audio-recordings notes from the chat rooms in Zoom or Teams and field notes were transcribed verbatim and analysed using reflexive thematic analysis (23). This analysis followed the five stages of inductive reflexive thematic analysis (familiarisation, generating initial codes, searching for themes, reviewing themes and producing report) allowing the shift from descriptive to interpretative analysis (24). Analysis was conducted by AG (female, academic & clinical paediatric pharmacist), JC (female, children's research nurse) LB (female, PhD, academic paediatric pharmacist), FO'B (female, PhD, academic) and BC (female, PhD, academic children's nurse). Pseudonyms were applied alphabetically to parents.

Results

Seventeen parents (14 mothers, 3 fathers) participated; all had experience of medicines management of their baby post discharge from NICU (see Table 1). Eleven parents were interviewed one-to-one; eight remotely and three in cubicles on the ward. Six parents took part in small group interviews with two in each group; two group interviews were done remotely and one in a cubicle on the ward. Table 1 provides an overview of characteristics of the parents and their babies. 5 parents were recruited via social media and 12 (out of 27 parents approached) by research staff in the hospital sites.

The interviews (one-to-one or small group) lasted 18 to 93 mins (average 35 mins). Illustrative quotations are used throughout to support the findings.

Table 1: Characteristics of parents and babies

Parent	Role	Country	Baby	Gestational age at birth (weeks)	Time in neonatal unit	Child's age at time of interview
Abigail	Mother	Ireland	Girl	29	7 weeks	2 years
Bella	Mother	Ireland	Boy	24	18 weeks	4 years
Caitlin	Mother	England	Boy	35	15 days	17 months
Daisy	Mother	England	Girl	27 + 6 days	3 months	9 months
Elijah	Father	England	Girl	-	4 months	-
Ffion	Mother	England	Boy	40/40	3 weeks	14 months
Grace	Mother	Scotland	Boy	29 + 4 days	9 weeks	4 years
Hazel	Mother	England	Girl	26	3 months	8 months
Isaac	Father	England	Girl	-	-	5 years
Josie	Mother	England	Boys (3)	30 +5 days	4 weeks (n=2), 8 weeks (n=1)	2 years
Kelly	Mother	Ireland	Girl	38 + 4 days	1 month	27 months
Leah	Mother	England	Boy	39	2 days plus other admissions	3 months
Maddie	Mother	Wales	Boy	28 + 6 days	3 months. Plus, long-term hospital admission.	13 months
Nora Owen	Mother Father	Wales	Boy	39 + 6 days	3 weeks	3 months
Penny	Mother	England	Girl	30	5 months	16 months
Quisha	Mother	England	Boy	27	8 months	10 months

Note: - denotes missing data.

One overarching interpretive theme, 'A hard won capability', and four major themes were generated from the analysis of the data (see Figure 1). Whilst each of these major themes is distinct, they each inform and relate to each other. The themes are:

- Being in NICU and the prospect of going home: emotional and practical challenges Living the reality of being at home: the uncertainty associated with giving medicines
- Being at home: battling the system and a lack of support/knowledge
- Suggesting ways forward: parents' lived insights into improving information and resources.

The overarching theme, 'A hard won capability', reflects the challenges faced, the skills and knowledge and the strategies used and proposed in relation to parents' experiences of medicines management of their baby post discharge from NICU. Additional illustrative quotes are presented in Table 2.

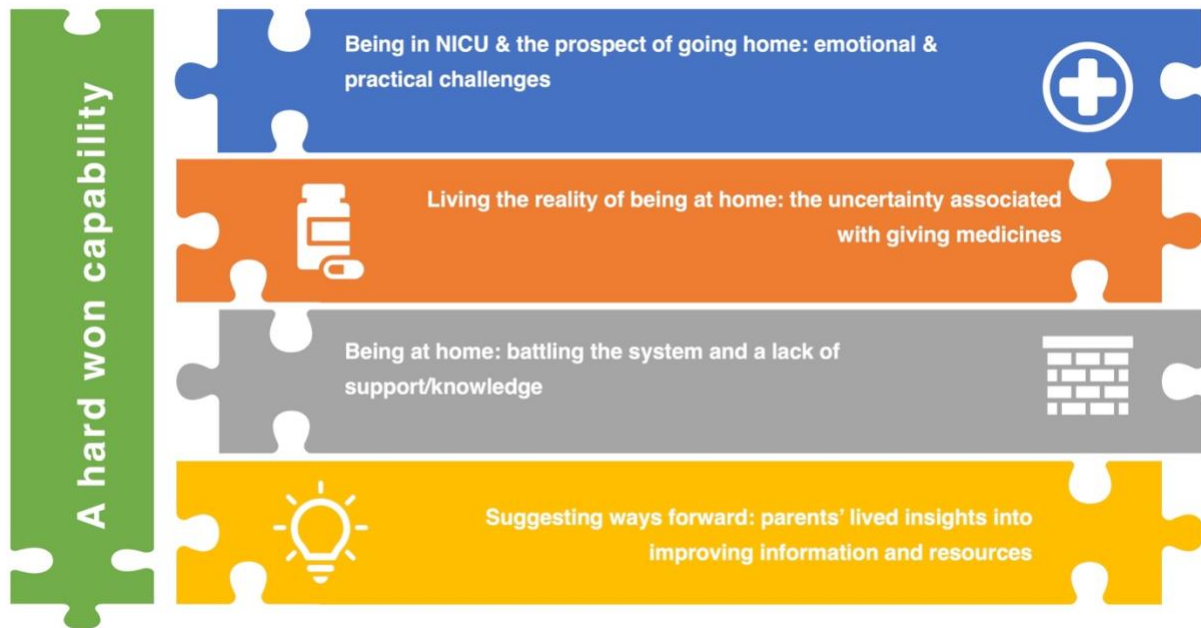


Figure 1: Overview of overarching and major themes

Theme 1: Being in NICU and the prospect of going home: emotional and practical challenges

Within this theme parents’ responses to and the emotions evoked by their baby’s admission to NICU and subsequent discharge home, are explored. The initial experiences of being in NICU provide the context for their experiences of taking their baby home. NICU was described as “*a shell shocking... [and] terrifying environment be in*” (Abigail). Quisha described herself as being “*really scared*” noted that this was heightened because her “*English is not so good*”. Typically, parents described their baby’s trajectory through NICU as being a “*very up and down journey*” (Bella) with a sense of fear of what would happen next. Parents often were torn between feeling they needed to be in NICU but also pulled by their responsibilities at home; this was particularly challenging for parents with other children. Abigail explained “*really my mind was everywhere you know*”. The pull to go home was strong and for some parents, this superseded any other considerations:

“I didn't care what they gave me to come home.... If I was giving her medication for every half an hour, I wouldn't have cared. Just get me home!” (Kelly).

Although some parents were given information about and opportunity to practice giving their baby medication, this was not the case for all. Grace said she thought that there was “*an assumption that we kind of knew what we were doing*”. Many parents had not been involved in learning about or giving their baby medications whilst they were in hospital or where they had been, the timing varied. This was seen as a missed opportunity, and Abigail explained that she “*wasn't really hands-[on] involved in helping administer medication*”. However, some parents were proactive about finding out about the medication their baby was prescribed. Bella explained she would regularly ask:

“What's this medicine for..... what does it do... is that medicine stopped now?.... I just was afraid that something would be missed andI got very used to being very involved in the day-to-day” (Bella).

Parents were aware that giving medication required the acquisition of skill and confidence and that some medicine-related tasks could challenge health professionals. Josie reflected that when she saw

a nurse “struggling” she thought “if she doesn’t know, how on earth am I gonna manage this at home?” (Josie). Hazel talked of the importance of practicing giving medicines before her baby was discharged home:

“it gives you that confidence... even it though it was sort of simple putting it in the bottle.... it is such a big scary thing with her being so small” (Hazel).

Parents experienced various levels of advice pre-discharge ranging from “nothing.... they literally put them into a bag handed them to me and off we went” (Abigail) through to being given “a piece of paper and it was like ‘there’s dosage, off you go’” (Bella), to a schedule (timetable) of medicines. Elijah was positive as he explained “we were given time to practice”. Some parents were exposed to more detailed information supported by videos, demonstrations by the nurse, support from a specialist and links to websites. However, typically this related to management of equipment (e.g., PEG tubes) rather than medication. Bella said that “the hospital should be more aware of the holistic needs that a family has instead of just focusing on maybe just the baby’s needs”.

Theme 2: Living the reality of being at home: the uncertainty associated with giving medicines

For many parents the joy of being at home was muted by the sudden realisation that giving their baby medication was complicated, and many talked of being terrified by the responsibility of the role and the potential for error. Daisy explained “trust me.... I didn’t think it would be this hard”. Josie summed up her terror, explaining:

“when your babies are premature, you’re terrified of everything, so you do exactly what you’re told ... I remember thinking ‘I’m really daunted by this, I do not know what I’m doing’ (Josie).

Another mother talked of initially “being confused... [having to do] everything yourself” (Quisha). Caitlin talked of the pressure to ensure her baby “had exactly the right amount of milk and medicine”. However, parents instigated strategies to help them cope with the stress and challenge and support their proficiency and capability. Ffion explained “we worked out what worked for us”. Typically, this involved creating a schedule or a list to keep things on track as one of the mothers explained:

“I just did my own [list]...I’ll have morning meds in one section and then like the afternoon’s and then at night. So I did just write everyday morning, afternoon, night and then every day when I’ve given it I just cross it off so I know I’ve done it” (Penny).

Some parents talked of the role of giving medication made them feel initially more like “a nurse... [although acknowledged that] over time I turned into a parent” (Bella). Most responsibility fell on the mothers as any information shared had usually been shared solely with the mothers.

Most parents second guessed themselves and at times, worried about “have I done this right”? (Josie). The fear of overdosage was visceral, Bella explained “I was terrified of giving the wrong amount” and parents were concerned about the consequences underdosing or of omitting doses:

“we were never given the, I suppose the comfort, that if he doesn't have it, what it could do, what to look out for. For those four days we were on tenterhooks” (Nora).

Some parents put checking processes in place to reduce the risk similar to those they had witnessed in hospital. Quisha explained that *“I tell my husband come check it ... check if I am right... I don't wanna give him more or less”*.

Parents were vigilant about giving medicines and some were concerned about not knowing about potential *“side effects”* (Bella) and *“I didn't know it wasn't licensed for children”* (Kelly). Information about potential adverse effects did not appear to be routinely shared with parents:

“we were given the prescription, and it was literally on a notepad paper the nurse wrote it down from obviously her own file. And it was like... there you go... so nothing about side effects” (Abigail).

Other concerns related to whether medicines could or should be prioritised or what to do if a dose was missed and that this could create a sense of *“panic”* (Josie).

Theme 3: Being at home: battling the system and a lack of support/knowledge

For some parents battles with the system started before their baby was discharged. This was most obvious in the families living in Ireland where financial aspects of the health system added complexity. Abigail recalled *“fighting for everything... [and being] the only one in the battle”*.

All parents talked of the challenges of managing medicines at home; this was especially complicated with the interplay of different medications. For some babies, this could be compounded, by parents having to consider their babies' oxygen therapy requirements. Bella sums this dilemma up:

“I was constantly overanalysing... Was that a side effect of the medication? Is that normal? Is he lacking oxygen? Do I need to increase the oxygen? I didn't know, I wasn't confident” (Bella).

Changes to medication or the form in which the medication was dispensed, could create additional challenges and make parents doubt themselves. Quisha's capability was diminished when the sildenafil she had ordered as a repeat prescription was sent through to her in powder form, as she was used to it being made up for her as a liquid and she did not know *“how to mix this or what do I need to put in there”*. Quisha eventually gained the advice she needed from the hospital pharmacist. Some parents were disconcerted when the brand of medication they were used to and trusted was changed without explanation. Another aspect of medicine administration that created challenges, was when the route was changed meaning parents felt unsure about how to translate prior learning to a new situation:

“I only ever saw them put it in through that [nasogastric tube]. And of course, putting it into his mouth is totally different. So I used to mix it in with milk but again I was like ‘Does it matter if it's warm or does that affect the medicine?’ I wasn't sure” (Josie).

Sustaining supplies of medications was often complex. One mother recalled how *“we were never given information on how to get [ongoing supplies] ourselves”* (Nora). Another parent talked of how the medications were *“a pain to get hold of”* (Penny) especially when it was not clear who had

responsibility for prescribing, and the delays this could create and the number of calls she had to make. Abigail recalled the stress associated with getting medication dispensed:

"I remember having nearly a meltdown in the chemist. Like how hard is it to order this brand? And they were like 'Well that one costs 350 euro, to order you need to ring the DPS scheme'. And I was like 'None of that was relayed to me'" (Abigail).

This stress needs to be considered in the context of the parents already having to deal with so many factors caring for their premature baby at home; typically, parents talked of being *"so busy with him, there's so much work"* (Quisha). Nora summed up many parents' experiences saying:

"when you're going home with the baby that's poorly you don't need to be chasing other professionals" (Nora).

The challenges of medicines management were compounded by a sense of isolation from people who could provide clear advice, support and reassurance and explain *"don't worry about it, it's absolutely fine"* (Josie).

For some parents, the professionals such as General Practitioners (GPs) and other community health professionals to whom they turned for help and had little knowledge of the medications or the needs of their baby. Caitlin talked about the problems this created:

"we've been sent home a few times from hospital... with medicines for the GP to continue [and] the GP's been a bit unsure about what they've told us to do... It's hard when it's just a piece of paper to show them" (Caitlin).

Hazel echoed these concerns. Parents were sometimes positioned as the person apparently expected to, and capable of, being the conduit between the hospital and community; this taxed their own understanding and was stressful. Isaac suggested *"a linked up IT system"* was needed to support communication. Being at home and being expected to know what to do was at odds with the relatively sheltered experience of being in hospital, where skilled and knowledgeable help was readily available. Without access to knowledgeable HCPs some parents turned to the internet, although this had limited value and was not trusted. As Kelly explained *"every website seems to have health written in it, but you don't actually know whether it's factual or not"*. Grace wanted real information rather than *"just kind of Googling ...or TikTok"*. Other parents also talked of the responsibility placed on them to ensure their GP was informed of the medications their baby was prescribed; this was deemed to be unreasonable. Reasons for this included the GP letter being lost requiring the parent to fill in the gap by going to see their GP. Penny explained that *"if you haven't got all of them bottles, you don't know [what to tell the GP]"*. Owen made his feelings clear:

"I think it's the reliance on the parents ... to make sure that all the information, the finding of the GPs, the online patient's script, whatever, the initial one done, that the responsibility is put on the parents and it's not possible" (Owen).

For some parents, their sense of responsibility also included checking whether the medication should be stopped or continued. Kelly recalled her actions:

"so I just kind of stopped them [spironolactone and furosemide] naturally myself, but nobody had told me to stop them bar the nurse kind of mentioning it in passing" (Kelly).

Theme 4: Suggesting ways forward: parents' lived insights into improving information and resources

Although there were examples of good practice relating to informing parents and promoting skills and confidence relating to medicines management; many parents felt ill-prepared and ill-equipped to be capable, confident, skillful and informed. One mother reflected on the lack of priority given to medicines management, recalling:

“we did have a CPR class... so I don't see why they can't do medication administration class and support” (Abigail).

Based on their experiences and their reflections, parents were able to provide clear ideas about ways in which HCPs in the neonatal unit could better help them prepare to manage their babies' medicines at home.

At a minimum, processes need to improve on the experiences many parents described as just being *“given your medicines and basically off you pop get on with it”* (Penny) or information *“done to tick a box as opposed to meaningful engagement to support the parent”* (Bella). Daisy suggested that a system to help remind parents about when to give medicines as she sometimes *“forgot”* to give a dose.

Three key aspects were identified: more consistent, better-timed and more clearly presented and useful information shared with both parents; who should provide the information; and opportunity to practice.

Even parents who felt that *“on the whole [preparation] was fine”* (Caitlin), still talked of having some questions they would have like asked pre-discharge:

“we were giving [multivitamins] to him in his milk. I wasn't 100% [sure]... when I got home whether it was okay to put the other [medicines] in his milk” (Caitlin).

Other parents recalled feeling overwhelmed by input and information on the neonatal unit but not being able to take it in or recall it accurately. The timing of information was also important as information given at the start of the neonatal unit journey might not seem important until they were discharged. Abigail had forgotten about the booklet they had been given soon after admission and only came across it under her bed (where her husband had put it) when she was tidying things up at home. Grace said that for her the right time was *“the days leading up to the discharge”*.

Caitlin emphasised the importance of information being shared and returned to during their stay in the neonatal unit as *“the more you see and hear something, the more it kind of sinks in”*. Caitlin also thought that HCPs should include her husband noting that it would have been *“helpful... when my husband had come to pick us up, they'd [HCPs] done a run with us there together”*. Quisha talked of how she sometimes missed out on being able to talk to the doctors *“because I couldn't go early morning”* when they did the ward round. Elijah talked about sharing information was important since he and his wife *“shared responsibilities [for medicine administration]”*.

Verbal information was valued as it engendered confidence and the HCP could provide additional explanation and reassurance and telling you:

“don’t forget or don’t mind about this one... Like this is the big one or the serious one and just make sure administer it in the morning” (Bella).

Structured, planned written information (either in a group or one-to-one) was perceived as being valuable as it provided a back-up or reminder; suggestions included *“some sort of written plan”* (Nora) or a *“logbook”* (Abigail). Parents suggested that this structured information should contain information including the timing of medication, dosage, administration, adverse effects, and which medications were the most important. This could be done one-to-one or in a group. This would both inform parents and would be useful when parents were engaging with community-based HCPs to improve communication and reduce the need for having *“to check with the hospital”* (Penny). However, parents warned against too much detail. Kelly explained she *“probably wouldn’t have wanted to know everything”* whereas another mother explained:

“I’m not gonna sit through and read through all this about where it was manufactured and who did x y and z. But a really simple sheet without too much written on it [would be helpful]” (Caitlin).

This mother further explained that the sheet could also contain contact information as this could reduce worry about who to contact and whether this contact was legitimate. Another benefit of written information was that it allowed parents to go through information at their own pace with the chance to *“get your head [round it]”* (Josie).

Parents also wanted information and skills acquisition to be offered and available to their partners, noting it *“would be nice to know that [partner] had a resource”* (Kelly). Some parents talked of storing up questions to ask their consultant at the next clinic visit, as they were unconvinced they would get clear or informed replies from community based HCPs. However, as Bella explained, the consultant indicated that these were questions the GP should be answering. Bella’s response was *“I know, but you’re the one who knows [baby’s name] the best, so that’s what we were doing”*.

Whilst parents thought that the consultants and doctors were knowledgeable it was suggested that they *“might not necessarily have the personal touch..... they’re very textbook.. they can sometimes be a little bit cold [whereas] the nurses are extremely warm”* (Bella). Caitlin agreed that information would be best shared *“by the nurses and the healthcare assistants.....the ones that were caring for [baby’s name] day-to-day”*. Although hospital pharmacists were perceived to be experts and *“good at their jobs”* they were thought of as being *“more removed”* (Bella), so less likely to be involved in giving medicines management advice pre-discharge.

Many parents wanted to have been able to practice giving medications prior to discharge as they recognised that this task was a *“massive responsibility”* (Nora). This was not routinely done on the neonatal unit and typically, parents had minimal or no opportunity to practice before discharge. Isaac suggested that it would help if they had *“been witnessed when [they] were administering medication”*.

Table 2: Additional illustrative quotations

Theme 1: Being in NICU and the prospect of going home: emotional and practical challenges	
You're kind of terrified you're waiting, probably an element of PTSD I'd say you're waiting for the next bad thing	Bella
I watched them [videos] all a few times before he came home and then I went to the hospital, she told me that there was a special person that dealt with this and she showed me ...like live, what happens if he takes it out, how to clean it, how to put the peg in, how to feed him and all.	Quisha
The nurse who always attended the baby explained clearly what was to be done and what was not.	Elijah
It was just such a kind of I think emotional time anyway, I don't think that the medication side of it was maybe prioritised.... almost because there was so much else to think about.	Grace
Theme 2: Living the reality of being at home: the uncertainty associated with giving medicines	
It would've been helpful for me if perhaps when my husband had come to pick us up they'd done a run with us there together. Rather than when I get home and I feel like it's on me to remember everything and its erm you know do everything myself.	Caitlin
I was terrified of giving the wrong amount, I was terrified of in case I gave a double dose I was so tired ... A constant fear ... We just got paranoid about overdosing him.	Bella
[I'd used] the wrong syringe for one of his medicines for the first few weeks before I realised I was giving him a lower amount than he was supposed to have.	Caitlin
You get overwhelmed. You forget. I've missed doses, I won't lie, I've missed them. But I tell myself it's not the end of the world, what matters is you pick up you keep the pace	Daisy
I didn't know that I didn't know which ones were... the most important... [which ones] you're not just gonna ignore..... but you do panic when you do forget ..cos that happens.	Josie
We both shared responsibilities and made sure time was taken off...we always had reminders	Elijah
I only realised that I was only supposed to be giving on an empty stomach...to be fair I mixed it with feeds. I think it was when I came home one day, when it was dispensed, and the pharmacist wrote 'Give 30mins to an hour before meals'. Then I went online to read and I realised 'Oh I've actually been giving [it to] her every day with food. So, what is that doing to her'?	Daisy
Theme 3: Being at home: battling the system and a lack of support/knowledge	
You had to have the prescription for [the respiratory monitor] so you could claim it back. You had to rent them from the company... it is a fight ...to get your money back. Why am I shelling out all this money to try and get my baby home, when it should be really provided? (Abigail).	Abigail
As a parent you don't really understand... so [GP] would say 'Oh don't worry about it they've just changed the bottle' or if it looks different 'Don't worry no one's using that one anymore, this is the newest one'.	Josie
So, our doctors [GP] didn't [prescribe it]... then you'd have to phone and get a hold of the hospital to get hold of dietician and then get them to get hold of the pharmacy in here and then get the pharmacy to get hold of you to get your medicine. ...It takes like a day or two without that medicine and obviously if it's important if she needs it. So, it was a nightmare.	Penny
Like some things... you don't understand but they're [community professionals are] asking you to explain and you're sort of like 'I don't know, that's all I know'.	Hazel
[In hospital, it's different] if I had any questions or any concern, anything, then I just tell the nurse to come, call them, and then I could tell them anything.	Quisha
In a perfect world you know the hospital and the community would be completely communicating and united.	Isaac
Theme 4: Suggesting ways forward: parents' lived insights into improving information and resources	
You're told things [on neonatal unit], but you don't remember everything because there's so much information.	Nora
Having everyone in a room [in neonatal unit with a professional] saying 'This is your meds' as a sort of group intro, then individual [information]... If I was running the unit. that would be my use of time.	Isaac

I just think you're more confident if someone's sitting down with you, reassuring you...	Bella
I think a little checklist or a little booklet or whatever for the hospital nurses or staff to show that they've trained the parents, that wouldn't be the worst idea like a mini training program	Quisha
I think there should a logbook a proper book sent home with you, nothing was sent home with me it was literally given on a piece of paper.	Abigail
I think having a bit more, not so much, communication but just feeling that there was a bit more of a joined up-ness like you say health visitor, GP, neonatal hospital setting as well	Grace
Perhaps, being given just a direct contact number and somebody ... making it not seem like you'd be ringing about something trivial if you know what I mean if you were ringing about or I've forgotten, am I supposed to give this or this or whatever (Caitlin).	Caitlin
If you've got the information and the medicine in front of you... or a picture of the bottle or something on the information, you can get your head [round it]...Having it written down a few days in advance would've been great because I could've then sat and gone through that so then I could've asked questions in the in the last couple of days before they were discharged so that I was reassured with anything that I wasn't sure about.	Josie
Writing is the last thing I like to do, so what I do is I have a medicine basket So what I give comes out of the basket, so at the end of the day if I see that two bottles are left in the basket I know we still have two more to go.	Daisy

Discussion

The study aimed to explore parents' experiences of medicines management of their baby post discharge from NICU. The findings clearly show that parents acquired the skills and knowledge they needed to become capable in the challenging task of administering medicines to their baby. The term capable infers the 'ability or power to do something' and to a greater or lesser extent, parents' power or ability to manage medicines was constrained due to various factors including stress, lack of preparation and information about medicines management, uncertainty related to medicines management, communication problems and lack of support within the community. Despite these challenges parents developed strategies for safely and reliably managing medicines administration and they assimilated knowledge, built their confidence and achieved a capability in medicines administration, albeit that this was 'a hard-won capability'.

Parents talked of the stress they experienced whilst their baby was in the neonatal unit and their experiences aligned with the experiences of other parents as evidenced in studies and systematic reviews (25-28). The alteration of parental role has been identified within the global literature as a source of stress for mothers and fathers in neonatal units (26). Lack of parental involvement and engagement in caregiving whilst in neonatal units and during the discharge process, impedes parents' preparedness to care for their infant at home (26, 29). Despite longing to go home, parents must accommodate the transition from the high initial stress of the neonatal environment to a similarly stressful environment of being at home and responsible for administering medicines. This is compounded by their awareness that their baby is small and fragile (30).

Typically, parents' knowledge and skills were acquired in an ad-hoc manner, with little formal education and preparation from HCPs prior to discharge from the neonatal unit. The need for planned support, information and preparation for transition is identified in other studies as being important (2, 30). There is good evidence that family centred care and education within NICU can empower parents and improve their skills and knowledge (28). Family integrated care can also reduce maternal stress (27). However, there is little evidence that such programmes and approaches are addressing medication administration. Most medication administration on NICU remains nurse

led (9). Where education on medicines administration does not occur, parents must rely on other ways of acquiring knowledge and skills. As seen in other work, a strong thread of experiential and reflective learning (31, 32) was evident in the way that parents talked of developing their ability to manage medicines. Their learning mostly occurred within the home, without support from HCPs and was triggered by the requirement to develop their capacity to manage medicines safely.

The uncertainty associated with giving medicines and fear of making a medication error, was compounded by the communication problems and lack of support within the community. Parents in this study and other studies felt unsupported within the community and found the lack of expert advice compounded a sense of isolation and heightened their sense of responsibility to manage on their own or rely on asking hospital-based professionals for advice (10). Other studies have identified parents' role and the stress inherent in being expected to act as the go-between for information sharing and communication between professionals (33).

Based on the insights from the parents in this study, and supported by literature specific to neonatal medication administration, the way forward would seem to be the implementation of a parent-led, participatory framework to support and educate parents about safely, capably and confidently administering medicine (9). Robust written and verbal information for parents about medications can reduce the likelihood of errors (34)

Such an approach would build on the more in-depth evidence of the benefits provided by family centred interventions to support parents in neonatal units (e.g. enhancing knowledge and skills) (27, 28). Although there is less evidence available on the impact of post-NICU discharge support and education interventions, multiple benefits for parents (e.g., increased competency and confidence) have been demonstrated (34). As with parents in other studies, parents proposed improved engagement with community-based providers and services (33, 36). The strategies the parents proposed to improve their preparedness, confidence and capability were based on their experiences and are ones that are relatively simple to implement. They are also evident in guidance on preventing home medication errors (37). They included better education and opportunity to practice, written information and review of medication. Parents developed their own schedules for guiding their medicine administration. Other studies have shown aide-memoires can be useful, although some concerns are raised about accuracy (38, 39).

The strengths of the study include the study design which encouraged the engagement and interaction of parents who were supported to share their experiences. The study also had some limitations. Parents who participated were predominantly mothers (only three fathers participated). Data was not collected on socio-economic status, ethnic group, national identity, religion, sexual or gender identity. The sample was not representative of the population as a whole; as such, the findings may not reflect parents from more vulnerable groups or in more marginal circumstances. The shift to small group or one-to-one interviews rather than using focus groups and the impact of COVID restrictions on face-to-face interactions reduced the opportunities for parents to interact with each other and share ideas; this may have limited the findings generated. Whilst the majority of participants were recruited within two years from their neonatal discharge a small number of participants (n=4) were interviewed between 3 and 5 years post discharge and therefore may not have had the same level of recall about their experience. Another limitation relates to the limited demographic data (e.g., birth weight, medical acuity, duration of admission, ethnicity,

socioeconomic status) routinely collected in this sub-study; this means that the influence of such factors on parent responses could not be considered.

Conclusion

Confidence and competence in medicines administration was 'a hard-won capability' for the parents in this study. HCPs are well positioned to support parents in preparation for discharge home. Preparation should include practice giving medicines, an overview of the practical issues they may face following discharge and standardised written information, including how to obtain further supplies of medicines. Improved communication between hospital-based HCPs and those in the community would also help reduce difficulties for parents at this particularly vulnerable time.

Parents described both the weight of responsibility of giving medicines to their baby and their fear of making a mistake and the unknown consequences should this occur. Provision of simple medicines information, co-designed with parents, as early as possible prior to discharge, could provide reassurance and have the potential to make a huge difference. Standardising this information across all neonatal units in the UK and Ireland, and in the community could ensure a consistent message was provided to parents, no matter who provided this information.

A set of PADDINGToN resources have been co-designed with some of the parents involved in this study and will be made available.

Other matters

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Ethics statements

No animal studies are presented in this manuscript.

The studies involving humans were approved by London - Bloomsbury Research Ethics Committee (IRAS ID: 21/LO/0351) and the Rotunda Hospital Ethics Committee (REC-2021-O13). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

No potentially identifiable images or data are presented in this study.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Conflict of interest statement

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest

Author contribution statement

Idea for the article (AG, LB, FOB, JC, BC); design, implementation, conducting the project (AG, LB, FOB, JC, RD, CB); data analysis (AG, LB, FOB, JC, BC); and writing (AG, LB, FOB, JC, BC, RD, CB).

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