

BMJ Open Quality Redesigning care to support earlier discharge from a neonatal intensive care unit: a design thinking informed pilot

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ABSTRACT

Background Preterm infants may remain in neonatal intensive care units (NICUs) to receive proper nutrition via nasogastric tube feedings. However, prolonged NICU stays can have negative effects for the patient, the family and the health system.

Aim To demonstrate how a patient-centred, design thinking informed approach supported the development of a pilot programme to enable earlier discharge of preterm babies.

Method We report on our design thinking-empathy building approach to programme design, initial outcomes and considerations for ongoing study.

Results Through the use of design thinking methods, we identified unique needs, preferences and concerns that guided the development of our novel early discharge programme. We found that stable, preterm infants unable to feed by mouth and requiring nasogastric tubes can be cared for at home with remote patient monitoring and telehealth support. In addition, novel feeding strategies can help address parental preferences without compromising infant growth.

Conclusion A patient-centred, design thinking informed approach supported the development of a pilot programme to enable earlier discharge of preterm babies. The programme resulted in a reduced length of stay, thereby increasing NICU bed capacity and limiting hospital turn-aways.

INTRODUCTION

Background

In the USA, nearly 1 in every 10 babies are born preterm¹ and estimates suggest that between 64.0 and 77.9 babies per 1000 live births are admitted to neonatal intensive care units (NICUs).² After initial acute care, these infants remain in NICUs to gain weight via nasogastric (NG) tube feedings. These babies, sometimes referred to as ‘feeders and growers,’ stay in the NICU until they reach feeding maturity and are able to consume adequate oral nutrition.³

Disadvantages of prolonged-NICU stays

NICUs are noisy, disruptive and potentially harmful for newborn babies. Extended NICU stays can affect infant growth and

development, increase risk of infection, disrupt the family unit, impair maternal-infant bonding and impose additional burdens and cost on the parents, providers and health system.⁴ Additionally, for rural patients, travel between home and the hospital further increases the burden on families and may delay parents’ ability to return to work.

Advantaged of earlier NICU discharge

Earlier discharge of preterm infants decreases the infection risk, breast milk and medication errors, and neurodevelopmental concerns around overstimulation of prolonged NICU stays.^{4–8} With adequate medical support and monitoring, early discharge improves care quality while decreasing the overall cost of care.⁹ One early discharge programme demonstrated over 2000 hospital days saved over a 7-month period, with an estimated US\$10 609 saved per infant discharged.⁹ Another programme found length of stay reductions of 17 days/per patient and cost savings of nearly US\$18 000/patient.¹⁰ A small pilot early discharge programme demonstrated a reduction in length of stay of 10.6 days and cost savings of US\$7674/patient.¹¹ Beyond cost, early discharge programmes are also associated with high-satisfaction and preparedness, and positive quality indicators (eg, growth and readmissions).¹² Prior research highlights potential savings, but also recognises a need for strategies to monitor and mitigate health risks of earlier discharge.¹³

Design thinking approach

We employed principles of design thinking to guide our innovation and care redesign. Design thinking is an approach that focuses on empathising with stakeholders, incorporating multidisciplinary perspectives and rapidly prototyping solutions.^{14 15} Design thinking has been used to tackle a wide range of complex problems.^{16 17} Within the health-care context, design thinking considers



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patient and provider perspectives to increase the likelihood of successful implementation and sustainability.¹⁸ Given that parent comfort with a new care model would be essential for its success, a design thinking approach was ideal for ensuring that we incorporated parent perspectives into redesign plans. By actively seeking out parent perspectives throughout the project period, we hoped our new care approach would meet the needs of these families and enable us to identify and address potential barriers early in the redesign process.

In traditional quality improvement efforts, teams may jump right to solving problems; in design thinking, an early emphasis on interviewing and developing empathy, while reviewing existing literature, helps ensure the project focuses on addressing the correct problem before designing solutions. In addition, design thinking encourages an iterative approach, where the programme is modified throughout development to better meet the needs of patients, families and healthcare providers.

Aims and objectives

In this manuscript, we demonstrate how our patient-centred, design thinking informed approach supported the development of a pilot programme to enable earlier discharge of preterm babies. We report on our programme design, initial outcomes and considerations for ongoing study.

METHODS

Setting

A 30-bed NICU that cares for a combination of acutely ill infants as well as stable and growing premature infants, situated within a rural academic medical centre/level III referral hospital that serves a population of 1.9 million patients across the region.

Our team

Our team consisted of one physician, one nurse practitioner, one nurse, a managed care organisation representative, a social worker and two patient representatives (mothers of previous NICU patients). We were also supported by members of the innovation staff who brought additional multidisciplinary perspectives to the team.

Patient and public involvement

The public was involved in the selection of this project as a focus for healthcare redesign funding support. Following project selection, the use of a design thinking approach involved parents of the target patient population in all phases of the redesign. The team itself had two patient-innovation-partners included as team members. The patient innovation partners were identified through a prior role serving as advisors to the intensive care nursery follow-up clinic. The process also involved interviewing others with lived-experience. As families completed the programme, they were invited to join a committee where they could provide feedback and guidance on further

programme refinement. Due to the voluntary nature of the committee and the demographics of the surrounding community, committee membership tended to be upper-middle class and white. Consistent with parents of babies who spend time in the NICU, many experienced postpartum depression and anxiety. Parent voices are included in the manuscript and in public presentation of results.

Methods to build empathy

Interviews

We interviewed 53 stakeholders, including 16 parents and 9 neonatologists, 5 neonatal associate providers, 15 nurses, as well as a social worker, a speech language pathologist, 2 lactation consultants, a dietician, a parent support person and representatives from two similar neonatal early discharge programmes. Interviews were conducted by a member of the project team, with another member serving as the scribe. Semistructured interview guides, including a parent and a provider version, were written adaptively and reevaluated after each interview. Due to the COVID-19 pandemic, interviews were conducted over the phone or via videoconferencing software (Zoom or WebEx). Interview duration ranged between 15 min and 1.5 hours.

Patient journey maps

Our interviews informed the development of patient journey maps which depict the newborn's journey from hospital to home, with challenge points for the family emphasised. To create these maps the team focused on personas from the interviews and documented care experience from birth to discharge, with key events and the associated parental concerns and feelings. This visual depiction of the care experience enabled the team to visualise meaningful opportunities for improvement along the care journey.

Literature search

We searched the literature on feeding and nutrition (including growth, NG tubes, enteral feeding tubes and sprinkles), parent education practices for preterm infants, physiological and remote/home monitoring (focused on apnoea and intermittent hypoxia), psychosocial support needs, early discharge and hospital cost, with an emphasis on articles including the family perspective. This search was iterative, with additional searches conducted as new areas to explore surfaced through the other empathy-building methods.

Analysis

We used an iterative, team-based approach to review all observations and findings. As we identified new insights, we confirmed findings in subsequent interviews, and clarified themes with the patient representatives on our team. We used the findings of our interviews, patient journey maps and literature searches to inform one another. We then applied these insights to inform our programme design, seeking feedback throughout the development

process to make modifications and ongoing improvements.

RESULTS

Empathy research

Patient safety concern

Through the interviews, we learnt that a major obstacle to widespread adoption to early discharge programmes stems from patient safety concerns. Specifically, health-care teams worried about incorrect NG tube placement and episodes of apnoea causing intermittent hypoxia. These themes surfaced in nearly all interviews despite an existing early discharge programme reporting no such adverse events.¹⁹

Reassurance and support needs

Parents saw value in an early discharge programme; one mother expressed 'leav[ing] your baby at night goes against everything that you are supposed to do.' Despite perceived benefits, parents expressed concern that they were unprepared to care for their preterm infant at home and indicated a need for reassurance and support. To help ameliorate these concerns, parents suggested framing the programme as a remote step-down unit rather than an early discharge programme; this labelling helped convey a more consistent level of care and oversight would be provided. Maternal depression and isolation were commonly experienced after leaving the structured support network of the NICU.

Complex care

The patient journey maps helped highlight the complexity of care involved in a hospital stay and the desire for families to be home sooner. The needs for clear communication and feeding support came to the forefront, as did challenges with transportation and the time demands involved with lengthy hospital stays while trying to meet other commitments (eg, work and existing childcare responsibilities). The patient journey mapping demonstrated that the current experience for feeders and growers results in potentially prolonged hospital stays, inconsistent with parents' and hospital systems' goals.

Feeding preferences

Interviews unearthed strong opinions on breast-feeding and nutrition; many parents wanted the opportunity to exclusively breast feed and not use a bottle, which is typically very difficult with premature, underweight infants.^{20 21} This finding led to extensive research on human milk fortification and breast feeding, with the goal of identifying a strategy that was aligned with parent preferences while still supporting optimal growth.²²⁻²⁹

A design thinking informed programme

We developed our programme to address the needs, preferences and concerns identified in our empathy research while also drawing on the results of our literature search to highlight safe, evidence-based practices. These steps

influenced the programme naming and led us to establish eligibility criteria, incorporate key programme elements and implement a novel feeding strategy. The design thinking process also led to many smaller tweaks to optimise the programme, including adjusting the volume on home monitors and modifying delivery of educational content to maximise parental comfort.

We adopted the term 'remote-step down programme' to convey care would continue to be delivered but would occur remotely rather than in the hospital. To ensure safety, eligibility criteria for the remote-step down programme included: the baby must complete an apnoea countdown, must be taking 30%+ of total feeding volume orally, must have reached thermoregulatory maturity, and be greater than 35 weeks postmenstrual age. While there is some variability in best practices, the apnoea countdown criteria used were no apnoea, bradycardia or desaturation events for 5-7 days (length of countdown is dependent on gestational age).³⁰ Thermoregulatory maturity was defined as maintaining temperature outside of isolette for 48 hours. In addition, both the attending physician and the follow-up clinic had to be comfortable with the decision based on infant stability and belief that the parents were good candidates for the programme, for example, they had the availability and seemed comfortable providing the care needed for their infant. Parents also had to actively select the remote-step down program rather than an extended hospital stay. Babies were excluded if they were in Department of Child and Family Services custody, as parental consent and training could not be achieved. Babies were also excluded if they had other comorbidities, oxygen requirements or congenital anomalies.

To address the patient safety concerns expressed by stakeholders and the need for reassurance and support expressed by families, our new programme transitioned feeders and growers' care home earlier, incorporating the following elements: weekday daily telemedicine rounds, continuously recorded remote monitoring (pulse oximetry), enhanced feeding and lactation support, a weight scale and parental emotional support and health education. Telemedicine rounds typically ranged from 5 to 15 min, depending on the parent. Parents sent weights through the patient interface of the medical record prior to the telemedicine appointment so that the provider could calculate feeds and growth in advance. For parents that wanted real-time support with NG Tube replacement, this could be provided during the telehealth visit. Once the NG tube was discontinued, telemedicine rounds shifted to weekly until 48 weeks. Telemedicine rounds were billed, consistent with hospital policies. These elements have mutually re-enforcing goals; for instance, daily telemedicine rounds by the advanced practice registered nurse helps provide parental support and reassurance, while also creating a checkpoint for daily vital signs so that the medical team can regularly assess infant safety and growth. Similarly, the continuous monitoring enables data collection to occur, with oxygen saturation

being recorded so that the medical team is aware of any apnoea events or intermittent hypoxia. Typically, in the NICU babies are monitored until discharge, even after the NG Tube is discontinued. The goal was for the new care model to provide for the same safety assurances, with trends monitored in both instances, = alleviating concerns about the cardiorespiratory stability and potential for intermittent hypoxia among this population. Monitoring was reviewed daily by examining histograms of the data, supplemented by additional review if family members voiced any concerns.

The educational component of our programme, consisting of but not limited to infant CPR, safe sleep and identifying illness in their infant, was a critical part of our efforts to address parental concerns. Another key aspect of the educational component was the opportunity to learn and practice NG tube insertion, first on a simulator and then on their own baby. The parent educator provided one on one education to meet the unique needs of each family. A packet of written materials as well as web-based information was available to all participant families. After being taught the aforementioned skills, parents were required to demonstrate the skills (either through simulation or on their infant, depending on the skill) to demonstrate learning prior to discharge, with additional support provided by the programme registered nurse as needed. To help parents overcome feelings of isolation with the transition home from the hospital, we also set up a weekly family support group, moderated by a social worker.

To address feeding preferences and provide further parental reassurance, we developed a novel feeding strategy where moms were given the opportunity to exclusively breast feed. In the NICU, preterm babies are often fed with human milk fortifier (HMF). HMF provides significantly higher amounts of protein than formula—and therefore, can better correct weight deficits—but is not typically used in the home setting. For our programme, we sent families who selected this nutritional option home with HMF ordered through the NICU. Parents were instructed to either administer the HMF using an oral syringe dispensed near the nipple while the baby is feeding from the breast, or for those who preferred, a more traditional bottle approach was also offered. By referring to the HMF supplementation as a medicine, rather than a formula, and enabling administration through an oral syringe rather than a bottle, parents who felt strongly about breastfeeding felt less conflicted about this approach. We also provided lactation support and weight checks. Tracking weight provided reassurance and early identification of any growth plateaus indicating the need for increased protein fortification. Management by our small team enabled creation of more deliberate, preference-aligned feeding plans and greater consistency around implementing the selected approaches.

Table 1 Infant characteristics and outcomes (n=14)

Infant characteristic or Outcome	
Sex (male), n(%)	7 (50)
Age at birth (week +days/7), mean (range)	32.17 (24.57–35.71)
Body weight at birth (kg), mean (range)	1.91 (1.07–2.82)
Length of stay (days), mean (range)	25 (8–78)
Length of Stay reduction, mean (range)	15.43 (5–42)
Required CPAP or Intubation, n(%)	9 (64.29)
%PO at discharge, mean (range)	55.03 (25.70–75.00)
Duration of home NG tube use (days), mean (range)	13.43 (3–40)
Absolute growth (kg), (weight at 48 weeks—birth weight), mean (range)	3.22 (1.36–4.14)
Relative growth (weight at 48 weeks/birth weight), mean (range)	2.69 (1.50–4.85)

CPAP, continuous positive airway pressure; NG, nasogastric; PO, by mouth.

Formative pilot case series outcomes

During our initial 5 months of the programme (29 July 2020 to 30 December 2020), we had 23 eligible babies, 9 parental declines and enrolled 14 babies. Compared with average prepilot length of stay data for comparable babies, the 14 babies in the programme reduced length of stay an average of 15.43 days/baby (range 5–42), for an aggregate decrease in 216 ICU days (see [table 1](#)).

There have been no adverse events or readmissions and babies at home continue to document excellent growth. Parents have been extremely satisfied with the programme, including the novel feeding strategies. Parents of enrolled babies all reported: being very satisfied with the programme, agreeing or strongly agreeing that their baby has good weight gain (10/11 survey respondents) and was sleeping better (100% of respondents), and reporting agreeing or strongly agreeing that they were satisfied with the information received about their baby's nutrition plan (100%), knowledgeable about the baby's nutritional needs (100%), and understand how to prepare milk for the baby (100%). One parent expressed appreciation of the programme and the support the family received:

We were thrilled to learn about the program after our daughter was identified as a good candidate. We were committed to spending as much time as possible with our newborn, and this has allowed us to do that in the comfort of our home while still giving her the extra medical care she needed to thrive. We've received incredible support and care from the team, which has allowed us to focus on our daughter's long-term health while jumpstarting our day-to-day life with her much earlier than we would have otherwise. It's

impossible to prepare for many of the challenges that face infants who need time in the NICU and we could not have asked for a better way to tackle them.

Healthcare providers shared similarly positive perceptions of the programme.

DISCUSSION

This study illustrates the development and initial outcomes of a remote step-down early discharge pilot programme for premature infants. While several larger institutions have recently implemented similar programmes, the approach has not scaled more broadly due to lingering safety concerns, as reflected in our interviews.^{31 32} Others have attempted to demonstrate the safety of home NG tube use, but the heterogeneity of population, including the complexity of medical conditions, makes it difficult to extrapolate to the preterm infants acquiring oral feeding skills that were the focus of the present programme.³³ Accordingly, our programme's incorporation of continuously recorded pulse oximetry is novel and helps to demonstrate safety in a population at risk of cardiorespiratory immaturity. The nutritional management strategies offered in our programme were also unique. HMF has typically been unavailable in the outpatient setting, serving as a barrier to families who would like to provide breast milk and avoiding bottle-feeding for preterm infants with high protein needs.

While the pilot has been successful, we acknowledge several challenges and limitations. Initially, staff buy-in was challenging, as this was a significant transition from existing practice. After initial reluctance, we faced the opposite problem; staff discussed the programme with families where the infants did not meet inclusion criteria, resulting in some family disappointment. In terms of limitations, while we believe the focus on incorporating parental feedback into initial and ongoing design, implementation, and evaluation strengthened the programme, we recognise that this is a small case series and our results cannot be generalised. Generalisability is further limited by the lack of racial and ethnic diversity; 13 of the 14 patients were non-Hispanic white and one was Hispanic. In addition, we did not collect information about reasons for decisions not to enrol in the programme; in the future we will need to explore whether this stemmed from concerns about a novel programme or if there are modifications that will improve programme acceptability. It will also be helpful to explore how the demands of parental support differ between the home and hospital setting and how social and work pressures play into enrollment decisions, as individual family circumstances may shape these choices. In addition, we recognise that the subjectivity of clinician assessments for programme eligibility could inadvertently increase health inequities; accordingly, developing more objective strategies to determine eligibility may help limit the potential for biases to be introduced. Further, while we are optimistic

about this programme being sustained, sustainability is not addressed within the pilot itself.

Of note, the development of this programme during the COVID-19 pandemic should be acknowledged. While prolonged NICU stays raise the risk of healthcare-acquired infections, in the COVID-19 pandemic context, prolonged hospital stays also raised family member concerns regarding COVID-19 exposure. These compounded risks may have increased the acceptability of an early discharge programme. Further, while the COVID-19 pandemic introduced new stressors on the hospital, it also fueled efforts to implement and fast-track enhanced telemedicine capabilities; these initiatives undoubtedly facilitated the remote monitoring, daily rounds and overall support of these patients and families. We are excited about this programme's future and our ability to expand on these supports to continue to better meet patient and family needs.

CONCLUSIONS

A patient-centred, design thinking informed approach supported the development of a pilot programme to enable earlier discharge of preterm babies. Initial results suggest the programme has been successful—with length of stay reductions comparable to prior research, while not compromising safety.^{10 11} Ongoing study and evaluation, including larger-multicentre programme adoption, are needed to confirm safety, inform programme refinement and optimise sustainability.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This work was deemed non-human subjects by the Dartmouth-Hitchcock IRB, STUDY02000343.

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